

Non disabled researchers and disability studies

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ABSTRACT

The theoretical contribution explores the role of nondisabled researchers in disability research and points to the possibilities this collaboration could offer to advance the research in gender studies and in disability studies.

The chapter starts with an overview of the conceptual path leading from the social model of disability to feminist disability studies: the theorisations of disability have been nourished by feminist and gender studies, although this has often not been acknowledged by feminist and gender scholars. Then, starting from the debate hosted on the International Journal *Disability and Society* between 1997 and 1999, in which the role of non disabled researchers has been questioned and criticised, the chapter uses examples of specific research paths, to describe how the contribution of non disabled researchers to disability studies can help in uncovering and exploring the intersections between discriminations based on gender and on disability. A brief exploration of possible paths for the future, inspired by the current focus on the concept of fluidity both in gender and in disability studies, concludes the chapter.

Keywords: non-disabled researchers, gender studies, disability studies, feminist disability studies

INTRODUCTION

On 1st September 2016 the WISE Women in a RISE (RISEWISE) project launched in five countries, (Italy, Sweden, Portugal, Turkey and Spain), with Slovenia joining in 2018. The four-year project aims to promote co-operation and share research and development competencies regarding women with disabilities. The activities are carried out through a partnership of 18 Universities, NGOs and SMEs.

RISE (Research and Innovation Staff Exchange) is a programme run by the European Union to encourage intersectorial and/or international research and co-operation projects with funding for secondments within the partnership. As part of their secondments (assignments of a member of one organisation to another organisation for a temporary period), participants remain with one or more partners for up to 12 months (not necessarily consecutive) out of a total of 540 months for the entire project. During this time participants develop contacts and collaborations at local, regional or national level, embarking on research projects and gathering experiences and competencies which would otherwise be difficult to share.

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In RISEWISE, the partnership includes many different research disciplines and applies each of them to study different environments. Each Partner has planned to apply its expertise in one or more disciplines to one or more environments. Table 2.1 shows the partners and their competences for each environment. (The Universities' acronyms are in *Italics*). Table 1 indicates that all the environments and disciplines are covered by the set of partners in the project, to a varying degree.

In the early stages of the project, training was provided (primarily but not exclusively) for future participants from the world of academia who lacked specific knowledge of disability. The aim was to provide them with a common understanding so they could interact with the NGOs involved, associations of and for disabled people, and develop ideas for co-operation and planning. To achieve this objective, disabled and non-disabled experts held seminars, which were videoed so they could be seen by participants unable to attend in person. A list of resources was also drawn up (articles, books, videos) to provide participants with information on the evolution of disability studies and help them collocate their disciplines and research interests within a context which took account of existing knowledge of disability and disabled people and the debate on the issue at international level. Where possible, preference was given to experiences and research pathways involving women (academics and non-academics) with disabilities.

The information pathway led to a reflection on the role of non-disabled people in disability research and in association with disabled people. This chapter is based on the ongoing reflection which was first shared during project meetings and is now being put into effect in a formal text.

As shown in the following pages, the debate on the issue remains particularly animated. Experience gathered as part of RISEWISE shows the positive effect of interaction. Exchanges and co-operation are providing awareness which is changing not only the professional experience, as participants explore different concepts, approaches and methodologies, but also their personal experience, as each person's identity is compared to their fellow participants'. The exchanges always have an intersectorial and an international dimension, since participants are required to go on secondment to a different type of organisation to their own, and to a different country. It is easy to see how this enriches experiences, co-operative pathways and reciprocal knowledge, turning a project aimed at a specific group (women with disabilities) into an exploration and analysis of other dimensions such as class, ethnicity and gender. The initial understanding of the diversity within a generic term such as "women with disabilities" has widened to include many more facets. Furthermore, the fluidity of the concept of disability introduced in recent years as part of the latest theories has helped blur the concept of "us and them" which the participants might have had at the start of the project. Co-operation between disabled and non-disabled people might increase further in future, particularly now that the concept of identity itself is being reviewed and debated from many different angles.

Research Disciplines	Daily living environments					
	Home	Work	Education	Health	Entertainment and Social life	Others (Travels, etc.)
Social research	AAATE, AFADIS, AIAS, FRATERNA, UCM, UNIBS, UNILJU	AAATE, AFADIS, AISM, METU, UCM, FRATERNA, UNIBS., University of Ljubjana	AAATE, AFADIS, AISM, METU, SU.	AAATE, AFADIS, AISM, UNIBS, UCM, FRATERNA, .	AAATE, AFADIS, AISM, UCM, FRATERNA.	AAATE, SU, AFADIS, AIAS, AISM, SENT, UCM.
Mediation	AIAS, UNED, UNIBS.	AFADIS, UNED, UNIBS.	SU, UNED.	AFADIS	AFADIS, AIAS, UNED.	AFADIS, UNED.
Psychology	AIAS	METU, UCM	METU, UCM	AFADIS, AIAS, UCM	UCM	AIAS
Law	AISM, ENGELLI, UMINHO, UNED, UNIBS.	AISM, ENGELLI, SU, UMINHO, UNED, UNIBS, UNIGE.	AISM, METU, SU, UCM, UNED.	AISM, ENGELLI, UMINHO, UNIBS.	AISM, ENGELLI, UNED.	AISM, ENGELLI, UNED, UNIGE.
Cultural diversity	AISM, UNIBS, UNILJU	AISM, UCM, UNED, UNIBS.	AAATE, AFADIS, AISM, ENGELLI, FUNKA, METU, SU, UCM.	AFADIS, AISM, UCM, UNIBS.	AAATE, AFADIS, AISM, ENGELLI, FRATERNA, FUNKA, SU.	AISM, SENT, UCM
Accessibility and Inclusive Design	AAATE, AIAS, ENGELLI, FRATERNA, FUNKA, SU, UNIGE.	AAATE, AISM, ENGELLI, FRATERNA, FUNKA, METU, SU, UCM, UNIBS.	AAATE, AFADIS, AISM, ENGELLI, FUNKA, METU, SU, UCM, UNED.	AAATE, AFADIS, AISM, ENGELLI, FRATERNA, FUNKA, SU, UCM.	AAATE, AFADIS, AISM, ENGELLI, FRATERNA, UMINHO, FUNKA, SU, UNIGE.	AISM, ENGELLI, FRATERNA, SU, UNIGE.
Assistive Technology and AAL	AIAS, FUNKA, SU, UCM, UMINHO, UNIGE.	AIAS, FUNKA, SU, UCM, UMINHO.	FUNKA, SU, UCM, UMINHO.	FUNKA, SU, UCM, UMINHO.	AIAS, FUNKA, SU.	AIAS, FUNKA, SU, UNIGE.
Violence and Discrimination	AAATE, ENGELLI, UNIBS, UNIGE., UNILJU.	AAATE, AISM, ENGELLI, METU, UNIGE.	AAATE, AISM, ENGELLI, METU, UNIGE.	AAATE, AFADIS, ENGELLI.	AAATE, AISM, ENGELLI.	AAATE, AISM, ENGELLI.
Media Monitoring	ENGELLI, UNIBS.	ENGELLI, UNIBS.	ENGELLI.	ENGELLI, UNIBS.	ENGELLI, UNIBS.	ENGELLI.

Table 1 – Adapted from: Ferreira et al. 2016. For details about RISEWISE Partnership: <http://www.risewiseproject.eu/about-us/partners/>

The text that follows aims to illustrate the knowledge pathway from the first two years of the project, with reflections which have emerged from interactions with other concurrent

research pathways centred on achieving gender equality in the academic and business worlds. These approaches, which include the latest perspectives on critical disability studies, might facilitate structural change in public and private research organisations, promoting diversity and realising research and development pathways including groups who until now have been users of services but rarely actors and protagonists in academic research.

FROM THE SOCIAL MODEL OF DISABILITY TO CONTEMPORARY APPROACHES

Having first appeared in the 1980s primarily in the US, the UK and Canada, disability studies have since become a well-developed research agenda, with a distinctive set of concepts, theoretical frameworks, objectives and tools. This was initially facilitated by reflections made by disabled people¹ active in the disability rights movements in the UK, who in previous years had developed the “social model of disability” (hereafter the social model) drawn up by the Union of the Physically Impaired Against Segregation (UPIAS).

In the 1960s and 1970s, the social model had shifted the debate from disability on a personal level - linked to a medical model associated with suffering – to society as a whole, which “disables” some of its members through its values, mode of production, political economy, physical environment and 'welfare' system (Oliver, 1990). Disabled groups in the UK were inspired by the civil rights movement in the United States and took direct action against discrimination, poor access and inequality.

In the UK, however, the social model did away with the links between impairment and disability, with the former no longer seen as the cause of the latter: this meant that the links between disability and the body was no longer recognised. The idea was to avoid biological reductionism, which places the accent on physicality and is perpetuated by the concept of impairment. If there was to be a move away from the medical model, it had to be all-encompassing.

It was the rejection of the body which first triggered concern among disabled activists. They criticised the model from the inside, agreeing with the overall principles but underlining its inadequacy. Disabled activists believed that the model led to an extreme form of constructivism, in which the real experiences of disabled people are hidden, as if they can be overcome by changing the social order and overturning the ableist structure which permeates society.

“The distinction between impairment and disability at the heart of the social model of disability is viewed as an unsustainable version of the out-moded Cartesian nature/society dualism. It is argued that each side of any Cartesian binary divide – “normal” versus “abnormal”, “society” versus “nature” – is socially constituted and can only come into being through explicit or implicit reference to its opposite. This turns the spotlight on the work that dualisms do in constituting and fixing the “impaired” or “disabled” as “other”. (Carol Thomas, 2006, p. 179)

¹ At international level it is now preferable to use the term “people with disability” (particularly in the US), or disabled people (particularly in the UK), with the word “people” replacing adjectives such as invalid, disabled, etc. The advantage of this choice – which is shared and adopted by the author – is that a characteristic limited to part of a person is not attributed to the person as a whole; furthermore, the term “people” is neutral and has neither positive nor negative connotations. (Bencivenga, 2004, p. 110). Since this text refers to the UK’s social model which uses “disabled people”, the author has chosen to adopt this term and to keep other expressions used in quotations.

The difficulties and suffering which are often, though not always, linked to an impairment were thus re-emphasised by disabled people themselves to all those, disabled or not, directly or indirectly involved in research and studies centring on disabled people.

The reflection made by disabled women activists on the role of the body and impairment, elements which were overlooked by the social model, was taken up by disabled female academics in later years. This group focused their research projects on their physical condition and entered into closer debate with the feminist movement, which until then had never been involved with disabled women's activism and had gone so far as to distance itself completely. In fact, non-disabled feminists, perceiving disabled women as childlike, helpless, and victimised, had excluded disability from their analyses, in an effort to advance more powerful, competent, and appealing female icons: "As one feminist academic said to the nondisabled co-author of this essay: 'Why study women with disabilities? They reinforce traditional stereotypes of women being dependent, passive and needy.'" (Asch & Fine, 1988, pp. 3-4)

The debate which researchers identifying as disabled opened up with women and gender studies led to the creation of feminist disability studies (FDS). Unfortunately, the debate has remained almost completely one-sided. However, one only needs to read Garland Thomson's description of FDS to understand its close ties with feminist scholarship: "Just what is feminist disability studies? It is more than research and scholarship about women with disabilities, just as feminist scholarship extends beyond women to critically analyze the entire gender system. Like feminist studies itself, feminist disability studies is academic cultural work with a sharp political edge and a vigorous critical punch. Feminist disability studies wants to unsettle tired stereotypes about people with disabilities" (R. Garland-Thomson, 2005, p. 1557)

While disabled people were beginning to analyse how society interferes with some people's lives, disabling them, and to reflect on their experiences of impairment and disability, another issue was being widely discussed: the role non-disabled² researchers may have in disability research. This role came under scrutiny when greater self-awareness among disabled people of their relationships with their bodies and society opened new up perspectives, primarily the social model, requiring new research pathways to study its impacts and effects.

The role of non-disabled researchers has been widely debated and often criticised. At least as far as the social sciences are concerned, non-disabled researchers have begun to question their role make changes to their approach and offer up solutions. This has taken place both at an individual level, seeing as no research posts were occupied by disabled people, and in co-operation with disabled researchers on a shared research basis.

In recent years, however, a new model has emerged: critical disability studies which advocate for both accommodation and equality in all areas of life. In more general terms, society's view of disability has also become less rigid and more fluid. These changes have opened up new possibilities for co-operation, since the new approaches require all researchers to reflect on their identity and identity linked to the concept of disability, which has more and more fluid connotations.

The aim of the chapter is to examine what we have briefly presented in the introduction, opening up a relationship between non-disabled researchers and disabled researchers as well as disabled people who come into contact with them for reasons of academic research.

After a brief illustration of recent events, the latest developments will provide inspiration for possible new pathways which might provide innovative solutions and answers, ones which might finally enable constructive partnerships where, until a few years ago, abuses of power prevailed. "I

² The author has chosen to use the term non-disabled, aware of the possibility and common use of the alternatives, non disabled and nondisabled, which have been left in quotations.

have argued that research has essentially failed disabled people on at least three counts. Firstly, it has failed to accurately capture and reflect the experience of disability from the perspective of disabled people themselves. Secondly, it has failed to provide information that has been useful to the policy-making process and has contributed little to improving the material conditions under which disabled people live. Thirdly, it has failed to acknowledge the struggles of disabled people themselves and to recognise that disability is not simply a medical or welfare issue, but a political one as well.” (Oliver, 2002, p. 2) Written in 2002, these words are perhaps now superseded: the attenuation of the concept of disability itself, with more modern perspectives which alter its premises, opens up new possibilities and represents a major challenge for both disabled and non-disabled researchers in academia and in other institutional settings.

The paper is divided into five sections. The first section sets out the background of the study, providing an overview of the emergence of the emancipatory paradigm once the social model of disability has been defined in all its conceptual details. Section two provides information on the debate on opportunities for non-disabled researchers to study disability, while section three describes the theoretical perspectives developed by female academics who identify as disabled and who refer to feminist and gender studies. The fourth section reviews how the approach to disability is currently evolving, and focuses on the extent to which the concept of fluidity can help reflections on inclusion and empowerment. Finally, section five looks to the future with inspiration from an area of study where gender perspective is bringing about analytical changes with possible practical implications on disability studies: structural changes which favour gender balance in academia. This approach, previously designed to promote gender equality and progression for minority groups within universities, might also be used to facilitate training and academic career development for disabled and non-disabled researchers interested in (feminist) disability studies.

THE EMANCIPATORY PARADIGM EMERGES FROM THE SOCIAL MODEL OF DISABILITY

While in the UK the social model of disability contributed to a change in perspective, giving a new meaning to the word ‘disability’, in other countries the traditional, medical meaning remained in place. It was behind the World Health Organisation’s (WHO) formal definition in the International Classification of Impairments, Disabilities and Handicaps: “In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being” (World Health Organization, 1980, p. 28). This terminology, used in a classificatory approach, shaped the approach to impairment, disability and handicap worldwide for decades. The WHO definition remained valid until an update and revision of the previous classification was introduced in 2001: The *International Classification of Functioning, Disability and Health*, (ICF) introduced the concept of functioning referring to all body functions, activities and participation, while disability became an umbrella term for impairments, activity limitations and participation restrictions. Like its predecessor the ICIDH, the ICF is a classification of health and health-related domains, but it introduces a list of environmental factors recognising that an individual’s functioning and disability occurs in a context. “Previously, disability began where health ended; once you were disabled, you were in a separate category. We want to get away from this kind of thinking. We want to make ICF a tool for measuring functioning in society, no matter what the reason for one’s impairments... ICF puts the notions of ‘health’ and ‘disability’ in a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some

disability. This is not something that happens to only a minority of humanity. ICF thus ‘mainstreams’ the experience of disability and recognizes it as a universal human experience. By shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared using a common metric – the ruler of health and disability.” (World Health Organization, 2002, p. 2)

However, in many languages – the classification is adopted by 197 countries - the term ‘disability’ still retains the meaning described by the ICIDH. In this sense, it is still widely used in the social and medical sectors as well as by the general public, although the “new” concept is slowly but steadily entering into common use. It is important to remember that estimates of the proportion of disabled people vary depending on the definition of the term “disability”; this situation is very common, as definitions vary widely depending on the field of use. To give just two examples, in the medical field and the employment sector, disabled people often benefit from disability allowances and targeted employment paths based on a definition that may vary significantly, even in the same country.

However, back in the 1970s, activists in the UK proposed a change to the meaning of the word ‘disability’ that was revolutionary.

“The social model emerged from the intellectual and political arguments of the Union of Physically Impaired Against Segregation (UPIAS). This network had been formed after Paul Hunt, a former resident of the Lee Court Cheshire Home, wrote to The Guardian newspaper in 1971, proposing the creation of a consumer group of disabled residents of institutions³. Forming the organisation and developing its ideology, Hunt worked closely with Vic Finkelstein, a South African psychologist, who had come to Britain in 1968 after being expelled for his anti-apartheid activities. UPIAS was a small, hardcore group of disabled people, inspired by Marxism, who rejected the liberal and reformist campaigns of more mainstream disability organisations such as the Disablement Income Group and the Disability Alliance. (Shakespeare, 2010, p. 266)

While the medical model of disability maintains that people are disabled by their impairments or differences, the social model of disability introduced a new perspective, stating that disability is caused by the way society is organised, rather than by a person's impairment. Other organisations such as DPI, Disabled People International, a worldwide, cross-disability, non-governmental organisation, adopted the definitions of the social model of disability, rejecting the ICIDH definitions in 1981.

In the 1960s in the United States, a group of disabled students worked on removing architectural barriers at the University of California, Berkeley campus and in the surrounding community. In 1972 the group moved into the community, opening the first Independent Living Center. A few years later, the Independent Living Movement laid the groundwork for feminist scholars in disability studies to redefine notions of dependency and care.

In Table 1, the similarities between the Independent Living Movement and the social model are clearly shown through its vision of the medical model.

The ILM (Independent Living Movement) vision of the medical model, the sick and the impaired roles

The "Medical Model" assumptions

1. Physician is technically competent expert.
2. Medical care should be administered through a chain of authority wherein the physician is the principal decision-maker.

³ The letter can be downloaded at the following link <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Hunt-Hunt-1.pdf>. (Comment of the Author)

3. The "patient" is expected to assume the "sick" role.
4. The main purpose of medicine is the provision of acute/restorative care.
5. Illness is muted primarily through the use of clinical procedures such as surgery, drug therapy and the "laying on of hands."
6. Illness can only be diagnosed, certified, and treated by trained practitioners.

The Sick Role

People with disabilities are expected to play this or the "impaired role." The sick role consists of two interrelated sets of exemptions and obligations:

1. A sick person is exempted from "normal" social activities and responsibilities depending on the nature and severity of the illness.
2. A sick person is exempted from any responsibility for his/her illness. He/she is not morally accountable for his/her condition and is not expected to become better by sheer will.

In exchange:

3. A sick person is obligated to define the state of being sick as aberrant and undesirable, and to do everything possible to facilitate his or her recovery.
4. A sick person is obligated to seek technically competent help and to cooperate with the physician in getting well.

Because disability is often an irrevocable part of a person's existence, the person with the disability begins to accept not only the condition but also the belief that his or her very own personhood is aberrant and undesirable. Moreover, he or she begins to accept the dependency prescribed under the sick role as normative for the duration of the disability.

The Impaired Role

The impaired role is ascribed to an individual whose condition is not likely to improve and who is unable to meet the first requirement of the sick role, i.e., the duty to get well as soon as possible. Occupants of the impaired role have abandoned the idea of recovery altogether and have come to accept their condition and dependency as permanent. The impaired role is not a normative one or one prescribed by the medical model, but is a role a disabled person is allowed to slip into as the passage of time weakens the assumptions of the sick role. The dependency creating features of the medical model and the impaired role are most pronounced in institutional settings.

Table 1. Adapted from: The Independent Living Movement: History and Philosophy to Implementation and Practice. Social Change for the Integration and Inclusion of All People with Disabilities Into Society. A Workshop Manual by Maggie Shreve, Organization Development Consultant. (2011, pp. 7-8)

http://www.ilru.org/sites/default/files/resources/il_history/IL_Movement.pdf

The new perspective brought about by the social model required a new approach to research. Previous methodologies did not provide an adequate response to the emerging view of disability, one which attributed to society aspects once seen as purely personal, tragic and negative. The norm was non-participatory research, researcher-led, with some exceptions of participatory research, in which researchers "invite" participants into research. This led to an 'emancipatory paradigm' for conducting disability research, based on the concept of co-research. The term was coined by Mike Oliver in 1992 and outlined that year in a special edition of *Disability, Handicap and Society*, a peer-reviewed academic journal in the field of disability studies established in 1986 and, since 1994, known as *Disability & Society*. 'The development of such a paradigm stems from the gradual rejection of the positivist view of social research as the pursuit of absolute knowledge through the scientific method and the gradual disillusionment with the interpretive view of such research as the generation of socially useful knowledge within particular historical and social contexts. The emancipatory paradigm, as the name implies, is about the facilitating of a politics of the possible by confronting social oppression at whatever levels it occurs' (Oliver, 2006, p. 276).

The next section shows how the new paradigm underlined the Movement's concern over the appropriation of disability research by non-disabled researchers, and how criticism was taken into account, enabling a new type of co-operation to emerge and allowing concrete scientific research which brought benefits to disabled people.

CAN NON-DISABLED RESEARCHERS PLAY A ROLE IN DISABILITY RESEARCH?

In this section, we refer mainly to literature investigating the opportunities, advantages and disadvantages posed by non-disabled researchers taking part in disability research, with a brief overview of the wider context. In exploring the interactions between disabled people, activists from UPIAS and other organisations fighting for disabled people's rights, and non-disabled researchers, we try to understand the motivations on both sides.

The social model and the 'emancipatory paradigm' research model were not born in a vacuum, but at a historic moment when literature on 'critical social research' and 'action research' by researchers championing oppressed groups was flourishing. As in other alliances between researchers and oppressed groups, under the new paradigm disabled people and the organisations they founded and operated had control over the research process (not least its funding) and the issues it raised, taking on the role of non-disabled researchers. In the space of a few years, at least in the United Kingdom where the paradigm emerged, the role of funding important disability research passed to charitable agencies and trusts such as the *Joseph Rowntree Foundation*, an independent organisation working to inspire social change through research, policy and practice, and the *National Lottery's Community Fund*. The projects funded by both these organisations were led and coordinated by users rather than researchers and academics. Ten years after Mark Oliver's first paradigm, Colin Barnes closed a conference on disability by commenting: "By definition emancipatory disability research should be judged mainly by its ability to empower disabled people through the research process, but whether this is achievable is a highly contentious issue. It would be impossible to imagine that any one piece of research, no matter how comprehensive or rigorous, could empower all disabled people at the same time. Disabled people like their non-disabled peers are not an homogeneous group. And of course to eradicate disability and, therefore, empower the disabled population emancipatory research must resonate with non-disabled people too. With this in mind the emancipatory research paradigm must be seen not in terms of one single project or projects but as a process. Each piece of research must build on and develop what has gone before. It must seek to make a further contribution to our understanding and ability to erode the various forces: economic, political and cultural, which continue to create and sustain disability at both the macro and micro levels." (Barnes, 2001, p. 16)

Beyond the key issue of practical and organisational aspects of research, reflections focus on how the emancipatory disability research paradigm can be put into effect and on the balance of power between all stakeholders in the research process, regardless of their role.

It would be naive to deny that power relationships do not exist between disabled and non-disabled people, a dynamic which accentuates what happens in all research paths, and the balance of power between researchers and the subjects of their research has been extensively studied. Disabled activists have criticised mainstream disability research since at least the 1970s (Barnes, 2006; Hunt, 1981; Oliver, 1987). Studies produced by disabled researchers have underlined the extent to which non-disabled researchers oppress disabled people and their families, at least in the UK: 'Walking into Darkness', by Oliver et al., 1988; 'Able Lives', by Morris, 1989 and 'Cabbage Syndrome' by Barnes, 1990. "This was paralleled by a growing disillusionment with conventional social research strategies by researchers working in the 'developing' nations of the majority world,

black writers, feminists and educationalists.” (Barnes, 2006, p. 348)

The positive aspect of all this has emerged from reflections on ‘critical social research’ and/or ‘action research’, with partnerships between non-disabled researchers and oppressed groups leading to a new research paradigm, the emancipatory disability research paradigm.

The debate reached an important stage in 1996, when Emma Stone and Mark Priestley, both of whom were involved in disability research, attempted to introduce more ‘vulnerability’ into their research projects. They made themselves more accountable to disabled people by opening up their research rationale to the widest possible scrutiny, inspired by what Liz Stanley and Sue Wise had suggested years before (1983). It is worth noting that the Stanley and Wise text is about feminism, and focus on ways for women to break out of their oppression. This includes a repudiation of positivism, which claims that beyond the subjective experience and interpretation of individuals there is a knowable social reality. The exploration of the social construction of women’s everyday lives can be one of the starting point to start a process of liberation through three main principles for doing feminist research: the analytic use of feeling and experience to examine the personal should be the basis of feminist research, the researcher should be explicitly situated in any research she undertakes, making her direct experience of the research process an explicit part of her social science work, and recognising verbal and written language importance to the goal of liberation: “to break out of our ways of thinking, writing and speaking is, in effect to break out of how we presently live in all of its infinite aspects” (1983, p. 206).

Stone and Priestley proposed six principles which remained a reference point for many years afterwards.

The first two principles concern theory, and the first recommendation is to choose the social model of disability as the epistemological framework. The authors share the view of Abberley in a text on the development of a theory of disability as oppression: “when researchers in the 1990s still fail to locate their analysis within the epistemo-logical framework of the social model, their research cannot but be deemed oppressive” (Stone & Priestley, p. 704).

The second principle, again related to theory, is to surrender objectivity. The authors cite the experience of Paul Hunt, who as a resident of the Court Cheshire Home had been the subject of research in 1981. “Hunt condemns the researchers’ self-imposed and hypocritical obsession with ‘detachment’ - hypocritical since the researchers maintained distance from the disabled residents whilst siding with staff and experts. For Hunt, claims to ‘detachment’ and ‘objectivity’- where the context is one of oppression - are inherently flawed. Participant observation can only provide ‘superficial information’; ‘committed research’ provides results”. (Stone & Priestley, 1996, p. 702)

Two more principles refer to the goals of research, the first stating that it must achieve more than furthering the academic career of the non-disabled researcher, and in particular lead to improvements in the lives of those who become sources of data and information. This principle is strictly interconnected with the next one (the fourth). “Thus the political standpoint of the researcher is tied to political action in challenging oppression and facilitating the self-empowerment of disabled people. The researcher engages in processes of emancipation, rather than merely monitoring them from sympathetic sidelines. Moreover, the nature of that engagement should be determined by disabled people. It is at this point that the principles of activism become incorporated into the fourth (and arguably most fundamental) principle of the emancipatory paradigm.” (Stone & Priestley, 1996, p. 703)

As a second principle for research goals, the fourth of the six principles described by Stone and Priestley, research hierarchies must be reversed and the researchers “must learn how to put their knowledge and skills at the disposal of disabled people. They do not have to have impairments themselves to do this. Indeed, over the last 10 years I have met many people with impairments who are unsympathetic to the notion of disability as social oppression and many able

bodied people who are“ (Barnes, 1992, p. 122). “In understanding the importance attributed to reversing research hierarchies, it is vital to recognize that disabled people as a group are in an oppressed position and that research is conducted within a wider context of oppressive social relations built upon the privilege and power of non-disabled people. It is thus inappropriate to consider disability research production as an activity discrete from its social context.” (Stone & Priestley, 1996, p. 704)

The last two recommendations refer to research practice. “The fifth principle of the emancipatory paradigm is perhaps the most contentious within the paradigm and signifies the beginnings of divergence amongst the core of disability theorists.” (1996, p. 704) It is deemed essential to accept that disabled people’s experiences may be both collectivised and individualised, respecting the different stances within the social model of disability. Feminist perspectives commit to the principle of the personal as political, demanding research on the personal experience of impairment and disablement (French, 1993), and the primacy of such experiences as research data (Morris, 1991); other activists fear that such an approach will obscure the collective nature of disablement as a form of social oppression.

The last recommendation, the second on research practice, refers to the fact that “[i]ndeed, 'emancipatory' research (as with feminist and anti-racist research) is often regarded as synonymous with the use of qualitative data. However, such an association is problematic since there can be no simple causal relation between the use of qualitative data and the removal of dis-abling barriers” (p. 705). Thus, it is considered advisable to accept the use of both quantitative and qualitative data, as the problem is not the nature of the data but the theoretical paradigm which guides their collection and analysis: “... it would be misguided to equate emancipatory disability research with any one approach to data collection since both qualitative and quantitative methods can be used in an oppressive or an emancipatory context. While it is important to give primacy to the personal experience of disablement, the central issue is how this experience can be used at an early stage in the formulation and choice of appropriate research methods.” (p. 706).

The new paradigm enabled disabled people to go from “Nothing about us without us” to taking on a leading role in producing knowledge and research practices. Methodological rigour made it possible to nurture ties with academic research, and Stone and Priestley emphasise the fact that “[f]inally, if disablement studies, as well as disability politics, are to be taken seriously then there is a need to satisfy the rigorous demands of academe at the same time as furthering the political campaign for emancipation and equality” (1996, 715).

Views on the involvement of non-disabled researchers are not unanimous, and there are those in the movement who remain suspicious of people who do not identify as disabled carrying out disability research. In 1998, Simi Linton argued once again that: “The overwhelming majority of scholarship on disability either utilises or implies the third person plural: ‘they’ do this, ‘they’ are like that, ‘they’ need such and such. This contributes to the objectification of disabled people and contributes to their experience of alienation (Linton, 1998, p. 531).

Barnes (1992) had already observed that having a certain impairment does not automatically create an affinity with people who have the same condition or with disabled people in general. In this sense, Barnes recognises that emancipatory disability research concerns personal commitment rather than biology, and researchers who choose to make their knowledge and skill available to disabled people and their organisations may have their proposed co-operation accepted.

A debate published in *Disability & Society* between 1997 and 1999 helps us understand the different viewpoints emerging at the time. There are three stakeholders in the two-year debate, Robert F. Drake, Fran Branfield and Paul Duckett, featuring in an article and successive comments.

Robert F. Drake, Lecturer in Social Policy at the University of Wales, Swansea, published an

article with the telling title of “What Am I Doing Here? ‘Non-disabled’ people and the Disability Movement”. Drake, who had no disability at the time he wrote the article, explores the role that non-disabled people might play in contributing to the expansion of the disability movement. He states that one must avoid certain behaviour above all, such as talking for disabled people, and seeking positions of power within the movement. It is also important to choose research topics with care, for example avoiding carrying out research on disabled people and instead concentrating on society’s disabling effects on disabled people, and how it disables individuals.

Drake goes on to suggest three possibilities for non-disabled researchers wishing to carry out research on disabled people or associations of disabled people, that is organisations in which disabled people play active operational roles rather than associations for disabled people in which disabled people often lack decision-making and managerial status: “to expose the disabling aspects of society, its policies and practices, to supply resources to disabled people’s own groups, so long as these assets come without strings attached, not compromising the principles and goals of disabled people’s groups and finally to respond to specific requests (for information or other forms of help) from disabled people’s groups.” (Drake, 1997, p. 644) Drake then states that he aims to encourage debate on the issue since he is aware of the (legitimate) variety of different viewpoints.

He receives a reply in the next issue of the magazine, the first of 1998. An article by Fran Branfield from the Sociology Department at York University, Heslington, appeared in the *Miscellanea*, Current Affairs section: “‘Non-disabled’ people, no matter how ‘sincere’, ‘sympathetic’ or whatever, are always in the position of being ‘non-disabled’ people and all that this carries with it, domination, oppression and appropriation.” (Branfield, 1998, p. 143) Drawing on the socio-political reality of the movement, Branfield states that everything about non-disabled people – their history, culture, life experiences – is what oppresses disabled people. Referring to Drake’s text, Branfield underlines all the aspects which make it difficult to accept that non-disabled people might play a role in disability research: paternalistic expressions, talking “on behalf of others”, banal statements. At a delicate stage for the Movement, Branfield continues, when Disability Studies are starting to be recognised in the academic field, there is a great risk of appropriation by non-disabled people. “The disability movement is continually growing in strength. This has ramifications for many aspects of our lives. Not least the growing acceptance of ‘Disability studies’ within academia. For it now to be hijacked and reappropriated by ‘non-disabled’ people is something we must be on guard against. Social policy research centres, who spend large amount of resources researching in to disabled people’s lives are all too often run by ‘non-disabled’ people who have carved a comfortable niche for themselves out of our oppression. As disability research grows I believe we need positive discrimination to ensure that this work not only respects the views of the disability movement but also is undertaken by those of us who experience the day-to-day realities of ‘non-disabled’ peoples oppressive stance towards us.” (Branfield, 1998, p. 144) In conclusion, while not suggesting that the Movement should make a separatist choice, Branfield maintains that we can only break with the past if disabled people become instigators, decision-makers and organisers in their liberation.

The fourth issue of the journal published that year includes a response (in *Miscellanea*, Current Affairs) to Branfield’s text from Paul S. Duckett, Social Work Research Centre, University of Stirling. Duckett criticises Branfield’s exclusion-based approach, since it contrasts with the idea of inclusion which has enabled him to become involved in the field of disability. He calls into question Branfield’s binary opposition: “splitting disabled people from non disabled people, joining a familiar set of similar binaries: female/male, black/white, child/adult, homosexual/heterosexual etc. These are all binary oppositions sustained by this type of discourse where one binary is preferred to the ‘other’ and afforded socioeconomic and political privileges in

the process (employment, income, social status, voting rights etc.)” (Duckett, 1998, p. 625)

In a context in which the oppressed and their oppressors can (or must) exchange roles, the practice of oppression remains, and the issue which needs to be overcome is not resolved at all. Duckett introduces the concept of fluidity, which blurs the boundaries between disabled and non-disabled people. Not only can non-disabled people become disabled, but the opposite can occur, and there are endless nuances between people who describe themselves as disabled or are described as such by others. Duckett cites the segregation of people with learning disabilities by people with physical disabilities as an example of how those who consider themselves oppressed can become oppressors. He reminds us of the criticism within the Movement of the privileged status of members of a ‘white, male, spinal injured elite’ (Pag. 626). We would add here that it was disabled women activists in the Movement who first underlined how people sharing the same characteristics “appropriated” the concept of disability. Quoting Serge Moscovici’s theory of minority group influence, Duckett reminds us of the importance which the French author places on the support given to minority groups by allies outside their group membership who share their aims. “For a minority group to exert influence over majority groups, they are assisted if they have allies outside their group membership who will support their aims. It needs both internal and external calls for change. The dissent against a system of disability benefits that traps disabled people into lives on the margins of poverty can resonate more strongly if this dissent comes also (not only) from those not reliant on disability benefits, i.e. both disabled people in satisfactory employment and non disabled people. Their call is autonomous in that we can see little in how such dissenters will personally profit from the changes they call for, other than perhaps a ‘moral(e)’ victory. Non disabled people can add to the clarion call of disabled people. There is a place for non disabled people to speak up on disability issues. (Duckett, 1998, p. 627)

The debate concludes with Branfield’s (who has since moved to the Centre for Citizen Participation, Brunel University) reply to Duckett. Having reiterated the concepts from the previous text, Branfield outlines greater perplexities regarding the academic world. While it is true that Disability Studies are gaining a foothold, “[i]t is a documented fact that academic studies around disability are predominately conducted by non-disabled people. Even when it is undertaken by disabled people, there is a tendency to be ‘doing academic discourse’. The consequences of this all too often completely ignore and negate anything that has come from the disability movement.” (Branfield, 1999, p. 400) Quoting articles in which non-disabled researchers ignored research done by disabled people, Branfield states that academic discourse is already prevailing over the disability movement, excluding the experiential, subjective and emotional knowledge that sets it apart and preferring the more abstract, theoretical approach typical of academic research. Regarding the denial of inclusion implied in Branfield’s positions, an issue discussed vigorously by Duckett, Branfield replies that “For the disability movement to be inclusive, it must recognise that to be disabled does not necessarily mean being white, male, middle class and a wheelchair user. Disabled people are certainly not an homogenous group. However, to promote the idea that the disability movement must consist of, be led by and represent disabled people does in no way make it exclusive. On the contrary the disability movement must strive to include all disabled people. It is not inclusive in that it does not claim to represent all people. It is a movement of disabled people, if we wanted to include non-disabled people it would not be called the disability movement. It would be called everybody’s movement and, as such, would have no political voice. Our history is a history of domination by non disabled people. Why should we now want to give them our movement?” (Branfield, 1999, pp. 399–400)

The Movement has strong political components, and it is difficult to reconcile this in full with the academic world, which can rarely take account of politics and cannot make it a priority. However, Branfield’s position is not completely closed off and she hopes that non-disabled

researchers will embrace the thoughts of disabled people at personal level as well as in terms of professional growth and learning: “Non-disabled people should instead be looking to the disability movement to see what they can learn from us, how this can inform their thoughts, their writing, their actions. Non-disabled people must attempt to listen to our voices, and to be non-disablist and non-supportive of the old oppressive structures. To want inclusion in our movement is to deny us the reality of our everyday lives and it is to deny us our politics.” (p. 403)

Does this debate reflect the wider situation? No, since it refers to the specific context of the US and the UK, where the social model is known and shared at academic, charitable and political level – something which still does not occur in many other countries. Furthermore, the debate takes place between disabled and non-disabled scholars, and does not represent a level of theoretical analysis applicable to other sectors. These include NGOs and the health sector, where the medical model has survived for years, let alone the commonly-held view that disabled people are victims who are suffering.

However, the debate enables us to understand the concerns and perspectives within disability studies during those years, as well as giving greater insight into later developments which blurred the once-distinctive boundary between disabled and non-disabled people. Over time, the vision of disabled people as the oppressed and non-disabled people as the oppressors (at conscious or unconscious level) has been overcome, highlighting diversity and disability as issues not limited to a part of the population. It becomes possible to focus on nuances between constructions of disability and nondisability, leading to multiple identities, shaped by gender, politics, race. (Tregaskis, 2004)

Members of disability movements have criticised the involvement of non-disabled people in another, less theoretical context with a much wider potential impact than academic research, often inaccessible to the wider public: training and professional development, initially aimed at healthcare workers and professionals but later extended to other sectors such as public and for-profit organisations. A conflict has emerged between two types of training courses. The first, Disability Equality Training (DET), was aimed and provided by disabled people and inspired by the social model. In keeping with this model, the focus of these courses was to overcome environmental and social barriers and provide possible solutions (Gillespie-Sells & Campbell, 1991) Another type of course designed by non-disabled professionals centred on Disability Awareness Training (DAT); this saw disability as an individual problem and often used role play to enable participants to “experience” disability: exploring a city sitting in a manual or electric wheelchair, wearing special glasses to limit their vision, using gloves to simulate limited sensitivity and reduce their manual dexterity. “Little evidence exists that these exercises have a positive effect on either attitudes or behaviour but, despite this, they are used extensively in disability awareness training, both for children and adults. (...) by individualising and medicalising disability, and by focusing excessively on problems and difficulties, simulation exercises provide false and misleading information, and inculcate negative, rather than positive, attitudes towards disabled people. It is suggested that simulation exercises fail to simulate impairment correctly, and address neither the coping strategies and skills disabled people develop in living with impairment, nor the cumulative social and psychological effect of encountering social and physical barriers over a lifetime” (French, 1992, p. 257). Disability Awareness Training confirms the movement’s concerns over the medical, non-disabled world: “One of the most important influences of medicine—and the reason it has received so much critical attention in disability studies—is its active shaping of cultural perceptions of disability identity itself, which thereby structures how the nondisabled interact with people with disabilities.” (Wilkerson, 2013, p. 210)

FEMINIST SCHOLARS IN DISABILITY STUDIES

At the same time another reflection was emerging, one which contrasted the often gendered character of disability studies' and feminism's ableism.

As mentioned in the introduction, feminist academics' refusal to address disability issues meant that a theory uniting the two viewpoints could not be developed, at least not until women who identify as disabled could access an academic career and develop theories which united their views with those of the feminist movement.

Disabled activists saw the choice to distinguish disability and impairment within the social model while emphasising the former as a division mirroring the classic patriarchal split which mainstream feminists had challenged – the split between public and private, where the 'private' becomes a personal environment of no collective significance (Crow, 1996; Morris, 1996). Their new analysis questioned the division, relating the concept of disability to the public sphere and impairment to the private sphere as feminist movements had done. They denied that the two spheres could be kept separate and limited themselves to using the public sphere only. While aware that various feminist movements had excluded disabled women and their issues from research and theoretical agendas, disabled scholars 'brought the perspective of feminism to an analysis of the experience of disability, using the principle of making the personal political as her primary analytical tool' (Morris, 1991, p. 9). Reconceptualising their knowledge of the body and impairment in their own terms was designed to avoid the risk of leaving a conceptual gap which the individual or medical model would claim and occupy: "External disabling barriers may create social and economic disadvantages but our subjective experience of our bodies is also an integral part of our everyday reality. [...] Recognizing the importance of impairment for us does not mean that we have to take on the non-disabled world's ways of interpreting our experiences of our bodies" (Crow, 1996, pp. 210–211).

We limit our examples to Carol Thomas, Susan Wendell and Rosalynd Garland-Thomson, who have tackled three different aspects but have all featured their personal experiences in their own work, inspired by the feminist maxim 'the personal is political' and thereby refusing the pseudoneutrality of positivist and male traditions of thought.

Carol Thomas coined the expression "the psycho-emotional dimensions of disablism", arguing that disability studies should consider the socially imposed restrictions which shape disabled people's identity and subjectivity by working along psychological and emotional pathways (Thomas, 1999, p. 46). This adds a deeper understanding of the ways society shapes the inner existence of disabled people.

With the expression 'psycho-emotional dimensions of disablism', Thomas distinguishes between two types of social barriers: those which create external restrictions and limit people's activities (difficulties finding a job, accessible housing or financial resources for independent living), and the social barriers which create psychological restrictions for disabled people. These may include being hurt by other people's reactions and behaviour, or feeling worthless, of little worth, unattractive, hopeless, stressed or insecure as a result (Bencivenga, 2007, p. 16).

Another central and helpful concept coined by Thomas is that of 'impairment effects', 'the direct and unavoidable impacts that impairments (physical, sensory, intellectual) have on individuals' embodied functioning in the social world. Impairments and impairment effects are always bio-social in character, and may occur at any stage in the life course' (Thomas, 2010, p. 37). Neither impairments nor their effects can be reduced to biology, but the impairment has a bio-social nature, in other words, impairment and their effects are both corporeal and social in nature, and it then becomes very evident that 'the bio-material always intersects with the socio-cultural' (2007, p. 137). Thomas concludes that: 'The distinctions made between impairment and disability

(disablism) cannot [...] be mapped onto familiar biological/social or natural/cultural dualisms, nor should impairment be sidelined as an irrelevant category' (2007, p. 137).

Susan Wendell (1996) talked openly about her own experiences with chronic illness in her book *The Rejected Body: Feminist Philosophical Reflections on Disability*. The experience of people with chronic illnesses who are overlooked by the social model was already seen as important in redesigning the binary model in which health and illness are immovable concepts. This inspired reflections on more fluid experiences and the possibility of working on wellbeing within an illness, and contextualising the concept of health in a less distinct manner (Zola, 1982). Wendell interweaves her personal story with an interdisciplinary theoretical framework. She constructs a critique of biomedical power and the cultural and social forces which construct disabled people as 'other', as summarised by Bê (2012) problematising notions of perceived ability and disability. Wendell distinguished between those who identify as disabled and those who count as disabled, analysing what may count as disability. Moreover, she reflected on the damage created by the vision of disability as a taken-for-granted and stable category which is clearly recognisable. In fact, while people who may be perceived by others as disabled, for example members of the Deaf community, may not identify as disabled, some people with chronic illnesses who consider themselves disabled are not identified as such by others. In the latter case Wendell speaks of 'undistinguishable impairments': "like healthy people with disabilities, most people who have disabilities due to chronic or even life-threatening illnesses are not 'globally incapacitated'. [...] Thus there are issues of access for people with chronic and life-threatening illnesses that need to be addressed' (Wendell, 1996, p. 20).

The research fields of Rosemarie Garland-Thomson are the humanities and cultural studies. In her book *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (1997), she explored the construction of the disabled body in culture, discussing the role of medical, political, cultural and literary narratives in shaping the vision of certain bodies as inferior. Her aim is 'to alter the terms and expand our understanding of the cultural construction of bodies and identity by reframing "disability" as another culture-bound, physically justified difference to consider along with race, gender, class, ethnicity, and sexuality' (Garland-Thomson, 1997, p. 5).

Garland-Thomson adds disability to race, gender and sexuality as another example of a category of 'otherness' and underlines the similarities of the processes leading to the exclusion mechanism. Garland-Thomson links her thought to feminism, reminding us that "[m]any parallels exist between the social meanings attributed to female bodies and those assigned to disabled bodies. Both the female and the disabled body are cast as deviant and inferior; both are excluded from full participation in public as well as economic life; both are defined in opposition to a norm that is assumed to possess natural physical superiority" (R Garland-Thomson, 1997, p. 19).

At a time when the constructionist perspective dominates feminist thinking, while recognising its worth Garland-Thomson warns of the risk that "constructionism may contribute to erasing the material and bodily effects of those differences and the social categories we claim to be important. (Bê, 2012, p. 370). "[W]hile in the movement toward equality, race and gender are generally accepted as differences rather than deviances, disability is still most often seen as a bodily inadequacy or a catastrophe to be compensated for with pity or good will, rather than accommodated by systemic changes based on civil rights. (Garland-Thomson, 1997, p. 23). According to Garland-Thomson, the material existence of the disabled body demands accommodation as well as recognition.

It is obvious how these scholars' reflections are bound by personal aspects which could not have been shared by non-disabled people, since first-hand physical and psychological experiences are difficult to pass on or perceive. Nonetheless, one can consider whether there are other aspects

of disability from which people without first-hand experience may draw significant, scientifically-based conclusions: all those linked to the social and political environment.

GENDER AND FEMINIST STUDIES, DISABILITY RESEARCH: NEW ALLIANCES

Are only disabled people entitled to speak for other disabled people? Or to do academic research about issues related to disability? What does it mean to be disabled? What about people with invisible or minimal disabilities? Supporters of the more radical viewpoint maintain that research on disability should only be done by people who see their disability as their primary identity. But in fields such as sociology, for example, research into groups whose characteristics are not shared by the researchers is a commonly accepted practice. Academics are aware that it is impossible to fully understand an experience unless it is felt first-hand, but the entire practice of sociology, from Weber onwards, recognises that it is possible to empathise with other people's experiences. Leaving aside research into physical and psychological experiences, where the disabled researcher's identity can provide answers otherwise difficult to obtain, if the purpose of the research is to analyse the social experience (and the social model does just this), collaboration with non-disabled researchers should be considered acceptable.

As regards studies of gender dynamics and the influence of gender on social relationships, the recent focus on disability and disabled women from the feminist perspective has been influenced by increasing international recognition for disability studies, particularly Feminist Disability Studies. "Even though disability studies is now flourishing in disciplines such as history, literature, religion, theater and philosophy in precisely the same way feminist studies did twenty-five years ago, many of its practitioners do not recognize that disability studies is part of this larger undertaking that can be called identity studies. Indeed, I must wearily conclude that much of current disability studies does a great deal of wheel reinventing. This is largely because many disability studies scholars simply do not know either feminist theory or the institutional history of women's studies. All too often the pronouncements in disability studies of what we need to start addressing are precisely issues that feminist theory has been grappling with for years. This is not to say that feminist theory can be transferred wholly and intact to the study of disability studies, but to suggest that feminist theory can offer profound insights, methods, and perspectives that would deepen disability studies." (Garland-Thomson, 2011, p. 13)

Following the two parts of a special issue on Feminism and Disability edited by Eva Kittay, Alexa Schriempf, Anita Silvers, and Susan Wendell published by *Hypathia - A Journal of Feminist Philosophy* in 2001 and 2002, the most recent and significant contributions include K. Hall (ed.), *Feminist Disability Studies*, Indiana University Press, Indiana 2011, and another special issue on "New Conversations in Feminist Disability Studies", by "Hypatia", 30 (2015), 1⁴.

This new input is part of a path which has begun to shed more favourable light on co-operation between disabled and non-disabled researchers.

The solutions explored and accepted or refused are diverse, from arguing that academics should only study oppressed groups until those groups become empowered enough to study

⁴ The *Hypatia* issues include articles, among others, of Jenny Morris; Susan Wendell; Kate Lindemann and Lucia Carlson.

themselves, to suggesting participatory research as a solution, in which researchers and their subjects work together in a partnership. In the latter case, members of the group being studied cooperate to establish the outcomes of the study and are actively involved in observation, interviewing, or administering questionnaires. In this model, professional sociologists may serve as consultants who share their expertise on study design and data analysis in order to help their subjects achieve their desired goals, established by themselves. The idea of considering non-disabled researchers ‘experts’ who make decisions based on these shared standards involves, at least in part, disabled people in the formulation of the dominant cultural thinking.

Jenny Morris reinforces the idea of non-disabled researchers as allies. Starting from the consideration that all oppressed groups need allies, Morris attributes two possible roles to non-disabled researchers:

(a) Non-disabled academics and researchers should ask themselves where disabled researchers, disabled students and disabled academics are. This would allow them to recognise and challenge both direct and indirect discrimination, as they would recognise the way that discrimination against disabled people operates within their workplace (Morris, 2006).

(b) “Non-disabled people, if they make their living from being involved in the field of disability, should ask themselves whether/how they can do research which empowers disabled people, starting by questioning their own attitudes to disability. If non-disabled people are to carry on doing research on disability—as they undoubtedly will—what kind of research should they be doing? Turning the spotlight on the oppressors. Non-disabled people’s behaviour towards disabled people is a social problem—it is a social problem because it is an expression of prejudice. Such expressions of prejudice take place within personal relationships as well as through social, economic and political institutions and, for example, a study of a caring relationship therefore needs to concern itself with prejudice, in the same way that studies of relationships between men and women concern themselves with sexism.

(c) Our personal experience of prejudice must be made political—and space must be created for the absent subject. This point is illustrated by an example of research which needs to be done, namely, research concerning the experience of abuse within institutions. Such research would have three aims: naming the experience as abuse, giving expression to the anger, pain and hurt resulting from such experiences, and focusing on the perpetrators of such abuse, examining how and why it comes about” (Morris, 2006, pp. 291–292).

Rob Kitchin (2000) examined the extent to which disabled people are dissatisfied with academic research, and their opinions on how and by whom disability research should be conducted. He did so through in-depth interviews with 35 disabled people. The results confirmed support for the arguments advanced by disabled academics, regarding the alienation and disempowerment created by research conducted by non-disabled researchers.

“However, the majority of respondents recognised that research can play a vital role in the emancipation of disabled people. This can be fully realised if research is modified radically. The ideal model forwarded by the respondents was one of inclusivity: an equal-based, democratic, partnership between disabled people and disabled/non-disabled academics. The model did not preclude non-disabled researchers, but positively welcomed them. Such a model would be action- and politically-led, seeking to explicitly change social relationships. This model, because it seeks to balance the concerns and power of researcher and researched, interviewees felt would address their concerns of focus, lack of action, the inaccessibility of disability studies literature and levels of representativeness. As such, the viability of using inclusive models of research to examine

disability in society needs further investigation.” (p. 45) Moreover, “Academic research then needs to utilise non-academic media to ensure that the ideas and conclusions they draw reaches an audience who can act upon it.” (p. 31).

Another field in which academics and community members are brought together into research partnerships is Community-based participatory research (CBPR), an equal cooperation which fosters co-learning and empowerment but at the same time pursues both academic and community outcomes (Minkler & Wallerstein, 2003). Erin Stack and Catherine McDonald suggest that “academic and community partners work together to gather significant and applicable information, think and expound on that information, and finally act and evaluate the results” observing that dynamics which fostered empowering mechanisms during research activities “suggest the value of long-term partnerships between academic and community partners and of attending to and demonstrating respect in newer relationships; these dynamics may be essential to transforming broader unequal societal power dynamics” (2018, p. 87). Equitable, empowering partnerships can be promoted when both partners reflect during the research activities. Self-reflection may inspire academic partners to commit to “unlearning” processes on how to engage in a power-sharing research partnership with people with disabilities (Stack & McDonald, 2014, 2018). Critical reflection may also be beneficial to community partners, allowing them to recognise and assess the socially constructed barriers they face and in this way take more control over their lives (Dworski-Riggs & Langhout, 2010). While CBPR more often deals with people with developmental disabilities, the recommendations also appear applicable to research activities conducted with other disabled people, disabled adults and/or people with no chronic conditions.

In a recent publication, James Sheldon (2017), who identifies as a disabled person, summarises the implications for non-disabled researchers, emphasising the role of self-reflection, a requirement for researchers who do not identify as having a disability but are doing research on disability. “Research should be designed in such a way that it creates transformative experiences for those with disabilities, and likewise, creates paradigmatic shifts within the researcher as they encounter the stories and experiences of those with disabilities. Ultimately, researchers that are “non-disabled” should come to realize how their own identity is fluid, not just in terms of ability, but in terms of the many axes that form their identity” (p. 996-997).

And again: “When doing research as a disabled person studying disabled subjects, it is important to consider your own identity and how it influences your research process. Research should have catalytic validity and be a transformative process for participants, but it must also have autocatalytic validity and be a transformative process for yourself by challenging, questioning, and problematizing your own identity and experiences. Simply studying your own disability does not give you a magic insight into the experiences of others, and likewise, to tell your own story requires engaging with others’ experiences in order to understand your own, to move from mere autobiography into critically reflexive autoethnography” (p. 996).

While recognising the privileges of non-disabled researchers within academia, Sheldon proposes “that they still have something important to contribute in the study of disability. My argument for creating a space for disabled researchers within the field of education is not an argument that the ‘temporarily able-bodied’ (and able-minded) researchers should never contribute to the discourse around disability. Rather, it is more about the able-bodied/minded being willing to lift up voices of researchers who are marginalized within the discourse, to offer financial support and mentorship to those who are underprivileged within the academy. In doing so, we must remember that power dynamics are ‘fluid and constantly being (re)negotiated’ (McDonald, 2013,

p. 133) and that we cannot see oppression as a static entity. Much as we can shift between ability and disability as we move between contexts and through time, so can the nature of power dynamics in academia; we need to become aware of these and seek to make structural challenges, but the goal is not to “call out” particular able-bodied researchers but rather to change the structural relationships within the academy.” (Sheldon, p. 996)

THE FLUIDITY AND IMPREDICTABILITY OF IMPAIRMENT AND DISABILITY

McDonald’s reflection on the fluidity of power dynamics quoted in the previous paragraph is relevant, since not only the participants but also the researchers may gain new understanding of their identity during research. McDonald questions the possibility of white researchers studying people of colour, or men studying women and women’s issues, and also the potential for “straight” researchers to study the Lesbian, Gay, Bisexual, Transgender and Queer community. He concludes his articles by saying that “researchers should always attend to the ways in which their identities, as well as the identities of their participants, may be shifting in future research projects, as well as avoid making assumptions about their participants on the basis of the social identities that they ascribe to them. Because identities are fluid and constantly evolving, there is no way to know a priori how particular aspects of our identities will make a difference in the field.” (2013, p. 141)

In the last ten years, the relationship between impairment (a physical state) and disability has been analysed through new lenses, and it has come to be considered neither necessarily fixed nor permanent but possibly fluid and not easily predictable. This new perspective has consequences on how disability can be measured and on the self-definition of disability, but the reconceptualisation involves more cultural and social aspects. Social policies are another cultural aspect which affects “whether an impairment becomes disabling. Although most of the time in our cultural discourse we think of ‘disabled’ as being the opposite of ‘non-disabled,’ sometimes this is not the case in policy or other situations. Phrases that emphasize the fact that disability is on a continuum include ‘partial disability,’ being ‘not disabled enough,’ or ‘not deaf enough.’” (Barnartt & Altman, 2010, p. 10)

If we consider fluidity rather than stasis when talking of disability, we can analyse evolving cultural differences in defining what constitutes disability as well as how social processes and institutions create or deny the status of a disabled person (Barnartt, 2010). Accepting this perspective might be a new starting point for non-disabled researchers wishing to engage in studies involving disabled people. The expression “disabled and not-yet disabled people” can now be reconsidered in a new vision in which all of us are in a permanent state of fluidity, to various extents. This does not mean denying the concrete difficulties experienced by part of the population, either the result of bodily functions or social and cultural obstacles, but enabling interactions based on a new awareness of the potential fluidity of any situation we may experience.

When speaking about inclusive education research, Allan says that “[h]ow we apprehend, analyse and interpret patterns of exclusion is also shaped by the interplay of personal biography and intellectual training inside and outside of the academy” (2010, p. 11). If our individual biography shapes the way in which we receive and interpret the world, awareness of the fluidity of our condition can only benefit how we reflect on inclusion, exclusion, discrimination and empowerment.

It is worth noting that even the WHO classification currently considers variability and fluidity. As mentioned previously in this chapter, in May 2001 the World Health Organisation published the International Classification of Functioning, Disability and Health (ICF) as the new standard for classifying disability and health. The ICF is a means of describing and classifying the health and disabilities of populations. It is not a means of assessing or measuring the same, recognising that health also regards functioning, that is the ability to live our lives fully and as members of society. The WHO starts from the premise that at some stage in our lives, we may all experience a deterioration in our health which, in unfavourable circumstances, may become a disability.

As a result, disability is not an invariable objective condition. Furthermore, beyond variations in the individual's changing conditions, anyone may become "less disabled" if they receive different types of assistance which favour social and occupational integration. This concept expressed in the ICF mirrors what Garland Thomas describes as follows: "Disabled people do not suffer inordinately, but the conditions for human suffering are increased when we do not have access to the resources we need. To flourish among others and exercise the privileges and obligations of citizenship, we need access to the institutions, however flawed they may be, that provide these resources, which all human beings need. Without access to resources to put up against the accusation of wrongness, we will only find ourselves where we were before the concept and enactment of civil and human rights demanded access. We will be back to the asylums and the street corners, where many of us still are today." (Garland-Thomson, 2014).

In the ICF, the concept of disability is placed within a multidimensional continuum. All of us may find ourselves in a disadvantaged environment, and this may cause disabilities. The ICF acts as a means of classifying our health in these circumstances, taking the social aspects of disability into consideration. "If a person experiences difficulties in the workplace, it is of little importance whether the cause is physical, mental or sensorial. What matters is that we act on the social context, setting up networks of services that reduce the disability." (Bencivenga & Tinti, 2011, p. 142) The new ICF approach sees disability as a life condition which in a wider sense affects the whole community and, first and foremost, the institutions, and it requires integrated cooperation across every sector. An analysis of public sector services in a northern Italian city clearly showed that most cases of disability recognised for employment purposes in the public and private sectors stemmed from incapacitating conditions (heart disease, cancer, rare or degenerative illnesses), and that most of the participants had more than one condition (Bencivenga & Tinti, 2011). If they fall within a legally safeguarded category because of one or more certified disabilities, job-seekers may be asked to show documentary proof their condition and registration with a targeted employment scheme; however, their privacy is guaranteed since these documents do not include details of their condition. As a result it is not considered important and no one is bound to disclose their condition, but rather to provide information on any needs they may have. In a job interview or any meeting involving future contact, it is in both parties' interest to know whether there are specific needs (for assistance or support) – which might help the candidate carry out their work, and if there are any tasks which are inadvisable due to the candidate's health. Concentrating on how to make tasks easier for a person rather than what he or she cannot do has been a huge step forward for society. "As we manage our bodies in environments not built for them, the social barriers can sometimes be more awkward than the physical ones. Confused responses to racial or gender categories can provoke the question 'What are you?' Whereas disability interrogations are 'What's wrong with you? Before I learned about disability rights and

disability pride, which I came to by way of the women's movement, I always squirmed out a shame-filled, 'I was born this way.' Now I'm likely to begin one of these uncomfortable encounters with, 'I have a disability,' and to complete it with, 'And these are the accommodations I need.' This is a claim to inclusion and right to access resources." (Rosemary Garland-Thomson, 2016)

In the past, manuals were produced for schools and employers with a list of medical conditions, their associated symptoms and the technical aids required; fixed characteristics were attributed to each condition and individual variations were not considered. The new approach recognises the variations which may exist within the same condition, as well as positive or negative variations over time. Since they do not concentrate on a diagnosis or condition and do not even mention them unless the person concerned reveals them, the new approaches enable each person to be seen for what they can do, not for what the abstract, generic names and concepts we give them.

While the ICF proposed a change within the social and medical world, society has also reflected on a change to our identity and possible variables in our perception of ourselves. Critical disability studies have been defined by Margrit Shildrick (2012) as a postconventional approach to disability. Bringing together ideas from feminism, postcolonial studies and queer theory, she challenges the categories 'disabled' and 'non-disabled', arguing that conventional binary thinking should be rejected. She argues that the way forward for disability studies is to deconstruct the very categories that define disabled people as 'different' from their non-disabled peers. She suggests that such differences are neither viable nor sustainable; only by such a deconstruction can we further the position of disabled people and promote their inclusion and full social participation.

According to Goodley, thanks to critical disability studies "disability becomes entangled with other forms of oppression and revolutionary responses" (2013, p. 631). The creation of models of being and working in which similarities and differences co-exist is considered the main result of collaboration between disabled and a non-disabled persons in a research project. The experience, described by Tregaskis and Goodley, opens up the possibility of different reflections on possible collaboration in the research field: "what has really been at the core has been the necessity to develop good-enough relations of trust that we can be honest with each other about emotions and issues that trouble us. In part, then, what we are saying here is that our own research relationships are (or should be) a microcosm of how we behave with our research participants. In other words, we need to learn to treat ourselves and each other with as much care and respect as we afford to the research participants we work with." (2005, p. 373)

The lived identity and experience of disability in place and time, well beyond the mere physical aspects, is at the core of Garland Thomson's reflection, in particular through "the new concept of misfit as emphasiser of the particularity of varying lived embodiments and avoids a theoretical generic disabled body". The researcher aims at "extending a consideration of how the particularities of embodiment interact with the environment in its broadest sense, to include both its spatial and temporal aspects" (p. 592). To develop this perspective, Garland Thomson refers, among others, to Alcoff and her work on identity as a "learned ability" which is context-dependent, complex, and fluid (Alcoff, 2006, p. 187), adding to it the materiality of the body. Alcoff in her book refers to race and gender: "Because race works through the domain of the visible, the experience of race is predicated first and foremost on the perception of race, a perception whose specific mode is a learned ability." And

does not refer in her book to disability, if not to make a distinction: “One could make an overall point here about the lack of analogy between racial/ethnic/cultural identities, on the one hand, and identities such as age, disability, and sex on the other. All are generally visible identities, naturalized as marked on the body without mediation. But the markings that signify age, disability, and sex are qualitatively different in significance from those signifying race, ethnicity, and culture.⁹ This is not an argument about the virulence or priority of various forms or targets of oppression. It is simply an argument about the quality of the physical basis for sex categories vis-à-vis race categories. (p. 165) but in my opinion Garland Thomson makes a significant step forward in applying Alcott perspective to disability.

PROMOTING INCLUSION THROUGH STRUCTURAL CHANGE

The collaborations which took place within the RISEWISE project revealed that there is still a limited number of researchers identifying as disabled involved in of disability studies and that research in the field is often carried out solely by non-disabled researchers. It is also worth noting that not all disabled researchers are interested in disability studies or including a gender perspective in their research, and this makes the problem even more evident.

Let us try and envisage a path which might favour training and career development for researchers interested in disability studies in the medium-to-long term, including those who consider their disability their primary identity, people who do not have a “disability” (in the medical sense) which is formally recognised by the health system but still experience functional difficulties in an area of their daily life, and people who have functional or other limitations linked to the concept of “disability” or “functional limitation” but are interested in studying aspects linked to “disability”

We believe that to foster research in which disabled and non-disabled people can collaborate consciously, respecting the requests of disabled people and applying scientific rigour throughout the entire research path, it might be useful to analyse public and private research institutions to understand their mechanisms, internal structure and the formal and informal standards which govern the changes they make. This would trigger institutional changes which favour the inclusion of minority or disadvantaged groups while respecting their diversities.

Unlike the previous approach which saw integration (social, employment, educational) as the best way to reduce inequality and injustice towards disabled people, the current inclusion culture makes no distinction between disabled and non-disabled people. Instead it considers that everyone has different types of needs but has the same rights to participation and independence. This approach nonetheless struggles to achieve real results. When we talk about disability, we often concentrate on removing architectural and other barriers and providing ad hoc support based on different types of disability. With inclusion in mind, however, we might think about adapting instruments used in other contexts to help universities formally support inclusion for disabled researchers and progress their careers.

This approach is inspired by what has been taking place for some years now to promote gender equality, particularly career pathways for female researchers who are under-represented in senior academic roles, where the number of women whose qualifications entitle them to top positions is quantitatively significant. We might try to adapt strategies used in gender equality and apply them to structural changes which encourage training and career development for both disabled and non-disabled researchers interested in disability studies. This would provide greater representation and therefore more inclusive research paths both in terms of numerical representation and promoting research which includes the needs and desires of disabled people,

thereby including them fully in the academic field.

In the case of Italy, it is important to remember that Italian universities (and all public and private employers) are required by law to employ a certain percentage of disabled people, 7% for organisations with more than 50 employees. Data regarding the lead organisation in the partnership, the University of Genova, reveals that it has ~ 1,300 teaching staff and ~ 1,400 technical and administrative employees: it therefore employs almost 200 disabled people. The data refers to people with certified disabilities who have followed specific employment inclusion pathways, primarily in technical and administrative roles; it is obviously impossible to know how many more of its employees are people living with functional limitations which are not formally recognised or have not been disclosed to their employer, and which roles they hold. If we add to this a wider concept of “fluidity” as seen in the previous pages and apply it to disability, it is possible to imagine a wholly different panorama from the current one with greater numbers and variability.

Another advantage of fostering inclusive structural changes is the possibility of developing transversal competences in academia to ensure that inclusion pathways are provided for in individual research projects. This would not be limited to disability studies and would therefore encourage intersectional approaches which still rarely include disablism. Furthermore, researchers who see the discriminating aspects of institutions beyond mere architectural barriers (for which there is specific legislation, albeit disregarded in some cases) would find it easier to promote institutional change and support career development within universities through structural changes similar to those which are helping achieve gender balance throughout the academic world. Also, paths could be implemented which are similar to those used to engender research, extending the focus on disability (in its wider sense) to research not aimed at disabled people, and achieving a truly global social inclusion path.

TOWARDS DISABILITY INCLUSION PLANS?

If we wish to support collaborative research with subsequent benefits for disabled people and minimise the risk of exploiting their experiences conceptually, one problem which needs solving is the lack of academics who identify as disabled, people who would be fully entitled in the eyes of disabled people’s movements to carry out research in this area.

Not every country has professorships in disability studies – Italy is one of them – and this does not facilitate the training of disabled people who can carry out research to academic standards.

In order to foster training, recruitment and career development for disabled researchers, there are diverse strategies which might bring about organisational changes and help embed inclusion and diversity, more and more common in the academy.

A widespread strategy, assisted by funding from the EU’s Horizon 2020 programme, is the promotion of gender equality through gender equality plans (GEP). GEPs are initiatives applied in both the public and private sectors to define both the legal framework and the operational conditions for implementing gender mainstreaming. To create a GEP, the organisations identify a set of strategic actions which will allow them to achieve the expected results in terms of gender equality and balance.

In the specific context of research organisations and higher education institutions, the European Commission considers a Gender Equality Plan as a set of actions aiming at conducting impact assessment / audits of procedures and practices to identify gender bias, implementing

innovative strategies to correct any bias and setting targets and monitoring progress via indicators⁵ in the academic context. A similar set of actions could be implemented with the aim of counteracting biases towards disabled people, after establishing strategies and actions to identify them and, finally, to monitor their progress.

Just as GEPs usually begin by collecting gender disaggregated data, essential to defining the problem and identifying opportunities, in our case data would be disaggregated by the individuals' function and disability. The importance of disaggregated data stems from the need to present the case for intervention (showing imbalances/under-resourcing of inclusion-related activities), to address resistance and formulate GEPs. An analysis and review of policies, procedures and practices could help identify barriers to inclusion and draw up the actions necessary to address them. Collecting disaggregated data is becoming a widespread activity, and organisations now include a variety of underrepresented groups in their data. The National Center for Science and Engineering Statistics and the Directorate for Social, Behavioral and Economic Sciences of the National Science Foundation, for example, collected disaggregated data for a report titled "Women, Minorities, and Persons with Disabilities in Science and Engineering" in 2017⁶

We suggest to transform and adapt a Gender Equality Plan, which has been tried and tested in academic contexts, into a "Disability Inclusion Plan" tailored to the academic sector, thereby supporting regional and national disability inclusion strategies addressing the employment, educational and health sectors. This type of plan might be more useful than a Disability Equality Scheme: it is already tailored to an academic institution, and already tested on the basis of another type of discrimination – gender – which reduces women's access to and progression in academic careers. A GEP has a strong bottom-up approach and involves participants in active paths in planning, realisation and monitoring. In order to test the feasibility of this approach, we attempted to modify an existing GEP template used in the H2020 SAGE proposal. The aim was to consider its applicability in the same context – the academy – with a different but complementary aim, namely promoting the inclusion of disabled people (Table 2).

Proposed steps: - Assign the role of Self Assessment Team to the existing committee/office/bureau for disability related issues. Aims: - Verify the feasibility of the following macro actions; - Define microactions and deadlines for each macro action applicable to the specific context.				
o	Topic	Theme	Stimulating reflection on macro actions	Accessibility
	Knowledge about accessibility	Disability & Research Content	Protocols for researchers working on disability; Build Disability Awareness into Research Design & Practice; Creating Online Modules about Disability and Research	Actions transversal to all topics and themes: verify the accessibility of the venues, rooms, any places in which events are organised and mention accessibility in the information paper/electronic documents.
		Culture & Curriculum	Disability & Organisational Change Course; Disability Module for Undergraduates & Postgraduates; Integration of disability related knowledge into teaching in all disciplines	Verify the accessibility of websites and information about formal and informal events, celebrations, meetings, etc.

⁵ Source: European Commission Communication on 'A Reinforced European Research Area Partnership for Excellence and Growth' (COM(2012) 392 final).

⁶ <https://www.nsf.gov/statistics/2017/nsf17310/static/downloads/nsf17310-digest.pdf>

	Career progression of disabled staff	Inclusive Professional development	Early Career Disabled Researcher Supports; Tailored mentoring; Skills Training (Media, Funding, Management)
		Raising profile of academics	External Lecturers & Visiting Professors from Disability Studies field; Academic/Administrative Leadership Programmes for disabled staff/staff working in disability sector
	Work-Life Balance and Disability	Inclusive Culture & Management Practices	Staff Orientation; Inclusive Social Activities; Support for Carers and Flexible Working Arrangements
		Policy	Extended Leave for Medical reasons; Sabbaticals for staff returning from extended Medical leave; Improve Childcare Provision
	Inclusive Institutional Governance	Leadership & Management	University & Faculty Commitment to Disability Equality Plans; Unconscious Bias Training; Pledges from University Governance Supporting Equity in Disability
		Monitoring, Policy & Practice	Disability-proof policies; Key Performance Indicators & Targets; Workload Models; Disability Pay Audit

Table 2. SAGE template for Gender Equality Plans created from the SAGE wheel (SAGE public output) and modified.

As for what happens when implementing GEPs, it would also be important to promote parallel engagement opportunities in the form of: “cascading, networking, conferences and exchanges of experience, site visits, presentations of survey findings/recommendations for action and, most importantly, their adoption by governing bodies” (Drew et al, 2017, p. 330).

To sum up, adopting what we have called Disability Inclusion Plans, tools specifically adapted to Academies (similar in structure to GEPs but adapted to local situations and conditions), would favour the career progression of disabled researchers and researchers interested in disability studies at international and coordinated level, through mechanisms already tested and known to the Academies which have adopted GEPs. Another benefit of this approach would be that, given the specific aim of GEPs, the structural changes would not risk excluding or not including in a proper way disabled women.

CONCLUSION

Purely for reasons of space, this brief overview has not included names and ideas which are equally as worthy of mention in the chapter. We hope that the chapter and the bibliography will provide further insight into the issues discussed here.

We have tried to provide a path which gives a broad understanding of current reflections on the role of non-disabled researchers in disability studies, outlining the key stages in the debate and showing how direct and indirect interaction between disabled researchers and feminist researchers has fostered our analysis of what “disability” is.

Evolving approaches to disability and the appropriation of disability studies by disabled researchers show the possibility of self-reflection and of carrying out research activities including disabled people by including at every stage.

Finally, it is clear that new training and research possibilities are emerging thanks to changes in concepts of identity. This includes not only disability studies, but also other areas in which discrimination is still widespread. Supporting inclusion and respect for diversity are undeniable prerogatives. We hope that by widening structural changes within the Academies to include “disability” in all its facets and fluidity, as described and studied at global level, may result in future research both inside and outside of the RISEWISE project, which enabled us to formulate our proposal.

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