Emancipatory
Disability
Research

EDR

West Bank - Palestine

EducAid

SOCIAL INNOVATION
AND INCLUSIVE EDUCATION
FOR INTERNATIONAL COOPERATION

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Introduction

During the last years, the main focus of the International cooperation has been to work with the awareness of how much the conflicts and international instabilities make it difficult to tackle extreme poverty, for the social inclusion of the marginalised and vulnerable groups. Also being aware that the increase of migrations require promotion of strong fraternal and solidarity relations against the emergence of new radicalisms.

AIFO is aware of operating inside a complex reality formed by extraordinary opportunities and enormous obstacles, **where new instruments play a decisive role**, that are being built and supported and that can play a leading role in future. Thus we believe that it is important to dedicate resources to these.

At international level, it is important to remember that during 2015 there was agreement to work on 17 main objectives and 169 associated objectives that are not just about countries in transition but for the whole world. United Nations have adopted the new agenda of work till 2030.

Through the "Italian Network on Diversity and Development" (RIDS) AIFO wishes to focus on its goal to work for the implementation of UN Convention on the Rights of Persons with Disabilities (UNCRPD) as an international standard of reference for activities and projects of inclusive development so that policies and projects of international development cooperation are inclusive, right from their planning stage. Inclusive development for RIDS and AIFO means an approach to society's and community's development that promotes and safeguards human rights, that respects and values the human being, irrespective of their physical, social, cultural, ethnic and religious characteristics, their sexual orientation and other personal characteristics, promoting their full participation in life and society's activities, so that they can contribute to and benefit from the economic, social and cultural lives of their communities, as all other citizens.

The real challenge of social inclusion is the concrete participation of the most marginalised subjects of the society to the decision processes. If we take account of global economic crisis affecting the sustainability of the existing social welfare systems, the need of shifting the medico-social intervention plans from an "assistance-based approach " to "community-promotion approach " becomes clear. By "community-promotion approach" we mean developing and supporting new forms of care in the local communities through the joint actions of different social stakeholders.

The emancipatory research is considered a good methodology to reach this result. It is an Action Research based on the principles of self-advocacy and self-determination, that promotes active participation of people. People with disabilities will become researchers of their condition of vulnerability and their direct participation encourages the construction of consciousness, enlarging the partial vision of the single condition. People with different disabilities will come in contact and build mutual and inclusive understanding.

The emancipatory research contributes to reach one of the objective of RIDS:
- To strengthen the competence and the role (empowerment) of persons with disabilities and of the organisations which represent in countries, that is essential element of sustainability of CRPD, on the basis of " Nothing about us, without us".

Francesca Ortali - Head of Project Office - AIFO

Introduction

The aim of research initiative has been the promotion of social inclusion and the active participation of persons with disabilities in the Palestinian context, in line with the United Nation Convention on the Rights of Persons with Disabilities principles.

In order to gain this objective, the process focused on the enhancement of the local empowerment through the active involvement of one of the most vulnerable and marginalized group of the society, represented by women with disabilities (EducAid, 2012).

This research is based on Emancipatory Research Methodology, which represents one of the most advanced and innovative approaches in the domain of participatory research.

This introduction introduces the theoretical background of emancipatory research through a brief literature review, from the participatory research to the major contribution of the pedagogy and the theatre of the oppressed elaborated by Freire and Boal. The linkages between the emancipatory research methodology and the capability approach elaborated by Amartya Sen are evidenced. Particular attention will also be devoted to the main features of this methodology and to the applications of the Emancipatory method to Disability Research, with a focus on awareness-raising processes related to the UNCRPD and the biopsychosocial approach to disability.

Theoretical background of the Emancipatory Research

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From the traditional approach to the Participatory Research

The scientific knowledge produced by Universities and Research Institutions has a strong influence on social, economic and political policies and on the cultural development of societies. Therefore, reflections and investigations on research methods are crucial to understand the impacts of the different approaches on research structures, processes and final outcomes. Currently, one of the most debated issues is the analysis of the power relations embodied into research activities. This kind of analyses and critiques challenge the traditional top-down approach of academic research influencing social sciences and in particular development studies. The developments of participatory methods stimulated the rise of bottom-up practices, with a progressive increase of the engagement and of the involvement of research subjects in the different steps of the research conduction for development purposes.

This approach to social research, strongly popularised in the 1980s with the work of Robert Chambers (Chambers, 1983), led to a complex and wide review of the dominant models of research and fieldwork activities and contributed to cutting-edge understandings on the concept of development itself. Chambers' original contribution consisted in a vivid critic to the conventional surveys methods, which were characterized by superficial data collection and ethnocentric attitude of the development experts due to their standardized approach and their weak knowledge of the research subjects (Libanora, 2010). Through Chambers' critical point of view, the academic world began questioning about the mainstream research practices and interventions. Soon it was realized that, without the adoption of participatory practices and better operational tools, the biases and the distortions of the non-participatory research would have always invalidated progresses and surveys in the development field.

From the 1980s then, the importance of participation gradually increased and spread, from the minor development interventions to the very heart of the development mainstream (Cornwall, 2000). Moreover, participation started being perceived as a basic human right: as Ferguson advocated, people cannot realize, for example, the right to health unless they can also exercise the democratic right to participate in the decision-making process about service provision (Ferguson, 1999).

From the mere idea of consulting people in the first forms of participatory approaches, in the 1990s participation started being perceived as a process through which the marginalized groups could influence and share control over development initiatives and decisions. Nowadays, terms like "ownership" and "empowerment" are essential part of the participatory research interventions, and participation today is being mainstreamed and institutionalized at the micro and macro levels of the methods for development work and research.

The birth of emancipatory processes: theoretical basis and first practical applications

The advancement of Participatory Methods stimulated the rise of bottom-up practices, with a progressive increase of the engagement and of the involvement of research subjects in the different steps of the research conduction for development purposes. When the research questions are focused on marginalization, the participatory approach establishes a mechanism whereby the marginalized groups of the society are encouraged to take active part in the research activities, sharing with researchers their opinions and experiences.

The Emancipatory Research represents the step forward: as suggested by the term "*Emancipatory*", the participants are not only expressing their point of view or facilitating the survey, but they also have the opportunity to gain the ownership of the whole process. In the emancipatory approach, through the acquirement of skills and expertise in research conduction, the research subjects lead all the research activities, from the decision of the research strategy to the results dissemination: the professional researchers become only a scientific support\facilitator and this shift of power relations is determinant for the individuals in order to actively become part of the knowledge production and of the decision-making process for policies of their concern.

Through this approach, the marginalized groups of the society acquire specific knowledge for active participation and research implementation, developing awareness on their own social and economic conditions. Through critical discussion and analysis of the research questions, the participants become aware of their rights and of the structural causes of their oppression, elaborating practical solutions in order to improve their living conditions and becoming able to control the process of knowledge production on themselves. The strategy, moreover, has the aim to sensitise and empower communities and institutions, encouraging social transformation and inclusive policies. It is nowadays clear that development interventions cannot be sustainable and long-lasting without an effective participation of the stakeholders in all the processes.

In particular, with the verb "*to emancipate*" it is meant the opportunity to free oneself from the restraint, the control or the power of someone else, and in particular to free oneself from any kind of slavery (Boog, B. W., 2003). Emancipation has been set as the main goal of a large number of social, political and religious organization during the eighteenth, nineteenth and twentieth Centuries. The struggle for equal rights and social justice and the efforts to gain more power, including the political power, have been conducted by different marginalized groups: poor, cultural and ethnic minorities, religious associations, women, homosexuals etc… Emancipation represented thus the main social and political purpose of the most important social critical theories[1] of the previous century. Many of these approaches have been inspired by Marx and Engels's critiques of capitalism: their criticism on the cultural institutions representing the dominating ideology of the ruling classes, based on the capitalist economy, has been reflected in a subject-subject relationship between researchers and researched subjects, which progressively gave birth to the Emancipatory Research Methods.

As we above mentioned, this methodology had its first practical applications in the recent times, but its historical pathway started with the innovative approach to pedagogy, which have been offered by the work of Paulo Freire and Augusto Boal.

The work of Paulo Freire for emancipation and empowerment

The figure of Paulo Freire has significantly inspired the participatory and emancipatory approaches in development interventions. The action-research methods that he created have been experimented for the first time in the San Paulo's favelas. This approach strongly influenced the elaboration of the Participatory Rural Appraisals (PRAs) which are having the aim of empowering and raising awareness among the beneficiaries of development interventions. The PRAs represented, in fact, one of the strongest source of influence of all the participatory methods.

Starting from the 1960s, the Brazilian educator started to advocate a new critical pedagogy with his innovative theoretical elaboration. While working among the poor and the illiterates in the tough environment of the favelas, Freire began to embrace a non-orthodox form of liberation theology. Through the field experience, he started a process of popular education and awareness-raising (that he defined "*conscientisation*") which during the 1970s has spread throughout Latin America. In his main work, "*Pedagogy of the Oppressed*" (1968), he strongly affirmed that marginalized people have analytical skills and should be enabled to investigate their own realities and reflect upon their living conditions.

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[1] In particular, among the critical theories it is worth mentioning the critical sociology of the Frankfurter Schule of Adorno and Horkheimer and others and the critical pedagogy, which will be analysed in the following lines.

Thus, Freire contributed as a theoretical background to the participatory methods elaboration, and, in particular, his analysis was useful to structure the first drafts and trials of the emancipatory research. The basic principles, identified in his critical pedagogy, are indeed the following:

- Poor and marginalized are able to analyse their own realities
- Empowerment is necessary in order to develop analytical skills
- Self-critical awareness is an important prerequisite. The involved participants should reflect critically on their values, concepts, behaviours, etc…
- The society's outsiders have to act as catalysts and facilitators in the research process (Kumar, 2002).

As can be noticed from the last principle, the marginalized people are pinpointed as facilitators in the research process: the selected target is not only participating, but the minorities are engaged in active involvement, implementing the main research activities by themselves. Therefore, the Brazilian intellectual's perspectives have been widely used in the theory and practice of emancipatory development since the beginning of the 1970s. To quote him: *"At all stages of their liberation, the oppressed must see themselves as women and men engaged in the ontological and historical vocation of becoming more fully human. Reflection and action become imperative when one does not erroneously attempt to dichotomize the content of humanity from its historical forms. The insistence that the oppressed engage in reflection on their concrete situation is not a call to armchair revolution. On the contrary reflection - true reflection - leads to action. On the other hand, when the situation calls for action, that action will constitute an authentic praxis only if its consequences become the object of critical reflection"* (Freire, 1996 : 47-48).

Pedagogy and Theater of the oppressed: the influence on the Emancipatory Research

With his work, Freire shaped the basic principles of the participatory and emancipatory research methods in terms of faith in the capacity of the marginalized groups to depict and analyse their own realities and to drive their own development. He strongly affirmed the value of emancipation: people's mobilization conducts to inclusive decision-making processes where the marginalised groups begin to create their own history and engage themselves in their own development paths. As he pointed out, "*No pedagogy which is truly liberating can remain distant from the oppressed by treating them as unfortunates and by presenting for their emulation models from among the oppressors. The oppressed must be their own example in the struggle for their redemption.*" (Freire, 1968 : 54). Starting from his theories, and with the contribution with another Brazilian educator, Augusto Boal, the Theatre of the Oppressed has been created and developed as an innovative practice to promote learning processes where participants examine and analyse their reality: through the creation of images based on their direct experience they are able to investigate the power relations and the root causes of their oppression and afterwards they act to transform the circumstances according to their vision of possible alternatives (Picher, 2007). This approach of political function of art (Boal, 2006) was useful to advocate for a participatory culture that promotes the right of everyone to fully participate in the organization, maintenance, and transformation of their society and daily life.

The emancipatory research, developed in early 1990s (Oliver, 1992), is a step forward and a progress from the participatory frame toward the liberation of marginalized groups from their condition of oppression and straggle. Paulo Freire and Augusto Boal represent then the pioneers of this kind of methodology with their work in the educative domain (Justo & MgSc, 2005). In fact, as affirmed by Boog, the historical development of action research, created in the first forms by Freire, reveals that it had emancipatory intentions from the very beginning (Boog, 2003). Action research and its participatory applications have been designed to improve the researched subjects' capacities to develop skills (including professional skills), improve the problem-solving attitude, increase their chances of self-determination, and to gain more influence on the decision-making processes of organizations and institutions in the context where they act. The Emancipatory method implies similar expected results:

- On one hand, the aim is to develop or improve personal and professional competences

specifically linked to the process methodology of the research participants.
- On the other hand, the objective is to enhance the transversal abilities to compare problematic situations and critically reflect on one self-conditions.

Emancipation is thou strongly linked to the empowerment processes, as the self-awareness is a key condition for the achievement of equal opportunities and participation in the decision-making mechanisms of the society.

In conclusion, the emancipatory approach and its theoretical background fully consist in promoting democratic practices in the social, economic and political fields, helping the marginalized groups to engage themselves in the debate over strategy and process for social changes.

Emancipatory method and capability approach: Sen's capability approach and the right of participation

One of the most interesting field of application of the participatory and emancipatory methods is due to the connections between the philosophical standings of Amartya Sen and the pragmatic techniques of participation in development surveys and interventions. Although they are formulated on different epistemological assumptions, the analysed research methods and Sen's capability approach (CA) share various affinities (Libanora, 2010). Indeed, similar attention has been devoted to the agency of the poor by the capability approach through participatory methods that combine the Freire position and the Amartya Sen concept of freedom (Frediani, 2010). For detailed analyses and a literature review, see Clark, Biggeri and Frediani (2017, forthcoming).

The CA has been developed during the 1980s and this new theoretical approach opened an interesting prospective in the economic debate as it challenged the vision and the perceptions of the actors as an utility maximising machine (Biggeri and Anich , 2009; Testi, Biggeri and Libanora, 2011; ARCO, 2015).

In Sen's perspective, in fact, the material endowment of resources is not sufficient to define an individual's wellbeing: in one of his first work, in fact, Sen introduces the two innovative concepts of "*functioning*" and "*capability*". To mention his words: "*A functioning is an achievement whereas a capability is the ability to achieve. Functionings are , in a sense, more directly related to living conditions since they are different aspects of living conditions. Capabilities, in contrast, are notions of freedom in the positive sense: what real opportunities you have regarding the life you may lead*" (Sen, 1987 : 36). Therefore, in the CA the material wealth considered in the standard economic conception is replaced with the idea of "*well-being*", meant as a combination of "*being and doing*" (Biggeri, 2010). What an individual is enabled to do and to be depends on means and resources at her disposal, and it depends as well on the opportunity and the ability to transform those means (*capabilities*) in desired goals, self-realization and ambitions (*functionings*). The passage from capability to achieved functioning is realised through an individual choice process (*agency*), which depends on individual abilities, personal and familiar characteristics, as well as community level factors. According to Sen, the series of objectives which are potentially reachable constitutes the capability set of the person and the opportunity to extend this set represents a crucial element of the individual well-being and development.

As we can notice, the strongest contact point between the emancipatory approach and Sen's perspective is the central importance given to the individuals: the person is not considered as an insignificant pawn of an homogenous group. Each individual is recognise as a single human entity, with her specific features, desires and opinion. As illustrated in the **Figure 1.3**, in the CA great relevance for the policies implementation is also given to the human and environmental context of the person: the same attention is devoted in the participatory research methods, where the researcher has to tailor tools and survey methods according to the cultural framework in order to create the best conditions for community engagement and participation.

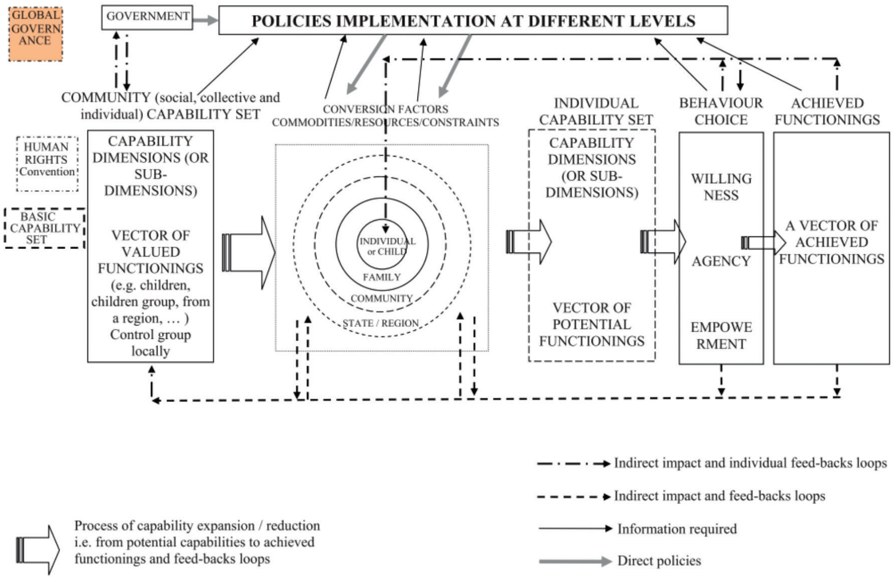

Figure I.1 The capability approach: capability framework for policy implications
Source: Trani, Bhakshi and Biggeri, 2011.

Therefore, putting the person and her freedom at the centre of the analysis is one of the pillars of both the emancipatory and the capabilities approaches. In particular, the process of individual choice, which in the CA is specified with the function of agency, and the centrality of people, seen as ends and not means, are two of the main assumptions that facilitate the theoretical integration of the approaches. Another common thread is the notion of development as a broad and multidimensional concept, as specified also in the structure of the Human Development Index[2] (Biggeri and Chiappero, 2010). For Sen as well, the person has to perform an active role in the development paths: as analysed by Biggeri and Libanora (2011 : 80), "*the participation of the stakeholders is essential to the process and implies the reflection of subjects about their own condition, opportunities and constraints in their cultural, social economical and political environments*". Through participation, in fact, the individual enhances her agency and enlarges her capability set. Besides some differences, the emancipatory and the capabilities approaches are similar in many aspects and they reciprocally strengthen the analytical and empirical message of both: it is important to push forward the boundaries of social science and development organizations showing the advantages of an involvement of economical and social actors, included the marginalized pockets of the society (Biggeri, 2011). In fact, in Sen's perspective, the locals have to play an active role during the development interventions in order to activate a capacity building process, gaining empowerment at different levels and ownership of the whole development path

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[2] As is well known, the Indian economist Amartya Sen took part to the first formulation of the concept and the measuring model of the "Human Development Index" (HDI) with the support of the United Nation Development Programme (UNDP). The definition of the Index has strongly been influenced by Sen's capability approach: the index, in fact, doesn't rely only on the material possession of the person, considering as well other dimensions like, among others, the life-quality and the expected years of schooling (UNDP Human Development Report, 2015).

(Biggeri and Chiappero, 2010). Moreover, as a consequence of the emancipatory approach, the development process is at least as important as the outcomes: therefore, the actual impact of any planned action in this kind of inquiries has to be measured in terms of community agency enhancement and individual empowerment.

Let's now move to a deeper analysis of the main features of the Emancipatory Research, starting with the description of the principles which characterize this approach and describing then the required steps for the implementation of the Emancipatory Method.

Emancipatory Research: principles and methodology

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The involvement of the marginalized groups in the research process

The main aim of this methodology is promoting empowerment among the marginalized groups of the society. In this methodology, the research objects become the subjects i.e. researchers themselves through a process of training and awareness raising. What is important in this approach, in fact, is the process that conducts to the acquirement of personal and technical skills which allow the participants to critically analyse their living condition and elaborate problem-solving strategies. The path of empowerment and emancipation is then one of the most important result that this kind of research can provide. The results of analysis assume - according to the UNCRPD - a different meaning (self-awareness, an instrument for individual and social empowerment) bringing quite often a different perspective and creative solutions to NGO and policy makers.

As above mentioned, the Emancipatory Research is thus structured and implemented through the collaboration among expert researchers and a group of people who are part of a fragile and marginalized pocket of the society. All the activities are jointly decided and the research is carried out by the participants who are specifically trained. Through the research activities conducted on individuals which share their similar living conditions, the participants are able to achieve and enhance their self-awareness. This approach then change the social relations in the research production (Oliver, 1992) and the activities of the data collection and analysis are able to generate social changes in the current dominant dynamics of marginalization.

Here we would like to summarize the key elements of this approach in order to clarify the main aspects of this emancipation pathway.

- First, it is crucial to ensure that **all the participants can play an active and decision-making role in the research**. Most of the activities have to be interactive and the role of the expert researchers has to become marginal: they only facilitate the process which has to be conducted by the participants.
- It is important to use methods that help people to share and learn from each other's experiences and struggles, understanding different ways of overcoming barriers and obstacles. These methods conduct to individual and collective reflections, in respect of the human dignity and the right to privacy: through this process the participants gain new awareness about the structural causes of their living conditions.
- Another key issue is the **awareness raising** on the national and international rights and entitlements as citizens: this legislative framework is a useful instrument for discussions and reflections. Persons involved in the emancipatory research can then examine their own **life experiences and** compare them with their **rights**. In particular, the most important international reference is the UNCRPD (Deepak, 2012).
- The last important aspect is the **dissemination strategy.** It is particularly important to promote this kind of approach through the communication with institutions and organizations[3] which

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[3] As specified by Deepak, an Indian doctor that have been working for 30 years alongside AIFO which

can actually change policies and improve the daily life of the participants. The sensitization of the institutions and the public opinion on the conditions of marginalization is useful to gain support in the accomplishment of solutions that promote and protect human rights. Share the emancipatory experience and communicate the value of the participatory approaches is then crucial to establish new sustainable and inclusive pathways.

The issue of the Emancipatory Research then is not how to empower people but which research can people conduct in order to facilitate the process of self-empowerment (Oliver, 1992). The researchers have then to put their knowledge at the disposal of their research subjects, allowing them to use it in whatever way they choose. This shift in the social relations of the research production place the control in the hands of the researched, not the researchers (Oliver, 1997).

After this brief introduction to the essential features of the Emancipatory Research, we can now focus on the different stages of implementation that characterize this methodology.

The main steps for planning and implementing an Emancipatory Research

"Research" is a systematic way of studying, analysing and understanding an issue in order to gain new information and knowledge (Deepak, 2011). Emancipatory research is a form of applied research, which is controlled and implemented by people in a condition of social, political and economical marginality. The aim is to promote awareness among the participants on the conditions and the barriers they have to face at the different levels, elaborating sustainable and suitable solutions to overcome their hardship. Most often, this kind of research targets as participants people with disabilities.

In the Emancipatory Methodology (for example, women with disabilities in our case) members of the research subject participate as researchers in the process. As already specified, they have to work in partnership with senior experts researchers in order to be supported in general and more specifically iiin case of scientific support's need (building tools for the analysis, complex statistical elaborations, …).

There different steps are required to plan and carry out an Emancipatory Research process (Deepak 2012). The main ones are listed as follow, but they do not necessarily need to be implemented in this order:

- A pre-condition for the Emancipatory Research is the full understanding by expert researchers of their supporting role i.e. limiting their ego. Other qualities required to the expert researchers are (i) high degree of knowledge of the issues and of the processes, (ii) awareness of potential asymmetries of power in co-creating and training the research subjects and (ii) understanding the trade-off between the desire to reach results and the complexity of the research.
- Identification of possible topics for the Emancipatory Research and elaboration of a research plan
- This first step represents the preparation of the research ground. The emancipatory research can represent a valuable transformative process (Deepak, 2012) for the participants, their families and the communities. When a research centre decide to experience this methodology, the expert researchers need the strong support and advice of the counterpart that will implement the research. It is also possible the case in which a marginalized group ask for the scientific support in order to analyse a specific issue through an inclusive methodology. Therefore, after the identification of the topic and of the subject, it is necessary a first draft of the research protocol that has to be jointly elaborated.
- Identification of the group that can conduct the research
- Not all the stakeholders which take part of the process are involved in the research process in the same way. Usually, a smaller group of persons has a more regular and deeper involvement in the research. Among the group, it may be easier for the group to self-select a couple of people with a constructive attitude and leadership skills to guide the whole process. It is

is the main Italian NGOs working on disability, if the Emancipatory Research is based on people with disabilities it is crucial to include in the process and in the dissemination strategy also the main SHGs (Self-Help Groups) and DPOs (Disabled People's Organizations) that work on the considered research matters (Deepak, 2012).

anyway important to consider that all the member of the group have the right to participate and express their opinion in order to structure and implement the different activities with an authentic inclusive method. A core group with the leadership role will be responsible of the organization of the meetings and trainings and will supervise the whole process.

- Identify the external scientific support
- The conduction of the Emancipatory Research requires skills from different disciplines, such as statistics, sociology and anthropology. If the research intention comes from a group of marginalized people without professional research expertise, the monitoring process has to develop through the scientific support of the expert knowledge from a research group that can be local, national or international.
- Organizing trainings for the people that will conduct the research
- One of the main activity of the whole process is represented by the trainings of the research subjects that become the implementers of the research. The participants, in fact, need to acquire general skills on how to work in a group, how to resolve conflicts and problems and on how to work with people in vulnerable conditions when conducting the Emancipatory Research. They also need to learn some technical skills on the research methods and on the specific tools that will be elaborated and used during the implementation.
- The training sessions will be leaded by the experts who need to facilitate the learning process through the use of images, graphic schemes and including other participatory methods.
- Identify the supporting mechanism for the Emancipatory Research Implementers
- In the specific case of an Emancipatory Research conducted with a group of people with disabilities, it might be necessary to provide specific adjustments to the tools and the process in order to allow full accessibility to all the activities implemented. For example, for people with visual impairments it will be crucial the availability of large size printout of documents and braille documents and the help of a sign language interpreter (Deepak, 2012).
- Decide the research questions
- Usually, the research questions of an Emancipatory Research are focused on barriers and discrimination: for the participant it is useful and interesting to work and reflect on the main factors of marginalization in order to elaborate solutions for an improvement of their daily life. The research questions should be focused then on social stigma, lack of access in the labour market, isolation, abuse, influence of the family, lack of services etc… The research topic and questions are chosen through group discussions where every participants can freely express his point of view and his experience. The different inputs coming from the discussion and then usually organized in term of importance and feasibility for the research or through the construction of problem trees.
- Choose the methods to conduct the research
- The Emancipatory Research is usually seen as qualitative research. As can be noticed in our project, a combination of qualitative and quantitative methods may be possible in order to have a deeper comprehension of the chosen topic. Quantitative research deals mainly with numbers and percentages while the qualitative approach is used to understand the reasons and the extent of a problem and causal links.
- Involving communities in the research
- The key aim of the Emancipatory Research is to involve and sensitise a larger group of people. It is crucial to involve in different stages of the process the community, the institutions and different organizations dealing with the research subject.
- Analyse the research results
- The Emancipatory process requires different levels of analysis of the results. The information collected must be analysed in ways that allow the research participants to improve their understanding on the experience: this is the most important way to promote the empowerment in the Emancipatory Research. The process of data analysis is usually conducted by the research experts or by trained participants. It is extremely important to bring the key findings back to the participants and to the communities: some of the results might be difficult to understand so it is important to share the results with a simple and clear language.
- Disseminate the research results
- It is important to include in the research protocol the dissemination activity and strategy. The

relevant stakeholder with who is important to share the research result and process are: the local communities, local and national associations, local and national authorities, national and international NGOs and specialized institutions dealing with the research topic (Deepak, 2012). A communication plan is needed to identify the best ways to reach and inform all these stakeholders and to adapt the research information for each target. Equally important is to share the research experience and results with the scientific community through articles and reports in scientific journals.

As previously mentioned, the Emancipatory approach is particularly suitable for the research in the field of disability: in the next sections the analysis concentrates on the applications of the Emancipatory method to Disability Research, with particular attention to the UNCRPD and the awareness-raising process related to human rights.

Emancipatory Methodologies in Disability Research

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UNCRPD, Human Rights and the biopsychosocial model of disability

The conventional debate on human rights usually focuses on political rights in the restricted sense, while there is also a need to recognize the importance of human rights in relation to the main public and private institutions and systems that exercise control over people's live in an undemocratic way. Research institutions and Universities represent such bodies and, as we already mentioned, the scientific knowledge they produce have a strong influence in the cultural development and in the social, economic and political policies in the society (Lynch, 1999). The Emancipatory Research then recognizes the moral right of the research subjects to lead the control and exercise the ownership over the knowledge produced about them. It is a human right issue and it constitutes the right of a democratic political membership in the community. People have the moral right to participate in the process that generate knowledge about them. The slogan *"Nothing about us without us!"* refers exactly to this concept: it has been used by Disabled Peoples Organizations, as part of the global movement, to obtain full participation and equal opportunities for, by and with persons with disabilities. The active involvement of persons with disabilities in the elaboration of the first United Nation Convention on the Rights of Persons with Disabilities (UNCRPD) was one of the most powerful example of how to put in practice the right of full participation in order to contribute to the development of inclusive societies.

As previously observed, the Emancipatory Research method has been often applied in the Disability Research, with the aim of empowerment and inclusion of people with disabilities (PwD). In this framework, the CRPD represents the theoretical basis for the right of participation of PwD: the convention is part of the International law of the United Nations and it has been elaborated in 2006 through a participatory process. The convention represents the basis for all the interventions of Participatory and Emancipatory Research in the field of disability. As clarified in the Article 1, in fact, *"The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."* (UNCRPD, 2006).

In the Article 3 of the Convention, there is a list of the main general principles which can be summarized as follows:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- Non-discrimination;
- Full and effective participation and inclusion in society;
- Respect for difference and acceptance of disability as part of human diversity and humanity;
- Equality of opportunity;
- Accessibility;
- Equality between men and women (UNCRPD, 2006).

As we can notice, the principles of the Convention correspond to the basic assumptions of the emancipatory approach. Moreover, the principle of equal rights implicates that *"each person and of all individuals are of equal importance, that these needs must become the foundation for the planning of society and that all the resources are committed in such a way to assure that each* *individual has the same opportunity to take part"* (UNCRPD, 2006). The Convention represents then the fundamental international framework for the Participatory and the Emancipatory Disability Research.

- Another important aspect to highlight is that the CRPD refers to disability using the Biopsychosocial model. In contrast with the medical model that considers persons with disabilities as sick, unable and invalid, the Biopsychosocial model is based on the respect of the human rights: elaborated by the psychiatrist G. Engel at the end of the 1970s, this model considers disability through the biological, psychological and social dimensions, offering a holistic approach based on the socially constructed barriers. (Borrell-Carrió, F., Suchman, A. L., & Epstein, R. M., 2004). In line with this model, in the preamble of the Convention, in fact, disability is defined as the *"results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others"* (UNCRPD, 2006). The Biopsychosocial model is considered *"the ontological and epistemological basis for the research production"* (Priestley, 1997 : 91), and it is the theoretical background for the emancipatory approach in this field.

Moreover, in the light of the above-mentioned definition of disability, the Article 33 of the Convention includes national and international monitoring mechanisms that have to be preferably conducted by people with disabilities. The features of the Emancipatory Research perfectly fit in the monitoring system of the CRPD, being a political instrument that give voice and make persons with disabilities protagonists of their own rights protection.

The Biopsychosocial model when encounters the emancipatory research is very much in line with the capability approach and the central role of the values and aspirations of people and their active participation as agents of change.

Disability Research and the Emancipatory paradigm for social transformation

Disability Studies is a relatively new and rapidly expanding field that offers radical challenges to conventional thinking about the traditional research approaches. In 1992, a British researcher and disability activist, Mike Oliver, coined the term "*emancipatory disability research*" to refer to a radical new approach to research in the disability field (Oliver, 1992). Since then a big debate started about whether such an approach is a "*realistic goal*" or an "*impossible dream*" (Oliver, 1997).

Many factors exclude people with disabilities from the decision-making process related to the policies that affect the quality of their life: this contributes and exacerbates the oppression and the discrimination against them. As we already mentioned, in the last three decades the debate on the role of research has widened and the dominant research traditions have been criticized in the attempt to produce a shift in the nature and the purpose of the research toward a stronger inclusion and empowerment of people with disabilities.

As specified by Barton, "*Research is a social act.*" (Barton, 2005 : 317) and, as such, it involves the interaction among a range of individuals and groups with consequent ethical, procedural and political issues. When it comes to social justice, equity and citizenship, the knowledge production cannot be viewed as neutral, and in the struggle for the inclusion the Academia has to deal with material and ideological barriers that impair a full participation of people with disabilities.

The value of Participatory and Emancipatory Disability Research is the transformative and informative contribution for the collective understanding of the ways in which disability is socially produced (Oliver, 1997). In these research methods, persons with disabilities are empowered using the expertise of professional researchers towards this end.

As already noted, the Emancipatory Research is applicable to researches working with all form of marginalized and oppressed groups, but it particularly developed in the 1990s in the field of disability research. Encouraging a shift in the purposes, the process and the outcomes of the activities, this method changes the social relations of research production toward a more enabling and emancipatory knowledge production on disability (Barton, 2005).Persons with disabilities, which have historically been excluded and oppressed from the dominant culture, are then empowered and encouraged to self-reflection and exploration to the informal and taken-for-granted elements of their context and living conditions. This realization of a dignified relationship for all the research participants is not only a methodological issue but it requires fundamental changes in the way the research is planned, implemented and disseminated. For example, the dissemination of the research findings has to be in accessible formats for PwDs.

As observed by Barnes, the most important characteristics of the emancipatory disability research are "*the problems of accountability, the role of the social model of disability, the choice of methods, and empowerment, dissemination and outcomes*." (Barnes, 2003 : 3). In this approach, researchers put their knowledge and know-how at the disposal of persons with disabilities and their organisations through non-hierarchical activities of data collection, analysis and dissemination that weaken the disabling power-relations of the traditional approaches. People with disabilities who follow the Biopsychosocial model consider the right to be involved in disability research as crucial in order to enhance the quality of the research outcomes (Mercer, 2004). The mainstream social research might be considered a failure for persons with disabilities, since it is mainly irrelevant to their actual needs and it does not significantly improve their living conditions and material quality of life (Oliver, 1992).

Applying the slogan "*Nothing about us without us*" to the research is a challenging task but the development of an inclusive research culture, in which researchers with and without disabilities can share expertise and cooperate, is essential in the construction of a more accurate knowledge production and a more respectful society. The "*emancipation*" as research outcomes can be measured in different ways, since the self-empowerment of persons with disabilities might develop in several forms: from the documentation of the social barriers and the condition of oppression, to the achievement of a new perception of disability. Those emancipatory effects can only be judged in a long term perspective after the research conduction and in a separate manner from the specific research outcomes (Oliver, 1997). The strongest become the political process of collective empowerment, the more it become unacceptable for people with disabilities and other oppressed groups to tolerate investigatory methods based upon exclusionary relations of research production. The ultimate finality of Emancipatory Research then, should not be mere inclusion but rather a radical societal change toward disability and marginalization to achieve the democratic goals of equality and justice.

Chapter 1 - The process[4]

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Emancipatory research is a bottom-up practice, which stimulates a progressive increase of the engagement and of the involvement of research subjects in the different steps of research processes. When the research questions are focused on marginalization and marginalized groups, this approach establishes a mechanism whereby the marginalized pockets of the society are encouraged to take active part in the research activities, sharing with professional researchers their opinions and experiences and gaining the ownership of the whole research process. In the emancipatory approach, through the acquirement of skills and expertise in research conduction, the research subjects lead all the research activities, from the elaboration of the research strategy to the dissemination of the results: professional researchers become only a scientific facilitator and this shift of power relations is determinant for the individuals in order to actively become part of the knowledge production processes and to increase their influence at the decision-making level.

As mentioned, the research process we are analysing is aimed at analysing the marginalization faced by women with disabilities in the West Bank. This first chapter will describe the different steps of the process which have been conducted by the women with disabilities from Beit Sahour, Nablus and Ramallah, along with the technical support of ARCO Lab and the logistical assistance of EducAid and three local DPOs. The analysis will start with the description of the involved actors and the theoretical framework of the Emancipatory Research applied on the target of people with disability. After a general description of the implemented activities, the focus will move on the different profiles of the participants who are in charge of the research implementation. Afterwards, we will analyse the preliminary activities, the research protocols and the problem trees for the three different groups.

1.1- Framework of the emancipatory research project in the West Bank

1.1.1 - Brief description of the involved actors

As already mentioned in the introduction, the analysed case study deals with an emancipatory research (ER) process linked to the project Partip-Action, co-funded by the Italian ministry of Foreign Affairs and International Cooperation (MAECI) and implemented by the Italian NGO EducAid in partnership with RIDS (Italian Network on Disability and Development). The project has been implemented in the West Bank, specifically in the municipalities of Beit Sahour, Ramallah and Nablus. The emancipatory research has been assisted and facilitated by scientific support of ARCO, a research lab of the University of Florence. In particular, ARCO provided the support of one trainer that has been involved in four field missions, with the aim of facilitating the implementation of the whole emancipatory research process.

The process saw the involvement of three groups of women: in Beit Sahour and Ramallah the groups were mainly composed by women with disabilities, while the group in Nablus was chiefly constituted by mothers and sisters of persons with disabilities and by workers and volunteers of

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[4] This chapter has been co-authored by Irene Pasqua, research assistant at ARCO

the local CBR (Community Based Rehabilitation) programs. Around twenty women composed each group.

The partners of the project were three DPOs (Disabled People Organisation) based in the three municipalities targeted by the project: the involved organisations are GUPWD (local branch of Beit Sahour), Stars of Hope (in Ramallah) and Aswat (in Nablus).

During the first field mission of ARCO researchers, a reference researcher and a rapporteur were identified in each group: the selected women played the crucial role of facilitate and make smoother the implementation of the whole ER process. The main researcher, in fact, was expected to favour the linkage among the various stakeholders involved in the emancipatory research process and to organise the logistic of the research activities, while the rapporteur was expected to draft the monitoring reports and the minutes of the main relevant research activities.

1.1.2 - Theoretical framework: UNCRPD and capability approach

The main theoretical references of this emancipatory research are the United Nations Conventions on the Rights of Persons with Disabilities (UNCRPD) and the Capability Approach (CA) elaborated by the Nobel prize Amartya Sen.

As mentioned in the introduction, when emancipatory research deals with disability, it is essential to refer to the UNCRPD as philosophical and political background. The UN Convention provides a new biopsychosocial approach to disability based on the concept of respect of the human rights. In particular, it promotes the full and effective participation in society of every person with or without disability on an equal basis: the physical, mental, intellectual or sensory impairments should not represent an obstacle to the inclusive and participatory development of the countries. Therefore, the involvement of persons with disabilities (persons with disabilities) in emancipatory research processes is perfec tly coherent with the approach of the UNCRPD: the participation in ER can be conceived as a path of empowerment and ownership of development processes that allows the participants to acquire skills and to increase awareness and self-confidence. Moreover, this kind of methodology enables persons with disabilities themselves to monitor, in an independent and rigorous way, how and to what extent their human rights are respected: as already highlighted, people with disabilities represent one of the most vulnerable group at risk and, especially when it comes to development countries, they are heavily exposed to dynamics of social and economical marginalization.

The second theoretical source of reference for the form and content of this project has been the Capability approach developed by Sen. As we have already specified, in Sen's approach the individual's wellbeing is not valued with the material ownings and incomes, but with the extension of the individual capability space (what a person potentially could be or do). This extension, as already mentioned in the introduction, depends on individual resources and on the ability to convert these resources into achieved functionings: the conversion factors include the personal characteristics as well as community and environmental factors as well as their values and aspirations.

Like the emancipatory research, the CA put the person, her context and her right of choice at the centre of the analysis. From a practical point of view, moreover, the CA identifies the enlargement of the individual space of freedom and the flourishing of the person with her desires, beliefs and preferences as the main aim that should be pursued by a society (Nussbaum, 2000).

The idea of applying the Capability Approach to the field of disabilities is suggested by Sen himself: *"CA provides broader insights into the issues related to disability since it proposes to look not only at what a person actually does (his/her functionings), but also at the range of possibilities from which he/she can chooses that specific functionings."* (Sen, 1999).

This perspective asserts that disability can be considered as a condition that causes new vulnerabilities and that restricts the individual capability set, influencing the main conversion factors. Such condition requires then the development of new abilities, exploiting the residual capacity in a different way (Biggeri and Bellanca, 2010). In this theoretical framework, the emancipatory research approach finds its natural application.

1.2 - Overall picture of the emancipatory research project

1.2.1 - General description of the implemented activities

The main aim of the project is to increase the awareness of the women involved in the Emancipatory Research (ER) process for what concerns disability, the UNCRPD, participation and emancipatory methods.

The project started in August 2015, with the first mission in the West Bank of ARCO researcher, who spent 3 weeks in the field to organize the first steps of the work with the support of EducAid and the local partners. The bulk of time available during the mission was used to implement three training sessions in Beit Sahour, Ramallah and Nablus. Each training session was articulated on different preliminary activities in order to start the co-elaboration of the three research protocols containing one main research question, a structured methodology, a plan of activities and a list of deliverables.

Moreover a plenary assembly, that saw the involvement of all the three groups, was organised in Ramallah in order to let the women become familiar with the above cited concepts and to perceive themselves as an integrated group with a common goal.

During the first mission, the following activities have been implemented in order to reach a joint draft of the different research protocols:

1) Collective discussion about the dimensions of wellbeing: the main aim of this activity was to push participants to think about the complexity of the concept of wellbeing, composed by a variety of "*ingredients*" needed to have a good life. In Beit Sahour and Ramallah the participants have been asked to rate the dimensions of wellbeing to identify the most important ones;
2) Collective discussion about the barriers experienced by women with disabilities in their daily life: the activity was conceived with the aim of reflecting on factors that prevent persons (and in particular women) with disabilities from enjoying a fair level of wellbeing;
3) Collective participatory exercise based on the "*perceived counterfactual*": this activity was projected to push participants to discuss about abstract situations, to favour a partial detachment from their personal condition and a transition toward a "*research oriented*" aptitude;
4) Clarification of the role that will be played by the rapporteurs and by the reference researchers;
5) Frontal lessons to introduce basic elements of epistemology and a set of methodological tools;
6) Interactive session to let the women familiarize with the introduced methodological tools;
7) Collective drafting of a problem tree: the reorganisation of the identified barriers in a map of problems is finalised at reflecting about the connections among the limitations by mapping the anatomy of cause and effect around the different issues. Through this analysis, the participants pass from the identification of a list of problems to the design of a structure of processes leading to the exclusion of Women with disabilities in Palestine
8) Collective identification of the research question starting from problem tree prepared during the previous activity
9) Collective drafting of the research methodology that has been used to answer the research question
10) Collective drafting of the plan of activities and of the plan of deliverables.

From the month of September, an intensive work started among the three groups: each of them, with the remote scientific support of ARCO, began the first elaboration of the research tools though group discussions and collective brainstorming sessions. Particular attention has been played by the identification of the suitable indicators: the main concepts and dimensions identified in the well-being analysis and in the problem tree elaboration had to be translated and converted into measurable indicators, both from a qualitative to a quantitative point of view.

As it will be detailed in the next chapters, the three groups decided to differentiate the research tools. The group of Beit Sahour and Nablus chose to conduct a quantitative survey with the use of questionnaires, while the women from Ramallah agreed on a qualitative inquiry through the

employment of a focus group discussion and various life course interviews.
The second mission of ARCO researchers (January 2016) has been crucial for the finalization of all the research tools and for the setting of the data collection activities. In particular, the first discussions concerned the questions to add, drop or change in the different tools and, for Beit Sahour and Nablus groups, functional explanations and an interactive session have been dedicated to the accurate data entry compilation. Moreover, the groups have been expected to increase their awareness about the overall process of emancipatory research, from the already carried out preliminary steps to the activities of the data analysis and dissemination of the results.
During the mission the process of co-creation of the research tools saw a parallel activity of practical trainings for the participants about the use of the research tools: as previously highlighted, in the emancipatory processes, members of the research target are playing the active role of co-researchers, acquiring specific technical skills and gaining the ownership of the whole process.
The conclusive outputs of the second mission have been the final versions of the following tools:

- The questionnaire for the survey in Beit Sahour
- The manual for interviewers in Beit Sahour
- The questionnaire for the survey in Nablus
- The manual for interviewers in Nablus
- The topic guide for life course interviews for Ramallah
- The topic guide for teachers interviews for Ramallah
- The guide for Focus Group discussion for Ramallah

Starting from February 2016 then, the three groups dedicated their attention to the first interviews trials, experimenting the elaborated tools and putting into practice the acquired skills: at this stage of the process, regular meetings were useful to share the feedbacks from the operative experiences as a peer learning activity to strengthen the field work implementation. During this phase, special care has been dedicated to the finalization of the translation process from English to Arabic. A special mention must be made of the efforts of one of the blind women from Ramallah who spontaneously decided to translate all the tools used by her group in the Braille system.

From the month of April, the three groups started the field work implementation and the data collection procedure: these activities continued until the month of August, when ARCO conclusive mission took place with the aim of supporting the data analysis process and of the results dissemination. During the last mission, in particular, the researcher from ARCO organized three final group discussions in order to evaluate the whole data collection process with the feedbacks from the researchers. During these three sessions, the different groups presented and analysed the preliminary results of the research activities and jointly discussed about the elaboration of the most suitable strategy for the results dissemination. These final meetings have been crucial for the exit of the project since the held discussions leaded to the elaboration of insightful interpretations of the results thanks to the direct participation of trained persons with disabilities and care givers. Their direct life experience and their empathy with the interviewees, combined with the skills acquired during the previous training sessions (September 2015 and January 2016), proved to be extremely effective in the data collection and in the elaboration of the research results.

1.2.2 - Portrait of the participants' profiles

The whole project saw the participation of 50 women with and without disabilities, organised in three different groups: Beit Sahour, Ramallah and Nablus. Among the participants, 76% are women with disabilities, characterized by different kind of impairments (mobility, visual, sensorial, cognitive, psycho-social). About 10% are care givers of a person with disabilities coming from the family background (parents or relatives). The remaining (around 14%) is made up by CBR workers and volunteers (mainly from the Nablus group).

Table 1.1 Participants' district of residence

District	(%)
Alshoyok	2.22
Beit Fajar	4.44
Beit Omar	4.44
Beit Sahur	2.22
Beit Taman	2.22
Burqa	4.44
Daer Samet	2.22
Deir-Sharaf	2.22
Dora	4.44
Hebron	11.11
Howarah	4.44
Ithna	2.22
Karas	2.22
Nablus	20
Ramallah	15.56
Salfeet	6.66
Tfon	2.22
Zatara	6.67

Source: ARCO, 2015.

The three groups members are coming from 18 districts of the West Bank (as shown in the **table 1.1**) and the majority of them lives in rural areas (66.67%). Most part of the women are member of a DPO (82.98%) and, through the association partner of the project, they have been selected and assigned to 3 groups:

- The group of Beit Sahour, composed by 19 women with mobility, hearing and visual impairments (coordinated by the DPO GUDP),
- The group of Nablus, mainly composed by parents or relatives of people with disabilities and persons with cognitive and psycho-social disabilities (coordinated by the DPO Aswat),
- The group of Ramallah, composed by 16 members with mobility and visual impairments (5 women with disabilities, 6 mothers of children with disabilities, 4 volunteers or CBR workers. This group is coordinated by the DPO Stars of Hope).
- This division is shown by the table 1.2.

Table 1.2 Status of the ER participants

Group	Status (%)		
	PwD	Relative_of_PwDs	Other
Beit Sahour	100	0.00	0.00
Nablus	33.33	40.00	26.67
Ramallah	87.5	6.25	6.25

Source: ARCO, 2015.

Not surprisingly, the women participating to the groups of Beit Sahour (who are on average 27 years old) and Ramallah (28 years old) are younger than the women from Nablus (39 years old). The family background of the participants is heterogeneous: about 20% of them are married, 4% are divorced and 2% widow. The remaining 74% are single. The percentage of unmarried among women with disabilities is 84%.

The **table 1.3** reports the level of education among the participants. It is interesting to notice that the level of education is higher for women with disabilities than for other women, as clearly emerges by comparing the data from Nablus to the data from Beit Sahour and Ramallah.

Table 1.3 Education level of the ER participants

Group	Education (%)			
	No education	Intermediate School	High School	University
Beit Sahour	0	5.26	21.05	71.68
Nablus	6.67	13.33	26.67	53.33
Ramallah	6.25	0.00	31.25	62.5
Total	4.00	6.00	26.00	64.00

Source: ARCO, 2015.

As we can easily notice, the percentage of women holding a university degree among the participants is really high in all the three groups: it is worth to stress the fact that, according to the Palestinian Disability Census, only 5.3% of persons with disabilities holds a university degree (PCBS, 2011). Basically, the group of women who participated to the ER, per se, is not representative of the average condition of women with disabilities in Palestine.

Nevertheless, even in this selected target, the level of English language and computer skills is pretty low. Moreover, only few women have a deep awareness of human rights and social protection: in particular, not even 10% of the whole body of participants has an appropriate acquaintance with the UNCRPD, as shown in the **table 1.4**.

Table 1.4 Skills of the ER participants

Level	Knowledge CRPD (%)	Spoken English (%)	Written English (%)	Computer skills (%)
Poor	35.71	42.86	38.78	18.36
Fair	26.19	24.49	24.49	4.08
Average	28.57	20.41	18.37	28.57
Good	4.76	10.2	12.24	22.45
Excellent	4.76	2.04	6.12	26.53

Source: ARCO, 2015.

For the purpose of the ER process and considering the three groups together, it is also interesting to highlight that 23.81% of the participants have already had a previous experience in participatory research, while only 4.35% (exclusively from the group of Beit Sahour) had already been involved in an emancipatory research project. The percentages related to the three groups are:

Table 1.5 Previous experience in research of the participants

Group	Experience Emancipatory (%)		Experience Participatory (%)	
	Yes	No	Yes	No
Beit Sahour	11.11	88.89	22.22	77.78
Nablus	0	100	35.71	64.29
Ramallah	0	100	10	90

Source: ARCO, 2015.

With this overall portrait of the participants' profiles, we can now move to the research protocols analysis: the next paragraphs, in fact, will report in details the emancipatory research plan and the implemented activities of the three groups.

1.3 - Description of the preliminary research steps

1.3.1 - Description of the preliminary activities

During the first mission (August 2015), the three groups had to co-design the whole research plan: in order to decide the main research questions and to draft the protocols, four preliminary activities have been implemented, as listed:

1. Interactive discussion on the Dimensions of wellbeing
2. Barriers identification
3. Structured focus group with Matrix Score (Only for Beit Sahour and Ramallah)
4. Parti-numbers exercises (Only for Nablus)

These exercises drove to the problem tree elaboration, where the different dimensions analysed have been connected through cause-effect relations that facilitate the emersion of the research questions.

Before the examination of the research protocols, this paragraph will analyse the major results of the participatory methodology used in the mentioned preliminary activities.

It is important to highlight that the different composition of the group of Nablus pushed toward a global re-orientation of the activities: the centre of the Nabuls discussion, in fact, shifted from women with disabilitiess to care givers.

1. Interactive discussion on the Dimensions of wellbeing

During this first activity, the participants of the three groups were asked to indicate and freely discuss the dimensions of wellbeing, which they considered relevant to enjoy a good life. In a second step, each participant was asked to indicate the three most important dimensions. The votes were then aggregated to build a rank of wellbeing dimensions.

The outcomes of this participatory exercise for the three groups are summarize in the following tables.

Table 1.6 Dimension of wellbeing identified in Beit Sahour

DIMENSION	**COMMENTS**
To be able to participate and cooperate	Some participants highlighted how good is to help others to raise their awareness
To have job opportunities	The participants highlighted the need of a “suitable” job: a job that respects one’s preferences, values and skills in coherence with one’s education
To see one’s rights respected	Also in terms of dignified life
To enjoy stability in all aspects of life	
To have good relations within the family	Participants said that this means to receive support while their freedom of choice is preserved. Participants talked about the opportunity to fully participate to the social and economic life of the family
To have opportunity of mobility	In particular to have a personal car. Other participants cited the concept of accessibility of the environment: the opportunity to travel abroad has also been mentioned.
To have opportunity of leisure	Leisure in terms of social relations. Some participants cited also the opportunity to buy “useless” things (nice clothes, make up). Another participant highlighted how nice could be to get back to childhood and fly.
To have access to appropriate education	The participants underlined the issue of the quality of the education
To receive flowers	
To get married and have a family	According to some participants this is a dimension that is often neglected by women with disabilities as they believe that is impossible for them to get married and have their family. So they prefer to talk about other issues (such as job).
To have freedom of choice	As self-determination: to choose school, job, whether to go out or not etc…
To have access to health care and rehabilitation	
To have experience of the diversity existing in the world	To meet other cultures and traditions. One of the participants said “stability kills life”
To have access to information	
To be safe	
To belong to something	

To communicate with others	Cited in particular by persons with hearing impairment. They underlined that to find ways to communicate is possible if good methods are provided
To practice art and sport	In particular, participants mentioned acting as a way to express oneself and talk about one's problem

Source: ARCO, 2015.

During this activity, the group of Beit Sahour concentrated special attention to the work dimension and to the labour market issues. As shown in the table, one of the most interesting reflexion that came out from the focus group concerns the chance, for women with disabilities, to build a family from their own: strong agreement, in fact, emerged on the fact that generally women with disabilities are convinced that they have no chance to get married and have children, so they often don't even consider this dimension as a possible element of their wellbeing.

Table 1.7 Dimensions of wellbeing identified in Ramallah

DIMENSION	COMMENTS
To have access to sufficient income	Material wellbeing was explicitly seen as instrumental to achieve wellbeing in other dimensions
To have access to appropriate education	The concept of appropriateness of education was seen as (i) ability to provide skills that can be used on the job market, (ii) ability to provide accessibility and respect of dignity
To have access to suitable job	The job was defined "suitable" if (i) it is able to valorise one's qualities and potentialities and (ii) is based on non-discrimination and respect of rights. To have a job was seen as a form of freedom as it is a good justification to go out from home without having to answer to too much question from other family members
To enjoy good food and coffee	It was basically the conviviality
To enjoy good health	Both physical and mental
To be stable	All the participants saw stability as a very relevant dimension of well-being. Stability was seen as a prerequisite to imagine themselves in the future, to elaborate a project of life and to improve their own lives
To have opportunities to face challenges	It meant not to have a boring life and the be able to be ambitious
To be free	Basically was seen in the light of the relations within the family and the occupation
To have rest and leisure	
To be able to elaborate a positive view	To have a positive attitude toward life was seen as a prerequisite for personal development in all fields of life

To love and be loved	Also in relation to males
To be in contact with nature	This was a dimension severely hit by the occupation (lack of space and of mobility)
To have the opportunity to cooperate	To be able to do things with the others
Reconciliation with oneself	
To be able to communicate	It meant to have a real exchange with other persons
Self-satisfaction	While discussing this point it emerged that self-satisfaction is given by a combination of self-esteem and self-confidence. In other words this was not seen as an achieved result but also as a potentiality

Source: ARCO, 2015.

In the group of Ramallah, particular attention has been focused on the concepts of "*appropriate education*" and "*suitable job*": both the definitions are linked to the respect of the person's dignity and attitudes (as suggested also in the capability approach of Amartya Sen). Another important focus emerged in this group concerns the emotional aspects of the individuals: most part of the discussion has been dedicated to the dimensions of love, self-satisfaction, freedom and self-reconciliation.

Table 1.8 Dimensions of wellbeing identified in Nablus

DIMENSION	COMMENTS
To be safe	It includes both safety of public places and at home. The women stressed the presence violence inside and outside the home. Also the Israeli occupation contribute to decrease the safety
To be healthy	Including access to health services. Both physical and mental health
To enjoy stability	It included stability on work and stability from the consequences of the military occupation. The occupation makes everything difficult to plan. It is particularly important the stability of the family.
To be free	
To preserve dignity	
To have good relations with other family members	Including both nuclear and extended family
To have good relations with friends	
To have access to education	
To see one's rights respected	It is due also to an effective enforcement of existing laws and international conventions (such as UNCRPD)

Satisfaction of basic needs	It was conceived as a pre-requisite to enjoy the other dimensions of well-being: it is not possible for example to have good relations if you are pressed by the satisfaction of basic needs
To have access to economic resources	
To have access to job	To have a job and to be productive is a way to be respected within the society
To have access to culture	It starts within the family
To have access to leisure	The participants stressed the lack of public spaces where it is relaxing and nice to stay
To feel the emotion of victory	Both as concern personal challenges and the collective situation of Palestinians
To be empowered	It meant to have self-confidence and acceptance of their children with disabilities. It meant to be able to take decision and to see them respected.
Access to good food	To have enough resources and time to have healthy food of good quality
Access to technology	
Good governance	It is seen as collective public goods. It is a sort of catalyser of other dimension of well-being
To live in a peaceful environment	
To enjoy contact with nature	It is stressed the link with agriculture and with healthy food. It is not a matter of leisure but a matter of roots. It is important for mental equilibrium
To have access to information	
To live in an accessible environment	

Source: ARCO, 2015.

The women from Nablus focused their discussion mainly on the family aspects, identifying many dimensions that deal with the wellbeing at home: good relation with family members, safety, accessibility and a peaceful environment have been some of the most important feature of their idea of good life. As already mentioned, the group of Nablus is composed by caregivers (mothers, sisters or relative of a person with disability) so the attention of the group for home stability is not surprising.

2. Identification of barriers

In this activity, the participants were asked to indicate and freely discuss the barriers that prevent them and the other women with disabilities or caregivers to fully participate to the society. These barriers have been used as starting point to elaborate the problem trees of the three groups.

Table 1.9 Barriers identified in Beit Sahour

BARRIER	COMMENT
Lack of accessibility	In particular physical accessibility of the environment
Lack of resources from public institutions	
Lack of integrated services from organisations	
Lack of implementation of laws to protect PWD's right (e.g. job placement)	In particular associations etc. do not imply PWDs
Lack of job opportunity	
Not sufficient access	Teachers has no specific training to include students with disabilities. Participants underlined that lack of access to education modify negatively all the development of one's life
Lack of access to technology and other devices that can favour autonomy and participation	
To live in a male dominated society	Women with disabilities have to face two different level of discrimination: as persons with disabilities and as women. Gender is particularly a disabling factor in the access to work
Lack of social connections	"Wasta" (Arabic term that means "interpersonal connections, clientelism") is extremely useful to find a job. Families of persons with disabilities have a weaker social network
Active social stigma	Persons who talk about you in a paternalistic or offensive way
Passive social stigma	Implicit lack of confidence in PWDs abilities. Fear.
Israeli occupation	The participant were polarised on two main positions. Someone said that occupation is not good but that PWD should blame the Palestinian much more than the Israeli government for their problems. Other said that the occupation is one of the main causes of many problems. For example, the lack of mobility is due also to the occupation and that the lack of mobility causes other problems such as the weakening of social networks. All these problems hit more than proportionally PWDs.
Wrong behaviour of the family	Overprotection and reduction of the freedom of choice of persons with disabilities and of women in particular.

Source: ARCO, 2015.

In the barriers identification, the women from Beit Sahour highlighted in particular the problems linked to stigma and discrimination. These social dynamics, due to the perception of disability and to gender inequalities, influence all the aspects of life: the access to the labour market, the quality of education, relations and social inclusion and even the family members' behaviour.

Table 1.10 Barriers identified in Ramallah

BARRIER	COMMENT
Overprotection	It is something that prevent from the opportunity of fully participating to job and education. It is much stronger from men than from women
Lack of accessibility of public spaces	It affects particularly the opportunity of having social relations outside the family
Social stigma	It undermines the ability to feel worth of having a good life. Moreover, it creates pressure on WwDs as they need always to demonstrate more than the others.
Lack of self-acceptance	Often induced by social stigma and lack of acceptance within the family
Gender related discrimination	It is stronger for women with disabilities. It is hard to receive trust from the others
Culture	The vision of women and of women with disabilities as human beings who are less able to bear responsibilities etc. is hard to be demolished
Prejudice toward young people	"Often Palestinians seems to care more about age than about experience". This hit persons with disabilities more severely
Prejudice concerning beauty	Only "beautiful" persons have the opportunity of working in shops and restaurants
Access to work	In particular physical accessibility and lack of access to collateral services (e.g. transport). The impact of the barrier is different according to the kind of disability
Self-stigma	Self-stigma tends to induce fear of the exterior world and depression. In both cases the results is that the person avoid going out and do not discover which are the available opportunities

Source: ARCO, 2015.

Even the group of Ramallah pointed out a lot of reflections on prejudices and discrimination. Particularly interesting was the attention for the self-stigma and the lack of self-acceptance: often women with disabilities underestimate themselves and renounce to interaction, social activities and opportunities. Sometimes, this dynamic happens even among the family members, creating dangerous vicious cycles of overprotection and lack of inclusion.

It is relevant to notice that individual and social empowerment processes take time to occur and the need of self-esteem is an important step of this process. The fact that the ER is lasting for long time and "time-demanding" and request continuous interaction is central for the success of the ER itself.

Table 1.11 Barriers identified in Nablus

BARRIER	COMMENT
Role of the family	The problem of the family is often the lack of acceptance of the child with disabilities and the subsequent sense of guilt
Growing inequality	It is a problem as it tend to undermine the informal solidarity networks and social cohesion
Social problems	Tensions that risks to undermine the cohesion of the Palestinian society
Occupation	Basically, it affects each domain of life and reduce the ability to plan even the most simple activities of daily life.
Access to economic resources	The main problem here is the high level of overall unemployment and the high level of prices (compared to wages)
Unfair way of spending public resources	The participants show a huge level of scepticism toward the actual leading class both at the local and at the national level
Discrimination toward PwDs	It affects also the care givers that suffer because of the discrimination suffered by their children
Discrimination toward women	
Lack of social services	Deriving from the allocation of public resources and from the lack of sensitivity of policy makers
Lack of access to devices	

Source: ARCO, 2015.

The group of Nablus analysed the barriers from the caregivers' point of view: particular attention has been given to the lack of acceptance of the person with disability within the family members, and the consequent sense of guilt. A lot of importance has also been given to the political issues that affect the Palestinian society: inequalities, occupation, unemployment and unequal access to public resources and social services have been, for Nablus, the main topics of the discussion on the barriers that prevent a full and effective participation.

3. Structured focus group with Matrix Score

In this third exercise, as suggested by the methodology elaborated by Biggeri and Ferrannini (2014), the dimensions of wellbeing that received more votes in the first activity have been analysed in depth. In particular, the participants were asked to indicate the level of opportunity of four functional characters as concerns the enjoyment of the three dimension of wellbeing, which received the higher scores. The rate to indicate the level of opportunity of each character has been expressed "*per consensus*" after a discussion. The main objective of this exercise was to push the participants to put distance between their future role as researchers and their personal condition: that's why the exercise requires the evaluation of "*fictional characters*". In the following table it is possible to understand in detail the structure of the Matrix Score with the different sections and the different opportunities that have been voted by the participants from the group of Beit Sahour and Ramallah.

Table 1.12 Structured FGD with Matrix Score

Opportunity of..	**How much is important this wellbeing dimension (rate from 1 to 10)**	**Level of opportunity of MOHAMMED Man 18-20 years old Living in the West Bank Not yet married Middle class family No disability (rate from 1 to 10)**	**Level of opportunity of AMINA Woman 18-20 years old Living in the West Bank Not yet married Middle class family No disability (rate from 1 to 10)**	**Level of opportunity of SAMIRA Woman 18-20 years old Living in the West Bank Not yet married Middle class family Mobility impairment (rate from 1 to 10)**	**Level of opportunity of FATIMA Woman 18-20 years old Living in the West Bank Not yet married Middle class family Mental Illness (rate from 1 to 10)**
… being economically stable					
…having a suitable job					
… having appropriate education					
… having freedom of choice					

Source: ARCO, 2015.

With this exercise, the women from both the groups could reflect on how in practice the gender issue influences the various dimensions of wellbeing. Moreover, in the table it clearly emerges the difference in the dimensions, caused by the social stigma and the lack of opportunities, due to disability. It is also interesting to highlight how the perceived opportunities change depending on the kind of disability: in both the groups, the character with mobility impairments seemed to have more opportunities to gain economical stability and freedom of choice than a person with mental illness.

4. Parti-numbers exercises (Only for Nablus)

Parti-numbers methodologies are methods that aim at producing quantitative data through participatory research methods. The specific objective of the exercise was to understand how the presence of a child with disabilities influences the allocation of the resources of a monthly household budget and how it influences the time use of the mother. Also in this case, the general objective was to favour the detachment of participants from their individual experience, in order to induce the shift toward a more research-oriented approach.

This specific activity has obviously been made only in the group of Nablus, which is composed by the feminine caregivers of persons with disabilities. In the other two groups, as already shown, the detachment has been reached through a matrix score elaboration on the dimensions of wellbeing, which has the same objective and use the same strategy to reach the needed scientific detachment and to develop serious reflection on the role of the researcher among the group.

Let's now analyse the implemented activity: the first step was the setting of a scenario. The scenario was made up by two families (family A and family B) showing the following characteristics:

Table 1.13 Scenario of the parti-numbers exercise

Characteristics	Family A	Family B
Composition	1 father 45 yo	1 father 45 yo
	1 mother 45 yo	1 mother 45 yo
	1 son 15 yo (no disability)	1 son 15 yo (no disability)
	1 daughter 17 yo (no disability)	1 daughter 17 yo (no disability)
	1 son 13 yo with severe mobility impairment	1 son 13 yo (no disability)
Work	only the father works and has lower intermediate wage (2500 NIS[1])	only the father works and has lower intermediate wage (2500 NIS)
Housing	the family owns her house (no rent to pay)	the family owns her house (no rent to pay)
District	urban Nablus	urban Nablus
Religion	Muslim	Muslim

Source: ARCO, 2015.

Basically the two families differ only for the presence of a son with a severe mobility impairment. In the second step, the participants were asked to indicate how family A and family B allocate their budget among various category of goods and services consumption. The exercise was well understood by the participants who began to think to these fictional families from an external point of view, though starting from their personal experience. According to the results, there is an overall reduction of "*unnecessary*" expenditures, such as clothing, self-care and leisure. This is due to the increase in the amount of money needed to cover health care (as expected), education (due to the higher cost of special education) and gas\electricity\other services (because of the higher length of time spent at home). Moreover, it is interesting to notice that for family A it is impossible to save money. In other words, the comparison among the two fictional families highlights that the presence of a child with disabilities tend to increase the economic vulnerability of the familiar context (by denying the ability to save and by reducing unnecessary expenditures).

Table 1.14 Household budget identified during the parti-number exercise

Expenditures Categories	Family A	Family B
Food	600	500
Electricity/Gas/Other basic services	650	500
Education (including fee)	450	300

Health care (including assistance)	600	100
Clothes and self-care	50	200
Transports and communication	120	200
Leisure	30	400
Savings	0	300

Source: ARCO, 2015.

In the final step, the participants were invited to imagine the typical day of the adult women of family A and family B. They were asked to take into consideration a day during the week. According to the discussion, the mother of a son with mobility impairment has less time to rest (and the quality of rest is lower). She will spend more time at home (with more time used for housekeeping). The total burden of active care is higher for the woman from the family A (5.5 hours compared to 4 in family) but the most significant difference is in the distribution of the care provided by the woman. The opportunity to have time to work and to maintain social relations is much higher for the woman living in family B (even in the case of homework). The participants underlined also that social relations for women A are often centred on the child with disability. An interesting point emerged during the discussion is the issue of passive care: basically women said that they are compelled to stay long time at home just because the child cannot be left alone even if they do not have any kind of active care to do. The women underlined how this sort of empty time may result even harder than active care.

Table 1.15 Women time use identified during the parti-numbers exercise

Activity	Family A	Family B
Rest	5	7
Housekeeping	6.5	5
Active care of son with disability	3.5	0
Care of other children	1	2
Care of other family members	1	2
Work	1	4
Transport	1	1
Social relations	1	3
Passive care of son with disability	4	0

Source: ARCO, 2015.

Through this activity, the women could experiment the research-attitude needed for the emancipatory survey: the added value of the Emancipatory processes is that the researchers are part of the research target itself, so they can find the perfect balance between the objective and scientific approach and the empathic attitude due to deep comprehension and identification.

1.3.2- Problem trees elaboration and identification of the research questions

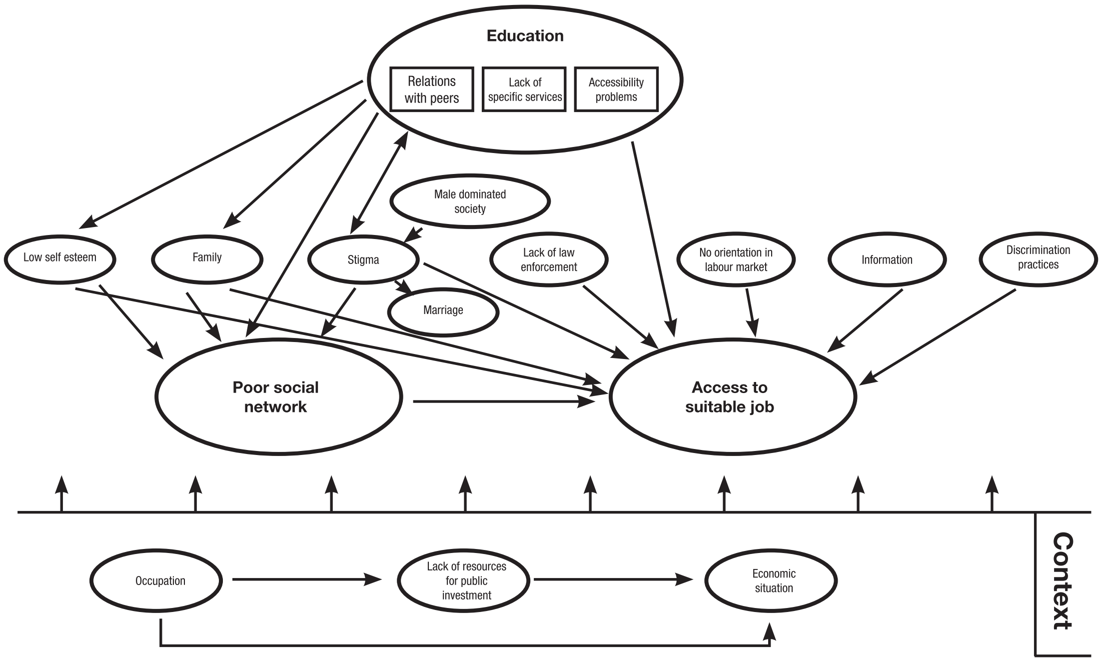
All the preliminary activities that have been described were leading to the problem tree elaboration: in particular, the analysis of the barriers and of the wellbeing dimensions has been functional to orientate the groups' decision on the research questions, which basically emerged through the discussion on the cause-effect relations among the different issues.

It is crucial to emphasize that this final exercise was particularly useful in order to accomplish a change of attitude among the participants: the problem trees discussion and elaboration, in fact, easily drive from the passive listing of problems to a reflexive approach and applied reasoning: the problems are mapped and put in relation creating families of linked issues with the cause-effect logic. This process resulted in an image of reality, where the women could pinpoint the focal problems and reflect on the research questions and the possible solutions in the concrete complexity of their living environment. Within the considered process of emancipatory research, the problem tree elaboration represents the key element that allow the participants' detachment from the passive attitude, broadening the awareness and developing self-consciousness of their role of researchers.

Let's now analyse the three discussed problem trees.

The next figure reports the map of problems elaborated during the training in Beit Sahour. The three topics that were particularly stressed during the discussion were (i) the issue of education and the problems identified within the education system, (ii) the problems that lead to the lack of access to suitable job and (iii) the lack of social networks for women with disabilities. It is interesting to notice how the participants were able to identify and "*isolate*" macro-contextual factors (such as the occupation and the overall economic situation) as factors that are able to influence every other aspect but, at the same time, not being impacted by the disability issues.

Table 1.16 Problem tree from Beit Sahour

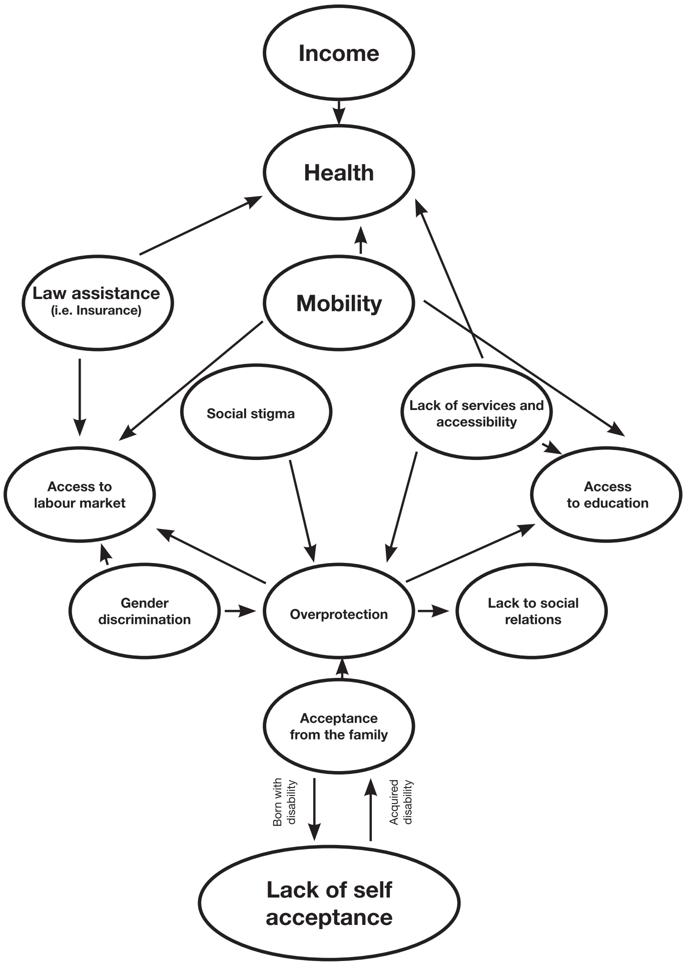


Source: ARCO, 2015.

As can be noticed from the problem tree, the group of Beit Sahour focused particular attention on the causes of the weak access to suitable job for women with disabilities: from the personal and social factors (low self-esteem, familiar overprotection, social stigma and discrimination dynamics) to the technical difficulties of the society (lack of law enforcement, insufficient information and orientation in the labour market). The access to suitable job is also strongly influenced by two dimensions which cover the same importance in the context: the poor social network and the problem connected with education, which are tightly linked to many of the already mentioned elements. This attention to the labour market access, drove the group decision on the main topic of their survey: the general objective of the ER conducted in the Beit Sahour is to identify the factors that hampers or foster the access to suitable job of women with disabilities in the West Bank. The participants also chose to pursuit their aim through a quantitative survey based on a structured questionnaire which has been jointly elaborated with the scientific support of ARCO Lab.

The next figure, instead, reports the map of problems elaborated during the training session in Ramallah. During the discussion, the participants stressed the role played by the family, highlighting in particular the dynamics of overprotection and lack of acceptance. Both these phenomena tend to hamper the possibility to participate to the society for Persons with disabilities and for women in particular. In last instance, the final effect is a lack of self-acceptance.

Table 1.17 Problem tree from Ramallah



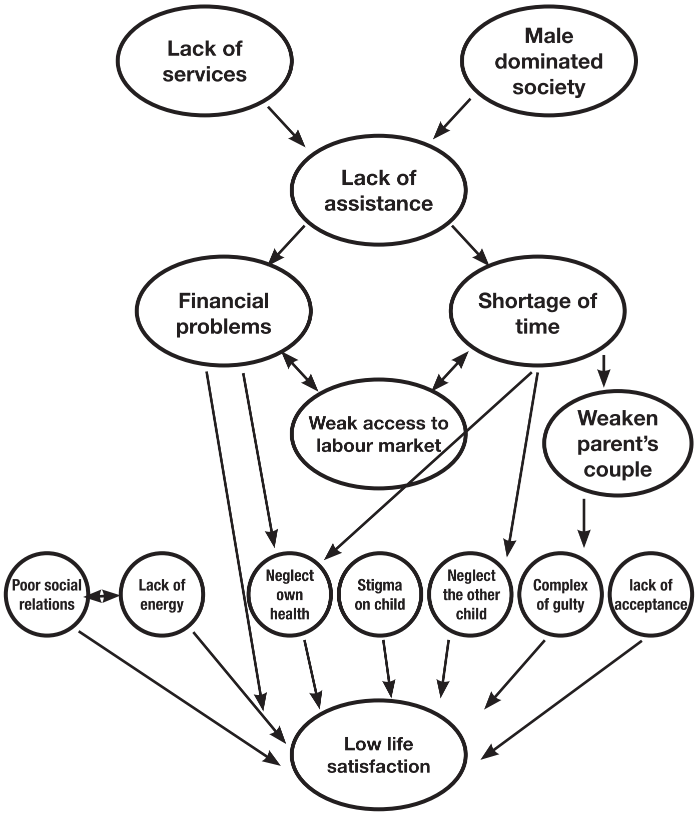
Source: ARCO, 2015.

Due to the interest of the women from Ramallah to the familiar interactions, the group decided to

analyse, as general objective of their ER research, the role of the family as factor able to promote or hamper the full participation of women with disabilities in the society.
Unlike the two other groups, in Ramallah the participants preferred to implement a qualitative methodology: they will conduct 16 Life Course Interviews with man and women with disability in a range of 18 – 40 years old. Moreover, one Focus Group Discussion with parents of people with severe mental disabilities will be implemented in order to investigate the difficulties faced by the families in the inclusion of their children, since the target of persons with mental illness and cognitive disabilities has been pinpointed by the ER participants as the most delicate and vulnerable. In addition to this two research activities, the group of Ramallah decided to interview also 8 teachers committed to disability issues in both mainstream and special schools: these additional interviews will be particularly interesting, since their aim is to analyse the role of school and education in the inclusive development of children

The next figure report the map of problems identified in Nablus through a collective discussion with the women participating to the training session. The map is centred on women providing care to a son or daughter with disabilities. The main point emerged is the vicious circle linking the lack of assistance from the family and from outside (e.g. public services), the subsequent shortage of time, the lack of access to labour market and the subsequent scarcity of economic resources. This vicious circle is considered by women as the main “*engine*” of their marginalisation and to stop this circle should be a priority for policy makers and DPOs.

Table 1.18 Problem tree from Nablus



Source: ARCO, 2015.

As it clearly emerges from the picture, the vicious cycle leads to low life satisfaction of the familiar caregivers: the participants in the group of Nablus, therefore, decided to set as main objective of their research the wellbeing of female familiar caregivers of person with disabilities by analysing the way they use their time and how the "*burden of care*" affects the gap between the activities that women effectively implement and the desired ones. The collection of data needed to analyse the issue is based on a large scale survey that sees the involvement of 150 women: in particular, the survey has targeted mothers, sisters and wives of persons with disabilities who live with the person with disability and who takes care of him in a relevant way.

1.4 - Research protocols and preliminary results

1.4.1 - Beit Sahour and a questionnaire on the access to the labour market for women with disabilities

As noted from the problem tree analysis, the group of Beit Sahour decided to set as main objective of their research the access to the labour market for women with disabilities in the West Bank: in particular, their work aims at the identification of the main barriers and facilitator factors that hampers or foster the access to suitable job for the selected target.

The key issue that drove the research protocol elaboration has been the concept of suitability of the job. The group managed to reach a joint definition, outlining as suitable each job which is not conceived only as a source of material earnings but also as a way to give value to one's life, to define one's identity and to practice the skills acquired thanks to education. This has led the group to the formulation of the following research questions:

- Are the skills provided by education useful to find a suitable job?
- Which are the factors that makes the familiar context to work as barrier or facilitator when a person with disability is looking for a job?
- Which are the physical barriers experienced while working or while looking for a job?
- Which is the role played by social stigma while looking for a job?
- Which is the degree of respect of rights on the job for women with disabilities who are working?

As already said, the women from Beit Sahour decided to implement their research through the use of a quantitative methodology based on a structured questionnaire. This group decided to interview 200 women with disability between 18 and 45 years old, with at least 50 women with mobility impairment, 50 with visual impairment and 50 with hearing impairment.

Among the 200 interviewees, at least a quarter were supposed to have an ongoing or a recent (in the last three years) working experience.

The women have been sampled purposively among the DPOs and administrative registers according to the just mentioned criteria. The aim of the research, in fact, is not picturing statistics on a representative sample, but is to advocate the situation of market access in the West Bank for women with disabilities and to raise awareness and empowerment among the participants through the emancipatory process. It is important to highlight that is it difficult to select a random representative sample since a large part of the total population of women with disabilities in Palestine is hidden by the families and it is not officially registered.

The data collection is implemented through a single personal questionnaire, composed by the following 6 sections:

- Section 1: Information about the interview
- Section 2:Introduction and Education
- Section 3: Job and Employment
- Section 4: Political and Social Participation
- Section 5: Background information
- Section 6: Disability Assessment

As can be noticed from the structure, the first two sections are mainly useful to delineate the general background of the person. Also the last two dominions explore more general information about the person: in particular, the last section is dedicated to the disability assessment, namely a classification of the body functionings difficulties and the activity limitations. The central part of the questionnaire represents instead the core of the survey: all the questions of the section 3 and 4 are in fact focused on the inclusion in the society, from the labour, social and political point of view. With the aim of understanding the working conditions of women with disabilities in West Bank, the key questions mainly investigate the favourable factors in the access to the labour market, the links between job and education and the different barriers faced in the research of a suitable employment. Moreover, it has been decided to investigate also the discrimination faced by the women with disabilities in the working environments and the interviewees' personal satisfaction concerning the working-life.

At the beginning, the group pointed out some difficulties in the data entry filling process, due to the straggle with the Excel format and the demanding matching with the questionnaire. Despite the initial mistakes, ARCO staff clarified the problematic points of the filling process and with the final elaboration great improvements have been registered.

1.4.2 - Ramallah and the life course interviews on the role of the family

The main objective of the emancipatory research conducted in Ramallah is the analysis of the family as a factor able to promote or hamper the full participation of women with disabilities in the society. A particular focus has been dedicated to the access to education and job: in both cases the research takes into consideration the access as an outcome but also as a process in which the family play a central role. The questions try to identify the dynamics of overprotection among the families and the consequent effects on the participation of children with disabilities in the education system and in the job market. Attention will also be paid on the gender difference which occurs in the analysed topic.

As previously noted, the women from Ramallah decided to implement a qualitative research based on semi-structured interviews and focus groups: 8 interviews are now implemented with teachers from mainstream and special schools, and three focus group will be conducted: one with parents of children with severe mental disabilities, and two with people with disabilities on the role of the family and on gender discrimination.

The core of this group research is 16 Life Course Interviews conducted with man and women with disability. The age cohort of the interviewees is from 18 to 40 years old, and the sample distribution will be explained in details in the third chapter.

The main topics of the interviews have been: autonomy, acceptance within the family and access to education and work.

The role of the family has been investigated in different aspects of the interviewee's life course. Through the methodology of the Life Course Interviews it was possible to investigate in details the deep values and the perceptions of the person, analysing the most crucial events and experiences that influenced the direction of the interviewee's life path.

At the beginning of the fieldwork, the women from Ramallah faced some difficulties in conducting and reporting the Life Course Interviews, since this qualitative methodology is not easy to handle. With the help of ARCO senior researchers, the women could improve the quality of the interviews and of the reports and they acquired the appropriate strategies to cope with the research tools.

1.4.3 - Nablus and the questionnaire on care and time use

As already noted, the group of Nablus was composed by women who take care of a relative with disabilities, so the participants decided to focus their research activities on the family but from the point of view of the caregivers. The main objective of the research has been set as the investigation about the wellbeing of female caregivers of a family member with disabilities, by analysing the way they use their time and how the "*burden of care*" affects the gap between the activities that women effectively implement and the desired ones.

In particular, the research has been based on two different sets of research questions:

- The first set concerns the amount of time the women spend for various kind of activities and the relative impact on their quality of life. For example:
- How much time do the women spend for rest?

- How much time do you spend for the care of your child\brother with disability?
- How much time do you spend for leisure?
- The primary objective of this first set of question was the assessment of the size of the burden of care.
- The second set of research questions focused on deprivation, in terms of time poverty. To the women have been asked to assess whether the quantity and the quality of the time they have for their various activities is sufficient. The research tried to understand whether the women face a restriction in their freedom of choice and to what extent.

The data collection was based on a large-scale survey with the involvement of 150 women who are caregivers of a person with disabilities. In particular the survey targeted mothers, sisters and wives of persons with disabilities who live with the person with disability and who takes care of him in a relevant way.

In order to take into account, the evolving needs of persons with disabilities over the life course, the sample has been stratified according to the age of the person with disability

- 0-10 years
- 11-25 years
- 25+

Given the influence of the context and the complexity of the Palestinian society, the survey sample involved women from urban areas, rural areas and refugee camps.

Also in this case, the sample of the caregivers is not representative of the whole population, for the same reasons expressed for the group of Beit Sahour. The interviewees, in fact, has been selected through the registers of the DPOs partner of the project.

The structure of the questionnaire was the following:

- Section 0: Information about the interview
- Section 1: Personal Information of the Caregiver
- Section 2: Care
- Section 3: Personal Information of on the Person with Disability
- Section 4: Background information
- Section 5: Time use
- Section 6: Disability Assessment and Rehabilitation Services

The core sections are then the second and the fourth. In particular, the investigation focused on the daily "*burden of care*" of the interviewees, trying to understand if the burden is shared with other family members or external helps and to which extent the burden is considered a limit to the interviewee's freedom. The section on the time use, instead, considers the time dedicated by the caregivers to different activities, investigating how the interviewee evaluates her time schedule and the different barriers that prevent the best time use possible.

Let's now proceed to the detailed description of the research results which have been jointly discussed and elaborated by the three groups researchers and the staff members from ARCO Lab.

CHAPTER 2- Results from the Field Research of the Group from Beit Sahour

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Federico Ciani (University of Florence and ARCO – Action Research for Co-Development)

The field research implemented in Bet Sahour involved a group of around 20 researchers under the logistic support of GUPwD-Bethlehem. According to the research protocol elaborated with the support of ARCO researchers (see chapter 1), the researchers interviewed 200 women. The research was focused on access to education and to a suitable job. The bulk of the activities related to data collection and data entry was managed by the researchers themselves with the support of GUPwD and Educaid staff and the technical assistance of ARCO researchers. The data analysis was implemented by ARCO researchers under the guidance of the women with disabilities involved as researchers. The results were discussed and commented during three focus group discussion held in August-September 2016: the FGDs saw the participation of the researchers and of ARCO staff members.

2.1 - The Profile of the Interviewees

The age of the interviewees ranges from 18 to 45 years while the average age is 28.9 years. 98% of the interviewees is Muslim while only a narrow minority of them is or has been married (14.5%). As discussed in the FGDs and as highlighted by the field research in Ramallah[5] the lack of marriage opportunities is perceived as one of the most relevant forms of discrimination by women with disabilities in Palestine.
Coherently with the research protocol, the research involved women with visual, hearing and mobility impairments with a good balance among the different impairments (see figure 2.1). Women with psycho-social and cognitive impairments were excluded as the researchers were not fully confident in their ability to properly interview them. Moreover, the researchers expressed their will to avoid to interview parents or other family members instead of women with disabilities.

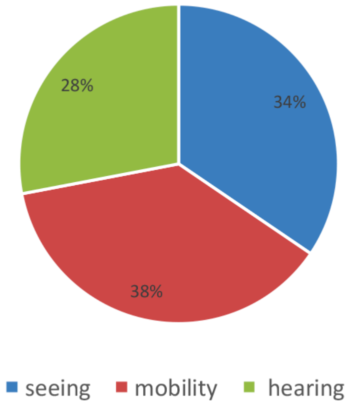

Fig 2.1 - Main impairments of the interviewees
Source: authors' elaboration

The sample includes both women born with a disability (63%) and women who acquired their disability over the life course (37%). Slightly less than a half of the respondents (45.5%) reported that more than one member of the family (including the respondent herself) has a permanent impairment or a chronic disease. According to what emerged during the FGDs, this high percentage of families having more than one member with a disability or a chronic disease is

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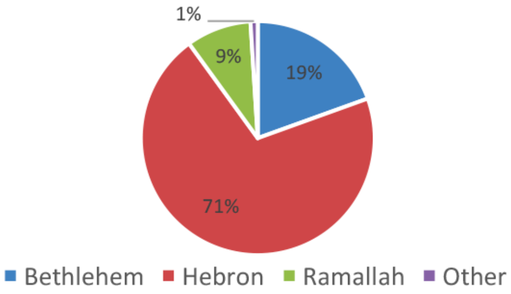
[5] See chapter 3

partly due to the general high prevalence of chronic diseases (such as diabetes) and partly to genetic disabilities linked to the high frequency of intermarriages.

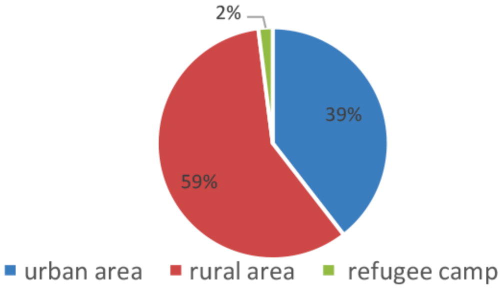
The survey has been mainly focused in the governorates of Bethlehem and Hebron (see figure 2.2) while the distribution of the interviewees among urban and rural areas (see figure 2.3) is quite balanced. Women with disabilities living in refugee camps are, on the contrary, underrepresented. This issue was discussed during the FGDs and the researchers explained this datum in two ways. First, the most part of the researchers administered questionnaires in areas not too far from their homes[6] and no one of the is living in a refugee camps. Second, DPOs based out from refugee camps often tend to have weak linkages with the social fabric of the refugee camps. This fractionalization is not limited to the disability sector but involves civil society at large: refugee camps end to have their own NGOs, their own service providers etc.

Fig 2.2 - Governorates of the interviewees



Source: authors' elaboration

Fig 2.3 - Area of the interviewees



Source: authors' elaboration

In average, the households of the interviewees are composed by 6.6 members. The mean demographic dependency rate is 0.52: it means that, in average, there are two persons in active age (15-65) for each person in dependent age (less than 14 or more than 64 years old). The employment rate in the surveyed households is quite low (around 43%) while in 47% of the families there is no or just one person currently working.

The very most part of interviewees' household (95.5%) is the owner of the house they are living in. The average number of person per room in the household is 1.6 and is higher than 2 in 27.5%

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[6] This was due to the mobility problems of the most part of researchers and to the high transportation costs for women with disabilities who are compelled to use private transport.

of the household. In other words, overcrowding is a quite widespread problem and risks to hamper women with disabilities' ability to reach a fair level of life quality within their homes.
The socio-economic status of the household was assessed using two methods. The first one is a direct question about the perceived vulnerability of the household. Basically interviewees were asked to indicate how easy is for the family to meet the monthly needs. The results (table 2.1) shows that a non-negligible share of the families seems to experience some forms of economic problems.

Tab 2.1 - Household perceived economic vulnerability

	(%)
very low	3.0
low	19.5
High	57.5
very high	20.0

Source: authors' elaboration

The second method was based on objective indicators concerning the ownership of assets[7] and the housing condition[8]. This information set was processed through factor analysis to create a wealth index using the procedure suggested by DHS (Rutstein and Johnson, 2004). The cross tabulation of the wealth index and of the perceived vulnerability (see table 2.2) shows a substantial coherence between these two indicators. It is interesting to notice that it means also that the interviewees are, in average, aware of the economic conditions of their families.

Tab 2.2 - Household perceived economic vulnerability and wealth index

Perceived economic vulnerability	**Average value of the wealth index**
very low	1.06
Low	0.60
High	-0.05
very high	-0.59

Source: authors' elaboration

Interviewees were also asked to which are the available sources of economic support in the case relevant, sudden and unpredictable economic needs. The data shows that family networks, savings and informal credit are considered the most affordable sources while access to formal credit and to remittances is a viable option for just a minority of the interviewees.

Tab 2.3 - Viable sources of economic support

Possibility to get additional resources…	**(%)**
… from the extend family	42.5

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[7] The assets taken into consideration are: ownership of a second house, ownership of a shop or other business place, ownership of a computer, ownership of a refrigerator, ownership of a satellite dish, ownership of a car, ownership of agricultural land, ownership of farm animals.

[8] The dwelling characteristics considered in the index are the ownership of the main house, the material of the floor and the number of rooms

… by selling assets	15.0
… by using household savings	33.5
… thanks to remittances	8.0
… by getting a loan from the bank	10.0
… by getting informal loans	58.5

Source: authors' elaboration

Table 2.4 presents the average number of available options for each quintile of the distribution of the wealth index. It is interesting to notice that the families showing lower values of the wealth index tend to have less viable sources of support in case of need. In other words, poverty and lack of options in case of emergency are two sides of the same coin: poorer families are also the more fragile ones. This datum needs to be taken into consideration while designing policies and planning the target of actions.

Tab 2.4 - Household wealth and sources of economic support

Quintile of wealth index distribution	Average number of available sources of support
1st quintile	1.00
2nd quintile	1.34
3rd quintile	1.81
4th quintile	1.90
5th quintile	2.38

Source: authors' elaboration

To sum up, the presence of social and economic problems such as unemployment, poverty, vulnerability, bad housing conditions are widespread among the surveyed households. This is not unexpected given the general economic situation of the West Bank but we need to consider this data in the light of the extra-needs of persons with disabilities and of families having a person with disability among his members (Zaidi and Burchardt, 2005). The issue of social and political participation was considered extremely relevant by the researchers despite it is not directly linked to core of the research (i.e. education and access to suitable job). As a consequence, few questions about this issue were included in the questionnaire. In particular, the interviewees were asked to indicate whether they can participate as the others to a set of social activities.

Tab 2.5 - Participation to social life

Activity	(%)
participate to rituals and festivals	69.0
participate to social activities	62.5
participate to discussions within the family	67.0
feel respected within the community	74.5

Source: authors' elaboration

The data shows that the most part of women declare to have the opportunity to participate as the others to the social life of their family and of their community. During the FGDs organized to discuss the results with the researchers, they underlined that this picture might be too optimistic. As a matter of facts, the definition of “participation” might be different for women who are used to discrimination: for many respondents to participate might be conceived as “being present at”. For what concerns the participation to civil society organization, a quite large share of the interviewees (43%) participate to the activities of a disabled people organization (DPO). A much smaller share participates to organizations not linked to disability (17.5%). This relevant difference might be an indicator of a sort of “segregated” participation. As will be shown, this kind of issue will emerge about other topics analyzed on the next sections.

2.2 - Access to Education: Facilitators and Barriers

As discussed in the preparatory FGDs, the access to education is considered as fundamental step to achieve the full participation of women with disabilities to the society. Access to education has direct consequences on the probability to find a suitable job in the future and on the development of the person at large (awareness, ability to have social relations etc.). Moreover, in the case of women, access to education has an extremely relevant indirect effect: to go to school is usually considered by the family as an acceptable reason to go out and gain more freedom and autonomy. According to the collected data (see tab 2.5), 21.5% of the interviewees is currently enrolled at school, 69.5% is not currently enrolled but has been enrolled before while 9% have never been enrolled. This last share rise to 20.83% for women aged 34 or more and falls to 4.17% for those aged 24 or less. This difference can be considered as an evidence of an overall improvement of access to education for women with disabilities over last 15-20 years.

Tab 2.6 - Enrolment in education

		currently enrolled (%)	not enrolled anymore (%)	never been enrolled (%)
	Total sample	21.50	69.50	9.00
Age class	18-24	45.83	50.00	4.17
	25-34	11.25	82.50	6.25
	34+	2.08	77.08	20.83

Source: authors’ elaboration

This observation is confirmed if the level education is taken into consideration. In particular, the share of women who had access to secondary or university education increased substantially across the age groups (consider that around 45% of those belonging to the age group 18-24 are still enrolled in education).

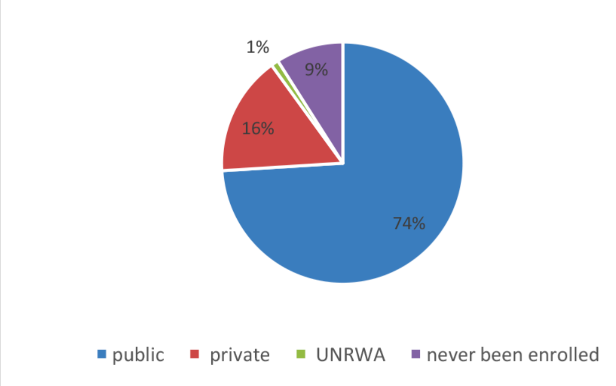
Tab 2.7 - Level of education

Level of education								
	Total	no education	elementary	intermediate	secondary	college diploma	BA or more	Other
Age class	18-24	4.17	2.78	9.72	38.69	34.72	8.33	1.39
	25-34	6.25	5	8.75	22.5	15	42.5	0
	34+	20.83	4.17	22.92	10.42	8.33	33.33	0

Source: authors’ elaboration

Referring to the last year spent in education, about three out of four interviewees attended public school. The low share of women who attended UNRWA school is linked to the low share of interviewees living in the refugee camps. It is worth to notice that the share of interviewees who attended private schools defined these schools as schools for student with special needs. In 43.75% of cases these special schools are boarding schools.

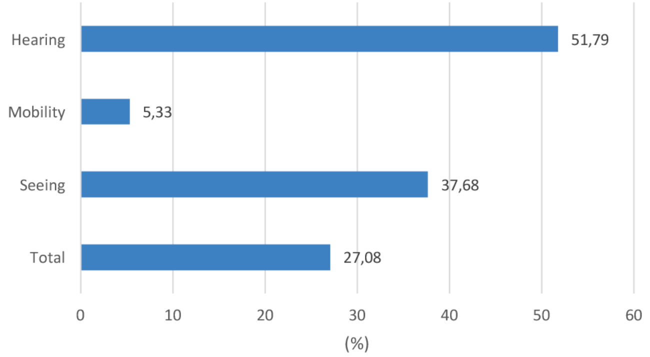
Fig 2.4 - Kind of school attended



Source: authors' elaboration

More in general, almost one interviewees out of three (29.5%) declared to have had at least one year of education in a school for students with special needs. It is interesting to notice that this percentage is more or less constant across age groups. On the contrary the kind of disability of the interviewees is closely linked to the kind of school attended. For example, more than a half of the interviewees with hearing disabilities have spent at least one year in a school for students with special needs. According to what discussed in the FGDs, this is due to the not sufficient ability of the Palestinian public education system to provide effective inclusive education to student with hearing and visual disabilities. As a consequence, the presence of segregated education for students with disabilities seems to be still widespread.

Fig 2.5 - Share of interviewees who had at least one year of education in a school for students with special needs



Source: authors' elaboration

Coherently with the principle of self-determination of persons with disabilities, deprivation in education (as well as in other fields) should be defined according to the desires of the persons more than according to the compliance with legal thresholds (e.g. compulsory education). Moreover, it is worth to remember that education has both an instrumental and an intrinsic value that goes beyond human capital accumulation to involve issues such as life skills, relational abilities etc. Consequently, it is not only relevant to measure the access to the education (e.g. the achieved level of education) but also to understand whether the achieved level is coherent with the desires of the person herself. According to the collected data, 47% of the interviewees declared to have had to stop attending school against their desires and aspirations. If we focus the analysis on those who are not enrolled in education anymore, this share rise to 58.75%. It is interesting to notice that differences associated with the different impairments are moderate and the share of women who declared to have left education against their will is higher among women belonging to younger cohorts (see table 2.8). Considering that the overall access to education increased over the years (table 2.6), a possible interpretation of this data is that the preferences of women with disabilities toward education changed: in other words, younger generations of women with disabilities tend to desire more education than older ones. Comparing the interviewees according to the kind of impairment, is it possible to notice that deprivation in education is more widespread among women with visual and hearing impairments than among those with mobility impairments.

Tab 2.8 - Reasons leading to quit education

		stopped against will	**stopped when desired**	**still in education**
	total	47.00%	33.00%	20.00%
age class	**18-24**	33.33%	22.22%	44.44%
	25-34	53.75%	36.25%	10.00%
	34+	28.13%	21.88%	50.00%
impairment	**seeing**	46.38%	30.43%	23.19%
	mobility	41.33%	37.33%	21.33%
	hearing	55.36%	30.36%	14.29%

Source: authors' elaboration

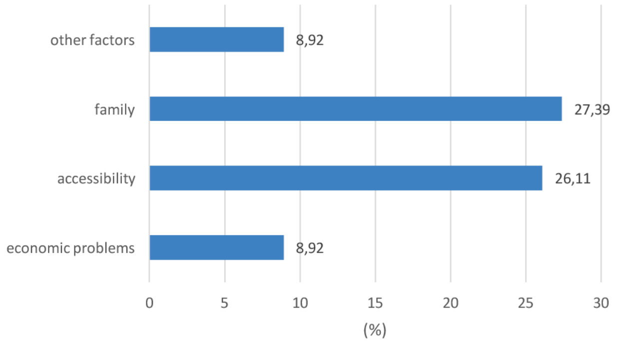
Tab 2.9 - Reasons leading to quit education among women who are not enrolled anymore

		stopped against will	**stopped when desired**
	total	58.75%	41.25%
age class	**18-24**	60.00%	40.00%
	25-34	59.72%	40.28%
	34+	56.25%	43.75%
impairment	**seeing**	60.38%	39.62%
	mobility	52.54%	47.46%
	hearing	64.58%	35.42%

Source: authors' elaboration

To deepen the issue of deprivation in the education area, the interviewees where asked to indicate which where the factors (barriers) that prevented them to reach the desired level of education. The list of potential barriers was elaborated during a preparatory FGD on January 2016 and includes: the family believed that the interviewee reached the desired educational level, education is too much expensive, it is too complicated to physically reach the school, schools were not accessible, the environment at school was not inclusive (i.e. relation with peers), health problems, marriage, commitment to work to help family, commitment to other family duties (i.e. caring), the interviewee was not successful in education, the interviewee achieved the desired level, the political situation (including the occupation). Considering the women who were not currently enrolled in education at the moment of the interview, 50.32% of the interviewees reported to have had no experience of relevant barriers, 20.38% identified one main barrier while 29.3% reported to have had experience of two or more barriers. This confirms that marginalization dynamics are often the result of complex interactions among heterogeneous factors. Figure 6 shows that barriers linked to the family and to the accessibility of the schools system and to the role of the family are considered the most relevant ones. Economic barriers are considered relevant by a minority of the interviewees as well as the political situation. This last datum is someway surprising and might be interpreted a sign of the resilience of the interviewees: the political situation and the problems deriving from the military occupation are incorporated in the daily lives and are not perceived as barriers.

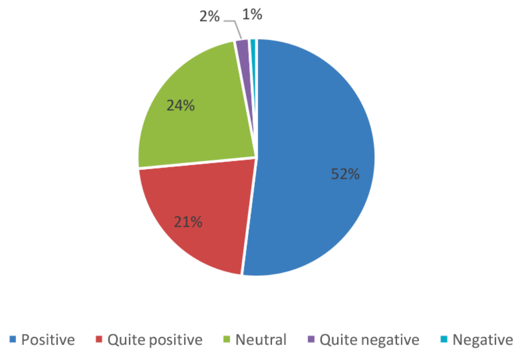
Fig 2.6 - Main barriers leading to undesired interruption of the experience in education



Source: authors' elaboration

Despite barriers linked to the family are considered a determinant of the deprivation in terms of education by a large share of the women, the most part of the interviewees is considered a positive actor for what concern the experience in education.

Fig 2.7 - Perception about the role of the family and the experience in the education system



Source: authors' elaboration

This partial incoherence was discussed during the FGDs organized on August 2016. Several interesting aspects where underlined during the discussions. First, many interviewees might have been simply reluctant in defining the family has a negative factor in their experience in education. Second, over their lives, the interviewees might have elaborated an idea of what a supportive family is that do not correspond to the definition of the researchers: in other words, the family might have been considered has having played a positive role has it were able to protect, to fulfill the basic needs of the interviewees as well as to provide them a comfortable environment from a material and relational point of view. Finally, the idea of what a woman with disability can and cannot do and, hence, of what a family should allow her to do and be is deeply rotted in the context: many researchers underlined that Hebron (i.e. where the most of the questionnaires were administered) is considered as one of the more traditionalist cities in the West Bank.

The analysis of the general level of satisfaction about the experience in the education system shows an heterogeneous framework with about one interviewee out of three that declares to be poorly satisfied of not satisfied at all and slightly more than one interviewee out of four that declare to be more or less satisfied. The level of satisfaction is higher among interviewees belonging to younger cohorts as well has among interviewees having a mobility impairment.

Tab 2.10 - General satisfaction about the experience in the education system

		very high	**high**	**intermediate**	**low**	**very low**
	total	8.5	19	43	14	15.50
age class	**18-24**	9.72	20.83	5.83	12.5	13.75
	25-34	10	20	42.5	13.75	13.75
	34+	4.17	14.58	39.58	16.67	25
impairment	**seeing**	5.8	24.64	44.93	10.14	14.49
	mobility	12	21.33	46.47	14.67	5.33
	hearing	7.14	8.93	35.71	17.86	30.36

Source: authors' elaboration

It is interesting to notice that only slightly more than a half of the interviewees (57.50%) declared that the skills acquire during the education were useful or very useful to increase the probability of finding a job. This datum might be explained partly through the lack of inclusiveness of the education system, partly through the misalignment between the skills required by the job market and those provided by the education system and finally, as will be explained in the following paragraph, by the relevance of other channels such as personal social networks.

2.3 - Women with Disabilities and Access to a Suitable Job

The preparatory FGDs identified the lack of opportunities to get a suitable job as one of the main drivers of the marginalization of women with disabilities in the Palestinian society. As a matter of facts, access to job for women with disabilities has a bi-directional linkage to autonomy building processes, to empowerment and to the opportunity of being recognized as members of the society. The researchers defined a suitable job as a fairly paid job that is able to give the right value to the abilities of the person without any forms of discrimination. The discussion highlighted the need of contextualizing the issue of access to job for women with disabilities in the Palestinian context. It means to take into consideration two main problems. Firstly, Palestine at large is characterized by a high overall unemployment rate (around 17%[9] in the West Bank). Secondly, women participation to labor force is very low 19.4%[10] for women aged 15-64. As a consequence, we need to be aware that to add to this scenario a third level of discrimination (i.e. to have a disability) requires the ability to take into consideration the interaction among the different factors influencing the context.

During the elaboration of the research protocol[11], the researchers identified the need of having a sizeable share of interviewees who had at least some experience about paid job. This was due to the need of having both information about access or lack of access to job and about the inclusiveness of the job places for those who had the chance to find a job. The researchers decided to oversample women who had at least a job experience while identifying the interviewees. As a consequence, the data that are going to be discussed are far from being statistically representative of the situation of women with disabilities in Palestine.

Among the interviewees only a minority is working or has been working. According to research protocol 61 women who are currently working were interviewed (30.50%). It is possible to notice that the prevalence of women totally devoid of an experience on the job changes according to the kind of impairment (table 10): once again women with mobility impairment are the better off group.

Tab 2.11 - Employment status

		currently working (%)	**unemployed with past working experience (%)**	**unemployed never been working (%)**
	total	30.50	5.00	64.50
impairment	**seeing**	27.54	7.25	65.22
	mobility	38.67	6.67	54.67
	hearingl	23.21	-	76.79

Source: authors' elaboration

This difference is even larger if we take in consideration only women who are not currently enrolled in education as these last ones are supposed to have a "good reason" to be not involved in job related activities. In this case the most part of women with a mobility impairment was working at the moment of the interview while only 31.03% and 35.29% of women with visual and hearing impairments respectively were in the same condition. This seems to confirm a trend already observed for the analyzed aspects of education.

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[9] Source: PCBS, 2014

[10] Source: PCBS, 2014

[11] Exhaustive information about the research protocol and its elaboration are available in chapter 1

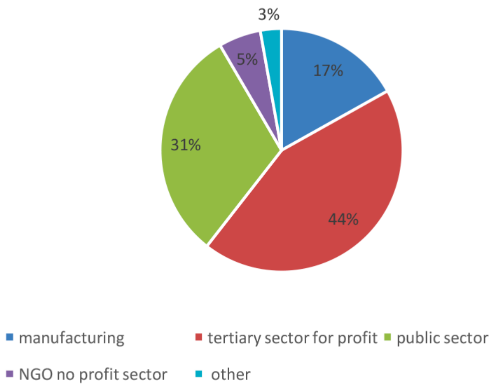
Tab 2.12 - Employment status of the interviewees not enrolled in education

		currently working (%)	unemployed with past working experience (%)	unemployed never been working (%)
	total	40.54	5.41	40.54
impairment	**seeing**	31.03	10.34	58,62
	mobility	53.57	3.57	42.86
	hearing	35.29	-	64.71

Source: authors' elaboration

For the interviewees who are working, the bulk of job opportunities is provided by the tertiary for profit sector and by the public sector (see figure 2.8). A lower share of women is working in the manufacturing sector. Quite surprisingly, the non-profit sector (including DPOs and NGOs) seems not to be a valuable source of job opportunities despite the huge number of national and international NGOs who are operating in Palestine and in the West Bank in particular and despite the pervasive presence of DPOs. It is someway coherent with the complaints emerged during the FGDs about the lack of respect of the Palestinian law about the disability quota system for the third sector.

Fig 2.8 - Sector of employment of the interviewees who are working

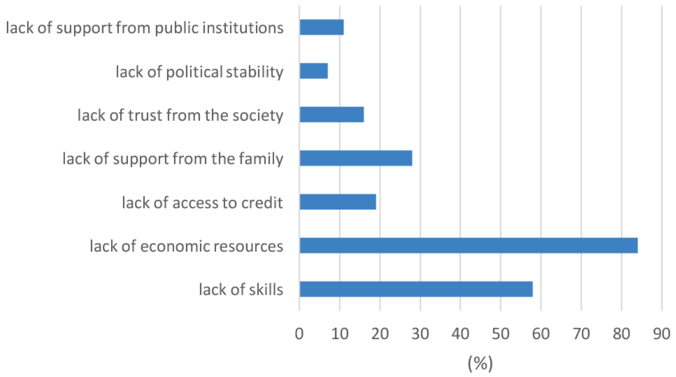


Source: authors' elaboration

It is interesting to notice that about 97% of the women who are working are wage earners while very few of them are self-employed or entrepreneurs (5.5%). Despite that, a half of the interviewees considers self- entrepreneurship as a viable option for their future. The lack of economic resources and the lack of personal skills are perceived as the main barriers to the startup of an enterprise. Also the lack of support from the family is a relevant barrier for 28% of the families.

Fig. 2.9 - Relevant barriers to the setup of an enterprise
Source: authors' elaboration

The lack of participation to job market is not always an undesired condition. In the analyzed sample 14.5% of the interviewees declares to be not willing to get a job. This share is higher among women belonging to older cohorts (18.75%) and lower among women with mobility impairment compared to those with visual and hearing impairment (23.21% and 13.04% respectively). It is



now worth to remember that all the interviewees are in active age (maximum 45 years old) and that the very most part of them is not married and consequently has not any children.

Tab 2.13 - Willingness to accept a job

		currently working (%)	**would like to find a job (%)**	**would not like to find a job (%)**
	total	30.00%	55.50%	14.50%
age class	**18-24**	9.72%	76.39%	13.89%
	25-34	43.75%	43.75%	12.50%
	34+	37.50%	43.75%	18.75%
impairment	**seeing**	27.54%	59.42%	13.04%
	mobility	38.67%	52.00%	9.33%
	hearing	21.43%	55.36%	23.21%

Source: authors' elaboration

Besides the willingness to get a job, it is interesting to analyze the level of proactivity in trying to reach this goal. The interviewees were asked to indicate whether they have been actively looking for a job in the year before the interview. The data shows that the share of those who did something to get a job is significantly lower than the one of those who declared to be willing to accept a job (41% versus 55.5%). It is worth to notice that more than 35% of women belonging to the older cohort and 37.5% women with hearing impairment has not been actively looking for a job in the year before the interview.

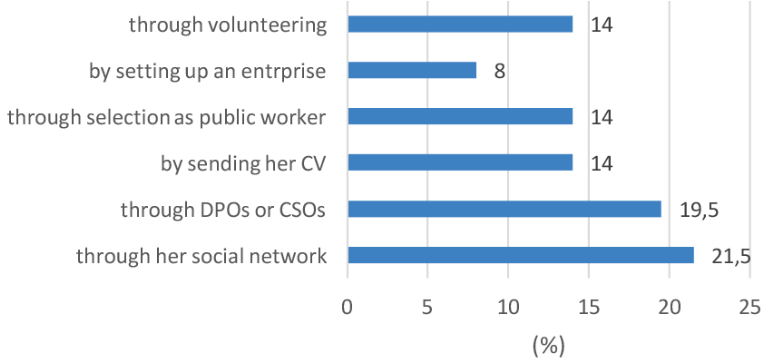
Tab 2.14 - Pro-activity in looking for a job

		currently working (%)	actively looking for a job (%)	not actively looking for a job (%)
	total	30.00%	41.00%	29.00%
age class	**18-24**	9.72%	38.89%	51.39%
	25-34	43.75%	51.25%	5.00%
	34+	37.50%	27.08%	35.42%
impairment	**seeing**	27.54%	42.03%	30.43%
	mobility	38.67%	40.00%	21.33%
	hearing	21.43%	41.07%	37.50%

Source: authors' elaboration

It is interesting to analyze the channels used by the women to look for a job. According to the collected data, personal and household social networks are the most widely used channels. According to what emerged during the FGDs discussion, social connections are partly transparent and partly part of the clientelism that dominates large part of the social and economic Palestinian life. It is worth to notice that this kind of mechanism tend to favor the intergenerational transmission of social exclusion. DPOs and CSOs are considered another relevant channels in particular if we consider that also volunteering activities are often implemented in CSOs and DPOs. These two channels are pointed out as relevant by respectively 19.5% and 14% of the interviewees. The high relevance of these channels may be interpreted as an indicator of the risk that women with disabilities tend to have access to job market through special channels as the mainstream ones are not inclusive.

Fig 2.10 - Action to find a job



Source: authors' elaboration

If we focus the analysis on the women who are working, the very most part of themthinks that the current job can be defined more or less suitable (83.5%). Taking into consideration women who are not working, the analysis of the barriers experienced by the interviewees provide a quite complex framework. The lack of accessibility of the environment and of transportation is considered a relevant barrier by a quite large share of the interviewees. The political situation is the most relevant barrier. During the FGDs, the researchers underlined that the political situation and in particular the military occupation has two main impacts on job market accessibility: first, it has a negative impact on the ability of the economic system to offer job opportunities; second, the military occupation prevents workers from having a safe and efficient mobility. This second point is particularly relevant for works who have a disability. The discrimination from colleagues and employers are relatively less relevant than other barriers even if it is interesting to notice the sizeable difference between women with mobility impairments and women with hearing or seeing impairments. In general women with mobility impairments seems to be more sensitive to environmental barriers while women with hearing and seeing impairments are more influenced by discriminatory dynamics.

Tab 2.15 - Barriers experienced by the women

Kind of impairment				
Barrier	**Total (%)**	**seeing (%)**	**mobility (%)**	**hearing (%)**
lack of environmental accessibility	43.50	44.93	50.67	32.14
lack of accessible transportation	45.00	56.52	42.67	33.93
discrimination from the colleagues	35.50	37.68	28.00	42.86
discrimination from the employers	35.00	39.13	28.00	39.29
lack of law enforcement	44.50	52.17	42.67	37.50
political situation	53.00	52.17	56.00	50.00

Source: authors' elaboration

During the preliminary discussion about the research, the researchers identified the family as a crucial component of the process leading to the access to a suitable job. The interviewees were asked to indicate whether the behavior of their family was supportive or non-supportive in a set of critical domains (identified by the researchers during the FGDs discussion). In 5 out of 6 domains the most part of families is identified as supportive even if the share of non-supportive families is non negligible. Splitting the sample according to the kind of impairment of the interviewees, it is possible to identify some interesting differences. Families of women with mobility impairments seems to be more able to be considered supportive in particular for the ability to offer the chance to conciliate job and other family duties.

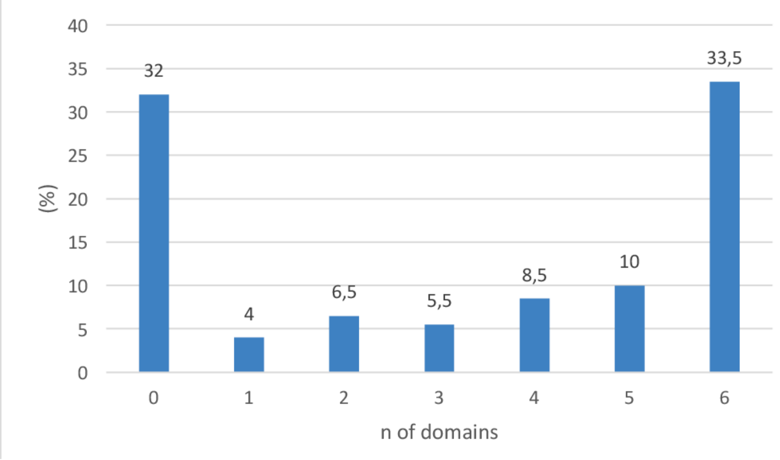
Tab 2.16 - Barriers to access to job

		Kind of impairment		
Barrier	**Total (%)**	**seeing (%)**	**mobility (%)**	**hearing (%)**
allowing to have useful education	53.5	49.28	57.33	53.57
providing means to overcome environmental barriers	52	47.83	56	51.79
fostering the development of self-esteem	59.5	55.07	65.33	57.14
providing economic support	42.5	36.23	49.33	41.07
supporting the conciliation of job and other family duties	52.5	49.28	60	46.43
fostering autonomy	58.5	55.07	61.33	58.93

Source: authors' elaboration

Figure 2.11 tries to sum up the situation concerning the role of the family by clarifying whether the results shown in table 2.15 derive families having problems in being supportive in certain domains and not in others of from a polarized situation in which there are a lot of families who are fully supportive and a lot of families not supportive at all. The data show that about one third of the families is supportive in all the domains while another third (32%) is not supportive at all.

Fig 2.11 - Number of domains where the family is considered supportive



Source: authors' elaboration

As explained in the introduction to this paragraph, while dealing with the access to suitable job for women with disabilities, we need to simultaneously take into consideration at least two different levels of discrimination: on related to gender and one related to disability. The interviewees were asked to indicate whether it would have been easier for them to get a suitable job if they were men. In general, more or less one half of the interviewees identifies a strong additional discrimination linked to gender. This share is higher for women belonging to older cohorts and for women with hearing impairments. These results were discussed by the researchers during a meeting with ARCO facilitators. The researchers underlined that the percentage of those who perceive a relevant gender based additional discrimination is quite low as, in the case of job, the binding factor of the discrimination is disability and not gender. In other domains (such as marriage), the opposite is true and the main driver of discrimination is gender.

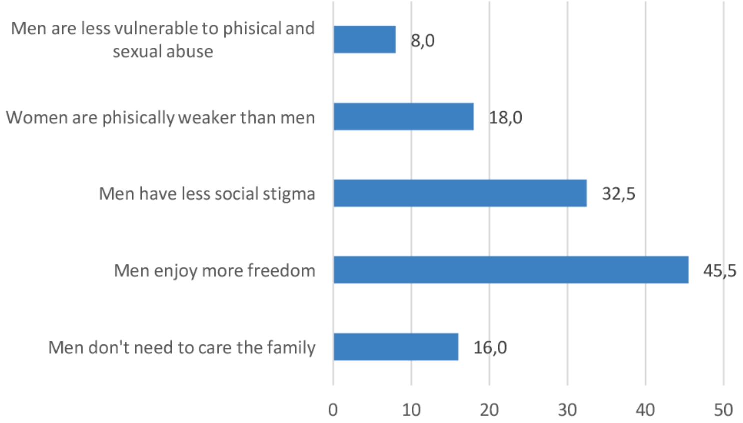
Tab 2.17 - Gender and discrimination in the access to job

		totally different (%)	different (%)	slightly different (%)	the same (%)
	total	18.00	30.50	20.00	31.50
age class	**18-24**	13.89	29.17	20.83	36.11
	25-34	15.00	31.25	22.50	31.25
	34+	29.17	31.25	14.58	25.00
impairment	**seeing**	14.49	30.43	21.74	33.33
	mobility	20.00	28.00	18.67	33.33
	hearing	19.64	33.93	19.64	26.79

Source: authors' elaboration

The reasons why men with disabilities have a better access to job than women are chiefly linked to the higher degree of freedom they can enjoy (in particular toward the family) and the higher degree of respect they can enjoy from other members of the society.

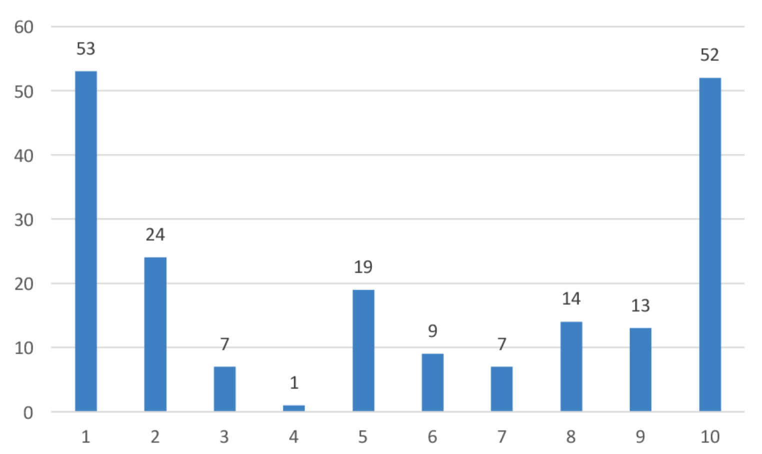
Fig 2.12 - Causes of gender based discrimination



Source: authors' elaboration

To conclude, the analysis of the satisfaction of the interviewees for what concern their job situation give us a polarized picture. More than a half of the interviewees answered 10 or 1 (i.e. full and no satisfaction).

Fig 2.13 - Satisfaction about situation on the job



Source: authors' elaboration

The average satisfaction about job changes across groups. Differences across age groups are negligible while women with hearing disabilities present a lower level of satisfaction than women with other impairments. Not surprisingly, we can identify strong differences due to the current job status: women who are currently working shows a very high level of satisfaction while those who have never been working are characterized by the lowest level.

Tab 2.18 - Satisfaction about job situation and across group differences

	Total	5.39
age class	18-24	5.2
	25-34	5.54
	34+	5.38
impair-ment	seeing	5.72
	mobility	5.57
	hearing	4.75
job status	currently working	7.8
	unemployed but working before	6
	unemployed never been working	4.1

Source: authors' elaboration

2.4 - Conclusions

The analysis of the information collected during the research provides a quite complex framework. Even if it is possible to identify some interesting general trend, it is crucial to always take into consideration the high heterogeneity, the high number of relevant variables and their interactions. The data highlights an overall improvement in the access to education over the years. At the same time the expectations of women with disabilities as concern education has been increasing over the same period: in other words, younger women with disabilities tend to desire more education. As a consequence, the research identifies a relevant share of women who can be defined deprived in terms of education has they had to stop their education before reaching the desired degree. According to what emerged during the research the main barriers to the achievement of the desired degree of education are linked to the family and to the ability of the system to provide accessible education for persons with disabilities. These results are coherent with those presented by another research about the accessibility of the Palestinian education system implemented by ARCO researchers and Educaid (RIFERIMENTO, XXXX). It is worth to remember that this research does not take into consideration women with cognitive e psycho-social disabilities that are usually characterized by higher levels of marginalization.

Access to a suitable job is a critical point for Palestinians in general and for Palestinian women in particular. All the more so, the picture delineated by this research is not devoid of problems. First of all, a quite large share of the women who are not working are not actively looking for a job (around 30%). Despite that, the sample of interviewees shows a relevant level of potentialities that could be mobilized through appropriate measures. For example, about a half of the interviewees thinks that to set up an enterprise is a viable option.

Besides the specific aspects concerning education and access to suitable job, it is interesting to underline some crosscutting issues. Firstly, the kind of impairment the interviewee is living with matters: the analysis shows that persons with hearing impairment have stronger problems in having access both to education and to a suitable job: practically it means to have a higher probability of having experienced segregation in education, of not reaching the desired level of education, of being unemployed, of not being actively looking for a job etc.

Secondly, a quite large part of the interviewees seems to link the achievement of certain results (e.g. to have higher participation or to get a suitable job) to disability related organizations. In a way, the research highlights the risk that a large part of the social and economic activities of women with disabilities are implemented in a sort of parallel disability-related world instead of through a full participation to the society. Third, the role of the family is as much relevant as much difficult to be typified. This research is not able to provide us a univocal model of family: quite the contrary, the relation between a woman with disability and her family in the Palestinian context is complex and heterogeneous. For example, taking into consideration the issue of access to job, the information provided by the interviewees lead to identify both supportive and not supportive families. It means that it is not possible to think to policy interventions automatically relying on the family as a resource or identifying it as a barrier: on the contrary, only through an *ad hoc* analysis of the resources available for the woman with disability it will be possible to understand which is the role of the family in the overall architecture of her life and of her project of life

More in general what appears quite clear from this analysis is that the several forms of deprivation and marginalization and the different barriers and facilitators experienced by women with disabilities need to be carefully analyzed before planning interventions. The intervention cannot disregard the individual set of resources and of obstacles and the elaboration of an individualized project for the person. To clarify this point let's take into consideration social participation and access to job. Table 2.19 shows that these two phenomena tend to be associated: in other words, women who are more marginalized on the job market tend to be more marginalized in the participation to social life and viceversa.

	Number of domains of participation without discrimination				
Job status	**0**	**1**	**2**	**3**	**4**
not working and not looking for a job	25.45	1.82	25.45	20.00	27.27
not working but looking for a job	6.38	12.77	4.26	27.66	48.94
working	7.27	7.27	10.91	25.45	49.09

This result is something relevant for aggregate analyses but, while working at the individual level, we need to be aware that a person who has a low social participation and a low participation to job market (i.e. column “0” row “not working not looking for a job”) is different from a person with the same situation but a quite strong social participation (i.e. column “4” row “not working not looking for a job”). The awareness about this kind of differences and heterogeneities should drive the planning of intervention addressed to women with disabilities including intervention aimed at improving their employability or their access to education.

CHAPTER 3 - Results from the Field Research of the Group from Ramallah[12]

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The main objective of the research activities implemented in Ramallah is the analysis of the family as a factor able to promote or hamper the full participation of women with disabilities in the society. In reality, as we will see, family related issues has been framed in general context of life of the persons with disabilities. As a consequence, this research will deal with other topics too (e.g. education, relation with peers, etc…). The field research has been implemented by around 20 women with disabilities coming from Ramallah and its surroundings. All the activities were implemented thanks to the logistic support provided by the local DPO Stars of Hope.

As previously mentioned, the research planned by this group adopted qualitative methodologies: in particular, the researchers implemented 3 focus groups with different selected targets, 16 life course interviews and 6 interviews to teachers with a different background of experience concerning education of children with disabilities. As noted, in the global context of the emancipatory research, only the women from Ramallah decided to conduct a purely qualitative research, while the other 2 groups decided to collect data for a more quantitative analysis. The coherence of the whole process of emancipatory research has been anyway granted by regular plenary sessions with the contemporary participation of all the researchers who could share their field experiences and their progresses, activating a process of peer learning.

The whole process has been implemented with participatory methods with the involvement of all the women participating in the research. The coordination of the activities has been provided by EducAid staff, with a significant help from the DPO Stars of Hope, while ARCO researchers have been in charge of the technical support of the process and of the coordination of the final data analysis, implemented starting from the inputs of the women with disabilities. The results have finally been examined and commented during the focus group sessions which took place in August-September 2016, during the last field mission of ARCO staff members.

3.1 - The methodology

The research conducted in Ramallah has his focus on the influence of families in the active participation of people with disabilities in the Palestinian society. A particular focus has been dedicated to the access to education and job: in both cases the research takes into consideration the access as an outcome but also as a process in which the family play a central role. The questions which have been selected by the researchers[13] try to identify the dynamics of overprotection among the families and the consequent effects on the participation of children with disabilities in the education system and in the job market. Attention has also been paid on the gender-based differences which occurs in the analysed topic.

It is important to remember that the whole structure of the emancipatory process has been designed in order to delineate a feasible research methodology and to favour the shift toward a research-oriented aptitude about disability: the participants of Ramallah, in fact, identified

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[12] This chapter has been co-authored by Irene Pasqua, research assistant at ARCO Lab.

[13] Here-hence, the group of women who participated to the emancipatory research will be defined researchers

the most relevant research questions and became familiar with the emancipatory research methodologies, taking part to every step of the project, from the co-design of the setups to the implementation of the fieldwork.

As previously noted, the women from Ramallah decided to implement a qualitative research based on 3 different techniques: semi-structured interviews, focus groups and life course interviews. Let us now briefly analyse the specific techniques and the results which emerged from the three different approaches.

3.1.1 - The semi-structured interviews to the teachers

The women from the group of Ramallah decided to conduct 6 interviews to teachers from mainstream and schools for student with special needs: the interviewees work in elementary, intermediate and high schools and they have been selected on the basis of their commitment on disability related issues.

The technical tool the researchers from this group decided to apply was the semi-structured interview. A semi-structured interview is not composed by a rigid set of questions but it an open dialogue which allow new ideas and new questions to emerge as a result of the interviewee's discussion. The team of researchers from Ramallah decided, with the technical support of ARCO staff members, a framework of themes and topic to be explored: during the field work, the women used an interview guide which represented an informal outline of the interview with questions which could be asked in different ways[14]. Thanks to this flexibility, all the interviews have been tailored to the context and to the interviewee's attitude and narration. This unrestricted method had been useful to analyse the language used by the teachers, understanding indeed their perceptions and values which emerged in each answer.

This batch of interviews has been particularly interesting since the collected data have been useful to understand in detail the problems of the Palestinian education system concerning the accessibility and the participation of people with disabilities. Since the research objective set by the Ramallah researchers focuses on the role of families, in the interviews it was important to highlight the teachers' opinions on the hampering or promoting factors coming from the familiar background of students with disabilities.

3.1.2 - The focus group discussions

A focus group is a qualitative methodology which consists in gathering together people from similar backgrounds or experiences to discuss a specific topic of interest. The group is usually composed by eight to sixteen more people and the activity is led by few facilitators with the help of a group interview format. The participants are homogeneous on the basis for recruitment but they are unknown to each other.

This methodology provides a forum to discuss issues and explore subjective matters, such as expectations, attitudes, feelings and experiences. The aim of the focus group is not to reach a

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[14] The main topics addressed during the semi-structured interviews have been:
1. Drawing a picture of the accessibility of the Palestinian education system
2. Analyse which are the material and the non-material barriers faced by students with disabilities during their educational pathway
3. Understand the role of Palestinian families in the participation of children with disabilities in education
4. Highlight the differences between boys and girls with disabilities and eventually different attitudes of the families
5. Analyse which are the policies currently into force for involving families in education and participation
6. Understand how to improve those policies
7. Understand how to improve familiar support in the participation of people with disabilities in the Palestinian society.

consensus but to have insights into the believes of the participants.
The women from Ramallah selected this specific methodology in order to compare perceptions and struggles in participation of a larger number of people with disabilities and also to create the chance for parents of children with disabilities to meet and share their daily experiences, reflecting on the impact of the role played by families. In particular, the emancipatory researchers from this group decided to conduct 3 focus groups:

- **1 FGD of women and men (mixed) with disabilities to assess gender differences**

- **1 FGD with parents of men and women with severe mental disabilities with a specific focus on this topic**

- **1 FGD with parents of men and women with non-mental disabilities to assess the point of view of families**

This activity was then useful to identify the key issues of the research from different targets' perspective and to collect feedbacks on possible pathways of improvement. The women from Ramallah well managed the facilitation of the discussions, using the support of few guidelines which had been previously drafted with the technical help of ARCO staff members. In fact, the group facilitators are clearly the most critical factors influencing the effectiveness and usefulness of focus groups since they are responsible for guiding the flow of group discussion across the specific topics selected.

3.1.3 - The life course interviews

The core of Ramallah research are 16 Life Course Interviews conducted with man and women with disability. Through the life-course interviews[15], the researchers from Ramallah explored the role of the family as a factor able to promote or hamper the autonomy and the freedom of choice of women with disabilities in the Palestinian society. In particular, these dimensions have been analyzed as concerns the access to education and to job.

The researchers from Ramallah completed 16 Life Course Interviews and the sampling has been created through the help of the staff members of Stars of Hope, who selected the interviewees from the network of the DPO activities, adopting the following criteria:

- **Both genders**

- **4 different type of impairment: mobility, hearing, visual and moderate mental impairments.**

- **2 age cohort: 18-30 and 31-40 years old[16].**

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[15] See, for example, Hutchinson (2010)

[16] The sample, then, has been distributed as follow:
- one woman with mobility impairment aged 18-30
- one woman with mobility impairment aged 31-40
- one woman with visual impairment aged 18-30
- one woman with visual impairment aged 31-40
- one woman with hearing impairment aged 18-30
- one woman with hearing impairment aged 31-40
- one woman with moderate mental impairment aged 18-30
- one woman with moderate mental impairment aged 31-40
- one man with mobility impairment aged 18-30
- one man with mobility impairment aged 31-40
- one man with visual impairment aged 18-30
- one man with visual impairment aged 31-40
- one man with hearing impairment aged 18-30

The focus of this methodology is the everyday life of the interviewee, his habits, his perceptions and how in the daily life he copes with the disability. In particular, in the storyline of every interview, the researchers from Ramallah had to identify the main trajectories, transition and turning points in the life of the interviewee. To clarify these concepts:

- **Trajectories: trajectories point to the organization of particular experience over the life course. A trajectory can be conceptualized as a pathway of development over the life span. Trajectories are typically long term, such as: schooling, work and parenthood". In this respect, a life course incorporates multiple trajectories such as work careers and family pathways.**

- **Transitions: Trajectories are marked by transitions. Trajectories are subject to short-term transitions ranging from leaving school to retirement. These transitions make up a larger trajectory, which evolves over the course of a life. Distinct events are often marking transitions– for instance moving from school to work or from one job to another – but do not necessarily alter the course of a life. Thus, they do not carry the significance of turning points. They refer to changes in status and role which are generally known about and prepared for – such as from being single to being married, or from student to full-time worker.**

- **Turning Points: Turning points lead to changes that are more fundamental. Turning points mark a change in the direction of the life course, with respect to a previously established trajectory, that has the long-term impact of altering the probability of life destinations.**

In sum, the researchers put their attention on both continuity and the more substantial changes in the life course of interviewees. This process has been extremely important in order to deeply understand the circumstances in which the participants' have lived and how they have responded to those circumstances or to the new changes occurred during their pathways: in particular, the women from Ramallah explored the different opportunities and barriers the interviewees had to face, the decisions they have made within those contexts and the most significant interactions they have had in the different stages of life.

The core research questions have been the following:

1. Which are the dynamics leading to the acceptance or to the non-acceptance of the person with disability within the family? Are there differences among men and women with disabilities?
2. Which are the conditions that lead to the creation of overprotection or of autonomy development for the person with disability as concern their relation with the family? Are there differences among men and women with disabilities?
3. Which is the level of bargaining power of the person with disability within the family? Are there differences among men and women with disabilities?
4. When are families able to foster or to hamper the participation of the person with disability to education? Are there differences among men and women with disabilities?

When are able families able to foster or to hamper the participation of the person with disability to the job market? Are there differences among men and women with disabilities?

The aim of the interviews was to identify the dynamics leading to the acceptance or to non-acceptance of the person with disability within the family and to understand which are the

☐ one man with hearing impairment aged 31-40
☐ one man with moderate mental impairment aged 18-30
☐ one man with moderate mental impairment aged 31-40

conditions that usually lead to the creation of overprotection or of autonomy for the person. Another key issue was to understand the level of the bargaining power of the person with disability and whether the family hampers or foster the participation in education and employment. It was also crucial to understand how the gender gap influences all the analyzed topics.

The structure of the interview was the following:
1. About the life situation and the life course in general.
5. In this section the interviewee is invited to freely talk about his overall life experiences, with no interest on the details but on the flow of the life course.
2. Life situation during childhood
6. Particular attention will be focused on the role of the family and the caregiver activities to promote the inclusion during childhood
3. Participation in education and training
7. This section is dedicated to the educational pathway, with particular attention to the role of family in the interviewee's freedom of choice concerning the kind of education and schools
4. Participation in employment
8. The questions of the section four aim at recollecting the story of the participant's working life and how the employment trajectories have been influenced by the family members
5. Living arrangements
9. Now the focus shifts to the opportunities for community and independent living and the role of the family in the freedom of choice on this matter
6. Role of the family
10. With special attention to the acceptance of the disability and the promotion of the autonomy
7. Gender Issues
11. This section is dedicated to the social stigma regarding gender issues
8. Concluding comments

As we can notice from the structure, the role of the family has been investigated in the different aspects of the interviewees' life course. This methodology represented for the group of Ramallah an interesting technique of data collection since the qualitative approach allow to investigate in details the deep thoughts and values of the person, through an analysis of the significant relations and experiences that influenced the direction of the interviewee's life path.

It is worth to notice that life course interviews are a quite complex methodology. The researchers is expected to find an equilibrium while trying to identify relevant events (i.e. often sensitive events) without hurting the interviewee. Moreover, the researchers highlighted the risk of a process of identification with interviewees' experiences as they personally share many of the reported problems. The pilot interviewees identified this kind of difficulties: the reports were too short and incomplete and the answers were not clear and precise. Thanks to the support of Stars of Hope, Educaid an ARCO staff and, first of all, thanks to the commitment of the researchers, the quality of the interviews and of the reports improved considerably.

A special mention must be made of the efforts of one of the blind women from Ramallah who spontaneously decided to translate all the tools used by her group in the Braille system. This personal initiative was one of the strongest feedbacks of the deep engagement of the research participants, representing the true values and aims of the whole emancipatory process.

3.2 - The results

Let's now move to a deeper analysis of the collected data. In this section, we will analyse the main themes and the key issues that emerged in the interviews and in the focus groups conducted by the women from Ramallah. These results have been widely discussed during the last mission of ARCO staff (August-September 2016), which was useful for the researchers to share their impressions and their understandings on the fieldwork activities and on the matters that raised from the data collection.

Instead of tables and charts, the elaborated results of the qualitative investigation conducted by the group of Ramallah are composed by detailed descriptions of the experiences and of the perceptions of the participants. In order to enrich the analysis we decided to report some extracts of the most significant statements of the interviews and of the focus group discussions, which have been translated from Arabic to English by the cultural mediator who followed the whole emancipatory research process.

3.2.1 - Disability: acceptance and re-organization

The first theme which emerged analysing the different Life Course Interviews, is the impact of the acceptance of the disability on the different spheres of the social and private life of the interviewees. The disability has to be acknowledged and accepted by both the person and the family in order to recreate a new balance in the daily life, from the psychological, social and practical points of view. The acceptance of disability should not be intended as the mere absence of discrimination (including introjected discrimination) but as the awareness that each person, regardless of the presence of an impairment, has the right and the potentiality to live the life she\he has reason to value.

The collected information covers both cases of persons born with an impairment and of persons who acquired their impairment over the life course. This last case is particularly interesting as the researchers are able to compare the life before and after the onset of the disability. As emerged in one of the FGDs, *"It's difficult for Person with disability to accept the disability, especially if it is caused by accident"* (FGD-Gender). When the disability is acquired, the process of acceptance is more problematic: often the person is completely unprepared to face the impairment which might occur suddenly, by accident and with no notice. On the other hand, it is also very difficult to accept the gradual worsening of the own conditions, with a day by day loss of the normal functionings of the body, of the intellectual faculties or of the psychological balance. In both those cases, new challenges emerge: several adjustments are required in order to re-establish a daily routine, and the person tend to divide his life in two separate terms, comparing the habits before and after the occurrence of the disability.

As noticed analysing the collected data, there are mainly two opposite ways to behave when the disability emerges: in the best case, the person reacts and starts using his\her residual resources to re-organise his\her life trajectory:

"I was born without disability but at the age of 15 I had an accident at school: I fell down and hurt my head badly so my sight was partially damaged. Then I went through a surgery, but it failed so I started to lose my eyesight gradually. At the same time I started to lose my confidence and people had a negative attitude toward me, but I met people who really encouraged me so after a while I became stronger. Before the accident my grades weren't good, but after the accident I studied harder in order to succeed and to achieve my goals, I became more self-confident, I integrated in the society and now I'm participating in many social activities." (LCI-28-F-VISUAL[17]).

In other cases, the person, discouraged by the occurrence of new difficulties, might feel lost and overwhelmed: *"I was a so active and clever in school, but after the surgery I lost interest and felt board"* (LCI-18-M-HEARING).

The process of acceptance depends then to different factors; as highlighted in one of the activities conducted by the researchers from Ramallah

"The time required to get used to the disability depends on many factors, by the age for example: if the person is younger it will be easier. It also depends on the chances to find a medical solution as the physical therapy and surgeries." (FGD-Gender)

The role of medical intervention is ambiguous. On the one hand the availability of good quality health care services can mitigate or even cancel the impact of the impairment on one's life. On the other hand, the over-medicalisation of disability risks to postpone the issue of acceptance. As a matter of facts, a key step for the acceptance is represented by the idea that the person cannot fully recover. This is something that has to be gradually acknowledged and admitted by both the person and the family. As mentioned in the interview conducted with E. a young boy who lost his hope to recover from his impairment after the failure a failed surgery *"…my mother and*

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[17] The Life Course Interviews are marked with the following standard abbreviation: "LCI-AGE-GENDER-IMPAIRMENT"

father actually suffered a lot, but not because of my disability but because of their desperation to find a solution to my ear problem." (LCI-18-M-HEARING). Facing the reality that the person has a lifelong disability might be daunting for the person as well as for the beloved ones. But the denial of the truth soon creates vicious cycles of vain hopes and frustration. The energies and resources that are used to achieve an unachievable full recovery could be used to set up processes of rehabilitation or, better, habilitation. Accepting the disability doesn't mean that the person is not capable anymore: it is the understanding that some changes are required since the daily routine needs to be re-organized. Without the acceptance of the reality, the family and the person cannot achieve the attitude necessary to move forward and set new accomplishments and projects.

The person born with a disability grow up with the impairment and, as everyone, develops different skills and inclinations which are useful to settle his own personal and professional goals. On the contrary, in the cases of acquired disabilities or for people in worsening conditions, the person often lose the ability of doing some of the daily life activities and it might become difficult or even impossible to cultivate and accomplish the know-how or the objectives the person might have desired and cherished for long time. The acceptance of the disability, in these circumstances, could also mean to elaborate a new life project including different professional ambitions.

"I finished my bachelor on social work with good grades but I am currently not working: the employers refuse to hire me because of my disability, there is no accessibility in the transportation and working places and the salary is low. My previous office was in the second floor and there were no helping devices." (LCI-31-M-MOBIL).

These episodes happen quite often, especially in societies where the level of accessibility of schools, workplaces and public areas is extremely low: in Palestine, despite the Law on Persons with Disabilities approved in 2004, people with disabilities still represents one of the most vulnerable and marginalized groups, facing impairments in the use of public transportation, in the access to public buildings and, consequently, in the social integration.

3.2.2 - The importance of social life for a strong integration in the society

Social networks are a crucial part of everyone's life. The presence of a disability induces a re-organization of the social networks of the person: the changes might concern the quantity, the quality and the variety of social relations. As we could notice from the life course interviews, the experiences of the integration are strikingly different one from the other, from heavy level of segregation to an intense social activity. In the best cases, the occurrence or the worsening of an impairment does not lead to major changes in the individual social network:

"Before the disability I had a good relation with my friends, I visited them and did many activities together. Also after disability our bonds haven't changed, they still contact with me and we do many activities together. They helped me to accept the disability and to facilitate my inclusion in the society." (LCI-35-F-MOBILITY)

In some other cases, the disability creates a distance between the person and his friends which might recover with the passing of time, when the beloved people get used to the new conditions of the person.

"I had a good relations with my friends. I visited them and did many activities together but after I had the accident they didn't contact me, so I was forced to make new friends. When I returned to school, it was difficult at the beginning, my mates didn't communicate with me. It took some time but later on they accepted me and also my teacher encouraged me to study hard." (LCI-28-F-VISUAL).

On the other hand, it is important to highlight that only a small share of people with disabilities are able or allowed by the families to actively take part to social activities in the Palestinian society. As emerged in the Focus group on gender issues*, "90% of persons with disabilities don't participate since there is no accessibility. The person have to struggle to be a part of any social activity."* and also *"the situation is even worse if the person is not able to accept the disability: in such cases, he would exclude and isolate himself form all activities."* (FGD-Gender). For these reasons, the DPOs and the associations play a crucial role in supporting the integration of people with disabilities in local communities. Through the activities in the associations, the person can meet and rely on new people, familiarize with the concept of disability and expand his social network. The connection with a DPO is also extremely useful for the person to be supported in understanding his rights, in order to raise his awareness on his professional, educational and social possibilities in the local neighbourhood. A DPO might also be useful to increase the chances to receive any specific support from the government for economic relief and assistive devices. Unfortunately, in the Palestinian territories *“there is lack of quality and quantity of organizations that take care of people with disabilities”* (FGD-Families) and, as specified in the focus group with relatives of children with mental disability, the shortage and the inadequacy of the associations is particularly relevant for this target:

“*There are no organizations that take care of the mentally disabled people, they only receive health care supports. But there is no such a thing as organizations that take care of them completely, or even integrate them in the society. There are few organizations that take severe cases of mental disability and take care of them, and even these organizations they don’t take care of mentally disabled individuals of all the ages.”* (FGD-Mental disabilities).

In fact, the Focus Group Discussion that involved relatives of people with mental impairment, the participants strongly highlighted the heavy need of support from the associations, which are playing a key role in supporting the families and in improving the quality of social life of people with disabilities in order to strength their integration and participation in the Palestinian society[18].

3.2.3 - The duplicity of the family: essential support and overprotection

As previously mentioned, the family plays an important role in the process of acceptance of the disability: the familiar support is extremely important to rebuild the daily routine of the person and normalize the psychological balance and the social integration of the person. As specified by a young boy with acquired hearing impairment:

“My *parents are really supportive; they support my job, they always encourage me in finding new job opportunities and they thought me not to feel ashamed of my disability, or to surrender. They are always encouraging me to be strong and independent, they want me to think about my future and to make plans for settling in, get married and create my own family. Their support is crucial and my personal opinion is always taken in consideration, so the fact I have hearing impaired hasn’t affected on whether my family should or shouldn’t take my opinion.”* (LCI-18-M-HEARING).

The support from parents and relatives is significant in the major aspects of the person’s life: especially when it comes to children, the family has a decisive role in deciding about the school and the future, fostering the integration of the child in a suitable environment or discouraging and underestimating the possibilities of the person and of the surroundings. As suggested by the interview with a teacher coming from a primary special school,

“*In general, 95% of parents enrol their disable children into schools and teachers encourage them to do so, while 5% of them tend to hide their children and prevent them from integration in the society either for reasons of fear or stigma. Families and parents are advised to encourage, to push their children to take an active part in their communities. Moreover, it is extremely important the communication between children and parents: for example, if the family learn the Braille code, the blind child will feel more motivated since the closest people are familiar with his/her communication language.”* (T.INT-ELEMENTARY-SPECIAL[19]).

With the help from the parents, the child can better understand his\her points of strength and his\her weakness of the learning processes and of the personality, training his\her self-awareness in order to guide the future plans in directions that fit with his\her skills and his\her abilities. It is important that the parents communicate with the child in order to reach joint decisions about the school environment, choosing, if possible, the most suitable option among special and mainstream schools.

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[18] As will be shown in chapter 4, these qualitative findings are perfectly coherent with the results from the quantitative survey implemented in Nablus

[19] The interviews to the Teachers has been coded has following: “ T.INT-SCHOOL LEVEL- SPECIAL or MAINSTREAM”. For example, (T.INT-ELEMENTARY-SPECIAL) refers to an interview with a teacher who is working in an elementary special school.

The family also plays a crucial role in integrating the child with disability in the local community, encouraging him in taking part in social activities in order to become more self-confident and independent. In one of the Life Course Interview conducted with a girl with moderate mental disability, she declared that the support from her relatives has been crucial to settle her social life:

"*My life has changed since my relatives are supporting me, taking me with them to their friends and letting me participate to the weddings too. (…) My parents have always supported me in my education, after I dropped school they looked for a special school that takes care of the cases like mine. My family has accepted my disability ever since I was born, they knew how to deal with my case, and my mom was really patient with me she has taught me everything; eating manners, how to take care of my personal hygiene and to respect others. My mom loves all of my siblings and me equally, and she is not ashamed of me she always takes me with her to social events and visits. (…) I think my parents support has made me optimistic."* (LCI-17-F-MENT).

It is not always easy for the families to cope with the disability of a relative: often the parents have to make huge sacrifices in term of money and time in order to help the child in living in a friendly and healthy environment. In the interviews emerged that the Palestinian government distributes an insufficient supply of funds in support of people with disabilities, so the families are forced to face heavy health expenses for medicaments and assisting devices. In the case of mobility impairment, for example, the house needs to become accessible for the person and the special devices which are required might be expensive and difficult to find in Palestine. Also medicines and medicaments might create economic hardship in the household budget. As highlighted in the focus group concerning the role of the family, one of the participants declared:

"Is it is difficult for the families to accept the children with disability, especially if she/he is the first child, and if she/he has mental disability since this kind of impairments need more cares and attention. Providing treatments for the disabled children can be expensive and this would put a burden on the family: if the family members feel under pressure, the child live in a negative environment." (FGD-Families)

These sentences has been confirmed during the first focus group discussion, where a mother of a child with mental disabilities said:

"I am an employed lady and I would love to integrate my child in the society; it is important for them to have a social network and to learn good manners. Having a child with disability can be very hard, especially if both the parents work, because much time and attention are required". (FGD-Mental Disabilities).

The family has then a strong influence on the process of "*normalization*" of the life of the person with disabilities. For the child with impairment it is crucial to be treated equally to the siblings, otherwise the child might feed different and underestimate himself. As reported by one of the interviewee,
"My parents gave me everything I need: clothes, food, housing, affection and tranquillity. I have never felt the feeling of inferiority, and that made me love my family even more. My father and my mother have always supported me, inviting me to their friends and to picnics, exactly as they did with my siblings" (LCI-18-M-HEARING).
On the other hand, the family is not always able to understand which are the needs of the person with disabilities: often the parents are worried because of their child's impairment, so they put strong limitation to the child's freedom creating vicious cycles of overprotection and miscommunication:
"*We are afraid of the harassments, whether it was sexual or physical, that our children with disabilities might face, from neighbourhood children, strangers or even relatives. The idea of them to be independent is scary to us because of the risks they might face."* (FGD-Mental Disabilities)
All in all, even in cases where it is possible to find an explicit attempt of the family to foster

the participation of the person with disability to the society, we can often observe a sort of "*embedded participation*" that is the tendency to build a space for participation controlled by the family. This inclination tends surely to be stronger for women with disabilities. In a smaller number of cases, and in particular in the case of persons with mental disabilities, we have levels of overprotection that give rise to segregationist processes. One typical example of the overprotection has emerged in the interview of a young boy with intellectual impairment:

"My family can't understand what I need and my parents are not able to accept me: they keep me at home and they don't allow me to include and to participate in social activities. They are worried about me because they think other people are not able to communicate with me." (LCI-19-M-INTELLECTUAL).

Many families are extremely worried about the external interactions of their child and these fears lead the kids to social and educational constraints and to restrictions in their decision-making power. As highlighted in another interview:

"Many problems occurred when I asked my parents to treat me like my brothers and sisters: in fact, my parents didn't allow me to visit my friends, and at the beginning my family believed that I couldn't attend the college. They didn't encourage me to depend on myself because of my disability and I didn't participate in any decisions related to family matters" (LCI-25-F-VISUAL).

Social stigma and discrimination are the strongest causes of the dynamics of overprotection: it is important to report that finding reliable data on disability in Palestine is very difficult due to a lack of official registration especially for women with disabilities (EducAid, 2013). Often, in fact, the family is not willing to expose the disable child to the community because they fear popular judgements and social intolerance, so the practice of hiding at home the person with impairment is still quite diffused, with a strong negative impact on the social and professional opportunities for the child. In the specific focus group on the role of families, the point of view of the participants came out with solid and clear statements:

"The overprotection of disabled individuals, whether they have mental disability or other forms of disability, is always negative. Having child with disability can be difficult, but that doesn't mean that the parents of children with disability shouldn't teach their children the values of giving, of being independent independence, and of possessing good manners. When the parents are overprotecting, their children cannot experience self-determination, they would have no confidence in themselves and they wouldn't develop their life skills." (FGD-Families).

3.2.4 - Discrimination: the challenge of education and employment.

Discrimination affects many aspect of the person's life: two of the domains where prejudices and stigma have the strongest influence are education and employment. In the research conducted by the group of Ramallah, the access to education is one of the major focus: the researchers have been able to catch the main aspect of the school experience of children with disabilities from the points of view of families, teachers and children themselves. What emerged from the overall analysis of the collected data is that education is a crucial step in the accomplishment of the full participation of people with disabilities in the society. Unfortunately, this field is also considered one of the most problematic and challenging for the child with impairments, due to the inadequacy of the school system and the lack of awareness of the teachers. In fact, despite the Law on Persons with Disabilities, approved in 2004, more than two thirds of Palestinian persons with disabilities were never enrolled at educational institutions and 53.1% are illiterate (DSC Birzeit University, 2012). These percentages on education are even more astonishing considering that the literacy rate of the Palestine State is 96.7% (UNESCO, 2015).

One of the main barriers to achieve a fully inclusive education is the accessibility: the shortage of assistive devices and facilities represents the first strong impairment to the school integration of the child, who is physically not able to reach the classroom or to follow the lessons. As mentioned by one of the teachers

"The absence of accessibility is an important obstacle. For example, there is no sign interpreter in schools and universities for Persons with hearing and speech impairments. Often the schools refuse to hire one so the parents are forced to hire a private sing translator to communicate to

their children in schools or university. Unfortunately, there are no laws which protect their rights." (T.ELEMENTARY-MAINSTREAM)

The lack of environmental accessibility in the most part of the mainstream schools creates a huge challenge for the child and his family, that sometimes are forced to address their needs to special schools which are very few in the Palestinian territories.

"In special schools, the interaction among the students is healthy and based on mutual respect, and of course it depends on the students' personality. The mainstream schools should become more inclusive: for a blind child, for example, it is important to attend school in the neighbourhood, in order to avoid the unfamiliarity of the surrounding space and environment." (T.INT-ELEMENTARY-SPECIAL)

Another crucial aspect is the qualification of teachers: often the children are underestimated or even discriminated in the class because the teachers are not trained to deal with disabilities. As highlighted by one of the teachers,

"The educational services available for disabled girls and boys still don't reach the aspired level, since the school system is not able to comply with the proper education requirements. In the kindergarten stage, the teachers and nannies are not qualified and the teaching tools were not responsive to the special needs of the children. In the elementary stage, the syllabi don't respond to the special needs of the disabled students: for example, no Braille printed books were available in the elementary or high school levels. Nevertheless, some Braille printed books are available in some universities for the visually impaired students." (T.INT-HIGH SCHOOL-MAINSTREAM)

The lack of the awareness of teachers and the shortage of assistive learning devices might turn the school experience in a circle of frustration and dissatisfaction for the child. As clearly emerged in the narration of a young girl with mental impairments:

"I didn't like my school; I always ran away from school. I didn't feel accepted, the teacher used to get me out of class to clean the school yard and help our cleaning lady, or even clean the school's bathrooms. That's why I used to run away from school or hide on the school's roof hoping that the teachers and the principal wouldn't see me. Sometimes I feel that my right to education has been violated: while the other kids used to go to kindergarten to study and to play, I stayed at home. When I went to school, I felt that I was left behind, the teachers didn't accept me, so they didn't make any effort to let me participate in class or to explain me the things I couldn't understand. I felt that I was different than the others: many other children didn't want to play with me and they even used to make fun of me. The school has not been cooperative with my disability, the principal used to call my mom every day and to complain about me. Fortunately, my mother decided to take me out of that school" (LCI-17-F-MENT).

The training of teachers seems to be a priority. It is interesting to remember that, in last instance, teachers are the medium of all the improvements that can be introduced in the education system. As emerged in the following interview, the behaviour of teachers can create dynamics of exclusion and segregation that are not justified by the absence of assistive devices or by not adequate infrastructures but by the lack of a human rights based approach to disability:

"The situation worsened because of my hearing disability. I preferred to sit in the first rows to hear better the teacher but, as I am tall, the teacher moved me back. This prevented me to follow the lectures as the others" (LCI-18-M-HEAR).

The child with disability then has to face many material and non-material barriers: from the lack of teachers' expertise on disability matters to the poor services and accommodation in the school buildings; the deprivation in education negatively affects then the future plans and professional opportunities of the person, creating often a bad spill-over on the self-confidence of the person.

Fortunately, not all the school experiences that emerged from the Life Course interviews have been negative. If the child has the chance to experience an inclusive and accessible atmosphere in school, the experience in education will have a positive impact on his psychological balance, on his social interactions and on the employment opportunities as well.

"I was really happy when I was at school, I was a good student; I used to study hard, I was never late to school and I used to wake up early and with full energy. I also loved my friends from school, and I am still in touch with some of them. I had a good relationship with my teachers, I used to hate weekends and holidays, because I knew I wouldn't see my teachers and my schoolmates. At that time I also took part to many extracurricular activities, and I really loved sport." (LCI-45-F-MENTAL)

As suggested in different teachers interviews, there are quite a lot of amendments that should be implemented by the Palestinian school and government institutions in order to improve the accessibility and the quality of the education for children with disabilities.

"It is necessary to build strategies and policies to improve education for people with disabilities and make it mandatory, besides providing trained teachers and establishing accessible centres to learn any career suites their abilities in order to guarantee their satisfaction and their ability to independently produce their income" (T.INT-HIGH SCHOOL-SPECIAL)

Moreover, in order to reach effective results, it is important to work at the same time with the families, in order to improve their supportive attitude toward the child, and with the local organizations and DPOs to enforce the awareness raising activities and sensitize the local population at different levels.

To conclude, we'll mention some of the challenges that people with disabilities have to face in the job market. It is worth to stress the fact that the access to education has deep consequences on the chances to find a suitable job for the person: the marginalization encountered during the school experience is often reflected in the lack of valuable opportunities to find a fairly paid job that matches with the person's skills. The high rate of unemployment (see Chapter 2) and the widespread discriminatory attitudes of the employers have then a negative spillover on the access to the job market for people with disabilities:

"…when I applied for a new job and went to the job interviews, the employers refused to hire me because of the disability and advise me to work at schools for people with visual disability. They think that I cannot properly do my job, they have a negative attitude towards persons with disabilities." (LCI-25-F-VISUAL).

As clearly pointed out in various life course interviews, the impairment-based exclusion from job opportunities might affect the motivation of the person, especially when it comes to qualified and skilled people who previously went through vocational trainings or high level educational programs.

"Frankly my experience with the job market was tragic: after my university graduation I wrote the ministry of education's employment test, but after I finish the interview the committee said that I was not suitable for the teaching position just because I am partially blind. Facing the rejection was extremely frustrating: I got rejected just because I am partially blind, they have assumed that my disability wouldn't allow me to do my job as required and they have assumed that I wouldn't be good enough to deal with students as required. The ministry of education's committee wrote "unfit" beside my name and they haven't hired me, and that made me feel depressed." (LCI-30-M-VISUAL)

Some of the interviewees reported also the precarious and demanding conditions they have been forced to accept in order to receive any sort of income. Due to the underestimation of the skills of people with disabilities, the contracts which are offered to them are often temporary, occasional and underpaid.

"I have faced many obstacles in my professional career: at the beginning I was working at a bakery but, since I have an hearing impairment, I couldn't hear when my boss was calling me or yelling at me to do a specific tasks so he fired me. After that, I relative of mine offered me a job

after I explained to him my conditions: he respected my disability and hired me. To be honest, I don't think I will look for another employment, even though this job irregular and underpaid." (LCI-18-M-HEAR)

In addition to these aspects, it is important to consider that the access to a suitable job is even more difficult for women with disabilities. As most part of the interviewees highlighted, women have to face an heavy additional discrimination related to gender inequalities.

3.2.5 - Gender inequality: an additional burden of discrimination

"The discrimination against women is stronger than the one against male, in all the aspect of life: job, education and participation in the social activities and even being active member in DPOs in more difficult. Moreover, men with disability have more chance to marry than female with disability. Some families of man with disability don't allow their son to marry a woman with disability because they think she will never be able to work since she is incapable." (FGD-Gender)

As specified in the Focus Group Discussion hinged on gender issues, women with disabilities represent one of the most vulnerable pocket of the Palestinian society. In different life course interviews it emerged that women are exposed to heavier social stigma in all the dimensions of life: for example, they have a worse access to education and employment. The higher unemployment rate of WwD and the expenses for the medical needs linked to the disability have a strong impact on the financial situation of the families. Women with disabilities then become source of shame and sometimes they are even considered a disgrace for the family (DSC Birzeit University, 2012).

"There are huge differences between girls and boys, also in the way they are unequally treated by their families. There is a relevant discrepancy, as boys receive more care and attention even if they are disabled. This is due to the fact that we are living in a male dominant society and priority is given to males as in all other aspects of life. Often girls with disabilities don't receive enough encouragement from the family, while boys usually receive more support and positive feedbacks from the parents." (T.INT-HIGH SCHOOL-MAINSTREAM).

One of the most significant witness on this issue comes from the Life Course Interview to the young boy with hearing impairment: in fact, it is quite surprising how firmly he affirms that his life would have been completely different if he was a girl.

"I believe if I was a female the disability would have had more influence over my life. In our society, disabled girls are exposed to stigmatization, lack of marriage opportunities, discrimination in education and employment and mobility restrictions. This is a cruel society when it comes to women issues. I think also the relation with my parents would have been different if I was a female: they would have put me under a lot of pressure in hanging out for example, as my family is really conservative and women are not allowed to mingle without a legitimate escort. Moreover, women are not allowed to socialize with men at all, even to close family members, and they are not free in choosing their outfits. As a female I wouldn't be allowed to have any employment opportunity, I would only go to school but under very specific conditions and restrictions." (18-M-HEAR).

The attribution of inferior status of women with disability is reflected in the societal behaviors, strengthening their circuits of exclusion and isolation. The vulnerability of women with disabilities also increase their exposition to violence and abuses in the familiar and communitarian contexts (EducAid, 2012).

"Violence exists in its different forms: physical, verbal, and psychological. People with disabilities are often exposed to these three types of violence in their community or even in their families. Yes, domestic violence against disabled individuals exits; some harass their disabled children orally, physically and even sexually. Especially when it comes to females with disability, the abuses are frequent and harmful: women are often sexually harassed even by their relatives and

their siblings." (FGD-Families).

Marriage is also seen as one of the most critical points in gender differences. In the focus group for relatives of people with mental impairments, some of the participants pointed out that getting married is a very crucial issue for every person with disabilities, also because of familiar restrictions.

"Some relatives look at their kid with disabilities with pity, some say that it is a punishment of previous mistakes, and some say the disability is a disease and it may be contagious that's why they don't think they should get married to avoid infecting the others with the disability." (FGD-Mental disabilities).

Finding a partner is, in fact, one of the main problems for every person with disabilities, but for women this issue is much more critical because of their weak social inclusion: for cultural reasons this element affects more women than men, and it adversely influences independence, autonomy and self-confidence. Women with disabilities tend to experience more problems in having babies, in taking care of other family members and in dealing with house works: in the most traditional context of the Palestinian society, this increases the social marginalization of women with disabilities and affects their chances of creating a family on their own.

The issue of marriage is then perceived as one of the domains characterized by the most severe form of discrimination. In the case of men with disabilities the family tend to push the person to find a wife and to create a family. Going back to the interview to man with hearing impairments that has been already cited, it emerges that the family encouraged him *"to think about my future and to make plans for settling in, get married and create my own family"* (LCI-18-M-HEARING). On the other hand, for women with disability both the family and the society take their non-marriageableness for granted. This gender based discrimination is well exemplified by an episode happened in a village nearby Ramallah and reported by the researchers during the discussion of the results. Basically two young persons with disabilities (both with an hearing impairment) got married. The whole village was shocked by this marriage. The point was not that two persons with disabilities married together but that a girl with a disability found a husband.

In conclusion, we can deduce that gender inequalities worsen the social stigma and the environmental barriers of women with disabilities, that have to face the double burden of being women and disabled: in the Palestinian patriarchal society a WwD has less freedom and less opportunity to finish her education, find a job or get married compared to a man in the same conditions (EducAid, 2012).

3.2.6 - Conclusions: the critical exit from the "*safe circle*"

The overall picture that emerged from the data collected during this qualitative research is complex and multifaceted. As we could notice, the framework is heterogeneous: the living conditions and the restrictions that people with disabilities have to face strictly depend upon many factors, as the type of disability, the gender of the person, if the disability was acquired or from birth, if the family could accept the disability, etc…

Every life course interview was in fact different from the others: each interviewee reported the personal unique experiences that have been crucial to define each step the person has made since so far as well as the direction of his or her future life path.

Besides all the specific peculiarities, the *file rouge* that emerged from the collected information is that every person own a "*safe circle*", which namely is a set of familiar people, factors and activities that the person deals with in the daily routine. As deduced from the attribute, as long as the person stays inside the comfortable and well-known "*circle*" of experiences and relations, he or she will feel safe and protected. This circle differs from person to person, and its extent may change according to several factors, such as the severity of the disability, the cultural level of the family, the number of activities the person is involved in etc… Nevertheless, every person can always trust and count on the protection of the beloved friends and family members. This is happening for people with as well as without disabilities.

What emerged from the Life Course Interviews is that the person faces critical challenges when he or she is forced to exit the “*safe circle*”: in fact, leaving the restricted set of friendly surrounding always represents a frustrating and demanding shock which compels the person to new adjustments and changes in the life routine. This process is relevant both for people with and without disabilities, but the person who has to deal with an impairment are usually more vulnerable to changes: the psychological resilience of persons with disabilities, in fact, to adapt to life tasks is often weaker due to the social and practical disadvantages we discussed in this chapter. Moreover, in the case of persons who do not have a disability, the exit from the safe circle is usually a gradual process: since the childhood the person began to gain and manage a space of autonomy and to enlarge it year by year, step by step. In the case of persons with disabilities, the exit from the safe circle is often a sudden change as often families tend to overprotect the person as long as it is possible until the clash with the exterior word is unavoidable.

As emerged from the Life Course Interviews, the exit from “*safe circle*” might be represented, for example, by the beginning of the school or of a new working experience, because both imply the interaction of the person with a new set of people and activities which upset the ordinary balance of the routine with unpredictable challenges. This process might be marked by negative emotions, fatigue and sense of powerlessness since the social discrimination and the lack of accessibility for persons with disabilities adversely impact the person’s ability of rebuild his or her own life tranquillity.

Despite these features, the experiences which have been reported in this analysis lead us to the conclusion that the different events which everyone crosses during live modify the quality and the extent of our “*safe circle*”: after a first impact which might be challenging, the person might be able to recreate a safety net adjusting his or her life in ways which might not be dreamed possible, thanks to the support of few reference points and, most of all, thanks to the self-awareness that having a disability does not mean being incapable, helpless or hopeless.

In other words, families and institutions should began to foster the autonomy and the resilience of the person with disability since the early childhood: it is worth to remember that the point is not only to have a successful exit from the safe circle but also to been able to manage and to take profit of possible failures.

CHAPTER 4 - Results from the Field Research of the Group from Nablus

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The field research implemented in Nablus is focused on care givers and chiefly and mothers and sisters of persons with disabilities. The field research in Nablus saw the participation of a group of around 20 researchers who are women members of the DPO Asswat. The data collection involved 143 women who are care givers of a person with disability. Coherently with the research protocol elaborated during the first field mission of ARCO researchers, the main topic of the research is the quality of life of care givers and this issue is addressed starting from the analysis of the time use patterns: during the preliminary FGDs, the researchers from Nablus pointed out the availability of time (both in terms of quality and quantity) as the engine of the multidimensional deprivation of care givers. As in the others field research the data collection and the data entry were managed by the researchers themselves with the support of GUPwD and Educaid staff and the technical assistance of ARCO researchers. The data analysis was implemented by ARCO researchers under the guidance of the women with disabilities involved as researchers. The results were discussed and commented during three focus group discussions held in August-September 2016: the FGDs saw the participation of the researchers and of ARCO staff members.

4.1- The Profile of the Interviewees

The data collection involved 143 women coming from the governorates of Nablus (70.63%), Salfeet (27.97%) and Jenin (1.40%). The women live both in urban (44.06%) and rural areas (53.15%). The average household size is 6.2 members while in more than a half of the household only one member is currently working.
The interviewees were asked to indicate the degree of perceived economic vulnerability of their household. The most part of the interviewees declared to experience a condition of more or less severe economic vulnerability. More than on interviewee out of four reported a condition of extreme vulnerability

Tab 4.1- Degree of perceived vulnerability of the family

Degree of vulnerability	(%)
very low	5.59
low	15.38
high	52.45
very high	26.57

Source: authors' elaboration

While discussing about possible indicators of the economic status of the household, the researchers pointed out the opportunity to have access to private health care services as good proxy of the material deprivation experienced by the household[20]. As a consequence, the interviewees were asked to indicate how often a member of the family is compelled to postpone or to avoid at all a private medical examination. Table 4.2 shows that about one interviewee out of three report more or less severe form of deprivation. Moreover, the cross tabulation with the perceived economic vulnerability shows a substantial coherence between the two indicators.

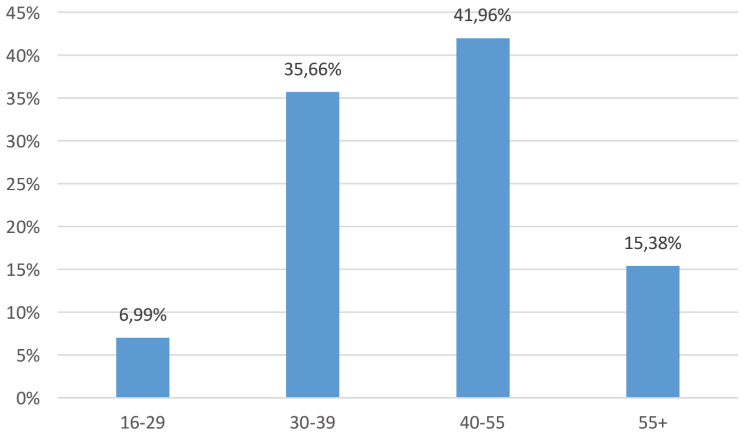
Tab 4.2- Frequency of delayed access to healthcare

		always (%)	**often (%)**	**occasionally (%)**	**never (%)**
	total	11.19	20.98	48.95	18.88
perceived vulnerability	**very low**	0	0	0	100
	low	0	13.64	36.36	50
	high	12	13.33	65.33	9.33
	very high	18.42	44.74	34.21	2.63

Source: authors' elaboration

The age of the interviewees ranges from 18 to 79 years while the average age is 43 years old.

Fig 4.1- Distribution of the interviewees across age groups



Source: authors' elaboration

Basically all the interviewees are Muslim (98.6%) and a large majority of them is married (86.04%). The education level reached by the interviewees changes according to the age: younger interviewees tend to have a higher level of education: for example, there are no women without education in the age classes 18-29 and 30-39 while they account for 18.18% of the women aged more than 55. This is coherent with global trend of increased access to education for Palestinian women over the last decades (see also chapter 2).

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[20] It is worth to remember that only 50% of Palestinians are covered by a health insurance (that is compulsory only for public workers). Obviously, this prevent a large share of the population from having an appropriate access to health care services (Rashad and Sharaf, 2015)

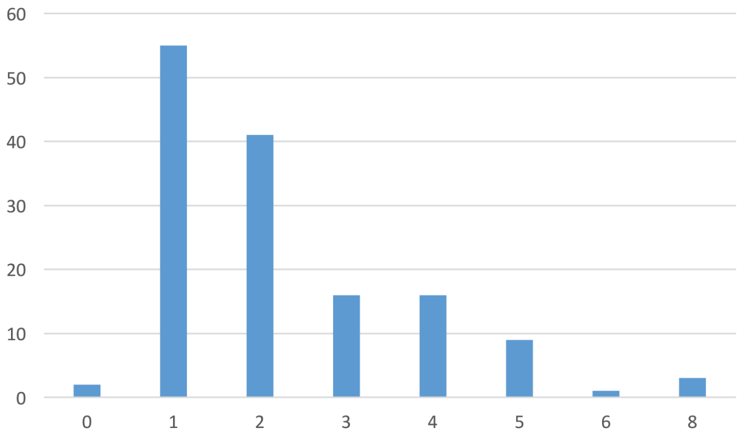
Tab 4.3- Education level reached by the interviewees

		no education (%)	elementary (%)	intermediate (%)	secondary diploma (%)	BA or more (%)
	total	4.90	17.48	20.28	41.26	16.08
Age class	**18-29**	0.00	0.00	0.00	60.00	40.00
	30-39	0.00	9.80	17.65	45.10	27.45
	40-54	5.00	23.33	23.33	40.00	8.33
	55+	18.18	27.27	27.27	27.27	0.00

Source: authors' elaboration

Only a minority of the women is currently working (17.48%) while the majority of them has no experience on the job at all (68.53%). Despite this very low involvement in the job market, 80% of the interviewees was not actively looking for a job at the moment of the interview. Even focusing the analysis on the women who are not currently working, it is interesting to notice that 75% of them is not actively looking for a job while this share decrease to 70% if we exclude women who are older than 55 years old. To sum up, a very large share of the interviewees seems to be completely excluded from the job market. This widespread marginalization is confirmed if the perceived opportunity to get a decent job is analyzed. The distribution of the perceived opportunity (ranging from 1 to 10) is heavily left-skewed and the average score is 2.26. The average is even lower if the analysis is focused on women without any experience on the job market (1.73) and for women aged 30-39 (1.94). In such a framework, re-activation policies targeted on these categories are at the same time a urgent need and a valuable challenge.

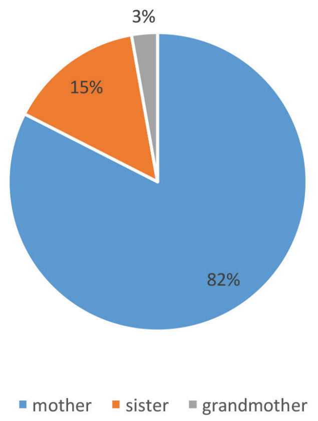
Fig 4.2- Perceived opportunity to get a job (1-10)



Source: authors' elaboration

Taking into consideration the relation of the interviewees with the person with disability, as shown in fig 2, in the very most part of cases the interviewee is the mother of the person with disability. It is interesting to notice that in our sample we don't have at all women who are wives of a person with disability.

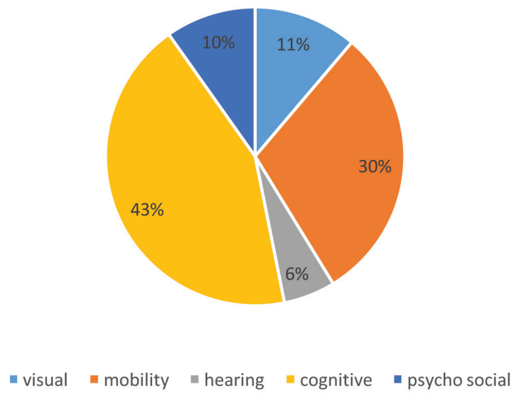
Fig 4.3- Interviewees' relation with the person with disability



Source: authors' elaboration

Moving from the caregiver to the person with disability, the age of the persons with disabilities ranges from 16 to 79 years old. The survey covered care givers of both men and women with disabilities with an almost perfect balance (72 men and 71 women). Concerning the typology of the disability, it is worth to underline that a large part of the interviewees is the care giver of a person with psycho-social or cognitive disability (53%) while hearing disabilities are probably underrepresented in our sample. It is interesting to notice that all the typologies of disability are covered in the sample.

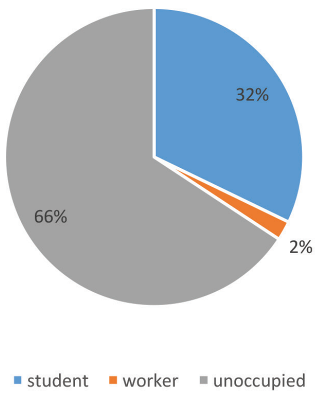
Fig 4.4- Interviewees' relation with the person with disability



Source: authors' elaboration

Interestingly, the most part of the persons with disabilities (namely 66%) are not occupied nor as students nor as workers. This point is extremely interesting as it has clear consequences on the care activity of the interviewee. The percentage of persons who are working is extremely low (2%): this confirms the difficult situation highlighted in chapter 2 even if the high presence of persons with psycho-social and cognitive impairment in our sample probably tend to worsen the general picture.

Fig 4.5- Occupation status of the person with disability



Source: authors' elaboration

4.2- The care activity

The care activity is one of the main topic addressed by this research. As highlighted during the focus group discussions, the care activity tends to become an all-encompassing activity and the whole life of the person is shaped around activities linked to the care of the person with disability, of the house and of the other household members. In this sense the ability of the person to share the burden of care is crucial to maintain a fair level of quality of life. Moreover, as will be shown, the care of the person with disability is often additional to other forms of care (care of other household members and housekeeping).

The data reported in table 4.4 shows that the large majority of the interviewees perceive herself as the primary care giver of the person with disability. Despite that, the share of those who are the main caregivers of other household members and of those who are the main person in charge for housekeeping is very high too.

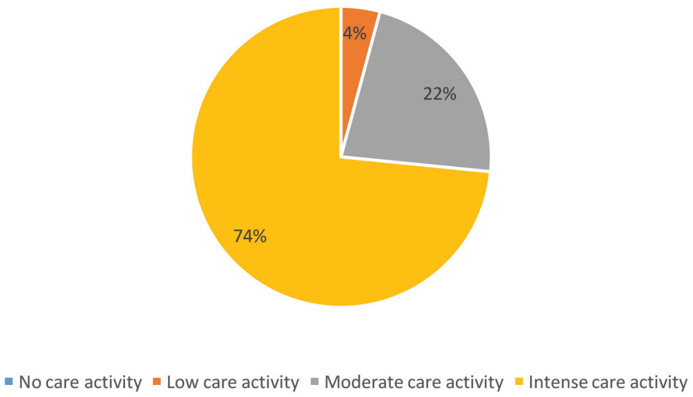
Tab 4.4- Care activities

	(%)
main care giver of the PwD	93.71
main caregiver of other HH members	83.22
main person in charge for house keeping	92.31

Source: authors' elaboration

An indicator based on the sum of the three variables has been computed to summarize this information. Obviously the range of variation of the indicator is from 0 (no weight of care activities, i.e. the person is not a main care giver nor the main person in charge for housekeeping) to three (high weight of care activities). Basically, three interviewees out of four are, at the same time, the main care giver of the person with disability, the main care giver of the other household members and the main person in charge for housekeeping.

Fig 4.6- Intensity of care activities



Source: authors' elaboration

The ability (or the opportunity) of the interviewees to get support from other persons for the daily care activities is potentially extremely important to maintain a fair level of quality of life of the main care giver. To share the burden of care is important not only in practical terms but also from a psychological point of view. Table 4.5 shows that the only affordable source of support are the other women belonging to the nuclear family as they are always or often available in 47% of cases. The role of male members of the nuclear family is much more negligible as it is present in a systematic way only in 24% of cases. The support coming from the enlarged family and from neighbors and friends substantially is not significant. This is a quite unexpected result given the strong emphasis often laid on informal networks by scholars, practitioners and policy makers. The role played by NGOs and public institutions is even less significant.

Tab 4.5- Sources of support for care activities

source of support	always (%)	often (%)	occasionally (%)	never (%)
women from the nuclear family	30.77	16.78	26.57	20.28
men from the nuclear family	14.69	9.79	45.45	28.67
other relatives	1.40	3.50	17.48	76.22
friends	0.00	0.00	4.90	92.31
paid caregiver	2.80	0.00	1.40	93.01
NGOs	3.50	4.20	23.08	67.83
public institutions	0.00	4.20	10.49	83.92

Source: authors' elaboration

Considering that we can define as systematic support a source of support that is constant (i.e. the answer is "always") or at least available some days each week (i.e. the answer is "often")21, it is interesting to notice that more than one third of the interviewees is totally devoid of support and that only 24.48% of them has access to more than one source of support.

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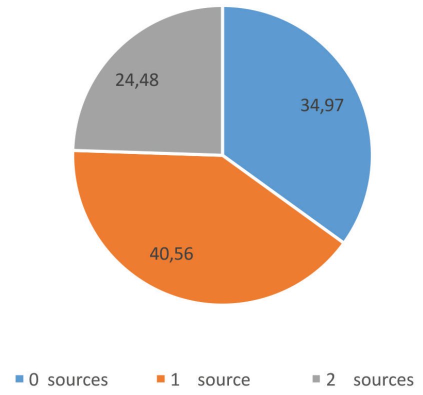
21 Note that this coding (i.e. always= each day, often= at least a couple of time per week etc.) was elaborated with the participation of the researchers and then confirmed during the training of the researchers who were going to be in charge for the data collection

Fig 4.7- Sources of systematic support



Source: authors' elaboration

These results were deeply discussed during the focus group discussions organized in Nablus. Concerning the role of the nuclear family, the researchers underlined that the difference between men and women are linked to the patriarchal structure of the Palestinian society: mothers tend to reproduce the gender dynamics experienced during their childhood while organizing the care activities within their household. As a consequence, sons are much less involved than daughters. The weak contribution to the care activities of informal care networks external to the nuclear family is linked to several factors. First, the stigmatization of persons with disabilities (in particular in the case of psycho social and cognitive disability) is translated in a scarce aptitude to provide care to persons with disabilities (unless they are members of nuclear family). Second, the main care giver of a person with disability tend to think that no one is able to take care of the person as she does. Quite the contrary, many care givers are not confident in other persons for what concern the care of her son\daughter with disability. A third relevant factor emerged during the discussion and was confirmed also during the qualitative interviews organized in Ramallah22: the mother of a child with a disability tend to feel guilty as the child was her own mistake. As a consequence, she must take her own responsibility and expiate her fault. This sense of guilt is not a creation of the mothers but a sort of internalization of the social stigma toward disability. In other words, the problem is not only the lack of support but also the lack of willingness to accept support coming from outside of the nuclear family as it would mean to share the shame of a child with a disability with a "stranger".

The extremely marginal role played by NGOs and by public services is linked to the structural weakness of Palestinian institution that brings to the absence of a coherent policy framework and of the relative actions at the national and local level. Moreover, the bulk of available services are focused on early childhood and it is very hard to find structures providing support services for adolescent and adults with disabilities.

These data are coherent with the answers of the interviewees when they were asked to indicate whether they were willing to share the care activities in a different way. As shown in table 6, only 55% of them thinks that it is a viable option. This share rise to 66% in the case of women who do not have any form of support.

Tab 4.6- Willingness to share care activities and availability of support

	(%)
Total	45.5%
0 sources	66.0%

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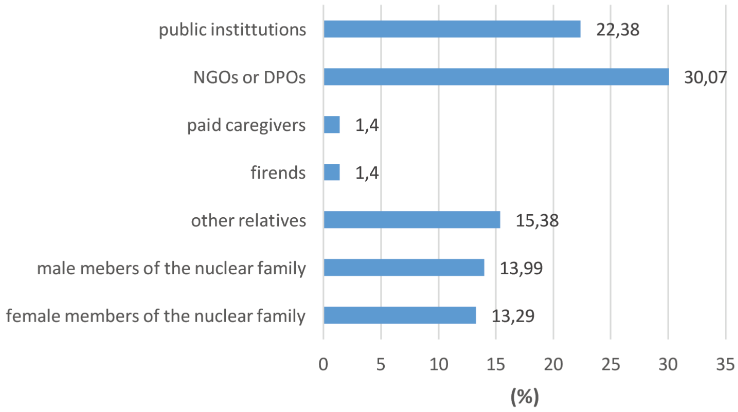
22 See chapter 3

1 source	48.3%
2 sources	48.6%

Source: authors' elaboration

The interviewees were also asked to indicate which sources of additional support are more desirable for the future. Each interviewee could indicate up to three answers. As it is possible to see in figure 8, NGOs and DPOs are seen as the most desirable source of additional support for the future. During the focus group discussions, the researchers underlined that it is mainly due to the need of specialized support (e.g. rehabilitation, psychological support) and to the lack of confidence and deep dissatisfaction toward public institutions. Personal networks and paid caregivers are not seen as a potentially relevant source of additional support, confirming the low relevance of informal networks.

Fig 4.8- Preferred sources of additional support



Source: authors' elaboration

It is possible to profile caregivers by simultaneously taking into consideration the intensity of the care activities that is on their shoulders and the degree systematic support that is available to share the burden linked to care activities. Table 7 shows that one interviewees out of four has to face the highest level of care with the lowest level of support. We can consider these women as the most overloaded ones. To have a more precise profile of the interviewees allows to elaborate customized interventions and to move away from the conception of care givers as a homogeneous group characterized by the same kind of needs and resources

Tab 4.7- Profile of the interviewees according to care and support

		care activity intensity		
		low	**intermediate**	**high**
support availability	**low**	0.00%	9.09%	25.87%
	intermediate	0.70%	6.29%	33.57%
	high	3.50%	6.99%	13.99%

Source: authors' elaboration

All the information that has been just discussed are about the daily care. The interviewees were also asked to indicate the available sources of support in case of emergency (defined as a deviation from the usual situation of the family and in particular of the person with disability). The results reported in table 8 clearly shows that in general the nuclear family is by far the most affordable source of support not only for daily care but in case of emergency too. According to the researchers, this is partly due to the same issues discussed before and partly to the low ability of public institutions and NGOs\DPOs to timely provide adequate support in case of emergency.

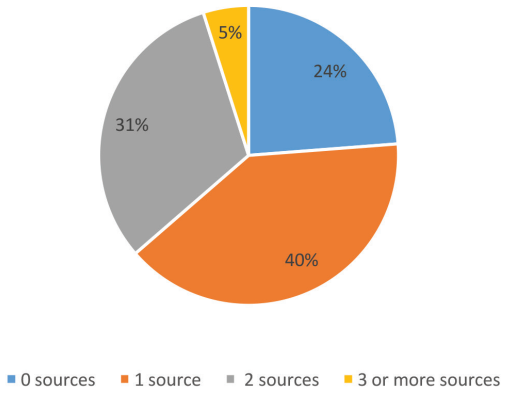
Tab 4.8- Sources of support available in case of emergency

source of support	always (%)	often (%)	occasionally (%)	never (%)
women from the nuclear family	40.56	16.78	20.98	21.68
men from the nuclear family	23.78	10.49	38.46	27.27
other relatives	4.90	6.99	23.08	65.03
friends	0.00	0.00	5.59	94.41
paid caregiver	2.10	1.20	3.50	93.20
NGOs	6.29	3.50	16.08	74.13
public institutions	0.00	2.80	13.29	83.91

Source: authors' elaboration

In average the share of families who do not have sources of support at all in case of emergency is relevant but lower than in the case of daily care (24% vs 35%). The opposite is true for care givers who have more than one source of potential support. The availability of support in case of emergency and in daily life is strongly correlated (the Pearson coefficient23 is 0.59): it means that caregivers who has more support in their daily life tend to receive more support in case of an emergency too. This led to the conclusion that we don't have two separate support networks (one for emergency and one for business as usual).

Fig 4.9- Sources of systematic support in case of an emergency



Source: authors' elaboration

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23 The Pearson coefficient is an index aimed at the measurement of the linear dependence between two variables. The Pearson coefficient gives a value between +1 and –1, where 1 is perfect positive linear correlation, 0 indicates the total absence of linear correlation, and –1 is total negative linear correlation.

It is possible to furtherly refine the profiling of the interviewees by simultaneously considering the intensity of care activities, the sources of support during the daily life and the sources of support in the case of an emergency. Ideally the most vulnerable group is the one composed by women simultaneously characterized by a high intensity of care activities and a low level of support available both during the daily life and in the case of an emergency (14.69% as shown in table 9, first column, last row). This kind of profiling techniques allows to better identify the needs of the care givers and to plan tailored interventions.

Tab 4.9- Profile of the interviewees according to care intensity and support availability both during the daily life and in case of an emergency

	N of support sources available in case of emergency			
Support - daily care profile	**0**	**1**	**2**	**3 or more**
high support - low care	0.00%	0.70%	2.80%	0.00%
high support -intermediate care	0.00%	0.00%	6.99%	0.00%
high support - high care	0.00%	1.40%	11.19%	2.10%
intermediate support - low care	0.00%	0.70%	0.00%	0.00%
intermediate support - intrmediate care	0.00%	5.59%	0.70%	0.00%
intermediate support - high care	2.80%	4.20%	6.99%	0.70%
low support - low care	0.00%	0.00%	0.00%	0.00%
low support - intermediate care	6.29%	2.80%	0.00%	0.00%
low support - high care	14.69%	5.59%	2.80%	6.29%

Source: authors' elaboration

4.3- Time use patterns

The information collected through the survey allow us to carry out a global analysis of time use patterns. In this way care activities can be analyzed in the wider framework of the allocation of time among several activities implemented by the interviewees. Basically the interviewees were asked to indicate how much time they use for an exhaustive24 list of daily activities in a normal day during the week. The sum of all the time share is equal to 24 hours and the interviewees were asked to report it with an approximation of half an hour.

The data reported in table 11 shows that, in average, the interviewees spend 3 hours per day for the care of the family member with a disability. The average total amount of care is obtained summping the care of the person with disability, the care of other family members and housekeeping activities and amounts to more than ten hours per day (i.e. more than a full time job).

Differences among interviewees tend to have a quite strong influence on time allocation. In general, the time available for rest is higher for women having a low intensity of care activities (the difference is 1.3 hours). The care of the person with disability is more demanding in terms of time for caregivers of persons with psycho-social disabilities (in average 1.2 hours more than the general average). It is interesting to notice that care givers of persons with psycho-social disabilities seems to be the most disadvantaged group as their time use pattern is not only characterized by an higher amount of time allocated for care activities (3 hours of total care more than the general average) but also by less time foe leisure (one hour less than the average) and

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[24] Exhaustive here means that the sum of all the activities is 24 hours. In other words, through the activities in the list we are able to classify all the possible activities of a typical day

less time for religion, volunteering and self-care (totally 1.4 hours less than the average). Also the time use for mobility is very low (a half of the average)

The presence of more sources of systematic support seems not to relief the caregiver from the care of the person with disabilities but from other duties linked to care and chiefly from housekeeping. This result is someway coherent to what observed by the researchers about the difficulties of many caregivers to accept the support of other persons for the care of the person with disability.

Not surprisingly the intensity of the care activities is strictly linked to the total amount of time used for care activities even if, in this case too, the bulk of difference is due housekeeping (3 hours vs 4.6 hours per day).

Table 12 report the correlation between the time allocated for several kinds of care activities and other activities. The stars indicate correlations that are significantly different from 0[25]. The time used for the care of the person with disability has a significant and negative correlation with the sleep duration (similarly to housekeeping). Leisure is the activity with the strongest negative linkage with the care of the person with disability while the care of other members of the household is not negatively correlated to leisure or religion.

While the care of adult members is to significantly linked to other activities, housekeeping has the highest number of significant correlations with other activities. On the whole it is interesting to notice that the different kind of care activities tend to have a different relation with the other activities. Obviously this should be considered while planning interventions to support caregivers.

Tab 4.10- Correlation coefficients between care activities and other activities

Activity	Care of the person with disability		Care of children		Care of adults		Housekeeping	
care of PwD	1		0.066		-0.1161		-0.0422	
sleep	-0.2071	*	-0.4256		-0.0296		-0.2155	*
self-care	-0.1453		-0.3222	*	0.16		-0.3753	*
housekeeping	-0.0422		0.115	*	-0.0965		1	
care of children	0.066		1		-0.1539		0.115	*
care of adults	-0.1161		-0.1539		1		-0.0965	
occupation	0.0366		-0.1023		-0.019		-0.2755	*
mobility	-0.2904	*	-0.2739	*	-0.0086		-0.2759	*
religion	-0.2441	*	-0.113		-0.0074		-0.2715	*
volunteering	-0.0797		-0.0274		0.0336		-0.0147	
leisure	-0.3975	*	-0.1085		-0.0802		-0.2376	*

Source: authors' elaboration

Tab 4.11- Time us patterns among the interviewees

		sources of support			care intensity			kind of disability				
Activities	**Total**	**0**	**1**	**2**	**low**	**intermediate**	**high**	**visual**	**mobility**	**hearing**	**cognitive**	**psycho-social**
Sleep	6.9	7.0	6.8	6.8	8.1	6.7	6.9	7.7	7.0	6.6	6.8	6.1
Self Care	1.2	1.2	1.3	1.2	1.3	1.3	1.2	1.4	1.3	1.4	1.3	0.6

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[25] The significance is tested through a t-test. Basically it means that the coefficient are different from zero with a probability equal to 95%

Housekeeping	4.4	4.7	4.5	3.9	3.0	4.2	4.6	3.3	3.9	4.3	4.7	6.3
Care PwD	3.0	3.3	3.0	2.6	2.7	2.7	3.1	3.1	3.0	2.3	2.9	4.2
Care others	1.8	1.7	1.8	1.9	1.2	1.7	1.8	1.3	1.7	3.0	1.7	2.4
Total Care	10.4	10.9	10.6	9.6	8.2	9.9	10.7	9.1	9.8	10.9	10.5	13.5
Occupation	1.2	1.3	0.7	1.7	1.5	0.8	1.3	0.8	0.7	1.0	1.6	1.3
Mobility	1.2	1.0	1.3	1.3	1.3	1.4	1.1	1.5	1.2	1.4	1.2	0.6
Religion	1.6	1.5	1.6	1.6	1.3	1.8	1.5	1.7	2.0	1.3	1.4	1.1
Volunteering	0.4	0.3	0.4	0.6	0.3	0.4	0.6	0.6	0.4	0.3	0.5	0.1
Leisure	2.3	2.0	2.6	2.3	3.4	2.7	2.1	2.6	3.0	2.7	2.0	1.3

Source: authors' elaboration

It is interesting to notice that the perceptions of the interviewees about the activities that is possible and not possible to do are coherent to what emerge from the analysis of time allocation. For example, the interviewees were asked to express their perception about the feasibility of having social relations with persons who are not members of the nuclear family. As you can see in table 11, the share of caregivers who experience strong difficulties is much higher among women who do not receive support than among women who have one or more sources of support.

Tab 4.13- Social relations outside from the nuclear family

		sources of support (%)		
		0	**1**	**2**
feasibility of having social realtions	**extremely easily**	0	1.72	28.57
	easily	18	31.03	28.57
	with slight difficulty	36	32.76	11.43
	with great difficulty	36	22.41	28.57
	impossible	10	12.07	2.86

Source: authors' elaboration

The survey collected information about the appropriateness of time allocation according to the preferences of the interviewee. Basically the interviewees indicated whether the quantity of time usually spent for each activity is appropriate, too much or too few. According to the results reported in table 13, the share of care givers who is willing to spend less time taking care of the person with disability is not large (19%) and smaller than the share of those who would like to have more time for care (28.67%). In other words, despite the most part of the interviewees perceives a deprivation in terms of available time for activities such as sleeping, leisure, volunteering and religion, the most part of them do not perceive to spend too much time in caring activities. This partial incoherence might be linked to the problems of care givers in accepting a support for care activities (see previous section).

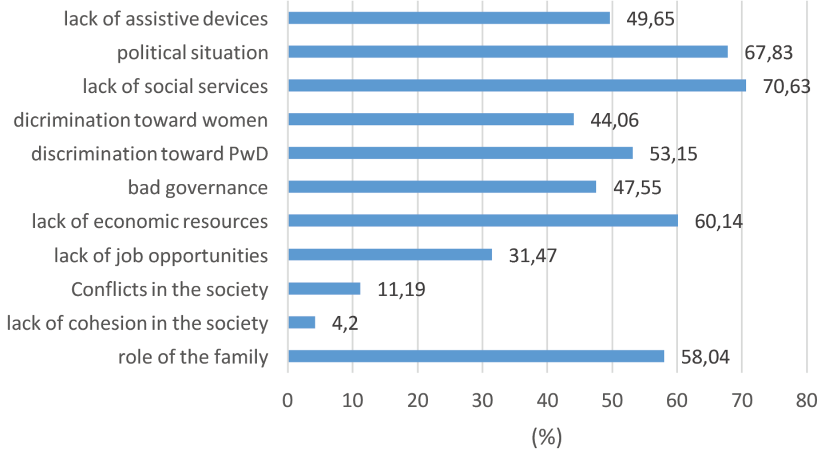
Tab 4.13- Appropriateness of time allocation

Activity	I would like to have more time for this activity (%)	I would like to have less time for this activity (%)	I think that the time for this activity is appropriate (%)
sleep	55.94	2.1	41.96
self-care	48.95	2.8	48.25
housekeeping	24.48	29.37	46.15
care of PwD	28.67	19.58	51.75
care of other children	34.97	15.38	49.65
care of other adults	33.57	41.26	25.17
occupation	34.97	11.89	53.14
mobility	20.98	13.29	65.73
religion	50.35	2.1	47.55
volunteering	55.24	0	44.76
leisure	56.64	9.09	34.27

Source: authors' elaboration

The interviewees were asked to identify the most relevant barriers that prevented them from achieving an allocation of time more coherent with their preferences. The lack of appropriate services is indicated as the most relevant barrier as 70.63% of the interviewees thinks that is extremely relevant[26]. Also the political situation is considered as a barrier given its linkages with the lack of safety in the urban environment and its impact on mobility. Lack of economic resources for the family is the third most relevant barrier while the lack of cohesion in the society and the conflicts within the Palestinian society seems not to play a relevant role.

Fig 4.10- Barriers preventing from a fair allocation of time



Source: authors' elaboration

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[26] The interviewees were asked to indicate a score between 1 and 10 to identify the level of relevance of the barrier. Score higher than 7 are considered as an indicator of extreme relevance of the barrier.

4.4- From time use to life satisfaction

According to the approach elaborated by the researchers, time-deprivation can be considered as an input to achieve a fair degree of wellbeing and, in last instance a fair degree of life satisfaction. As a consequence, the research moves from a mere quantitative assessment of time allocation to a more comprehensive analysis on satisfaction about daily activities and about life in general. The ability to plan one's weekly activity with sufficient autonomy is a crucial component of time satisfaction. On the one hand it is linked to the degree of control on one's life, on the other it may be conceived as an indicator the opportunity to make at least short term projects. Table 14 shows that the lack of autonomy and the ability to plan one's weekly activities are strictly related: among the women who do not perceive to have sufficient autonomy, around 75% experience more or less severe problems in planning her weekly activities.

Tab 4.14- Appropriateness of time allocation

		sufficient authonomy	
		yes	**no**
feasibility of planning weekly activities	very easy	22.41	5.95
	easy	41.38	19.05
	slightly difficult	25.86	39.29
	extremely difficult	10.35	28.57
	impossible	0	7.14

Source: authors' elaboration

During the preparatory focus groups, the researchers underlined that the problem with time is not only about the quantity of time allocated to each activity but also about its quality. For example, a person can have 8 available hours to sleep but if he\she is not able to rest properly, his\her satisfaction about this time will be low. To sum up, we introduce here the concept of time satisfaction, to simultaneously take into consideration the quantity and the quality of the time. The satisfaction about time changes according to the activity taken into consideration. The share of interviewees who are not satisfied is higher for social relations and occupation and lower (tough not negligible) for care activities. In other words, the interviewees seem to be satisfied about their role as caregivers while the problems arise when they have to conciliate this activity with other activities and, consequently, with other identities.

Tab 4.15- Satisfaction about time spent for certain activities

	satisfaction about the time for			
	rest	**care**	**social relation**	**occupation**
fully satisfied	31.47	31.47	28.67	41.96
quite satisfied	12.59	26.57	15.38	18.18
not so satisfied	46.85	36.36	42.66	26.57
not satisfied at all	9.09	5.59	13.29	13.29

Source: authors' elaboration

Taking into consideration the general satisfaction about time, it is possible to notice that a large part of the interviewees is not satisfied (79% considering both caregivers not so satisfied and those who are not satisfied at all). Once again, time satisfaction changes across groups: caregivers who receive less support are less likely to be satisfied about their time (88% versus 71.43% of not satisfied caregivers). The kind of impairment of the person with disability matters too: among caregivers of persons with hearing disabilities no one define herself satisfied about her time while caregivers of persons with mobility impairment are the better off group.

Tab 4.16- General satisfaction about time use

		general satisfaction abou time			
		fully satisfied	**quite satisfied**	**not so satisfied**	**not satisfied at all**
	Total	6.99	13.99	53.15	25.87
sources of support	**0**	4	8	54	34
	1	5.17	18.97	48.28	27.59
	2	14.29	14.29	60	11.43
kind of impairment	**mobility**	6.25	18.75	50	25
	hearing	0	0	87.5	12.5
	cognitive	3.23	9.68	51.61	35.48
	psycho-social	0	21.43	64.29	14.29

Source: authors' elaboration

It is interesting to explore the linkage between the satisfaction about time use and general life satisfaction. First of all, the general life satisfaction is quite low with an average score equal to 5.4. Table 17 clearly shows that life satisfaction is closely linked to time satisfaction: the average score among those who are not satisfied at all is 4.8 while it is 6.15 among those who are satisfied.

Tab 4.17- Life satisfaction and time satisfaction

		life satisfaction
	total	5.4
tima use satisfaction	**fully satisfied**	5.9
	quite satisfied	6.15
	not so satisfied	5.55
	not satisfied at all	4.67

Source: authors' elaboration

To sum up, the analyzed data show a that there is a relation between the burden of care, the general time use pattern (i.e. the time that the person is able to allocate to the other activities), the general satisfaction about the time and the general life satisfaction. The point is that this intuitive set of relations is framed in to a complex context. First, we have seen how many factors have an influence on these phenomena and these processes (the kind of disability of the person, the quantity and quality of the support that the person can receive, the relation with other forms of care). This heterogeneity of conditions and practices cannot be ignored. Quite the contrary, this level complexity led to need of carefully planning interventions and to deepen the knowledge of specific cases with a full assessment of the situation of the person with disability and of the family. Secondly, despite the linkage between the amount of care activities and, in last instance, life satisfaction, we have seen that it is not possible to simply provide services and support to the caregivers thinking that it will be automatically translated into an improvement in life satisfaction and quality of life: the acceptance of the support coming from outside the nuclear family is the result of a process that starts from the awareness that the care giver has the right to be something different from just a care giver. Finally it is important to be aware that to deal with the wellbeing of caregivers means to put on the table gender issues. It is not possible to imagine a discussion about care activities that ignore a rethinking of the role of the woman in the society and of the relations between genders.

Conclusion

The emancipatory research approach provides a valuable tool to simultaneously foster the production of knowledge on disability (and on women with disabilities) in the West Bank and the empowerment of the women who were involved in the research. As a consequence, these final remarks will be aimed on the one hand at summing up the main stages of the process and on the other at providing a summary of the main findings trying to draw some implications in terms of design of the future actions and policies.

The added value of the approach has been clear since the preliminary steps of the research (elaboration of the protocols, elaboration of the research tools, data collection, data analysis and dissemination).

During the identification of the research questions, the ability of the women to identify relevant aspects of the lives of women with disabilities and caregivers led the elaboration of a comprehensive research project based on different research methods and different perspectives. The support of ARCO researchers and of Educaid staff has been crucial to facilitate the elaboration of the research protocols. The initial participatory process was tailored to led the women to manage the feelings deriving from the interaction between their personal condition and their role as researchers in order to increase the quality of the research output: the objective was two avoid the risk that dynamics such as identification give rise to a lack of objectivity in the data collection.

During the elaboration of the research tools, women's knowledge of the general Palestinian context and in particular of the condition of women with disabilities was crucial to elaborate appropriate tools. Both during the training sessions and through the e-mail and skype exchanges the research tools were deeply refined and discussed item by item. The discussion involved the wording of the questions, their sequencing etc. The pre-pilot (that is a training session during which the women tested the research tools simulating interviews among them) led to a further refining of the tools.

The data collection has been self-managed by the women with a support coming from the DPOs and from Educaid staff that has been more or less intense according to the specific situation and the specific steps. In general, the level of autonomy reached by the groups as concern the implementation of the data collection has been more than satisfactory. Moreover, it worth to underline that for the most part of the women involved in the research the data collection was a chance to enjoy a higher level of freedom of movement and of autonomy with clear consequences in terms of self-esteem and enlargement of their capability set. The research process led to individual and social empowerment as clearly stated in the last meetings (November 2016).

The data entry and delivery phase has been radically different across groups due the different implemented methodologies. In Nablus and Bet Sahour, the women entered the printed questionnaires in an Excel spreadsheet specifically prepared by ARCO researchers. Despite the potential difficulties, the data entry has been fully accomplished and the quality of the delivered data was extremely high. For the group of Ramallah, the main problem was the translation of the interviews from Arab to English (needed to share the interviews with ARCO and Educaid staff). At the beginning, the quality of the translations was extremely poor and the consequent loss of information was too large. The problem was solved through the support provided by persons external to the group. Once this initial problem was solved, the quality of the delivered data provided was more than satisfactory.

The participation of the women to the analysis and interpretation of the results was crucial to increase the quality and the depth of the final research outcome. The first rough data analysis implemented by ARCO researchers was used as a topic of collective discussion so that the three groups has been able to provide comments and to indicate which further analysis where worth to be implemented not only for the research activities that saw their direct involvement but also on the activities of the other groups. In this phase, the potential of the emancipatory approach emerged with all its strengths. The personal knowledge of the context, the full ownership of the research process, the personal experience of the several forms of deprivation and discrimination led to identification of marginalization dynamics that would have risked to be hidden in a mainstream research. In other words ER, as in this case, can bring very relevant results in terms of findings, even superior to standard research.

Besides the previously underlined strengths, the process has not been devoid of criticalities. The difficulties in keeping up with the planned timeline led to difficulties in conciliating the timing of the research and the timing of the project (whose administrative and operative deadlines are, obviously, non-negotiable). This kind of problems was caused by several factors. In the first phase, the political situation and the security conditions (particularly in the area of Hebron) contributed to slow down of the elaboration of research tools. In other moments, the interaction between women private lives (marriages, health problems, family duties etc.) and research activities timing unavoidably led to a shift of scheduled activities. The intensity and the quality of women commitment toward the emancipatory research process shown a relevant degree of heterogeneity across individuals and, often, for the same person over time. Once again individual characteristics played a fundamental role. On the one hand women who experienced worsening of their health status or who had to cope with problems of other family members tended to reduce their participation to the research process. When this kind of problems involved women, whose role was particularly relevant within the research group the impact on the research was strong. Anyway, in the very most part of cases, the groups shown a fair degree of resilience and, after a first moment of crisis, they were able to identify new leaders and to go on with the activities. Conflictual dynamics among the actors involved in the research process emerged but were effectively managed through the mediation of Educaid. In a way, even if all these problems had an undeniable impact (particularly in terms of the timing of the scheduled activities), the overall ability of the research groups and of the other actors (Educaid, the DPOs and ARCO) to manage inconveniences can be considered an achievement in itself.

The research results and their possible implications in terms of policy and design of future activities has been discussed in detail in the previous chapters. It is anyway worth to sum up some cross-cutting issues emerged during the analysis according to their relevance and according to our ability to triangulate information collected to quantitative and qualitative methodologies.

In a person centered approach the values and the aspirations of the person plays a central role. It means that deprivation should not be measured according to a standardized threshold of achievement but according to the desired level of achievement. For example, focusing on the case of education, we saw that the expectations and the aspirations of women with disabilities has been changing across generation: younger women with disabilities tend to desire more education. In many cases their educational achievement are lower than the desired ones: several kinds of barriers in the family, in the society and in the education system itself, often prevented them from achieving the desired or planned level of education. In other words, they can be defined as educationally deprived. The need to invest on the school system to enhance its inclusiveness emerged as a clear priority. Teachers and, more in general, school staff should be an explicit target of investments through training and awareness raising activities: despite the undeniable relevance of “hardware investments” (assistive devices, increased physical accessibility etc.), it is worth remembering that, in last instance, teachers are those who can convert the availability of appropriate infrastructure into effective inclusive education.

Concerning access to job the situation seems to be extremely critical both for women with disabilities and for women who are caregivers of women with disabilities The most part of women who are not working seems to have a very low confidence in their possibility to be included into the job market. This is due to the interaction of several barriers including the role of the family and the overall lack of employment opportunities of the Palestinian context. Gender based discrimination directly and indirectly affects the opportunity of disabled women to get a job: for example, freedom of movement and motivation\trust from the society are examples of domains were the level of discrimination experienced by women is higher than the discrimination experienced by man with disabilities. The life course interviews highlighted the direct and indirect consequences of these forms of discrimination. The main direct consequence is a low participation to job market. The indirect consequences entail the long-term effects of recurrent frustrations and refusals on the future empowerment and proactivity of the person

Despite this undoubtedly critical situation, the research stressed the presence of potentially mobilizable energies: for example, we saw that a relevant share of both women with disabilities and care givers see the setting up of entrepreneurial activities as a viable option to improve their inclusion in the job market and in the society at large.

The role of the family at the same time extremely relevant and extremely heterogeneous and not easy to describe. It is not possible to generalize. Some families are identified as barriers by women with disabilities while others are considered as a crucial resource or facilitator as clearly emerges both from quantitative and qualitative data. The life course interviews show that, even for the same person, the family might be a barrier in certain domains a resource in others. At the same time the role of the family is not constant over the life course of the person. The life course interviews show the extremely relevant role played by the experiences lived during childhood and adolescence: this means that interventions such as education to parenthood for parents of persons with disabilities are extremely important. This kind of activities should be aimed at limiting the prevalence of overprotection so that persons with disabilities can be prepared to the exit from “the safe circle of the family” in order to achieve the highest degree of autonomy that I possible for them. In other words, autonomy is not a quality that one achieve during adulthood but the result of a process that finds its roots in early childhood.

Taking into consideration the point of view of caregivers, the research implemented in Nablus shows that women who are caregivers of a person with disability live under a strong pressure: on the one hand, there is the burden of care activities that absorb the most part of their time and of their energies. On the other hand, the social and cultural pressure and the introjected stigma induce them to not accept aid and support from outside the nuclear family in particular if the person with disability is her son or daughter. In this kind of situation to be a caregiver become an all-encompassing identity that leave no space for other aspects of life (including job, social relations, spirituality etc.).

A clear result of the research is the high prevalence of multiple discrimination for women with disabilities and for women who are caregivers of persons with disabilities. Their participation to the society is hampered by multiple, stratified and interacting barriers. If, on the one side, the caregivers tend to live their condition as a penance for their guilt (i.e. to have generated a disabled), on the other women with disabilities are almost completely excluded from the opportunity to get married and have their own family.

All in all, these results present a very complex framework that suggest to move away from standardized forms of services provision. Give the huge number of relevant factors that can shape the situation of each single person, an evaluation of individual resources, values and desires ad their structuration in a coherent project of life. In this sense to give rise to a process of individual empowerment of the person with disability is pre-condition and a fundamental part of the project of life. Interventions based on peer counseling and on self-awareness building are needed to push the person to elaborate a set of realistic objectives that reflect personal beliefs, values and the idea of one’s individual flourishing. A project of life should take into consideration the context of life of the person including the family of the person. As seen, the involvement of the families and of the caregivers in this kind of processes pass through the re-opening of the family to opportunities and options coming from the exterior world.

At the more aggregate level, the research has shown all the weaknesses (or even the lack) of public policies aimed at fostering the full and effective participation of persons with disabilities to the Palestinian society. This hole is partly filled by civil society organizations and by international cooperation but the development of a coherent and sound national policy on disability possibly elaborated through the participation of DPOs and of the civil society is an urgent need. The guideline for this change is the progressive but effective implementation of the UNCRPD.

Annex 1 - EDR Research Group Members West Bank - Palestine

RAMALLAH

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Nisreen Sulieman Wahdan

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Areej Hani Mohammed Abu Qree’a

Mara Hamael

Amal Mohammed Atta Zahran

Haddel Nassasra

Fatima Wasfe Mustafa

May Ahmad

Sali Mohammed Abu Srour

Raja, Abusaed

Mariam Zyoud

NABLUS

Shurooq Muhamadsalah

Wafa Haseba

Donia Nidal Haseba

Najah Hendeya

Amal Shabaro

Merfat Shabaro

Khoulod Antary

Fathiy Abu Mazen

Tahreer Dwaikat

Hiba Daghlas

Laila Zuhd

Ibtissam Ibrahim

Ulla Ibrahim

Rana Al Hazzam

Amany Zorba

Reem Abu Odeh

Suzan Abu Omar

Reem Saif

Samar Jawdt

Feda Daghles

Eman Odeh

Hanade Jabar

BETHLEHEM

Omayma Bradya

Doaa Dbabsa

Ayat Hlahla

Samea Al Rjob

Doha Al Tarda

Mayson Shrawna

Hana Abo Marya

Halema Mkamra

Razan Shebat

Sajeda Alama

Gada Zwahra

Tahrer Batran

Asma Anqawe

Reference

ARCO (2015). Biggeri, M. and Ciani, F. *Emancipatory Research Processes and Methods. Final Report Mission I*. Unpublished internal report, Action Research for Co-development.

ARCO (2016). Biggeri, M. and Ciani, F. *Emancipatory Research Processes and Methods. Final Report Mission II*. Unpublished internal report, Action Research for Co-development.

ARCO (2016). Biggeri, M. and Ciani, F. *Emancipatory Research Processes and Methods. Final Report Mission III*. Unpublished internal report, Action Research for Co-development.

ARCO (2016). Biggeri, M. and Ciani, F. *Guidelines and topic guide to the life-course interviews. Research protocol of Ramallah*. Unpublished internal report, Action Research for Co-development.

Barnes, C. (2003). What a difference a decade makes: reflections on doing ‘emancipatory’ disability research. *Disability & Society*, *18*(1), 3-17.

Barton, L. (2005). Emancipatory research and disabled people: Some observations and questions. *Educational review*, *57*(3), 317-327.

Biggeri, M., & Anich, R. (2009). The deprivation of street children in Kampala: Can the capability approach and participatory methods unlock a new perspective in research and decision making?. *Mondes en développement*, (2), 73-93.

Biggeri, M., & Bellanca, N. (2011). Ripensare le politiche sulla disabilità in Toscana attraverso l’approccio delle capability di Amartya Sen: from cure to care. *Quaderni, Regione Toscana, Firenze*.

Biggeri, M., & Ferrannini, A. (2014). Opportunity gap analysis: Procedures and methods for applying the capability approach in development initiatives. *Journal of Human Development and Capabilities*, *15*(1), 60-78.

Biggeri, M., & Chiappero, E. (2010). Sviluppo umano sostenibile, capability approach e cooperazione internazionale. *Biggeri M., Canitano G., Temi avanzati di economia e politica della cooperazione internazionale allo sviluppo, FrancoAngeli, Milano*.

Biggeri, M., & Libanora, R. (2011). From valuing to evaluating: Tools and procedures to operationalize the capability approach. *Children and the capability approach*, 79-106.

Boal, A. (2006). *The aesthetics of the oppressed*. Routledge.

Boog, B. W. (2003). The emancipatory character of action research, its history and the present state of the art. *Journal of Community & Applied Social Psychology*, *13*(6), 426-438.

Borrell-Carrió, F., Suchman, A. L., & Epstein, R. M. (2004). The biopsychosocial model 25 years later: principles, practice, and scientific inquiry. *The Annals of Family Medicine*, *2*(6), 576-582.

Chambers, R. (1982). *Rural development: Putting the last first*. London: Longman.

Clark D. A., Biggeri M., & Frediani A. A. (2017, forthcoming). *Sen's Capability Approach, Empowerment and Participation: Concepts, Methods and Applications*. Palgrave MacMillan.

Cornwall, A. (2000). *Beneficiary consumer citizen: perspectives on participation for poverty reduction* (Vol. 2). Swedish International Development Cooperation Agency.

Deepak, S. (2012). Promoting empowerment: Emancipatory research in community-based rehabilitation programme: A guide for CBR programme managers. *AIFO, Bangalore, India*.

Development Studies Centre - Birzeit University (2012). *The National Strategic Plan of the Disability Sector in the Occupied Palestinian Territories for the Supreme Council of the Affairs of Persons with Disabilities*. Birzeit, Palestine.

EducAid (2012). *Baseline survey sulle organizzazioni di persone con disabilità e la condizione delle donne con disabilità nei territori palestinesi occupati*. Unpublished internal report, EducAid.

EducAid (2013). *PARTICIP-ACTION: partecipazione attiva e inclusione sociale delle persone disabili in Palestina attraverso l'empowerment delle DPOs locali*. Unpublished internal report, EducAid.

Ferguson, C. (1999). *Global Social Policy Principles: human rights and social justice*. Department for International Development (DFID).

Freire, P. (1996). Pedagogy of the oppressed (revised). *New York: Continuum*.

Hutchison, E. D. (2010). *Dimensions of human behavior: The changing life course*. Sage.

Justo, L., & MgSc, F. E. (2005). *In a marginal voice. From participatory to emancipatory research*.

Kumar, S. (2002). Methods for community participation: a complete guide for practitioners. *Methods for community participation: a complete guide for practitioners.*

Libanora, R. (2010). Partecipazione e cooperazione internazionale: per uno sviluppo "dal basso"?, in Biggeri, M., & Canitano, G. (Eds.). *Temi avanzati di economia e politica della cooperazione internazionale allo sviluppo*. Angeli.

Lynch, K. (1999). Equality studies, the academy and the role of research in emancipatory social change. *Economic and Social Review*, *30*, 41-70.

Mercer, G. (2004). From critique to practice: Emancipatory disability research.*Implementing the social model of disability: Theory and research*, 118-137.

Nussbaum, M. (2000). Women's capabilities and social justice. *Journal of Human Development*, *1*(2), 219-247.

Oliver, M. (1992). Changing the social relations of research production?. *Disability, Handicap & Society*, 7(2), 101-114.

Oliver, M. (1997). Emancipatory research: realistic goal or impossible dream. *Doing disability research*, *2*, 15-31.

Palestinian Central Bureau of Statistics and Ministry of Social Affairs (2011), *Disability Survey, 2011*. Press Conference Report, Ramallah, Palestine.

Picher, M. C. (2007). Democratic Process and the Theater of the Oppressed.*New Directions for Adult and Continuing Education*, *2007*(116), 79-88.

Priestly, M. (1997. Who's research? A personal audit. In: Barnes, C., Mercer G. (eds) *Doing Disability Research*. The Disability Press , Leeds, pp 88-107.

Rashad, A. S., & Sharaf, M. F. (2015). Catastrophic economic consequences of healthcare payments: Effects on poverty estimates in Egypt, Jordan, and Palestine. *Economies*, *3*(4), 216-234.

Rutstein, S. O., Johnson, K., & MEASURE, O. M. (2004). *The DHS wealth index*. ORC Macro, MEASURE DHS.

Sen, A., & Hawthorn, G. (1988). *The standard of living*. Cambridge University Press.

Sen, A. K. (1999). *Development as Freedom.* Oxford University Press Shaw TM & Heard.

Testi, E., Biggeri, M., & Libanora, R. (2011). *Valutare l'impatto dei progetti di cooperazione internazionale seguendo l'approccio allo Sviluppo Umano*. Rapporto UmanamENT E, www. umanam-ente. org.

UNCRPD (2006). *Convention on the Rights of Persons with Disabilities*.

UNDP (2015). *Human Development Report 2015: Work for Human Development*, Web version.

UNESCO (2015). *Adult literacy rate, population 15+ years (both sexes, female, male)*. UIS Data Centre, UNESCO.

Zaidi, A., & Burchardt, T. (2005). Comparing incomes when needs differ: equivalization for the extra costs of disability in the UK. *Review of Income and Wealth*, *51*(1), 89-114.