Outlines of an architecture of a service oriented to the development of skills of persons with and without disabilities

An innovative practice experience of inclusive research in Italians public services

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Abstract

Usually, university research has focused its efforts on criteria such as validity, reliability and objectivity that reflect the idea of the "mechanistic" man. The trend that was generated by this has led to the exclusion of those categories that may not be subject to such conditions, in particular, so-called vulnerable people such as women, children, and people with disabilities. With the development of different approaches to knowledge, we are witnessing a paradigm shift in the ability to discuss traditional approaches and the opening up of new knowledge possibilities. Despite many studies, although designed to give a voice, they still reflect the limitations and mindset of the traditional approach. For example, research is often conducted on people with disabilities but through the caregiver, or through proxy advisory professionals. Another indicator of the old tradition of research is the partial absence of studies that involved researchers and vulnerable according to a "symmetric approach". This work intends to present a municipal service built in co-design between different subjects, in which university research, practical experience of social services, schools, voluntary associations and social cooperatives, cooperate in a way non-hierarchical, in accordance with the references of the "inclusive research".

Keywords: Inclusive research, disability, social model of disability, development skills

1. Introduction

Traditionally, university research has focused its efforts on criteria such as validity, reliability and objectivity that reflect the idea of the "mechanistic" man (Carr, 2007; Hammersley, 2007).

The trend that was generated by this has led to the exclusion of those categories that may not be subject to such conditions, in particular, so-called vulnerable people such as women, children, people with disabilities or, as defined by Marks (2005), those with special needs, and the elderly (Humphrey et al., 2013). Hence the idea of "research self-reference" as an end in itself (Clarke 2003), devoid of content and social benefit, which has involved many researchers who were inclined to study only certain topics, under certain conditions, and in the interests of their own career. For these reason, some types of study are often criticized (Hargreaves, 1996a, 1996b; O'Reilly & Barot, 1997; Trifonas, 2009). With the development of different approaches to knowledge such as constructivism, social constructionism, discursive psychology, phenomenology and in general through the relativistic epistemology and especially those related to Heisenberg's principle that the '"observer determines the observed" (Heisenberg, 1935, 1958), we are witnessing a paradigm shift in the ability to discuss traditional approaches and the opening up of new transformations and knowledge possibilities (Ludovico, 2011).

This change is investing academic research, as well as several international institutions (UN, 2006; WHO, 1996). Despite many studies, although designed to give a voice and to involve people who previously were not even involved, they still reflect the limitations and mindset of the traditional approach. Thus there are studies on parental separation without the involvement of people who are separated; there are studies of people with disabilities without the involvement of the disabled, rather than by and with people with disabilities (Walmsley & Johnson, 2003).

In many cases then, research is conducted on people with disabilities but through the caregiver, or through proxy advisory professionals (Ramcharan et al., 2004). This places people with disabilities in a subordinate and passive position, and reflects a state of prejudice that is very serious and widespread (Nosek et al., 2001). People with intellectual disabilities are not able to make further comment. A final indicator of the old tradition of research is the partial absence of interventions and studies that involve academic researchers, social workers, family members and citizens, with and without disabilities. In the absence of such permanent conditions, we share the thoughts of Holland (2008) about the partiality of the research and the fact that the repercussions of research should take account of the life and needs of the people involved (Caron-Flinterman, 2005; Abma, 2006; Greene, 2006), and how public and private institutions organize their services to the public, both those with and without disabilities. That said, the research that tends to engage people with disabilities is increasing (Knox et al., 2000; Richardson, 2000; McVilly et al., 2006; Williams et al., 2008), although numerically they are still considered "exceptional".
We present here a practical paper aims to highlight a public service run in partnership between people with and without disabilities, in collaboration with various roles: academic researchers, associations of family members with disabilities, cooperatives, social workers, teachers, etc..

2. Framework

2.1 Disability as a social product.

Traditionally we are used to thinking of disability as a factor that is internal to people. Generally, the disabled person is identified in terms of his/her disability, from which descends a series of attributions as his being vulnerable, fragile, incapable and in need of help. This is due to a medic approach applied to people with handicap. If this setting is used to identify more precisely the kind of handicap and the necessary tools, it does not explain the reason why some quadriplegics are engaged in such sports as paragliding, which is, not allowing an understanding of the subjective meanings attributed to that handicap. It also precludes the study of how the identity of an athlete could, regardless of his/her impairment, be positive. For instance, there is the Italian pilot Zanardi who, after losing his legs in a car accident, has become a Paralympics bicycle champion. A paraplegic person who lives in the streets on Mount Illimani will always be "disabled", as will a paraplegic person who lives in Stockholm, with the same disability. Hence the belief is that it not the person who creates his own disability; that disability is not reducible to a vulnerable or defenseless individual, and especially that the disability is related to the context of the interactions in which the disabled person is engaged (Swartz, 2010; Walmsley, 2001).
The implications of a medical setting are found in the increase in the number of personal assistance services, in the activation of relational caring and healing, and in the increase of "addiction" in creating a thriving sector, that of disability, which entails considerable expenditure in terms of health resources (Thomas, 2007; Watson, Roulstone &Thomas, 2012). All are services of the highest ethical value but it is reifying the concept, and strengthening the idea of a person with a disability in itself, and especially not responding to the needs of people with disabilities, nor to all of us as citizens (Albrecht, 1992; Stone, 1996; Barnes, 2012).

If the impairment is a characteristic of the mind, the body, the senses of a person (and is of biological relevance), disability is a critical condition that occurs due to the political, economic and cultural actions that a company performs in terms of people who have a disability, and is attributable to capital expenditure. In this sense we speak of the social model of disability, for which the focus is on the interactions between people who have different needs, rather than on the pathology and treatment in respect of individual subjects (Hunt, 1966; Oliver, 2009; Morris, 2002).

In 2006, the UN Convention on the Rights of Persons with Disabilities, defined disability as "…the result of the interaction between persons with impairments and behavioral and environmental barriers that hinders their full and effective participation in society on an equal basis with others"

The European Union has officially entered the social model of disability policy in the Action Plan for 2003 (Commission of the European Communities, 2003). In concrete terms, this states that you are not, or do not become, "disabled" because you cannot see or do not use a leg or you do not understand what social rules are used by most people, but only when you meet environmental and behavioral barriers that limit the chance to live like and with others (Iudici, 2013). Ultimately, when we speak of a person with disabilities, in reality we are talking about "all of us", and what conditions we are able, or not able to create in terms of social integration. We are therefore talking of administrators, citizens, teachers, religious, social workers and researchers. Based on the social model, some research approaches have emerged in universities, such as emancipator disability research, self-determination empowerment (Wehmeyer, 1995, 1999), Self-determination learning model of instruction (Mithaug et al., 1998), participatory action research (Freire, 1970; Kemmis et al., 2005; Zuber Skerritt, 2004), *learned hopefulness* concept (Zimmerman, 1990), as well as research support and care inclusive (Aspis, 2000; Kemmis & McTaggart, 1988), followed by the project under examination that begins with the stimulating arguments of Walmsley and Johnson (2003).

2.2 Inclusive Research

The urgent appeal "Nothing about us without us" coined by Walmsley and Johnson has important consequences for scholars, and has had a considerable impact on the methodology of the research in this area. It is an emerging approach, not in opposition to other forms of work, such as empowerment or participatory research, but is based on direct collaboration between university researchers and people with special needs (Williams, 2005; Walmsley & Johnson, 2003; Nind & Vinha, 2012). In particular we share their thinking about the need for research through the direct involvement of the people being researched; from passive objectives of research to actors in the research. One way to represent a non-rhetorical involvement is to ensure that the people involved can make informed decisions about the research itself. This methodological process (horizontal and non-hierarchical) rests on the belief that any person can make his or her own contribution at a different level. There are, as well, the psychological theories on the development of childhood, in which we talk about skill levels, and in general an "anthropomorphic" epistemological paradigm based on the belief that man is an active subject capable of assigning meanings to things (Berger & Luckmann, 1969; Bateson, 1979; Watzlavich, 1981; Gergen, 1999). In this sense, the researcher is an expert in methods; the person with or without disabilities is an expert when it comes to stories and narratives that produce transformation, well-being or closing. This changes the traditional relationship between researcher and researched (Abma & Widdershoven, 2008; Schipper et al., 2010).

Some authors (Barnes, 1996) argue that the traditional asymmetry between those who carry out research in the field of disability and the research subjects (the 'disabled' subjects) implies a subordination that reifies the concept, making the people look even more like passive "objects of study". In this sense, the researchers would be part of the problem for people with disabilities, and certainly not the solution. In inclusive research, the researcher not only does not use a person under investigation in a self-referential way, but has need of their text and their narrative position. In operational terms, inclusive research is built around the sharing of expectations (Williams & Simons, 2005), the intent (Barton, 2005), methodologies, processes (Kellett & Nind, 2003) and results (Abma et al., 2009). Another foundational aspect of the inclusive research we share is that the outcome of the research should address the needs of people at risk of discrimination, and must be able to actually be usable by the people involved and explicitly represented (Walmsley & Johnson, 2003; Holland et al., 2008). It also shares the idea of Barnes (2006) that research into disability is both research on people who have impairments, and the people who study how the impairment results in disability.

Ultimately the inclusive approach is not an ideological end in itself, but draws attention to the development of skills of all those involved in the research according to different levels, from which one can define specific objectives, both for people with disabilities and for people without disabilities.

3. *Service Co-Design for the Support Training of Students with Disabilities*

The service described is managed through collaboration between the municipality of Melzo, the municipality of Liscate, and a cooperative founded by family members of people with disabilities - a cooperative of psychologists and educators, social workers, and university researchers. This is one of the few examples of institutional co-planning between public bodies (schools and municipalities), Third Sector organizations, and citizens, including children with disabilities and their families. The project is aimed particularly at those whom the institutions of neuropsychiatry define as "with learning disabilities", “pervasive developmental disorders" or the "mild intellectual retardation" which is often associated with disabilities. It is the description of a service run by people with disabilities and without disabilities

3.1 Normative References

The project references refer to Italian Law n. 328/2000, Lombardy Regional Law n. 3/2008 and Italian Law 104/92 (and subsequent amendments) and adopt the Convention on the Rights of Persons with Disabilities (December 13, 2006). These references are aimed at promoting the quality of life for the benefit of all citizens, equal opportunities, inclusion programs and school/social/work support of those persons in situations of disability. In this scenario, the integrated service system is configured as a network of shared responsibilities (institutions, Third Sector, informal solidarity networks, families etc.), aimed at ensuring the social inclusion of all citizens, especially those with disabilities.

3.2 Conceptual References

From what has been said in the preceding paragraphs, the "disability" is not considered a universal reality, but is understood as the product of social interactions that may or may not tend to define how pervasive the role of the "disabled" is in the person's life. We define this with the construct of “biographical career” (Turchi, 2007), as it outlines a way of life that assumes disability in terms of deficit and illness, starts rehabilitation and care interventions, and finally creates a "destiny determination". The second construct is the "biographical way", where the status of the person with disability becomes the status of a "person" which is dominated by other roles, and for whom the future is open to multiple possibilities. Activating a biographical journey is the responsibility of all stakeholders in the project, which has as its focus, the shared development of general inclusion-oriented skills, both in the person with special needs, and in so-called "normal" people.

3.3 Objectives

The general objectives of the service are:

- to promote a mode of action that generates opportunities for the development of skills and processes that foster social and labor integration.
- to facilitate competent management on the part of the social services of the local resources related to professional training and to provide tools and training programs / refresher courses for social operators.
- to implement methods of interaction between the various actors operating in the area, and to identify good practices that are replicable.

3.4 Lines of Action

1) Co-design by the various organizations dealing with disability.

This action reflects the origin of the project and involves continuous meetings between organizations that currently manage the project. These meetings are designed to bring out the needs of families of children with disabilities (which is to develop their children's skills in terms of using the services in the area), the needs of the municipalities (which is to develop citizenship skills, limiting welfare dependency), the needs of university researchers (who are the ones who know how people and the social services construct a "biographical way" or a "biographical career", and to share technical and scientific systematization) and the needs of social organizations (which are the ones which make available their ability to network and provide integration tools). These requirements are discussed and processed together. Generally, they give rise to proposals for improvement, not present before the common processing.

The difficulties relate to: a) change in the habits that derive from the most popular type of service management, i.e. the administrative bureaucratic model, which allows one to decide what to do immediately and alone (vision of efficiency in absolute terms), while the co-design model requires one to share selection criteria with respect to the management of the service (vision for efficiency in terms of the team: all contribute to a shared goal with shared methods) and b) the collaboration between managing bodies (temporary associations of business) where special attention and a substantial investment has been placed in generating a different positioning of operators, by performers, each with its own personal "educational style", to a team that manages change interventions with shared methods.

2) Design of personalized interventions in the school context

This action is aimed at students with special needs, and provides the definition of inclusive education projects shared between families, social workers and teachers. The individual care plan is drawn up once a year, and includes actions implemented by all of the roles described in pursuit of a shared goal. The difficulties concern a) the lack of flexibility of some educational institutions which are more responsive to scholastic performance that the skills of citizenship (Ali et al., 2012) and b) the improper request of some families that require many more hours of personal assistance exclusively for their child. This is a perspective that, as we have seen, would make people with disabilities more "disabled".

3) Laboratory for developing skills in terms of school choice and professionals

This action consists of laboratory activities designed to teach the person with special needs how to develop their own schooling and career. Role-playing and exercises simulate the specific activities of the types of school in the area (Camara et al., 2013). For example, they learn how to handle the demands of teachers, relationships with their classmates and with school staff. They learn to ask for help, and learn how to overcome their limitations. The difficulties lie in the fact that: a) some families "delegate" the choice of school to the leaders of the laboratory, b) it requires a lot of meetings with teachers and this is not always possible, and c) lack of information about interactions school in which the student is involved and this is not always easy to acquire.

4) Evaluation of processes that involve users of the services.

The evaluation process monitors how the various individuals implement the shared strategies at the project level. These meetings are managed by the researcher and by the evaluation team, and the focus is on bringing out the difficulties and strengths of the strategies proposed.

These meetings also involve students with disabilities, so they can express what has changed in their situation before and after the help provided by the operators of the Individual Educational Project (PEI) and the Laboratory. For example, in a project with the goal *"…to develop the skills to identify the implications of their actions"*, a student named Matthew was asked: "if in a conversation between your parents and teachers we are told that "*at some point Matthew, you started to think before you did things, being aware of what happens if you do a thing, for example, if you tell a lie*." What did you do before that time? What do you do now? "

This question resulted in a response from Matthew that the operator and the evaluation team and the research team used to create what happened during the year. In this case the child is involved in the evaluation process of the project.

The difficulties relate to practical organizational aspects: in particular, finding a time and a place for carrying out the assessment with the students involved in traditional teaching, and to share the day and time of the evaluation with the families.

5) Search of the "configuration" of disability

The research aims to identify which discourses are used to represent the disability and the services for disability. This means that the disability is produced by discourses that suggest it (see paragraph 2). The research also aims to capture the voices of the different people involved, particularly 1) families with children with disabilities, 2) experts who deal with disability (social workers, psychologists, educators, child psychiatrists), 3) the volunteers who provide help with regard to disability, 4) people with mild, moderate or severe disabilities; 5) citizens who do not have a direct relationship with people with disabilities. The data were processed. A first result given is one for which the reasoning of the volunteers reifies the disability attributed exclusively to the person, setting the relationship with them exclusively in terms of passive dependence on welfare and care. The differences between experts and citizens are not as relevant. The results will be presented in a forthcoming publication.

The difficulties are: a) to approach the stakeholders, especially medical ones, to provide their input, b) conduct interviews with people who are not accustomed to tell, for example, older volunteers and people with certain disabilities, c) to organize interviews, focus groups and the processing of data in a timely fashion in relation to the redesign phase of the interventions.

4. Conclusions

The present work aims to demonstrate that research can have a direct impact on services and their architecture, and that this can only be achieved by interpreting the resources of the area. In the context of disability, very often the relationship between research and application is based on an asymmetrical relationship in that disability has been studied as if it were an internal characteristic of the person. This setting is due to the application of the medical approach to issues that have a symbolic and psychological values within which that approach is not applicable. If it is true that intervention on an impairment basis can be done through the medical approach, and it is equally true that when we deal with integration, inclusion and participation, other conceptual frameworks are needed, then in the context of disability, we are finally witnessing a paradigm shift of epistemological and cultural invests, different disciplines and areas of work: the attention and research efforts are focusing more on interactions than on individual characteristics. This leads to a edistribution of responsibilities in terms of science and society. No longer are there volunteers guided by values and ready to make any sacrifice, and users who give help, treatment and moral care, but also more competent agencies and services that can create conditions for growth and for the development of skills for people with special needs and for the people who interact with them.

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