Social participation of elderly people – a qualitative study with particular focus on people with lifelong intellectual disabilities in later ages

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Abstract

The present article intends to illustrate a dissertation project focussing on the living experiences of people in the so-called third and fourth age, with particular regard to people with lifelong intellectual disabilities who enter old age. The sustaining assumption is that social participation of senior citizens and of people with disabilities is both meaningful at an individual level, and offers great treasure for every community in terms of social capital and social cohesion. Against this background, the overall aim is to explore participation experiences in old age by deploying a participative action research approach, which encompasses the direct involvement of social groups who still appear to remain underrepresented in social research. The outcomes of this study are expected to offer new insights in the lived realities of elderly people, with particular attention to the peculiar experiences at the intersection of lifelong intellectual disabilities, age and gender. Further, the project aims to reveal related crucial mandates arising for social work practice and social policy.

1. Research aims and research questions

This study focuses on the living experiences of people in old age and particularly of people with lifelong disabilities in later ages, who represent social groups at risk of marginalisation. Indeed, the general representation of elderly people, and particularly of those with disabilities, appears to involve the portrait of burdensome members of community who are not able to take part in the so called active and autonomous life which generally shapes the construction of identity in adulthood.

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Yet, this dissertation grounds in the overall assumption that social participation of senior citizens and of people with disabilities is both meaningful at an individual level, and offers great treasure for every community in terms of social capital and social cohesion.

Against this background, the focal aim of the study – which is still work in progress – is to explore participation experiences in old age, by reference to both a personal and a community level: on the one hand the intention is to reveal the strategies elderly people develop in order to participate in social life and to contribute to society as well as to capture the meaning people attach to their participation experiences over the course of life. On the other hand, the study aims to explore what social spaces and resources communities offer to elderly people, and what socially constructed barriers to meaningful participation may persist.

2. Theoretical background

The following sections seek to depict the theoretical framework this dissertation grounds in as well as the arising conceptualisation and operationalization of the notions set at the heart of the study.

2.1 Social participation

The review of literature and research reports, pertaining to social participation, reveals a lack of consensus on the conceptualisation, definition and measurement of the concept (Cardol et al., 2002, p. 28; Hammel et al., 2008, p. 1445; Levasseur et al., 2010b, p. 666; Eyssen et al., 2011, p. 983).

One branch of conceptualisations focuses on reciprocity and the common sharing of resources, in this manner stressing the community dimension and therefore the political nature of participation. An example is the conceptualisation elaborated by Mars and colleagues (2008, cited by Levasseur et al., 2010a, p. 2147) who assert that participation occurs when there is social contact and that it is constituted by receiving resources from society as well as by forms of contributing resources to society.

In contrast, other definitions of social participation shift their focus emphasising the dimension of individual performance. Such an approach is applied in the work of Dalemans et al. (2010, p. 537) who reserve the term for "the performance of people in social life domains through interaction with others in the context in which they live". In a similar vein, using the term of *community participation*, Dusseljee (2011, p. 4 f.) conceives the concept as "performing daytime activities by people while interacting with others".

Such performance-informed approaches may be criticised for overemphasising the individual dimension and thus for penalising vulnerable persons such as people with disabilities who may develop different ways and levels of performance compared to the mainstream of society. Indeed, these conceptualisations appear to ignore or at least to insufficiently take into account the relevance and impact of a person's social and physical environment.

In contrast, scholars such as Hammel and colleagues (2008, p. 1,459) emphasise "the interactive and transformative influence of the environment on participation choice, control and opportunity". In this conception, participation depends on "having access to resources and supports to participate freely" (ibidem, p. 1447, with reference to Barnes et al., 2000; Morris, 1993; Morris, 2001).

Levasseur and colleagues (2010a, p. 2144 ff.) highlight one further dimension of participation which appears to be valuable in the design of research projects aiming to explore people's participation experiences: the scholars urge that participation goes beyond a person's involvement in determinant activities and life situations insofar as it refers to "the personal meaning and satisfaction resulting from that engagement" (Levasseur et al., 2010b, p. 666).

This perspective is likewise accentuated in the work of Hammel and colleagues (2008) who conceive participation as a *cluster of values* which embraces “active and meaningful engagement; choice and control; access and opportunity; personal and societal responsibilities; supporting others; and social connection, inclusion and membership” (Hammel et al., 2008, p. 1445). Thus, the scholars suggest to apprehend participation as a *subjective experience* and as *expression of personal and social values* which entails the “dynamic interplay between people and their environments, not just at the immediate person/environment level, but also at the community, cultural, social and societal levels” (ibidem, p. 1459).

Against the background of these theoretical conceptualisations, the overall approach deployed within this study is focused on the personal strengths and potentials of senior citizens, with the intention to value their subjective experiences. Yet, giving weight to people’s subjective and unique contributions does not ground in an understanding of participation as equated with the accomplishment of personal skills or performance. Conversely, the intention is to avoid a one-sided view on participation, which may over-emphasise the individual dimension, but to highlight the substantial relevance and impact of the social and physical environment. Indeed, in the case of elderly people and people with disabilities taking part of social life is particularly affected by the accessibility of the physical environment, by the adequateness of physical and social spaces and resources as well as by the forms and availability of social support. In this sense social participation is related to social cohesion and solidarity, socio-economic safety and the presence of social and economic institutions shaped on people’s specific individual needs.

Thus, the overall aim of the present inquiry is to capture the political nature of participation. The underpinning hypothesis is that the political dimension is present and relevant not only at a macro societal level, but also at the meso and micro level of interpersonal relationships. In this sense Lorenz claims a major mandate for social work and its acts of assistance, which “whilst directed to single individuals, needs to go beyond that level and to reach a space which transcends the personal sphere” (Lorenz, 2012). This entails a “commitment that goes beyond the mere encounter with the person, implies an act of recognition" and means "forming not just personal relationships, but bringing out the social dimension in the micro structure of these interactions". From this derives a conception of rights that "need to be not simply available, but constructed and maintained" (ibidem).

Thus, theorising social participation and community life raises the question of vital values and principles individuals and groups refer to when they live together, develop and share common resources. In this sense the present research project is designed around an underpinning idea of social justice, active social citizenship and civil rights within a pluralistic, democratically structured society. In this regard, the study is mainly grounded in the theoretical framework developed by Martha Nussbaum who tightly connects her theory of social justice to issues regarding ageing and disabilities. In fact, her theoretical framework holds the need of giving and receiving care in its centre and is founded on the dignity of every single individual and on the development of everyone's capabilities (Nussbaum, 2002, p. 40 ff. & p. 83).

Further, Nussbaum suggests assessing society not simply by referring to the amount of material richness it offers to their members, but by taking into consideration to what extent society enables people to carry out an array of important activities related, for instance, to mobility or participation in political life (ibidem, p. 43 ff.). Hence, the aim of the present study is to analyse these essential issues by capturing the personal experiences of elderly people and people with disabilities in later ages.

2.2 Social capital

Issues of social participation are tightly bound to the notion of social capital. The present dissertation delivers a description of the theoretical development and the ground breaking conceptualisations of the term *social capital*, by reference to the works of the most influent scholars in this field, such as Bourdieu (1983 & 1993), Putnam (1995 & 2001), Coleman (1988 & 2005), Portes (1996 & 2000) and Pizzorno (1999).

The examination of social capital theories draws attention on the relevance of social capital for individuals and communities, but also on its potential problematic implications. Thus, the underpinning goal is twofold: on the one hand, the intention is to highlight the potential positive effects of social capital in terms of psychophysical well-being at an individual level and its benefits for society as a whole. In fact, Bourdieu (1983, p. 191) argues that the capital owned by every single member of a community is useful to the entire community since it brings safety and creditworthiness.

On the other hand, the study intends to take into account the potential problematic implications of social capital such as the marginalising or even anti-social effects of excessive bonding social capital (Portes, 1996, p. 20 f.). A further critical element to be included in an encompassing discussion of social capital is that it may be defined as a dimension of inequality in society (Braun 2010:9). Indeed, different social groups are differently endowed with social capital and have different access to its various configurations and benefits (Molyneux, 2002, p. 181).

Further, the present dissertation project encompasses a critical discussion of the appropriateness of the notion itself, in particular by pointing out the potential ideological implications of the term *capital*. Indeed, it is originally rooted in economic sciences, implies a reference to capitalism and may therefore convey its principles to the social field (Smith & Kulynych, 2002, p. 154 ff.).

Such critical reflections, in conjunction with the breadth and adaptability of the term, lead to the necessity to operationalize the conception for the purpose of this dissertation. First and foremost, in light of its core issues related to network embeddedness and participation, this research project approaches social capital stressing its network based dimension. Hence, the study is concerned with exploring the various forms of social capital, in terms of resources that can be gained by virtue of being embedded in social relationships and that can turn meaningful in shaping identity and social roles within community.

Further, this dissertation is fundamentally founded in the acknowledgement of the intrinsic value of human existence in all its variety and richness. It therefore rejects the colonisation of the social field by market-led and profit-oriented logics. Thus, the use of the term *social capital* within this research project is based on the attentive awareness of the concept's potential ideological impacts and critical facets.

2.3 Intersectionality theories

The present dissertation grounds in the assumption that people with intellectual disabilities in an advanced age are to be viewed as groups of population who are potentially exposed to a double or even multiple risk of disadvantage. Indeed, both old age and intellectual disabilities may represent dimensions of social inequality, and the same is to be said of gender. Such considerations invite to the inclusion of the so called *intersectionality theories* in the theoretical background of the present dissertation, by honouring the work developed by ground breaking scholars such as MacCall (2005), Hancock (2007 & 2011), Crenshaw (1991), Walby et al. (2012), Roseberry (2011), Sargeant (2011), Hankivsky and Cormier (2011), Winker and Degele (2011).

Taking into account intersectionality theories appears to represent a valuable strategy insofar as these tenets permit to explore group identities and experiences without ignoring *within-group* diversities. Indeed, the aim of this research project is to capture the lived realities of elderly people, deploying an approach, which avoids considering them as a homogeneous group but seeks to value their peculiar experiences at the intersection of age, disabilities and gender.

3. The research design

The following paragraphs aim to describe the research paradigms and methods supporting this research project and the motives, which justify the underpinning methodological choices.

3.1 The overall research approach and strategies

The overall research strategies and methods deployed within this work are indebted to the qualitative research paradigm. The study is being designed and conducted in an effort to analyse phenomena related to ageing and disabilities by capturing subjective experiences and honouring elderly people's voices. Such research goals invite to the use of qualitative approaches, which address the "socially constructed nature of reality" (Denzin & Lincoln, 1998, p. 8). Indeed, qualitative researchers endeavour to reveal and interpret the complexity of everyday social interactions in their natural settings as well as the meaning people bring to these interactions (Marshall & Rossman, 2011, p. 2).

In this sense, the present study aims to capture the subjective meaning elderly people ascribe to their participation experiences over the course of their life, drawing particular attention on people with lifelong intellectual disabilities in later ages.

Such research strategy shall be the expression of the underpinning conceptualisation of social participation. As emerges from the foregoing, participation is conceived as a multifaceted construct, which results from the dynamic interplay of individual and environmental factors and is constituted by a field of tension involving objective and subjective elements. Hence, the aim is to capture not only the forms and levels of participation developed in major life domains, which may be recorded in objective terms, but to concurrently focus on people's related personal experiences, representations and meanings. This subjective dimension as essential element of participation is to be valued and acutely taken into account in the endeavour to co-construct an authentic, comprehensive picture of social participation experiences in later ages.

In this attempt, the present research project is being designed with reference to a participatory action research approach. Such research tradition entails the "integration of research and action" whereby the researchers together with other research participants are actively involved in the endeavour to initiate processes of change (LeCompte & Schensul, 2010, p. 270).

Throughout the research process, the researcher perceives herself or himself as a learning subject who learns from the other participants what issues affect them, what meanings they attach to those matters and how they aim to achieve changes. Thus, participatory action research intends to be transformative by offering the opportunity to change worldviews, interpersonal relationships and eventually structures of inequality (ibidem, p. 271).

In light of the foregoing, the aim of action research is to be viewed as political in nature insofar as the focus is set on "uncovering, understanding and addressing the sources of inequity or disparity in participants' environment, beginning their own identification of the socioeconomic, political or cultural issue they themselves want to address" (ibidem, p. 271).

Against this background, the present research project encompasses the active involvement of senior citizens in the development of the research design as well as in the process of data collection and analysis. Thus, the relationship between the researcher and the participants is based on partnership and reciprocity. Participants are actively involved throughout the whole research process. Indeed, all participants are transparently informed about the research aims and strategies and are given the opportunity to express their related opinions. Further, the transcripts of all interviews are shared with participants who thus have the possibility to give their feedbacks and further contributions. What is more, two people have assumed a particularly active and engaged role agreeing to become *privileged informants* or supervisors. As such they will monitor the whole research process, have regular meetings with the researcher and discuss the research outcomes in progress, expressing their viewpoints and delivering indications, which will enrich the processes of data analysis and interpretation.

Eventually, the overall aim of this work is to address issues of social justice by revealing people's participation experiences and to achieve transformative effects. As LeCompte and Schensul (2010, p. 279 f.)

emphasise, the concrete strategies available to the researcher in this context embrace the support of advocacy: for instance, the researcher may have the opportunity to sustain the joining of advocacy groups with the aim to achieve policy or practice changes. In this sense, the present research project endeavours to sustain processes of change and to elaborate practicable indications for social work theory and practice as well as for social policy.

3.2 Strategies of data collection

The present study is being conducted by applying a life course perspective. Indeed, "for its sweeping scope and focus on biographical and historical dynamics", this perspective represents a "powerful tool in the social scientific investigation of ageing", whereby it considers "human development as guided simultaneously by individual, institutional, and societal forces" (Silverstein & Giarrusso in Angel, 2011, p. 35).

By valuing such approaches, the research strategies applied within the present project involve a narrative inquiry, and in particular the conduction of exploratory expert interviews and the collection of life histories.

The expert interviews are used as a research tool intending to provide context knowledge on the phenomenon of ageing and on participation experiences lived by elderly people. Up to now, a sum of ten experts has been involved, encompassing both professionals in the social and health sector and experts by experience such as parents of people with disabilities and a member of the self-advocacy group *People First*. The overall intention of the involvement of such experts is to explore their viewpoints on the central research questions and to capture the related issues they perceive as relevant. Most of the interviews still need to be transcribed and analysed, but some very first conclusions can already be drawn. First of all, the central questions of the present inquiry appear to be of relevance to the experts and to meet their interest. Indeed, they express their concern about the issue of participation opportunities offered to elderly people, particularly to people with lifelong disabilities. Indeed, many experts emphasise that the relatively new phenomenon of ageing among people with disabilities has not yet been addressed in adequate ways, neither by social services and social policy, nor by society in general. Offering elderly people the opportunity to shape their everyday social lives in meaningful ways appears to represent an important challenge perceived and addressed by the experts involved in the present study.

Still, as has been stressed above, the central focus of the inquiry is drawn on the involvement of elderly people themselves who participate in the study by recounting their life histories.

From the analysis of relevant literature, there can be concluded that biographical interviews represent a research tool, which resonate with the aims and purposes of the present study. Indeed, qualitative inquiries and in particular narrative approaches are considered to be adequate instruments for achieving manifold aims: capturing subjective perspectives, analysing the interactive construction of social realities and identifying the cultural frameworks and determinants of social realities (Küsters, 2006, p. 19, with reference to Flick, 1996, p. 28 ff.). These aims are congruent with the purposes of the present inquiry, which is indebted to the social constructivist paradigm and endeavours to reveal both subjective experiences and constructions of the social world and their social dimensions and determinants.

LeCompte and Schensul (2010, p. 118) define biographical research designs as “the study of individual people’s stories”, which embraces their history and lifestyle “that lead up to and may explain their current situation”. Thus, narratives and in particular life histories are useful to explore individual experiences that may be peculiar to their spatial and temporal context, but “patterned across individuals during that period of time and place” (ibidem).

In this sense, biographical research is assumed to be valuable in bridging the traditional gap between *micro* and *macro* (Riemann, 2006, p. 7).

Further, the collection of life histories can be embedded in an approach of empowering, emancipatory action research insofar as "individual narratives of suffering become the human face of social problems that must be solved" (Rubin & Rubin, 2008, p. 159).

In light of the foregoing, the overall research questions and aims of the present study appear to invite to the deployment of life histories which are used in order to give people voice and to express their personal experiences at the intersection of age, disabilities and gender.

The process of data gathering has been recently initiated: the first biographical interviews with people who enter old age are being conducted. Besides the above-described analysis of the theoretical background sustaining the deployed research approaches and tools, at this stage of the work the process of addressing ethical questions appears to represent a fundamental task on the part of the researcher.

3.3 Ethical implications

The decision to directly involve elderly people and in particular people with lifelong intellectual disabilities in later ages entails the researcher's responsibility to address crucial ethical questions. As has been stressed before, the participants of this study are to be considered vulnerable in double or sometimes multiple respects. Their free decision whether and in what terms to participate in the inquiry might be affected by their age, by intellectual and/or physical disabilities or by the fact of being dependent on care-giving institutions or services. Hence, the design and conduct of the present study requires a particularly sensitive, refined approach to ethical questions. In this sense, specific strategies are being developed in order to minimise people's risk of experiencing distress or harm caused by their involvement in the research process.

First and foremost, with the aim of acknowledging and going beyond the communal principle of *doing no harm*, a careful assessment of risks and benefits associated with the participants' involvement is being undertaken.

In fact, giving people voice in order to gain insight knowledge about their life situations entails guaranteeing them the benefits of holding tailored research outcomes. The intention is to counteract the tendency that groups of people who are commonly deemed as vulnerable "are frequently excluded from research without clear justification" (Smith, 2009, p. 253, with reference to Gurwitz et al., 1992; Larson, 1994). Yet, "actively seeking involvement and recruitment of marginalized and vulnerable groups in research also reflects the principle of justice by trying to ensure that the benefits of research and evaluation are equally distributed among all client groups" (ibidem).

Notwithstanding, the achievement of such benefits needs to be subordinated to the attentive assessment of potential risks research participants may be exposed to. In this sense, the researcher needs to place the welfare, safety and interests of research participants above his or her own personal or professional interests and above the acquisition of knowledge (Mkandawire-Valhmu et al., 2009, p. 1727; AASW, 2010, p. 36).

The acknowledgement of such principles entails assuring that people agree to be part of a study on the basis of authentic informed consent. Thus, prospective participants of the present study are given free choice on involvement and are assured that their decision whether to provide or deny assent does not imply any implications on their actual or future situation. In this sense, any denial to be involved in the research project is fully respected. Further, informed consent is conceived as an ongoing process of communication, which entails that all participants are given the right to revise the terms of their collaboration or to suspend participation at any stage of the process.

All these strategies can be applied only on the basis of appropriate, transparent information. Thus, particularly in the case of people with disabilities the researcher endeavours to develop adequate and understandable forms of communication and information deliverance. In this sense, with the help of the participants' reference persons, all informed consent forms are being elaborated in a comprehensible language, partly also by the use of pictograms. Further, also in the case of people who are represented by a legal guardian the researcher strives for explaining the aims and implications of the study also to the participants themselves endeavouring to deliver them a comprehensible description of the project and to assure that their participation is based on a free and deliberate decision.

This sensitivity for people’s dignity, rights and interests will characterise the researcher’s attitudes throughout the whole research process. This unquestionably implies the guarantee of confidentiality and thus of masking the participant’s identity. In fact, the construction of a trust relationship is essential in the process of collecting life histories which encompasses eliciting people’s intimate experiences, including sensitive topics. In this sense it is the researcher’s responsibility to guarantee people’s overall welfare by showing supportive, empathetic attitudes and comforting verbal and body language. Further, the researcher is constantly striving for developing modes of communication and interaction, which permit all participants to understand the research process and to actively participate in it. This entails the close collaboration with people’s reference persons who are providing precious sustain in accessing the field and in developing suitable ways of not only verbal communication, but also of alternative tools of interaction comprising the use of pictograms during the interviews.

Further, the researcher intends to conduct the study with respect for people’s daily routines and individual lifestyles. Thus, people are given the choice of the sites and times most suitable for conducting the interviews.

Hence, the overall aim is to engage in personal relationships characterised by respect and reciprocity, which implies addressing power relationships in the research process and thus mirrors the pivotal principles of participatory action research.

4. Expected outcomes

The outcomes of this study are expected to offer new insights in the lived realities of elderly people, with particular attention to the peculiar experiences at the intersection of lifelong intellectual disabilities, age and gender. Thus, this work aims to enrich sociological theories on social participation in the fields of ageing and disabilities, with reference to intersectionality theories and to the capabilities approach. By valorising participatory action research approaches, the project aims to deliver a contribution to address inequalities and to reveal vital mandates arising for social work practice and social policy.

5. Annotation

The present paper represents an amended and further developed version of the work presented at the Conference on Sociology and Social Work in Aalborg, Denmark, May 2013 as well as at 5th World Conference on Educational Sciences in Rome, February 2013. The related paper *Social Participation Of Elderly People* has been published in *Procedia – Social and Behavioral Sciences* and indexed by *Scopus* and *Science Direct*.

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