Raising-awareness and empowerment within the Particip-Action project The issue of disability in Palestine[*]

Processi di sensibilizzazione e di empowerment all'interno del progetto Particip-Action La questione della disabilità in Palestina

di Alessia Cinotti, Giulia Righini

This paper aims to analyse the role of feminine caregivers in Palestine through the outcomes of the preliminary step of the Emancipatory Research (ER) carried out in the PARTICIP-ACTION project (financed by the Italian Agency for Development Cooperation – Ministry of Foreign Affairs and International Cooperation). The ER is a bottom-up process that promotes a progressive involvement of vulnerable groups of people as researchers at first hand. In the case herein considered, the researchers are 30 feminine caregivers of relatives with disability. Starting from their own point of view, they investigated the dimensions of well-being towards a good quality of life, which is hampered, in Palestine, by a distorted perception of disability, cause of social marginalisation and exclusion.

Key words:
caregivers, disability, quality of life,
Emancipatory Research, social stigma

Questo contributo si propone di indagare il ruolo delle donne che ricoprono il ruolo di caregiver in Palestina. L'analisi si sviluppo a partire dai risultati della prima fase della Ricerca Emancipatoria (RE), sviluppata all'interno del progetto PARTICIP-ACTION (finanziato dalla Cooperazione Italiana allo Sviluppo – Ministero degli Affari Esteri e della Cooperazione Internazionale). La RE è un processo bottom-up che promuove un progressivo coinvolgimento di gruppi vulnerabili di persone affinché diventino, essi stessi, ricercatori. Nel caso preso in considerazione per questo contributo le ricercatrici sono 30 donne che si prendono cure di parenti con disabilità. A partire dal loro personale punto di vista, hanno indagato le dimensioni del benessere che permettono di raggiungere una buona qualità di vita, cosa che, in Palestina, è ostacolata da una percezione distorta della disabilità, causa di marginalizzazione ed esclusione sociale.

Parole chiave:
caregiver, disabilità, qualità della vita,
Ricerca Emancipatoria, stigma sociale

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Introduction

This paper aims to reflect on the key aspects emerged from the PARTICIP-ACTION project[1] final evaluation[2]. The project was carried out in the West Bank (Palestine), over a period of two years. PARTICIP-ACTION – consistent with the overall purpose of the Italian Cooperation, as set out in the *Three-year Programming and Policy Planning Document 2013-2015* (December 2012) – embraces three fundamental cross-cutting issues: *human rights*, *protection of the vulnerable groups* (people with disability) and *empowerment of women*.

The idea behind the PARTICIP-ACTION project came from the awareness that Palestinian social context is particularly stigmatising and not inclusive for people with disability, especially if they are women, who are one of the most vulnerable groups of Palestinian society. This situation limits their participation in society and entails continuous violations of their human rights. The negative attitude of society towards people with disability produces a very strong social stigma, which is reflected in all spheres of economic, cultural, political and social life. This is why people with disability are the most marginalised among the marginalised, the most discriminated among the discriminated (Italian Development Cooperation Disability Action Plan, 2013). As a matter of fact, there is no full correspondence between social practices and cultures and what granted by Palestinian Law 4/99, regarding civil and human rights of people with disability. In this Law, the definition of disability mainly refers to physical deficits and their effects on the capability of pursuing tasks: this deviates from the definition of disability provided by the Convention on the Rights of Persons with Disabilities – CRPD (UN, 2006), embracing only a medical point of view. Indeed, the Palestinian community reveals a still very scarce both culture and awareness-raising on the issue of disability: excessive state aids to people with disability hamper both the planning of their Life Project and the promulgation of new laws and initiatives based on human rights. Here is a demonstration of this distorted social

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[1] PARTICIP-ACTION: increasing active participation and social inclusion of people with disability in Palestine through the empowerment of local Disabled People Organisations (DPOs). It is promoted by EducAid, in partnership con AIFO, Stars of Hope Society, General Union of Person with Disabilities e Asswat Society and financed by the Italian Agency for Development Cooperation – Ministry of Foreign and International Cooperation.

[2] Evaluation Report led by Alessia Cinotti and Giulia Righini, with the scientific supervision of Roberta Caldin.

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representation: the official percentage of people with disability in Palestine is declared around 7%, with a real average of 15%, according to the World Report on Disability (2011). This leads to a potentially high rate of unregistered people with disability, especially in rural areas: some families prefer not to register their children as disabled – particularly their daughters – in order not to compromise the family's reputation with the social stigma of disability. This is why the project aims to protect and promote the rights of people with disability, made possible by the empowerment of the Disabled People's Organisations (DPOs). The strengthening of the DPOs' role is fundamental to make them more effective in addressing the needs of people with disability (particularly women), by developing an inclusive perspective, in accordance with the CRPD principles.

1. Theoretical framework

Nowadays, talking about disability goes hand in hand with the idea of "health". *Health* is considered a complex and multi-perspective concept that has evolved in the last forty years thanks to social, medical and scientific achievements. Into this wide-ranging framework, the World Health Organisation defines health as a "state of complete physical, mental and social well-being" (WHO, 1946[3]). Health is no longer "the absence of disease or infirmity", but it is a dynamic human condition strictly related to life environment. So, the WHO perspective leads to the description of health as a state of *bio-psycho-social well-being* (WHO, 2001) and as a *human right* (NU, 2006). WHO's point of view is open to *possibilities* and looks to a future when people can feel fulfilled and become active citizens in their society.

This ongoing process involves everybody, *including people with disability*, and therefore recalls the key principles of the inclusive cultural approach. The value of participation in social life is the core of inclusion, which is an existential modality, an ethical imperative, a basic right that nobody has to earn. Rather, governments and communities have the duty to remove barriers and obstacles that hinder social inclusion, providing appropriate resources and support to allow people with disabilities to grow in inclusive environments (Stainback, Stainback, 1990). Indeed, disability is both the cause and the effect of poverty, since people with disability are subject to discrimination and have no access to equal opportunities. Consequently, social policies that derive from inclusive perspective have to overcome the idea that facing disadvantages delivering goods and services is a good policy. Instead, they must aim to widen and guarantee the spectrum of individual

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[3] The Constitution was adopted by the International Health Conference, New York, 19–22 June 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.

and collective *capabilities* of choice (Sen, 1999). *Capabilities* do not concern mere basic human needs, such as food, health and survival, but full fundamental rights. Considering the issue of disability, the *Capability Approach* (Sen, 2006) states that the capabilities of a person with disability consist of the range of tangible and effective freedoms granted to that person. Disability is considered *capability deprivation* that has to be read as lack or deficiency in the empowerment processes (Caldin, 2013; 2016). Indeed, disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment (Oliver, 1996). Hence the management of the problem requires social action, and it is the collective responsibility of society at large to make the environmental modifications necessary for the full participation of people with disabilities in all areas of social life. The issue is therefore an attitudinal or ideological one requiring social change, which at the political level becomes a question of human rights (WHO, 2001).

2. The Emancipatory Research

In the PARTICIP-ACTION project was carried out an Emancipatory Research (ER): the ER is a bottom-up process that promotes a progressive involvement of vulnerable groups of people – in this case, both people with and dealing with disability – as researchers at first hand. As a matter of fact, if the research questions concern marginalisation of the most vulnerable groups of the society, the ER allows people – who suffer social exclusion – to take part in the activities, share opinions and experiences with professional researchers and reach full entitlement of the entire research process (Freire, 1971; Campbell, Oliver, 1996). In this case, indeed, the professional researchers were firstly responsible for training the participants on how to conduct a research, but afterwards they just worked as facilitators. It was mainly responsibility of the people with – and dealing with – disability to define the research problem, to collect the data, to analyse and disseminate the results. In this way these new researchers managed to increase their leadership and decision-making skills (Walmsley, 2010). Specifically, the ER was aimed to get to know the marginalisation process through the very personal experiences of both people with disability and their feminine relatives-caregivers.

The ER aimed not only to make the people with disability active part of the process, but also to increase their awareness on their human and civil rights, since they are citizens like all others. This process of awareness represents one of the strongest contact point between the ER and the inclusive perspective and it is so both significant and unique that, in this paper, we decided to mainly focus on that process rather than on the results. For this reason, we take into consideration only the preliminary step of the ER, which is the way the researchers defined the topic to investigate and the research problem to face.

From a methodological point of view, the ER was supported and guided by the Action Research for CO-development (ARCO)[4] identified by the Italian Association Amici di Raoul Follereau (AIFO)[5].

3. The experience of feminine caregivers in Nablus

In Nablus group, herein considered, the 30 women involved decided to investigate the *issue of well-being* through the analysis both of their use of *time* in a typical day and of the *burden of care* and how it interferes with their daily activities.

Their research was designed on the basis of two sets of questions. The first set concerned the amount of time spent on the different duties connected with the care-taking of relatives with disability and the consequent impact on their quality of life. The second set of questions focused on deprivation in term of time poverty. The women were asked to assess whether the quantity and quality of time they spent in their daily activities is adequate to reach a good quality of life.

The data collection was based on large-scale survey with the involvement of 150 women who were caregivers of a person with disability. In particular, the survey targeted mothers, sisters and relatives of people with disability who lived with those people and who took care of them in a relevant way.

3.1 *The feminine caregivers' point of view*

In order to better design the ER, the group of Nablus initially investigated the dimensions of well-being, which they consider deficient in their lives nevertheless necessary to reach a good quality of life. The participants focused their discussions mainly on the life condition of feminine caregivers both in the society and at home.

Analysing women's experiences, it clearly appears that the situation they experienced at home was strictly related to the role of those women in their society: if a woman does not feel respected, safe and free in public places; if

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[4] ARCO is a university centre offering research, consulting, and training services. It was founded in 2008 at PIN S.c.r.l. (Polo Universitario "Città di Prato") and it maintains strong connections with the Department of Economics and Management and the Department of Statistics, Informatics, and Applications at the University of Florence. http://www.arcolab.org/en/ (accessed on 30/04/2018).
The professional research in charge of the ER is Federico Ciani, PhD, ARCO-University of Florence.s her empowerment both at home and the e survey with the involvement of 150 women who are caregivers of a persn with disability.

[5] AIFO is a grassroots' organisation with groups and regional coordination covering the whole of Italy. It is also an international network organisation with member associations in India, Brazil and Mongolia. It is in official relationship with the World Health Organisation (WHO) and collaborates actively with Ministry of Foreign Affairs and is recognised by Ministry of Education of Italy for the training of school teachers. http://www.-aifoeng.it/ (accessed on 30/04/2018).

she has no access to appropriate education, to suitable job, to health services and if she has no freedom of choice, that woman will hardly find a way to be granted a decent role – as wife, mother, sister etc. – even at home. This is a clear symptom of a twisted vision of the social role of women that is mirrored also in the family dynamics.

Another important focus risen in the group concerns the identification of well-being's barriers. It is interesting to notice that the family itself seams to represent an important obstacle to feminine caregivers' quality of life because they can hardly accept the disability of the relative (Christian, 2010). For this reason, the women live with a deep sense of guilt due to two factors: to have generated a disabled son/daughter and to choose to take the role of caregiver.

The preliminary step of the ER continues with a particular activity called "parti-number exercise" that consists in setting up two scenarios of fictional families (A and B) that have exactly the same characteristics, apart from the presence (family A) or the absence (family B) of a son with disability (severe mobility impairment). Both families are composed of 45 years old father and mother, two sons and one daughter, aged 13 to 17. They live in the urban area of Nablus, where they own a house. The breadwinners are only the fathers, who earn 2500 New Israel Schekels (NIS). The "parti-number exercise" is a methodology that aims, as a first step to make the participants reflect on their own personal conditions in order to get detached from their role of caregivers; and as a second step to embrace their new role of researchers with gained awareness and ownership of the research. This process was enabled by the caregivers' discussion and reflection on these two scenarios (family A and B).

So, through the "parti-number exercise", the 30 researchers identified – starting from their own experiences – on the one hand, the two families' monthly costs (Table 1) and, on the other hand, the two families' daily routines (Table 2).

After having recognised categories, the women of Nablus allocated both the household budget among several expenditures categories (first step) and the time spent on the different activities of a typical day (second step).

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

Table 1
Household budget identified during the "parti-number exercise"
(source: ARCO, 2015)

As shown by the data in the table, Family A spends more money on food, basic housing services, education and health care, while Family B spends more on clothes, self-care, leisure, transports and communication.

According to these results, for Family A the main costs are on basic necessities: from the data of Nablus women, we can assume that whether the caregiver and the disabled relative stay at home the whole day, the housekeeping expenditures are higher. Moreover, the two categories that require the highest economic budget are education – including school fees – and health/assistance care. The necessity of Family A to invest so much on these two expenditures, leads us to another significant data: the savings. Family A, in contrast to Family B, cannot save any money. Furthermore, indeed, Family A cannot even afford "ancillary" costs, which are not connected to basic needs, but they can be considered fundamental for reaching the self-fulfilment (Maslow, 1962): having time and money to take care of yourself – for example, buying new clothes, having hobbies, doing sports, enjoying free time with friends outside the house etc. – might be a path to reach the well-being/well-becoming. These kind of activities can give the person a sense of his/her value that preludes *good quality of life*.

The highest money gap between the two fictional families is related to the category "health and assistance care" and consists of 500 NIS. This means that Family B has more economic chances to invest in their free time and leisure. We believe it is important to underline that these economic chances do not influence the family life only on a material level but have also a strong impact on their future *Life Project's possibilities*. Indeed, not only taking care of a person with disability is physically, psychologically and emotionally stressing, but also the presence itself of a disabled person tends to increase the economic vulnerability of the familiar context.

Activities	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

Table 2
Women time use identified during the "parti-numbers exercise" (source: ARCO, 2015)

Referring to the second step of the "parti-number exercise" (Table 2) – about the time spent on the different activities of a typical day – we can find some similarities with the results of the first step. The feminine caregiver of Family A spends more time at home than the caregiver of Family B: the longest amount of time is dedicated to the housekeeping and the *active* caretaking of the son with disability: 10 hours per day, and 4 more hours of *passive* care. Basically, the 30 researchers involved in the ER said that the caregiver is obliged to stay long time at home just because the disabled relative cannot be left alone even if she does not have to take any active care practice (Murphy, Christian, Caplin, Young, 2007). These 4 hours of *passive care* are a sort of "empty time", in which the caregiver is completely disengaged from any kind of activity; even towards the disabled relative it is just a safe-keeping time, distant from an educational perspective aimed to design a *Life Project*.

The number of hours dedicated to the *passive care* could be invested in other life dimensions of the disabled person, such as social and recreational activities, vocational experiences and educational opportunities. Actually, from the data analysis, it seams that the relationships with the person with disability is principally about care or assistance. Thus, we can infer that for the feminine caregiver and the person with disability it is extremely hard to play a "social role" (Goffman, 1986; Lepri, 2011) because they are stuck in a "mono-identity": for example, a mother only identifies with the role of feminine caregiver, while the disabled child only identifies with the role of son/daughter for a lifetime (Isa *et alii*, 2016).

Another significant point to highlight concerns the dimension of "rest": in Family A, despite the fact that the caregiver seams to have a lot of "free" time (no job, no social relationships, no leisure activities), she does not manage to rest for an adequate number of hours (only 5 a day).

In general, the care-time dilation tends to decrease the well-being dimensions of the caregiver and invalidate her state of health. Her physical, mental and social well-being is compromised by the excessive burden of care that restricts her set of capabilities. In other words, being feminine caregiver in Palestine is a capabilities deprivation that hinders her empowerment both at home and the society.

Conclusion

The ER provided a valuable approach both to foster the knowledge and the raising-awareness on the issue of disability and to promote the self-awareness and the empowerment of women involved in the research. As identified by the researchers, these are the key conditions to play an active role at home and in the community, fundamental factor to reach a physical, mental and social well-being.

In conclusion, we can make a few brief remarks on this paper through an inclusive perspective, by identifying some possible familiar, social, cultural and political changes towards the women's quality of life.

Considering the barriers identified by the women in Nablus, we noticed that the issue of disability is barely mentioned by the feminine caregivers. This leads us to state that the presence of a person with disability in the family was not considered an obstacle itself, but the real obstacle is the others' twisted perception of that condition. Actually, what women suffer is the social stigma – perpetrated by the family and the community – that affects both people with disability and their caregivers (Hunt, 1966; Gardou, 2011).

Moreover, the data relating to the economic vulnerability of the familiar context due to the presence of a person with disability demonstrates the lack of adequate and accessible public services, even in response of basic needs: education and health-care are significantly more expensive for a person with disability. This probably develops from a lack of sensitivity of policy makers that do not take into consideration the issue of disability when allocating public resources. If people with disability truly had the same social and civil rights of everyone else, they would have equal opportunities to access to mainstreaming services.

Moreover, accessible social services could be a response to the disabled people's need of socialization, education and development outside the family context. This would allow to build new relationships with people who are the caregivers. At the same time, this possibility would guarantee a different use of the caregiver's time. Indeed, the hours dedicated to passive care could be spent in a more productive and satisfying way, both for people with disability and their caregivers.

Another possibility to lighten the burden of care is the involvement of fathers – or other relatives – in the education and care-taking of the disabled child. Increasing the engagement of masculine relatives would contribute to develop a wider acceptance of disability and, consequently, an acquired knowledge and raised awareness. This might be a keystone of a cultural change for two reason: firstly, in the "disability history" the family has been the driving force behind social, cultural and political improvements in the inclusive direction (Pavone, 2010); secondly, it is plausible that, in the Palestinian patriarchal society, the possibility of a bottom-up change would be more effective if supported also by men, hand in hand with women.

All these factors are strongly integrated and interrelating and might positively contribute to widen the dimensions of well-being towards a better quality of life for people with disability and their caregivers.

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