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TITOLO TESI

Social inclusion of vulnerable groups through participatory and emancipatory approaches.

Implementing active citizenship and socially innovative actions in the framework of civil & human rights model of disability

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ABSTRACT

The research hypothesis of the thesis is that “an open participation in the co-creation of the services and environment, makes life easier for vulnerable groups”; assuming that the participatory approaches are processes of possible actions and changes aimed at facilitating people’s lives. The adoption of these approaches is put forward as the common denominator of social innovative practices that supporting inclusive processes, allowing a shift from a medical model to a civil and human rights approach to disability.

The theoretical basis of this assumption finds support in many principles of Inclusive Education, in particular its fundamental task to ensure that the gains achieved for a person in a problematic situation becomes beneficial for all.

In the hypothesis of research the main focus is on participatory and emancipatory approaches, as tools for facing emerging and existing problems related to social inclusion, accessibility, involvement in the design processes including the role played by vulnerable groups - in particular people with disability - as active citizens.

The framework of reference for the research is represented by the perspectives adopted by several international documents concerning policies and interventions to promote and support the leadership and participation of persons with disabilities and their families.

In the first part of this research an in-depth literature analysis of the main international academic publications on the central themes of the thesis has been carried out.

In particular the analysis addresses the frame of reference for the definition of the terms “disability and inclusion”, underlying the different models of intervention with disability - from Charity to Civil and Human Rights model, considering also different approaches and the movement of the Disability Studies.

After investigating the framework of reference, the analysis focuses on the main concepts and tools of participatory and emancipatory approaches, looking at methodological aspects for an inclusive research, which are able to connect these approaches with the concepts of active citizenship and socially innovative actions.

In the second part of the thesis two case studies concerning participatory and emancipatory approaches in the areas of concern are presented, and analyzed as example of the improvement of inclusion, through the involvement and participation of persons with disability.

The methods of survey used in this thesis were: literature analysis, questionnaires, interviews, Living Lab and focus groups, addressed to different types of professionals in the field of disability. This aspect has strengthened the interdisciplinary approach of research, allowing the investigation of the themes from different points of view, integrating the field of education with those of design, ergonomics, rehabilitation medicine, psychology, assistive technology and ICT.

To conclude, this thesis contributes to providing a knowledge-base that fosters a shift from a situation of passivity, sickness and patient care to a new scenario based on the person’s commitment to active role and participation in the elaboration of his/her own project of life.

Key words:

Inclusion, participatory and emancipatory approaches, vulnerable groups, active citizenship, social innovation, civil and human rights.

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“Whatever you can do or dream you can, begin it. Boldness has genius, power and magic in it!”

Johann Wolfgang von Goethe (1749 – 1832)

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INTRODUCTION

The theoretical point of view adopted in this research for analyzing emerging and existing problems related to inclusion, participation and accessibility by vulnerable groups is based on the Inclusive Education (UNESCO, 2000). The choice is strictly related to its objective, that consists in contributing to building a civil society, able to support a culture of diversity, social inclusion and accessibility for all. Operating against a culture of exclusion, recognizing different identities, providing people in problematic situations with the adequate support to be able to define her/his project of life, considering needs, objective and rights as the central position.

When I refer to the “vulnerable groups” I assume the definition provided by the Social protection and Social Inclusion Glossary of the European DG Employment, Social Affairs and Inclusion¹. This definition – also adopted also by the European Quality Assurance reference framework for Vocational Education and Training (EQAVET) - considers as vulnerable “*groups that experience a higher risk of poverty and social exclusion than the general population. Ethnic minorities, migrants, disabled people, the homeless, those struggling with substance abuse, isolated elderly people and children all often face difficulties that can lead to further social exclusion, such as low levels of education and unemployment or underemployment*”².

Taking into account that vulnerability involves several interrelated dimensions, such as:

- a) individual capacities and actions;
- b) the availability or lack of intimate and instrumental support;
- c) the neighborhood and community resources that may facilitate or hinder personal coping and interpersonal relationships (Mechanic, 2007).

The practical dimension of the Inclusive Education could be the link between different dimensions.

This is due to its intrinsic characteristic to be oriented to inclusion (preventing exclusion), empowerment, participation and emancipation, in order to allow everyone to have a place and a role in society, regardless of her/his condition. In this sense, Inclusive Education considers as its fundamental task to ensure

¹ Available at: http://ec.europa.eu/employment_social/spsi/vulnerable_groups_en.htm

² Available at: <http://www.eqavet.eu/qc/gns/glossary/v/vulnerable-group.aspx>

that the gains achieved for one person in a vulnerable situation become beneficial for all.

If I wish that the results of my research could have a positive impact on issues of education, providing evidence to the fact that participatory and emancipatory approaches operationalize the concept of Inclusive Education. Contributing to reduce exclusion from culture and community, it is therefore necessary to make a confrontation with:

- new theoretical framework of planning, including active citizenship, self-determination and empowerment;
- new ways of understanding complex issues, such as accessibility, exclusion and barrier free environments;
- new hopes, such as participatory and emancipatory approaches, information communication technologies (ICT henceforward), assistive technologies (AT henceforward), Design for All (DfA henceforward) and socially innovative actions.

The research framework is complemented by international documents and orientations as stated by the European Union (EU henceforward) ratification of UN Convention on the Rights of Persons with Disabilities (UNCRPD henceforward³), in which the EU recognizes the importance of the realization of development programs, inclusive and accessible to persons with disabilities (Article 32).

The intent of using participatory and emancipatory approaches for inclusion and accessibility, particularly in the area of disability, responds to the precise indication of the Madrid Declaration (EU, 2002) to promote and support the leadership of persons with disabilities.

The focus on these approaches - as possible instruments for the development and implementation of services, products and environments (Manoukian, 2005) - will also be aimed at highlighting and valorizing the pedagogical assumptions. Considering what is stated in many international and European documents, these approaches are assumed to be a set of concepts, tools and methods that can support the shift from the conception of a medical model to one based on civil and human rights (UNESCO, 1995)⁴ for the development of social

³ 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>

⁴ *“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*

innovative actions aimed at enhancing autonomy, active citizenship, accessibility and inclusion (Oliver and Barnes, 2010 and 2012).

The research hypothesis is that “*an open participation in the co-creation of the service and environment, makes life easier for vulnerable groups*”, and assuming that the participatory and emancipatory approaches are processes, rather than outcomes, of possible actions and changes aimed at facilitating people’s life. The adoption of these approaches is put forward as the common denominator of social innovative practices that supports the shift from a medical model to a civil and human rights model of intervention with vulnerable groups.

As reported in the definition quoted above, the most vulnerable members of society are ethnic minorities, migrants, elderly people, children, women and persons with disability. In this research I will refer mainly to persons affected by physical, sensory and intellectual disability, although many aspects outlined in the following chapters are relevant to all persons.

This thesis attempts to demonstrate that by facilitating participation starting from the first step of planning, it’s possible to design and develop services, products or environments that are easier to use, inclusive and accessible for all. This means providing the possibilities of participation in certain areas (e.g. the design of buildings, employment, education, leisure, communication, independent living, etc.) and fostering the empowerment of people, generating a spill over into other spheres of life.

This can support the transition from one method of intervention, characterized by a situation of passivity and patient care, to one based on inclusion, civil and human rights, active citizenship, participation and emancipation. Where the person’s project of life, needs, desires, objectives and expectations are at the centre of the process.

In this thesis I will try to link the theoretical point of view of participatory and emancipatory approaches with concepts, tools and methods aimed at supporting the inclusion of vulnerable groups (chapter 1 and 2).

New concepts, tools and methods, such as: Participatory Design and Living Lab (in chapter 3 and 6 - “case study 1”), Emancipatory Design and Life Coaching method (in chapter 3 and 6 - “case study 2”), Design for All and Social Innovation (in chapter 4 and 5) have been analyzed and used to complete the framework of reference in which the interactions based on the participation and emancipation may lead to a more effective inclusion, facilitating the life of people through their active and participative involvement in the design processes of services, products and environments. Because the quality of life,

life of the community, including all forms of public decision-making”. In Review of the present situation in special needs education. Paris: UNESCO, 1995.

one of the more important social and health outcomes, is associated with participation (Elliott & Barris, 1987; Patrick, Kinne, Engelberg, & Pearlman, 2000; Levasseur, Desrosiers, & Noreau, 2004).

Over the years, many participatory approaches have been developed to support not only the participation in technology design, but they have become increasingly engaged in different spheres of everyday life and no longer solely concerned with the workplace and technology. In this way participation includes a diverse collection of principles and practices aimed at making technologies, tools, environments, businesses and social institutions more responsive to human needs.

Although a precise definition of participation is too complex to provide due to the variety of meanings that it can assume. For this reason I wish to adopt a simple definition suggested by Pateman, according to which participation *“must include four elements - participation by someone, participation with someone, participation in something and participation for some purpose”* (Pateman, 1970). In this sense participation excludes situations where an individual merely takes part in a group activity, or where an individual is merely given information on a decision affecting him/her before it is executed, or where an individual is present but has no influence.

A central tenet of any participatory approach is the direct involvement of people in the co-design of infrastructures, the co-creation of “things” and the opportunity to support a greater inclusion and accessibility, both assumed as a principle aimed to eliminate or reduce the barriers that hinder the rights of persons.

The terms refer not only to social inclusion or physical access to buildings, but also access to information, technology, communication, economic and social life. In this sense ramps, corridors and doors, the availability of information in Braille, easy-to-read formats, supports, represent what I mean concerning accessibility. This is a concept that can ensure that a person with a disability has access to a workplace, a place of education or training (Bertolini, 1990), leisure, entertainment, voting, etc. Because without access to information, technology, places, environments, or the ability to move freely, many rights of persons are also restricted (UN, 2010).

This aspect is not only a shift from technology and work oriented productive activities towards social-health service provided and leisure engagements, but also as *“a new milieu for production and innovation and entails a reorientation from democracy at work to democratic innovation”* (Björgvinsson, Ehn and Hillgren, 2010). It basically means to democratize innovation through the involvement and participation of different stakeholders and target groups on

themes as - in this case - accessibility and inclusion for the design and implementation of services, products and environments. Once democratized, innovation needs to be put to the service of society and where it can create new social relations, becomes social innovation *“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”* (EU, 2011. Empowering people, driving change. Social Innovation in the European Union. BEPA report⁵).

Nowadays most societal challenges require taking the social dimension of innovation into account. This dimension refers to changes in habits, behavior and values, strategies and policies as well as organizational structures, processes and services. In this context, social innovation is seen as a possible solution to support participation, promote changes in design, development and provision of services, products and environments and also to reduce poverty, to create employment and to develop capabilities (Sen, 1999 and 2005).

In this framework participation can be a valid support for the development of social innovation, e.g. through the active engagement of the citizen, it can contribute to reshaping the society and pointing it in the direction of responsibility, policy, participation, inclusion, empowerment, co-creation and learning.

Despite rising overall contributions and works, a focused and systematic analysis of social innovation, its theories, characteristics and impacts, is still absent and this has led to it being developed through a “bottom-up process”, with little conceptualization of the political, institutional and cultural environments needed for propelling social innovation (EC, 2012. 7^o Framework Programme - Cooperation. Theme 8, Socio-economic Sciences and Humanities). In the framework of this thesis, the same bottom-up approach is adopted, considering participation and emancipation as concepts to be applied in different contexts and scenarios, encouraging socially innovative actions and active engagement of vulnerable groups.

The choice of focusing on these approaches for inclusion is due to the fact that it is more centered on the concept of the person and his/her context of life (including psycho-social and cultural-economic issues), than user or consumer. It is more concerned with cooperation than mere collaboration, and hence closer to the concept of co-creator (acting the role as citizen). This view, if

⁵ Available at: http://ec.europa.eu/bepa/pdf/publications_pdf/social_innovation.pdf

applied to the context of disability, can support the shift from a medical model towards a civil and human rights model in the interventions with disabled people, as indicated in the policies of many international documents. It allows focusing on new forms of relationships and participation in all spheres of life. Referring also to United Nations Enable⁶, which gives voice to the United Nations commitment to uphold the rights and dignity of persons with disabilities, the UNCRPD has played an important role in marking a paradigm shift. In particular contributing to the change from the view of persons with disabilities as objects of charity, needing medical treatment and social protection, towards seeing them as subjects with rights. As such, they are capable of claiming those rights and making decisions for their lives based on their free and informed consent, as well as of being active members of society. Based on the changes in society, it becomes clear that new approaches need to be developed and transferred in order to facilitate the inclusion and the understanding of phenomena affecting vulnerable groups' needs and expectations. This is especially so for the actors and agencies able to influence the way of considering all persons capable of being actives and emancipated, if supported by the right approaches and cultural attitude. For this reason the participation and emancipation are here presented both as theoretical approaches for addressing societal challenges and as a set of practical methods for responding to social needs, in particular facing emerging and existing problems related to inclusion and accessibility.

⁶ United Nations Enable is the official website of the Secretariat for the Convention on the Rights of Persons with Disabilities (SCRPD) in the Division for Social Policy and Development (DSPD) of the Department of Economic and Social Affairs (DESA) at the United Nations Secretariat. Available at: <http://www.un.org/disabilities/default.asp?navid=3&pid=17>

Research objectives

The general objective of this research is to further advance the understanding of the potential of participatory and emancipatory approaches in terms of inclusion, with a special emphasis on the involvement, empowerment and self-determination of persons, as advocated from the perspective of the Inclusive Education. Considering its potential to also improve the capacity of society to act and innovate in view of a systemic change, this framework means to go ahead in the direction of a model based on the concepts of civil and human rights, active citizenship and innovative socially actions for the interventions with vulnerable groups.

Specific objectives are:

a) To define an overview of the theoretical assumptions of the Inclusive Education, the terms of disability and inclusion, and the main models and approaches to disability.

b) To focus on concepts, tools and methodologies to address existing and emerging needs, as the lack of examples, practices, experimentations oriented to inclusion and accessibility to services and environments. This also includes an analysis of participatory and emancipatory approaches viewed as instruments for cutting the roots of marginalization, supporting active citizenship and socially innovative actions.

c) To analyze two different case studies concerning participatory and emancipatory approaches in order to verify the research hypothesis about “*an open participation in the co-creation of the services and environment, makes life easier for vulnerable groups*”. In particular assessing if these approaches can effectively support the shift from situations based on the medical model of disability (passive situation), towards ones based on civil and human rights (active situation). From this point of view, the person with her/his needs, desires, objectives and expectations is at the centre of actions and intervention. The case studies concerns:

- 1) Case study: realized in collaboration with the AIAS Onlus Bologna, concerns the development of a service of “Smarthomes for independent living experiences”. The service has been developed, tested and implemented using an innovative participatory method, the Living Lab.
- 2) Case study: concerns the experimentation of the “Life Coaching” method applied to a medical context, the Multiple Sclerosis Unit of IRCCS

Neurological Sciences of Bologna. The method is based on a non-medical approach aimed at supporting processes of change, empowerment and emancipation in the lives of the patients of the Institute. These has allowed the experimentation of a method of intervention where the person has a central role in the definition of her/his project of life.

The expected result consists in providing a knowledge-base that fosters a shift from a situation of passivity, sickness and patient care to a new scenario based on the person's commitment to an active participation.

Participation and emancipation are innovative and recent approaches and there are many aspects of their application that need to be studied and further explored in order to have more insights into how these can support changes in society at large.

Based on that, the focus of my research is to demonstrate that facilitating the open participation and co-creation in planning and design processes, leads to socially innovative scenarios where the active role becomes possible. Scenarios in which services, products and environments are more accessible and easier to use, favoring ultimately a greater inclusion.

More specifically, my purpose is to contribute to study participatory and emancipatory approaches by analyzing two samples of possible applications that guide people's involvement, integrating their needs, objectives and desires. The conclusions of case studies investigated in specific situations will therefore be referred to, but extendible to other contexts if considered as examples of social innovation practices that can be adapted, modified and implemented.

Framework of research

Research process in general consists of three main ingredients: the frame of reference, the methodology, and the areas of concern (Checkland and Holwell, 1998). This means that a particular combination of linked ideas is used in a methodology as a means of exploring defined areas of concern (see Figure 1).

Checkland and Holwell state that the researcher can learn things about all three elements in the research process; hence, I wish to strive to clarify my learning about these elements throughout my thesis.

In detail: the frame of reference, including the definition of disability and inclusion, is represented by the shift from a medical model to a civil and human rights model of disability.

The methodology to support this change of situation is based on the participatory and emancipatory approaches.

The areas of concern refer to two different case studies analyzed in this thesis, representing practical examples of participatory and emancipatory approaches applied to research and aimed to:

- 1) Development of a service of “Smarthomes for independent living experiences”, designed with the Living Lab method (applying a participatory approach).
- 2) Experiment of the Life Coach model (non medical model) with persons with disability, focusing on the active role of persons in defining her/his project of life (applying a emancipatory approach).

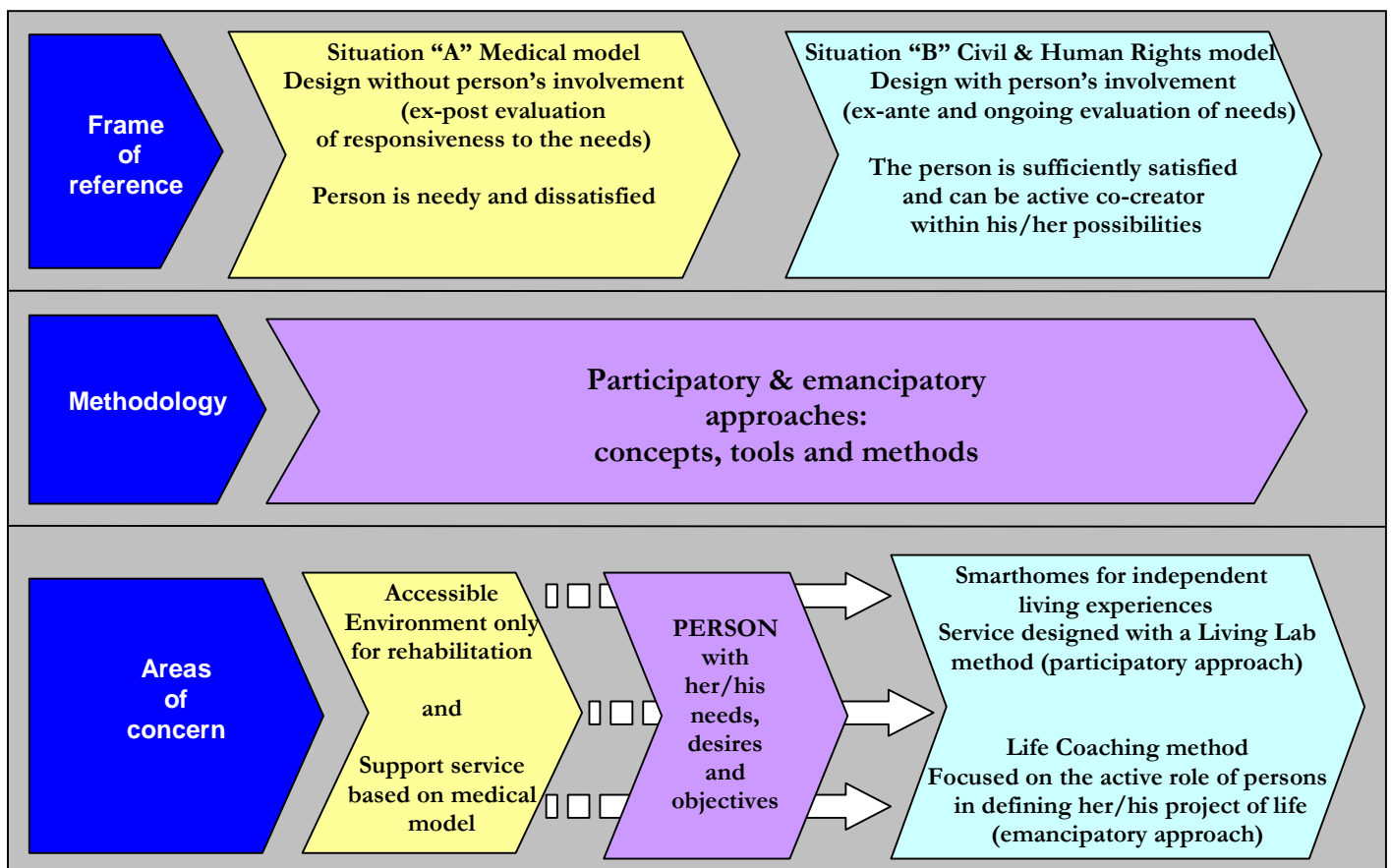


Figure 1: Framework of research

Hence, the starting point for my thesis is to present the theoretical background in order to give an idea about general context, this is described in chapters one. The premise of the chapters lies in the recognition of education as a universal right, as advocated by the Conventions on the Rights of the Child (UN, 1989) and the Convention on the Rights of Persons with Disabilities (UNCRPD, 2006).

Assuming the Inclusive Education (UNESCO, 2000) as the point of view adopted for facing emerging and existing problems related to inclusion, participation and accessibility by vulnerable groups.

In chapter two, the frame of reference that I contribute to is presented, in particular defining what I mean by the terms “disability” and “inclusion”.

An analysis of the different models developed to understand disability is also outlined, from structured models, to less rigid approaches and a free movement often defined a-theoretic as the Disability Studies (Barnes, 1995). This section will not attempt to provide a comprehensive review of the literature associated with these models and approaches, rather it examines many of the defining features, in order to demonstrate how disability is an evolving concept, that reflects cultural models, social attitudes and policy orientations.

Chapters one and two define the frame of references of the research, where I am going to demonstrate that a switch from situation “A” (medical model) to situation “B” (civil & human rights model) is necessary. In order to undertake a process of transformation that focuses on the person, not intended as “alone”, but surrounded by “networks”, formal and informal (family, friends, associations, agencies, institutions, etc.) that work together, not “on/for” but “with the person”. This person needs to assume the role of a co-creator and actively participate in the decision-making process, putting at the center her/his specific needs and desires first.

In chapter three, the concepts and tools related to my framework of interest are presented, which consist in interpretive perspective, soft systems thinking, and the analysis of innovative solutions.

This systematizing through the development of various content and methods (such as Participatory Design, Living Lab, Life Coaching, Design for All, and PALMI method), is presented as a comprehensive framework of reference for possible scenarios of innovation.

Following on, chapter four refers to methodology, where the action of my research approach is presented. It also focuses on these approaches as methodological approaches to be applied to the academic research field for an effective inclusive research.

In chapter five, I have tried to show to what extent the participatory approach to research can support active citizenship, for an effective involvement of

vulnerable groups, in particular persons with disability. How emancipation through research can contribute to the affirmation of a civil and human rights model of disability.

And finally to what extent both these approaches, their principles, concepts and tools can be used for research and design “how, what and for who”, in order to implement socially innovative actions.

Chapters three, four and five provide an in-depth analysis of concepts, tools and methodology related to participation and emancipation, and their application to support active citizenship and socially innovative actions.

The chosen methodology is aimed at illustrating that, in the transition towards a situation where services, products and environments are designed “with” the person, her/his role assumes a different connotation.

Including a new situation requires involvement and participation in the setting of goals, and enhancing empowerment and emancipation at the end of the process.

This means shifting from a situation in which perception is about a passive person (where the assessment of compliance needs is often ex-post) towards one in which the person is considered as active and perceived as participant (where needs analysis is ex-ante).

Next in chapter six, there is a description of two case studies that I have been involved in and the lessons learned from these. The cases concern the analysis of participatory and emancipatory practices, in order to provide two practical examples in the areas of concern.

Starting from the case studies selected, I try to show that the transition from situation “A” towards situation “B” requires greater flexibility by service providers, an open-minded approach, wider cultural attitude and a willingness to listen. This allows new emerging needs to be addressed, such as the involvement of the person in the design and co-creative processes, where innovative solutions can be found.

These solutions in the new situation “B” would be obtained from the intersection between local resources of context, aims and desires of the person involved. In the final remarks, reflections and conclusions are stated, together with implications for future research.

Methodology

The thesis was based on four methodological activities:

- 1) A survey of the relevant literature concerning inclusion, disability and rights.
- 2) A study of the international legal and political framework.
- 3) An overview of current news related to international projects on the themes of participation, emancipation, active citizenship, social innovation and Design for All.
- 4) An analysis of two case studies focused on participatory and emancipatory approaches, including methods of intervention for facing emerging and existing problems related to inclusion and accessibility to services and environments by vulnerable groups, in particular persons with disabilities.

Sources of information

The documents consulted for (1), (2) and (3) are given in footnotes and listed in the bibliography. The study of the international legal and political framework was based on a filtering process, considering mostly documentations coming from UE and US reported in the references.

Briefly, the thesis sought answers to the following questions:

- a) An open participation in the co-creation of services and environment, can it make life easier for vulnerable groups?
- b) What are the recurrent examples of good practices concerning inclusion and participation of such groups?
- c) To what extent participatory and emancipatory approaches are processes of possible actions and changes?

The information used to answer these questions was gleaned from six sources:

- 1) Data from the papers, project documents, and other relevant documentation on inclusion and disability supported by the EC since 1990.
- 2) Literature reviews performed on studies, academic publications, international policy guidelines and results of previous research projects. The methodology used for the literature review was to search the following databases: ProQuest Family Health, ProQuest Education Journals, ProQuest Nursing & Allied Health Source, ProQuest Eric,

ProQuest Social Science Journals, Google Scholar, and printed publications mentioning or focusing upon the main themes of the thesis. An extensive web search was conducted in order to identify on-line abstracts, reports, projects and other resources.

- 3) Interviews with persons with disabilities, professionals such as educators, care givers, rehabilitation therapists, psychologists, engineers, as well as ICT-AT experts and researchers.
- 4) Participation in Living Lab and focus groups with persons involved in the development, and implementation of the service of independent living.
- 5) Experimentation of the Life Coach method as non-medical approach aimed at supporting processes of change and emancipation in the lives of the volunteer participant patients.
- 6) Visits to rehabilitation centers, independent living centres, Design for All Foundation, including the building realized by the Foundation adopting a participatory approach for the accessibility.

Delimitation

Since participatory and emancipatory approaches include a collection of principles and practices aimed at making services, environments, products, technology, research, businesses, and institutions more responsive to human needs, some principles will be presented and deepened in the following. Examples of practices and methods that are provided (Human-Centred Design, Participatory design, Emancipatory design, Living Lab, Life Coaching, Humble method, PALMI method), as practical applications of participatory and emancipatory principles.

Different theories and philosophies, that can be considered pertaining to concepts of participation and emancipation, have been used in traditional application domains such as computer systems for business, healthcare and government.

And more recently in areas such as web design, e-government services, community networks, enterprise resource planning, social administration and community development, university/community partnerships, tele-health, communities of practice and political deliberation/mobilization (e-democracy), digital arts and design, scholarship and teaching with mediated technologies (e-learning).

In these areas the term “user” is often used when referring to the person to be involved in participation processes. In this thesis I have chosen to use the term

“person”, because it is closer to the concept of education, inclusion, rights, citizenship, and not linked to an idea of business or commercialization⁷. Moreover I think it could be important that people are not marked or defined only through expressions, for example related to their disabilities.

The term “person”, in the humanities, explains the theme of commonality of existential situations, in which each person has constraints and resources (Heidegger, 1927), and in this meaning here assumed.

Although many approaches for the involvement of person have been developed and applied, the processes leading to an effective participation and emancipation are considered to be complex.

For instance, considering some models of user-center development as Flynn and Jazi stated “*one reason for this complexity is the user-developer culture gap*” (Flynn and Jazi, 1998). This means that the level of communication is low between persons involved, researchers or developers concerning their mutual context. This, in turn, results in a situation where researchers and developers assume that personal requirements are completely known at the beginning of the process.

Conversably, people cannot understand the solution due to unfamiliar modeling languages and ignorance of the social context (Flynn and Jazi, 1998). In addition, person seldom have all the required knowledge about technological solutions and technological terms (Vidgen et al., 2004).

Hence, it becomes difficult for persons, researchers and developers to share and communicate. Pitts and Browne (2007) declare that the difficulty with involving user “*has its background in users’ as well as other stakeholders’ uncertainty of their needs, including their inability to articulate them clearly*”. In addition, Pitts and Browne point to the fact that analysts are often poorly trained in techniques of information gathering.

Hence, they shortcut the person involvement process and start developing the final solution too early.

This complexity has been faced till now for example through the elaboration of structural models as the ISO 9241-210⁸ standard on Human-Centred Design.

This standard provides some principles which include clear understanding of tasks and environmental requirements, encouraging iteration of design solutions and multi-disciplinary design.

⁷ EU Council Resolution of 15 July 2003 on Social and Human Capital Building social and human capital in the knowledge society: learning, work, social cohesion and gender (2003/C 175/02)

Available at: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2003:175:0003:0006:EN:PDF>

⁸ Available at: http://www.iso.org/iso/catalogue_detail.htm?csnumber=52075

In most cases the approach chosen seems to depend on the scope and availability of the resources available to the organization or institution involved. Basically all the approaches are moving away from seeing the potential users as “tester”, whose involvement is limited to the measuring of a performance, to one more centered on participants needs and rights.

However, as highlighted by Hyysalo “...to complicate the process of involving users even more, for several reasons it is considered impossible to ask a user “what are your needs?” (Hyysalo, 2003), and made the appropriate inquiries of regarding the psycho-socio-cultural-economic environment in which the future services needs to be developed and provided.

In this thesis instead, it is assumed that using a mix of research methods and participatory settings, including focus groups, interviews, questionnaires and especially Living Labs, it is possible to collect and observe the needs of persons involved. This information captures the complexity of the world outside the research centre, laboratories, organizations and allows insight in how the development of accessible services and environments could or should work. Trying to establish long-term relationships, allowing participants to become active co-creators, and to make it so that what is being designed enters their real life context.

In my research, I have focused on participation and emancipation as approaches for inclusion, accessibility and facilitation of the life of person. In this I have considered situations in which persons have the ability to choose whether or not they want to use and have access to a service, product or environment and whether or not they want to be involved in design and development processes.

This means that I have not examined final solutions. My research focuses on the needs of the person as the reasons for developing new models and approaches aimed at improving the level of participation, emancipation and commitment. This should work in both directions, providers to persons, persons to providers, and hopefully make life easier for all persons involved.

Lead users, organizational and marketing strategies, or commercialization opportunities, are excluded from my research.

In addition, even though one possible application of participatory approaches to accessibility is to create new businesses, my research focus is on participation, inclusion and emancipation, hence, business opportunities are not considered.

CHAPTER 1 – Theoretical background

1.1 Universal pedagogy

The premise of this chapters lies in the recognition of education as a universal right, as advocated by the Conventions on the Rights of the Child (UN, 1989) and the Convention on the Rights of Persons with Disabilities (UNCRPD, 2006).

In accordance with this recognition, I wish to consider “Universal pedagogy” as the theoretical background of this thesis. The theoretical model proposed agrees with the principles included in the documents cited above, incorporating the idea of a *“flexible curriculum and the development of literacy skills, accessible and applicable to students with different backgrounds, learning styles, and abilities”* (Rioux and Pinto, 2010).

It also represents a framework in which the main concepts dealt within the thesis are well suited. Moreover Universal pedagogy includes many principles of the Human Rights model of disability. In particular three main aspects that complete the rational of the pedagogical framework of this thesis:

- the active role of the persons with disabilities in the whole process and the importance to actively promote an *“environment in which the learner can effectively and fully participate in programmes, including those directly concerning them”* (Art. 29 of the UNCRPD, 2006).
- the importance of contextual factors, divided in: “external”, such as social attitudes and expectations, environmental barriers (including cultural and economic), technological structures, etc. “Internal”, such as personal factors, which include gender, age, coping styles, social background, education and other factors that influence how disability is experienced by the individual (WHO, 2001).
- the need to promote contemporarily socially innovative actions aimed at enabling the reduction of barriers or the implementation of environmental facilitators (WHO, 2002) such as: ICT, assistive technology, Design for All, for expanded performance of actions and tasks in daily living.

Universal pedagogy adopts the concept of universal design (Mace, Hardie and Place, 1996; Story, Mueller & Mace, 1998; Preiser and Ostroff, 2000; Sandhu, 2001) to apply to learning, addressing key issues that are raised when human rights principles are integral to the design, implementation and evaluation of

education policies and programs. It also assumes the principle of “*reasonable accommodation*” (UNCRPD, 2006), in order to guarantee that with the appropriate support, it is possible to accommodate a variety of learning styles and needs.

Universal pedagogy could also represent the theoretical background in which an inclusive approach to education can lead to the development of practical actions, ensuring that the gains achieved by a person in a problematic situation become beneficial for all. This means to contribute to building a civil society, able to support a culture of inclusion, operating against social exclusion, recognizing different identities. This provides people with the possibility of active participation in life processes, considering their needs, rights and desires to be in central position.

The choice of beginning with an introduction on the theoretical background and pedagogical approach, is due to the need to specify “how” to recognize this value of “*universal right*” to education, as advocated by the Conventions on the Rights of the Child and the Convention on the Rights of Persons with Disabilities.

In this sense Universal pedagogy provides the principles and the framework of reference for this recognition. But in order to also present a practical dimension to this theoretical background and put into practice the principles assumed, that means “what to do”, I wish to refer to Inclusive education. That starting from early childhood until adulthood can foster a culture of inclusion and participation, as premises for a more effective emancipation, including the research field.

1.1.1 Inclusive education

The practical dimension in which to develop practices and programs is represented by the Inclusive education, that as specified by Barton needs to involve the “*twofold activity of increasing participation and removing exclusionary barriers*” (Barton, 1997). Participation is at the heart of this thesis, such as the removal of barriers, and the assumptions by which inclusion and participation are premise of the emancipation, especially referring to learning and education.

But in order to avoid the misunderstanding of seeing Inclusive education merely as a new name under which exclusionary special education practices could be replicated (Slee and Allan, 2001), it is important to consider the framework of reference in which the practices should be developed, that in this

case is represented by Universal pedagogy, including the principles of Universal design (or Design for All) and Human Rights. This is because it can help to develop learning programmes and curriculum able of considering the presence of student with a variety of learning styles and needs.

In this way it could be possible to also avoid misconception about the oxymoronic nature of the term inclusive education. In fact, if it is true that *“schools were never meant to be for everyone and must, in order to function, position some individuals as failures”* (Slee, 2003), it also possible to change some aspects of the education system. The first of which is to continue to consider the educational system as based only on its function to position some individuals. Because an increasing participation of all learners (disabled or not) begins with the respect of the learning characteristics of everyone, individualizing learning processes, and not elaborating procedures to assess if *“passed or failed”*, or to position learners. It represents a shift in thinking about education and learning, from that which works for most learners to one that involves the creation of a rich educational environment characterized by learning opportunities sufficiently made available to everyone, so that *“all are able to participate in classroom life”* (Florian, 2010; Florian & Black-Hawkins, 2010).

Even if in recent decades inclusion has become a fundamental element of the education systems, the discrepancy between normative frameworks and the resources available to realize the right to education for all, seems to have not produced the expected results and still millions of people with disabilities have no access to education in 2014. Moreover, where inclusion is supported and put into practice, often raises issues related to new forms of marginalization. In fact, putting children with disabilities in mainstream schools is not enough, if inclusion simply *“changes the location of the schooling of the child but the negative stereotyping persists and the expectations for that child’s learning continue to be less than for other students”* (Rioux and Pinto, 2010). An inclusion that addresses place or environment but not the substance of learning could not be considered as an education for all, or at least not as inclusive education.

An inclusive education requires a framework that takes into consideration not just the right of access to education, but also the right of education for all students respecting the learning characteristics of everyone. In other words, it addresses *“children’s rights to education, as well as rights within education”* (UNICEF and UNESCO, 2007).

As argued by Barton, the importance of an education for all *“is one of the most important and urgent issues facing all societies concerned with the education of*

their future citizens” (Barton, 2003). From this point of view the concept of inclusion is part of a broader human rights model which supports the view that any kind of segregation is ethically wrong.

Inclusion can be seen as an *“ethical issue involving personal rights and any society’s will to recognize these rights in an effective way”* (Phtiaka, 2005), which could strengthen rights for children, youths and adults (with or without disability) respect learning and education issues.

Inclusive education is also assumed here to be a *“means of bringing about personal development and building relationships among individuals, groups and nations”* (UNESCO, 2003), and able to support the *“involvement of disabled people as with autonomy, desires, choice and control, in all sectors of life”*, as argued in the United Nation Convention on the Rights of Persons with Disability (UNCRPD, 2006).

Connecting these assumptions with the concept of *“conscientization”* (Freire, 1972) defined as *“the process of developing a critical awareness of one’s social reality through reflection and action”*, people can be active agents in the educational processes, developing the understanding and awareness of their own abilities, resources and the capacity to improve their life, acquiring *“self-determination”* (Wehmeyer, 1998) and skills (Sen, 1999 and 2005).

These elements thus have the potential to put in motion a virtuous circle, in which conscientization and empowerment go hand in hand and individuals can grow in understanding their place, role, responsibility in the community.

1.1.2 Inclusive research

The social agenda of the European Community developed over the past two decades, focused on education and lifelong learning not only as being drivers of the economy, but also as creators of socially cohesive societies. Considering that the voice of disabled people in Europe has grown over this period, there have also been efforts to promote their visibility, inclusion and participation. As reflected in the European Year of Disabled People (in 2003), the European Disability Strategy 2010-2020, the UN Convention of the Rights of Persons with Disabilities and the Europe 2020 Strategy.

Although the language of research and social inclusion is pervasive in European policy discourse, there is often a lack of clarity about its operational meaning in terms of which groups are to be included and what are the defining characteristics of research and inclusion (see chapter 4 for inclusive research as process of increasing participation and decreasing exclusion).

For this reason I am tentatively trying to suggest some challenges to Inclusive research, including a participatory approach in the involvement of groups.

Assuming “inclusive research” is research about understanding the world in order to contribute to change it, the fundamental aim is the empowerment of those participating in the research in terms of knowledge, skills and action (Walmsley & Johnson, 2003). In this view the voices of the participants are crucial and play an essential element for their credibility. The real-life experience of the participants is set within a broader context in which there is an ever present imperative facing the researcher, made by their assumptions, values and beliefs becoming increasingly transparent.

For this reason, researchers should respond to persons with disability’s “*demands for knowledge to create environments, products and services facilitating rights to full participation and equality*” (Priestley, Waddington, Bessozi, 2010). This requires awareness amongst researchers about the needs of persons with disabilities and to ensure an effective participation in the process of research.

The basic elements of participatory and emancipatory approaches for an inclusive research mainly consist in considering participants as co-creators of research instead of research subjects. Another element concerning the process of involvement, that needs to be included is reinforcement of critical awareness through encouraging self-confidence and self-determination. Self-determination is here assumed as a basic human right that “*enables people to control their lives and their destinies, including choice over personal activities, control over education, independence, participation in decisions, information on which to make decisions and solve problems, and so forth*” (Wehmeyer, 1998). All these elements contribute to support the processes of capacity building, achieving more empowerment and inclusion.

1.2 Challenges in an evolving society

According to the World Health Organization, more than one billion people in the world live with some form of disability. Nearly 200 million of these people experience considerable difficulties in functioning due to ageing, as well as the global increase in chronic health conditions. Moreover, people with disabilities have poorer health outcomes, lower education achievements, lower economic participation and higher rates of poverty than other people. This is partly because persons with disability experience barriers in accessing services, including health, education, employment, technology, products, transport, buildings as well as information. In Europe disability concerns an overall number of one out of six people, that is about 80 million. The poverty rate for these people is 70% higher than average, especially due to non-employment. People over 75 have a partial disability and more than 20% have a severe disability. Given this data, a comprehensive, updated and innovative scientific effort is required to come to a new understanding of disability that helps devise viable and effective policies to maximise inclusion and participation on equal terms (WHO, 2011).

It is therefore necessary to have a confrontation with new planning, including active citizenship, legal and voting accessibility, self-determination and new ways of understanding complex issues, such as deficits and taking charge, multiple disabilities, trauma and life re-organization. There are also further conflicts such as disability and migration, disability and detention; and new opportunities such as ICT, assistive technologies, aids and professional competences.

Given this situation, this thesis provide an overview of the challenges of Inclusive research, outlined here through trajectories of research into the main problem areas of disability and their interconnections. This view is based on the concept of inclusion in evolving society, that first took root in Scandinavia with the definition of the term “integration”, developed by the scientific community in the ‘50s and ‘60s and guaranteed rights for all. The shift in the concept of inclusion (Daniels, Garner, 1999) is easy: the latter indicates as a priority the access and participation of all - regardless of the severity of their deficits – to society, but pushes its commitment and its actions in favour of a lifelong participation, in all the dimensions of existence (school, work, family, society, environment) in which a subject lives and realizes her/his potential (Hollenweger, Haskell, 2002). The term “*inclusion*” was formalized for the first time with the Declaration of Salamanca in 1994, signaling the beginning of a renewal in culture (UNESCO, 2000). The inclusion theory is premised on the

social model of disability (Oliver, 1990 and 1996), as opposed to medical theory, and fundamentals for the Human Rights model (see chapter 2).

This paradigm emphasizes the difference between biological (impairment) and social (disability) conditions. It promotes the direct involvement of persons with disability and their families in policy decisions, focuses on removing barriers to economic, cultural, environmental, political, social domains (in school, the workplace, the leisure environment, etc.). It looks at the totality of a person's life, including educational, social and political spheres. It occurs first in context and then at an individual level, transforming the ordinary course of response, constructing the “*empowerment*”, which focuses on the decision-making processes of all the person with disability and their families (D'Alessio, 2005). This perspective emphasizes the principles of many international documents (as the International Classification of Functioning⁹ the UNCRPD, etc.), and constructs as: the person, the holistic approach, the integrative biopsychosocial model, the consideration of contextual factors, the relational perspective, the quality of processes and systems of participation in social life, including research.

Stainback and Stainback (1990) argue that “*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*”.

In accordance with this assumption, the trajectories of research proposed are based on the concept of inclusion as relevant issues to societal changes¹⁰ (Priestley, Waddington, Bessozi, 2010). Useful for providing suggestions to advance in the knowledge of innovative models for the development of accessible environments, equal rights (Bynoe, Oliver, Barnes, 1990), participation and equality for person with disability. The following is an outline of basic assumptions that led to this view of the issues.

The objective of the next paragraph is precisely to suggest trajectories of inclusive research aimed at understanding new barriers and emerging needs, using an holistic approach and an inclusive perspective.

⁹ WHO, 2001. ICF: International Classification of Functioning, Disability and Health. Geneva

¹⁰ EuRADE, 2008. European Research Agenda for Disability Equality

1.2.1 Suggesting possible trajectories of research

The contents of this section comes from a project proposal designed and submitted under the 7th Framework Programme (call identifier FP7-SSH-2011-2), including the contributions provided by partners that participated in the construction of the project¹¹.

In this paragraph I wish continue from the previous project structure and provide additional useful elements to define new trajectories of research aimed at understanding new barriers to inclusion and new forms of inequalities that a persons with a disability have to face in current societies. In particular for identification, assessment and generation of innovative strategies and solutions that could be adopted to reduce cultural, social, environmental and economic barriers to inclusion.

Aside from the concepts of Inclusive research and participation other concepts and assumptions were used to define the trajectories. These include the concept of: reasonable accommodation, self-strengthening of people with disabilities and holistic approach.

According to Art. 2 paragraph 4 of the Convention on the Rights of Persons with Disabilities¹² “*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*” (UNCRPD, 2006).

The co-evolutionary perspective and dimension of reciprocity underlying the concept of reasonable accommodation emphasizes the importance of the chargeability of human rights, especially the civil and political rights (Articles 1-21 of the Universal Declaration of Human Rights). Including the right to freedom of thought, citizenship, to form a family, etc., leading to the construction of the individual as a capable subject. This basic concept adopts the co-evolution and reciprocity dimensions, which indicates that the parties involved in a situation can/should both contribute to the success of the action itself, growing and evolving together. Reasonable accommodation is required to

¹¹ Proposal presented by the Department of Education Studies of the University of Bologna. Project partnership composed by: University of Surrey, Utrecht University, University of Applied Sciences and Arts of Southern Switzerland, Satakunta University of Applied Sciences, Associazione Italiana Assistenza agli Spastici Provincia di Bologna Onlus, Design for all Foundation, European Association of Service Providers for Persons with Disabilities, Institute for Health and Welfare, Young Foundation, Republic centre for support of persons with intellectual disability, The Center for Independent Living.

¹² UN, 2006. Convention on the Rights of Persons with Disability, G.A. Res. 61/106, Dec. 13, 2006

deal with problematic situations within the adequacy of the available resources. Inclusion is a goal (a regulative ideal) that helps and directs advancement 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).

Concerning the self-strengthening of people with disabilities, this assumption is based on the constant promotion of the “action and agency”. Investing in the process that leads to autonomous initiatives of agency (self as a product) is a major issue.

This can also be done through education that provides relevant opportunities to improve decision-making skills. The resulting interventions and policies need to go beyond the compensation of the disadvantages through the delivery of goods and services, expanding and ensuring the capacity to choose individually and collectively (Sen, 1999 and 2005). These choices do not only concern basic needs such as eating, health, education, but also the freedom and fundamental rights related to all dimensions of human life.

Last, but not least, integrated and holistic approach areas are needed in order to understand barriers and devise solutions to minimize them. Compared to approaches with a separate modality, this approach presents a view that analyzes intersections and conjunctions between different life areas. Including variables that allow the evaluation of dynamic factors facilitating or hindering inclusion, the support of the affirmation of civil and human rights and the reduction of barriers and obstacles.

On the basis of these concepts and assumptions, the hypothesis is that new trajectories of inclusive research can be devised and implemented at the intersections of different dimensions, which have traditionally remained separated, through the participation of persons with disability. These areas should be seen as integrated in the context of a complex and dynamic-faceted environment (physical, attitudinal, socio-economic and virtual), where new challenges and opportunities constantly emerging. In order to adopt and make easier the use of a holistic approach, a contextual map has been designed to organize and orientate the different research trajectories.

1.2.2 Contextual Map

Disability can be denoted as “cross-concept and universal”, “multi-dimensional social phenomenon”. Disability is an integral part of being human, is an equality approach which is recognized at present, but this may lead to an extended approach for all in the future. Addressing evolving challenges related to disabilities and contributing to future scenarios of inclusion requires the consideration of the existing and emerging needs of persons with disability, their families, friends, professionals and all the persons involved. From this viewpoint, it is sound to propose an holistic and dynamic approach in taking into account the multitude of aspects that are closely connected in the field of disability.

To facilitate this holistic understanding, following is proposed a Contextual Map in order to orient research and represent the framework where needs are analyzed, questions generate and new trajectories of research put forward.

The idea consists of using the Contextual Map to address the various disability issues in a cross cutting way. In order to systematize and structure the wide range of themes related to disability, the map is organized according to the areas identified in the EU Disability Strategy 2010-20, and the new priorities for disability research in Europe (Priestley, Waddington, Besozzi, 2010).

The map should be used not only to conceptualize three different dimensions of research (represented by the axes in figure 2), but also as an operational tool to visualize what resources, aids, facilitating or hindering factors for inclusion are available in a precise context and at a given time. Once the context are mapped in a cross cutting way, the design and implementation of case studies, experimentations and pilots, should be more efficient, besides the use of resources for the realization of best practices and recommendations.

The map includes three dimensions of research that could be used for understanding needs, situations and expectations. It means conceptualizing accessibility, inclusion and barrier-free environment in different sectors of life (“z” axis in the figure), investigating them with an integrated approach that avoids compartmenting or limited sectors analysis. The map could also be used to design actions, identifying a set of domains (“x” axis in the figure) where factors facilitating or hindering inclusion can be assessed, and scenarios of social innovation can emerge.

The last dimension (“y” axis in the figure) completes the framework considering the level of participation in the analysis of the intersection between sectors of life and domains. For this aspect is fundamental the involvement of persons with disability, families, friends, Disabled People Organizations (DPOs henceforward), activists in civil society, advocacy and lobbying organizations,

that could provide useful feedback, suggestions and contributions to the research and the development of policy (Oliver and Barnes, 2012). Promoting “analysis, understanding and action” are the core aspects around which the Contextual Map was designed.

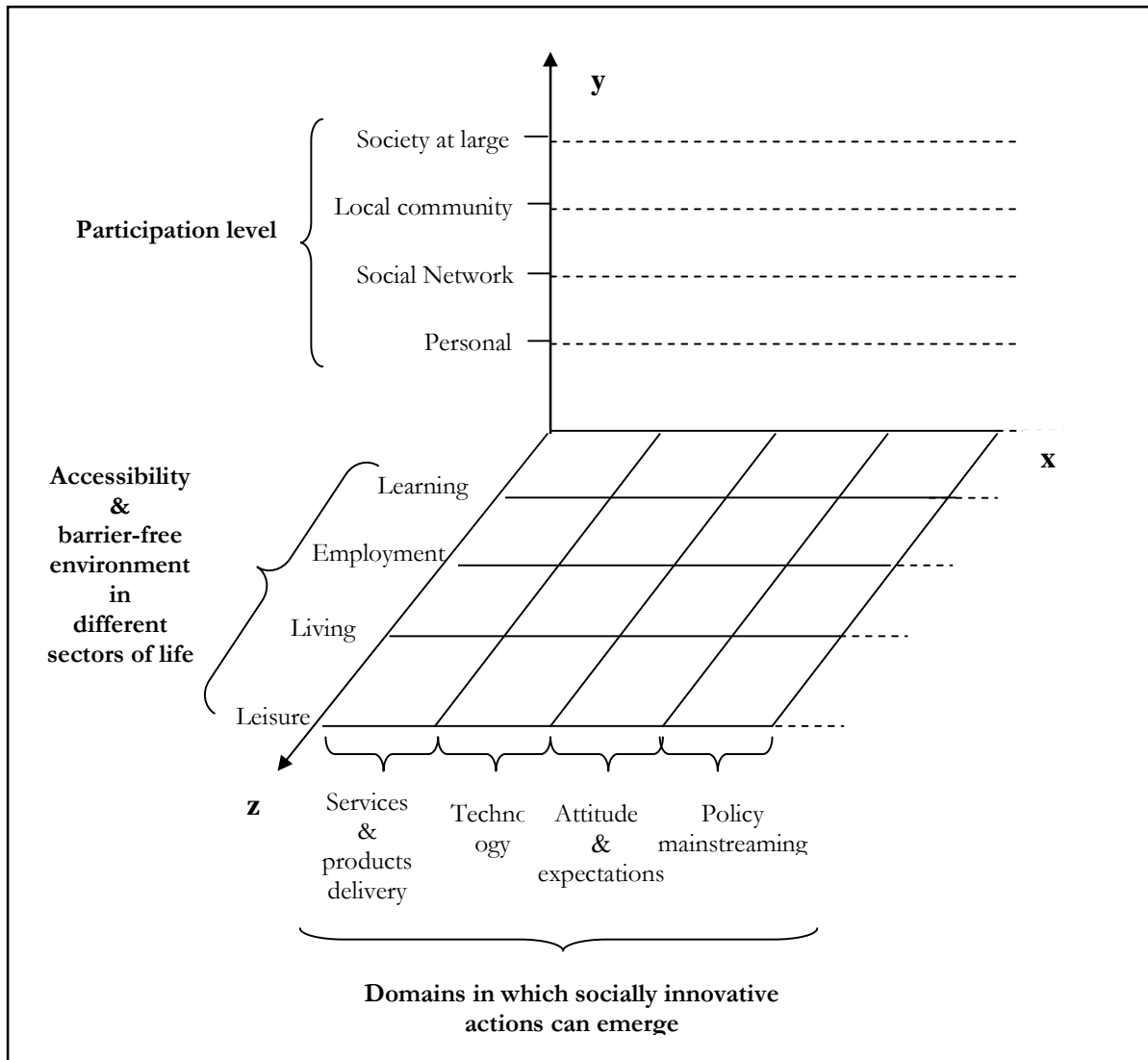


Figure 2: Contextual Map of possible trajectories of research

The three dimensions:

1) Sectors of Life - “z” axis

This dimension is based on the traditional approach to disability issues, where barriers are addressed and innovations are generated within 4 different “life sectors” or environments: learning, employment, living and leisure. These sectors are constituted by the ordinary dimensions of life, including different aspects of accessibility and inclusion that should be addressed to create a multifaceted barrier-free environment¹³.

The sectors of life chosen are also related to the work of Nirje (1972) about the scope of self-determination and the questions he posed to illustrate a list of statements made by people with mental retardation involved in a self-help group, and reported below:

- *“We want to choose our vacations ourselves and have influence over our education” (learning).*
- *“We demand that our capacity for work should not be underestimated” (employment).*
- *“We want to have an apartment of our own and not be infantilized” (living).*
- *“We want to have leisure time together with other (young) adults of the same age” (leisure).*

(Nirje, 1972, pp.178)

Reference to these questions and to what is reported in the EU Disability Strategy 2010-20 has led to the choice of what sectors of life are considered in the “z” axis of the Map.

2) Domains - “x” axis

This dimension is inspired by the International Classification of Functioning, and represents 4 domains: services and products delivery, technology, attitudes/expectations and policy mainstreaming. Within these domains facilitating or hindering factors can emerge, thus generating different scenarios of innovative developments. These domains are not exhaustive, but only illustrative, whereby it is possible to consider many other domains. The choice for taking into account these domains lies in the fact that are considered as possible tools or scenarios in which to develop actions in relation to the meaning of social innovation, civil and human rights and design for all (see chapter 5).

¹³ WHO, 2010. Community-Based Rehabilitation Guidelines

3) Participation level - “y” axis

This dimension implies the active involvement of people with disabilities, families and friends, DPOs, activists in civil society, advocacy and lobbying organizations for collecting feedback, suggestions, evaluations and new ideas coming from different sectors of life and domains. These contributions could be stimulated and reinforced through a participatory and emancipatory approach to research, in order to “change the social relations of research, trying to place the control in the hands of researched, not researcher” (Barnes and Mercer, 1997). This for stressing the need to involve person with disability effectively, not only to gather information and feedback, but also to foster an active roles, reciprocity, gain and empowerment, in order to became co-creator of research. The proposed framework would not be completed without a dimension which allows the analysis of barriers and assesses the impact, addressing change at multiple levels: personal, social network, local community and societal. The viewpoint means recognising that factors affect human behavior, at multiple levels and that assessing barriers or removing them requires the active involvement of persons to suggest effective solutions.

The level of participation and involvement in the research and analysis of the intersections between sectors of life and domains generating innovative scenarios is represented by parallelepipeds in the map. The level - height of parallelepiped - depends on the context characteristics, availability of resources and research aims.

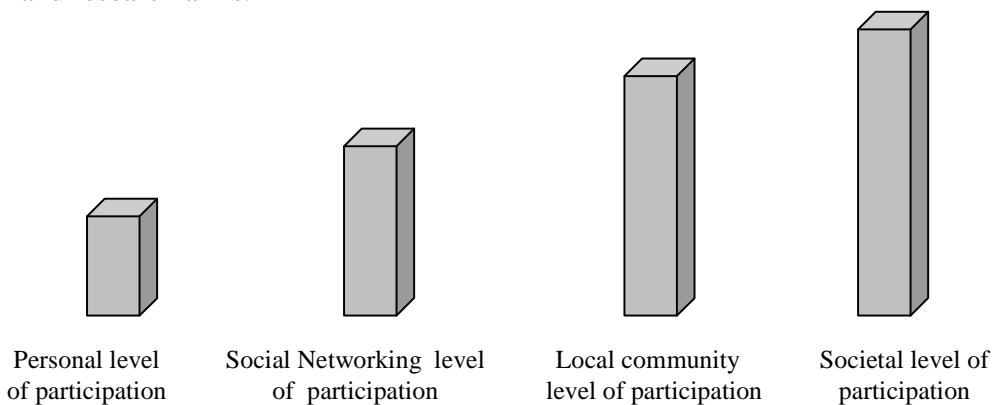


Figure 3: levels of participation

The intersections:

The intersections (or conjunctions) between life sectors and scenarios of innovative developments that should be analyzed may not include all the intersection points in the map, but those resulting from confrontations and feedback from the involvement of different participants, such as persons with disability, families, DPOs, agencies, professionals, researchers and experts. This should allow an active participation in society not only as beneficiary of research, services, products or environments - as object of research, but also as co-researchers and co-designers of research (see also chapter 5).

The intersections between life sectors and domains are the “hot” points of the research. These are the “spaces” in which effectiveness of services and products, technology, attitudes and policies - new or existing - could be analyzed and evaluated at different levels (such as personal, social network, local community and societal), providing evidences for reaching an innovative knowledge base.

In this thesis the combinations between the three dimensions are used for qualitative analysis, but it could allow a mixed-method study also using quantitative methods. This provides an in-depth insight into how barriers and inequalities – faced in different fields of life – often are intertwined with additional aggravating factors such as poverty, inaccessibility to the educational system, unemployment, social exclusion. So here solutions can emerge intertwining additional facilitating factors, such as learning supports, technology, accessible services, policy recommendations and participation.

Research should not address the whole fields such as learning or employment in themselves, but focus on intersections of the map, where to develop scenarios of innovative knowledge and actions.

In this framework there is also another dimension to be considered, “time”. Concerning this dimension, apparently not included in the Contextual Map, the reference is Bronfenbrenner’s Bioecological Model of Human Development (Bronfenbrenner, 1979). In particular considering the interaction between processes, person, context and time (PPCT model, hereinafter)

The final element of the PPCT model is time, that plays a crucial role in human development, that can be thought of in terms of relative constancy and change. Moreover, I have also considered what Elder stated, that “*individuals construct their own life course through choices and actions they take within the opportunities and constraints of history and social circumstances*” (Elder, 1998).

Referring to this assumption, it is clear that the trajectories of research highlighted below require a “*socio-historical contextualization*”

(Bronfenbrenner, 1995). As well as the intersections in the map (points of interest), such as the level of participation in research, innovative development and ultimately solutions, that can change over time. This clarification is aimed at highlighting the fact that the model of interpretation offered by the map does not intend to be only like a photograph of different contexts or scenarios. But as tool able to analyze the context evolutions, including different needs at different times (Bronfenbrenner & Crouter, 1982).

1.3 Progress beyond the state of the art

In order to inquire into new emerging needs and understand what factors hinder or facilitate inclusion, some sample of trajectories of research related to different areas of disability are reported here. These do not claim to be exhaustive, but explanatory of a holistic approach aimed at understanding what barriers exist to accessibility and inclusion. Each trajectory provides descriptive elements linked to open questions that could be used for future investigations. It also includes a contextual map for each trajectory, in which the intersections between life sectors (learning, employment, living and leisure) and domains (services and products delivery, technology, attitudes/expectations and policy mainstreaming) represent the space to be analyzed in deep. The analysis conducted with a participatory approach.

In this framework participation represents the basic element that drives the development of innovative actions to reduce exclusion, especially in the research field.

1.3.1 Education

The rate of attendance at school, in the age group between 16 and 19, for young people seriously disabled is 37%, and partially disabled young people is 25% (WHO, 2008). The current reductions in public financing to schools (often due to the economic crisis) on one hand, and the pressures by family and social demands on the other hand, create a problematic context for inclusion in schools. In this framework, support for person with disability is increasingly dependent on the skills and competencies of practitioners, who are therefore extremely relevant.

Possible trajectory of research

The key research needs are twofold: the first one trying to investigate - for some limited deficits such as blindness, deafness, physical disabilities - the role of professionals as communication facilitators, readers, etc., in encouraging personal autonomy.

The importance of this aspect is underlined by many national and international associations for the blind for instance (Caldin, 2006; Caldin, Bullo, Turatello, 2007).

The second one focus on the inclusive processes at school, starting with best practices in schools which seem to positively address issues related to inclusion, investigating for example the organization by “classes” or by “levels” of learning.

In this trajectory of research questions could be:

- What are skills and competences required for professionals (teachers, tutors, trainers, etc.) to reduce the limits generated by deficit such as blindness or physical disability?
- What are practices and processes possibly used by professionals for encouraging personal autonomy, especially in learning?
- What are samples of policy at national and EU level that can support inclusion in school?
- What are benefits vs limits of the organization by class?
- What are benefits vs limits of the organization by level?

Considering the trajectory “Education” in the framework of the contextual map further research questions can arise.

Education in the life sector of learning is cross-cut by all dimensions of possible social innovation, and this can generate research questions, for instance how to organize innovative service for persons with educational needs in order to facilitate learning in non formal contexts.

Regarding assistive technology and the relation with living, which environment can assistive technology be applied to (at school and/or house), how to facilitate people to take full advantage of new developments in terms of learning (Allsop, Gallagher, Holt, Bhakta and Wilkie, 2011).

Another life sectors that could be included is the intersection with employment, considering the role of education in the relation between learning (for example in the processes for competences certification) and access to Labour market (Polidano, 2010; Weddington, 1995).

An other can refer to the choice of policy and the consequent impact on education, or what are the best attitudes to support to social inclusion.

Possible solutions to these issues should also be evaluated considering the level of involvement and participation, that in the case of education can include personal, local and societal level (see fig. 4).

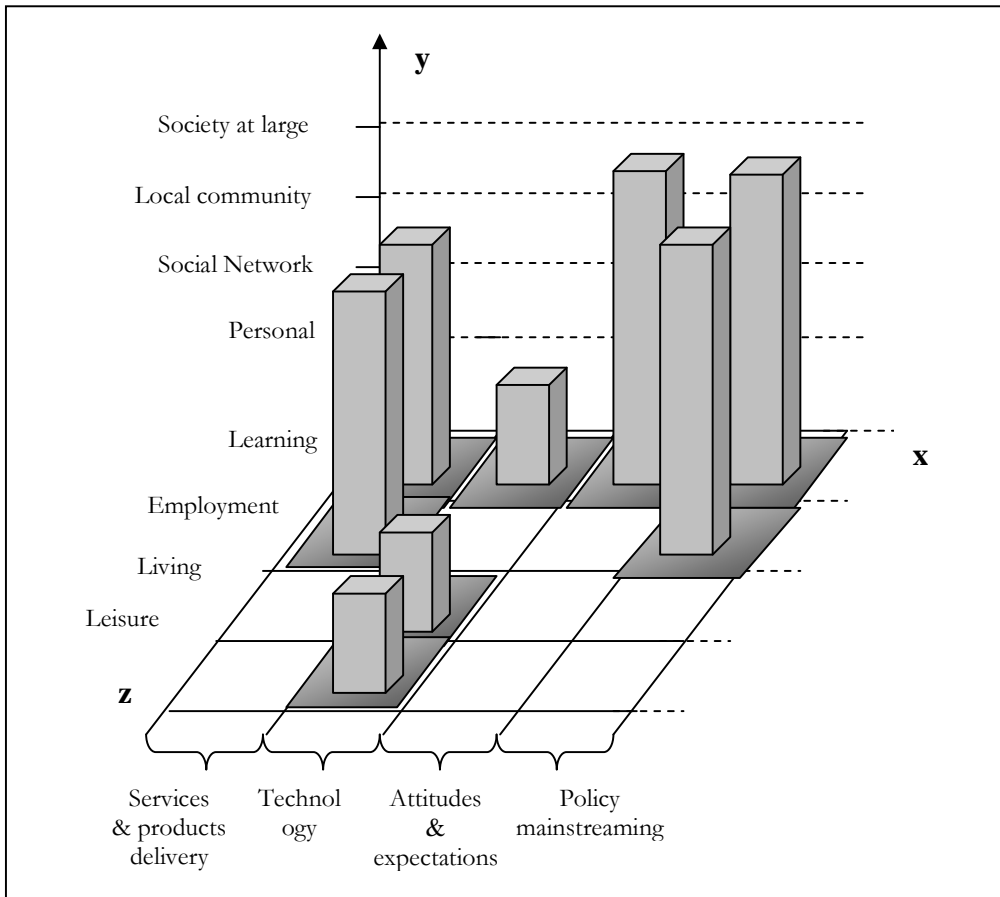


Figure 4: The trajectory Education

1.3.2 Ageing

People with disabilities often encounter problems as they age, but more importantly their families also encounter problems. This increases the need for care, at an age when the parents themselves need to be cared for. Moreover, the cognitive and relational functions of persons with disabilities tend to deteriorate with age. In such situations, the role of brothers and sisters, often already disadvantaged in personal and social opportunities, becomes relevant.

Possible trajectory of research

To provide more equitable provision of support for older people and families, there is a need for new knowledge. In this area great attention should be paid to the relation between the ageing and families. A specific research could be aimed at elaborating policy recommendations on support and guidance, especially on welfare forms of home care, which limit the institutionalization and ensure adequate and affordable housing. Another facet could also be represented by identifying whether designs of inclusive micro-environments in the home or community area can solicit, initiate and support solutions for mutual-help and solidarity of neighbors not engaged in work activities.

In this trajectory of research questions could be:

- What policy recommendations can face the problem of the ageing of parents of persons with disabilities?
- What are possible contributions by social and educational Agencies for supporting the ageing of parents?
- What are practices to improve the home-care and support measures of mutual-help?
- How to engage civil society in supporting families and what role of local authority?

In the trajectory “Ageing” the intersections taken into account refer to the life sectors of learning, living and leisure, cross-cut by the dimensions of services and products, assistive technologies for aged person designed for example using a Design for All approach, in order to focus on environment accessibility (living) and the social inclusion (Barnes, 2011).

Another intersection could consider the relation between the expectations of lifelong learning and ageing, as a possible field of investigation. Also the innovation of services generated by policy mainstreaming aimed at promoting accessibility to building, house living and environments.

Furthermore, assistive technologies can represent facilitating factors for living, as home automation, if practices and solutions to be adopted are studied and outlined.

Possible solutions to these issues should be also evaluated considering the level of involvement. For example in the intersections between leisure and service/products delivery the level of participation can be local; unlike in leisure and technology the level of involvement can be personal.

While considering the intersection leisure and policy, the level of participation should be at societal level. The same for the sector living. Differently the

intersection between learning and technology in the case of ageing can have a personal level of participation, such as for learning and attitudes (see fig. 5).

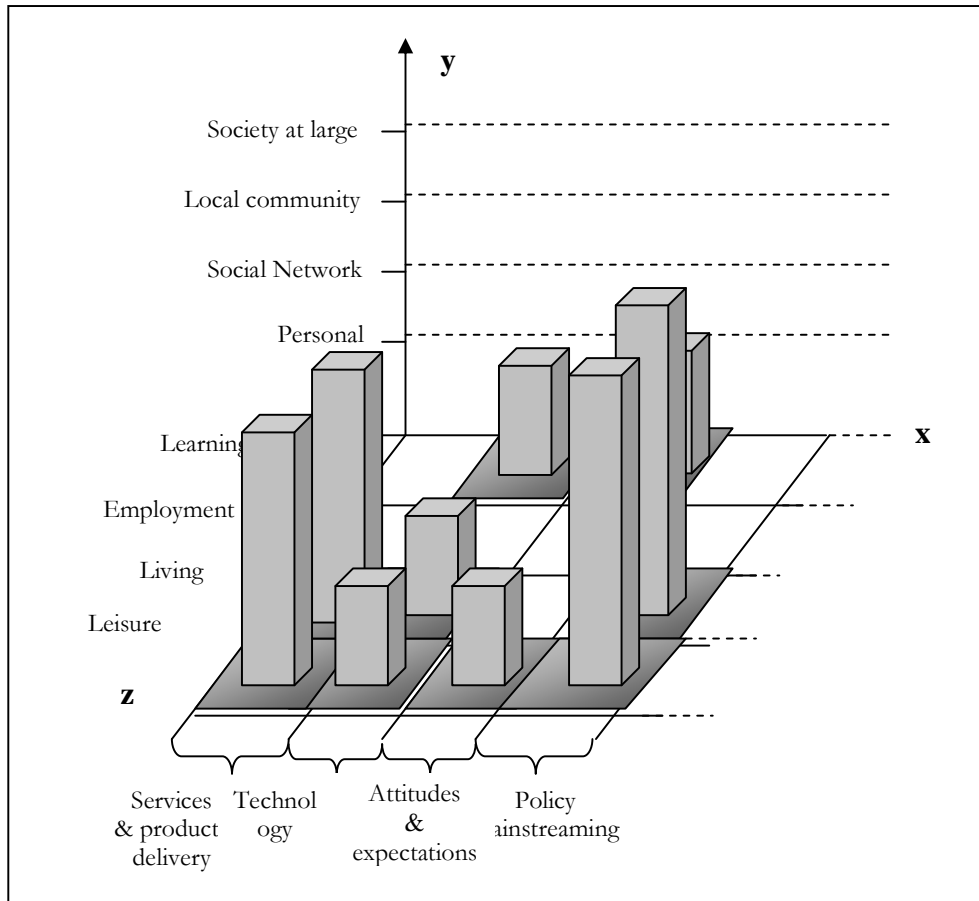


Figure 5: The trajectory Ageing

1.3.3 Multi-discrimination

Three examples of multi-discrimination are reported as follows: they could be analyzed in depth in order to gain a greater understanding of this trajectory of research, currently poorly investigated:

- a) It appears that there is significant discrimination in prisons against detainees with disabilities. These people are among those who have few alternative measures. This issue deserves, at EU level, a thorough investigation that raises awareness and produces new solutions.
- b) In migrant families who have children with disabilities there is wide vulnerability. The issue is of particular concern in some EU countries, where the families arrive already with a child with disability, believing they can receive more care and assistance in the new country. The reality is very different from expectations and results in practical difficulties of various kinds: assignment of adequate housing for the child's disability, access to services, lack of friendship and kinship networks, etc. For immigrant families, the school remains an essential reference, presenting itself as a welcoming educational community (Canevaro, D'Alonzo, Ianes, Caldin, 2011; Caldin, 2012).
- c) The connection between gender and disability is far from being sufficiently investigated. Nevertheless, women and girls with disabilities have been proved to be subjected to an enduring double discrimination: sexism as well as disability-related dynamics of social exclusion. Available research data indicates that women with disabilities are significantly poorer than men with disabilities. They are more likely to be unemployed and, if employed, they receive considerably lower wages than men with disabilities. Moreover, widespread stereotypes based on gender and disability greatly limit disabled girls and women from educational opportunities, access to public services and provisions, access to healthcare, and social environments more than either disabled male or nondisabled female counterparts. For these reasons, European agencies are now addressing multiple and intersectional discrimination in various areas of research (as proved by the recent European Fundamental Rights Agency project on access to healthcare, in which the Department of Education Studies of the University of Bologna has taken part of)¹⁴.

Possible trajectory of research

Starting from the definition of disability, it's important to take into account how to remove as much as possible this term from the idea of disease (see chapter 2). This is particularly relevant in situations of multiple-discrimination that risk being treated with medical approaches instead of being ascribed to the approach

¹⁴ <http://fra.europa.eu/en/publication/2012/inequalities-and-multiple-discrimination-healthcare>

based on rights and capabilities (Sen, 2005; Mitra, 2006; Biggeri and Bellanca, 2011; Biggeri and Santi, 2012), as the situation of prisoners with disabilities, migrant families with children with disability and women with disability. Therefore, research should investigate what solution to reasonably compensate the disadvantages suffered by offering resources and services, expanding and ensuring the capacity and power of individual and collective choice (Carazzone, 2006; Jones, 2001; Lansdown, 2001; Quinn and Degener 2002).

Considering the three samples of contexts described in which multi-discrimination manifests strongly, the needs of research should focus:

- a) For prisoners with disabilities on the experiences carried out on the accessibility of workplaces (Caldin, Cesaro, Ghedin, 2007).
- b) For migrant families with children with disability on how school and social-health services could implement support actions, as schools opened in non-school periods for language learning, educational services for early childhood education pathways that initiate parenting support, social services establishing information and training, etc.
- c) Recognizing gender inequalities is important if research is to acknowledge intersectional discrimination going beyond the state of the art. In this case by providing evidence of the fact that the woman with disability or girl's awareness of being excluded or discriminated on grounds of her disability rarely goes together with awareness of being discriminated on grounds of gender.

In this trajectory of research questions could be:

- How to compensate for disadvantages by offering services able to expand and ensure the capacity/power of individual and collective choice?
- What practices exist concerning prisoners with disabilities and access to the workplace?
- How school and social-health services could implement support actions for migrant families with children with disabilities?
- What practices or approaches recognize and reduce gender discrimination for women affected by disability?
- How to raise awareness and to whom to disseminate research findings about multi-discrimination?

In the trajectory "Multi-discrimination" for example the intersections between learning and services provided to disabled children with migrant backgrounds can require a local level of participation. Differently in the case of the

intersection between employment and policy if considering women with disability or prisoners with disabilities (see fig. 6).

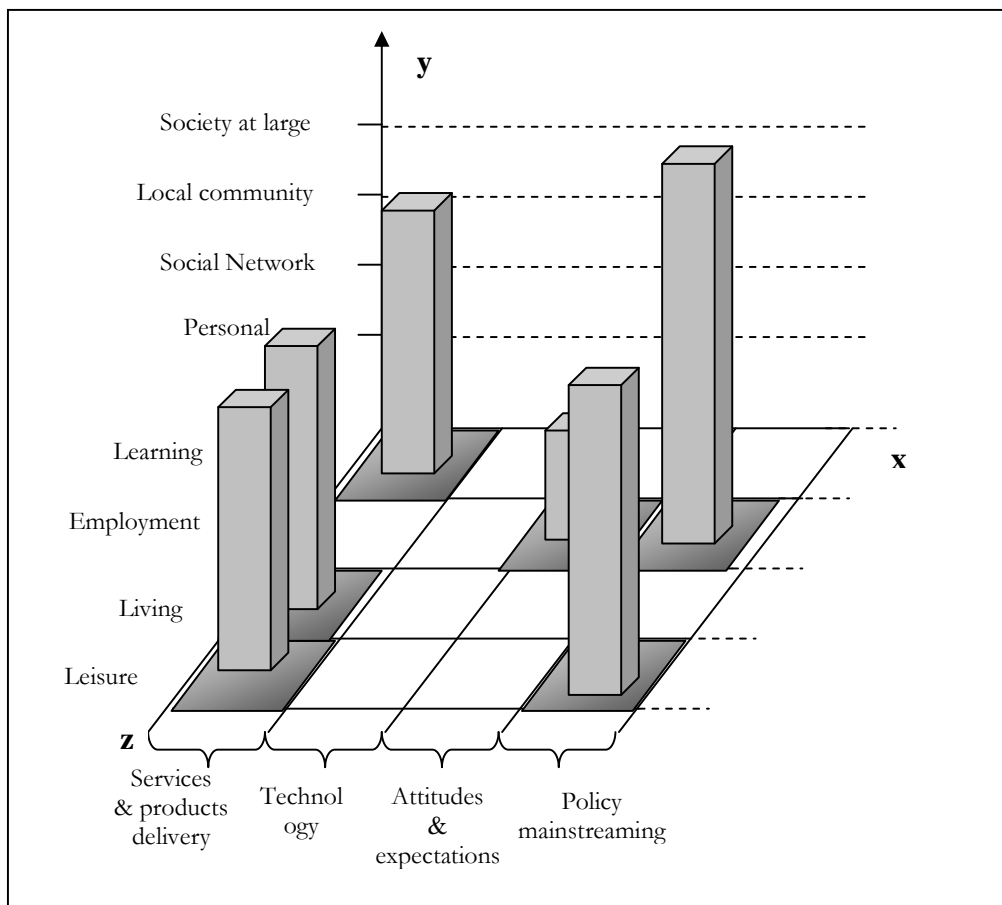


Figure 6: The trajectory Multi-discrimination

1.3.4 Multi-disability

There is an increasing trend of births of children with multiple disabilities, also deriving from prematurity (Caldin, Pradal, 2007). The services are not yet prepared for such an emergency and there are very few specialist available for the parents to turn to. For instance, insufficient protocols and agreements for

the communication process of diagnosis, often supported only by assistance at school.

Possible trajectory of research

In order to go beyond the state of art research should develop proposals of actions and practices to respond to the need of educating family members who, starting from their home care, become competent with constant processes of empowerment. Thus, parents and those who live in the context of the person affected by multi-disability, could acquire knowledge of rehabilitation and community-based education (Caldin, Milani, Visentin 2007 and Caldin, Milani, Orlando 2007 and Caldin, Milani, Visentin 2008 and Caldin, Serra 2011).

In this trajectory of research questions could be:

- What are samples of support services or best practices of home-care for children affected by multi-disability and for their family?
- How to transfer knowledge and practices of community-base rehabilitation?
- What data is available about the increasing trend in births of children with multi-disabilities?

In the trajectory “Multi-disability” the intersections considered refer to the life sectors of learning, living and leisure, cross-cut by the dimensions of services/products delivery, technology and policy mainstreaming. For example, learning could benefit new services aimed at facing open problems such as drug delivery and development of therapies during school hours. In this case the level of participation can involve the society at large or local community. The intersection between living and service could address situations in which parents fail to bring children to health and social services because they cannot be moved (children with breathing machines, etc.). The role of assistive technology in facing many problems due to multi-disability in the area of learning and living (accessibility) is still a theme with few references, that should require the involvement of different participants (family, education agency, social service, etc.) with a community level of participation in research focused on this aspect.

What policies can be mainstreamed in terms of living and social inclusion in case of multi-disability, especially for families that often feel alone, is an other interesting aspect to be analyzed using a community or societal level of participation in research.

While in the intersections between technology and living or technology and learning, in case of multiple disability the participation level can require a personal involvement, including family.

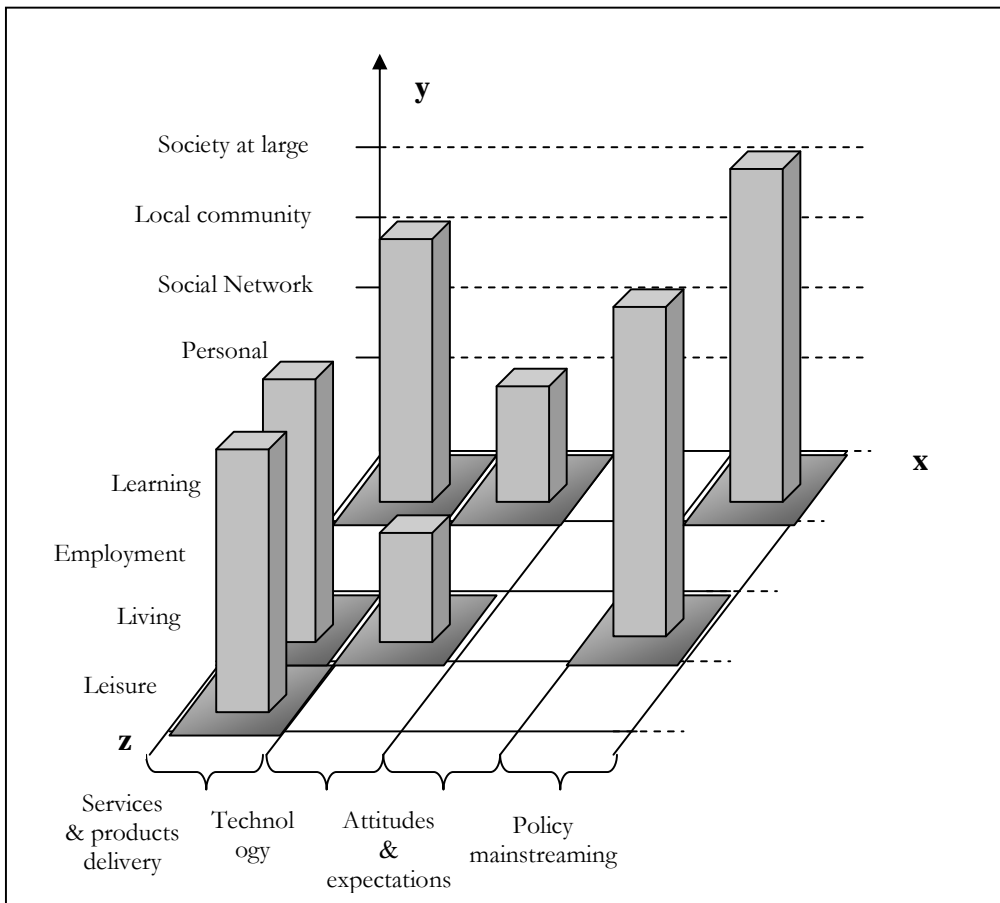


Figure 7: The trajectory Multi-disability

1.3.5 Injury

An increased incidence of trauma is a huge source of disability. The phenomenon, in all its forms, is quite recent and a policy must be addressed to this area.

The few specialized rehabilitation structures that deal with trauma, require a great economic expenditure.

The existing facilities are often inadequate for the people with who find themselves disabled (assistive devices, rehabilitative approach).

Consequently traumatized people themselves do not recognize these structures as environments that meet their needs and the current staff is not trained in the new rehabilitation approaches.

Possible trajectory of research

To provide more knowledge and support for this kind of particular situation research should focus on hypothesis of targeted experiments of parent-training, training medical, education and rehabilitation staff, in order to provide indications on how to define, manage and organize appropriate training modules.

In this trajectory of research questions could be:

- What possible policy can contribute to facing the increasing phenomenon of disability due to trauma?
- What facilities are needed and how should they be organised (social and medical services) to respond to the needs of traumatized people?
- What best effective practices exist regarding training modules of medics, care givers and educational staff?
- What are the implications in the re-definition of the project of life?

In the trajectory “Injury” the intersections refer to all life sectors, cross-cut by the dimensions of services, technology and policy mainstreaming.

For example, sectors as living and employment can take advantage of the development of a personalized solution to support eventual reduction of functionality.

In this case the level of participation could be personal. Another example concerns the inadequacy of existing facilities and the training of professionals. This requires more investigation, especially for solutions based on more effective learning, intervention practices addressed to traumatized people.

In this case the level of participation could require local community involvement, that could help to identify resources to improve training of professionals and sometimes families.

Policy, at societal level, could play an important role promoting the adoption of measures aimed at reducing possible forms of exclusion in leisure (e.g. practice of sport), or living (e.g. building accessibility).

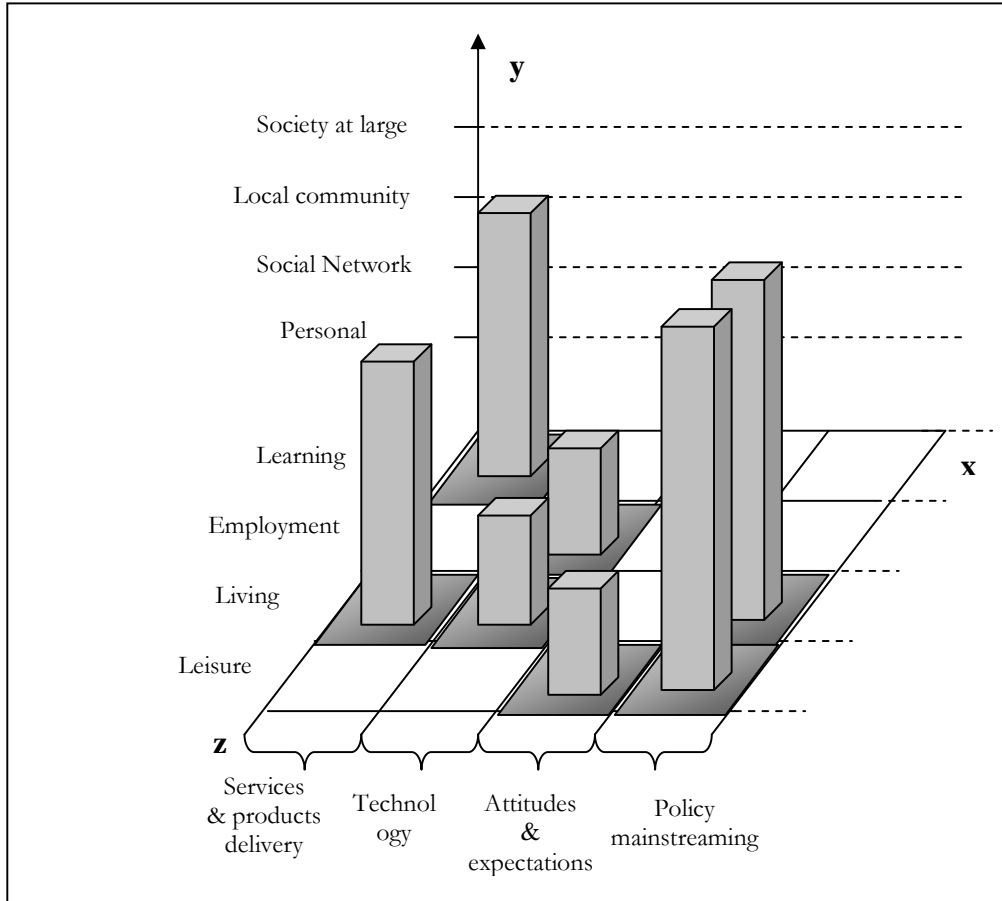


Figure 8: The trajectory Injury

1.3.6 Accessibility

In this trajectory of research accessibility refers mainly to Information and Communication Technologies (ICT) and Assistive Technology (AT). This specific sector plays an essential role in supporting daily life in today's digital society. ICT-AT are used in various fields of life such as "...at work, to stay in

touch with family, to deal with public services as well as to take part in culture, entertainment, leisure and political dialogues”¹⁵.

Possible trajectory of research

In order to provide support for understanding issues related to accessibility through ICT-AT, research should analyze and study how technology can contribute to the generation of innovative solutions, where services and product solutions are assessed on the basis of real life experiences.

In this trajectory of research questions could be:

- How to contribute to the generation of innovative solutions in the domain of services using ICT-AT devices?
- How to contribute in the mainstreaming of innovative technological solutions?
- How to disseminate information and tools to not digital natives people?

In the trajectory “Accessibility” the intersections refer to all life sectors, thanks to the strong use of ICT-AT in almost all areas of life, cross-cut mainly by the dimensions of services/products delivery and technology.

For example for services provided by ICT-AT, as recommended by the Digital Agenda For Europe (2010-2020), Action 64 *“Make sure that public sector websites are fully accessible by 2015: The Internet is becoming a major channel for the provision of services. Posing barriers for some citizens to access them – websites that are not built with accessibility features – leads to social exclusion and a negative economic impact. Expected effects and impacts concern an important part (15%) of the EU population that are disabled, many of the elderly, and about 60% of regular users who expect to benefit from improved web-accessibility”¹⁶.*

In this sense while the participation level can be personal in the development of solutions for leisure or living, it should be social networking or communitarian level in the development of services related to the employment or learning. Another example is technology, that crosses cut all sectors of life and that should develop and research solutions using a personal level of participation.

For example, adopting the Design for All method, through which manufacturers and service providers try to design and produce new technology for everyone, suitable for the elderly and people with disabilities.

¹⁵ e-Inclusion, http://ec.europa.eu/information_society/activities/einclusion/index_en.htm

¹⁶ Digital Agenda For Europe, http://ec.europa.eu/information_society/newsroom/ce/fiche-dae.cfm?action_id=222&pillar_id=48&action=Action%2064%3A%20Make%20sure%20that%20public%20sector%20websites%20are%20fully%20accessible%20by%202015

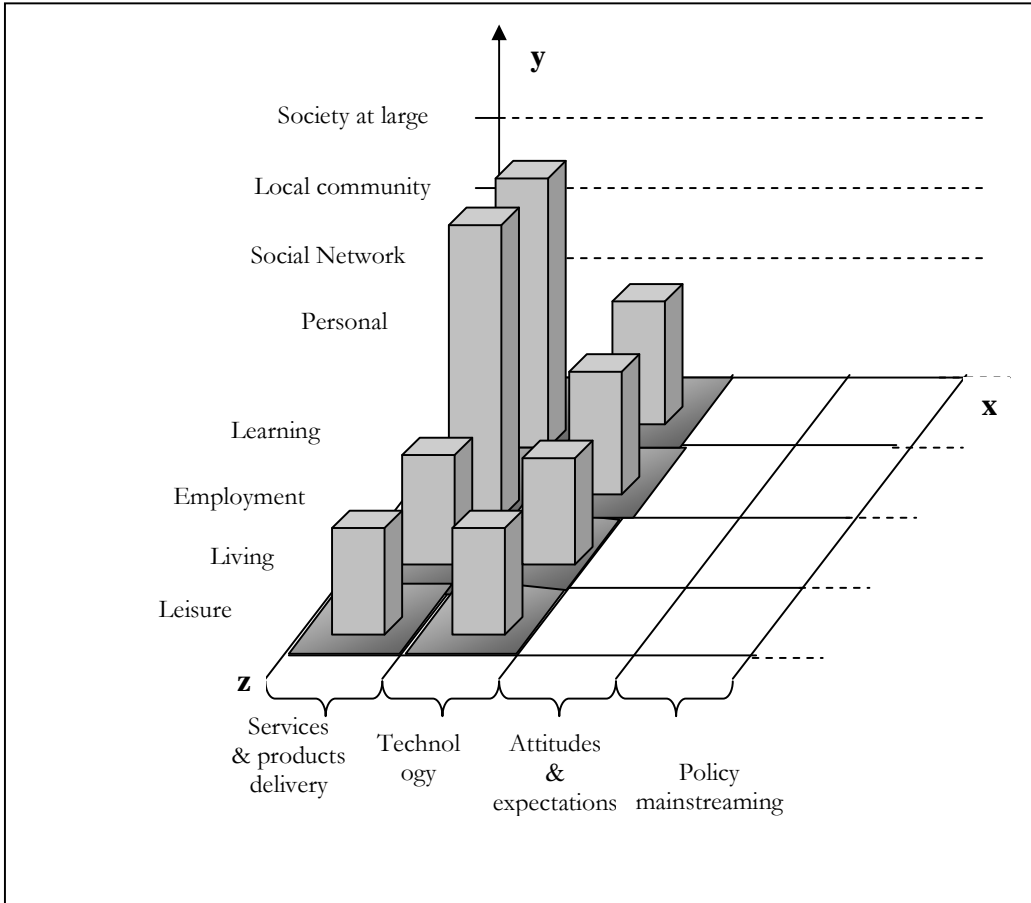


Figure 9: The trajectory ICT Accessibility

In this section of the thesis I have outlined current strands of inclusive research in the area of disability.

In order to face the challenges that this analysis highlights, what is needed are innovative research methods based on inclusion, as are the emancipatory and participatory approaches.

I think that for the realization of effective studies and research on disability aimed at providing evidence-based knowledge for policy and decision makers, it is necessary to adopt a holistic approach to understand and describe the complexity of the field, systematizing information from various contexts and scenarios of people's lives.

For this reason it is also necessary to widely develop and promote the participation and involvement of persons with disabilities, their families, DPOs, mixing bottom-up and top-down approaches, especially to engage non-academic participants in researches.

The trajectories of research described should be considered with a changing academic perspective, in order to find creative solutions capable of shifting from a medical model to approaching disability issues towards a model based on Human Rights.

Following this central path are questions and issues aimed at detecting, analyzing and researching the possible benefits, samples of social innovation, best practices, processes and policy recommendations, considering disability as a cross concept, universal, multi-dimensional social phenomenon and integral part of being a human.

CHAPTER 2 - Frame of reference

“*Words do things*” (Austin, 1962), they can be useful instruments, but also dangerous devices when their imprecise use refers to phenomena, which in the common mentality expresses “diversity” to be exorcized (avoided-wary of). The problem of terminology related to “disability” and “inclusion” identifies and distinguishes a particular anthropological vision, offering social representations rather than personal view, because all these terms are culturally constructed.

In the use of terms, it is important to explain the theoretical background of reference and the resulting operational dimension, choosing a few key-words that contain information useful for the understanding of the frame of reference of this thesis.

As indicated by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD henceforward), disability is itself an evolving concept, which identifies new obstacles and new facilitation for inclusion in a social context, historically situated.

This situation is linked to the evolution of society with regards to disability, which leads to different representations and perceptions, according to the importance of elements of obstruction or facilitation and actions put in place to reduce or to increase them.

EU countries that have worked more on inclusive processes have made it clear that what started as a “specialist” responses to disability have become beneficial for all, strengthening the EU membership and soliciting active citizenship.

The World Health Organization (WHO henceforward) and the United Nation documents, as the International Classification of Functioning, Disability and Health (2001), the International Classification of Functionality, Disability and Health for Children and Youth (2007), and even more interesting from a political point of view, as the Salamanca Statement (1994), the International Convention on the Rights of Persons with Disabilities (2006), the Declaration of Madrid (2007), and the European Disability Strategy (2010), represent the main documents used to define the frame of reference of the present research. In particular for what concerns the meaning and the understanding of the terms disability and inclusion.

The analysis of this documentation was the first step for the definition of the framework in which the concept of a “person with disability” was adopted. When using this definition, although related to a single person, I wish to consider as a constant element the existential aspect of the community and then

design innovative actions and interventions tailored to specific situations through the participation and, most notably, the emancipation of disabled people. The innovative aspects of these documents consist in providing an overview and a coherent vision of different dimensions of health at biological, individual and social level, introducing a category of contextual factors, which allow the planning and organization of interventions in the social and environmental field.

This also foresees a focus on the paradigm shift: the responsibility is no longer attributed to the excluded person because of a disability, but to the external structure.

From this view point, when talking about restricted participation I refer to “handicap”, whereas when I talk about limiting the activities I mean “disability”. It is also important that people are not marked or defined only through expressions related to their disabilities. For this reason the term “person”, that in the humanities explains the theme of commonality of existential situations in which each one has constraints and resources (Heidegger, 1927), is included in the definition adopted.

The perspectives contained in the international documents are addressed to policies and interventions which promote and support the leadership of persons with disabilities.

The way to support leadership, here hypothesized, consists in the adoption of open participation in the co-creation of environments (such as cultural, social, economical - products, services and buildings - educational, etc.), in order to make life easier for vulnerable groups, through the application of participatory and emancipatory approaches for the design of social innovative practices.

Before outlining in the next chapters how to adopt these approaches to facilitate people’s lives, I wish to present in the first part of this chapter some basic concepts regarding the meaning of the terms “disability” and “inclusion”.

In the second part a brief overview of the different models and approaches developed in order to deal with disability issues is provided.

It specifies that the main difference between models and approaches is that models are “rigid” structures that do not allow changes or modifications of their assumptions and references, whilst approaches are more flexible and adaptable instruments to be applied in different socio-cultural contexts.

The last paragraph presents the movement of the Disability Studies, whose features do not consist in having a defined frame of reference, but in following principles and adopting innovative contributions in relation to the contingent social and individual needs.

The presentation will try to outline a picture of different models developed to understand disability, from structured models, to less rigid approaches, until a

free movement often defined a-theoretic, the Disability Studies (Barnes, 1995). The difference between model and approach is that, while the first is more rigid and static, the second is a more dynamic process implemented according to certain principles.

This section will not attempt to provide a comprehensive review of the literature associated with these models and approaches, nor to explore with thoroughness the debate and theoretical differences among each of these. Rather, it examines many of the defining features, in order to demonstrate how disability is an evolving concept that in its representations reflects cultural models, social attitudes and policy orientations. A particular focus is on the elaboration of the participatory dimension in order to provide useful elements to define the framework of reference of the present thesis.

2.1 Definition of disability

In this thesis I wish to consider the word “disability” as an evolving term which reflects cultural, social, political, attitudinal and philosophical orientation of a society. To understand changing perceptions of disability it is important to remember that *“there is substantial anthropological and sociological evidence that societal responses to people with disabilities varies across time, culture and location”* (Barnes, 2011; Ingstad, 2001).

But in order to avoid the adoption of a generalist definition my choice is to refer to two precise meanings, the first provided by the World Health Organization and the second by the capability approach.

The definition provided by WHO considers disability as *“an umbrella term, covering impairments, activity limitations and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations”*. Thus disability results as an *“evolving concept”* representing a complex phenomenon, reflecting an interaction between *“features of a person’s body and features of the society in which he or she lives”* (WHO, 2007).

The second meaning assumed defines disability in terms of *“capability or functioning deprivation”*, that occurs when an *“individual is deprived of practical opportunities or functionings as a result of an impairment or health condition”* (Burchardt 2004; Mitra 2006, 2011; Welch 2002).

The reason I wish to refer to the definition originating from the capability approach that is more flexible and adaptable to different contexts, needs and innovations in the field of research.

The importance of definitions in this field is due to the fact that, despite the interest in disability by social, political and academic participants, the dominant and common meaning attached to disability remains rooted in a view of individual tragedy, especially in the most industrialized and western countries.

Although the debate on the meaning of disability has been generated by disabled activists, movements, organizations and academics since the 1960s, it is still widely regarded as a health issue concerning mainly medical diagnosis of individual pathology, functional limitations and deficits (Goodley, 2012).

Thanks to the contribution of the disability movement and many authors, the realization that the dominant definitions of disability pose problems for individual and group identity has come to the light. This has led to the beginning of a challenge about the use of terminology and the attempt to build a disability culture that challenges the ideology of personal tragedy that continues to influence the dominant ways of interpreting and understanding disability.

It is important to highlight that the use of the terminology is strictly related to the kind of model or approach adopted in order to analyze, interpret and understand disability. For this reason in the next paragraphs I will provide a summary of the main paradigms developed to deal with the issues related to this field.

In general, the paradigm through which some definitions are elaborated has the power to determinate what kind of cultural, social and political approach will be used to cope with the phenomena. In order to clarify this point I wish to illustrate an example. For the medical model a disabled person's inability to find a job is attributed to their lack of ability to carry out the required tasks and activities, or capacity to undertake the necessary roles.

In this way, such arguments ignore the fact that despite environmental and attitudinal barriers many disabled people can compete successfully in the labour market and find paid work.

Contrariwise, if the issue is approached with a social model the reason by which the unemployment rate amongst disabled people is much higher than that of the non-disabled, it is more likely related to structural rather than personal explanations. This is because persons with disability generally experience exclusion from the workplace due to attitudinal, environmental, social and cultural barriers (Barnes, Mercer and Morgan, 2000 and 2002; Oliver & Barnes, 2010; WHO, 2011).

This model moves away from the individual to the social and collective disadvantage of disabled people. This consequently determinates different policy measures and responses.

The example reported shows the value of a social and cultural re-assessment of dominant thinking and behavior. The focal point of this example is not to *“replace error with truth but rather to engage in critical reflection to improve our understanding of the society and our subsequent actions within it”* (Bauman, 1990).

If disability is interpreted only as a tragedy, disabled people will be treated as victims of tragic happening or circumstance, because if situations are defined as real, then *“they are real in their consequences”* (Oliver, 1990). And if it is true that society continues to respond to disability in a predominantly individualistic way, for the influences of a medical model of disability, then it needs to shift the paradigm of reference and change the terminology used in order to provide new understanding, new social beliefs and new attitudes.

Another issue that I wish to clarify in this paragraph concerns the use of the term to indicate persons that live in a situation of impairment, handicap or disability, because I think it is important to be aware of the complexity concerning the issue of terminology. In the medical model and in health settings people with impairments are referred to as “patients”, that represents a precise health setting, such as clinics, hospitals, rehabilitation centres, etc. The social context instead largely prefers the term “people with disabilities”, although also the term “differently able” is currently diffused in some sub cultures.

Although a satisfactory universal definition is probably impossible to achieve, I wish to adopt that argued by the UNCRPD, in which persons with disabilities include those *“who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”* (UN, 2006).

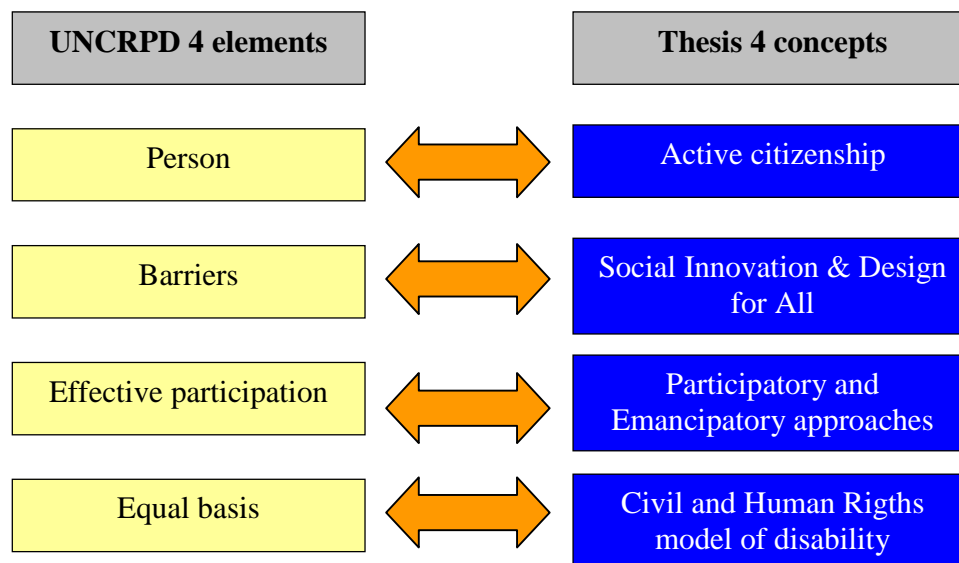
The definition enshrined in the UNCRPD considers four important elements, that are:

- a) Person
- b) Barriers
- c) Effective participation
- d) Equal basis

These elements are particularly relevant to the themes discussed in this thesis and will be analyzed in the next paragraphs and chapters. The reason for this lies in the fact that they *“provide the basis for research and actions in the field of disability”* (UN, 2006) and allows for the description of disability on the

level of body functions, activity limitations, participation restrictions, environmental factors and rights.

Furthermore, these four terms are in strict relation with four different concepts that represent the basis of this research in the field of disability, as shown below:



I will return to these elements and concepts in the next chapters (3, 4 and 5) where they will be analyzed in depth. I wish to introduce them in this section in order to show the relationship between: what is claimed by the UNCRPD, what I mean when using the term “people with disabilities” and the ideas adopted to provide evidence of the research hypothesis, according to which “*an open participation in the co-creation of the environment, makes life easier for vulnerable groups*”.

In particular, applying the concept of Active Citizenship to the element “person” could promote self-determination, empowerment and self-awareness. When dealing with the element “barriers”, the concepts of Social Innovation and Design for All could be used to implement services, products and environments reducing barriers and improving accessibility. The adoption of Participatory and Emancipatory approaches in the research field and interventions could ensure the element “effective participation” of a person

with disability. Finally, the element “equal basis” could be better guaranteed if considered in a framework of Civil and Human Rights model of disability.

Even if I have chosen to adopt the term “person with disability”, in some sections I will refer also to “disabled people” in order to avoid excessive repetitions. In this sense the two terms shall be used as if having the same meaning in reference to the elements and concepts reported above and the common experience characterizing people that, regardless of the impairments, disabilities or any other situations of life, face barriers to inclusion and a full participation in society.

2.2 Definition of Inclusion

The origin of the term inclusion can be brought back to the concept of “integration”, developed in the Scandinavian scientific community in the ‘50s and ‘60s which guaranteed rights for all (Stangvik, 1989). The shift in the concept of inclusion (Daniels & Garner, 1999) occurred when the term started to indicate access and participation as a priority regardless of the severity of deficits. Pushing the commitment and actions in favor of a lifelong participation (Santi and Ghedin, 2012), in all dimensions of existence (school, work, family, society, environment) in which a subject lives and can realize his/her potential (Hollenweger & Haskell, 2002). The term inclusion is formalized for the first time with the Declaration of Salamanca in 1994, signaling the beginning of a renewal in culture (UNESCO, 2000 and Caldin, 2001).

The inclusion theory is premised on the social model of disability (Oliver, 1990 and 1996), as opposed to the medical theory, and at the basis of the Civil and Human Rights model. This paradigm emphasizes the difference between the biological (impairment) and social (disability) conditions. Promotes the direct involvement of persons with disability and their families in policy decisions, focusing on removing barriers to economic, cultural, environmental, political and social contexts; including education, employment, leisure, sport, etc.

It looks at the totality of the social and political spheres; first on the contexts and then on the individual, it transforms the ordinary response, referring to the empowerment constructs, which focuses on the decision-making processes of persons with disability themselves and their families (D’Alessio, 2005). This perspective emphasizes the principles and theoretical ICF constructs: the person, the holistic approach, the integrative bio-psychosocial model, the

consideration of contextual factors, the relational perspective, the quality of processes and systems, the participation in social life. Stainback and Stainback (1990) argue that *“inclusion is a basic right that no one should earn”*, in the sense that governments and communities need to remove barriers and obstacles to social inclusion, with adequate resources and support to create inclusive environments and societies.

Persons with disabilities are not a homogeneous group, but there is a commonality of experience which unites them, namely barriers to full participation in society (EC, 2010c). The issue of inclusion is fundamental to the concept and definition of disability and referring to the authors cited above, three main types of exclusion can be identified (Harris & Enfield, 2003):

- Attitudinal: persons with disabilities may be excluded by attitudes of the non-disabled people (e.g. low expectations about what they can achieve, fear, ignorance, etc.).
- Environmental: this type of exclusion refers to constructed and manufactured environments (including transport and ICT), that are not designed to accommodate persons with disabilities.
- Institutional: exclusion occurs when persons with disabilities are not accorded the same rights enjoyed by others (e.g. the right to vote, to be employed, to attend school, to marry, to have children, etc.).

In the framework of this thesis - inclusion is considered as the founding element of a context structured in order to accommodate all possible diversity (as opposed to the integration model, where it is the individual who is accepted and fits in). When an inclusive approach accommodates the context, it can facilitate the lives of people especially if they are allowed to participate.

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, employment, research, policy and all aspects of society *“providing the necessary supports and reasonable accommodations to allow them to fully participate”* (ILO, 2012).

In accordance with the UNCRPD, 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”*, the dimension of reciprocity underlying the concept of reasonable accommodation emphasizes the importance of the chargeability of human rights, especially the civil and political rights (Articles 1-21 of the Universal

Declaration of Human Rights¹⁷), including the right to freedom of thought, citizenship, to form a family, etc., leading to the construction of the individual as a “capable” subject in an inclusive environment. Whereby, adopting basic concepts such as inclusion, co-evolution, reciprocity, participation and emancipation, it is expected that the parties involved in a situation can/should both contribute to the success of the action itself, 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 et al., 2011).

2.3 From a charity model to a civil & human rights model of disability

The objective of this section is to provide a brief overview of the different models to approach disability in order to highlight the different social and cultural attitudes, representations and how they have developed from the late 1900s to the present day. This overview consults a cross-section of influential accounts of disability as the basis of its understanding as evolving concept.

The overview summarizes the main conceptualizations of the phenomenon of disability, starting from the charity model, through to the social model and on to the civil and human rights model. Accordingly conceptions regarding disability have undergone changes from cultural context to cultural context, and from country to country. For this reason I think it could be useful to indicate the path which led to different meanings attributed to the concept of disability, and to shed light on the shift from a concept of passivity, victimization and welfarism (an issue of person), to one based on the active role, participation and respect of the human rights (an issue of society).

This paradigm shift provides the hope of being able to switch from interventions based on “normalization”, to socially innovative actions aimed to “facilitate” the lives of the people.

¹⁷ Available at: <http://www.un.org/en/documents/udhr/> (Accessed on 03rd April 2013)

Assuming that “*the exclusion and isolation of persons with disabilities are the result of stigma, discrimination, myths, misconceptions, and ignorance*” (Quin & Degener, 2002), all these elements need to be considered to understand the complexity of the issue, and design effective interventions for an effective inclusion of all persons in society.

Despite the contribution of the UNCRPD, which accords persons with disabilities full rights as citizens, attitudes based on stigma, discrimination and ignorance still persist.

In the last three decades there has been a paradigm shift regarding persons with disabilities as objects of research to seeing them as subjects, able to participate, self-determinate and take charge of their own life project (Lachapelle et al., 2005). This paradigm shift has been made possible by the development and affirmation of different models and approaches in the understanding of disability.

According to their general description, the models described are drawn mostly from North American and European sources, contributing to support the transition from a model based on a view of passivity, sickness and patient care (attitude towards person with disability), to a new one of commitment to active citizenship, self-determination and participation in the elaboration of his/her own project of life (attitude towards society).

2.3.1 Charity model

This model is historically situated in the period between the end of the 19th century and the Second World War. It was based on charity and benevolence rather than justice and equality, treating people with disabilities as helpless victims as needing care and protection.

This model didn't promote inclusion, it consisted of accepting the act of exclusion of persons with disabilities from society, mainstream education and employment. Moreover the focus was on the disability alone and how to get it cured, without considering the abilities of the person.

During this period persons were treated as passive beneficiaries of charity and the idea of a disabled person working and contributing to society was almost unthinkable.

The social attitude was to consider persons with disability as someone that “can't” (see, hear, walk, study, work, love, etc.), therefore the expectations of disabled people were low or non-existent. This also included the systematic removal of disabled people from the community into segregated institutions.

In the charity model persons with disabilities therefore were considered as objects who could only receive care and assistance, without participating in the processes which shaped their lives.

It sees them as “*individuals, with individual problems*” (Poizat, 2009), and simplifying “*if you solve the problems of individuals with disabilities, then the ‘problem’ of disability is solved*” (Stiker, 2005).

This approach led to the consequence that if disability is seen as an individual problem, services are always going to be inadequate, because individual needs can never fully be met.

The positive contribution of this model regards the compassion and the charitable impulse that have been generated in many associations and organizations dealing with disability .



Figure 10: Summary diagram of the components of the Charity model

2.3.2 Medical model

A precise beginning and end of the medical model of disability is not easy to establish. This is due to the fact that it is often accompanied by the charity model in literature and although considered as an outdated model from a theoretical point of view, its influence remains in different societies and cultures. In order to provide a summary of the historical path that led to the adoption of other more socially advanced and elaborate models, I wish to consider this model as situated between the end of the Second World War and the '80s -'90s.

The medical model is based on the postulate that situations, problems and difficulties experienced by a person with disabilities are directly related to their physical, sensory or intellectual impairments (Gary, 2005). Therefore this model considers people with impairments as sick and in need of a care and rehabilitation through “*making people with impairments fit enough to be integrated or reintegrated in society*” (EC, 2010a). In this model disability is seen and valued only in terms of the extent to which the individual can perform the activities of daily life in relation to functional independence and autonomy. The cultural approach, the social attitude and more in general the context and environment are not valued with a role for the inclusion, barriers reduction, empowerment and self-determination.

Nonetheless, it is important to recognize the importance of the medical model, because “*the medical aspects of disability must be addressed as part of a human rights approach to barrier removal*” (EC, 2010b). Moreover prevention, cure, alleviation and rehabilitation are fundamental concepts for disability, and need to be taken into consideration.

This awareness has led the World Health Organization to adopt Nagi's disablement model, based on three distinct concepts related to disease and health conditions: impairments, disabilities and handicaps (Nagi, 1965). All elements characterizing the elaboration of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH henceforward) in the 1980. In this section I will not review the ICIDH, but is important to cite this document because it will become part of the WHO family of international classifications of diseases and related problems. WHO released a major revision of the ICIDH in 2001, named as International Classification of Functioning, Disability and Health (ICF), which will be presented further (see section 2.3.4). It attempts to provide a coherent bio-psychosocial view of health states from a biological, personal, and social perspective. In this view human function and decreases in functioning is seen as the product of a dynamic interaction between various health conditions and contextual factors.

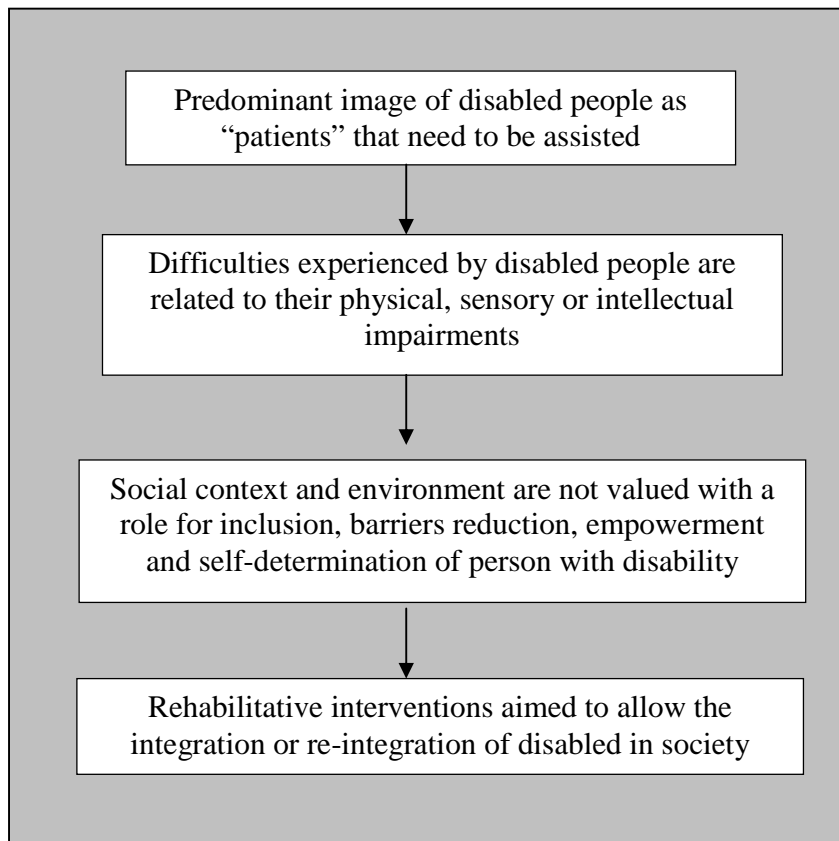


Figure 11: Summary diagram of the components of Medical model

2.3.3 Social model

The social model arose in response to the critique of the medical model of disability during the last 30 years. The origin can be traced back to the Civil and Human Rights movements of the 1960s and the contributions of the disability movement. An example is provided by the UK organization Union of the Physically Impaired Against Segregation (UPIAS), that in 1975 affirmed: *“In our view it is society which disables physically impaired people. 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).

It was during the ‘80s and ‘90s that thanks to the contribution of many authors; such as academics, persons coming from civil society and activists of the

disability movement, the social model affirms its principles and interpretation of the disability.

The term “social model of disability” was coined in 1983 by the academic Mike Oliver, that focused on the idea of a medical model (as individual) versus a social model, in particular referring to the distinction originally made by the UPIAS between impairment and disability, according to which:

- Impairment: is the loss or limitation of physical, mental or sensory function on a long-term or permanent basis (biological dimension).
- Disability: is the social situation of people with such impairments. It is the loss or limitation of opportunities to take part in the normal life of society on an equal level with others (social dimension).

In this sense the impairment is *“lacking all or part of a limb, or having a defective limb, organism or mechanism of the body”* and disability *“the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities”* (Oliver, 1996).

The social model assumes that *“It is not the impairment which disables, but attitudinal and other barriers in society at large”* (Oliver, 1990) and that interventions with persons with disability conducted within a comprehensive social framework are about the removal (or reduction) of barriers at an individual level, but also about the removal of physical and attitudinal barriers in society at large.

The European Council had already identified in 1992 handicap as *“fundamentally individualistic”*; in the sense that this term has evoked personal conditions, imputed to the subject *“fomenting prejudice and hostile attitudes, hiding the relational and contextual problem and focusing only on the medical one”* (Litrè, 1873 and Larousse, 1877).

The social model was developed in response to the attitudes inherent in the charity and medical models, such as:

- the representation of a handicap and disability situation as a problem that affects only individuals;
- the extreme medicalization of disability and its negative effects on the self-identity and self-determination of people with disabilities.

As argued by Mike Oliver *“disability cannot be abstracted from the social world which produces it; it does not exist outside the social structures in which it is located and independent of the meanings given to it. In other words,*

disability is socially produced” (Oliver, 1992). This changing perspective has resulted in the development of a disability movement which examines the social, political and economic aspects that have marginalized and oppressed persons with disabilities.

Oliver did not intend the social model of disability to be an all encompassing theory of disability, rather a “*starting point in reframing how society views disability*” (Oliver, 1990b).

The traditional medical model focuses on disability as physical impairment, with the goal of maximizing individual physical potential.

Although medical intervention is acknowledged as an important process for people with disabilities, it has been criticized for its individualized focus, its preoccupation with the “*physical or cognitive limitations of the “patient” and with enhancing their ability to function “normally” within society*” (DeJong, 1979).

Research conducted under this paradigm has focused “*its inquiry in disability on long-term dysfunction in the lives of people with disabilities, and ignores the social implications*” (Verbrugge, 1990).

The social model seeks to define disability in terms of social and environmental limitations, shifting the focus of inquiry away from individual impairment and society’s construction and interpretation of disability.

Simi Linton explained that the impact that disability theories can have by comparing it to Women’s Studies when “*feminists differentiated between ‘sex’ and ‘gender’, they allowed gender to be analyzed as a social construction separate from the biological determinant of sex*”.

Similarly, when “*disability scholars differentiate between “impairment” and “disability”, the social model may also be applied to disability*” (Linton, 1997).

The focus of disability research should be on the social factors which interact with the individual in “*either a disabling or empowering way*” (Verbrugge, 1990).

The social model aims to create a better understanding of the rights of persons with disabilities and to overcome the economic, social, and environmental barriers that affect their ability to engage in community like other citizens, to participate in society, to empower and self-determinate their life.

This paradigm shift has meant that persons with disabilities, along with their advocates and allies, are taking an increasingly active role in demanding that society acknowledge their rights, eliminate barriers to full participation and provide appropriate support, with the view that these interventions, “*will enable people with disabilities to live in ways that are personally satisfying, socially useful and meet national and international standards of social well-being, human rights and citizenship*” (Rioux, 1998).

Even if, the paradigm shift started with the social model, many in the disability movement itself realized that this model was not sufficient to make a complete analysis and understanding of disability.

For example, impairments can be barriers to full participation in society, regardless of social attitudes and appropriate accommodation, as *“the experience of going blind requires major psychological adjustments in the person affected which are not related to social attitudes or appropriate accommodation”* (Hull, 1997).

The social model of disability should not be considered as a *“monolithic entity, but rather as a cluster of approaches to the understanding of the notion of disablement”* (Lang, 1998).

This model assumes that disadvantages faced by disabled people are due to a form of institutional discrimination.

Concerning this perspective it is important to notice that the disability movement believes the “cure” for the problem of disability lies in changing society. For this reason it has also used to influence the political context, in order to secure the rights of persons with disability, with the objective of ensuring that *“they enjoy the status of full citizenship within contemporary society”* (Lang, 1998).

However, some criticism of the social model have been developed, in particular referring mainly to two points.

The first is that impairment itself can be a barrier to full participation in society, regardless of social attitudes and appropriate accommodation.

The second is that persons with disabilities are a vulnerable group that need help through social protection measures only.

The disability movement itself realizes that the social model is not sufficient to make a complete analysis of disability. For this reason other models and approaches that attempt to resolve some of these problems are reported in the following chapters.

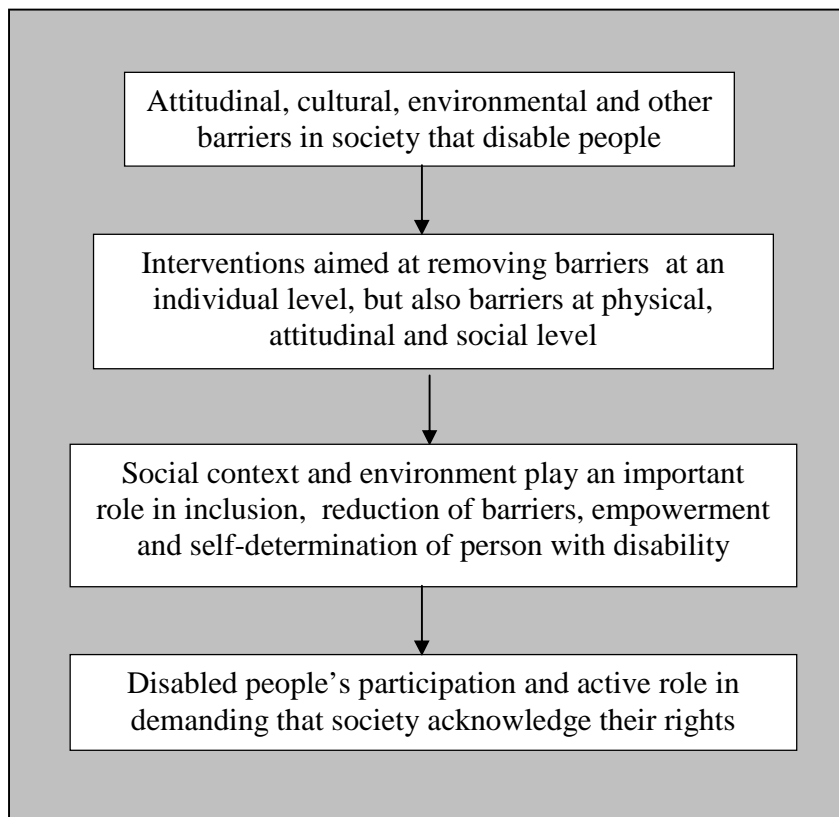


Figure 12: Summary diagram of the components of Social model

2.3.4 Bio-psyco-social model

At the beginning of the 2000s WHO implemented a major revision of the ICIDH that lead to the elaboration of the International Classification of Functioning Disability and Health. The so-called “Bio-psyco-social model of disability” was developed in this framework.

In this model, further development led to the International Classification of Functionality, Disability and Health for Children and Youth (2007, ICF henceforward), functioning and disability are seen as a dynamic interaction between health conditions and contextual factors, including personal and environmental.

The framework previously defined by Nagi and the ICIDH have presented the disablement process as “*a linear progression of response to illness or consequence of disease*” (Nagi, 1991).

From this point of view, disabling conditions have been considered as static situations, with a consequential element that can be summed up as “if you have an illness, then you have an impairment, a disability a handicap”.

The perspective developed in the framework of ICF to face the disability issue instead is based on an ongoing process of interaction between biological, personal and social aspects of life.

Therefore the bio-psyco-social model represents a sort of compromise between medical and social models, considering:

- the health: representing diseases, disorders, injury or trauma, aging, and congenital anomaly;
- the disability: an umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual health condition and contextual, social, environmental and personal factors;
- the body structures: the anatomical parts of the body such as organs, harms, limbs, and their components;
- the impairments: temporary or permanent limitation in body function or structure as a significant deviation or loss;
- the activity limitations: difficulties an individual may have in executing tasks or activities;
- the participation: involvement in a life situation, or problems and restrictions an individual may experience (ICF, 2001).

Other characteristics of the bio-psyco-social model included in the ICF consists of organizing activities and participation into sub-domains, including:

- Learning and applying knowledge;
- General tasks and demands;
- Communication;
- Mobility;
- Self-care;
- Domestic life;
- Interpersonal interactions and relationships;
- Major life areas;
- Community, social, and civic life.

The ICF also includes two contextual factors, environmental and personal:

- a) Environmental factors: are physical, social, and attitudinal environment in which people live. The sub-domains of environment include the following factors:
- artifacts (as products and technology);
 - natural (as support and relationships);
 - attitudes (social and cultural);
 - services (including systems and policies);
 - buildings and constructions.

The environmental factors can be used to identify elements of the person's environment that facilitate or hinder the level of function and disability (ICF, 2001).

- b) Personal factors: are the features and background of an individual's life that are not part of health conditions. These factors can be: sex, race, age, lifestyle, habits, coping styles, social situation and psychological assets (ICF, 2001).

This framework of reference is used to gather descriptive information about functioning and disability in each sub-domain, identifying the presence of a decrease in functioning.

A 4 point scale is used to record the severity of impairment: none, mild, moderate or severe impairment. It includes also a code 8 - as not specified- and code 9 - as not applicable (ICF, 2001).

This scale is used with identified qualifiers to assess performance or capacity. A performance qualifier *"should be used to describe what a person does in his or her current environment, including whether assistive devices or other accommodations may be used to perform actions or tasks and whether barriers exist in the person's actual environment"*.

While capacity qualifiers *"should be used to describe a person's inherent ability to execute a task or an action in a specified context at a given moment"* (Jette, 2006).

In other word, the performance qualifiers define what people can do in his/her environments, whilst the capacity qualifiers provide a description of person's ability to function. The ICF does not classify people, but the health conditions associated with them.

This is also described by Steiner when discussing the potential utility of the ICF framework as a clinical problem-solving tool for rehabilitation clinical care,

able to support clinicians to “*understand patient’s functioning and disability related to his/her condition*” (Steiner, 2002).

In this way, once an activity limitation or participation restriction is identified, it is necessary to apply the qualifiers to further define the capacity or performance (these qualifications are not included in this thesis and for further information I suggest readers can visit the WHO website¹⁸).

The main feature of the bio-psyco-social model consists in overcoming the opposition between the medical and social model through their integration, as a form of reaction to the impasse of the debate couched in accepting a medical or a social model to approach disability.

The development of the ICF is an important moment in the “re-conceptualization of the nature of disability” (Edwards, 2003), even if it was promoted as “*an essential tool for identifying and measuring the effectiveness of rehabilitation services*” (Üstün et al., 2003), rather than of wider social exclusion.

Another important aspect for the purposes of this thesis included in the ICF and supported by the bio-psyco-social model, is represented by the introduction of the term “participation”, covering a more social aspect equated with capacity and actual performance in real life situations.

In particular the assumption according to which the level of participation of a person depends on the result of the complex interrelation between his/her impairments and the environment in which he/she lives.

Different environments have different impacts on the person, producing a different level of participation.

¹⁸ Available at: <http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf> (Accessed on 03rd April 2013)

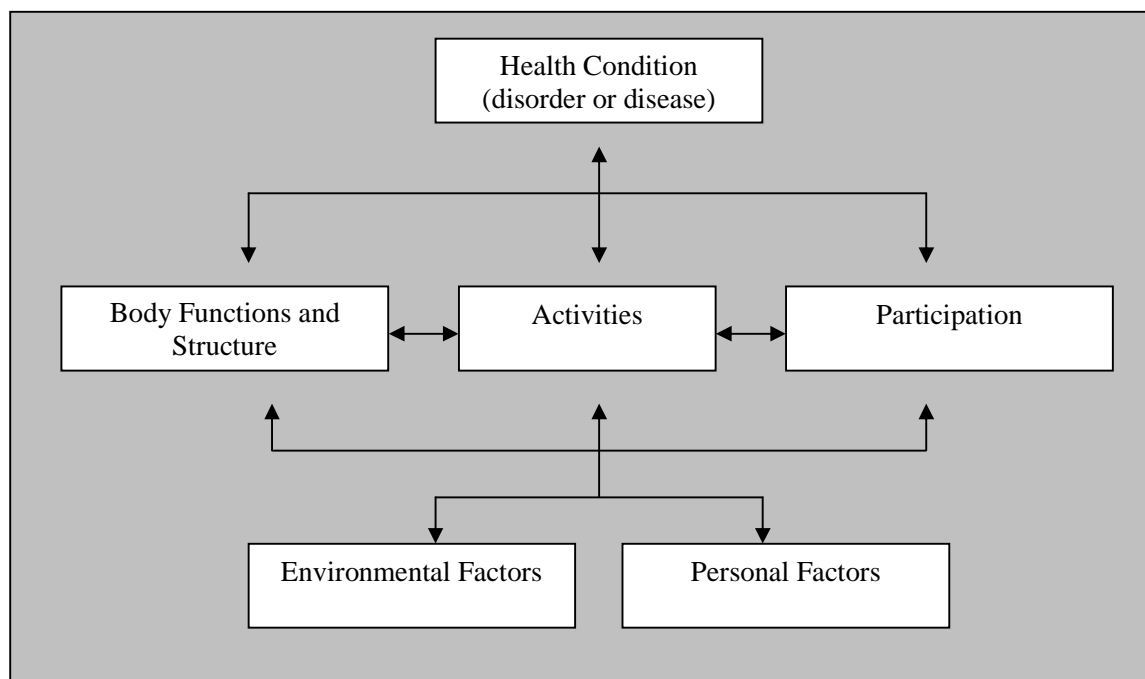


Figure 13: Summary diagram of the interaction between the components of the Bio-psyco-social model as represented by ICF. Source: WHO (2001, pp.18)

2.3.5 Civil and Human Rights model

The Civil and Human Rights applied to disability issues are particularly relevant for the aims of this thesis, because it is assumed as the framework of reference for the development of new trajectories of research through participatory and emancipatory approaches.

This means when exploring possible applications of the concepts of active citizenship and social innovation to interventions, it is based on a vision of disability as a rights problem (see paragraph 5.2).

Although I refer to civil and human rights as a unique model of reference, these rights are usually conceptualized in most of the literature on disability issue as separated.

The first (civil) are rights that an individual enjoys by virtue of citizenship and aimed at providing disabled citizens with an equal treatment. The second (human) are rights that an individual enjoys by virtue of being human and aimed at providing equal opportunity.

It is important to consider that this difference has led to the development of two different models which address disability issues (one based on civil and the other on human rights). Although they represent two different models, I wish to consider both as parts of a unique system, in which the equality of treatments (civil rights) and equality of opportunity (human rights) are guaranteed.

In this framework disability is viewed not as a medical entity or an individual problem, but as a rights issue. Once explained how I wish to interpret the relationship between these rights, that is as “an unique framework of reference”, a brief summary of the two models as presented by academic literature is reported below.

The civil rights model of disability was developed by the disabled people movement in the 1970s and 1980s. It focuses on challenging and removing barriers which prevent disabled people from living a full and active life.

These barriers are many, varied and can lead to institutional discrimination, such as: the construction of buildings that are not accessible by disabled people, information provided in ways that disabled people cannot use it, attitudes and stereotypes about disabled people that prevent them from having the same opportunities as non-disabled people (Russell, 2002 and Waddington & Diller, 2002).

Historically, at the forefront of using civil rights to affirm an equal treatment for persons with disability there is the promulgation of the American Disabilities Act (ADA)¹⁹ in 1990, with the aim of prohibiting disability discrimination.

This Act has played a leading role in developing disability law in and outside the United States, with more than forty countries adopting formulations of the statute. As an antidiscrimination statute, the ADA entitles persons with disabilities to be treated equally to the general population, on the basis of a sort of agreement between the State and the individual, and related to the constitution of each country (whereas human rights are considered a universal right).

While human rights are basic rights inherent with birth, civil rights are inherent with the creation of society (Tharoor, 2001). The concept derives from the Latin translation of *ius civis* (rights of citizens), and was inspired by the 14th Amendment to the American Constitution²⁰ as “*the rights belonging to an*

¹⁹ Available at: <http://www.ada.gov/> (Accessed on 03rd June 2013)

²⁰ Available at: <http://www.usconstitution.net/constamnotes.html> (Accessed on 03rd June 2013)

individual by virtue of citizenship". In this view civil rights imply the citizen's ability to fully participate in the civil, social and political life of the state, without any sort of discrimination regardless of disability, gender, religion, race, national background, age or sexual orientation.

Through the adoption of a civil rights dimension, persons with disability can become active subjects and not passive objects; participants in driving research that should attempt to understand the significance of events, not only their causes.

The civil rights model finds the causes of disability in social terms that reflect on civil rights problems. 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). An ethical issue that involves personal rights and society' will to recognize these rights in an effective way.

But due to the fact that an equal treatment does not always ensure equal opportunity, the civil rights models is not adequately empowered to bring about disabled citizens' full participation and social inclusion.

In order to remedy the limitations of this model and ensure inclusion, participation and equality, the disability Human Rights model was further developed.

This model aims to conceptualize a framework that focuses on building an inclusive rights-based society able to understand and be committed to diversity, equality, and the participation of all.

This framework moves beyond the social model's emphasis on formal equality by acknowledging that people with disability are entitled to equality by virtue of their equal humanity.

The human rights model has been developed as a result of two main factors:

- the first one is the contribution of the disability movement in recognizing that disabled people are entitled to the full enjoyment of human rights;
- the second is the recognition that despite of the growth of international conventions on human rights in recent decades, such as the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social and Cultural Rights (ICESCR), and the adoption of specific covenants against racial discrimination (CERD), discrimination against women (CEDAW), children (CRC), migrant workers (CRMW), and indigenous people (DIP), persons with disabilities were not specifically cited within these treaties (Mégret, 2008).

These two factors gave rise to the development and implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD), adopted on the 13th of December 2006. The Convention has the

specific objective to address the lack of specific human rights protection for disabled persons, because *“disability is a Human Rights issue. So long as people with disabilities are denied the opportunity to participate fully in society, no one can claim that the objectives of the Universal Declaration of Human Rights have been achieved”* (WHO, 2011).

The UNCPRD has become over time the most representative manifest of the Human Rights model of disability, internationally recognized and ratified by many countries, whose starting point was constituted by the models of: Human Right to Development, The Disability Human Rights Paradigm and the Capability approach (Stein, 2007).

The Human Rights to Development model was officially recognized in 1986 by the United Nations General Assembly declaration, as framework that combines civil, political, economic, social and cultural rights within a single instrument, while the Disability Human Rights Paradigm combines some aspects of the social model of disability, the Human Right to Development and the Capabilities approach (see paragraph 2.4.2).

These elements have contributed to the elaboration of a holistic rights theory that have led to a model that acknowledges the role of social circumstances and environmental characteristics in creating disabling conditions, that prevent full participation, equality and inclusion.

In this model empowerment has a much broader scope than in the medical and social models, and includes: self-determination; participation in decision making; changes to the environment based on the concepts of design for all; human rights legislation; accessibility to the skills, knowledge, and support systems that facilitate functional independence.

In particular this model necessitates the participation of people with disabilities in the process of societal reconstruction and for this reason is assumed here as framework of reference, that will be used to place other concepts as participation, emancipation, active citizenship and social innovation, further developed in the next chapters.

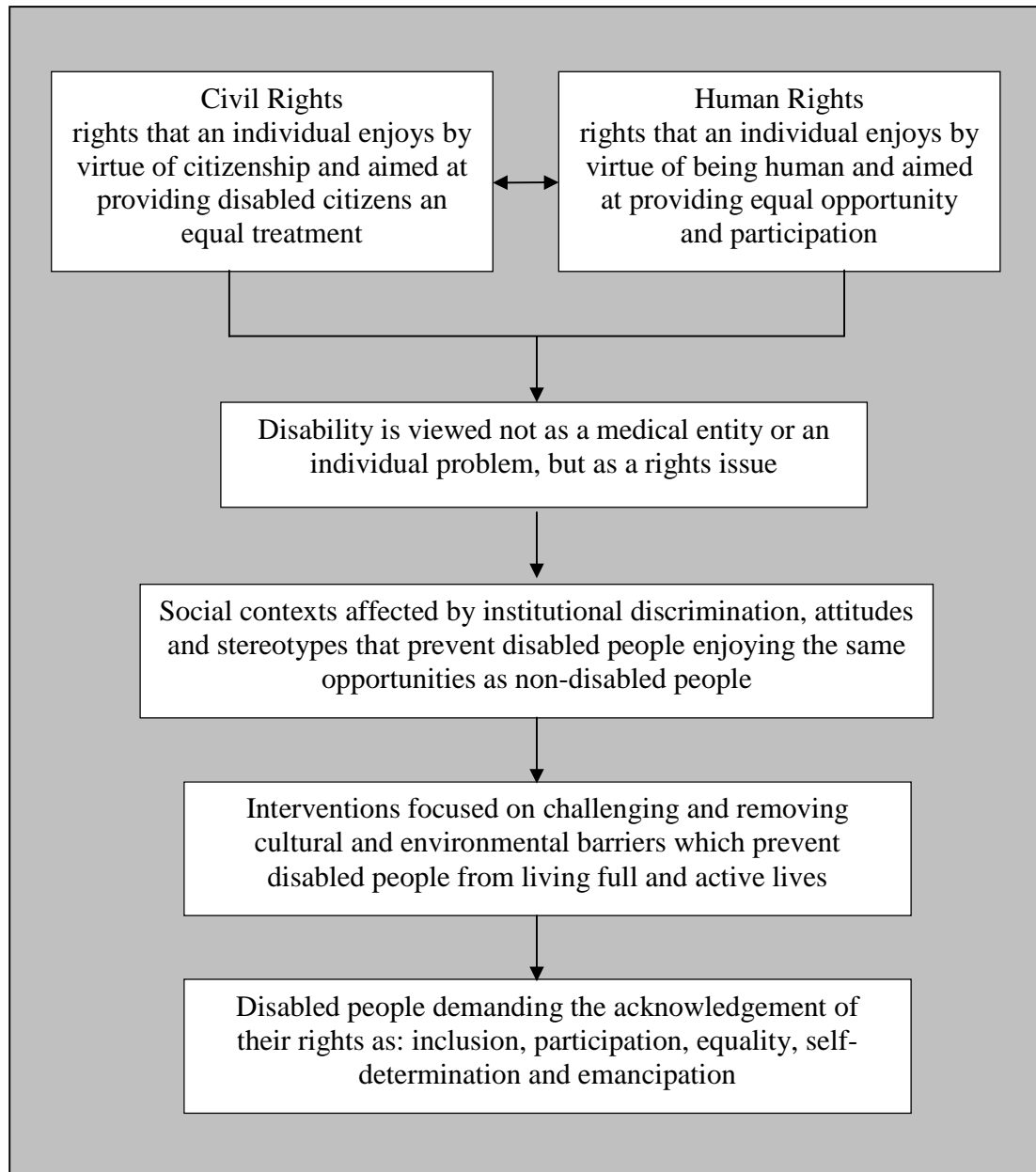


Figure 14: Summary diagram of the components of the Civil and Human Rights model

2.4 Approaches to understanding and coping with disability issues

The approaches described in this paragraph complete the picture of the main models developed in order to understand and deal with disability.

It is important to consider that the direction in which research is going and contributions from civil societies such as the disabled people organizations, associations of families, professionals (Priestley et al. 2010 and 2010b), is increasingly moving towards a holistic approach, able to include many more contributions coming from different models and approaches. This aspect could mitigate limitations and criticisms levelled at theories and practices that have undoubtedly positive effects for the inclusion, participation and respect of the rights of persons with disability.

For example, the ICF and the bio-psycho-social model are recognized internationally, but the arrangement of the body functions, activities, and participation components recall the linear, hierarchical, and causal relationship of the medical model (impairment, disability, and handicap). But this should not affect the good practices produced by the bio-psycho-social model for understanding and developing interventions to support persons with disabilities. Moreover, although there has been an evolution of models (from charity to civil and human rights) and approaches, these are not mutually exclusive. An example is provided by the Human Rights model that embraces areas covered by other approaches, although with a different perspective, as for the ICF and the Capability approach. Another example is provided by the implementation of the Community Based Rehabilitation approach, that while remaining out of the debate between other models of disability, such as medical, social or bio-psycho-social, it promotes human rights through the support of equal opportunities, empowerment and community participation.

It also should be taken into consideration that an evolving society often requires fast changes and adjustments to the theoretical constructs that seek to understand and explain its phenomena, in this case disability.

For this reason I wish to summarize some approaches, among which the Community Based Rehabilitation, the Capability approach and the Disability Creation Process, able to respond more immediately to the needs of changing society, which are more flexible and adaptable to different environmental and cultural contexts than models described above.

2.4.1 Community Base Rehabilitation approach

The Community Based Rehabilitation (CBR henceforward) is an approach which has grown in developing and low-income countries starting from the 1970s with the emerging of two concepts, the primary health care and the community participation in health (WHO, 1981). CBR was promoted initially as a local initiative to bridge the gap between an increasing burden of disability in developing countries and the lack of professional and financial resources. CBR was formally endorsed by the World Health Organisation in 1978, and since this endorsement larger scale projects were established especially in Africa, India, and south east Asia.

The CBR attempts to “*combine physical rehabilitation through medical care with empowerment and social inclusion through the participation of both the individual with a disability and the community in the process of rehabilitation*” (DFID, 2000), and in its implementation remained out of the debate between other models of disability (as the medical, social, bio-psycho-social or human rights models). Nevertheless, assuming what is sustained by WHO, it promotes and protects human rights while also creating equal opportunities. Empowering individuals to take action for improving their lives and community to fully participate in developing positive attitudes among the people involved.

The central aim of the CBR approach was to build positive partnerships between rehabilitation, personnel, disabled people and their families, improving community attitudes toward people with disabilities. In other words, the ultimate goal of CBR consists in improving the everyday lives of people with disabilities through basic medical rehabilitation, social inclusion and political equality, making the best use of the resources available at local and communitarian level.

The field of CBR has learnt from the experiences of other community development programmes in poverty, childhood, and women’s issues. This has allowed the CBR to set out the debate on concepts such as participation; the significance of what disability may be from the basis of the socio-cultural context; the concept of community diversity; needs’ identification; mobilization strategies. It has also stated the principle that knowing the communities in which persons live and work is crucial in defining possible interventions to their lives.

Concerning the theme of participation, and according to the aims of this thesis, I wish to focus on this theme through the lens of the CBR approach.

In CBR approach the concept of participation has been conceptualized as a “*means and an end in itself*” (Boyce & Lysack, 2000). Acting as “means” it

can be conceptualized as “instrumental participation”, that is the process of involvement through which to achieve common social goals (for example the process for the establishment of an Assistive Technology centre or an Independent Living centre) . This form of participation tends to be “*short term and does not necessarily lead to an increased capacity of persons to participate*” (Boyce & Lysack, 2000). When acting as an end in itself it can be conceptualized as “transformational participation”, that is a longer term process through which to “*develop and strengthen the self-capabilities of people to be involved in social development*” (for example the development of policy recommendations, or the organization of movements for the promotion of social justice).

In accordance with the work of William Boyce and Catherine Lysack, three functions of community participation have been identified:

- 1) Community participation as “contribution”: its function consists in a voluntary donation of people’s resources to a common goal (participation as an instrumental means). Participation as contribution is based on a “top-down” approach by the authorities and barriers to participation are commonly addressed by educational and motivational strategies (Cohen and Uphoff, 1980).
- 2) Community participation as “organisation”: its function consists in organizing people in common activities (participation as both means and end), in order to achieve social integration of disabled individuals, group cohesiveness and common objectives (Pateman, 1970). The barriers are believed to be derived from operational problems and are addressed by technical strategies.
- 3) Community participation as “empowerment”: its function implies both the development of management and the ability to make decisions which affect people’s lives (participation as a transformational end), including the right to self-organize social relations at local level (Boyce, 1993).

The barriers to participation are believed to be derived from social conflict and are addressed through compromise on conflicting policies or by removal of social barriers through political reform (Mikkelsen, 1995).

Assuming what is argued by these authors, the purpose of community participation is the empowerment of people with disabilities, necessarily involving a transformational phenomenon influencing the process of community decision making.

This aspect should introduce changes in social conditions, as the improvement of social relationships (between disabled and other community members), the reduction of alienation and stigma.

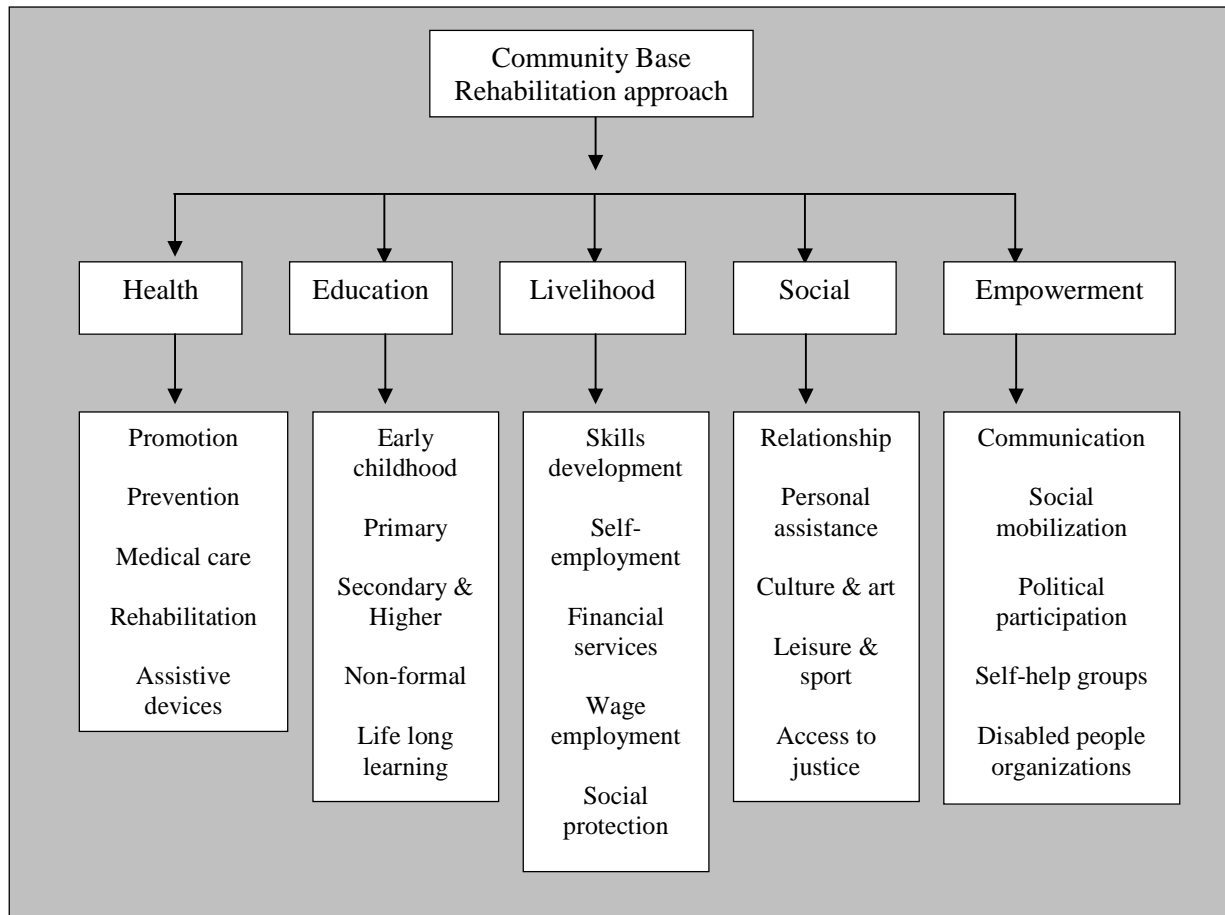


Figure 15: Summary diagram of the components of the Community Base Rehabilitation (CBR)

2.4.2 Capability approach

The Capabilities approach was originated during the 1980s by the economist-philosopher Amartya Sen and further developed in the framework of social sciences and humanities by the philosopher Martha Nussbaum. The capability approach provides an interesting view in understanding disability and the obligations of society to respect people with disability. The central goal of the capabilities approach is agency. It seeks to “*provide individuals with the means through which to develop their potential regardless of whether targeted recipients of resources elect to use them*” (Simonnot, 1995). The approach embraces the rights issue, by recognizing that ensuring citizens’ abilities requires prescriptions on impediments as well as affirmative institutional support.

The capabilities approach considers all people as individually worthy of regard, autonomy, and self-fulfillment, and that every person must be treated as an end in him/herself, rather than as the instrument of the ends of others (Nussbaum, 2000).

Capabilities are the conceptualization for interpersonal comparisons of the freedom to pursue well-being, that Sen named “*well-being freedom*” (Sen, 1992). In other word capabilities are means through which needs are met. A kind of freedom to achieve alternative functioning combinations or various life styles.

In the capability scheme of Nussbaum, that diverges significantly from Sen’s by determining what fundamental entitlements States owe their citizens, a list of ten central capabilities that individuals require to flourish are enumerated

Nussbaum’s ten central capabilities are as follows:

- 1) life (the faculty to live one’s full lifespan);
 - 2) bodily health (having good health, including reproductive capability);
 - 3) bodily integrity (freedom of movement and bodily sovereignty);
 - 4) senses, imagination, and thought (cognizing and expressing oneself in a “truly human” way);
 - 5) emotions (loving, grieving and forming associations);
 - 6) practical reason (critical reflection and conscience);
 - 7) affiliation (self-respect, empathy and consideration for others);
 - 8) other species (being able to co-exist with other species and the biosphere);
 - 9) play (the ability to enjoy recreation);
 - 10) control over one’s political environment (via meaningful participation) and material surroundings (through property ownership and holding employment).
- (Nussbaum, 2000).

The capabilities approach relates the same objectives espoused in the Civil and Human Rights model, and provides more guidance on the otherwise abstract content and moral priority of those rights (Stein & Stein, 2007). In this sense Nussbaum argues that central capabilities “*have a very close relationship to human rights*” (Nussbaum, 2000).

However, although Nussbaum’s capabilities approach provides important guidance for conceiving of human rights as a means of ensuring “*general human flourishing*” (Nussbaum, 2006), it falls short as a universal theory because of its failure to enable the flourishing of all people with disabilities (Stein & Stein, 2007). These limits are due to the following interrelated reasons:

- a) the capability approach does not recognize the humanity and equality of those who function below the ten central capabilities, because only those individuals who come close to attaining those enumerated functions can live a “*fully human life*” that is “*worthy of human dignity*” (Stein & Stein, 2007);
- b) the capability approach either excludes or qualifies the inclusion of certain persons with intellectual disabilities from society;
- c) although the capabilities approach seeks to protect social interaction, it does not sufficiently ensure the participation in society and the inclusion, that guarantees disabled persons’ meaningful contact with the population at large (Silvers & Stein, 2007).

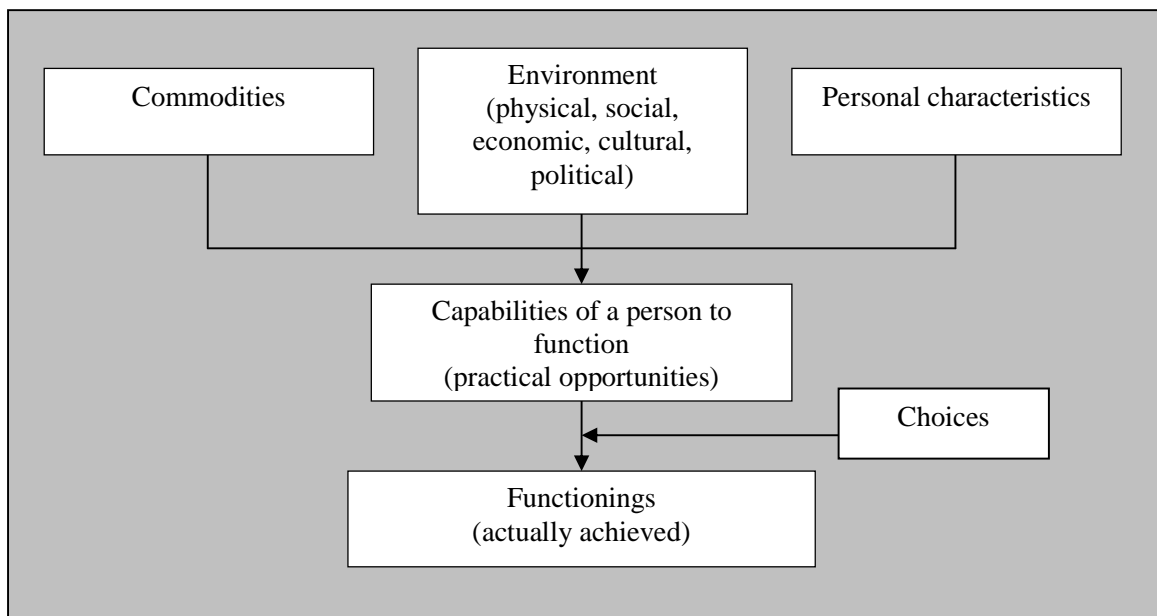


Figure 16: Summary diagram of the interaction between the components of the Capability approach

2.4.3 Disability Creation Process approach

The Disability Creation Process (DCP henceforward) has its origin in Canada and has become a very interesting area of research in the past 30 years. This theoretical conceptual model relates to the understanding of causes and consequences of disease, trauma and other disruptions to the integrity and development of a person. It is well validated and widely applied both in Canada and internationally (Fougeyrollas et al, 1996). The framework of the DCP was developed in relation to international debates on the revision of the ICF and ICIDH (Fougeyrollas et al, 1998), and is based on an interactive, anthropological, universal, person-environment dimension, that allows for an interdisciplinary approach founded on different concepts, that are:

- risk factors (causes);
- personal factors that are sub-divided into: organic systems (impairments), functional capabilities (disabilities) and socio-cultural identity;
- environmental factors;
- life habits (handicap situations).

The traditional medical model is necessary and undoubtedly of high value when it is directed towards a diagnostic (etiology, pathology, manifestations) and curative approach, but it is important to not forget the insufficiency of the curative medical model in understanding the social consequences of a disability situation and the role played by the respect of rights and equality. The DCP's perspective instead is "*global, holistic, and ecological, it illustrates a destigmatisation of the disability process and reflects the ideology of human rights and equality*" (Levasseur et al., 2000). This approach is used to describe, in an innovative way, the links between personal and environmental factors that determine the result of the performance of daily activities and social participation. Moreover the DCP makes a "*distinction between capabilities and social participation*" (Fougeyrollas et al., 2002), allowing the identification of independent and dependent variables and the causes and consequences of changes (Levasseur et al., 2004).

In this way the diverse obstacles or facilitators encountered in real life become new priorities of research, elements to be considered for the implementation of interventions and development of innovative social actions when approaching disability. In fact, the environmental factors in interaction with a person's impairments and functional limitations may compromise the accomplishment of her/his life, including activities and social roles.

Of particular interest in DCP is the concept of participation, as well as for the ICF. For this reason and in accordance with the theme of this thesis, I wish to take a closer look to this concept through the lenses of the DCP and ICF models. Although empirical studies are still needed to clarify the conceptual and operational definition of participation, this is considered by both models as an important concept that can foster the involvement of persons, or, if not applied, determinate a handicap situation until a social exclusion (Badley, 1987; Minaire, 1992; Nagi, 1965; Oliver, 1986; WHO, 1980). The aim of this focus on - participation consists in briefly describing participation features as defined by these two approaches, including similarities and differences.

Concerning the DCP it is useful to remember that it is based on the interaction between individuals and environment, and consequently the participation – called “social participation” - is “*operationalised via the concept of life habits, which are defined as daily activities and social roles valued by the person corresponding to his or her age, gender, and sociocultural identity*” (Fougeyrollas et al., 1998).

Whereby, as argued by Fougeyrollas social participation in the DCP is the “*interactive result of factors intrinsic to the individual (e.g., personal characteristics, organic systems, and capabilities) and extrinsic factors in the physical and social environment*”, whilst capability means “*the intrinsic ability of an individual to accomplish a physical or mental activity regardless of the environment*” (Fougeyrollas, 2002).

In other words, participation is the result of the interaction between the individual’s health condition and contextual factors that include both personal and environmental factors.

The DCP model identifies 12 life domains, 6 referring to daily activities and 6 to social roles, that are:

DCP domains of daily activities	DCP domains of social roles
1) Nutrition	7) Responsibility
2) Fitness	8) Interpersonal relationships
3) Personal care	9) Community life
4) Communication	10) Education
5) Housing	11) Employment
6) Mobility	12) Recreation

The ICF includes 9 domains, each of which can be used to denote activities or participation (or both), and are:

- 1) Learning and applying knowledge
- 2) General tasks and demands
- 3) Communication
- 4) Mobility
- 5) Self-care
- 6) Domestic life
- 7) Interpersonal interactions and relationships
- 8) Major life areas
- 9) Community, social and civic life

Participation is defined as what an individual is doing in a real life situation, and the activities denote the individual's ability to perform a task or action (the term "activities" used in the ICF refers to "capabilities" in the DCP). Whereby the gap between activities and participation reflects the different impacts between "*standardized environments and real environments*" (Levasseur et al., 2004).

Considering the similarities between the two approaches, both have a view of participation as an interactive and evolving process, recognizing the role of activities and the involvement in the environment as important indicators, because personal and environmental factors affect participation, since the interactions operate in both directions, the health condition may modify or be modified by participation.

Referring to what was assumed by Mélanie Levasseur about participation, also shared by ICF and DCP, it is possible to highlight three main similarities in the definition of the concept, as:

- a) Definitions of participation: in both approaches considered as the individual's real life situations.
- b) Concept of social participation: in the DCP, and its counterpart "participation" in the ICF, takes into account the performance in daily activities and social roles.
- c) Participation domains: 8 of the nine ICF domains correspond to the 12 DCP domains. For example, the DCP domains "Housing, Mobility" and "Interpersonal relationships" are similar to the "Domestic life, Mobility, and "Interpersonal interactions and relationships" domains of the ICF. Furthermore the ICF domain "Major life areas" could be considered as inclusive of the DCP domains: employment, recreation, nutrition and fitness, as showed in the following table:

DCP domains		ICF domains
Personal care	⇒	Self-care
Communication	⇒	Communication
Housing	⇒	Domestic life
Mobility	⇒	Mobility
Responsibility	⇒	General tasks and demands
Interpersonal relationships	⇒	Interpersonal interactions and relationships
Community life	⇒	Community, social and civic life
Education	⇒	Learning and applying knowledge
Employment	} ⇒	Major life areas
Recreation		
Nutrition		
Fitness		

Despite the similarities of the two approaches about the concept of participation, there are several differences, and the main concern:

- a) Terminology: the DCP in referring to the concept of participation uses the terms “social participation” and “capability”. Instead the ICF considers only “participation” and “activities”.
- b) Framework of reference: the DCP is based on the anthropological model of human development and disability (Fougeyrollas et al., 1998), whilst the ICF is based on the integration of two different models: the medical and the social model (WHO, 2001).
- c) Conceptualization of participation components: in the DCP, social participation is the outcome of the interaction between the individual (as intrinsic individual factors) and his or her environment (as extrinsic environmental factors). On the other hand, in the ICF, participation is the outcome of the interaction between the individual’s health condition, activities, body functions, and contextual factors, including both personal and environmental factors.

- d) Conceptualization of personal factors: in the DCP personal factors include the individual's health problems, capabilities, organic systems and personal characteristics. In the ICF, health conditions, activities, body functions/personal factors are three conceptually distinct components.
- e) Conceptualization of environment: in the DCP the environment has a direct effect concurring to determinate the social participation in the same way as personal factors. The environmental factor of the DCP also represents a key variable that contributes to distinguish personal capabilities and performance in regard to social participation. In the ICF the influence of the environment is mitigated, because it predominantly focuses on the individual rather than on the environmental factors. In practice in the ICF *"the impact of environment is not considered an explanatory element of participation"* (Noreau & Fougeryrollas, 1996).
- f) Classification of capabilities and participation: capabilities and social participation in the DCP are two distinct components and conceptualized separately (mutually exclusive), while in the ICF the same domains may correspond to activities and participation.
The ICF suggests distinguishing between these two concepts solely by using qualifiers, that means *"activities represent what the individual can do in a "uniform" or "standardized" environment, while participation is the performance of the same activities in the "real" environment"* (Levasseur et al., 2007).
- g) Measurement tools of participation: the DCP in order to operationalize this model has developed a specific tool, the Assessment of Life Habits (Fougeryrollas & Noreau, 2003). This tool, whose acronym is Life-H, quantifies the degree of accomplishment and type of help used, satisfaction with the accomplishment of daily activities and social roles, and the perception of the individual. The ICF has adopted a checklist as measuring instrument that considers the individual's performance in certain tasks, activities, and roles (WHO, 2001).

In the following table are summarized the main similarities and differences of both models about the concept of participation²¹:

SIMILARITIES	DCP	ICF
a) Definition of the participation	As individual's real life situations	As involvement of the person in life situations
b) Concept of social participation components	Performance of daily activities and social roles in real life situations	Involvement of the individual in life situations and real environment (in ICF called only as "participation")
c) Participation domains	12 domains	9 domains (7 of these ICF domains correspond to the 12 DCP domains)
DIFFERENCES	DCP	ICF
a) Terminology	Social participation and capabilities	Participation and activities
b) Framework of reference	Anthropological model of human development and disability	Medical and social model
c) Concept of participation components	Result of the interaction between intrinsic individual factors and extrinsic environmental factors	Result of the interaction between the individual's health condition and contextual factors that include both personal and environmental factors
d) Concept of personal factors	Grouped with the individual's health conditions, capabilities and organic systems	Distinct from health conditions, activities and body functions
e) Concept of the environment	Directly influences social participation as determinant factor	Mitigated, influence of the environment not clearly identified conceptually
f) Classification of capabilities and participation	Mutually exclusive	With or without overlap, at the discretion of the ICF user and using solely qualifiers
g) Measurement tools of participation	Life-H (performance, type of help required, satisfaction and perception of individuals)	ICF Checklist (performance)

²¹ This table is adapted from the article of Mélanie Levasseur, Johanne Desrosiers and Denise St-Cyr Tribble : *Comparing the Disability Creation Process and International Classification of Functioning, Disability and Health Models*. In Canadian Journal of Occupational Therapy. June 2007, vol. 74, pp. 237.

What is considered important here is the fact that these approaches have assumed the concept of participation, although from different perspectives, as a means and an end for the development of greater inclusion, respect of the rights, and support of the empowerment of persons with disabilities.

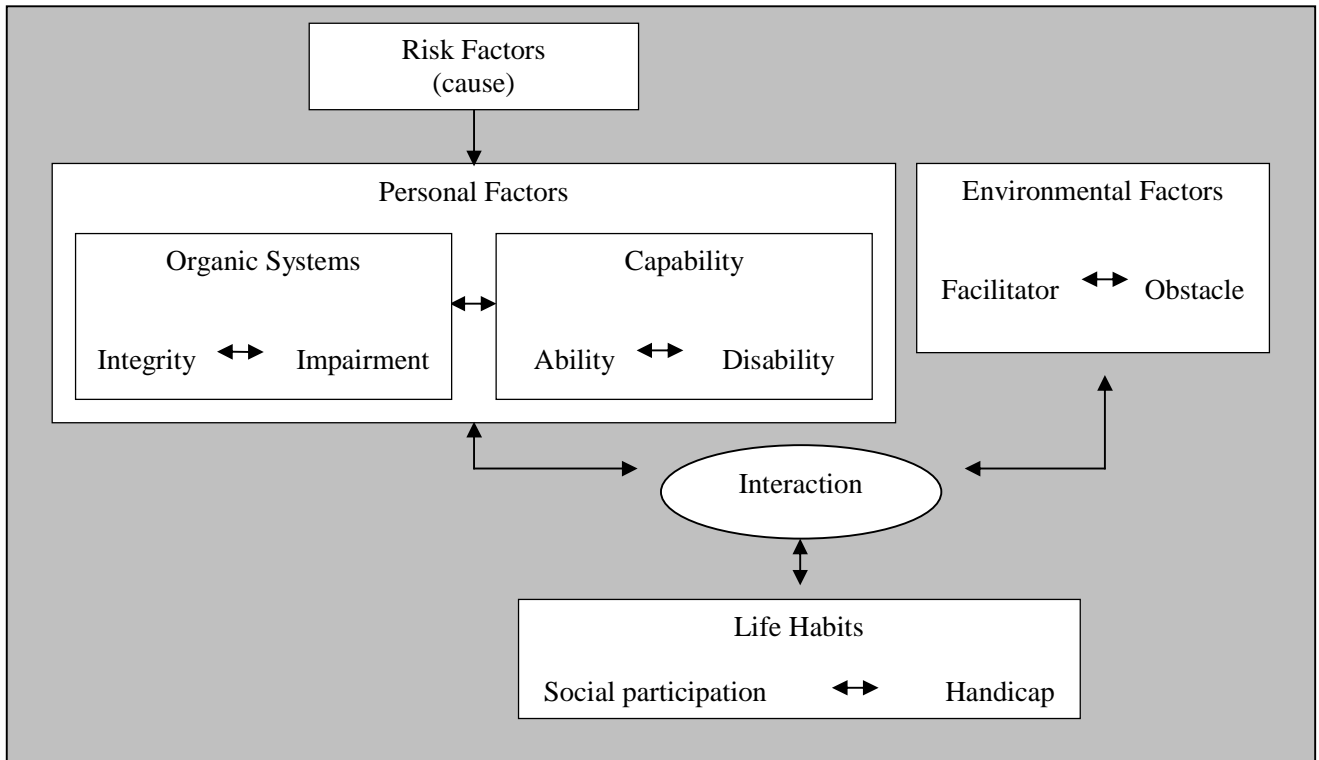


Figure 17: Summary diagram of interaction between components of the Disability Creation Process (DCP)

2.5 Movement of the Disability Studies

The movement of Disability Studies is a phenomena that emerged in the 1950s, fueled by: the support of the rise of the civil rights movement in North America during the 1960s-70s; the reaction to the failure and indifference of social sciences to consider physical impairment and “*human embodiment as an important issue*” (Gleeson, 1997); the contribution provided by the UK disability movement through the idea that disability is structured by social oppression, inequality and exclusion (Thomas, 2004).

This movement laid much of the groundwork for the current development of disability studies. It was the actual persons with disabilities that shifted the perspective away from a focus on individual deficiency and pathology, towards a focus on social barriers (inaccessible environments, exclusion, prejudice, discrimination), that prevent equality, inclusion and full citizenship.

It was not until the 1990s that Disability Studies began to emerge with an academic identity of its own (Oliver and Barton, 2000), and a first definition of Disability Studies was provided only in the 1993 by the Society for Disability Studies²² (a professional organization of scholars from around the world), for which Disability Studies “... *examines the policies and practices of all societies to understand the social, rather than the physical or psychological determinants of the experience of disability. Disability Studies has been developed to disentangle impairments from the myths, ideology and stigma that influence social interaction and social policy. The scholarship challenges the idea that the economic and social statuses and the assigned roles of people with disabilities are the inevitable outcomes of their condition*”.

According to this definition one of the merits of the Disability Studies is that trying to speak to both academics and disabled people, produces results that “*persons on the street will understand, as well as satisfy the academic credential*” (Oliver and Barton, 2000).

Disability studies is a form of enquiry defined as “*atheoretical current*” (Barnes, 1995). This is due to the fact that many of its contributors are either practitioners, social workers, advocates or disabled academics e.g., Paul Abberley, Mike Oliver, and other authors such as Colin Barnes, Jenny Morris, Tom Shakespeare and Len Barton. Despite this, disability studies have in a certain sense channeled the thrust of different social movements to arrive at a coalition of the marginalized. This thrust has undoubtedly encouraged an increasing broad view of oppression among disabled (Abberley, 1991).

This has led for example to the development of new perspectives, exploring concepts such as “multi-discrimination” (as disability and gender, disability and

²² Available at: <http://www.disstudies.org/> (Accessed on 17th May 2013)

migration, or disability and ageing). An other example is the contribution to the debate about the concept of “normalization” and the affirmation that “*humans are characterized by varying sets of needs which cannot be described through references to norms*” and that “*people do not desire current social standard of normality, but rather seek a fuller participation in social life*” (Abberley, 1991). Another important contribution is the foundation of a “materialist history of disability”, that thanks to the work of Oliver (1990) showed as concrete attitude towards impairment and disability has “*differed between modes of production*”, depending also on socio-political and economic dynamics. For these authors disability is a “*historically and socially specific outcome of social development*” (Gleeson, 1997), assuming that material changes may liberate person with disability from oppression, acknowledging the material importance of both body and disability in social relations (considering social relations as products of the practices which humans pursue in meeting their needs). Whereby what is argued is that the emphasis for a transformative social and political practice should focus on changing the material structures which marginalize and de-value the capability of people with disability. What makes Disability Studies’ viewpoint distinct is an “*explicit commitment to assist disabled people in their fight for full equality and social inclusion*” (Thomas, 2004), view that assumes a political significance that should be reflected in all the spheres of social life, because the oppression that persons with disability face daily is embedded in the normal processes of everyday life.

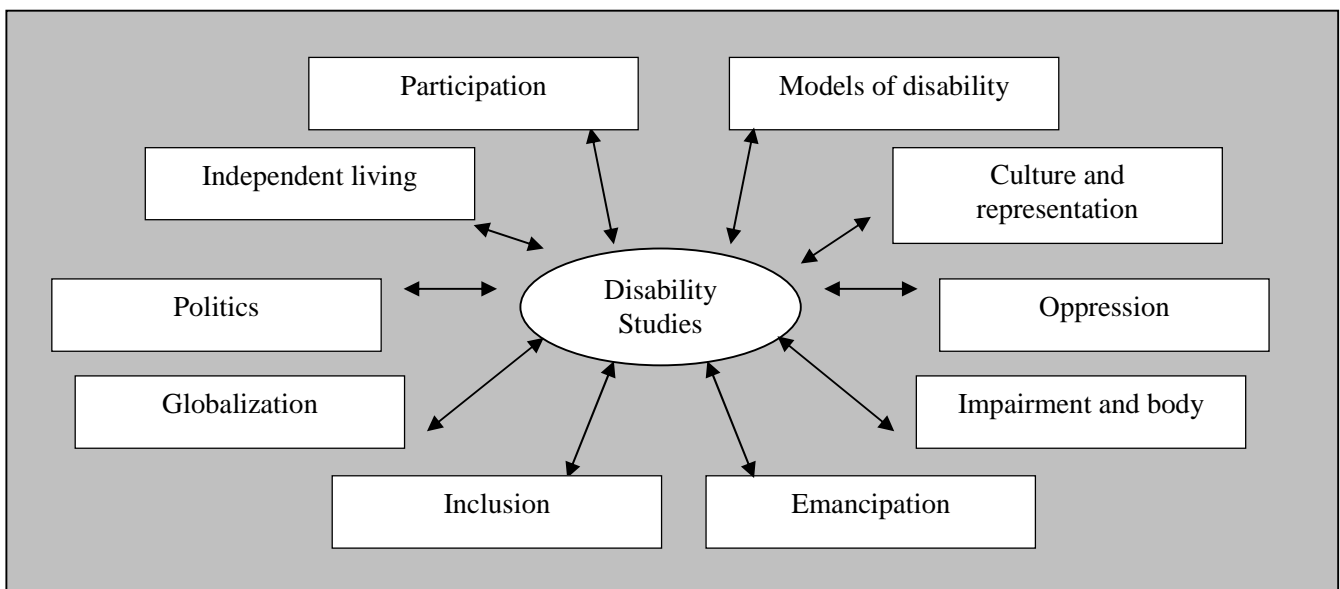


Figure 18: Summary diagram of the components of the Disability Studies movement

CHAPTER 3 - Concepts and tools for participatory and emancipatory approaches

The concepts behind this thesis are used to verify the initial assumption that “*an open participation in the co-creation of the environment, makes life easier for vulnerable groups*”. In this sentence participation is considered as a set of processes and tools, rather than an outcome, that can produce innovative actions and social changes. The precise aim of this chapter is to explore a series of concepts and tools to be used to foster the adoption of participatory and emancipatory approaches. Subsequently, it will find evidence of the fact that the adoption of these can encourage an open participation in the development and co-creation of services, products, environments, researches, making life easier for vulnerable groups.

The presentation of these themes concerns two target groups. The first one is represented by vulnerable groups, most notably persons with disability and older people. The second includes all the professionals interested in applying participatory approaches in their work contexts, projects, activities and daily life. It hopes to provide useful elements for persons often outside the research setting or piloting experience. These tools are based mainly on the collection of contributions and suggestions coming directly from participants, who became active in their role of citizens. Considering that a lack of knowledge of these tools does not allow for the possibility of thinking about different ways to involve people in the design of processes of services or products, the concepts and tools described in the next paragraphs are:

- User-centred design;
- Human-centred design;
- Participatory design;
- Emancipatory design;
- Living Lab;
- Design for All and the HUMBLE method.

Two reasons led to the choice of these tools, the first is derived from the outcomes of literature analysis on the theme. The second concerns the

observation of two cases studies related to the use of participatory and emancipatory approaches and tools (see chapter 6).

It's important to stress that the concepts and tools reported need to be instantiated in a specific context, including: the specific sector to which they are applied (such as the field of services, products, research, design of environments); the features of the territory, including cultural and social attitudes; the nature of the community of professionals involved; the characteristics of the participants included, just to mention a few.

3.1 User-centred design

The user-centred design (UCD henceforward) is a design philosophy in which users' needs are taken into consideration starting from the early stage of a design process (Norman and Draper, 1986). The UCD was initially implemented into ICT applications, such as interface development in software systems (Vredenburg, 1999) or in virtual environment (Hix and Gabbard, 2002). Currently this philosophy is spreading into other fields, because it is aimed at supporting the entire development process in order to create applications which are easy to use and that are of added value to the users. This requires that researchers and developers should collaborate with users, industries (or other stakeholders) beginning at the identification of the problem and arriving at solutions for validation.

The importance of UCD for the purposes of this thesis lies in the fact that it represents a useful example of reference concerning a structured approach aimed at optimizing the user interface on the basis of people's needs, rather than forcing the users to change their needs to accommodate the system. This aspect could be considered as forerunner of the concept of reasonable accommodation (UNCRPD, 2006), and particularly useful in supporting a cultural approach that considers the individual as a "capable" subject, in particular in the expression of his/her own needs and desires. Moreover, the major characteristics are: the active participation of real users, an iteration of design solutions and awareness about the importance of including users from the beginning and during the process cycle up until the realization of products. Over the last two decades three main UCD models have been developed :

- the Cooperative design model;
- the Participatory design model;

- the Contextual design model.

Before briefly summarizing these models, I wish to specify that only the participatory design model will be analyzed in depth in the next paragraph, because it can be better linked with the concepts of inclusion and respect of rights, especially from a pedagogical point of view. In fact the main difference between participatory design and the other two models consists of , not so much in practical terms, but rather in terms of vision and impact on common sense and society at large. In fact cooperative design and contextual design consider a person only as user, and consequently involved in the processes of production as a future client. Participatory design contrariwise intends to represent a change in the concept of involvement of people (disabled, elderly or not) not so much for their role as potential users, but for the respect of their rights as people, and their capability to learn and understand as individuals. Moreover, this model fits better within a framework of reference based on civil and human rights approach to disability, considered as a field to be studied with an “inclusive research” approach (see chapters 4 and 5).

3.1.1 Cooperative design model

The cooperative design model was developed in Scandinavia in the 70s and is based on the awareness about the importance of a creative involvement of potential end users in the design process, based on an “*equal footing*” (Greenbaum and Kyng, 1991). The cooperative design is often used for complex design situation such as applications of ICT (Bødker et al., 2000).

The characteristics of this model lie in two principles: that the interaction between the designer and the user is essential and that the design environment of the project is cooperative.

Regarding the first principle, it is considered the responsibility of the designer to guarantee the users’ satisfaction and that direct interaction between both is necessary to the design process.

This implies that cooperation should be included in the stages of: preparation, sensitization, analysis, sharing and conceptualization.

In the second principle, cooperative design is seen as a creative activity with an evolutionary nature where designers and users (with different

intent and background knowledge) work together to achieve better knowledge in different fields and studies.

3.1.2 Participatory design model

The Participatory design model is characterized by the attempt to actively involve the end users in the design process to help ensure that the product designed meets their needs and is usable (Schuler and Namioka, 1993). It was developed in North American and Scandinavia in the 90s, and inspired by cooperative design.

This model is assumed to be the most useful and important for the purposes of this thesis for its application to the disability field and its aim to foster a cultural change in the concept of involvement of people.

People are invited to participate in several stages of an innovation process: from initial exploration and definition of the problem, on the focus of possible ideas for solution, implementation and development, assessment of the process and outcomes (for a detailed description of this model see paragraph 3.3).

3.1.3 Contextual design model

The contextual design model was developed in the mid of 90s, and characterized by the assumption that user context research may be the start of the design process. It includes ethnographic methods for gathering data relevant to the design process and it can be defined as a customer-centred approach applied in the actual context (Beyer & Holzblatt, 1997). Contextual design has primarily been used for the design of IT systems, including hardware (Curtis et al, 1999) software (Rockwell, 1999), been adopted as a usability evaluation method (McDonald et al, 2006), and applied to the design of digital libraries and other learning technologies (Notess, 2004). It has also been widely used as a means of teaching user-centred design and human-computer interaction (Weinberg & Stephen, 2002), and is based on five principles (Holtzblatt and Beyer, 2013), which are:

- 1) System design must support and extend users' work practice

- 2) People are experts at what they do but are unable to articulate their own work practice
- 3) Good design requires partnership and participation with users
- 4) Good design is systemic
- 5) Design depends on explicit representations

This model also consists of 6 steps (Beyer and Holzblatt, 1998):

- a) Contextual inquiry
- b) Work modeling
- c) Consolidation
- d) Work redesign
- e) User Environment Design
- f) Prototyping and Implementation

The contextual design model is a timely solution to a real problem, structured, rigorous and systematic, capable of respecting the needs of users by enabling them to “*participate in the design process, and be adopted by a wide range of designers, from student learners to researchers to professional designers*” (Preece, 2011).

3.2 Human-centred design

For holistic reasons relating to the description of these participatory concepts and tools, it should be added that in recent years the term “user-centred design” has been joined by other synonyms, such as “person-centred design” or the more well-known “Human-centred design” (HCD henceforward). Some authors such as Steen and Walters differentiate user-centred design and human-centred design, arguing that “*human-centred design places more emphasis on different stakeholders’ varying needs and broader contexts*” (Steen et al., 2004; Walters, 2005).

This clarification lies in the will to highlight the change, even if only in terminology, towards a dimension that focuses more on the human aspect of the individual and her/his needs. This means that the term human-centred design nowadays covers a wide range of approaches that, according to the International Organization for Standardization 13407 standard (ISO 13407 Model, 1999), are characterized by four principles:

- 1) The active involvement of users, a clear understanding of them and task requirements
- 2) An appropriate allocation of functions between users and technology
- 3) Iteration of design solutions
- 4) Multi-disciplinary design

These principles have been implemented with the subsequent ISO 9241-210 (ISO 19241-210 Model, 2010), on HCD processes for interactive systems, including:

- 1) Clear understanding of user, task and environmental requirements
- 2) Encouraging the early and active involvement of users
- 3) Being driven and refined by user-centred evaluation
- 4) Including iteration of design solutions
- 5) Addressing the whole user experience
- 6) Encouraging multi-disciplinary design

These standards provide requirements and recommendations for HCD principles and activities throughout the life cycle of computer-based interactive systems. Therefore it could be interesting to adopt these not only in the ICT field, but also in other sectors, such as service provision, products realization and environment design.

In any case, the affirmation in the use of the term human-centred design reveals that design is evolving from “*functionality and usability to desirability, responding to the hierarchy of human needs*” (Kelly, 2002).

This change of vision should contribute to the adoption of a framework of reference in addressing disability issues more based on the Civil and Human rights approach to disability. Aimed not only to encourage participation but also the emancipation of persons. This insight is explored in the next chapters (see chapter 4 and 5), in which it is argued that people should be able to have a say in the designing of research, services, products and environment, in other words; of their future. This ensures that peoples needs are considered directly by people, and not only by designers or researchers. In this way participants could become co-designers or co-researchers working with professionals and academics across a range of disciplines. This could allow persons to “*address wellbeing in terms of their lived experiences of what works, why and how*” (McIntyre-Mill, 2009), in order to enhance their own capabilities, but also the capabilities of the designers, researchers, professionals of services/products who learn from their experiences, allowing a better match across perceived needs and design options.

3.3 Focusing on Participatory design

The choice of focusing on Participatory design (PD) lies in the fact that it fits better within a framework of civil and human rights in the interventions with persons with disability. Because it looks at an individual more as a person with rights, than merely as a user.

From this point of view, participation represents a “*means and an end that can enhance the capability of people to make choices for themselves*” (McIntyre-Mills, 2009) on the basis of their real needs. Therefore PD is assumed here not only as set of concepts and tools, but also as a useful process to enable people to make links concerning their experiences and contexts for bringing possible changes affecting:

- capability, empowerment and emancipation of persons (individual level);
- cultural attitudes, active citizenship and social innovation (community level);
- respect of rights and inclusion (social level).

This desirable change in the participation of people with disabilities in various areas of design should be brought to major attention, not just because they are involved as users, but because they are “persons and citizen” with rights. Another important element that contributed to the choice of this process as the most applicable to the disability field (with respect the others cited) is that it has already been experimented in a wide range of application areas, such as public and private service sectors, manufacturing, local and centralized administrations, hospitals, libraries, law offices, schools and universities. The PD first took root in North America and Europe, in particular in the Scandinavian workplace democracy movement and in England, thanks to a socio-technical approach which argues for the importance of the social dimension of work, especially in the context of technological growth and business development.

As mentioned in the previous paragraph the PD is an evolving practice among design professionals, developed with a strong reference to the role of participants in the design and introduction of computer-based systems at work “*with a more human, creative, and effective relationship between those involved in technology’s design and its use, and in that way between technology and the human activities that provide technological systems with their reason for being*” (Suchman, 1993). The PD could represent a diverse system of principles and practices aimed at making services,

products, research, environments and institutions more responsive to human needs, and consequently to rights. A central tenet of PD is the active involvement of people in the co-design of services/infrastructures, and co-creation of products/environments they use, that means to support a better match of responses and solutions perceived, and real needs.

This active involvement has also led to the emerging concept of “*democratic innovation*” (Björgvinsson et al., 2010), that basically means democratizing innovation through the involvement and participation of different stakeholders and target groups on themes relevant to them. In addition this new concept is complementary to what social innovation means (see chapter 5) and relevant for the establishment of environments that allow the development of innovative actions, such as the Living Lab (see paragraph 3.5).

A participatory approach values the concept of the person as an active agent, the context’ resources (or agency) which can improve her/his inclusion, and together create innovation. Nowadays it is possible to think about a broader application of the PD, but in order to adopt and adapt its application in the field of disability, I wish to suggest possible requirements of defining a process as “participatory”, what criteria of inclusion/exclusion, what tools and techniques, all resulting from the analysis conducted on the theme.

3.3.1 Requirements for a participatory process

Listed below are the requirements which could define a process as “participatory”, pointing out that from a practical point of view, it is not easy to have meet all these requirements:

- reduction of barriers to participation (structural, environmental, attitudinal, etc.);
- access to relevant information;
- focus on people’s real needs;
- promotion of self-determination;
- liberation of the creativity (e.g. for the solution of social problems or the design of a product for all);
- generation and systematization of practical knowledge (results should be of immediate and direct benefit to participants);

- support empowerment and awareness in the people of their own abilities and resources, in particular in their capability;
- involvement of participants in the entire research process (e.g. from the formulation of the problems, the hypothetical solutions, the interpretation of the findings, the planning of collective actions based upon them);
- make conflicting action possible (e.g. possibility to take alternative positions on the same problem/issue emerged);
- transformation and improvement of the lives of those involved.

3.3.2 Criteria of inclusion/exclusion

Talking about participatory process requires a reflection upon the possible criteria of inclusion/exclusion of the people involved. This criteria responds to the following questions:

- who would benefit from participation;
- which differences and commonalities exist within the participants (professionals, designers, researchers, non-professionals, etc.);
- what kind of disability/health conditions are relevant;
- what can affect the involvement;
- what can facilitate/hindering factors to take part in the process;
- what kind of expectation participants could have.

The answers to these questions could provide input and sound basis for working with people interested to be involved in a participatory design process.

3.3.3 Techniques and instruments

The systematic involvement of people in the design of research, services, products or environments, requires specific techniques and instruments. As a matter of fact, there are different approaches available and which one to choose seems to depend on the scope and on the availability of resources.

The premise concerning the application of these techniques is that a participatory process has to primarily consider the main features of the context where it is to be applied:

- the type of organization or institution;
- the needs, the nature of change and the innovation desired (social, technological, cultural, environmental, etc.);
- the number and typology of people involved.

The techniques and instruments included in the PD and listed below have the precise aims to support the process of participation and establish a long term relation between participants, disabled and non, in order to pose the basis for a relationship based on mutual trust. The main are ethnographic techniques integrated with more traditional PD techniques (Blomberg et al., 1996; Bødker, 1996; Beyer and Holtzblatt, 1997; Kensing and Blomberg, 1998; Kensing, 1987; Grønbæk et al., 1997), including:

- Contextual interviews
- Participant observations
- Living labs
- Focus groups
- Case-based prototyping
- Case history
- Simulations
- Scenarios development or mock-ups
- Design games
- Cooperative prototyping
- Audio or video recordings

Concerning these techniques, I wish to focus on a relevant aspect often considered to be complex. This complexity refers to the level of communication and possible cultural gap between the participants and the designers, researchers or developer (Flynn & Jazi 1998). The complexity can be addressed to a certain extent using for example a “*two-way communication*” (Gore, 2007); or some elements of structural models as the ISO 9241-210 standard, or implementing a Living Lab environment (Björgvinsson et al., 2010). Basically all these tools and techniques move away from a vision that sees the persons as a “tester”, whose involvement is limited to the measuring of a performance, towards a more important and active role as subject, provider of feedback, creativity and information regarding the psycho-socio-cultural environment. In which the future service, products or building will be designed and realized. In this way it

could also support the establishment of long-term relationships, allowing participants to become active co-creators of what is designed and applied to their real life context.

In this paragraph I have touched some of the issues related to PD. I know I have left out some references and contributions, but the focal point is to present tools and techniques of the process, including considerations about future challenges for PD. This consists in supporting a culture of active participation, not only to match perceived needs, but mainly for building a sense of engagement. It also provides an alternative perspective on participation, more based on the respect of the rights and on the development of innovation more “*democratically-oriented*” (Björgvinsson et al., 2010). It is also important to consider the change in the role of designers, researchers and professionals involved in participatory approaches, that have to facilitate and build spaces which allow: the confrontation and inclusion of heterogeneous participants (legitimizing marginalized groups); the respect of rights and needs, cultural diversities; the promotion of self-determination, supporting participants to contribute as co-creators of possible innovative actions, services, products or environments.

3.4 Emancipatory design

Emancipatory design could be defined as a process aimed at changing the social relations in the realization of research, services, products or environments, leaving power of choice and control also in the hands of participants. This means that a project (such as ICT, health innovative service, assistive technology, accessible buildings, etc.) needs to include people effectively, not only to gather information and feedback, but also to foster an active role gaining empowerment and emancipation.

In the adoption of a tool that could represent a way to support the emancipation of vulnerable groups is important to consider:

- the person's role: as co-creator of services, products, research or environment;
- the objective of the project: that should include reciprocity, gain and empowerment of participants to guarantee an effective emancipation;
- the method applied: as based on reflexivity;
- the use of the knowledge (acquired and generated): as for changing the social relation of between designer, service providers, researchers and the participants;
- the nature of the beneficiary: individual, target group, stakeholder or society at large;
- the information and data required: as determined by the real needs of the participants;
- the perspective: the experiences of participants in relation to their context.

For a better explanation of this tool I also wish to refer to the work of Gerry Roberts and Bob Dick "*Emancipatory design Choices for Action Research Practitioners*". In their article the authors stated that "*the process choices made in action research can determine how emancipatory an experience- is for participants*" (Roberts and Dick, 2003), stimulating a cyclic process in which alternate change (action) and understanding (critical reflection). In this process of choice some tensions could arise, and considering what argued by the authors about emancipation and empowerment that "*may be better achieved if researchers and participants give attention to all six of the tensions*" (Roberts and Dick, 2003), briefly reported below:

- whether the process is data or theory driven;
- the level of skill of practitioners in using emancipatory processes;

- action emphasis versus a research emphasis;
- the level of sophistication of the methodology in use;
- the style and extent of participation;
- differing epistemic beliefs especially between participants and practitioners.

This tool for the design of projects could guarantee an effective process of emancipation. A possible implementation could be to include some principles of reference borrowed from the emancipatory disability research approach, defined firstly by the work of Barnes and Sheldon, in order to better define the tool as emancipatory.

The insight is aimed at providing additional elements for a practical application of an unstructured and not clearly defined tool, mostly clear in its theoretic explanation, but lacking in real application, especially outside of pilot and experimental contexts.

The principles considered and borrowed by the emancipatory disability research approach²³ are:

- Model of reference: this principle concerns the choice of the model of reference, that should fit with the aims of the project (as the Cooperative design, Participatory design, Contextual design model, Human-centred design, etc.). The reason for this choice is related to a re-interpretation of what was argued by Zarb about the difference between participatory and emancipatory approach, where “*the former is a pre-requisite to the latter*” (Zarb, 1992). In this way the adoption of a participatory process could be the basis to better define an emancipatory approach for the design, once considered the following other principles to implement the process chosen.
- Accountability: as a key component of the emancipatory process, if used to challenge stereotypical assumptions (in the case of disabled people, seen as static, vulnerable, dependent, lacking imagination and resourcefulness), supporting positive attitudes (considering people as active, self-determinate, participatory and provided with practical knowledge and creativity).
- Role of experience: of the designers and the participants as an important source of information in order to understand the social,

²³ The principles considered when applying a design tool aimed to the emancipation of participants are based on the emancipatory research approach described in detail in chapter 4.

cultural, economic context where to design and develop a project of service, product , research or environment.

- Change in social relations: an emancipatory design tool should encourage a process of change in social relations between designers, service providers, researchers, giving power of choice and control also in the hands of participants.

A clear definition of the components related to the emancipatory design as a process has not been elaborated in any publication or documents analyzed on the theme. Hence, it is solely a personal interpretation of the possible application of this principles, for elaborating more structured components to be included in the tool.

3.5 Living Lab

The input for this paragraph is derived from the work realized in the framework of a number of the 6th and 7th Framework Programme projects, especially in the ICT domain as well as from the experience collected from the various Living Lab, currently running throughout Europe and worldwide²⁴ (see figure 19). The Living Lab are open innovation ecosystems, and consist of the establishment of permanent communities of users who are involved in an interactive basis in service or product innovation at various stages in the design, development, validation and marketing process. The user-driven innovation is fully integrated within the co-creation process of new services, products or environments. The aim of Living Lab is to facilitate user involvement in innovative processes, suggesting a system that is human-centric (in contrast to technology-centric). For this reason I wish to substitute the term “user” with “participant” or “person”, because I think it would fit better with a human-centric approach. Living Lab often operates in a territorial context (city, agglomeration, community, region), integrating research and innovation processes within public-private partnerships. The concept is based on a systematic co-creation approach, integrating research and innovation processes (Bilgram, Brem, Voigt, 2008; and Pallot, 2009). These are integrated through the co-creation, exploration, experimentation and evaluation of innovative ideas, scenarios, concepts and related artifacts in real life cases. Living Lab involves stakeholder communities, not only as observed subjects but also as a source of creation (Schumacher, Feurstein, 2007; and Kusiak, 2007). This approach allows the stakeholders involved to consider (concurrently) both, the global performance of a product, a service or a solution and its potential adoption by others. Their feedback and information is collected by means of various socio-ethnographic research methods, as focus groups, surveys, testing, polls, etc.

The concept of Living Lab started to be developed in the late 90s at the Georgia Institute of Technology, where it was developed for capturing a live experience from an educational situation and then provide it to participants for later access and review (Abowd, 1999).

In 2006 the European Commission funded two projects, CoreLabs and Clocks, with the aim of advancement and promotion of a common European innovation system based on Living Lab (EC, 2009). An important role in the development of the concept at EU and international level was played also by

²⁴ Available at: http://www.openlivinglabs.eu/llmap_cc

the European Network of Living Lab (ENoLL), which was launched in November 2006 by the EU Finnish Presidency and supported by the subsequent ones. This association, aimed at supporting the adoption of the Living Lab paradigms, has already 129 Living Lab sites at European level, operating in different domains, from new technology in homes for independent living or like constructed environments (Markopoulos and Rauterberg, 2000) to e-Health, energy efficiency, intelligent mobility, rural development, inclusion of the elderly and disabled people.

This network includes the partnership of hundreds of public bodies, including Municipalities, Innovation and Development Agencies, Universities and Research institutes; thousands of companies, especially SMEs; and thousands of participants organized in user communities (Santoro and Conte, 2009).



Figure 19: Map of Worldwide Living Labs. Source: European Network of Living Labs (ENoLL)

3.5.1 Set-up features

The features of the set-up and implementation of a Living Lab include:

- Definition of the mission of the Living Lab.
- Identification of all the relevant stakeholders, professionals, policy and decision makers to be involved. It implies the establishment of: 1) the community of service/technology developers (for designing and making available innovative products and services to be tested within the Living Lab environment); 2) the community of public or social stakeholders at local level; 3) the community of professionals (from academia, public administration, industry and consultants); 4) the community of participants/users (willing to co-create and utilize the provided product or services) grouped according to the specific interests or needs (Santoro and Conte, 2009).
- Definition of aims and a work plan with the involvement of all stakeholders.
- Implementation in the context of a consolidated and real life experience (this is important to guarantee a base line of expertise and experience necessary to design a credible “living” laboratory).
- Development of a supporting ICT collaborative platform, for facilitating the communication among the various components of the Living Lab; collecting feedback; supporting the co-creation processes among the various participants, considering what was argued by Santoro and Conte, that *“the specific configuration of the IT supporting platform depends upon the domain of applications and services which the Living Lab is targeting as well as the typologies of constituency and expected use scenarios”* (Santoro and Conte, 2009).

3.5.2 Principles to be adopted

These principles refer to the work developed in the framework of the CoreLabs project, and are briefly summarized as follow:

- Continuity: to strengthen creativity and innovation, in relation to a collaboration built on trust.

- Openness: to create an innovative process based on the gathering of many perspectives and creating enough incentive to achieve rapid progress.
- Realism: to generate and facilitate the establishment of realistic situations and behavior, focusing on real users and real-life situations.
- Empowerment of users: to engage participants in order to develop an innovative process based on human needs and desires.
- Spontaneity: to inspire usage, explore personal desires, contributing to meet social needs (Adapted from CoreLabs, 20007a).

3.5.3 Success factors

Analyzing the literature on the theme and the projects realized for developing, testing, adopting or using the Living Labs, three main success factors can be assumed to assess the effectiveness of this tool, including:

- 1) Innovation: it can be measured in terms of the quality of the innovation developed and the creativity applied to meet needs and requests gathered.

From a quantitative point of view, the successful implementation of Living Labs can be monitored on the basis of the following impact metrics (CoreLabs, 2007b):

- a) Number of new, innovative added-value products or services designed, implemented and validated;
- b) Number of held patents;
- c) Number of peer-reviewed publications and participation in conferences, meetings, workshops.

- 2) Participation: it can be assessed considering qualitative and quantitative aspects. Concerning the qualitative dimension, it can be analyzed (through interviews, questionnaires, focus groups, etc.) the level of involvement of persons in their role as active citizens. And as stated by Santoro and Conte, to be “*empowered to influence the development of services and products which serve real needs, and contribute to improve the processes of participation in the R&D and innovation lifecycle*” (Santoro and Conte, 2009).

The quantitative impact metrics can be the number of different actors involved:

- a) Number of citizens involved in the activities of the Living Lab;
 - b) Number of stakeholders, relevant to the specific targeted market, including SMEs, organizations and associations, public and private bodies, etc.;
 - c) Number of policy makers, local agencies or public authorities (cities, provinces, regions).
- 3) Sustainability: it can be measured using qualitative criteria, as the durable employment creation, level of inclusion (including equality issues) and competitiveness. The quantitative criteria that can be assumed is:
- a) Amount of funding mobilized, including number of venture capitals or private funds involved.
 - b) Number of links established outside the specific local context (including the access to new competences of markets for the specific sector targeted).

In this paragraph I have described the main characteristics for the establishment of a Living Lab, considered as one the most innovative and recent tools supporting a participatory approach.

This is capable of overcoming cultural barriers to the inclusion of persons, meaning they become active citizens in the co-creation of solutions to meet socio-economic challenges, such as e-Health, ICT AT, innovative public services, accessible buildings and new trajectories of research.

In particular in the Living Labs the interaction and collaboration of different subjects enables to bring the needs, desires, requirements originated in real life settings in a process of participation and driven service/product development, *“this allows for a dramatic reduction of the iteration cycles during the service/product development and for a significant reduction of the investment costs associated, thus optimizing the use of the resources available”* (Santoro and Conte, 2009).

This tool also allows a participant-driven market demand creation, through *“the structured request to potential users categories for additional services and/or products which have a huge commercial potential since the outset”* (Santoro and Conte, 2009).

3.6 Design for All

Since the middle of the last century the concept of disability has gradually shifted away from assumptions about the functional limitations of individuals towards the awareness that is how societies are organized, in terms of physical and cultural infrastructures, that plays an important role in the cause of the disablement process.

Nowadays there is a general recognition that persons with disability experience a range of environmental and social barriers that inhibit their “*active participation in the economic, political and cultural development of their communities*” (Barnes, 2011). It is also widely recognized that this situation of exclusion concerns the design and construction of physical and cultural infrastructures. In order to address these issues and reduce environmental and social barriers some initiatives, such as the UNCRPD (see Article 9), have begun to adopt the principles of universal design into the production of the physical and cultural environment (Imrie, 2000).

This paragraph provides a broad overview of the developments in this field that in according with Colin Barnes represents is an “*essential element in the struggle for a fairer and just society*” (Barnes, 2011), adding that the universal design can be a useful tool for supporting: the active citizenship of people with disabilities; the design of solutions that consider their needs; the development of socially innovative actions.

The concept of “access for all” to physical and cultural environments is currently expressed with two different terms: “Design for All” and “Universal Design”. These terms are often used as synonymous and, although coming from different currents of thought and presented in many publications as having their own distinctive characteristics, it is possible to identify a definition able to unify both terms.

This definition refers to a broad spectrum of ideas aimed at producing services, products and environments that are universally accessible and designed for all, with particular attention to vulnerable groups such as older people and persons with disabilities.

The term Universal Design was coined for the first time by the architect Ronald Mace at the conference “Designing for the 21st Century: An International Conference on Universal Design”²⁵ (1998) and indicates “*the design of products and environments to be usable by all people, to the*

²⁵ Available at: http://www.ncsu.edu/ncsu/design/cud/about_us/usronmacespeech.htm

greatest extent possible, without the need for adaptation or specialized design”.

Thanks to the work of another architect, Selwyn Goldsmith, it assumed also the meaning of “*free access for disabled people*” (Goldsmith, 1997).

Universal design is based on the following seven principles²⁶:

1) Equitable use: the design is useful and marketable to people with diverse abilities.

E.g., people with motor disabilities limiting the use of a mouse are enabled to access the web contents via the keyboard. Or that persons who are blind can navigate and understand web content utilizing a screen reader. In other words, this principle recommends that the same interface can be used by all participants.

2) Flexible in use: the design accommodates a wide range of individual preferences and abilities.

E.g., this means people with disabilities could use specialized literacy, reading and writing software, hardware applications, or Braille in the case of blind users.

3) Simple and Intuitive: the use of the design is easy to understand, regardless of the user’s experience, knowledge, language skills, or current concentration level.

This principle recommends that designers and researchers provide clear instructions in simple language, providing feedback during and after tasks performed.

4) Perceptible information: the design communicates the necessary information effectively to the user, regardless of their sensory abilities.

This principle recommends to adopt multiple modes of presentation of information, considering: what essential information, peripheral or secondary contents, and devices to be used (for example supplying video content with synchronized captions).

5) Tolerance of error: the design reduces hazards and adverse consequences of accidents.

This principle is crucial for persons with various cognitive disabilities or who could stumble into accidental interaction with controls due to limited motor functionality.

²⁶ Adapted from: Centre for Universal Design, 2011

6) *Low physical effort: the design allows efficient usage with minimum effort.*

E.g., in the case of persons with visual disability using the web (pages, applications, resources, etc.), it is particularly important provide a reasonable visual and spatial contrast between the functional areas of web pages, so as to guarantee that controls can be easily managed by using the keyboard alone.

7) *Size and space for approach and use: appropriate space is provided to enable comfortable and effective use for anyone regardless of physical and sensory ability.*

E.g., for persons with motor disabilities or with low vision engaged in using the web, it can be difficult to keep focused on things such as cascading fly-out menus (which require high proficiency with the mouse), or to accurately select buttons that are small. In this case, web pages should have distinct navigation and functional controls.

Subsequently Universal Design was reported in the UNRPD as a strategy aimed at making the design of different environments, products and services accessible, understandable and usable by everyone, preferably without adaptation or specialized solutions, as reported in the Article 2: “*Universal design means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. Universal design shall not exclude assistive devices for particular groups of persons with disabilities where this is needed*”²⁷ (UNCRPD, 2006).

Based on a holistic approach, it’s also aimed at accommodating the needs of persons with disabilities, regardless of any changes they might experience in the course of their lives.

Consequently, Universal Design has become a concept that extends beyond the issues of accessibility of buildings, influencing policies and planning in all aspects of society.

Design artifacts, products, infrastructures and environments developed using the Universal Design approach must therefore be accessible to all people regardless of age, impairment, gender or ethnicity, acknowledging the diversity of the human condition.

A frequent cited example is a universally designed building with ramps, lifts and automatic doors that will not only be easily accessible for wheelchair

²⁷ Available at: <http://www.un.org/disabilities/convention/conventionfull.shtml>

users but also for people with baby carriages, shopping trolleys and luggage (Lepofsky and Graham, 2009).

Most recent is the term Design for All (DfA henceforward), used to describe a design philosophy targeting the use of products, services and systems by as many people as possible without the need for adaptation. DfA is design for human diversity, social inclusion and equality as stated by the European Institute for Design and Disability, on the occasion of its Annual General Meeting in Stockholm on 9th of May 2004²⁸.

Moreover according to the European Commission it encourages “*manufacturers and service providers to produce new technologies for everyone: technologies that are suitable for the elderly and people with disabilities*”²⁹.

The origin of Design for All lies in the field of accessibility and barrier free environment for people with disabilities and the broader notion of Universal Design. Although it is true that in the past there were some differences with other similar terms, nowadays the concept of DfA is identical to strategies known by different names (especially in certain geographical areas), such as Universal Design or Inclusive Design (Aragall and Montana, 2011).

The common aim of these strategies is practically the same and consists in designing and realizing services, products or environments to ensure that everyone, regardless of their gender, physical, sensory or intellectual abilities, age, lifestyle or any other aspect of human diversity is able to enjoy all the opportunities offered by the society.

Despite some critics arguing that the thinking underpinning the concept of Universal Design implies problems associated with widespread acceptability, and considering what was noted by Steinfield that “*the notion of universal design implies that there is a single universally acceptable solution to all design problems, and this assertion is both utopian and simplistic*” (Steinfield, 2006), in order to avoid any misunderstanding I have decided to refer to the term Design for All, as a design process largely addressed to all.

The EU Commission has funded research- via the EU’s 7^o Framework Programme to implement and apply DfA, as: the TIDE project – Technology Initiative for Disabled and Elderly people³⁰; IST e-Inclusion project, focused on

²⁸ Available at: <http://www.designforalleurope.org/Design-for-All/EIDD-Documents/Stockholm-Declaration/>

²⁹ Available at: http://ec.europa.eu/information_society/activities/einclusion/policy/accessibility/dfa/index_en.htm

³⁰ Available at: http://cordis.europa.eu/search/index.cfm?fuseaction=prog.document&PG_RC�=177389

making accessibility a basic requirement of all ICT tools³¹; eAccessibility research³².

Another initiatives at EU level to support the DfA was the establishment of the European Design for All e-Accessibility Network (EDeAN)³³, aimed at the exchange of best practices and expertise, that has led to the development of a DfA curriculum for designers and engineers to foster awareness of accessibility issues.

The Commission has also advocated the use of standardization to improve the effectiveness and uptake of DfA, as the M/473 Standardization mandate to CEN, CENELEC and ETSI to include “Design for All” in relevant initiatives³⁴.

As key concepts for evaluating accessibility and making the practice of respecting human diversity in a prospective of a barrier free environment, DfA comprises of interventions in environments, products and services which aim to ensure that everybody, regardless of characteristics such as age, cultural background, disability or gender, can access, use and understand them independently, and therefore participate in society. Its implementation is based upon two simple principles:

- 1) facilitating the use of products and services to all users;
- 2) ensuring that users' needs, desires and expectations are taken into account both during the design process and as part of post-production evaluation.

The approach taken to evaluate an environment in terms of DfA is for example to undertake a preliminary audit, which identifies the existence of barriers and areas for improvement. The barriers may be of different kinds, such as physical, sensorial, attitudinal, cultural or social. Solutions are then designed to reduce the functional distance between the different components of the environment and human capabilities. This can be done both by adapting the environment to the needs of the majority of people and by enhancing individual capabilities by using technology, such as glasses, adapted keyboards, text-to-speech software. On the basis of this approach the disability is thus defined as the result of the interaction between the person and his/her environment, where the environmental factors can facilitate or hinder the full functioning and

³¹ Available at: <http://cordis.europa.eu/ist/so/einclusion/home.html>

³² Available at: http://ec.europa.eu/information_society/activities/einclusion/archive/accessibility/index_en.htm

³³ Available at: <http://www.edean.org/central.aspx?sId=641160I327I323I259530&lanID=1&resID=1&assID=99&inpID=3&disID=1&famID=3&skinID=3>

³⁴ Available at: http://ec.europa.eu/enterprise/standards_policy/mandates/database/index.cfm?fuseaction=search_detail&id=461

participation of the person. In other words “*access for all is only possible with appropriate human involvement*” (Barnes, 2011), if we wish a globally inclusive society as a realistic and achievable goal.

3.6.1 The HUMBLE method

Design for All can be applied in many areas, such as services, products and environments; and different contexts, such as private companies, public bodies, no-profit organizations, territorial agencies, research departments, etc.

In order to provide practical elements in the adoption of the DfA, I wish to explore the features of the HUMBLES method. This is a method developed on the basis of various experiences of companies coming from different sectors and countries. It consists in a successful procedure including seven progressive stages. Each stage is represented by a letter, that together with the other compose the acronym HUMBLES.

It’s interesting to note that the meaning of the name deals with a necessary attitude for undertaking success challenges.

This method is mainly directed at organizations whose products or services will directly interact with their final client, user or consumer. It can include public administration, health agencies or other agencies, services providers, manufacture companies, transport, buildings, multimedia products, etc. It can be applied to companies that “*value aspects as ethics and respect towards citizens*” (Aragall and Montana, 2011).

The seven phases reported below are adapted from the work of Francesc Aragall (Founder and President of the Design for All Foundation) and Jordi Montana: “*Universal Design. The HUMBLES Method for User-Centred Business*” (Aragall and Montana, 2012).

1) Stage: Highlight design for all opportunities (letter “H”)

At this stage the participants using this method need to try to imagine what new opportunities for their own organization could result from the development of a new service, product or environment. The main opportunities offered by the method, are:

- Increasing the number of users, consumers, clients³⁵ or simply persons.

³⁵ The terms refer to the meaning used by the authors, whereby “user” as person who uses a non-consumable product or service (whether or not he/she has paid for it); “consumer” as

- Preventing problems: to know ones users, consumers, clients or person in depth enables to avoid possible conflicts due to unexpected or wrong access/usage of a service/product/environment.
- Improving external and internal reputation: to respect human diversity, individuality and needs can contribute to improving the external reputation of a company, public authority or NGO, leading to an increasing approval by society at large. Working experiences adopting socially responsible methods increase self-esteem and have a positive impact on the workplace atmosphere.
- Creating loyalty: persons are loyal when a relationship of trust based on satisfaction has been established, and does not end with the fruition of a service or the purchase of a product.
- Innovation in products and services: to achieve success in a service delivery or the realization of a product, it's important to be creative in order to meet persons' needs and desires.

2) Stage: User identification (letter "U")

At this stage, focusing on the aspects of human diversity is encouraged, i.e., age, laterality, dimensional diversity (size), functional limitations, religious and cultural habits, family structures, illnesses and allergies, sexual orientation and different economic resources.

3) Stage: Monitor interaction (letter "M")

This stage is aimed at establishing a deep knowledge of persons' needs and wishes, which needs to get to know, listen to, observe and use as a co-creative elements.

The aspects to be monitored are: persons' wishes and needs (using: direct observation, internet monitoring, expert assessment, focus groups, written or phone-bases questionnaires, etc.); complaints, reputation and satisfaction.

4) Stage: Breakthrough options (letter "B")

The main objective of this stage is to select "*options for improvement*" (Aragall and Montana, 2011) from the previously identified in the other stages. These options can "*generate opportunities while being easy to adapt to the culture*" of the organization, that means to "*prioritizing the*

person who use a consumable or perishable product or service (whether or not he/she has paid for it); "client" as a regular buyer (Aragall and Montana, 2012).

improvements according to the features” of the context (Aragall and Montana, 2011), the organizations and persons involved. In this view the main aspects that should be considered are:

- The potential increase in clients and users.
- Reconciling improvements with the strategy of the organization.
- Assessment of the investment effort required.
- Promoting a sense of opportunity.
- The capacity for development and implementation improvements.
- The capacity to manage the project.

5) Lay out solutions (letter “L”)

At this stage the process of the development of service, product or environment requires five elements: investigation, exploration, development, execution and evaluation.

The process, here generalized, needs to be adapted to the context, the organization, the circumstances, the type of service or product chosen to be developed or implemented. In addition ten steps need to be taken into account (Aragall and Montana, 2011):

- 1) Conduct a thorough study of each aspects to be improved.
- 2) Avoid reinventing the wheel.
- 3) Identify the scope for innovation.
- 4) Study feasible solutions.
- 5) Consults clients, users, consumers about possible solutions.
- 6) Ensure flexibility in the course of action.
- 7) Drawn up an exhaustive briefing.
- 8) Design the prototype.
- 9) Test the prototype.
- 10) Test the resulting product or service.

6) Stage: Efficient communication (letter “E”)

At this stage, after having tackled solutions, the task is to conduct an in depth analysis of the communication with the persons involved. In particular considering the following aspects: flexibility, avoiding stigmatization, sincerity and honesty, simplicity, reciprocity and permeability.

7) Stage: Success evaluation (letter “S”)

This stage is aimed at measuring the success in implementing the method, in particular the “*process involved in developing the innovation and its results*” (Aragall and Montana, 2011).

The criteria suggested to be applied are: functionality, expressivity and credibility.

In this chapter a series of participatory concepts, tools and methods were presented, in order to give the reader the right references for understanding their application, especially when using participatory and emancipatory methodologies (as presented in the next chapter 4).

These tools, along with principles and strategies, are to be regarded as the components of a process aimed at involving people. On one hand trying to find solutions to social and individual needs through the design, implementation and realization of services, products, researches and environments. On the other, using approaches based on the inclusion as the way to reduce oppression and discrimination of vulnerable groups, through contributions coming directly from people.

In this process of involvement it is important to draw a path on which it is possible to detect and generate satisfaction, participation and emancipation “*not only in its being present but in its becoming*” (Mainardi, Solcà, Fratus, 2006). Improving the accountability in the inclusive process and the reflective dimension at different levels: personal, institutional, communitarian and social (Mainardi, 2010). With the common aim to create contexts of open participation, making life easier for all.

3.7 PALMI method

Considering the participatory concepts, tools and methods identified in the literature analysis, I wish to present also the method PALMI³⁶. This method provides an interesting perspective of intervention based on the participation of all stakeholders in the process involving users, families, services, agencies, experts and professionals. The PALMI method was developed as “dialogical participatory structured approach” (Mainardi, Solcà, Da Vinci, 2003). It integrates specific aspects of the Delphi method and Meirieu’s learning groups³⁷, as a dialogic situations device aimed at countering the “normal functioning of groups”. It intends to allow equal legitimacy in assessing the quality of services provided to all stakeholders involved, starting from the final users.

The PALMI was developed by Michele Mainardi, Solcà Paola and Leonardo Da Vinci, members of the Department of Business and Social Sciences of the University of Applied Sciences of Italian Switzerland, in the framework of a research on user satisfaction and quality management in housing units for people with mental disabilities (Mainardi, Solcà, Fratus, 2006).

The assumption of the method was that it’s possible to increase user’s satisfaction, the quality of services provided and perceived, involving all participants in a dialogic process of evaluation.

From this perspective, user’s satisfaction is based on finding correlation between expectations and perceptions of stakeholders and the effective performance provided.

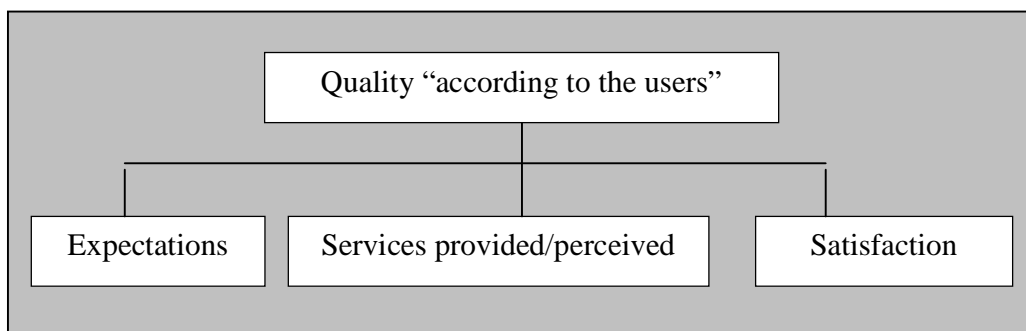


Figure 20: The dialogical participatory approach PALMI

³⁶ The dialogical participatory approach “PALMI” takes its name from the initials of authors names (Paola Solcà, Leonardo Da Vinci and Michele Mainardi).

According to this method, the confrontation between the participants involved is allowed by the circularity of the qualitative relationship between performance-expectations-satisfaction.

This dialogic relation allows the collection of qualitative feedback provided by each participant that adds value and contributes to the evolution or accommodation of both expectations and performance, influencing the satisfaction of all the persons involved.

The dialogical and participatory strategy takes into account the specific characteristics of each individual partaker, enabling:

- 1) The involvement and mutual consensus of the aspects to be investigated (in a dialogical-participatory process it is essential that individuals can be considered as effective partners).
- 2) The research of shared denominators that could lead to growth in the level of satisfaction of all of the stakeholders.
- 3) The effectiveness and efficiency of the participatory process, in order to reach successful results concerning the appreciation of the perceived performance and the development and maintenance of the quality of the institutional performance delivered.
- 4) The possibility of strengthening roles and responsibilities avoiding total control by any one individual or organisation.
- 5) Mutual respect between the parties. Without this condition the three previous steps lose their meaning.

The method is therefore aimed at:

- a) Allowing the assessment of the desirability and feasibility of possible alternatives to the current scenarios, identifying new solutions and analyzing their real possibility of implementation.
- b) Being simple, structured and efficient in its application in order to permit easy validation.
- c) Contributing to the process of problem solving and informed decision-making, enabling all stakeholders to be aware of their perceptions about services provided and institutional contingencies.

³⁷ Ziglio E., 1996. *Gazing into the Oracle: the application of the Delphi Method to Public Policy*. London, Jessica Kingsley Ltd.

3.7.1 Structure and phases

The PALMI method is characterized by a structured process consisting of a preliminary stage and five subsequent phases (see figure 21). The first (phase 1) seeks to ensure that every single participant (user, operator, family member, manager) can reflect and formulate personal considerations and suggestions about performance expectations of the service that will be provided (products). This phase is followed by a confrontation with the group of “experts” (phase 2), in order to create a space for discussion in which the personal points of view are re-elaborated in order to define a group agreement which respects both the current scenario/situation and the emerging priorities or needs.

The results coming from the confrontation and sharing of thoughts in the second phase, are synthesized (intergroup product) in order to provide feedback to new groups, consisting of the experts previously consulted and the other participants (user, family, professionals, etc.), but assembled in heterogeneous groups (phase 3). The outcomes are brought as proposals to the manager of a service (public or private) in order to evaluate the desired feasibility and opportunity of the proposal.

Based on the results summarized in the proposals, the individual actors reflect on how to tackle specific aspects and priorities in operational terms, including the elaboration of an intergroup proposal.

Following this, the stakeholders interact with the groups in order to find a consensus on the proposal shared with the manager (phase 4).

Once the results of this final consultation with stakeholders are collected, an effective feasibility analysis is carried out.

The final phase is therefore characterized by the creation of an area of confrontation between participants, aimed at formulating a shared final agreement on priorities and strategies for pursuing them (phase 5).

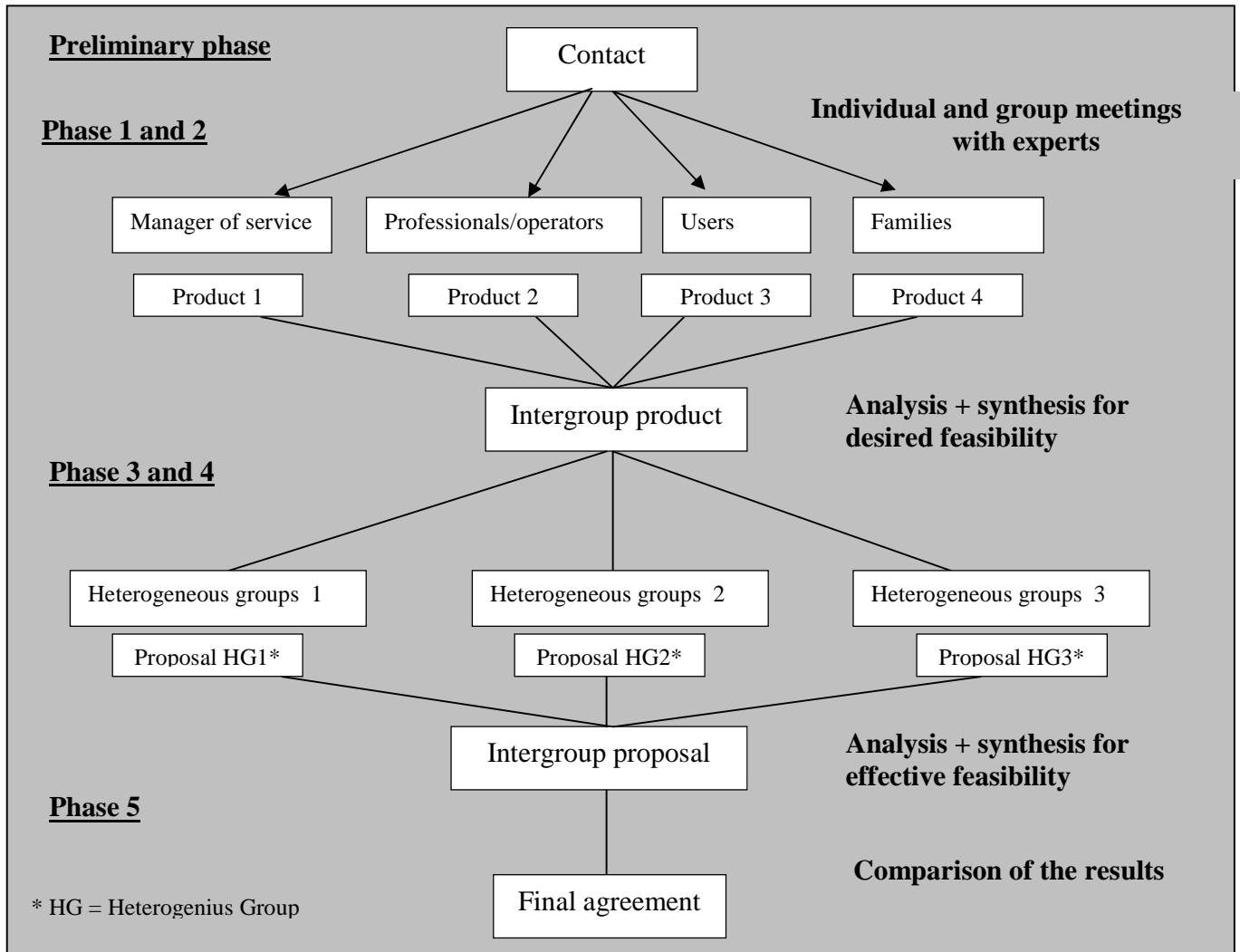


Figure 21: The structured process of PALMI method

CHAPTER 4 - Methodological approaches to research

The premise of this chapter lies in the fact that many factors contribute to the oppression and discrimination of disabled people and to their exclusion from different sectors, in particular research. It attempts to provide evidence of the fact that using a methodological approach based on the inclusion of persons with disabilities could represent a way to reduce oppression and discrimination through the contributions coming directly from them.

In recent years the dominant research paradigms, their principles and values have been criticized by disabled people, organizations and academics about their purposes, effects, outcomes and applications of research.

Beginning with this premise and reflecting on a review of the literature concerning the involvement of disabled people in the research field, I will briefly explore the approaches aimed at attempting to investigate physical, structural, ideological and cultural barriers to their participation in the academic research field.

This chapter describes the methodological approaches considered for: the development of the thesis and defines a theoretical framework of reference aimed at reducing or removing barriers to inclusion. Within this framework the intent is to provide evidence of the fact that if research is able to support the adoption of concepts, ideas and tools inspired by the sense of participation and the emancipation of disabled people, it will be possible to generate changes in the inclusive factors influencing the social relations of the research products and facilitating their quality of life.

This aspect is used to reinforce the research hypothesis “*an open participation in the co-creation of the service and environment, makes life easier for vulnerable groups*”, and to suggest how approaches based on participation and emancipation could support the shift from a medical to a civil and human rights approach to disability.

Following on from the previous chapter in which participatory concepts and tools were described (chapter 3), this one concerns methodological approaches to an inclusive research. This will lead to the next step, where there will be suggestions how these approaches can be linked to concepts such as active citizenship, civil and human rights and social innovation (chapter 5).

4.1 Disability and research: a brief introduction

As stated by Len Barton “*research is a social act. As such, it involves interactions and relationships with a range of individuals and groups which entail ethical, procedural and political issues*” (Barton, 2005). If research is a social act, to not include disabled people in this field represents social discrimination, acting as a form of oppression of vulnerable groups.

The issue is strongly related to the ways in which disability is socially produced and consequently addressed. For this reason the debate on the participation of disabled people is started within a framework based on a social model of disability.

Some issues have been identified from this perspective, characterizing the relationship between research and involvement of disabled people.

The main issues are related to: social justice, equity, citizenship, policy, power relations, accountability, material, cultural and ideological barriers to participation. In addition there are concepts such as empowerment and emancipation, the role of researchers (disabled and not), usefulness and relevance of research products and outcomes, that have been developed by many authors over the last two decades (Oliver, 1997; Shakespeare, 1996; Barnes, 1996; Abberley, 1992).

The debate about these issues has led to a theoretical advancement in the participation of disabled people in research, especially for what concerns the different set of social relations of research production as summarized by Mike Oliver with the term “*emancipatory form of research activity*” (Oliver, 1992).

The emancipatory form of research represents the third and last step towards an inclusive research. The first two are action-research and participatory research, that are explored in order to provide a sort of path among the approaches with different levels and grades of involvement, from the less inclusive towards the most inclusive and participative.

These three approaches, action-research, participatory and emancipatory researches contain several principles that support what has already been theorized by Walmsley and Johnson concerning what they call “*inclusive research*” (Walmsley & Johnson, 2003).

Research about understanding the world in order to contribute to change it, in which the fundamental aim is the empowerment of those participating in the research in terms of knowledge, skills and action.

In this view the voices of the participants are crucial and play an essential element for their credibility.

The real-life experience of the participants is set within a broader context in which there is an ever present imperative facing the researcher, made by their assumptions, values and beliefs becoming increasingly transparent.

4.2 Action-research approach

The first step in the path towards an inclusive research is represented by the action-research (AR henceforward). This method of research is built progressively and its aim is to generate a change in the same environment where the research is applied. AR includes a series of research methods based on change that means “action”, and understanding that means “research”. The term was introduced for the first time in 1946 by the Kurt Lewin (Lewin, 1946), and further developed by Zuber-Skerritt (Zuber-Skerritt, 1992) as theoretical framework known as the CRASP model, in which action-research is characterised as:

- Critical (and self-critical) collaborative enquiry;
- Reflective practitioners being;
- Accountable and making the results of their enquiry public;
- Self-evaluating their practices;
- Participatory problem-solving and continuing professional development.

AR has an interventional intention. Following a strategy based on the introduction of prototypes and novel technology into the life world of the participants with the specific aim of changing their behaviour and practices. This is a trait shared with some branches of design research, as the co-development of concepts or the creation of personal artefacts in the design research process.

AR consists of four dimensions (Avison et al, 1999):

- the category of action-research used and its focus;
- the tradition and beliefs implied by its assumptions;
- the research process, including: themes, levels of organization involved, extent of change, and the role of the researcher;
- the style of presentation adopted.

These dimensions confer to research a particular qualitative aspect able to associate research and practice, so research informs practice and practice informs research synergistically. AR combines theory and practice (and researchers and practitioners) through changes and reflections on an immediate problematic situation within a mutually acceptable framework. This qualifies AR as an iterative process involving researchers and practitioners acting together on particular activities, including problem diagnosis, action intervention, and reflective learning.

This framework represents a type of foundation on which the pedagogy of action research has tried to refine and establish a unifying framework of reference (Avison et al, 1999).

Although the benefits that AR has created in the field of research are indubitable, considering the involvement of participants and stakeholders, it has not been as satisfactory as other approaches (Matthew, 2002).

As a matter of fact, adopting a participatory point of view helps to understand the limits of the AR approach that should be analysed and overcome. In general AR proposes an active participation on behalf of the researcher, and acknowledges the impact this presence has on the outcome (Kaptelinin and Nardi, 2006).

Moreover the researcher gains first-hand experience, but it is still the experience of the researcher, not the participants. In order to overcome these limits, what is suggested here is to go beyond using firstly a participatory and secondly an emancipatory approach to research.

Underlining the need for this further step in research, especially in the field of Inclusive education and Inclusive research, what is taken on board here is what was argued by Kemmis (2006) about “*the connection between education and emancipatory ideals that allow educators to address contemporary social challenges*”. Including the fact that educational trends in recent decades may have led to the “*domestication of educational action research*”.

As reported by the author some action research lacks a “critical edge”, in particular the lists five examples of inadequate action-research applied to educational contexts. One of these examples is of particular relevance for the topic of this thesis, that which refers to action research conducted “*solely to implement government policies or programmes, in order to achieve conformity with what the policies or programmes intend, without subjecting those intentions, their presuppositions, and their frameworks of justification to critical examination*” (Kemmis, 2006).

In order to avoid the risk of a lack of critical examination, an aspect of particular importance for vulnerable groups, the contributions of the

participants involved should be used to reach findings not necessary justified only “*by appeal to authority*”.

Referring to this concept and to what was highlighted by Kemmis in the article “Participatory action research and the public sphere” (Kemmis, 2006), it is indubitable that different results of research can be achieved if using an AR or a participatory approach, especially in the context of Inclusive Education and the interventions with vulnerable groups.

For example, considering the set of research questions reported below, different outcomes will be reached depending on if there is an (AR) or a participatory research approach because the assumptions are different from the beginning of the research:

Research questions	Assumptions of the AR approach	Assumptions of the PR approach
What problems or barriers (socio, cultural, environmental) have the research addressed?	Researchers point of view based on elements perceived or considered as barriers	Participants’ needs, based on real barriers to be faced in their everyday life and really lived as limitation
What aspects, dimensions of practices (education, employment, accessibility, inclusion), understandings and situations did they problematise?	Problematise issues objectively, from the perspective of researchers without creating any communicative space for participants	Problematise issues subjectively, from the perspective of disabled people including the point of views of professionals, families, educators and volunteers, opening a communicative space for conversation between participants
What issues are considered in addressing specific problems (e.g. the use of ICT or the improvement of the independent accommodations	Theoretical knowledge and technical, economic and social problems	Practical knowledge and critical questions considering also attitudinal, educational and political problems

These research questions are examples used to introduce the participatory and emancipatory approach to research. Before introducing these two approaches, and despite the above considerations on the limits of action-research is important to recognize the contributions that AR has provided.

An example is provided when using instruments as participant observation, non-directive interviews, tales of life stories and questionnaires.

This has allowed the AR approach to be used as a successful method of research applied in many areas, especially in the educational field, as for the relationship between school-work, in training programs for teachers, educators and parents.

The action-research has also provided its contribution in the multi-disability field and in the analysis of forms of home care.

However, in order to have an advancement in terms of innovative approaches able to understand existing and new issues, the exploration of new approaches to research is suggested here, in the next paragraphs.

4.3 Participatory research approach

In the second step on the path towards an inclusive research, the methodological approach considered is the participatory research. In order to introduce this idea I have decided to adopt what Zarb's (1992) theory explains "*that it is essential to make a distinction between 'participatory' and 'emancipatory' research. The former is a pre-requisite to the latter...*" (Barton, 2005).

For this reason, following what is suggested by Zarb, first a brief summary of the main features relating to the participatory research is proposed (PR henceforward) and in the next paragraph the ones concerning the emancipatory approach.

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

Participation is an alternative approach to research, often associated to social transformation in the developing countries.

Three particular attributes are used to distinguish participatory research from conventional research:

- a) shared ownership of research projects;
- b) community-based analysis of social problems;
- c) orientation toward community actions.

The application of the Participatory approach to research grew from the experience of adult educators, especially in developing countries such as Africa, Asia, and Latin America, who while working with oppressed people, realized that the rise of specialization and professional expertise had led 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) 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.

Following this view, people are active agents in the research process, because if involved in the 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 based on the confidence that information has been understood and interpreted, can impact on three dimensions:

- 1) personal dimension: developing a sense of self-confidence and capacity undoing the effects of internalised oppression;
- 2) relational dimension: developing the ability to participate, negotiate and influence the nature of relationship and decisions made within it;
- 3) collective dimension: through actions based on cooperation.

These dimensions are strictly related to the Canadian model of the Disability Creation Process (see chapter 2), based upon an interactive and anthropological model that introduces personal-environmental factors (social, cultural and physical dimensions that determine the organization of the environment and society), that can be obstacles or incentives for the individual participation of disabled people (Levasseur et al, 2007).

Therefore, considering both conscientization and empowerment as features included in the PR - and impacting at personal, relational and collective levels - it results as an instrument able to encourage participation and to support socially marginalized people, in particular disabled people to:

- a) critically investigate and analyse their reality;
- b) undertake collective actions to bring constructive changes into their lives.

This also requires a change that should consist in the development of critical consciousness of both the researcher and participants, the improvement of the lives of those involved in the research process and the transformation of societal relations of the products of research.

The dominant research paradigm indeed tends to ignore ethical issues, such as that the information providers are denied any control over the products and results of the research.

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 regarding research on Women, Blacks and the Third World (Stone, 1996). Deserving a focus not only on the similarities, but also on the differences between the disabled movement and the experience of Blacks and Women the most notable is the fact that whilst the status that 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 that people should only be treated 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).

The table below shows the main key features of PR collected from the different authors quoted above, and compared with the elitist research paradigm:

Main aspects	Conventional approaches to research	Participatory approaches to research
Person's role	Object of research	Co-researchers
Objective	Observation and abstract conceptualization	Authenticity: the information generated is used by participants themselves for life improvement)
Method	Research is not directly linked to actions (they can be separated)	Research and action are inseparable (they represent a unity)
Knowledge	Used to provide theoretical basis or academic orientations to be explored	Used to promote actions in order to change or improve existing local actions
Beneficiary	Academics and professionals (producer and beneficiaries of knowledge)	Disabled people (primary beneficiaries of the knowledge created)
Data analysis	Use of methods that meet the goals chosen by researchers	Use of methods easily understood by participants
Perspective	Researchers attempt to be neutral and value -free	Valorisation of the views, feelings and experiences of participants

It is important to note that are two significant ways in which PR differs from conventional approach to research. First, the ideological stance and emphasis on making researchers' values and premises explicit are generally not reported in conventional research.

Second, conventional research is being undertaken without the participation and control of the participants (Tandon, 2005).

At a theoretical level, starting from this distinction, a further step in the evolution of the epistemology of the PR approach was developed. In particular making a link with action-research and evolving in participatory action-research approach, 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 located in, and are the product of particular circumstances that produced them and by which they are reproduced in everyday life (Kemmis & McTaggart, 2007).

The material changes in the process highlighted above also avoid any risks 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 not to focus on epistemological and terminological questions related to the differences between PR or participatory action-research, but the contribution of both to the development of research projects based on the involvement of people.

Assuming these contributions and trying to define a summative frame of reference, the characteristics of research projects that wish to include vulnerable groups should:

- a) attempt to promote self-determination and the liberation of the creativity for the solution of social problems and reduction of barriers (cultural, environmental, attitudinal, etc.);
- b) adopt an action orientation, in which 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) make a focus on determinate needs, increase awareness of problems and commitment to solutions within the beneficiaries, through a dialectic process and not as a static picture of reality;
- g) assist participants to collect data and analyse the information, 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 their own conclusions, enables people to solve their 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.

In this paragraph I have focused on the need for a participatory research approach to provide “*unwelcome truths*” (Kemmis, 2006). I have tried to describe this approach referring to substantial problems of research, such as criticism, ethical issues and empowerment. This **is** because I believe that participation, collaboration and cooperation can support a mutual understanding between researchers and people involved in research projects, where “*the way things are is open to question and exploration*” for “*understanding reality in order to transform it, and to transform reality in order to understand it*” (Kemmis & McTaggart, 2001, 2005).

4.4 Emancipatory research approach

The last step of the path towards an inclusive research concerns the emancipatory research approach (ER henceforward).

It is useful to start again from what Zarb assumed 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).

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).

This means that research projects need to include effectively 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 subjects of research but rather co-creators of research.

The ER approach has its genesis in the social model of disability and in the growth of the Disability movement, the raising awareness of the disillusion of positive and interpretive research paradigms in the 1960s, the consequent critic 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.

Another influential contribution was provided by Mike Oliver’s suggestion to follow “*critical inquiry, praxis or emancipatory research*” (Oliver, 1992), most notably for chancing 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 life of disabled people, is included also in many International documents.

The intent of using the emancipatory research approach to disability research responds to the precise indication of the Madrid Declaration³⁸ to

³⁸ 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

promote and support the leadership of persons with disabilities. The focus on this approach 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.

Emancipatory approach to research is based on the reciprocity, gain and empowerment, methods used within the feminist paradigm (Lather 1987; Ribbens 1990), and the concept of reflexivity (Oliver 1992) developed by the Disability Studies movement.

In this way the value of research can be gauged by asking how far the process of participation has made a contribution to individual or collective empowerment and whether improvements in the lives of disabled people have been achieved in any measure as a result (Carmichael, 2004).

This means that the first result should be the reduction of barriers and the promotion of disabled people's individual and collective empowerment (Barnes 2003), as implicit transformative aim of emancipation.

The six core principles of an emancipatory research approach are summarized below in order to provide further elements that characterize this approach.

These principles were defined firstly by the work of Barnes and Sheldon, in which used "*not as rules for doing disability research*" (Barnes & Sheldon, 2007), but mostly as principles for designing projects of research able to guarantee a process of emancipation.

1) The model of reference

This principle relates to the choice of the ontological model of reference (Priestley, 1997) that is the social model of disability. Previous models of disability based on the individual limitations have not provided a sound framework for research which strives to be emancipatory.

The shift from a medical to a social model of disability represents an ontological foundation in which disabled people are like all people, and since their needs of involvement are not met by the academic system research might seek to facilitate a fundamental restructuring of that system (Triano, 2000).

2) *The accountability*³⁹

The principle of accountability is a key component of the emancipatory research approach.

First of all because both research and researchers operates within a market-led environment where continued career prospects are determined by the ability to secure profitable research contracts.

Accountability becomes a particular challenge when the participation of vulnerable groups is sought.

In the conventional approach of research for example disabled people seem to be assumed as incapable of finding solutions to their own problems. Instead, researchers are deemed to be the experts, who know what is best for disabled people and frequently make decisions about their lives without consulting them.

In this sense emancipatory research is aimed at successfully challenging stereotypical assumptions of disabled people as static, vulnerable, dependent, lacking agency and imagination (Davis and Hogan, 2004) into people considered as active, self-determinate, participatory and provided of practical knowledge and creativity.

3) *The objectivity*

It is interesting to consider what is argued by the disability activist Paul Hunt that suggests that research can never be detached and impartial because “*facing with any socially oppressed group, social scientists have a choice of only two alternatives: either a firm commitment to serve the interests of the oppressed group to end their oppression, or a commitment to serve the interests of the oppressors to continue their oppressive practices... There is no middle way*”.

It is also difficult to support the idea that those involved in disability research should put aside any claims to objectivity because it is “*precisely those who try to take a detached view of oppression who cannot be objective*” (Hunt, 1981).

In response, all that researchers (disabled and not) can do is make their position clear at the outset.

³⁹ For a further focus on the standards for accountability see the British Council of Disabled People (BCODP) project, in “Disabled People in Britain and Discrimination: A case for Anti-discrimination Legislation” (London: Hurst and Co.) available at: <http://www.leeds.ac.uk/disability-studies/archiveuk/index.html>

This means stating clearly their ontological model, ensuring that the research methodology and data collection strategies adopted are “*logical, rigorous and open to scrutiny*” (Morris, 2003).

4) *The choice of methods*

The emancipatory research approach has generally been associated with qualitative rather than quantitative data collection strategies, in part because such strategies allow more scope for participants to take control over their words and thus affect the direction of the research (Shakespeare, 1996).

Moreover quantitative research methods have been somewhat discredited within Disability Studies in the wake of various large-scale surveys conducted in Britain.

Considering that all data collection strategies may have strengths and weaknesses in researching on disability, what is important is that the choice of research methods can be determined by the needs of the research participants.

5) *The role of experience*

Concerning the role of experience it is important to consider that the use of personal experience as the only analytical tool can “*obscure the collective nature of disablement as a form of social oppression*” (Stone and Priestley, 1996).

Whilst experience may be “*a necessary starting point*”, it should not be viewed as “*an end in itself*” (Kelly et al., 1994). Instead, it is crucial that researchers “*locate individual’s narratives in the wider socio-cultural context, and explore narratives principally, though not exclusively, for what they tell us about disability and other sources of oppression*” (Thomas, 1999).

For example, referring to inequality in education, solutions must be sought at various levels. At the macro level through legislation, policy and guidance; at the micro level, because individuals, both staff and pupils can make significant differences to young people’s lives. It is at this micro level that listening to the insider perspective becomes most important. At the macro level however, it may be that such accounts have little or no value (Clifton, 2004).

It is therefore essential when considering the question of experience that researchers be aware of the struggles disabled people have been in and still are involved in their social context. (Barton, 1998).

In particular the personal experience of participants is an important source of information in order to understand the social and cultural context, besides from being a basic principle to be adopted in a process of emancipation.

6) *Practical outcomes*

This principle highlights the importance that research findings are disseminated appropriately, in a variety of formats in order to allow practical outcomes to reach those who need to be reached (Ward and Flynn 1994).

It is not enough simply to write academic journal articles or book chapters to be read by fellow academics and researchers. Findings must also be disseminated widely, in accessible ways requiring innovative approaches and using different tools.

The table below shows the main features of ER collected through the literature reviews conducted, and in relation to the elitist research approach:

Main aspects	Conventional approaches to research	Emancipatory approach to research
Person's role	Object of research	Co-creator of research
Objective	Observation and abstract conceptualization	Emancipation through reciprocity, gain and empowerment of participants
Method	Research is not directly linked to actions (they can be separated)	Reflexivity at the basis of the relation between research and action
Knowledge	Used to provide theoretical basis or academic orientations to be explored	Used to change the social relation of the research productions
Beneficiary	Academics and professionals (producer and beneficiaries of the knowledge)	Society in its whole
Data analysis	Use of method that meet the goals chosen by researchers	Use of methods determined by the needs of the participants
Perspective	Researchers attempt to be neutral and value -free	The experiences of participants in relation to their social context

In order to provide a reality for these notions, the next paragraph proposes strategies and tools for applying participatory and emancipatory approaches to research.

The aim is to suggest how to use these approaches focusing on: research questions, participants' involvement, level of emancipation and impact on lives.

4.5 Proposal of strategies and tools for applying participatory and emancipatory approaches to research

In this paragraph I will tentatively propose strategies and tools for applying participatory and emancipatory approaches (P&ER henceforward).

The strategies and tools described are not exhaustive, although the intent is to provide practical elements, not only theoretical principles and constructs, in order to contribute to the advancement and implementation of an inclusive research.

These suggestions are based on the literature review conducted on the theme, mainly articles dealing with experience realized in developing countries in the last two decades, having a longer tradition of participation, demonstrating that sometimes a developed country could learn from others (Kaner 1996, Pretty 1995 and Krishnaswamy 2004).

Before introducing strategies and tools, I wish to make a synthesis of the key elements to take into consideration and hopefully adopt- in the case of P&ER, representing the goals of both approaches.

Resuming what was exposed in the previous paragraphs of this chapter and referring to the main authors, a sort of scale follows including the basic elements of participatory and emancipatory approaches for moving towards an inclusive research.

Recognizing that elements often overlap and is not easy to precisely respect the order suggested, these are:

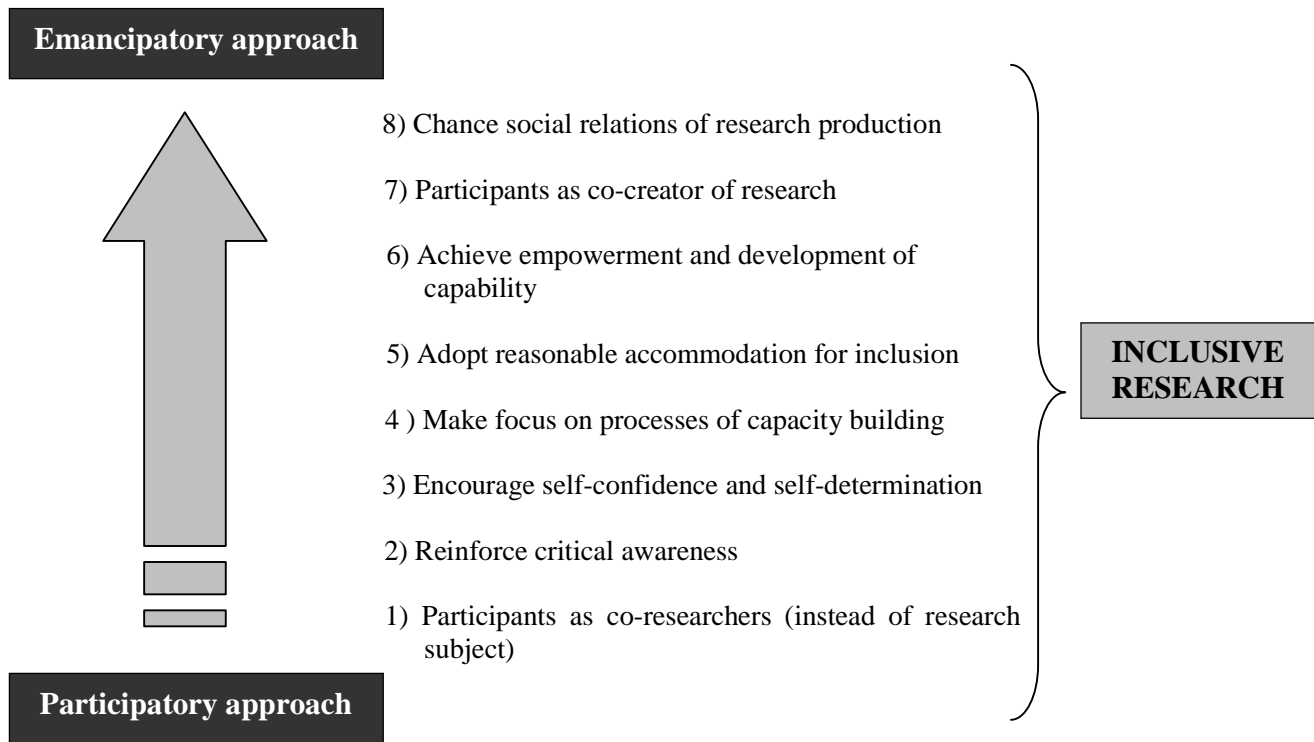


Figure 22: Scale of the basic elements of participatory and emancipatory approaches for moving towards an inclusive research

The strategies and tools described below are models that can be applied in both approaches (that differ only for the kind of goals defined), adapted to different contexts, socio-cultural scenarios and research field, as education, accessibility, employment, ICT and assistive technology, independent living, health care, etc.

Considering that appropriate tools need to be designed and strategy applied with sensitivity when working with vulnerable persons.

The strategies and tools have been organized in phases. Strategies mentioned under a particular phase can be used in other different phases of research, as well as for the tools.

1) Phase: Definition of the goals of the research

Strategy	<p>Development of an agreement or statement involving all the participants in the research (identified through participatory processes). The aim is not provide details of specific actions of research, but describe:</p> <ul style="list-style-type: none"> - Goals - Research methods for collecting data and analysing results - Values and principles of the participants - Level of emancipation to be reached
Tools	<p>a) Project plan: once the goals of the research project are defined it is important to realize a shared project plan including: the scheduling of tasks, definition of timetable, deadline, work packages, etc.</p> <p>b) Scale of the level of emancipation to be reached</p>

2) Phase: Creation of relationship based on confidence

Strategy	<p>Creating relationships based on confidence means including three requirements: competence, reliability and sincerity (that together guarantee confidence). In accordance with Krishnaswamy (2004) “developing the research question is not the starting point of the participatory research process” and even more for the emancipatory.</p> <p>Creating confidence is necessary before defining the research question, because “creating space for informal communication and regular interaction amongst research participants” is at the basis of trust building.</p>
Tools	<p>a) Communication plan for sharing and organizing the information flow (e.g., mailing lists, exchange of contacts, etc.)</p> <p>b) Informal meetings</p> <p>c) Training activities and tutoring processes (if required)</p>

3) Phase: Definition of a common understanding

Strategy	<p>Once goals and confidence have been created amongst participants, an other phase is to define a common understanding, ensuring agreement about</p>
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	<p>the expectations, investment in the process and active engagement (avoiding the risk that any one person dominates the research process). Therefore, it is important to facilitate the capacity of participants to take part in the research process. The strategy consists in: organizing the facilitation of meetings; to take into account the needs of all participants when negotiating the common understanding or the goals of the research.</p>
Tools	<p>a) Facilitating meetings: facilitators (that could be researchers, disabled people, professionals, educators or family members) should encourage an effective participation in meetings, considering issues such as: the adequate access to information, environments, instruments, as well as the necessary time for discussion. b) Check-list of concepts, ideas, values and principles to be adopted in the research. c) Memorandum of understanding: that broadly outlines what the research hopes to accomplish. This can represent an overly formal way to define a collaborative process, providing clarity and helping to resolve future conflicts (Krishnaswamy, 2004).</p>

4) Phase: Identification of beneficiaries and stakeholders needs

Strategy	<p>Identifying the needs of beneficiaries and stakeholders guarantees an effective involvement. They can be representative of different interests and fields (e.g. community members, academic institutions, local, regional or national authorities, associations, civil society organizations, small and medium enterprises, etc). Due to this heterogeneity it is important to facilitate their participation in the research, supporting a more comprehensive identification of needs and relevant issues. Enhancing the capacity of different stakeholders to mediate, negotiate and represent their interests in wider social contexts, in order to have an impact on the social relations of research productions.</p>
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Tools	<p>a) Check-list of beneficiaries and interested stakeholders to be involved</p> <p>b) Action plan for needs analysis, including: design of the instruments to collect information, analyze data, etc.</p> <p>c) Involvement strategy: e.g. adopting a “snowball method” to find others and define how they will benefit by participating in the research.</p>
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5) Phase: Identification of the research questions

Strategy	Once a common understanding is defined (including concepts, values and principles) and the needs of beneficiaries and stakeholders are collected, identify the research questions choosing a series of selection criteria, including: feasibility, usefulness, transferability, sustainability, cost-effectiveness, economic impact, time of doing research.
Tools	<p>a) Template in which to report and prioritize identified choices or alternatives which must be addressed (e.g. distinguishing among important or necessary, useful or interesting, etc.)</p> <p>b) Selected criteria to evaluate potential actions to be matched with the issues identified. Rating each action for each criterion or issue (e.g. 1, 2, 3 for high medium and low), it is possible to give to each potential action a “relative value” or priority compared to the other actions, allowing to narrow down a long list of agreed priorities by which generate one or several research questions.</p>

6) Phase: evaluation of the emancipation of participants

Strategy	The assumption of this strategy is that increasing participation and the involvement of participants, never by itself constitutes emancipation, unless and until it is disabled people who are controlling the research as co-creators deciding who should be involved and how. The emphasis is therefore on people working together to achieve the goals of research, leaving time and space to reflect on what contribution for the emancipation of persons.
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<i>Tools</i>	<p>a) Selection criteria to evaluate the level of emancipation reached by participants and the change of the social relations of research production (mostly qualitative criteria).</p> <p>b) Interviews, questionnaires, focus groups, Living Lab, round tables</p>
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7) Phase: dissemination of research outcomes

<i>Strategy</i>	<p>It is composed of different levels of dissemination and activities, including:</p> <ul style="list-style-type: none"> - Web dissemination: identification of relevant websites (at local, national and international level), asking for establishing cross-linking, use of the web 2.0 resources (tagging, google analytics, followers/following, RSS, etc.) and social network. - Live dissemination: participation in open meetings, conferences, fairs, events targeting professionals, educators, disabled people organizations, teachers, researchers and relevant stakeholders. - Other forms of dissemination: articles, papers, press release to relevant online/offline magazines, reviews, TV and radio programmes, etc.
<i>Tools</i>	<p>a) Dissemination plan</p> <p>b) Exploitation strategy</p>

In this chapter I have outlined some issues, interpretations and questions that I consider important in terms of inclusive research. This is not an exhaustive analysis nor is it without limitations. It has been suggested from the position of a disabled researcher who is committed to inclusion in research. In conclusion I have identified some implications in terms of participation and emancipation in order to provide a grounded framework for the understanding of the suggestions that will be presented in the next chapter.

CHAPTER 5 – Participatory and emancipatory approaches: supporting active citizenship and socially innovative actions within the civil & human rights model of disability framework

In order to switch from the theoretical level of the research to scenarios of practical application of the constructs described in the previous chapters, the following three hypotheses are presented to link the participatory and emancipatory approaches with three key concepts of this thesis: active citizenship, civil and human rights and actions of social innovation. In detail:

- To what extent the participatory approach to research can support active citizenship for an effective involvement of disabled people?
- To what extent emancipation through research can contribute to the affirmation of a civil and human rights model of disability?
- To what extent participatory and emancipatory approaches can be used for the design and implementation of socially innovative actions?

The initial assumption of this chapter 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 research.

The slogan, in line with the United Nation Convention on the Rights of Persons with Disability⁴⁰, 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 creating social changes, contributing to the research production and finding conditions to participate in the development of socially innovative actions.

This chapter first demonstrates the link between participatory approach and active citizenship, secondly between emancipatory approach and civil and human rights.

A series of practical examples are provided to support the idea of these connections. In addition a focus on possible implications within the framework of the Inclusive education is tentatively suggested.

⁴⁰ 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>

In the last part of the chapter these connections are proposed as seeds for the growth of projects and prototypes of social innovation.

It addresses the challenge 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, empowerment and emancipation, for the advancement of the principles and rights included in the United Nation Convention on the Rights of Persons with Disability.

The purpose is to provide evidence to answer the three research questions highlighted above, finding suggestions in the literature review and international documents, proposing as insight the application of participatory and emancipatory approaches to encourage the support of the active citizenship, the affirmation of a civil and human rights approach to disability and socially innovative actions.

This means drawing up scenarios in which disabled people can play an active role in the research field (development of critical consciousness), adopting the concepts of active citizenship (improvement of their lives), civil and human rights (transformation of fundamental societal structures and relationships), in order to provide advancements on ethical issues and provide suggestions for innovative solutions.

5.1 Participatory approach and active citizenship

Starting from what highlighted in chapter 4, regarding the features of research projects that wish to include disabled people, features of particular relevance for linking active citizenship and participatory approach are here focused on, where both:

- a) attempt to promote self-determination and the liberation of the creativity for the solution of social problems and reduction of barriers (cultural, environmental, attitudinal, etc.);
- b) adopt an action orientation, in which 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.

On the basis of these features, and considering the contributions of many authors on this issue, I will try to strengthen the idea of a connection between the participatory approach and the active citizenship in the disability field.

These features are of particular interest, as proved by Jenny Morris, in the debate on the meaning of citizenship for disabled people and the way of viewing citizenship (Morris, 2005).

I wish to consider self-determination (point a) as the basic element through which individuals can “choose”, involving 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).

Self-determination is therefore used as key aspect of what it means to be a free and equal citizen, and as “*right to live self-determined lives*” (Wehmeyer, 1998).

Moreover “*a person cannot achieve self-determination if they experience direct or indirect discrimination*” (Morris, 2005), as the unequal access to education and employment opportunities that represent evident manifestations of discrimination.

Allowing the participation of disabled people in academic research can represent a way to face this phenomena, providing elements, data and suggestions about how to reduce discrimination and improve access to education, training, employment and research.

Referring to the action orientation (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). The author shows the relationship among the communitarian emphasis on responsibilities and reciprocity, and the issue of the limits to 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 means they need to provide opportunities to research on themes emerged directly by the perceived needs of disabled people, to be involved in research processes from the beginning, with the right supports, methods and tools.

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 possible disabled people's involvement (Santi, 2010).

This participation gives expression to self-determination and provides opportunity to make contributions, as a basic integral part of being a citizen, considered free and open to participate in definition of needs, the way to be responded and tools (i.e. assistive technology), shaping the cultural attitude, social expectations and political decisions that affect their lives.

In conclusion, self-determination, action orientation, participation and involvement, if connected with the features of participatory approach to research can support a full and equal citizenship by themselves, providing relevant contributions to research.

In particular avoiding the risk that research could be implemented and adopted only if in line with what the government policies or programmes intend. This without subjecting those intentions, assumptions and frameworks to critical examination, producing findings that can be justified only by the convenience of the authority.

In this way, maintaining the 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 able to address challenges, respond to social needs, reducing emerging and existing barriers to inclusion and active citizenship.

The active role as citizen should be to act as a "person" with her/his needs, desires and expectations at the centre of research, actions and interventions.

And contributing to support the transition from a common attitude of considering disabled people as victims of a state of passivity and patient care, towards a different attitude based on the responsibility and the consciousness of the importance of the involvement in research projects not "*on*" but "*with*" them (Reason and Heron, 1986).

5.1.1 Practical examples

This section focuses on examples that show ambitions, processes and results aimed at creating favourable conditions for applying participatory approach, including elements of active citizenship in disability contexts. Comprehensive coverage is not claimed, rather examples of practices presented to show possibilities in a range of contexts.

1) *Example*

This example is provided by the project “Reconnecting Excluded Communities and Life Long Learning (RECALL)”, started in 2009 and ended in 2012, financed by the Lifelong Learning Programme - KA3 Multilateral projects.

The project was led by the Nottingham Trent University and aimed at meeting the needs identified from research in working with user groups of people with learning disabilities and their teachers/trainers. This research has shown that on leaving compulsory education, people with learning disabilities, who have previously been provided with transport to allow them to access community activity, suddenly become excluded from lifelong learning and community activity because of their lack of independent travel skills.

Three modes within the RECALL project were implemented and tested to allow the target audience to plan, rehearse and then reconnect with learning, employment and other community opportunities through a personalization of users’ needs.

The Challenge mode used games based on learning approaches and context awareness to engage users in rehearsing, reflecting on and reinforcing the ways in which they have planned their reconnection with these opportunities. The Usage mode also offers self directed learning opportunities by specifying and personalising the key community and road safety messages that they require to be triggered by location. RECALL is an application developed for the Android Operating System and specified in English, Bulgarian, Greek and Romanian.

In the UK and Greece RECALL worked with end user groups of people with learning disabilities and with Deaf people. In Romania with people with physical disabilities and sensory impairments and in Bulgaria involved mainly people with mobility impairments. Testing and piloting of the products measured the performance against agreed indicators to ensure that these met the objectives of increasing independence and inclusion for the target groups and of reconnecting excluded learners back to their communities and lifelong learning opportunities.

Using a participatory design approach one of the main impacts of the

project has had on the beneficiaries targeted has been to contribute greatly in reinforcing the contribution of lifelong learning to active citizenship and personal fulfilment; to supporting the development of innovative ICT-based content; to increased participation in lifelong learning by people with special needs.

(Available at: <http://recall-project.eu/about/>)

2) Example

Another example of the participation applied to active citizenship in a context of disability is represented by the active citizenship movement in Palestine through the role of community based rehabilitation projects (CBR henceforward).

In this country the economic and political conditions make the situation difficult and create additional problems and poverty. It has been widely argued that community based programmes offer considerable advantages to the classical institutional forms of health and rehabilitation services delivery (Giacaman, 2001). With about 10 years of experience in operating CBR for disabled people, the Palestinian experience points to potentially serious problems relating to the conception and operationalization of such programmes in real life situations. But when the projects are operated holistically in the context of social movements existing with a broader democratic agenda engaging different groups - including a disability movement - as is currently taking place in Palestine, these can also turn into a mobilizing force for the social rights of all excluded groups.

According to Nilsson & Qutteina (2005), these projects have empowered individuals and parents on various aspects of active citizenship, such as improved basic daily living skills and coping mechanisms, reduced stigma and isolation and increased social inclusion. In addition, people in special needs are more respected in their families and have become more visible and more vocal (Alevriadou & Lang, 2011).

3) Example

This example is provided by the project “DISCIT”, started in 2013 and financed by the 7^o Framework Programme. It aims to produce new knowledge enabling European countries and the European Union to achieve full and effective participation of persons with disabilities in society and the economy. In investigating the social and political conditions for making such participation a reality, the project adopts a multifaceted understanding of active citizenship to operationalise the notion of “full and effective participation” in the UN Convention on the Rights of Persons with Disabilities.

Adopting a multilevel and institutional perspective, DISCIT examines

how different types of policies can be mutually supportive in enhancing active citizenship for persons with disabilities.

(Available at: <http://www.discit.eu>)

5.1.2 Focusing on participation, active citizenship and inclusive approach

Active citizenship is closely connected to equal rights in society, and according to Kjellberg (2002), three elements are included in citizenship:

- 1) *civil citizenship*: is based on the idea that each person is equal before the law. It is comprised of personal integrity, freedom of speech, religious liberty, freedom of thought and right to property;
- 2) *political citizenship*: includes the right to vote in elections and the possibility of being elected to positions of trust;
- 3) *social citizenship*: covers the principle of welfare for all, which covers each human being's rights to a secure economic situation and the right to education, social service, health care and participation (Marshall, 1964). All people with disabilities should receive the support they need within the ordinary structures of education, health, employment and social services, within the human rights framework.

All these three elements make the model of active citizenship “*the most important paradigm within the settings for disabled people*” (Alevriadou, A. & Lang, L. 2011), whose objective is a full participation in society. This model is based on: quality of life, emancipation, support and coaching and empowerment (Cappelle, Le Roy & Verkest, 2008; Van Gennep, 1997):

- *Quality of life*: refers to the possibility of people to plan, organize and guide their life in all areas. The focus is on the implementation and the complementary of specific supports in order to determine physical, psychological and functional well-being.
- *Emancipation*: focuses on the optimisation of the individual's development and his/her equal position within the society.
- *Support and coaching*: refers to the implementation of methods (e.g., coaching) and strategies of development, functioning, well being of the disabled people. These objectives can be reached by offering

support in different ways by - social networks, organizations and additionally by the professional and services.

- *Empowerment*: aspects of the quality of life, emancipation and support are integrated into empowerment, this provides an improved possibility of a person to succeed. Believing in ones capabilities offers power and energy in becoming conscious of the situation and the need for social rights. It also permits the person to communicate, participate, to live, to work and to spend free time with others and to move within a broader society.

At a personal level, empowerment refers to the enhancement of self-esteem and self-confidence, feelings of control and of owning one's own life, self-efficacy, a sense of coherence (Van Houten & Jacobs, 2005).

At community level, it includes participation in community activities; the increase of a sense of belonging and the construction of a common identity.

It can also support the creation of social networks and self-organisations; including the enhancement of problem-solving capabilities as a "*community competence*" (Alevriadou, A. & Lang, L. 2011).

As argued by Alevriadou and Lang, at this level active citizenship and Inclusive education can help disabled students to be strong participants in personal empowerment, characterized by collective action to create changes at educational, formative, societal and political level.

All these constitute active citizenship and, according with Reiter and Schalock (2008), for disabled people it is a "*shift from dependence and passiveness to autonomy, self-awareness, and self-direction*".

Autonomy, self-awareness, and self-direction are also viewed by the authors as three steps for the enhancement of citizenship education, including:

- *Social education*: the capacity to be involved in meaningful interpersonal relationships, free choice, the setting of goals, planning of the actions and evaluation of the outcomes.
- *Career education*: the ability to develop specific vocational skills according to personal capabilities, to enhance the wish to be engaged in productive and creative life.
- *Independent living*: the possibility to live an autonomous life.

The success of the acquisition of active citizenship is expressed both at person level, through an enhanced sense of self-worth, self-confidence and social skills.

At social and educational levels, as a paradigm shift from a medical model of approach to a social one based on civil and human rights.

The link between active citizenship and inclusive education is represented by their common roots in *“the same earth”* (Alevriadou, A. & Lang, L. 2011).

These roots are values including: community, equity, entitlement, inclusion, variation and participation. The same earth is represented by the gradual affirmation of rights. Firstly civil rights and then human rights and a way to understand people with difficulties, trying to find innovative solutions to meet their needs, coming from persons directly involved in the educational processes.

Considering that *“if the goal for citizenship education is to educate Europeans that are capable of participating in a democratic society, the most fundamental measure is to give pupils opportunities to practice participation in democratic dialogues. It seems that all teachers, in all lessons, must offer all pupils a horizontal classroom dialogue”* (Sandström, Kjellin & Stier, 2008, pp. 49).

In this sense preparation for citizenship skills and competences for disabled students should be an explicit part of inclusive education, and more widely of the formal education system, from pre-school to university level and beyond, as part of adult education and lifelong learning.

Although active citizenship sometimes seems to concentrate on an individual developing approach whilst inclusive education contrariwise uses a more holistic approach, what is important is to put emphasis on disabled students as currently active citizens in interaction with each other, with adults and with the community.

Whereby it would be desirable that all the actors, agencies and aspects of education should be aware that *“citizenship is best learnt through experience and interaction with others, as inclusive education imposes”* (Alevriadou, A. & Lang, L. 2011).

This could allow the educational system to provide the opportunity for teachers, educators, school administrators, students and families to develop an environment that reflects societal ideals as equality without discrimination (Pivik, McComas & Laflamme, 2002).

Education as citizenship would challenge the school effectiveness paradigm, implying educational change and requiring it to assume a

complimentary paradigm of student's social inclusion (Edwards, & Usher, 2000).

According to these authors it could very interesting and useful to promote the need for further research in this field, in order to analyze and support the relations between active citizenship and inclusive education.

5.2 Emancipatory approach and civil and human rights

In this paragraph I will try, tentatively, to explore the emancipatory approach to research showing the links with the civil and human rights and the oppression that disabled people currently experience in their lives.

The participatory research approach, together with the model of active citizenship, help disabled people to fulfil self-determination, responsibility and participation in the community.

Emancipatory research (ER henceforward) instead is more strictly connected with a different understanding of disability, as indicated by the civil and human rights approach to disability that focuses on the problems of lack of rights (Lawson, 2006).

In this brief dissertation on the theme I decided to focus on the discourse concerning civil and human rights.

An individual enjoys civil rights by virtue of citizenship and they are aimed at providing an equal treatment.

An individual enjoys Human rights by virtue of being human and they are aimed at providing equal opportunity and participation for all.

Although they represent two different models, here they are assumed to be an unique framework in which civil rights and human rights are guaranteed.

In this unique framework disability is viewed not as a medical entity or an individual problem, but as a rights issue.

In this view ER is not only an approach, but rather part of the struggle of disabled people to have their rights recognized with reference to the control of decision-making and the research processes that shape their lives.

Although participatory research may give support to this model of disability, it is not inherently associated with it.

In ER the processes and outcomes are part of the liberation of disabled people and of the change of society to ensure their full rights.

Historically, society viewed persons with disabilities through a medical model that considered “handicapped” individuals as naturally excluded from mainstream culture.

Due to this model disabled persons have been systemically excluded from social opportunities, including to participating in the definition of their life project and emancipation from oppression and exclusion.

In the 1960s this model was replaced by the social model of disability that became the dominant theme advanced by the disability rights movement (for a more detailed chronology on the development of these models refer to chapter 2).

In the 1970s and 1980s the American disability rights proponents viewed discriminatory attitudes toward disabled citizens as the key obstacle to social inclusion and started to propose a civil rights approach to disability for challenging and removing barriers which prevent disabled people from living full and active lives.

These barriers are many and can lead to institutional discrimination, such as: the construction of buildings that are not accessible by disabled people, information provided in ways that disabled people cannot use, attitudes and stereotypes that prevent from having the same opportunities as non-disabled people (Russell, 2002 and Waddington & Diller, 2002).

Their most significant result was in the 1990 with the promulgation of the Americans Disabilities Act (ADA henceforward), prohibiting disability based discrimination.

As an exemplar of the social model, the ADA has played a leading role in developing disability law outside the United States. The ADA entitles people with disabilities to be treated equally to the general population. But although civil rights are directed at ensuring equal treatment, they don't guarantee equal opportunity and a full social inclusion.

To remedy the limitations of the disability civil rights approach, I have decided to also refer to the Human Rights approach to disability. This approach moves beyond the social model's emphasis on formal equality by acknowledging that disabled persons are entitled to equality by virtue of their equal humanity, not because they satisfy the same norms (Stein & Stein, 2007). Under this approach, all individuals with disabilities are entitled to civil rights measures combined with equal opportunity, as argued by the UN Disability Rights Convention.

In this paragraph I wish to consider both civil and human rights as the basic elements of the model of reference in addressing disability, for the following reasons:

- 1) Human rights are aimed at creating equal opportunity, but this does not necessarily imply an equal treatment as provided by civil rights, and vice versa.
- 2) While human rights are basic rights inherent with birth and considered universal, as humanity is a “*timeless entity based upon appeals to reasons and absolute truth*” (Mckenzie & Macleod, 2012). Civil rights are related to the creation and functioning of society (Tharoor, 2001) and, for this reason, here considered more realistic in achieving them. Civil rights derive from the Latin translation of *ius civis* (rights of citizens), and are inspired by the 14th Amendment to the American Constitution as “*the rights belonging to an individual by virtue of citizenship*”⁴¹. For this reason are here regarded as indivisible from a participatory approach and active citizenship.
- 3) Examples of civil rights are freedom of speech, press, and assembly; the right to vote; the right to equality in public places. Violations of civil rights occur in instances of discrimination against an individual solely based on a person’s race, sex, religion, age, physical limitation, national origin, and in some instances, even sexual preference. These rights include a class of rights and freedoms that protect individuals from unwarranted government actions and ensure one’s ability to participate in civil and political affairs without discrimination or repression.
Human rights include: the right to life, to freedom, the pursuit of happiness, to be free from prejudice on the basis of race, gender, national origin, color, age or sex. To be free from slavery, to freely associate with whomever you like and to join groups of which you’d like to be a part, freedom of thought and the right not to be prosecuted for ones thoughts. All these rights must be considered in addition to civil rights, in order to promote an equal inclusion for all persons in an evolving society.

This framework requires the participation of people with disabilities in the process of societal reconstruction, so that they may assert their rights in responding to their needs fostering their emancipation.

⁴¹ Available at: <http://www.usconstitution.net/constamnotes.html>

For this suggestion I have also considered what Sen has pointed out, that it is *“the availability of political and civil rights which give people the opportunity to draw attention to their needs and to demand action from the government”* (Sen, 1999b).

Whereby, linking the emancipation to the notion of civil and human rights could be a possible way to strengthen the role of disabled people in the definition of needs and the consequent actions to meet them.

The adoption of these rights is strictly connected to the concept of active citizenship described in the previous paragraph and the role played by the participatory approach.

Summarizing the main differences and characteristics of Human and Civil rights:

Human rights	Civil rights
Provide citizens with equal opportunities	Provide citizens with equal treatment
Are those rights that an individual enjoys because of being human	Are rights that an individual enjoys by virtue of citizenship and being a member of society
Are universal	Are contextual
No government body, group or person can deprive human rights to an individual	Protect the individual from discrimination and unjustifiable action by others, government or any organization
Are considered a universal right	Are related to the constitution of each country
Do not change from one country to another	Differ from one nation to another
Are universally accepted rights regardless of nationality, religion and ethnicity	Fall within the limits of a country’s law, and pertain to the social, cultural, religious and traditional standards, and other aspects

From this point of view, civil and human rights imply the citizen’s ability to fully participate in the social, academic, institutional and political life of

the state without discrimination regardless of disability, gender, religion, race, national background, age or sexual orientation.

In this sense through the adoption of a civil and human rights dimension disabled people can become active subjects and not passive objects, participants in driving research that should attempt to understand the significance of events, not only their causes.

In this way researchers and the researched can become agents of change, mutually enriching and capable of developing 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), that means to apply the right to inclusion and participation in society on equal terms with others, as in academic research.

It's also interesting to notice, for example, that the United States made a significant contribution to protect the rights of people with disabilities by enacting laws or policies primarily in education and civil rights (Stein & Stein, 2007).

The ER approach could represent not only a set of technical procedures, rather a process for the demystification of existing ideological, cultural and political structures, as it has been for Black People and Women movements (Maguire, 1987).

Notwithstanding some differences, the alignment with other oppressed groups has allowed disabled people to draw on the experience of feminist (Goodley, 2004) and anti-racist theorists in many areas, such as research. This provides the possibility to act with an active role in approaching social needs, in finding innovative solutions and in the attempt to reduce barriers to equal opportunities, for every individual to fully participate in democracy and citizenship.

The civil and human rights approach finds the causes of disability in social terms that reflect on the cultural attitude towards rights problems.

What is stated here is to suggest ways to support active citizenship and develop innovative solutions through the participation and emancipation.

The integrating theme running through this application of a participatory and emancipatory approaches finds its transformative aim in facing disability as civil and human rights problem, in order to find innovative solutions to respond to different claims as equity, equality and accessibility (Mckenzie & Macleod, 2012).

The focal point is to locate the ER approach where the person finds the right conditions to contribute what he/she is able to, hopefully not only in the field of research.

This thought is also based on the concept of resilience and the possibility to find the right and reasonable accommodation in order to foster an active involvement of persons and an effective participation.

From this perspective the role of the researcher (when non-disabled) is to facilitate these goals, through participation aimed at contributing to individual, collective and social empowerment and emancipation, because 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).

This also implies the theme of accountability, a key component of the emancipatory research approach, not only for the researcher but also for the disability community and its representation.

Referring to this issue, it is important to mention the contributions of Mark Priestley and Lisa Waddington concerning the new priorities for disability research in Europe.

These authors put the emphasis on the fundamental role played by Disabled People Organizations “*as active partners in research rather than the recipients of scientific knowledge*” (Priestley et al, 2010a).

This theme, already faced in some projects such as the British Council of Disabled People’s 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, as for instance the barriers disabled people face when attending 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 and human rights approach which supports the view that “*any kind of segregation is ethically wrong*” (Alevriadou & Lang, 2011), an ethical issue that involves personal rights and society will recognize these rights in an effective way.

This perspective also emphasizes the principles of the International Classification of Functioning Disability and Health, which covers: the person, the bio-psycho-social model, the consideration of contextual factors, the relational perspective, the quality of processes and systems of education, the participation in social life.

The latter principle is of particular interest as it is strictly related to the concepts of inclusion, because, as stated by Stainback and Stainback (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”*.

The key questions for the call for evidence which this paragraph has tried to answer started from a civil and human rights approach to disability to suggest a new trajectory of inclusive research. Focusing on participatory and emancipatory approaches, aimed at supporting active citizenship and socially innovative actions, producing more useful and relevant research results for people and society.

This trajectory needs to be understood as a process, rather than an outcome, to find a sort of common denominator for socially innovative practices.

Practices should be designed and approached through an investigation together *“with”* disabled people rather than *“on”* them, considering the social relations of research production as crucial aspects.

Assuming that civil and human rights are a pre-requisite of inclusion and what Oliver argues *“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, 1987), it is therefore necessary that research becomes part of the solution, avoiding the risk of segregation and exclusion, offering equality, opportunities and active participation.

Accordant with Oliver’s scheme (1992), I have added a new section, including the themes presented above, (inside the dashed box) as trajectory of inclusive research, in order to systematize concepts and approaches in a framework of reference already known:

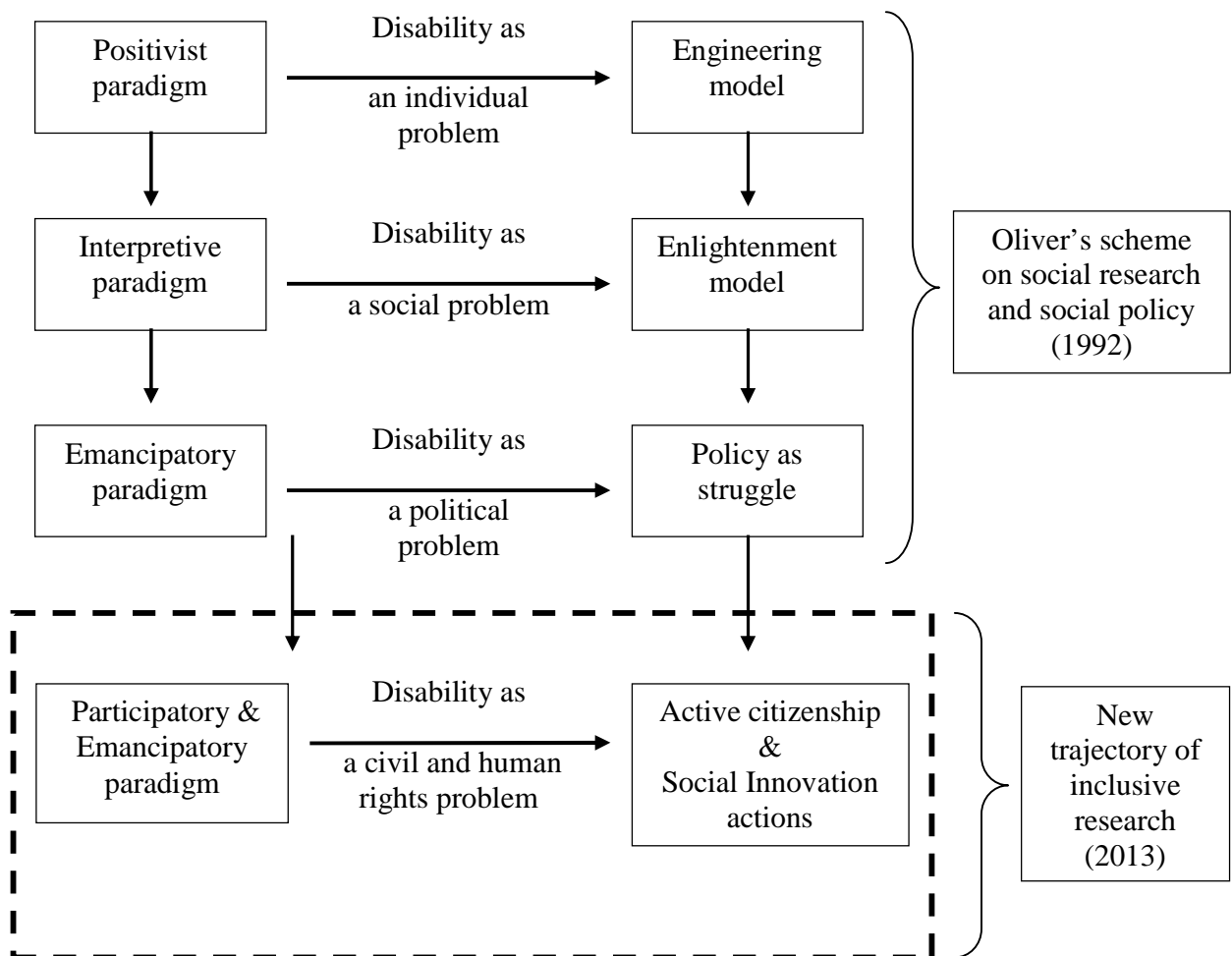


Figure 23: New trajectory of inclusive research

In order to gain more impact and possibly find innovative solutions for concrete changes at political, economic, legislative, attitudinal and behavioural levels, it is important to focus on the design of projects characterized by accountability and involvement of disabled people, disabled people organizations, disabled researchers and non.

Projects aimed at implementing positive practices and prototypes of socially innovative solutions, such as new products, services, models, markets, processes and environments, that simultaneously meet social

needs, leading to improved capabilities and relationships, with an improved use of assets and resources.

Finally, I believe a lot of the fundamental principles within the participatory and emancipatory approaches are of practical use to those concerned, as well as to research, which needs to assume a different theoretical paradigm of reference, based on participation and emancipation.

In this way, if the civil and human rights model tries to reduce barriers, the paradigm suggested could be used to re-think a world designed and realized without barriers to disability.

5.2.1 Practical examples

Two projects in which the emancipatory approach meets civil and human rights are reported in the following examples.

The first characterized by the use of Living Lab (see chapter 3), method particularly adapted for fostering the emancipation.

The second example concerns the issue of education and emancipation, addressed through a research project connected to the right of preventing discrimination based on a person's race, sex, religion, age, physical limitation and national origin.

1) Example

This example refers to the "TOBI" project - an European integrated project started in 2008 and ended in 2013, financed by the 7^o Framework Programme - which developed practical technology for brain-computer interaction (BCI) for improving the quality of life of disabled people and the effectiveness of rehabilitation through the establishment of Living Labs.

(Available at: <http://www.tobi-project.org/>)

2) Example

This example refers to the experience of the research project "Education and Emancipation", realized by the Centre for Critical Research on Race and Identity, located at the University of KwaZulu-Natal (South Africa).

This project is embarking on three sub projects which are to be executed over a 5 year period and which are funded through a major grant from the Department of Higher Education and Training. The purpose of the research is to collate existing research and to generate new data that can enable the Department and other Higher Education Institutions to act more effectively in attending to the broad concerns of access, throughput, social cohesion and discrimination.

Of particular relevance for the aim of this paragraph is the third sub-project that aims to collate existing research on the obstacles confronting members of certain social groups and in particular women and black students. The evaluative audit of the research will focus on the individuals and units undertaking such work which would form the basis on which the Department can identify gaps in the knowledge base for effective policy formulation and commission of research specific to such gaps.

As a suggestion, a similar project could be designed for studying obstacles, concerns of access, social cohesion, discrimination and emancipation of disabled people in the contexts of education and employment.

(Available at:

http://ccrri.ukzn.ac.za/index.php?option=com_content&view=article&id=293&Itemid=100083).

5.2.2 Focusing on emancipation, rights and inclusive approach

This short paragraph tries to focus on the relationship between emancipation, rights and education. The main assumptions for the linkage of these concepts are that education should foster democracy and enlightenment.

The relationship between democracy and emancipation can be seen in the application of civil and human rights.

While considering that - emancipation has also a historical educational link to enlightenment, as exemplified in the work of Immanuel Kant (Bingham, 2010), I am tentatively trying to make a sort of syllogism by which to affirm that enlightenment on rights to be reached includes emancipation that is primarily possible through education, in particular an Inclusive education.

The choice of considering Inclusive education as the framework in which to put into the relation so many different concepts lays in the fact that it is addressed to the equality of human beings, embracing also the human rights and democratic principles.

Moreover, it is important to highlight how through the lens of inclusion, being educated does not mean only attending school for a number of years, rather it means being provided with the instruments to understand the world and the society in which one lives and acts.

This understanding could be the premise for increased awareness about equality of treatment (Civil Rights) and opportunity (Human Rights), that are the basis of an educational process aimed at wider emancipation for all. If it is true that “*democratic interaction can reconfigures the social order*” (Bingham, 2010), is also certainly known that the first democratic interactions take place in school.

Consequently educating children about equality and rights could help to re-found the social order with a view to a greater inclusion and emancipation, as Jacques Rancière’s lesson shows that “*there cannot be a method of education that does not partake in the explanatory order of society*”.

The school historically represents a method for bringing people to become emancipated, in this sense emancipation is reflected in and reflects the form of school.

This was noted by Bingham in the discourse of Rancière, that emancipation can be “*achieved through the process of schooling, and, the process of schooling can be seen to carry the assumptions of emancipation*”.

5.3 Participatory and emancipatory approaches for the design of socially innovative actions of inclusion

In line with International and European documents, the idea supported in this paragraph is to adopt the participatory and emancipatory approaches as a set of strategies and tools that can support the adoption of a model based on the attempt to address disability problems through socially innovative actions.

Problems that could be addressed also through the application of the concept of the active citizenship (UNESCO, 1995), in order to enhance autonomy, accessibility and inclusion (Oliver & Barnes, 2010 and 2012).

If I wish to re-interpret the suggestion of Zarb about the difference between participatory and emancipatory research, I can see the former as a pre-requisite to the latter.

Furthermore, if I compare them with the relationship between active citizenship, social innovation and inclusion, I can see the former as a pre-condition for developing action of social innovation, both concepts aimed at facing civil and human rights issues.

Once I have adopted the participatory approach for sustaining an active citizenship model, I may consider the emancipatory approach for sustaining socially innovative actions of inclusion.

The next step could be to provide evidence for a possible practical application of these approaches. These could 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, where *"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, 2010a).

Taking into consideration what Mike Oliver suggests about *"the way to produce unalienated research is to change the social relations of research production"* (Oliver, 1992), this paragraph attempts to create links with the principles of social innovation (SI henceforward), that is based on the transformation of social relations.

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).

In this framework, social and material relationships of research production could change, in particular if this challenge is addressed through the participation and involvement in the design of innovative practices and actions. Following this line, research could gain greater transformative potential (Zarb, 1992) and produce effective emancipation.

In order to avoid what Oliver has considered as the failure of feminist and third world research to effect practical change, that is “*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).

It seems that it is necessary to tie the social relations with research production on the basis of what could be innovation for a barrier free society. In this way it could be possible to answer a wide range of needs, directly addressed by disabled people primarily through participation. Once positive practices of SI in tackling social needs are developed, they should be explored in order to understand whether they could be scaled up in other contexts and countries.

Moreover the core elements of SI – namely, novelty, changing of focus from ideas to implementation, effectiveness, meeting social needs and enhancing society’s capacity to produce - together with the PR and ER approaches, could bring about scenarios, in which the issue of the rights is addressed from different perspectives.

In this way features of SI can be linked to characteristics of these approaches, such as: openness and collaboration, the grassroots and bottom-up approach, co-production, mutualism, the creation of new roles and relationships with a better use of resources, the development of assets and capabilities (Caulier-Grice et al, 2012).

The unifying theme running through this application of concepts is that active citizenship and social innovation have a common objective in facing disability as a rights problem, in order to find new solutions which respond to different requests such as equality, inclusion and accessibility (Mckenzie & Macleod, 2012).

It is in this sense that participatory and emancipatory approaches applied to research should move within a rights analysis and be used to design socially innovative actions, in order to avoid regression into “*mere description or observation, providing only superficial information*” (Stone, 2006).

In order to address these issues, what is suggested is to apply participatory and emancipatory approaches to research that could significantly enhance the quality of lives of disabled people. If contributions resulting from the application of these approaches to theoretic research leads to the implementation of innovative ideas or prototypes, the task could be fulfilled with evident benefits, i.e.:

- a) local dimension and more effective representation;
- b) greater accountability;
- c) faster processing in order to address social needs and produce changes;
- d) new ways of producing research;
- e) participation in the development of projects from the earliest stages of design;
- f) greater empowerment, emancipation and reflexivity.

Considering the benefits highlighted and matching the relationships of research production with the concept of social innovation, the result could contribute most notably to produce new solutions and 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 the decision-making skills and self-assurance of disabled people. In this way the resulting practices or actions could go beyond compensating the disadvantages, through the development of products, services and environments, expanding and ensuring the capacity to choose individually and collectively (Sen, 1999 and 2005).

These choices do not concern only basic needs such as eating, healing, educating, but also the inclusion, accessibility, freedom and rights related to all dimensions of life.

Taking into account the common features of the social innovation (reported in a document realized in the framework of TEPsIE project⁴²), I will try to link these features with the research approach based on the principles of participation and emancipation.

To put in relation the characteristics of what is nowadays named social innovation with participatory and emancipatory approaches to research has the precise purpose of founding and supporting the idea that these approaches are particularly useful for the design of socially innovative actions.

⁴² Available at: <http://www.tepsie.eu/>

The features of the SI are as follows:

- a) Cross-sectoral
- b) Open and collaborative
- c) Grassroots and bottom-up
- d) Co-production
- e) Mutualism
- f) Creates new roles and relationships
- g) Better use of assets and resources
- h) Develops assets and capabilities

The linking between the features of the SI and participatory and emancipatory approaches is described below⁴³:

a) Cross-sectoral

This feature of SI refers to its nature of cutting across many sectors, involving participants working together from different fields, such as education, businesses, civil organisations, public authorities, social enterprises and foundations. This heterogenic aspect is also presented in participatory and emancipatory approaches that, if correctly applied in the field of disability (but also for ageing) require the involvement of experts and professionals of different sectors. An example is provided by researches in the field of Information and Communication Technology and Assistive Technology in which engineers, informatics, academics, experts of education and training processes, disabled people and their families play an important role, whose involvement can assume different values, starting from simple participation until self-determination, empowerment and emancipation.

b) Open and collaborative

Social innovations are often inclusive and engage a wide range of actors. This thanks to information and communication technologies that have allowed and enabled people to collaborate together in new ways. This open and collaborative form of online collaboration has interesting aspects. Examples come from many different sectors, as open resource houses or open educational resources. This characteristic is also required in the participatory and emancipatory approaches, especially if applied to research, that for example could foreseen the involvement of persons though with difficult in moving from home to the place of research. In this

⁴³ These points are adapted from: TEPSIE project (2012) . Defining Social Innovation.

sense some examples in the field of Independent Living have showed evidence of the need of organizing the research providing reasonable accommodation in terms of reduction of barriers, that could be environmental, cultural, attitudinal, social or political.

c) Grassroots and bottom-up

Social innovations are “bottom-up”, “grassroots”, realized at local level and connected by networks. These features can also be found in research projects based on principles of participation and emancipation. In particular bottom-up processes in the identification of needs, research questions and possible solutions. Such as for the features of local level and network connection, that could represent a resource rather than a limit when the achievements of a research project are reached in a specific context and designed to be flexible, adaptable and transferable to other contexts.

d) Co-production

The boundaries between producers and consumers are increasingly being blurred, as users have become producers, or “*prosumers*”(Toffler, 1984), that in a social field means a shift from the conception of individuals as passive recipients of services to one that foresees their involvement. The same is what happens for the shift from a medical to a social model of disability, and as suggested here, reinforced by the civil and human rights approach where people are not only active, but also self-determined, empowered and emancipated.

The core idea of co-production is that people can be resources and that “*no service that ignores this resource can be efficient*” (Boyle & Harris 2009). The same aspect is present in the participatory and emancipatory approaches, where co-researchers go beyond the idea of engagement or consultation, assuming an active responsibility in participating and trying to reach the emancipation.

An example is provided by the research in the field of Assistive Technology where the collaboration between experts, researchers and disabled people (researcher or not) guarantees the efficacy and usability of the technological products.

e) Mutualism

The notion of mutualism is based on the assumption that “*individual and collective well-being is obtainable only by mutual dependence*” (Kellner, 1998), and although this feature is more applicable in contexts of social

and health care, it can also be taken into account in the field of research, in particular when applying the participatory and emancipatory approaches.

f) Creates new roles and relationships

Social innovations can be identified by the new type of social relationships they create, as new forms of governance, collaborative action, improving the inclusion and participation of marginalised and vulnerable groups, since “*enabling users to become producers, or patients to become carers, or students to become teachers*” (Caulier-Grice et al, 2012).

This feature is perfectly in line with what foreseen by participatory and emancipatory approaches, by which emancipation is also reached through the changing of social relations of research’s production and the role played by different participants. Especially for co-researchers that, assuming new roles often enhance their capabilities, empowering and enabling to better satisfy their needs.

g) Better use of assets and resources

The better use of assets and resources is a feature of - social innovation, especially when under-used, not used at all or “*latent*” (Caulier-Grice et al, 2012) as the knowledge, competencies and relations that communities have at their disposal, or in case of materials or tangibles resources such as finance, sponsorships, spaces, buildings, etc. This characteristic, beyond being a useful approach in a period of economic crisis, is included in the participatory and emancipatory approaches. It can also be translated into practice through tools and methods. An example is provided by the Design for All in the re-use and adaptation of buildings and environments (see chapter 3) or by the case of the High Line in New York where an abandoned railway line has been turned into a public park.

h) Develops assets and capabilities

The last - feature of SI consists in, among others, the aim of developing the capabilities of beneficiaries, enabling them to meet their own needs which in the case of research about disability (or the field of the elderly), is an explicit aim of the participatory and emancipatory approaches. The development of capabilities highlights the importance of human agency and advocates participation, considering people as active, creative, and able to act on behalf of their desires, aspirations and possibilities. This is in compliance with the civil and human rights approach to disability suggested in the previous paragraph, characterized by the shift from a situation of passivity, sickness and patient care to a new one of

commitment in the elaboration of ones own life projects and innovative solutions.

The linking of social innovation and participatory and emancipatory approaches is aimed at providing a suggestion concerning how to face social change from the perspective of disabled people living in an evolving society. Social change for disabled people means change which is based on the recognition that they are limited by the barriers that society creates, rather than by their impairments. Therefore it is important to stress the role of society, culture, education, research and agencies for making the lives of disabled people better, giving them greater choice and control, enabling them to participate equally in society and modelling social change.

This implies a radical transformation that ensures that society treats disabled people as full and equal citizens (civil rights) through involvement and participation; aiming to strengthen, promote and protect equality (human rights), through emancipation. Disability is the inequality that people with impairments experience as a result of discrimination, inaccessible environments and a lack of resources, support and opportunities. This causes poverty and social isolation, that is proposed here to be addressed using approaches based on participation and emancipation that reflect the same aims of social innovation. The first one of these aims is represented by attempting to do something radically different for the purpose of promoting social justice. In this way innovation should not only improve the lives of disabled people, but also model and promote social change and emancipation.

Referring these premises, finally I'd like to suggest four principles for innovative interventions:

- 1) Innovative interventions should improve the lives of disabled people and their families, providing opportunities for greater choice and control. This should lead to greater participation in social changes and the design of services, products and environments, responding to what persons want or desire, rather than others assuming this on the behalf of disabled people .
- 2) Innovative interventions should build on and develop the capabilities of disabled people, enabling them to: participate as equal members of society (that means active citizenship and civil rights); have equal opportunity to live the lives they choose (that means human rights); strengthen their social relationships, permitting positive contributions to meeting their own needs and those of others (that means to participate and become emancipated).

- 3) Innovative interventions should encourage disabled people to bring about change for themselves and their communities, being developed and led by themselves and their organisations.
- 4) Innovative interventions should adopt an orientation towards the design of services, products and environments based on the key concept of the Design for All, respecting the human diversity in a prospective of a barrier free environment, ensuring that persons' needs, desires and expectations are taken into account both during the design process and as part of post production/delivery evaluation.

5.3.1 Practical examples

In this paragraph I have reported four examples of innovations developed through the involvement of disabled people and, in a certain way with a participatory and emancipatory approaches.

The first three examples concern the projects described in the report produced by the New Economics Foundation (NEF)⁴⁴, an independent think-and-do tank that inspires and demonstrates real economic well-being. These projects are related to the first three principles reported above.

The last example refers to the fourth principle and is related to the project IDEaLL network⁴⁵.

1) Example

This example refers to the initiative of the Regional SEN Transition to Employment Initiative, involving nine local authorities in South Wales (Caerphilly, Bridgend, Carmarthenshire, Rhondda Cynon Taff, Neath Port Talbot, Swansea, Merthyr Tydfil, Pembrokeshire and Torfaen). These authorities works with young people aged 14-19 who have complex needs that include a learning disability and/or autistic spectrum disorder, in order to help them through the transition to adulthood and to become as independent as possible in their adult lives. It uses an innovative and comprehensive model of support, working closely with young people and their families and

⁴⁴ Available at: <http://www.neweconomics.org/>

⁴⁵ Available at: <http://www.ami-communities.eu/wiki/IDeALL>

professionals to develop a transition plan centred on the young person. This plan, and the support around it, is built on the young person's capabilities so that they have greater choice and control over their lives.

The aim of the project is to raise the aspirations and motivation of young people, and increase their participation in learning, volunteering, employment and social opportunities, so fostering a greater degree of independence and inclusion in the community. It is also about working towards a change in practice amongst those working with young people and their families and carers, through training and support.

At the core of the project work is the idea that planning should happen with young people and not for them. The young people decide who works with them and how, directing their hopes and dreams for the future.

(Available at: <https://www.realopportunities.org.uk/>)

2) *Example*

This example concerns the project "Creating Opportunities And Skills Teams Alliance (COASTAL)", that helps disabled people to get a job. The aim of the project is to provide employment and training opportunities for individuals experiencing serious illness, disability and/or social disadvantage. It is based on the belief that disabled people are full and equal citizens, with a right to personalised support that promotes their choice and independence within the labour market and their inclusion in the community.

COASTAL brings together six local authorities of Wales (Bridgend, Neath Port Talbot, Swansea, Carmarthenshire, Pembrokeshire and Ceredigion) that work in collaboration with a range of voluntary sector providers as part of an alliance to achieve a strategic and consistent approach to services. Individual service users are offered a detailed and comprehensive needs assessment. This is used to produce a personalized programme of support to overcome barriers to engagement in learning, training and employment in order to meet the participant's needs (including: access to appropriate education and skills training, supported employment or work experience, support with job applications, CV writing, interview skills and so on)

The main tool is to develop procedures and plans for employers, so

that they can understand the issues and legislation around employing adults with learning difficulties and other health and mental issues. The COASTAL website has several downloadable tools available to help organisations develop better informed equality and diversity schemes and procedures. This shows that COASTAL is committed to changing local communities and society, as well as helping individuals.

(Available at: <http://www.coastalproject.co.uk/>)

3) Example

This example refers to the experience of the Norfolk County Council and the Norfolk Coalition for Disabled People (NCODP). The partnership involves contracted services, as well as more informal links across the two organisations, and has involved having staff mutually seconded across the organisations. There have been particularly close links between the Council and NCODP around the personalisation agenda. The main contract that the NCODP delivers is for direct payment services and self-directed support. This is one of the largest examples in England where a disabled people organization provides self-directed support services on this scale. They provide support to almost 2,500 people in Norfolk, hold almost 2,000 supported accounts for people with direct payments, and its payroll service supports over 1,500 personal assistants.

The NCODP approach to self-directed support is rooted in the belief that people who use direct payments or personal budgets are best placed to provide each other with peer support as part of the SDS service. The NCODP has also established six Independent Living Groups (ILGs) across the county, and a Skype ILG operates for disabled people who cannot attend group meetings. These groups support over 190 members, and provide peer support and expert insights into personalisation and self-directed support. As well as giving users and carers the chance to share experiences, the groups allow people to make their voices heard on the radical changes taking place in social care. In Norfolk, representatives from each of the ILGs are members of the Personal Budgets Advisory Group, which presents the groups' ideas and views directly to commissioners, providing a critical insight function to the council, helping to improve services, and identify gaps.

NCODP has also created a Norfolk Youth Disabled People's Forum, which is a group for young people with disabilities in Norfolk based on the social model of disability, aiming to provide a forum for young people, and to support a new generation of leaders for the NCODP. This group meets once a fortnight, and is completely led by members, although there are staff for support if required. Over the past two years they have been involved in a range of activities, including activism, media and film production, public speaking and the creation of a website. All of these activities build a strong network of support and advocacy among people living in Norfolk, and are intended to achieve radical social change for disabled people, encouraging them to bring about change for themselves and their communities.

(Available at: <http://www.norfolk.gov.uk/news/NCC116129>)

4) Example

This example refers to the “IDeALL” project, in which the Design for All community brings together design professionals and experts, applying a design approach to social topics, addressing and integrating human diversity, social cohesion and equality beyond differences (culture, age, ability and social background).

The main objective is to provide anyone with access to environments, goods and services, equally and without having to make adaptations. Even today, this clear social need receives hardly any attention from the private sector, or is perceived as a marginal corporate social responsibility topic rather than a core business concern. This is despite the fact that organizations which apply Design for All approaches, focusing on users' needs and behaviour, demonstrate innovation and market competitiveness (IKEA, TOTO, FIAT, Fujitshu, OXO, Nexpresso to name but a few). Considering the social and economic stakes related to the project, promoting this approach among companies and public authorities is a key driver for economic performance, social cohesion, barrier free environment, participation and emancipation for all.

(Available at: <http://www.ami-communities.eu/wiki/IDeALL>)

CHAPTER 6 – Case-studies on Participatory and Emancipatory approaches

6.1 Exploring two case studies

In this chapter I will explore two empirical case studies. These cases represent “delimited phenomena” (Flyvbjerg, 2006) observed over a precise period of time. The choice of these cases within the strategy of research is due to their features and exploratory reasons, in particular to the fact that the population observed was heterogeneous rather than homogenous; to have involved two small groups of participants. This means that the results of the analysis and the insights gained don’t allow the presentation of conclusions for understanding a larger number of cases, but permit focus on confirmatory aspects - rather than disconfirmatory (George and Bennett, 2004; Gerring, 2006) - in relation to the initial hypothesis of research, according to which “*an open participation in the co-creation of the services and environments, makes life easier for vulnerable groups*”.

The first case represents the perspective of the participatory approach. The second, the perspective of the emancipatory approach. Material from the case studies illustrating these perspectives are presented here. The methods of analysis used are discussed in the final section of this chapter, including some reflections on practicalities and issues (Yin, 2003).

In the second part of the thesis I will relate to these perspectives analyzing these two case studies in order to provide:

- a) Examples on how to put into practice theoretical concepts, principles, approaches and methodologies dealt with on a theoretical level in the previous chapters.
- b) Evidence of the fact that the knowledge-base that this thesis was founded on can be applied to different contexts and projects. This can help to foster shift from a situation of passivity, sickness and patient care - often characterizing persons with disability - towards new scenarios of active participation and emancipation in the elaboration of life projects.
- c) To prove the initial research hypothesis, demonstrating that facilitating the participation in the planning of processes or design of actions can lead to socially innovative scenarios where an active role becomes possible. Scenarios in which research, services and

environments become more accessible and easier to use for all, supporting ultimately a greater inclusion.

The first case study was realized in collaboration with the multi-professional team of AIAS Bologna Onlus⁴⁶ and the Emilia-Romagna's Center for Assistive Technology of Corte Roncati⁴⁷. It concerns the development of a service of "Smarthomes for independent living experiences". This service has been developed, tested and implemented using an innovative participatory method, the Living Lab (described in chapter 3).

The method of analysis was based on participant observations during: coordination meetings, the weekends of autonomy in the apartments (Smarthomes), Living Lab meetings and through questionnaires, interviews, focus groups and a "diary of the experience" written by participants.

The observations have covered a period of more than one year, starting from the initial phase of the experimentation till its end (November 2012-December 2013).

The second case study concerns experimentation of the Life Coaching method applied in a medical context, at the UOSi Multiple Sclerosis Unit of IRRCs Neurological Sciences Institute of Bologna⁴⁸. It is a non-medical approach aimed at supporting processes of change, empowerment and emancipation in the lives of the patients of the Institute.

This case study - realized with the voluntary participation of four patients and personally conducted as certificated Coach⁴⁹ - allowed the testing of Life Coaching, a method of intervention where the role of the person involved is central to the definition of her/his project of life. The method experimented turned out to be more maieutic than rehabilitative, more social than medical. It demonstrated effective support in the processes of changing and emancipation. This experimentation covered a period of six months (from September 2013 to February 2014), starting with the identification of participants until the final evaluation of the experience realized.

⁴⁶ Available at: <http://www.aiasbo.it/>

⁴⁷ Available at: <http://www.ausilioteca.org/cra>

⁴⁸ Available at:

<http://www.ausl.bologna.it/isnb/chi-siamo/organizzazione/le-unita-operative/riabilitazione-sclerosi-multipla>

⁴⁹ Certification by the International Coaching Federation (ICF). Available at: <http://www.coachfederation.org/>

In both case studies the participants represented a specific population, and not a sample representative of any conditions - or part - of people with disabilities. For this reason the study realized and observed considers mainly the processes that people have directly lived and judged. Especially in relation to the questions about “how” and “how much” participatory and emancipatory approaches can make life easier for vulnerable groups, improving the quality of life and supporting social inclusion.

The cases may at first appear as unrelated to each other, since the first is driven by a participatory approach and the second by a more emancipatory approach. Instead, as stated by Zarb’s theory about participatory and emancipatory approaches that “*the former is a pre-requisite to the latter*” (Barton, 2005), these two case studies - although different - share the same intention. They consist in exploring how persons with disability can face different situations, considering as central their role, needs, desires, objectives and perspectives. For the first case through the development of autonomy and independence using aids and assistive technologies. Regarding the second through a non-medical model focused on person’s commitment and active role. Each case is described in the following sections, focusing on some aspect of the overall theme of the thesis.

6.2 The analysis conducted

The analysis conducted was organized on three different levels:

- 1) The first level of analysis began as I drew upon my developing theoretical understanding of participatory and emancipatory approaches.
- 2) The subsequent second level of analysis focused on the initial research question “*an open participation in the co-creation of the services and environments, makes life easier for vulnerable groups*”. And secondly on the assumptions formulated within an inclusive research approach, including:
 - a) A focus on the shift from a system based on the medical model of interventions with vulnerable groups, towards a model based on the Civil and Human Rights approach. Adopting participatory and emancipatory approaches for implementing active citizenship and socially innovative actions.

- b) The rejection of deterministic beliefs about disability and associated ideas that exclude the possibility of achieving goals, therefore shifting from a situation of passivity, sickness and patient care to a new scenario based on the person's commitment to active role and participation in the elaboration of his/her own project of life.
- 3) The third level was characterized by my interest in looking into interviews, focus groups, Living Lab, formal and informal meetings, coaching sessions and observations. In order to explore and provide evidence of the three main ingredients of the research process used (Checkland and Holwell, 1998): the frame of reference, the methodology, and the areas of concern (see Figure 1 in Introduction).

I used these levels of analysis and assumptions to support a deductive approach to the preliminary analysis of the data. Thus, I engaged in a further iterative process in which I reflected on practice through the lens of my developing theoretical ideas.

I also combined this with a more inductive approach, allowing further ideas and concerns relating to the concepts of participation and emancipation, as they emerged from interviews, observations, meetings, etc. which in turn helped to shape the themes of my analysis.

Whilst there are, inevitably, connections and overlaps between these three levels I did not see these as a problem in my analysis, but rather as challenges that have led for example to: the design of the Contextual Map (in chapter 1); the merging of Civil Rights and Human Rights in a unique approach to disability (in chapter 2); the definition of strategies and tools for applying participatory and emancipatory approaches to research (in chapter 3 and 4); the suggestions of new trajectories of inclusive research (in chapter 1 and 5).

6.3 Case study 1 - Participatory approach for the development and implementation of a service of “Smarthomes for independent living experiences”

This case study investigated how to develop a service of “Smarthomes for independent living experiences”⁵⁰, through the participation of a group of young persons with disabilities (group of participants, hereinafter). The experimentation was aimed to promote living experiences in apartments through innovative activities. The activities were characterized by means for the development of personal autonomy addressed to young adults and adults with disabilities.

The apartments used for the experimentation are “ambient assisted living”⁵¹, with facilitating aids, accessibility solutions and assistive technology, as well as an environment with green areas located in the city centre of Bologna.

The experimentation covered the use of two apartments for conducting weekends of autonomy. It was carried out over nine weekends, one per month from February to December 2013. The main activities initially planned for the development of the service included:

- An active role of the group of participants in the weekend of autonomy for the development and implementation of the service. The involvement was realized through the Living Lab method.
- Everyday and practical activities inside the apartments for the development of skills and competencies aimed at achieving more autonomy - in particular away from their familiar surroundings - with the adequate support of two professional educators.
- Activities outside the apartments in the external environment for the development of autonomy in an urban setting.

The special equipment of the apartments - including home automations and technological aids for personal autonomy - were adapted and customized in collaboration with the technical staff of AIAS Bologna Onlus and Emilia-Romagna’s Center for Assistive Technology of Corte Roncati. In accordance with and following the continuous feedback provided by the group of participants before and during the weekends of autonomy.

⁵⁰ The term used to nominate the service “Smarthomes for independent living experiences”, indicates apartments provided with home automation and assistive technology.

⁵¹ See the EU Ambient Assisted Living Joint Programme, available at: <http://www.aal-europe.eu/>

The participatory method of the Living Lab was adopted in order to enable an effective participation and to foster the inclusion in the process of developing and implementation of the service of “Smarthomes for independent living experiences”.

Before, during and after the analysis many observations were realized during meetings and informal conversations that took place with all the participants involved in the experimentation. The purposes of these were:

- to clarify questions about the observations;
- to encourage the group of participants to begin to think about their experience during the weekends of autonomy;
- to help to build relations of trust between all the persons involved in the experimentation.

6.3.1 Participants

The group of participants was composed of 4 young persons with disabilities and two professional educators of the District of Porretta Terme and the District of Casalecchio di Reno (located in the Province of Bologna). The group was already involved in paths of autonomy promoted by a three years project “Pathways to independence”, included in the 2013 districts planning and carried out by the Cooperative Libertas.

The participation in this experience had provided them with the opportunity to be involved as active co-creators of the service of “Smarthomes for independent living experiences”. In particular through the provision of suggestions and advice to find solutions for adapting the apartments for everyday living experiences (not only to be used as showroom). This experience allowed them to enrich their lives including the possibility of living in a barrier-free environments with special equipments, such as home automation applications and technological aids.

The group of participants included: two males and two females with different disabilities, aged between 19 and 20 years, and with the following diseases:

- a) E.: mild-delay at the cognitive level
- b) A.: hemiparesis and mid-delay at the cognitive level
- c) M: slight-delay at cognitive level
- d) F.: spasticity

The group of participants in the weekends included also two educators of the Cooperative Libertas, and one coordinator of AIAS Bologna Onlus for the logistic and organizational issues.

Concerning the development and implementation of the services of independent living, other participants were: the technical staff of the Emilia-Romagna's Center for Assistive Technology of Corte Roncati, including: one physical therapist, one professional educator, one engineer and one coordinator.

6.3.2 Institutions involved

The institutions involved in the experimentation for the development of a service of "Smarthomes for independent living experiences" - analyzed as the first case study - were:

- USL Bologna DSMDP (UOC NPIA Specialist Services) and Emilia-Romagna's Center for Assistive Technology of Corte Roncati, in charge of:
 - Definition of the procedures for the use of the apartments;
 - Development of tools for: scheduling, documenting the experience and evaluating the level of satisfaction of the participants;
 - Providing technical support and monitoring the experiences during the weekends;
 - Training of staff involved;
 - Customization, management and maintenance of equipments, aids and technology used in the apartments during the weekends of autonomy.

These institutions also provided: one physical therapist, one engineer, one professional educator and one coordinator for supporting the effective realization of the experimentation.

- District of Porretta Terme, Socio-Health Unit "Adult with disability", in charge of:
 - Elaboration of the annual planning of the project "Pathways of independence" addressed to persons with disabilities;
 - Monitoring and assessment of technical interventions required for the customization and adaptation of the apartments, on the basis of the

documentation produced and the feedback provided by the group of participants;

- Participation in the training activities and coordination meetings.

- District of Casalecchio di Reno - ASC INSIEME Consortium for Social Interventions, in charge of:
 - Elaboration of the annual planning of the project “Pathways of independence” addressed to persons with disabilities;
 - Monitoring and assessment of technical interventions required for the customization and adaptation of the apartments, on the basis of the documentation produced and the feedback provided by the group of participants;
 - Participation in the training activities and coordination meetings.

- AIAS Bologna Onlus, in charge of the management of logistical and organizational issues, including:
 - Management of the network of institutions involved;
 - Customization of apartments;
 - Provision of training and information for use of environmental resources (aids, technologies, etc.);
 - Cleaning of the apartments;
 - Contribution to the documentation of the experience.

- Passo Passo Association, in charge of:
 - Promotion of the experimentation;
 - Participation in the monitoring and assessment of the activities carried out;
 - Management of the relations with the families involved.

- Cooperative Libertas, in charge of the Socio-Educational Home Care service (service contract with the District of Porretta Terme and ASC INSIEME), addressed to the persons with disabilities. Coop. Libertas also provided the two professional educators to support the group of participants during the weekends of autonomy.

- University of Bologna - Department of Educational Studies, in charge of observing and analyzing the experience as a case study, through participation in the coordination and Living Lab meetings and the realization of interviews and focus groups with the participants involved.

6.3.3 Setting

The apartments used for the development and implementation of the service of independent living are located within Emilia-Romagna's Center for Assistive Technology of Corte Roncati.

The apartments were designed and realized as barrier-free environments for experimenting and evaluating accessibility solutions, accessories, aids, assistive technologies and home automations addressed to persons with disability, elderly people and their operators.

These apartments are also used for training courses addressed to rehabilitation professionals, social caregivers, engineers, designers and educators.

The disability of reference influencing the characteristics of the apartments and equipments are: physical, motor, multiple disabilities, cognitive and sensory impairments.

The main features of the apartments are as follows:

- a) Apartment at ground floor (80 s.q.m.), for two young and one educator, high-technological flat characterized by:
 - Orientation of a user with severe motor disability, serious and limited autonomy in daily life;
 - Assistive technologies and home automations;
 - Attention to the functions of care for the caregivers.



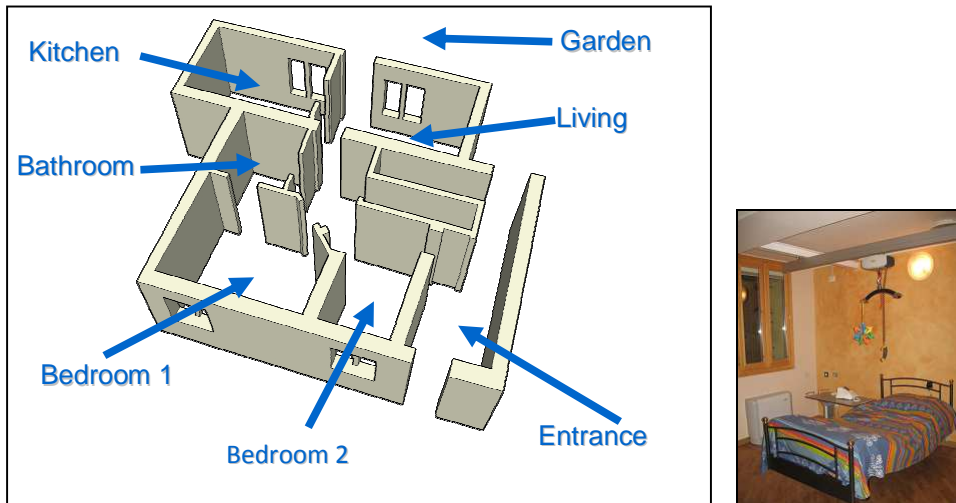


Figure 24: Images of the Smarthome on the ground floor

- b) Apartment on the first floor (50 s.q.m.), for two young and one educator, medium technological flat characterized by:
- Orientation of an older user with moderate physical disabilities with partial autonomy in daily life;
 - Assistive technologies focused on solutions for facilitating daily life and ergonomics.

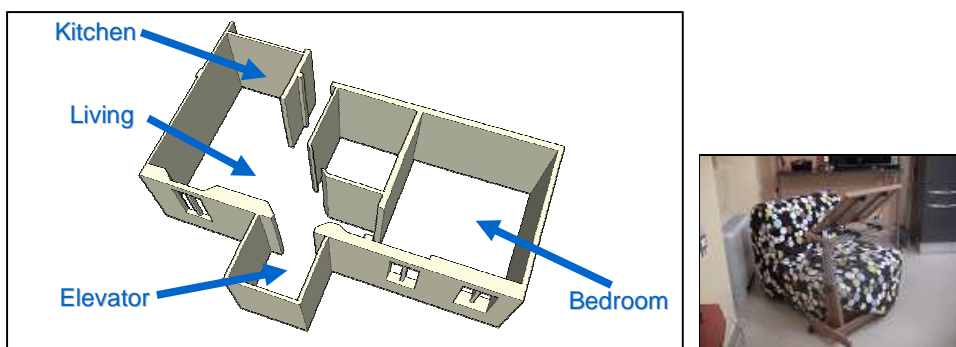


Figure 25: Images of the Smarthome on the first floor

The apartments are among the most innovative in Italy for the provision of aids, equipment and assistive technologies aimed at improving and implementing paths of autonomy. The purpose of developing a service of independent living was aimed at increasing the range of activities by persons with disabilities, whether congenital or acquired. The apartments were made yet more suitable for daily life (during a short period of stay) through the involvement and feedback of the group of participants, collected during the weekends of autonomy, the Living Lab meetings and through the adaptations made by the technicians and engineers of the Emilia-Romagna's Center for Assistive Technology of Corte Roncati. This shifted the apartments from a use of "showroom", to one of barrier-free and accessible apartments "to be lived in".

6.3.4 Experimentation process

The experimentation process was designed in order to analyze the requirements for developing and implementing a service of independent living, through the experience of stay in apartments provided with home automation and assistive technology, designed for carrying out paths of autonomy. Three levels of analysis were taken into account:

- Micro: at this level the focus was on psychological aspects, either for the group of participants or for the professional educators involved in the weekends of autonomy.
- Meso: at this level the analysis considered the perception of the service, by the group of participants, the educators and the other professionals involved in the experimentation.
- Macro: at this level costs, involvement of network's institution, roles and responsibilities were investigated.

The preliminary phase of the experimentation was organized through meetings between the different institutions and the participants involved in the weekends of autonomy. In particular:

- Meeting with the network of institutions in order to define the management of logistic aspects and organizational issues.
- Meeting with the group of participants for: functional assessment made by the staff of the Emilia-Romagna's Center for Assistive Technology of Corte Roncati; collection of information about objectives and expectations; preparation of the apartments.

- Training course on the use of the apartments, addressed to the professional educators participating in the weekends of autonomy, and aimed at raising awareness, understanding and familiarizing with the equipment, aids, assistive technologies and home automations within the apartments.

During the implementation phase n. 6 coordination meetings were organized between the institutions responsible for the realization of the experimentation: Emila-Romagna's Center for Assistive Technology of Corte Roncati, District of Porretta Terme, ASC INSIEME, AIAS Bologna Onlus, Passo Passo Association and Cooperative Libertas, with the objective of analyzing strengths and weaknesses arising during this phase. Emila-Romagna's Center for Assistive Technology of Corte Roncati also organized the experimentation process – and structured the weekends of autonomy – following the logic of the “Living Lab” method, adding the value from the direct involvement of the group of participants. The participants became co-designers and co-creators of the development of the service, providing ideas, suggesting solutions, and giving feedback. In order to study improvements and adaptations to increase and optimize the activities to be carried out inside the apartments. Testing and setting procedures, equipment, aids and technologies on the basis of their real needs.

The monitoring phase was recorded throughout the whole experimentation, using the following tools:

- Coordination meetings;
- Feedback collected through the Living Lab meetings;
- The disabilities of the arm, shoulder and hand (DASH)⁵² questionnaire, and the instrument IPPA - Individual Prioritised Problems Assessment (Wessels et al, 2002), for outcome analysis in occupational rehabilitation.

These tools were used by the physical therapist and the professional educator of the Emila-Romagna's Center for Assistive Technology of Corte Roncati to assess functional requirements, accessibility and evaluation of the ability to perform certain activities in the apartments. These were also used for the definition of the structure of the interview for gathering other information, including the level of participation.

⁵² Available at: http://www.dash.iwh.on.ca/system/files/dash_questionnaire_2010.pdf

- Diary of the experience, written and used by the group of participants to report problems and needs, suggest possible solutions and ideas, on the basis of what emerged during the weekends of autonomy;

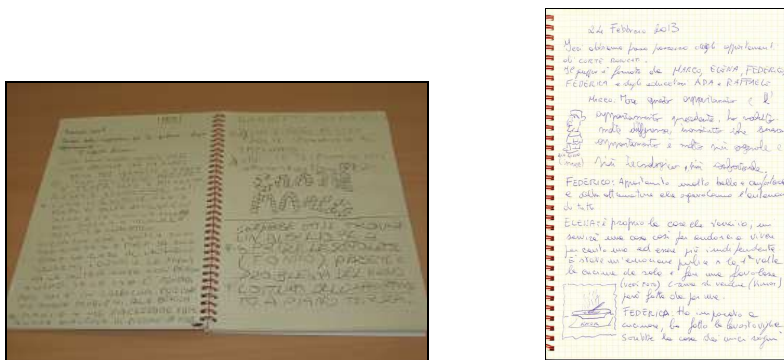


Figure 26: Images of the Diary of the Experience

- Interviews and focus groups with all the participants, including the two professional educators involved in the weekends of autonomy, the professionals of the Emilia-Romagna’s Center for Assistive Technology of Corte Roncati, and the responsible of the different institutions.

6.3.5 Focusing on the participatory approach applied

The participatory approach applied for the development of the service of “Smarthomes for independent living experiences” was characterized by two levels of involvement by the group of participants.

The first level is inherent to the experience carried out during the weekends and within the Living Lab meetings, through which the participants have contributed to the design and implementation of the service. The second level concerns the active role in using environments, tools and assistive technology to increase the level of autonomy and independence. This kind of contribution is more spontaneous and less dependent by structured methods of participation - such as the Living Lab. It provides a positive value either for the individual, in terms of self-determination, empowerment and rise of self-confidence (Wehmeyer &

Abery, 2013) and for the service, that can benefit from suggestions and ideas resulting from the real needs of participants.

These two levels of participation were defined in order to avoid the involvement of participants only as simple “testers” or “users”, roles that do not allow the co-design or co-creation of a service, product, research or environment.

6.3.6 Lessons learned

The lessons learned from this case study focus on the results of the experimentation analyzed through the lens of the participatory approach. This approach has influenced the outcomes of the experimentation in a positive way - as reported in the interviews and focus groups realized. Strengths and weaknesses of the experimentation have indeed influenced and have been influenced by the kind of participants' involvement.

Concerning the strengths: the experimentation carried out differs from others experiences realized within types of occupational therapy or physiotherapy. While these only have purpose related to functional assessment and rehabilitation, the experimentation observed has an “inclusive educational aim” (without excluding other aims to the rehabilitation). The social-health care context in general - if not always - lacks this aim. In the case of the experimentation realized the professionals involved assumed a maieutic role in supporting and encouraging the independence of the group of participants. In addition the participants contributed not as “testers or users”, but rather as co-creators of a service. This aspect allowed a rise in awareness and better understanding of what can be achieved with aids and supports, greater autonomy and ultimately increased self-determination and self-esteem. In this case the inclusive educational aim has influenced and benefitted all persons involved, through the realization of a learning environment characterized by mutual collaboration, sharing and participation; creating a sort of virtuous spiralling cycle.

Weaknesses were related to organizational bonds that often didn't allow for practicing innovative methods of participation – such as the Living Lab. In this case it has provided the possibility of a new window of cultural horizons. Characterized by greater participation and involvement in the definition of services, shifting from a situation of “customer satisfaction” to new one of “customer participation”.

The high number of institutions involved in the development and implementation of the service of “Smarthomes for independent living experiences” caused a certain level of complexity in the coordination and management of resources, spaces and communications. The lesson learned is that in order to encourage other similar experiences of participation, cultural changes are necessary in organizations, including the processes and practices of the institutions involved.

Therefore, returning to the initial research hypothesis: “*an open participation in the co-creation of the services and environments, makes life easier for vulnerable groups*”, this case study has demonstrated that the institutional culture must become more “open to participation”. In order to make services provided and life easier for all the participants of the ecosystem, at an institutional, professional, personal and familiar level.

Participants’ point of view

The participants’ point of views was investigated through the use of different instruments, such as questionnaires (DASH and IPPA), Living Lab meetings, interviews and the collection of information reported in the diary of the experience written by the group of participants. This tool was used to provide suggestions and ideas about supports and adaptations or customizations of aids. It was useful to better understand the level of autonomy when using aids and technologies aimed at improving independence at home. The following words were declared by one participant in an interview for a television Channel⁵³ to disseminate the experimentation’ results:

“...referring to our experience in the apartments, talking about the great importance of aids that have allowed us to discover new ways to perform everyday activities are possible. Some of these aids were then adopted and used also in our homes with an evident improvement in the quality of life. An important part of our experience was the collaboration with engineers and designers to improve the functioning of aids and supports with practical solutions, on the basis of our needs”.

An other important aspect highlighted by participants during the experience is that it was an opportunity to acquire more knowledge and

⁵³ Available at: http://www.youtube.com/watch?v=5-glaCgQHI&feature=player_embedded#at=17

information about the variety of aids, assistive technologies and home automations available. As stated by a participant during a focus group:

“...the use of these apartments improves our quality of life because we get to know and become more aware of the aids that are available on the market”.

The participation in the development of the service provided not only the opportunity to know and become more aware about the supports available on the market, but also to find personal solutions in their use, testing their functionality and possibility of adaptation before purchasing.

The participation also allowed the group of participants to feel listened to and taken seriously as adults, with their own challenges, needs, desires, ideas and solutions. This aspect promoted the achievement of new capabilities - as for instance in one case when preparing a dish of pasta, or in an other being able to access and use the bathroom in autonomy - encouraging accountability, self-confidence, self-determination and the use of creativity for the solution of everyday' life problems.

It's also interesting to report some feedback from the families to show and support the initial hypothesis of research on how an open participation in the co-creation of a services - in this case of independent living in apartments provided with home automation - has made life easier, especially for two of them. As stated by the mother of F.:

“...F. at home shows a greater autonomy, now he prepares breakfast, lays dishes on the table and manages everything alone, such as the microwave, and takes more decisions by himself”.

Another interesting feedback was provided by the mother of M., according to which:

“...he is very happy and enthusiastic about this experience, which makes him more independent from the authorities and even his family. Now he goes to the supermarket alone and also cooks for his brother. He has also improved in terms of awareness about his personal skills”.

From this feedback it's possible to recognize that participation can contribute to the rejection of deterministic beliefs and create new scenarios where vulnerable groups can be leading participants of a shift from a

situation of passivity to one based on the person's commitment and active role in the elaboration of his/her own project of life.

Professionals' feedback

The professionals' feedback was gathered through interviews and focus groups. The feedback of the two professional educators involved in the weekends of autonomy were very positive. Especially about the level of participation and emancipation achieved by the group of participants. Among the positive aspects described by educators there is the fact that the group of participants was:

“...the first agent in producing change”.

As stated, the possibility of sharing the experiences of autonomy in the apartments has given the opportunity to:

“...increase synergies and skills that an individual alone would not”.

Highlighting the importance of the dimension of the group for the achievement of new skills and competencies.

In addition, the educators affirmed that the possibility to use supports, provide feedback for a better adaptation to participants' needs, and consequently for finding the best solutions to carry out everyday activities:

“...the experience has helped the participants to increase awareness about their possibilities. And I think this was the biggest goal achieved”.

The participatory approach, according to educators, has also allowed the strengthening of the group's relationships and dynamics. Both in a positive way, with regard to the sharing of experiences aimed at achieving a greater autonomy and in a negative way, due to a sort of over-focus on their own individual needs - and therefore not always attentive to those of others. The educators claimed that the emancipation of the group of participants also increased. This was demonstrated by the increased capability of preparing food, washing the dishes and using the bathroom in autonomy, for instance, contributing to:

“...believing more in their own potential and possibility of independence”.

This allowed the achievement of many of the objectives already foreseen in the three year project “Pathways to Independence”.

The support they have received has also been a very positive aspect, attentive and respondent to their needs. A key element to avoid is that the participants are seen only as the testers of a service. Which actually has been developed with the contributions of all the participants involved, becoming co-creators.

The support provided by staff members of Emilia-Romagna’s Center for Assistive Technology of Corte Roncati played a fundamental role, the availability of welcoming any requests of customization or adaptation, and their useful reflections. For aspects related to the usability of tools and accessibility of the environments - to enable the realization of the experiences of independent living - and in terms of participation. It is precisely on this point an interesting recognition was that:

“... in situations like those faced during the experimentation, if it is important to ask for a change of perspective to persons with disability when they act for a greater involvement - and thus participation - it is equally important to ask for a change also to the operators and professionals. They too often still think in terms of “I know what you need”.

Institutions’ evaluation

The evaluation provided by the different institutions involved was positive. An example is as follows:

“...autonomy is an important sphere of people’s lives, it is a basic element to be searched for in order to gradually improve the quality of life of each person. This is what has been put into practice during the weekends of autonomy”.

In accordance with this affirmation, it is useful to consider a possible limit highlighted during an interview with a representative of one of the institutions involved. This limit concerns the fact that it may not be possible for the participants to continue the experience of new or greater autonomy at home. Therefore any achievements gained could remain confined only to a specific time and dedicated environment. In order to avoid this limit, the role and contribution that could be provided by families is very important so as to

exploit the potential improvement of aspects such as independence, self-determination, empowerment and emancipation, outside the boundaries of “safe situations”.

6.4 Case study 2 - Experimentation of the “Life Coaching” method as emancipatory approach applied in the interventions with persons with disability

The second case study describes the experimentation of the “Life Coaching” method applied as non-medical intervention with persons with disability and tentatively as emancipatory approach.

In accordance with the framework of reference adopted in the first part of this thesis (see chapter 1 and 5), the objective of the experimentation consisted of providing a complementary service and testing its efficacy.

It is not a substitute or alternative to those already provided by the UOSi Multiple Sclerosis Rehabilitation Institute of Neurological Sciences, but based on a different approach.

It is more social and less medical approach, which differs from the care relationship because it is based on the desire to improve and change, not on the need of assistance and medical care. It is characterized as a relationship of support for persons in achieving their objectives, through a concrete and action-oriented method. The reasons that led to the choice of this method refer to:

a) Personal experience

This reason refers to my personal experience as a person affected by a neurodegenerative illness and the path embarked upon after the diagnosis.

Through this experience I have had the possibility to meeting and discussing with many professionals over recent years - mostly medical - who provided much information on pathology, advised on therapies and solutions for care.

But none has ever asked me “*what do you wish to do with your life besides dealing wit the illness?*” or “*what are your objectives or aspirations?*”, considering or not the disease.

Starting from this question, I have begun to search a possible methods of intervention which are “not medical-base”, able to provide support, not based on the need of care, but on the willingness to change or improve the quality of life, to desire something better or simply to face everyday issues. A method in where the role of the persons is central to the definition of her/his objectives and challenges, independently from the illness, put into practice through action-plans aimed at generating change. Ultimately fostering the emancipation from a situation of passivity (as a patient) to one of an active role (as a person) within his/her possibilities.

Finally, after a wide search I have identified the method of “Coaching” as the most suitable method. I have attended a specializing training course⁵⁴ obtaining the certification of the International Coaching Federation (ICF)⁵⁵, and I have started to coach persons belonging to vulnerable groups.

b) Research interest

Concerning research interest, my willingness to experiment the Life Coaching method was because I think that it fits with non-medical intervention addressed to vulnerable groups, in particular persons with disability and the elderly. It supports a shift from a medical model of intervention to one based more on concepts such as: active citizenship; centrality of the person in the elaboration of her/his life’ project; self-determination (Wehmeyer & Abery, 2013); participation (Levasseur et al, 2004) and emancipation (Oliver, 1996), as advocated by many international and EU documents and policies (see chapter 1 and 2).

These aspects, along with the concept of inclusion, have as primary purposes the participation of all persons in social life - regardless of any impairments, deficits or functional limitations, including all dimensions of life in which the person can live and fulfil his potential (Hollenweger & Haskell, 2002).

The concept of inclusion, as formalized with the Salamanca Statement (UNESCO, 1994), marks the beginning of a cultural renewal and the adoption of an approach based on a social model of disability (Oliver, 1990) - in opposition to the medical model - and here further expanded adopting the Civil and Human Rights perspective in the intervention with vulnerable groups.

This model promotes the active involvement of persons, focusing on: the reduction of social and cultural barriers; the improvement of residual functions, capability and resilience (Canevaro et al, 2001).

This perspective also embraces principles and theoretical constructs of the International Classification of Functioning Disability and Health (WHO, 2001) regarding: the person, the holistic approach, the relational perspective, the quality of the processes, the systems of participation in social life.

Within this framework of reference the proposal of non-medical intervention is represented by the Life Coach method.

This method is based on the assumption that the demand for a coaching path is not due by the need of care as traditionally conceived, but by the desire to improve the quality of life or change it for the better. In accordance with the UN Convention on the Rights of Person with Disabilities - Article 24, point c) - in which recommended measures, practices and methods are able to provide a

⁵⁴ At the Escuela Europea de Coaghing. Available at: <http://www.escuelacoaching.com/>

⁵⁵ Available at: <http://www.coachfederation.org/>

“reasonable accommodation to the needs of each individual” (UNCRDP, 2006). Where reasonable accommodation is defined as the ability to deal with problematic situations using appropriate resources (Canevaro et al, 2011) that often, especially in situations of vulnerability, persons can discover through a dimension of reciprocity.

This dimension of reciprocity, that characterizes the relationship of coaching, is strictly related to the concept of reasonable accommodation. Such as coaching’s aim of supporting persons to discover her/his resources for achieving her/his objectives is strictly related to self-determination, empowerment and emancipation. The same principles that are contained in the UN Convention on the Rights of Person with Disabilities and other international documents.

6.4.1 Participants

The participants chosen for the realization of the experimentation of Life Coaching were patients already assisted by the UOSi Multiple Sclerosis Rehabilitation Institute of Neurological Sciences.

The criteria for inclusion/exclusion defined in collaboration with the team of the Institute, were:

- Cognitive functioning was not compromised;
- Ability for problem-solving was not compromised;
- Time elapsed from the diagnosis of the disease (1 to 12 months);
- Gender equality (considering that the population affected by the disease presents a greater case study of women);
- Age (25-55 years).

Motivation was another aspect added to this list, related to the fact that the participants, who were volunteers, had to be motivated by a desire to improve their life situation, reaching new goals through implementing actions aimed at change. Change not necessarily related to the situations caused by the disease, but to any sphere of life.

The participants attended a preliminary interview with the psychologist of the Institute, aimed at introducing the experimentation and assessing the level of motivation and interest to take part as volunteers.

The individuals identified were:

- a) V.: 25 years old, female. Type of Multiple Sclerosis: relapsing-remitting. Years since diagnosis: 7.

- b) B.: 50 years old, female. Type of Multiple Sclerosis: relapsing-remitting. Years since diagnosis: 13.
- c) P.: 43 years old, male. Type of Multiple Sclerosis: relapsing-remitting. Years since diagnosis: 20.

6.4.2 Institutions involved

The institutions involved in the experimentation of the “Life Coaching” method as an emancipatory approach in the interventions with persons with disability in medical context - analyzed as a second case study - were:

- UOSi Multiple Sclerosis Rehabilitation Institute of Neurological Sciences of Bologna. The Institute carries out day hospital and outpatient services through a multidisciplinary approach to patients with multiple sclerosis, providing diagnosis, identifying therapeutic paths and taking charge of patients. The Institute provided a team of professionals to identify the participants, plan and monitor the experimentation, including: one psychologist, one neurologist and one coordinator for supporting and monitoring the realization of the experimentation.
- Department of Education Studies “G.M. Bertin” of the University of Bologna, in charge of providing the pedagogical references to define the experimentation, to observe and analyze the experience through the realization of interviews with the participants involved.

6.4.3 Setting

The setting of the experimentation was in a medical context, structured in integrated health units within the Hospital Bellaria⁵⁶, which is located at the UOSi Multiple Sclerosis Rehabilitation Institute of Neurological Sciences. The introduction of a non-medical method, such as Life Coaching within a medical situation, was an innovative element to the setting in itself.

⁵⁶ Available at: http://www.ausl.bologna.it/applications/iap_app02/iap?id=15745&action=site

Moreover, thanks to the open mindness and holistic approach adopted by the Institute through multidisciplinary interventions, it was possible to put into practice what is argued in many international documents (as the UNCRDP, European Disability Strategy, Europe 2020, EU Disability Action Plan), about themes such as: inclusive approaches, de-institutionalization, active-role and participation.

From this point of view, the context and setting were key elements for a positive adoption of the new method of intervention.

They were not focused on issues and problems strictly related to the disease (clinical situation), but rather on their desire and willingness to change and improve the situation of the persons involved (active situation).

Remaining within a broader process of assistance and care aimed to better qualify competences and strengthen synergies between the different actors and professionals involved.

6.4.4 Experimentation process

The experimentation was carried out for 6 months, from September 2013 to February 2014. The preliminary phase included four meetings with the staff of the Institute, whilst during the implementation phase 5 coaching group sessions with the participants were realized (one session every 15 days, of the duration of 1 hour and ½ - 2 hours). The psychologist of the Institute also attended these sessions, who also monitored the progress of meetings.

The experimentation process was designed to:

- Verify the complementarities of service of Life Coaching proposed in relation to other service already present at the Institute, in accordance with a system of intervention based on a holistic approach;
- Explore the assumptions of the effectiveness of intervention, as method aimed at promoting changes and improving the quality of life.
- Offer a non-medical approach, which puts the person at the centre of the process of change, starting from her/his desires, aspirations and objectives.

The first coaching group session was aimed at presenting the initiative and introducing the Life Coaching method.

The other sessions focused on participant's situations; supported the definition of objectives, the assumption of commitment; evaluated opportunities and identified challenges; elaborated action plans; set out the specific results to be

achieved (participants were also provided of support by call phone and via Skype).

During the period of experimentation coordination meetings with the psychologist of the Institute were arranged in order to guarantee continuous monitoring of the progress, backed up also through initial and final interviews and the completion of a questionnaire to assess the impact of the initiative on the quality of their lives.

The coaching model adopted (described in section 6.4.5), is defined as “ontological-transformational” and based on the conversation (session), which are structured in six phases as follow:

- Generate context/relation.
- Understand the current situation (focus on the issues).
- Support the definition of objectives leading to a declaration of commitment.
- Facilitate learning (through feedback to allow exploration of new points of view).
- Transform objectives into action plans.
- Monitoring of: the commitments, the actions planned and the results achieved.

During the different phases beliefs which may limit or open new scenarios are investigated; possibilities are evaluated and the levels of commitment are measured in achieving the defined goals.

6.4.5 Focusing on the emancipatory approach applied

In this section I wish to present the reasons that led to considering the method of Life Coaching as a possible tool for an emancipatory approach in interventions with vulnerable groups.

In particular, through the description of the method used I wish to highlight the aspects closely related to the active role of the individual in defining their own life project. It is possible to have a greater awareness of ones own resources in order to become more emancipated in different life situations - personal, professional, familiar - not necessarily related to the disease, pathology or disability.

This method is based on the definition of concrete objectives, not abstracts, directly verifiable, measurable, and attainable through an accurate definition of an action plan. The term “coach” comes from the Hungarian language and it

means “type of transport”, that allows the persons to go in the direction they wish. It is defined by the International Coaching Federation as “*a creative process that inspires persons to maximize their personal and professional potential*⁵⁷” that allows people to learn to develop strategies of action directed at improving the quality of life.

Once the strategies and actions are defined, the rest of the coaching process is based on that practice. The person (*coachee* as defined by the method) should be brought to act, to transform thoughts and desires into concrete actions. Since if there is no action, there is no emancipation; and neither exploration of possibilities that could lead to finding extra-ordinary solutions.

The emancipatory aspect of the method emerges, considering also what is not coaching. Coaching is not a unilateral exchange, but common construction, a shared process aimed at action. Coaching is not comparable to psychotherapy, or psychological support, and nor to counseling between an “expert” (who holds the power of knowledge) and a “patient/client” who is in a situation of need. Coaching is not a relationship based on the need of care, but on the desire to improve the quality of life and change.

The coaching model used is defined as “ontological-transformational”. The ontological aspect consists of considering language as a key to understanding human phenomena and characterized by a “*generative character that allows to create and shape the future*” (Echeverría, 1994).

It is starting from language’s acts or “*performative verbs*” (Austin, 1940; 1962) that coaching supports person to plan actions to be transformed in reality. The transformational aspect of the intervention intends to move from a “*position of control to one of commitment*” (Maturana, 1995). The theoretical assumptions refer to the constructivist theory, the systemic approach (Watzlawick, Beavin, Jackson, 1967; Bateson, 1972), linguistic and sociology. The constructs and principles drawn from these theories are therefore the basis of the definition of this method which supports persons in dealing with a problem, a relationship, a project or adopting a different perspective. This allows the choice of solutions and decisions making - emancipatory aspect - that are the best possible for the person, and for the whole ecosystem that surrounds her/him, so that all its members can enjoy the benefit (Whitmore, 2003).

⁵⁷ Available at: <https://www.icf-italia.org/cose-il-coaching>

6.4.6 Lessons learned

The lessons learned from this case study concern two main aspects. The first is related to the effect of the application of a non-medical method within a medical context. Both from the point of view of patients - especially referring to possibilities of increasing their emancipation - and from the point of view of the institution.

The second aspect concerns the effectiveness of the method of Life Coaching when used with vulnerable groups.

Concerning the first aspect, it was very interesting to observe how people in a medical context often - if not always - assume a passive role. In which they expect to be informed on "*what and how to do every thing*". If from the point of view of diagnosis and treatment it makes sense, it doesn't when it comes to choosing how to deal with everyday life, even in the presence of functional limitations, diseases or disabilities. In this sense, the experimentation of the method showed how patients became disoriented and astonished when asked "*what do you want to do with your life, now?*" or "*what do you wish, what are your objectives or aspirations, considering or not the disease?*".

Through these and other questions - specific to the method used and focused on the whole life situation, not only on the part affected by the disease – it emerged how difficult is to open up to new projects or perspectives of life. It showed how unusual for patients to come back to desire, or to plan new objectives, especially it is for patients return to a state of desires, or to plan new goals, especially if they required in medical contexts. However, at the same time it results as extremely useful for persons that if supported can re-learn how to use their potential, resilience and capability. This can include new strategies of action aimed at reaching new goals, regardless of the deficit or functional limitation.

This aspect is closely linked to the emancipation of the individual from a passive role (as "receptor" of medical indications only), towards a more active and aware role, in order to improve her/his life or change it for the better. This is an interesting point of reflection, that connects with the effect produced by the introduction of this method in a medical context.

First of all, for contributing to support a holistic and multidisciplinary approach in the interventions of the institutes. That along with an attitude of openness has showed how complementarity of medical and non-medical interventions represented a positive element for both patients and operators.

From this point of view, one of the outcomes of the experimentation was the reflection about the opportunity to transfer some of the techniques and tools of

the method of Life Coaching to professionals and operators (such as neurologists, physical therapists, caregivers, educators).

The insight to transferring techniques and tools of this method is not to create a new job profile (i.e. a sort of Disability coach), but to encourage the acquisition of new skills and competences aimed at providing the possibility of working with patients not only as persons to be assisted, but also as pro-active agents for the improvement of her/his life. This is an aspect that is often not addressed by therapeutic treatment, but it can help to define the objectives and strategies to achieve improvement, based on motivation, self-determination and empowerment.

This point can be linked with the second important aspect that emerged from the experimentation that is represented by the presuppositions of effectiveness of the method - especially supporting persons in a process of emancipation. The presuppositions of effectiveness identified were:

a) For the person (named coachee by the method):

- Motivation for self-development.
- Commitment to the program (definition of objectives, action plan, monitoring of expected results, etc.).
- Accountability towards her/his improvement and self-determination
- Intellectual honesty.
- Disposition to listen and to change/improve.

b) For the Coach:

- Confidentiality about the contents emerged during conversations with the coachee.
- Flexibility and willingness to support the coachee in the achievement of objectives and meeting of own needs.
- Deep trust in the possibilities of the coachee.

These presuppositions of effectiveness are at the basis of results, including:

- developing a greater self-determination;
- fostering the capabilities to renew desire, to plan new objectives of life;
- facing change - in personal or professional life - with greater self-confidence;
- improving interpersonal relationships;
- enhancing accountability (considered as the ability to respond);
- increasing emancipation for improving the quality of life.

After presenting the presuppositions of effectiveness, I wish to show the possible limits of the method. Considering that coaching is a method that uses

language to support persons to undertake actions that transform reality, this requires good language skills and abilities. As it is based on the transformation of the system where a person lives, from a position of control to one of commitment, cognitive functions also should not be compromised.

These aspects limit the possibility of using the method with every type of disability, allowing its use only for some cases, such as with physical and sensory disabilities, due to trauma or neurodegenerative diseases.

Concerning this reflection and for what disabilities the method can be effective - and in what contexts - I think that could be very useful and interesting to try to apply the method to rehabilitative contexts (as support aids centres or institutes specialized in provision of prothesis). Because when people come in those contexts they often have to re-define their life, goals and challenges, starting from situations of trauma, impairment or functionality limitations.

Moreover, I think it can be very interesting to try to use the method even with people affected by mild-delay at the cognitive level. Especially for researching on issues related to the involvement of families and a different approach of the operators in the interventions.

Participants' point of view

The participants' point of view was investigated during the coaching sessions and through interviews. The feedback provided was very positive, especially if compared to the aims of the experimentation, including:

- to test the usefulness of a method more social and less medical, different from the care relationship because it is based on the desire to improve and change, not on the need of assistance;
- to provide evidence base of its emancipatory and maieutic features;
- to prove the assumption according to which coaching can be a method able to foster a shift from a situation of passivity towards new scenarios of active participation in the elaboration of one own project of life.

Some of the feedback of the coachees collected at the end of the experience is reported as follows:

V. *"... the experience as very positive, I was able to put into practice and implement my action plan and I made some changes in my life ..."*

To the question *"What are you going to take home (what have you learnt)?"*, the answers were:

B. "...the desire to try to change something that does not work in my professional life..."

V. "...new insights and new points of view..."

P. "...I have confronted my shyness, and now I am more self-confident..."

In terms of the goals of the method, the feedback shows how these were achieved, inasmuch as they supported the participants in dealing with their objectives and the definition of the action plans to reach them, providing different perspectives and allowing for new insights.

6.5 Research methods applied

6.5.1 Interviews

In preparation for the interviews and focus groups a reflection was conducted on the observations and informal discussions that had taken place with participants of both case studies. In so doing, I drew on my own developing theoretical understandings of participation (as outlined in the first part of this thesis) to identify what aspects to be investigated.

Aspects that could be considered as tangible proofs of the rise of self-esteem, self-determination, satisfaction and consequent emancipation.

These then became the focus for the interviews, this meant that although all the interviews followed a similar format, each one was prepared individually following this preliminary consideration of the observations.

At the same time, I was careful to ensure that all the participants were given the opportunity to talk about aspects of their experiences. In particular those that were less visible during the observations, for example what was learned during the weekends of autonomy and effectively used in everyday life (in case 1), or what strategy, plan or action of coaching was applied to different situations of life (in case 2). Interviewees included key informants, in particular professionals, operators, and representatives of the institutions involved in the case studies observed.

The interviews were addressed to the following categories: psychologist, professional educators, physical therapist, engineers and health-coordinators, involving a total of n. 15 persons.

6.5.2 Questionnaires

The number of questionnaires completed (n. 9) was not sufficient to trace an accurate picture of the issues analyzed from a quantitative point of view. In any case, the questionnaires used for the two case studies were:

- a) for the first case study: the “Disabilities of the Arm, Shoulder and Hand (DASH)” questionnaire, and the instrument “IPPA - Individual Prioritised Problems Assessment” (Wessels et al., 2002). These tools were used by the physical therapist and the professional educator of Emilia-Romagna’s Center for Assistive Technology of Corte Roncati to assess functional requirements, accessibility and evaluation of the ability to perform certain activities in the apartments. These were also

used to define the interview's structure for gathering other information, including the level of participation.

- b) for the second case study was used a questionnaire for the assessment of the quality of life, the "International questionnaire investigating quality of life in multiple sclerosis (MusiQoL)".

6.5.3 Living Lab

The Living Lab method (described in section 3.5) was applied during the experimentation of a service of "Smarthomes for independent living experiences", described in case study 1.

The Living Labs are open innovation ecosystems, and consist in the establishment of permanent communities of users who are involved on an interactive basis in service or product innovation at various stages in the design, development, validation and marketing process.

This approach was used to facilitate participant involvement in the innovation process aimed at implementing a new service (Bilgram, Brem, Voigt, 2008; Pallot, 2009).

The Living Lab saw the participation of the group of participants, the professional educators and the staff members of Emilia-Romagna's Center for Assistive Technology of Corte Roncati, for a total of n. 10 persons, for n. 6 meetings.

The set-up of the Living Lab for the implementation of a service for experience of independent living, included:

- definition of the mission of the Living Lab;
- identification of the community and persons to be involved;
- definition of the aims and activities with the involvement of all participants;
- implementation of real-life experience and living laboratory within the apartments provided with home automation;
- collection of feedback for supporting the co-creation processes among the various participants.

The principles adopted for the establishment of the Living Lab were:

- Openness: to create a process based on the gathering of many perspectives to achieve rapid progress.

- Realism: to facilitate the establishment of real-life situations focusing on everyday activities.
- Empowerment: to engage participants in developing and finding solutions based on their needs.
- Spontaneity: to allow the exploration of personal solutions, contributing to meet real needs.
- Continuity: to strengthen creativity and innovation.

6.5.4 Focus groups

Focus groups were realized for both the case studies, with the aim of gathering information and feedback, allowing the observation of people in a more natural conversation pattern than typically occurs in a one-to-one interview.

In particular this has provided the opportunity to focus on specific aspects related to participation processes, awareness of the involvement, level of emancipation, perceptions, opinions, beliefs, and attitudes towards the services experimented.

Adopting a critical approach to focus groups, discussions have involved different participants (4-5 per focus group) and questions were asked in an interactive group setting where participants were free to talk with other group members, providing the opportunity to analyse the strength with which both individuals and groups hold an opinion.

CHAPTER 7 – Final remarks

In this section, I put forward the findings from my research. I will start by repeating the initial hypothesis and objectives of my thesis. Then I will present a description of the results and how these findings can have an impact in terms of actions and finally the constant pedagogic features identified when applying participatory and emancipatory approaches.

The focus of my research was to demonstrate that “*an open participation in the co-creation of the service and environment, makes life easier for vulnerable groups*”. Gaining more knowledge about how the involvement of vulnerable groups such as becoming co-creators of services, research, products or environment can facilitate their lives.

My contribution to the body of knowledge of participatory and emancipatory approaches has been outlined with the aim to investigate the theoretical background and to observe two case studies focused on how to apply these approaches in the intervention with vulnerable groups, in particular persons with disabilities.

The general objective of the research was to further advance the understanding of the potential of participatory and emancipatory approaches in terms of inclusion, with a special emphasis on the involvement, empowerment and self-determination of persons, as advocated from the perspective of the Civil and Human Rights approach to disability.

The specific objectives were:

- a) To define an overview of the theoretical assumptions of Inclusive Education. Starting from the definition of the terms of disability and inclusion, following with a brief historical overview of the main models and approaches to disability.
- b) To focus on concepts, tools and methodologies that address existing and emerging needs, such as the lack of examples, practices, experimentations oriented at an effective inclusion in the processes of the design of services, research and environment, using participatory and emancipatory approaches. This has led to the analysis of these approaches viewed as instruments for cutting the roots of marginalization, supporting active citizenship and socially innovative actions.

- c) To analyze two different case studies focused on participatory and emancipatory approaches in order to verify the research hypothesis. In particular assessing if these approaches - once applied - are able to effectively support the shift from situations based on a medical model of disability (passive situation), towards ones based on civil and human rights (active situation). Therefore placing the person with her/his needs, desires, objectives and expectations at the centre of actions and interventions.

The knowledge I wished to contribute with this thesis is positioned on two different levels - conceptual and practical – and the combination of these two levels is the most innovative aspect of my work.

On a general level, my contribution is comprised of a selection of international documents and literature which is presented specifically in the entire first part of the thesis (chapter 1-5).

This selection is the result of an associative and adaptive process characterized by three main ingredients: the frame of reference, the methodology and the areas of concern (Checkland and Holwell, 1998).

This means that a particular combination of linked conceptual categories was used in the methodology as a means of exploring defined areas of concern, analyzed through the case studies (chapter 6).

Reporting this sample of literature on approaches, theories, methods and tools also has a methodological value since it was selected on the basis of my personal experience, both as a researcher and a disabled person.

On a specific level it concerns the analysis of the case studies and the operative findings that could be applied to many other contexts.

Concerning the first case study, about the development of a service of “Smarthomes for independent living experiences”, it regards the introduction of an “inclusive educational aim” in contexts usually characterized mainly by rehabilitation and functional assessments.

Through the participatory approach applied, the case study has showed that interaction between the participants (vulnerable groups) and professionals (operators of different fields) is not only a matter of transformation of social relations – that is the prerequisite to developing socially innovative actions - but also a matter of awareness and better understanding of what persons can do (capability), increasing their inclusion and consequently their self-determination and self-esteem.

In this case the inclusive educational aim has influenced and has benefited from the influence of all the persons involved, through the realization of a learning environment characterized by mutual collaboration, sharing and participation, creating a virtuous spiralling cycle.

Regarding the second case study on the experimentation of the “Life Coaching” method applied in a medical context, findings showed how it could be useful to introduce a non-medical method of intervention, based on the concept that it is the person, not the patient, who is living, feeling, wishing, and acting, despite illness or disability. Therefore, the operative section of my work has demonstrated that an emancipatory approach may play an increasingly larger role in facilitating a persons’ life.

Since participatory and emancipatory approaches have the explicit intention “to do real things” with “real people”, they need to become more pervasive in many different contexts in order to construct the reality they wish to achieve.

To make the findings from this thesis comprehensible and applicable in different contexts, such as academic research, health and social care services, associations, assistive technology centres, working environments, and especially in educational contexts, following are reported possible impacts of research in terms of actions:

- a) Formative evaluation of participatory and emancipatory approaches applied to the areas of concern: the participatory design of a service for the development of autonomy (independent living). The experimentation of a non-medical model of intervention with persons with disabilities aimed at putting at the centre of the process the person with her/his goals, desires, expectations, supporting her/his emancipation.
- b) Development of a theoretical and operative framework that provides policy and decision-makers with scientific evidence base able to support the shift from a medical model of disability towards one based on the Civil and Human Rights approach.
- c) Identification of the “constant pedagogical features” that could support and facilitate inclusive processes, and are: participation, emancipation, self-determination and empowerment. These features are essential for the development of a socially innovative scenario that allows an effective transition from a situation of passivity, sickness and patient care to a new one based on the person’s commitment to active role and participation in the elaboration of his/her own project of life.

Future research

During my research, I have identified some aspects that I believe are important to do more research about. These aspects are related to the need of more understanding and realization of experiences of inclusive practices. Not only with educational purposes, but also with the wider aim to shift from a situation of passivity (medical model) to a new scenario based on the person's commitment to an active role in the elaboration of his/her own project of life (Civil and Human Rights model).

I have also identified the need to further explore tools that can contribute to create scenarios in which services, researches, products and environments become more accessible and easier to use, favoring ultimately a greater inclusion. When it comes to understanding the participation and emancipation are innovative and recent approaches, I have acknowledged that there is a need of more research about practices in order to have more insights into how these approaches can support changes in society at large.

Related to the need of non medical methods of intervention, I have recognized that in the future we need to develop more experiments, research and practices with the involvement of vulnerable groups. Because there are several aspects that need to be understood if participatory and emancipatory approaches should have a sound scientific foundation and become able to grow.

One thing I believe needs more research with the involvement of vulnerable groups as co-creators of knowledge is the key principle. At the moment, this principle is derived empirically, but needs to be underpinned more theoretically and elaborated upon. Related to that, I want to highlight the importance of more research into the approaches of participation and emancipation and how these can be incorporated in organizational processes.

Another aspect I consider as relevant here is the inclusiveness of the process, that means how can we use participatory and emancipatory tools for design inclusive processes, and how we should handle the information generated from these processes. If those approaches are applied in different contexts, I see a need to gain insights of their characteristics, and the driving force behind these inclusive processes.

Finally, I believe that it would be fruitful to do more research on the key principles of emancipation, empowerment and self-determination. To develop sustainable tools, methods and practices for inclusion, I view it as important to understand how the principles affect and support each other as well as knowing how these principles take form in different situations.

Reflecting on the research and learning process

To conclude this thesis, my last reflection is on the research and learning process that I have undertaken during my doctoral experience.

First of all, my ambition in writing this thesis has been to describe theories, approaches, methods and tools as detailed as possible to make it possible for the reader to understand the background, the concepts and how the analysis has been made, and from that being able to judge if my interpretations are reasonable.

During my doctoral path, as a researcher and a disabled student, I have been involved in activities and projects with a multidisciplinary approach and the participation of professionals from different fields.

The possibility of working together with people with different backgrounds, competences, expectations and desires has deepened my insights about my research area. All the collected knowledge and learning experience that I have gained, especially during the observations of the case studies, cannot be explained and discussed easily in a thesis. There are so many things I have learned that go beyond the scope of this thesis.

The first thing is that in academic conferences and seminars, too often persons belonging to vulnerable groups, such as disabled or elderly, are absent and when attending are only as witnesses or testers, but never as co-researchers. Listening to some academics talking about situations that they have never experienced can be compared to listening to a white man talking about the emancipation of black women. I feel the need to thank all the people with disabilities encountered and from whom I have learned so much.

When I began my research, the main focus was on participatory and emancipatory approaches. I connected to mainly civil and human rights, but as time went on, the focus also included concepts such as active citizenship and social innovation. I am not certain if it is my research that caused this inclusion, or if it is due to environmental influences. Having an action-participatory-research approach makes me hope that my research could have an actual impact on the inclusion of vulnerable groups.

Another aspect that I have experienced during my research is the challenge of conducting both an experimentation (as coach conducting Life Coach sessions with persons with disability) and observations at the same time. This situation put high demands on me as researcher and disabled to be aware of my role in the process of analysis and to keep the research in focus while performing activities. In my experience participatory and emancipatory approaches represent a new challenge for the definition of sound research protocols.

I have handled this issue through a constant meta-reflection on the research processes that have been described in this thesis.

Finally, if I ask myself: “what can one learn from my lessons?”, the answer is that I believe that it is time to adopt a more holistic approach for the realization of an effective inclusion of vulnerable groups. Through the modernization of our methods and tools, we can empower persons so that they are able to play a central role in the definition of their life project. This facilitates the process of inclusion using participatory and emancipatory approaches for the design of socially innovative actions.

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List of abbreviations

ADA: American Disabilities Act
AT: Assistive Technology
CBR: Community Base Rehabilitation
DCP: Disability Creation Process
DfA: Design for All
DPOs: Disabled People Organizations
EC: European Commission
ER: Emancipatory Research
EU: European Union
HCD: Human-Centred Design
ICF: International Classification of Functioning
ICIDH: International Classification of Impairments, Disabilities, and Handicaps
ICT: Information Communication Technology
PR: Participatory Research
P&ER: Participatory & Emancipatory Research
SI: Social Innovation
SME: Small Medium Enterprise
UCD: User-Centred Design
UN: United Nations
UNCRPD: United Nations Convention on the Rights of Persons with Disabilities
UNESCO: United Nations Educational, Scientific and Cultural Organization
UNICEF: United Nations International Children's Emergency Fund
UPIAS: Union of the Physically Impaired Against Segregation
WHO: World Health Organization