Between barriers and inclusion

Multidisciplinary reflections on gender and disability

edited by
Cristina Càndito, Isabel Fanlo Cortés,
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SOMMARIO

Introduction[1]

1. Premise

Disability is an uncomfortable topic to deal with, even more so when women are involved. Indeed, the intersection of gender and disability, as distinct but intertwined discrimination axes[2], has left women with disabilities in a blind spot of the multifaceted debates about social justice until very recently, when *Women Disability Studies* finally emerged in the 1980s. As disabled persons, these women were invisible in feminist claims for gender equality. At the same time, as women, they were invisible in disabled people's struggles for the protection of their rights.

The reasons for this invisibility can be traced, on the one hand, to the way in which disability has been conceptualized in the past (§ 1), and, on the other, to the pervasive gender discrimination that is rooted in the public/private distinction, on which the patriarchal social order is still based (§ 2). As a result, women with disabilities still suffer complex forms of intersectional discrimination and social exclusion that prevent them from fully enjoying their fundamental human rights.

Confronted with this situation, the RISEWISE project[3] has tried to contribute to the social inclusion of women with disabilities by challenging all forms of stereotyping and discrimination against them in every sphere of their social life (§ 3).

The project, coordinated by the University of Genoa, involved the following universities and organisations of people with disabilities: Universidad Nacional de Educación a Distancia (Spain), Middle East Technical University (Turkey), Universidad Complutense de Madrid (Spain), Universidade do Minho (Portugal), Universitaet Linz (Austria), Università degli Studi di Brescia (Italy), Associazione Italiana per l'Assistenza agli Spastici della Provincia di Bologna (Italy), Fish — Federazione Italiana per il Superamento dell'Handicap (Italy), Asociación de Familiares y Amigos de Personas con Discapacidad de la Universidad Complutense de Madrid — Afadis Ucm (Spain), Fraterna — Centro Comunitario de Solidariedade e Integracao Social, Ciprl (Portugal),

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[1] Although the introduction was conceived as a team-work by all the editors, the paragraphs 1., 2., 3. were written by Paola Parolari, the paragraph 4. by Luciana Guaglianone, 4.1.1. by Isabel Fanlo Cortés, 4.1.2. by Cristina Càndito and 4.2. by Susanna Pozzolo.

[2] To grasp forms of complex inequality, the concept of intersectionality (especially when understood as structural intersectionality) has proven to be enlightening. For an overview of the vast and varied literature on this topic see S. Cho, K. Crenshaw, and L. McCall (2013). Toward a Field of Intersectionality Studies: Theory, Applications, and Praxis. *Signs. Journal of Women in Culture and Society*, vol. 38, n. 4, pp. 785-809.

[3] RISEWISE is the acronym for «RISE Women with disabilities In Social Engagement». The research has been funded by the European Commission within the Action MSCA-RISE project (Call: H2020-MSCA-RISE-2015; Grant Agreement no. 690874) and coordinated by Cinzia Leone, University of Genoa.

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Stemming from the research experiences promoted by this project, the essays collected in this book aim at providing new insights into several — and partly unexplored — aspects of social (in)justice, at the intersection of gender and disability (§ 4).

2. Ableism, disability, and the biopsychosocial model

Over the centuries, our societies have been shaped by ableism: that is to say, a network of (more or less conscious) beliefs, processes, and practices that produces a particular image of the self and the body (the 'standard body'), which is considered as 'normal' (i.e. typical of the human being). This idea of 'normality' has determined the nature and structure of our social relations, political institutions, legal norms, economic systems, urban spaces, and so on, making them inaccessible, or difficult to access, to anyone who does not meet that standard. In this ableist framework, disability is considered a state of impairment, while people with disabilities are conceived as 'broken' people to be repaired, if possible.

In the last few decades, such a 'medical model' of disability has been challenged by the so-called 'biopsychosocial model', according to which disability must be conceived as the complex and dynamic result of the interaction between the functional limitations of the person and a set of contextual factors, such as the social and institutional barriers that this person encounters in her or his environment. In this perspective, disability is no longer seen as a natural fact, an intrinsic feature of some persons, but rather as a social fact, deeply connected with how our societies are organized. Attention shifts, therefore, from the person to the context or, rather, extends to the person *within* her or his context. This means that it is the context which must adapt to the possible needs of different people, thus becoming accessible to everyone through the application of the principles of a new universal design, and not vice versa. Furthermore, the biopsychosocial model also implies the abandonment of a binary approach that clearly distinguishes between healthy people and people with disabilities, since (dis)ability becomes a matter of degree that can affect anyone at different stages of her or his life.

This revolutionary shift in perspective has been incorporated into the *International Classification of Functioning and Health* (ICF) developed by the World Health Organization, as well as into the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD, 2006). In particular, the CRPD (art. 3) states, within a comprehensive and fully inclusive approach, several fundamental principles such as respect for the inherent dignity and individual autonomy of people with disabilities, their full and effective participation and inclusion in society, equality of opportunity, and accessibility (understood in a comprehensive sense, referred not only to the elimination of architectural barriers, but to all aspects of social life). Moreover, among its innovative aspects, the CRPD also places an explicit focus on the gender dimension of discrimination on the basis of disability, when it states:

> 1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms. 2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention (art. 6).

Nonetheless, eradicating centuries of ableism has proven to be a difficult task to accomplish (even within feminist movement and theories, which for a long time simply ignored women with disabilities). Indeed, while legal principles have been established, social practices and people's mindsets don't seem to be keeping pace. And, in the meantime, people — and especially women — with disabilities are still denied the full enjoyment of their fundamental human rights.

3. Patriarchy, the 'sex-gender system' and the invisibility of women with disability

Discrimination becomes even worse when ableism meets patriarchy and its distinction between public and private spheres. In this distinction, which has been strongly criticized by (liberal) feminists, are condensed the rules of a discriminatory and oppressive gendered social order, based on the subordination of women. Indeed, the rigid gender roles that structure this social order — fuelled by a system of gender stereotypes specifically designed to justify the patriarchal narrative behind it — include the image of men as breadwinners, engaged in productive work, as opposed to the idea of women as caregivers, engaged in caring for the home and children, the elderly, and any other vulnerable subject.

In such a social order, where women are relegated to the private sphere, women with disabilities have become even more invisible than men with disabilities, to the point that not even the need to 'repair their impairment' — as proposed by the medical model — was perceived. Not to mention that, even in medicine and science, the standard body has been conceived, until very recently, exclusively as a male body, which has profoundly affected the very perception of disability[4]. No surprise, indeed, since the strength of the patriarchal narrative lies in the ability to present the male model as *the neutral* human model. Therefore, even when

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[4] Fortunately, a new approach is emerging, called gender medicine, where there is full awareness of the importance of taking into account the differences between male and female bodies (see, for example, https://www.gendermedjournal.it/; https://www.gendermedicineunife.eu/it/; https://log-studi-di-genere.unibs.it/).

Disability Studies and the civil movements for the rights of persons with disabilities emerged, women initially did not appear on the stage.

It was only through *Women Disability Studies* that the severe forms of intersectional discriminations suffered by women with disabilities finally came to be denounced. As Garland-Thomson (2005) masterfully summarizes, Feminist Disability Studies

> is more than research and scholarship about women with disabilities, just as feminist scholarship extends beyond women to critically analyse 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. It seeks to challenge our dominant assumptions about living with a disability. It situates the disability experience in the context of rights and exclusions. It aspires to retrieve dismissed voices and misrepresented experiences. It helps us understand the intricate relation between bodies and selves. It illuminates the social processes of identity formation. It aims to denaturalize disability. In short, feminist disability studies reimagines disability[5].

The literature on the subject, and feminism in particular, have taken up the theoretical and practical battle for inclusion by also insisting on and developing the concept of intersectionality and reflecting more on the traditional application of the concept of equality as equal treatment. The theoretical recognition of disability as a disablement, and therefore as a social problem (thanks also to the 2006 international convention), is now indisputable. However, its practical application remains completely open and problematic.

4. The RISEWISE project in a nutshell

The RISEWISE project has focused on the collective of women with disabilities from different perspectives. It has attempted to identify needs and best practices in several EU countries, representing different cultural and socio-economic environments, for the integration and improvement of their quality of life in several environments from the point of view of different disciplines. By applying a novel analysis method, based on the experience acquired through the exchange of researchers, innovation staff and practitioners in the European area among the participating institutions, the project has identified a set of multi-sectorial research lines that have contributed to enhance integration. In conclusion, the aim of the RISEWISE project has been to include all aspects of the lives of women with disabilities and the great innovation has been that women with disabilities were not only passive subjects of the research but also actively involved in the project as subjects and members of the research teams.

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[5] R. Garland-Thomson (2005). Feminist Disability Studies. *Signs: Journal of Women in Culture and Society*, vol. 30, no n. 2, pp. 1557-1587, p. 1557.

4.1. Interdisciplinarity as an approach to inclusion

4.1.1. The contribution of the social sciences and humanities

The content of this volume reflects the interdisciplinary nature and objectives of the Risewise project. One of the latter, as (just) mentioned, is to give voice to women with disabilities, through their direct involvement in research aimed at identifying their needs and expectations, as well as the barriers, which are not exclusively physical or tangible, that they encounter in everyday life. Listening to these women and gathering knowledge about their real conditions play a key role in designing solutions and spreading good practices capable of overcoming the obstacles that still stand in the way of their social inclusion. Even more so, as we know, these obstacles are not only due to an inability to move, see or hear, but are often the result of inadequate policies, discriminatory practices, stereotypes and prejudices.

In this framework are placed several essays published in the volume, starting with the opening one, *Barriers, double discrimination and empowerment of women with disabilities. A pilot study in Spain and Italy*. As the title suggests, this chapter presents and discusses the results of a survey conducted among women with disabilities in Spain and Italy, with the aim of collecting elements of knowledge on different aspects of their social and relational life, including sexual and reproductive, which are still considered taboo when talking about disabled bodies and minds. The next essay, *Women's voices: empowerment, recognition and multidisciplinary work to prevent and tackle discrimination and violence against women with disabilities. The experience in Bologna*, moves in a similar direction: it focused on the topic of violence and on the issue of doubly dangerous violence and discrimination, which are, according to the authors, subtle and invisible due to the systematic lack of a gendered approach to disability. To give as much voice as possible to women with disabilities, this research used, in addition to questionnaires, face-to-face interviews, and freely composed writing and narratives, where women were asked to express themselves and to tell their stories.

A mixed methodology is also employed in the research related to the essay *Exploring female MS patients' social engagement in Sicily*, which provides some interesting elements of reflection on the factors that can, respectively, help the participation of women with multiple sclerosis in social, educational, and professional environments (such as good socio-economic conditions) or undermine it (such as scarce knowledge about MS in the wider population).

Although, as mentioned above, the Risewise project has sought to investigate all forms of intersectional multiple discrimination that are faced by women and girls with disabilities, this publication shows that special attention has been paid to discrimination in access to social rights, such as employment and education.

In the essay *Disabilità, lavoro e prospettiva di genere* the Author, starting from an analysis of the Italian legislation on access to employment for persons with disabilities (where a gender perspective is completely absent), also deals with the issue of so-called smart working which, if not properly regulated, rather than a means of inclusion risks becoming another factor of discrimination for women with disabilities.

On the other hand, the chapter *Accessibility and inclusion in higher education in Turkey* explores the limits and potential of the current situation in Turkey regarding the equal educational opportunities of persons with disabilities and their accessibility in higher education (tertiary level education) institutions. From this analysis, some critical considerations emerge that, with due caution, could be extended to higher education systems in other countries.

Again to promote greater inclusion of students with disabilities, in *Guías de diversidad para apoyo al profesorado de la educación superior* the Author describes a project, carried out by the University Complutense of Madrid (Spain), in collaboration with University of Brescia and University of Genoa (Italy), aimed at guiding and improving the interaction of university professors with students with disability, through the development of a guideline. This guideline, which will be produced in Italian, English, and Spanish, should encourage the use of materials, teaching, and assessment methods that are more appropriate to the different needs of students, including those with disabilities.

Finally, the three subsequent chapters focus on the centrality of the body and the dynamics that affect it, returning to some core issues about social inclusion through the voice of the subjects with disability involved in the ethnographic research.

The essay *Sguardi dalla periferia. Riflessioni a margine di una ricerca su disabilità e professioni delle arti performative* reflects on the emotional work of ‘reverse’ care implicitly required of the woman performer with disability — co-author of the chapter — to make her body intelligible, to discredit stereotypes about the one-way dependency of people with disabilities and instead bring attention to human interdependence. This research, which was carried out during the No Limits Disability & Performing Arts Festival Berlin and the Norma Festival of Ostrava (edition 2019), has privileged the participant observation and the research technique referred to as shadowing.

In *Mujeres con discapacidad y sexualidad: una investigación empírica en el marco del «feminismo de la diversidad functional»* the Author investigates the taboo themes of sexuality and sexual assistance, starting from the stereotypes that affect and do not affect (without being liberating) the bodies of women with disabilities, from the outlined perspective of the Spanish functional diversity feminism. In this case, the research has privileged the biographical narratives of girls and women with recognized disabilities of various types and of some ‘intimate/sexual assistants’, all of them residents of Spain’s capital city.

The next chapter *Programa expresivo-corporal: la barrera corporal como elemento de análisis en la mejora de calidad de vida en personas con esclerosis múltiple* report the successful experience of an innovative training intervention (a real action-research) focused on the ‘body awareness’ and at the same time aimed at users and volunteers of the Italian Multiple Sclerosis Association (AISM), based in Palermo (Italy).

4.1.2. The contribution of the disciplines of the project of places, objects and communication

The RISEWISE project succeeded in bringing together different disciplines and provided them with a reason to seek new solutions, often based on methodologies known and valued in their use for research on accessibility of architectural spaces, for the enhancement of cultural heritage and for collective activities.

The pursuit of inclusion in its various aspects and implications constitutes a turning point in contemporary society. The revolution does not lie in the collective awareness of the need to create the conditions of autonomy for people with disabilities. Rather it can be seen in the field of research, where what appears as a generic affirmation of the value of diversity manifests itself in its broad scope.

The disciplines of the project of places, objects and communication by their nature are privileged fields to realise this concept, if we consider the shift from the concept of disability, taken to mean a label to be applied to categories of people who need special help, to the concept of context as the first obstacle in performing functions. Translated into the architectural field, for example, this does not mean that people with motor disabilities need specific aids to overcome the differences in level between floors, but that the space must provide routes that are accessible to everyone, including people with temporary or permanent mobility difficulties, as well as those who find some routes difficult or to those who need to transport things or people on wheels. This multiplicity of needs offers the designer opportunities to find ways to deal with reality in all its complexity. Moreover, this premise is the basis of the ICF (International Classification of Functioning and Health) developed by the WHO (World Health Organization), which describes the state of health of people in relation to their existential environment (social, family, work), in order to grasp the difficulties that disabilities can cause in the socio-cultural context.

As for the design of spaces and objects, the example linked to motor difficulties should not lead to the conclusion that the challenge is reduced to this single category. A wide range of issues must be taken into account in those contexts in which people are not limited to dealing with accessibility on a functional level such as reaching a destination or using an object. The aesthetic level must also be considered.

This happens when the built spaces, or their contents, are considered for their artistic value, which can be better appreciated by everyone when the variety of human nature is understood. This obviously also includes sensory, relational, and cognitive disabilities, as well as personal peculiarities, linked to the cultural context, but also to the gender dimension. In this respect, the observation of the relationship between context and people should bring to the fore the presence of gender issues. In other words, the differences must be considered when they are useful to bring about equality, so as not to fall into clichés which pay attention to women only in relation to the issues of childcare or — worse — of physical beauty, since it is precisely the necessary indistinction of roles and tastes between genders — not between people — that allows people to enhance their characteristics, even if these do not respond to the stereotypes imposed by the binary gender concept.

Accessibility must also be applied to different situations, and the chapter *Perception and Multiperception in Architecture* focuses on the enjoyment of architecture not only in its functional sense, starting from the perceptual theories of vision and extending to the relations constructed between body and environment during the exploration of space. The project of architecture has been enriched by multisensoriality, with the support of recent neurocognitive studies connected to the issue of inclusion.

Welcome to the Museum. Approaches for inclusive museums explains how the museum is being re-interpreted as a place not only dedicated to studies or conservation, but something that performs the essential role of providing a narrative of knowledge. This essay offers the opportunity to reflect on inclusivity inside the museum through the analysis of some significant examples.

The chapter *«We live in a plural world»: a framework for rapid interdisciplinary and community engagement* describes a participatory approach applied to product design, experimented in a community of elderly people in an inclusive framework which successfully encouraged different kinds of people to express their needs and to participate in the design process.

Social progress requires opening one's eyes to the complexity of reality. Moreover, it can also provide new stimuli in the field of research, communication and creativity by moving from the concept of disability to that of accessibility, in order to eventually achieve real inclusion.

4.2. Inclusion as a social and academic practice, from now to the future…

In the last chapter *European research projects as a driving force for growth* the project coordinator explains how the European RISEWISE project has offered a possible prototype to work together from different disciplines and perspectives thereby increasing the useful impacts of the results.

During the four years of the Risewise project, innovative objectives were pursued to break down barriers which still act as real walls[6]. These ranged from the creation of spaces for dialogue and communication, to the exchange of knowledge and experiences between disciplines. To this end, it was also important to bring together academics and those working on the ground. Spreading knowledge and gaining concrete experience made it possible to overcome traditional biases and imagine new solutions.

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[6] See L. Scudieri, L. Guaglianone, R. Escudero, and C. Crespo Puras (eds.) (2019). *Inclusión socio-laboral de las mujeres con discapacidad*. Madrid. E-Prints Complutense. Risewise Project (ISBN 978-84-09-12477-0).

Barriers, double discrimination and empowerment of women with disabilities. A pilot study in Spain and Italy

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Keywords: disability, women, discrimination, inclusion, empowerment

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1. Introduction

In the historical development of Western thought, there have been several ways of theorising and studying the concept of disability. Specifically, since the 19th century, there has been a shift from a purely biomedical definition of health — i.e. the absence of disease — to a dynamic and social conception. In the first conception, disability was defined as an individual attribute, caused exclusively by physical or mental impairment. Subsequently, disability was defined as the product of a number of factors in the individual's physical and non-physical environment.

This metamorphosis has accelerated considerably since the 1960s. Since then, disability has been increasingly interpreted as something that, in addition to its biological aspect, is constructed, from a phenomenological and constructivist point of view, as a social and political, historical and cultural phenomenon (Barnes, Oliver & Barton, 2002) brought about by processes of social categorisation (Allport, 1973) and the attribution of stigma (Erikson, 1964; Goffmann, 1983).

Moreover, this change has also been reflected in law and international relations. In 1948, with the creation of the World Health Organisation (WHO), health was defined as «a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity». In

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[1] Alessandro Senaldi (University of Bari), María Ángeles Medina Sánchez (University of Castilla-La Mancha, Complutense University of Madrid, Sabina Belope Nguema (Complutense University of Madrid), Carlos Canelles Quaroni (Complutense University of Madrid).

1975, the UN General Assembly adopted the Declaration on the Rights of Disabled Persons, aimed at recognising the rights of people with disabilities.

In 1978, WHO and UNICEF (United Nations International Children's Emergency Fund), with the Alma Ata Declaration, established the need, at the international level, to move away from the biomedical model towards the biopsychosocial model developed the previous year by George Engel (1977). The following decade was dedicated by the United Nations to disability-related issues, a subject that gained greater relevance. And so, in 1982, the World Programme of Action concerning Disabled Persons was drawn up.

In 1986 the Ottawa Charter was agreed, and two years later the Adelaide International Conference took place. This reformist spirit reached remarkable heights at the end of the 20th century. Through renewed international attention to the issue of human rights, the final steps were being taken towards the current understanding of disability. The Sundsvall Conference in 1991, for example, raised the importance of the environment in the inclusion of people with disabilities. Instead, in 1993 the UN, in order to establish international consensus on the issue, adopted the resolution on the Standard Rules on the Equalization of Opportunities for Persons with Disabilities and identified priorities for States to follow in order to create effective policies.

However, it was only in 2001, with the elaboration of the International Classification of Functioning, Disability and Health (ICF), that the biopsychosocial model was taken at the international scale as a framework within which to consider disability. From this point, it is possible to study its implications and develop univocal and uniform policies capable of including people with disabilities to a greater extent in the social fabric.

With the ICF, the concept of disability reaches a paradigm shift, as it is no longer a subjective attribute of individuals, but is relativised. In other words, it is related to contingencies, situations in which any person may find themselves and which cause, through interaction with each person's own characteristics, a worsening of the individual's quality of life and potential. This means that environmental characteristics, physical and non-physical, are central to the very making of disability.

For its part, the European Union (EU) has begun to legislate for people with disabilities since a Council resolution of 27 June 1974, by drawing up an action plan for their social and occupational integration. It defines rehabilitation as a wide range of measures aimed at establishing and maintaining the best possible relationship between the individual and his or her environment. However, it was not until the mid-1990s that a more systematic approach to the issue was adopted. In fact, it was only on 30 July 1996, with the approval of A New European Community Disability Strategy, that a change of pace was seen in the old continent. This document, inspired by the Standard Rules adopted three years earlier by the UN, recognises for the first time the need to protect the rights of this group and to integrate them to a greater extent. This would be done through coordinated actions and policies at European level for people with disabilities, based on the need to adopt the biopsychosocial model.

Subsequently, the Treaty of Amsterdam of 1999 further contributed to the development of measures to protect the rights of people with disabilities, inspiring several pieces of legislation in various fields[2] during the first decade of the 21st century. One of the most important was the adoption of the Nice Charter in 2000, which establishes the principle of non-discrimination (Art. 21) and «recognises and respects the right of persons with disabilities to benefit from measures to ensure their autonomy, social and occupational integration and participation in the life of the community» (Art. 26). Later, in 2004, the first Action Plan on the Integration of People with Disabilities (2004-2010) was approved, later repeated with the European Disability Strategy (2010-2020) and with the European Disability Strategy (2021-2030).

Despite the interest of the UN and the EU, issues such as discrimination and marginalisation of people with disabilities are often overlooked, not only in politics but also in science. This gap is, in some aspects, a consequence of the lack of international and European laws, which have not been able to impose a clear and unambiguous definition of disability, which overcomes the difficulties determined — according to Chiappetta Cajola (2014) — «both by the complexity and multifactorial nature of the concept and meaning, and by the theoretical model assumed [...] and the qualification of the different levels of severity»[3] (p. 312).

Moreover, this silence is even more pronounced when the focus is on women with disabilities, who are invisible both in academia and in more radical circles. In fact, the situation of women with disabilities has been ignored, both by Disability Studies — which, referring to the idea of a 'neutral' and asexual body, has traditionally been insensitive to the gender perspective — and by many feminist movements. As the situation of people with disabilities in general, and of women in particular, is narrated with a rhetoric focused on need, passivity and dependence on the family context, it continues to be perceived as a threat to feminism (or at least to first-wave feminism), focused on claiming women's autonomy and empowerment, as well as their emancipation from the roles imposed on them by society (Bernardini, 2013, 2016).

The need to address this issue, rather than more precise or defined research, is driven by the almost total absence of data on the subject (Nobili, 2020). This absence seems to be marked, firstly, by a series of problems attributable to disability (such as the lack of unambiguous definitions and the difficulty in accessing data), and secondly, by the lack of studies on the concept of «double disadvantage» (Morris, 1992, 1993).

This idea was developed by Feminist Disability Studies (FDS), a branch of studies born in the mid-1980s, which aims to integrate Disability Studies and feminist theories, insofar as both — to use Di Gennaro's (2017) words — «address the issue of identity construction of social groups at

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[2] i.e. telecommunications (Directive 1999/5/EC); transport (Directive 2001/85/EC); equal treatment in employment and employment conditions (Directive 2000/78/EC); increased accessibility of certain products and services.

[3] Translator's note: translated from the original in Italian into English.

risk of exclusion and marginalisation [...] through the interweaving of different scientific approaches and [...] assuming a multi-perspective and interdisciplinary logic»[4] (p. 264). According to the authors of this movement, women with disabilities are, on the one hand, exposed as women to patriarchal and sexist gender stereotypes, and, on the other hand, measured with the yardstick of a (supposed) normality, considered to be lacking and labelled as a disruption of what Parsons (1978) would call the 'normal' functioning of the individual.

Gender and disability are culturally, socially and politically determined and defined constructs. This has obvious repercussions on the processes of representation, identity construction and vision of one's own body (Garland-Thomson, 2002). Therefore, it is necessary to re-symbolise these constructs, making the discourses and individual experiences of women with disabilities visible, socialising them and giving them the possibility to identify the difficulties in their daily lives, and to assert their sense of self, their own autonomy and self-worth, in a word, their own empowerment.

To respect the commitment undertaken to bridge the lack of studies, policies and data, we decided to adopt a follow-up system that will provide, through the voices of women with disabilities, the first step to identifying problems and priorities to move forward in the process of their inclusion. This is why we have carried out this pilot study, which we hope will be able to encourage further research and projects that make use of suitable research tools and techniques, as well as to attract investors and inspire policies and practices that will help counteract and diminish structural or systemic discrimination.

Therefore, the aim of the research is, by analysing barriers — i.e. 'contextual factors' that the ICF identifies as elements in a person's environment that, by their absence or presence, limit functioning or create disability — to investigate the double disadvantage experienced by Spanish and Italian women with disabilities[5].

To do this — although it is not our intention to adhere to normative definitions or biomedical aspects, and we prefer to reason in terms of diversity, difference or positive human uniqueness (Deluze, 1997) — for this research we preferentially surveyed women with disabilities who were in possession of a certificate issued by the competent authorities in their country of residence[6]. The lack of a certificate may be due to the fact that they have not yet reached the percentages that enable legal recognition of their disability status. Cross-country comparisons can be very

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[4] Translator's note: translated from the original in Italian into English.

[5] On this point, we are aware — in line with Crenshaw (1989) or with Bello's latest thoughts (2020) — that the dimension of discrimination is intersectional, so that not only acts on a single stigma but involves, at the same time, all the stigmas weighing on an individual. Consequently, we are equally aware that it is very difficult to refer to individual categories of discrimination — such as in our case gender and disability — without also referring to the others (such as social class, sexual orientation, ethnicity, etc.).

[6] In Italy under Law 104/1992, in Spain under Royal Decree 1971/1999.

complex and often not comparable, an issue that is also addressed in the literature (Chiappetta Cajola, 2014). But it is possible to find authors who carry out comparative studies on disability between various countries (Darbà *et al.*, 2015; van der Zwan & de Beer, 2021). In our case, we are interested in studying women with disabilities in Spain and Italy.

As far as gender is concerned, it is worth pointing out that the study is aimed — in line with transfeminist theory (Koyama, 2001) — at both women and those who identify as women, so that other subjectivities can also be included in our research.

Finally, it should be specified that since the sample was mainly collected within a university setting it is made up of a majority of highly educated individuals. This last point is particularly important to bear in mind, as it could be suggested that a high level of education and training may correspond to higher levels of autonomy, independence and empowerment.

2. Methodology and data

2.1. Methodological aspects of the research

Given the health emergency caused by COVID-19, the survey was carried out using the UCM Social Work Faculty Survey Platform software (in conjunction with the LimeSurvey application), as it was considered the most suitable way in terms of safety, reduced collection times and cost reduction. The survey sent to the women was structured according to the biopsychosocial model described in the ICF, and following the fundamental principles of the ICF, which are according to Leonardi (2003) — universalism, the integrated approach and the multidimensional model of functioning and disability.

In particular, the ICF was considered suitable because, by linking health to the environment and promoting a method of measuring abilities and difficulties in relation to various activities, it makes it possible to identify all barriers that impede the self-fulfilment, self-worth, autonomy and affirmation of women with disabilities. In fact, looking beyond the purely materialistic and corporeal dimension of disability, it makes it possible to identify important elements of all dimensions of human functioning: family, relationships, work, psyche, city, etc., in which subjectivities are involved.

The link to the questionnaire was distributed between January and May 2020 by seven Risewise project partners. Three associations: Associazione Italiana Sclerosi Multipla, AIAS Bologna Onlus and Asociación de Familiares y Amigos de Personas con Discapacidad; and four universities: University of Genoa, University of Brescia, National University of Distance Education and Complutense University of Madrid.

The survey, divided into six blocks, is mostly closed-ended questions. However, in addition to quantitative data, some open-ended questions (qualitative matrix) were developed in order to collect more in-depth information and to allow the interviewees to express themselves freely. In all the blocks, emphasis is placed on the difference between the importance of and satisfaction with the different aspects surveyed for women with disabilities.

First block. In addition to questions related to socio-demographic aspects, questions on issues attributable to the health and type of disability of the women surveyed are also included.

Second block. Both issues concerning the level of education and the employment situation of women with disabilities are addressed. With a view to social inclusion, the issue of employment is of fundamental importance; indeed, work is not only a means to financial reward, but is also capable of «driving motivation towards mature and autonomous growth, it is self-affirmation, dignity [...] and a leap in recognised citizenship»[7] (Medeghini & Valtellina, 2006, p. 207). In addition, work offers a number of latent benefits such as: defining social status and identity; providing social contact and support; occupying and structuring time; fostering a sense of personal fulfilment (Shepherd, 1989). However, work environments can also be discriminatory and access to work is not guaranteed for women with disabilities, who face greater difficulties and barriers — such as exclusion from certain jobs or tasks (Palacios, 2008, p. 133), negative attitudes, not being taken into consideration, or even accessibility issues —; as well as basic accommodation needs, in their incorporation into a job. This last block is made up of a number of questions relating to the functions and tasks carried out by women with disabilities, as well as the necessary features of the working environment in terms of accommodations for carrying out these tasks, the means of access to the labour market and the level of satisfaction with these aspects.

Third block. The housing situation of women with disabilities is investigated: whether they live alone, independently, with the family or in sheltered housing, and the level of accessibility of the home, the estate or the neighbourhood in which they live. In addition, this block also investigates the level of services offered to women with disabilities in the above-mentioned settings and the level of satisfaction with them.

Fourth block. The focus is on understanding the level of use of communication tools (whether digital or not). Likewise, the use of the internet and social networks, in order to identify situations of digital exclusion, given that new digital and computer tools are very important for the social inclusion of people with disabilities (Baroni & Lazzari, 2013).

Fifth block. This relates to inspiring practices and discrimination. It also addresses sensitive aspects of the lives of women with disabilities. Thus, it investigates the difficulties women encounter in their daily lives, the possible forms of discrimination suffered (whether gender or disability-related) and the context in which they have occurred. In addition, from a qualitative point of view, a question was asked in order to identify inspiring practices, the answers to which could contribute, on the one hand, to reducing the difficulties encountered and, on the other hand, to preventing discrimination or abuse.

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[7] Translator’s note: translated from the original in Italian into English.

Sixth block. In this last block, entitled *Social relations, affectivity, sexuality*, the focus is on the intimate aspect of the lives of women with disabilities. Various authors have analysed the concept of femininity and the situation of women in society (Ardener, 2020; Brownmiller, 2013; Figes, 1986). In our study, having included in our sample all people who identified themselves as women, we did not want to offer an exclusive and unique definition of femininity. In our research we have preferred to consider the subjectivity that accompanies the definition of femininity in each of the participants. Our interest lies in each participant's own conception of femininity as a social and cultural construct, which may vary in different contexts. In this way, participants are allowed to define themselves and indirectly position themselves in society according to their own perception (Macdonald *et al.*, 2021).

2.2. Sample description

Of the 520 women who responded to the survey, 367 (70.6%) are from Spain and 153 (29.4%) from Italy. Their mean age is 39.82 years (SD = 12.40 years). The youngest is 18 years old and the oldest is 101 years old. In 75% of cases the age is less than or equal to 49 years. In addition, the age distribution of the women shows a slight positive skewness (Figure 1).

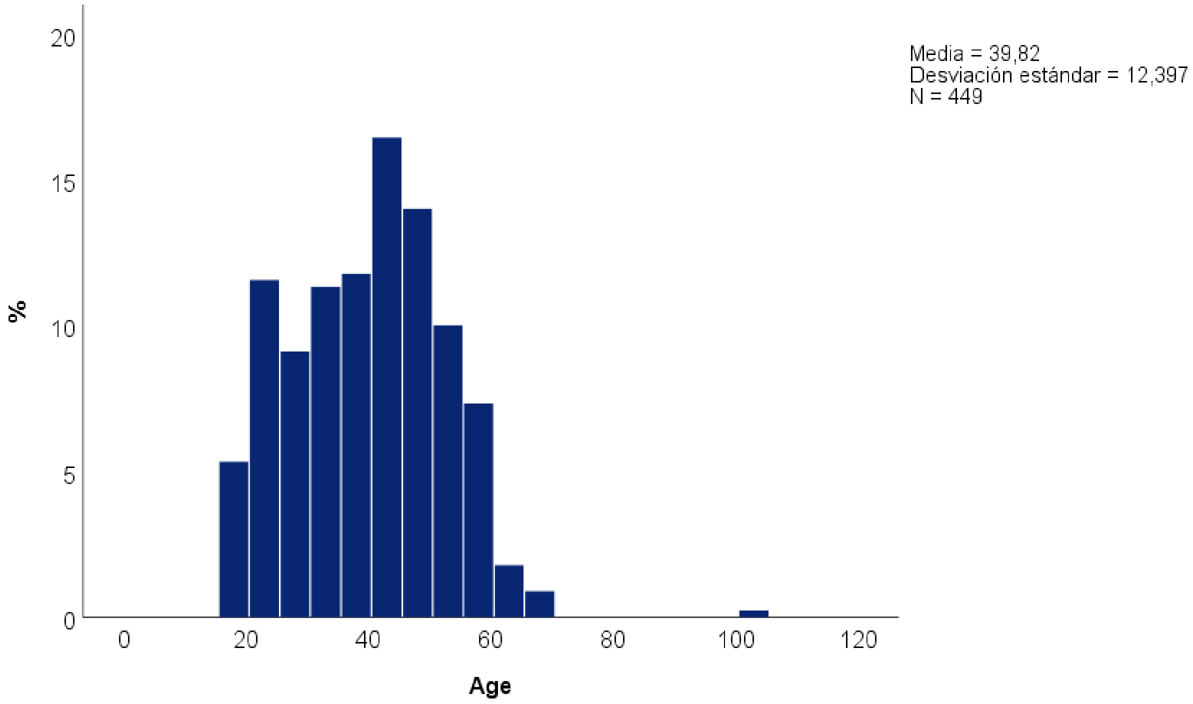

Figure 1. Age histogram.

As for the academic background of the women surveyed, 43.8% have completed high school or vocational training and 47.1% have a university degree (with a bachelor's degree being the most frequent, 35.3%) (Table 1).

The women surveyed show a good level of autonomy. When asked the question «with whom do you live?», most of them live in the family nucleus they have built (47.5%), 29.8% with their parents and 16.4% alone. In addition, most of them are living in independent housing (98%) and only 2% in sheltered housing or supervised flats. One third of these women have children (33.4%), however, 39.9% of them stated that disability has prevented them from having one or more children (Table 1).

Table 1. Sociodemographic data

Sociodemographic variable	N	n	%
Country	520		
Spain		367	70.6
Italy		153	29.4
Age	449		
18-30		117	26.1
31-41		122	27.2
42-49		106	23.6
50-101		104	23.2
Academic training	416		
None		2	0.5
Primary education		13	3.1
Compulsory secondary education		23	5.5
Baccalaureate or vocational training		182	43.8
University degree or bachelor's degree		147	35.3
Master's degree		41	9.9
Doctorate		8	1.9
Who do you live with	396		
With the family nucleus that I have built		188	47.5
With my parents		118	29.8
With other relatives (grandmother, aunt, etc.)		3	0.8
With roommates		13	3.3
Alone		65	16.4
With other people		8	2.0
Children and personal assistant		1	0.3
Where do you live	342		
In a home independently		335	98.0
In a residence or supervised apartment		7	2.0
Having sons or daughters (Mother)	332		
Yes		111	33.4
Not		221	66.6
Your disability prevents you from having one child or more than one	331		
Yes		132	39.9
Not		199	60.1

23.1% of respondents were born with a disability, while disability onset occurs most frequently between the ages of 20 and 50 (42.1%). In childhood and adolescence the onset of disability occurs in similar proportions (14.6% between 1 and 12 years; and 16.4% between 13 and 19 years). The lowest frequency is found after the age of 50, when disability occurs in only

3.7% of cases (Figure 2). Confirming what has already been said about the contingent nature of disability status, the data show how disability is something that can occur in a person's life and is not a condition inherent to individuals.

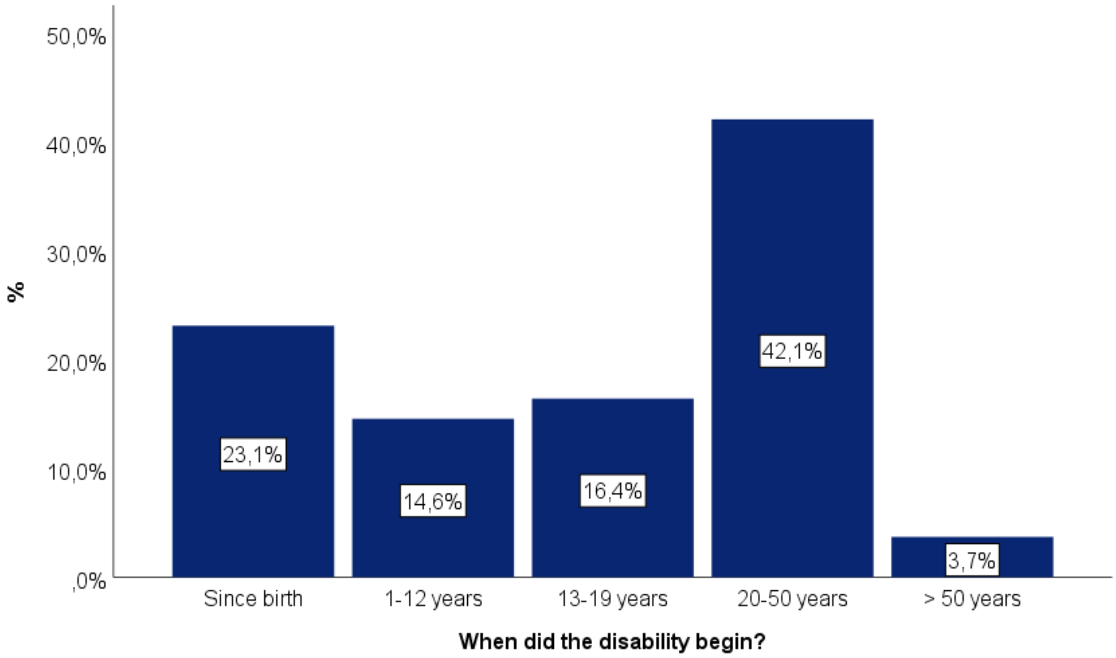

Figure 2. Distribution of age at onset of disability.

The most frequent disability among the respondents is physical (58%), followed by mental health (19.5%), hearing impairment (14.1%), visual impairment (11.9%) and the least frequent was intellectual (7.1%) (Table 2). In this case, we only considered whether a disability was present or absent, regardless of multiple concurrent disabilities. We also looked at which women have a single disability and which have several disabilities. In the latter case, the most frequent disability is still exclusively physical (44.5%), followed by mental disorder (12%) and 18% have multiple disabilities (Figure 3).

Table 2. Distributions of disabilities (separately)

Disabilities	**n**	**%**
Physical		
Yes	268	58.0
Mental health		
Yes	90	19.5
Hearing impairment		
Yes	65	14.1
Vision		
Yes	55	11.9
Intellectual		
Yes	33	7.1

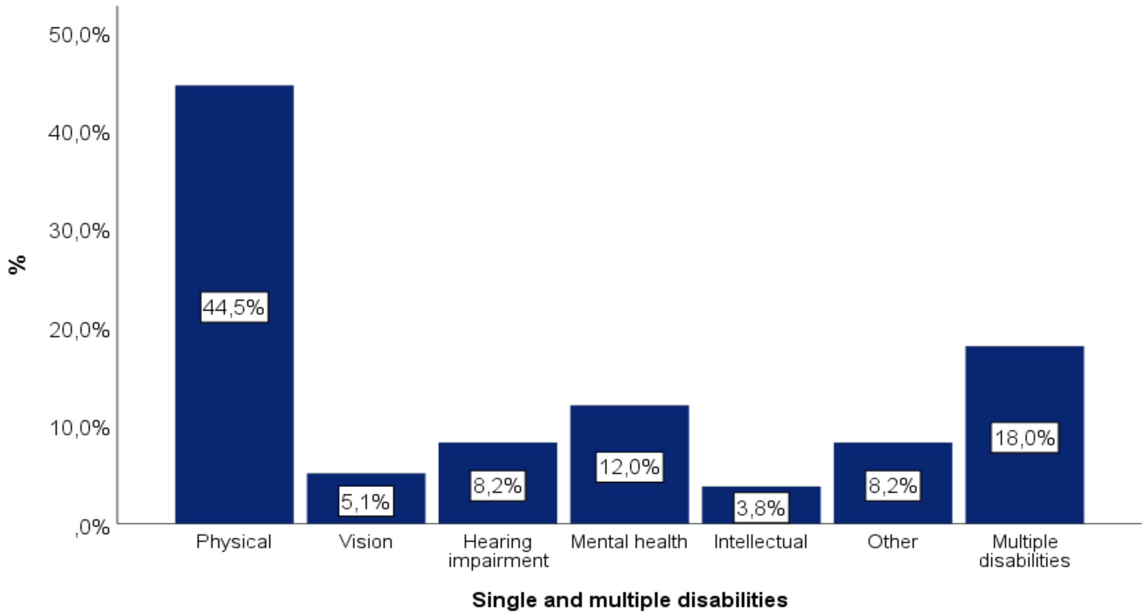

Figure 3. Distribution of disability.

There are significant differences in the distribution of disability between countries. For example, women with intellectual disability are more frequently found in Italy compared to Spain (6.7% vs. 2.3%, respectively) and Spain has a higher proportion of women with mental health disability than Italy ($p < 0.05$) (Figure 4). These differences are sample-based and cannot be extrapolated to the respective populations.

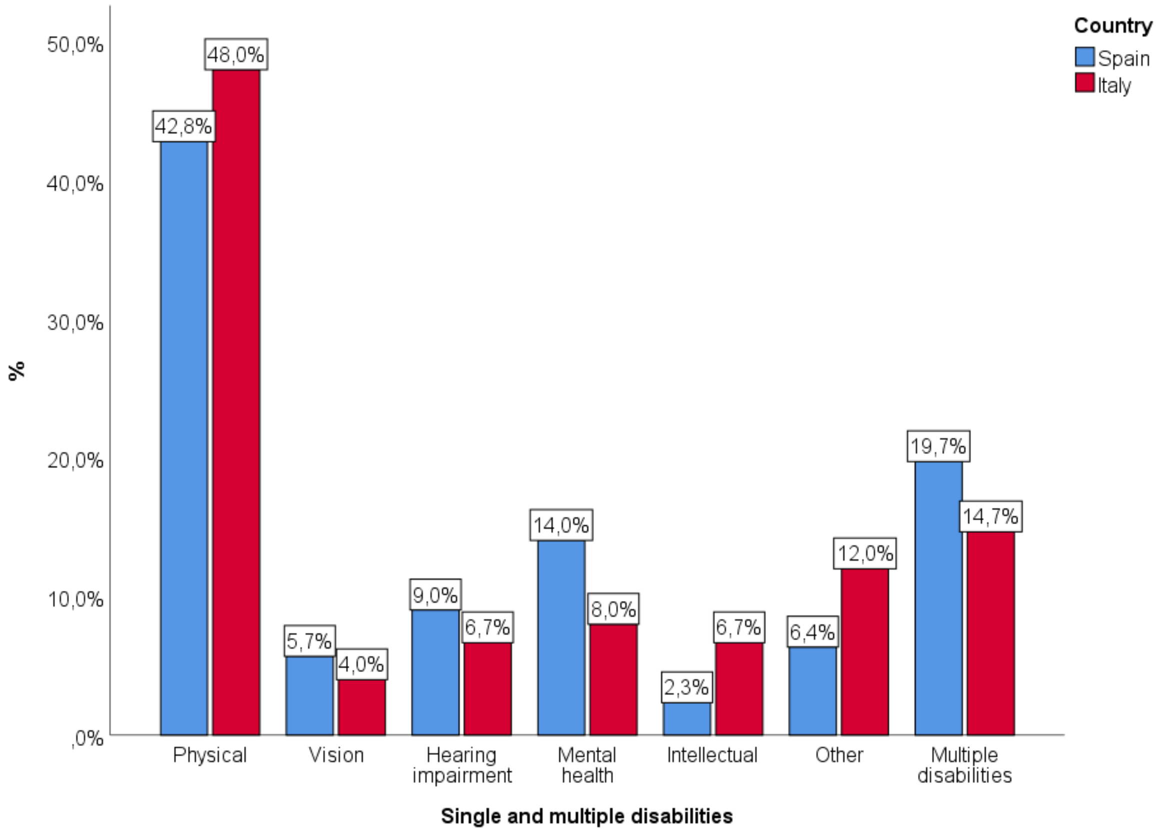

Figure 4. Distribution of disability by country.

2.3. Analysis strategy

The first step will be to describe each of the issues raised: work, information and communication technologies, accessibility, affective and social relations, representations of femininity, self-determination and discrimination. Secondly, a brief qualitative study will be added to some of the open-ended questions in the questionnaire, mainly on the issue of workplace accommodations and discrimination on the grounds of being a woman and/or a person with a disability. And finally, a joint analysis will be carried out to see if there is a relationship between what really matters to women with disabilities and their degree of satisfaction with these aspects.

All data processing was carried out with the IBM SPSS v25 statistics package (George & Mallery, 2019).

3. Social analysis of women with disabilities

3.1. Employability

Among the women surveyed, 32% are working. Students account for about a quarter of the total (24%), 11.9% are employed and students, and the rest are unemployed. It is worth noting that the majority of employed women are employed full-time (78.8%) (Figure 5).

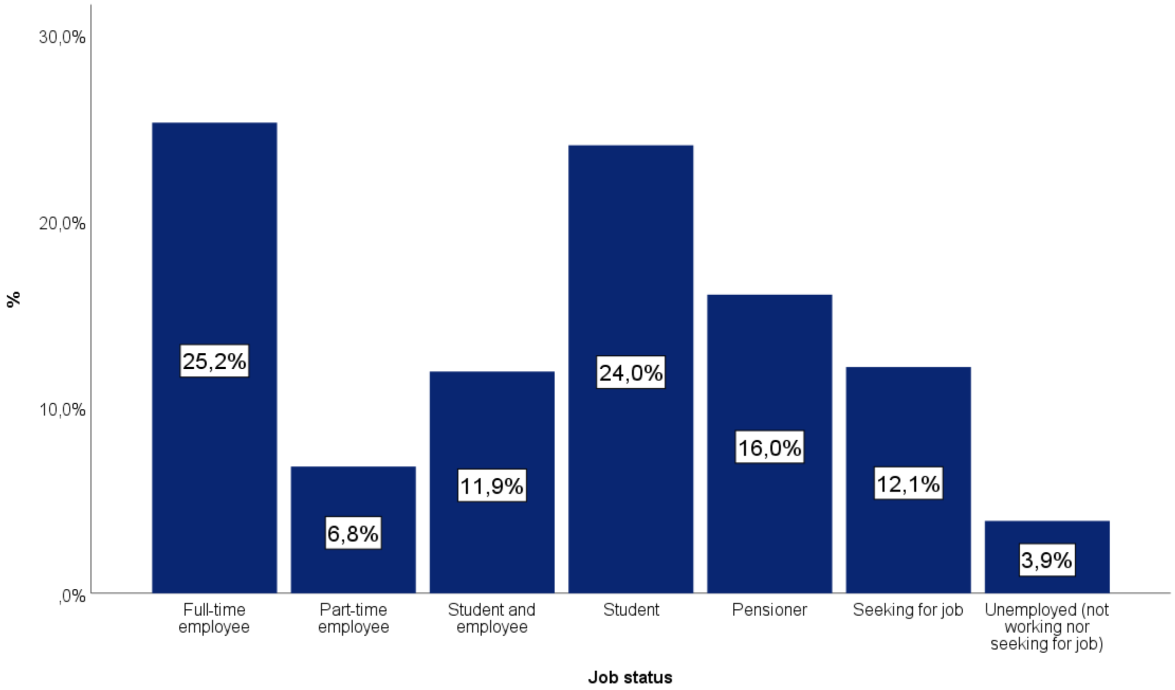

Figure 5. Distribution of professional status.

The main routes to employment were: sending a curriculum vitae (CV) to the employer (30.5%), competitive examinations (22.1%), personal contacts (21.4%), through a Special Employment Centre, an association or a foundation for people with disabilities (17.5%) (Table 3).

Table 3. Distribution of methods to find a job

Variable	**N**	**n**	**%**
How did you find your job?	154		
Sending my CV to the employer		47	30.5
Through competitive examinations		34	22.1
By personal contacts		33	21.4
Through an association or a foundation for people with disabilities		27	17.5
Through a Special Employment Centre		13	8.4

Among employed women, more than half said that their current job corresponds to their qualification (54.7%), 14.4% indicated that it only partly corresponds to their qualification. However, more than 30% feel that their job does not correspond to their qualification (Table 4).

On the other hand, more than half of them said that they had not been recruited through special quotas reserved by law for people with disabilities (53.3%). 42.8% were hired through quotas reserved for this group and the rest do not know if being a woman with a disability was a priority for the company (Table 4).

Table 4. Distributions of professional qualification and hiring by quotas

Variable	**N**	**n**	**%**
Does your current job match your professional qualification?	181		
Yes		99	54.7
Not		56	30.9
Only in part (I am more qualified)		26	14.4
Have you ever been hired through special reserved quotas by law for people with disabilities?	180		
Yes		77	42.8
Not		96	53.3
I do not know		7	3.9

Figure 6 analyses the employment situation of women with disabilities who are working, depending on whether or not their occupation corresponds to their professional qualification. Although there are no statistically significant differences in the distribution of employment status, it can be seen that among part-time employees there is a higher proportion of women whose qualifications do not correspond to the work they are doing.

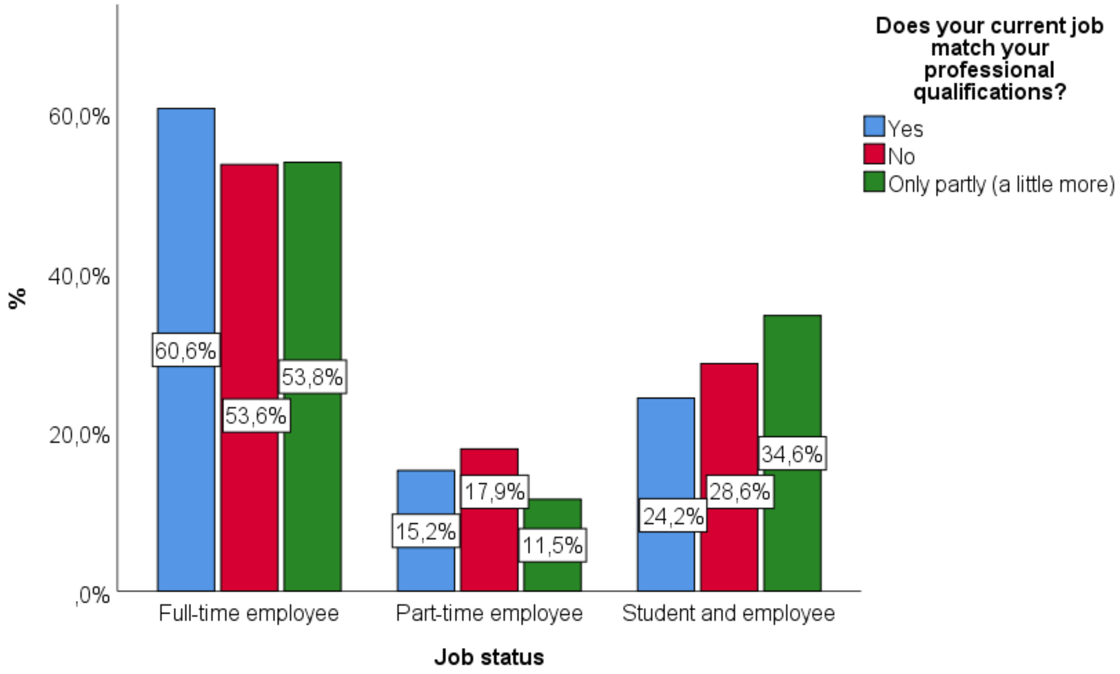

Figure 6. Distribution of professional status according to qualification.

As for workplace accommodations, 68.5% of women do not need them and 31.5% of women require some kind of accommodation. Of these, 29.1% stated that the accommodation has been provided completely satisfactorily and 49.1% stated that the accommodation has been only partially provided (Table 5). In addition, 43.9% of women who requested an accommodation in their workplace have a physical disability (Figure 7), which is equivalent to approximately 50% of women with a physical disability. This pattern is repeated across all disabilities, except for women with intellectual disabilities or with multiple disabilities. This tells us that companies are not yet accessible to all types of people.

Table 5. Distributions of the need for work adaptation and satisfaction with it

Variable	N	n	%
Do you need some kind of adaptation to carry out your work?	181		
Yes		57	31.5
Not		124	68.5
Have these adaptations been satisfactorily facilitated?	55		
Totally satisfied		16	29.1
Partly satisfied		27	49.1
Partly unsatisfied		4	7.3
Totally unsatisfied		8	14.5

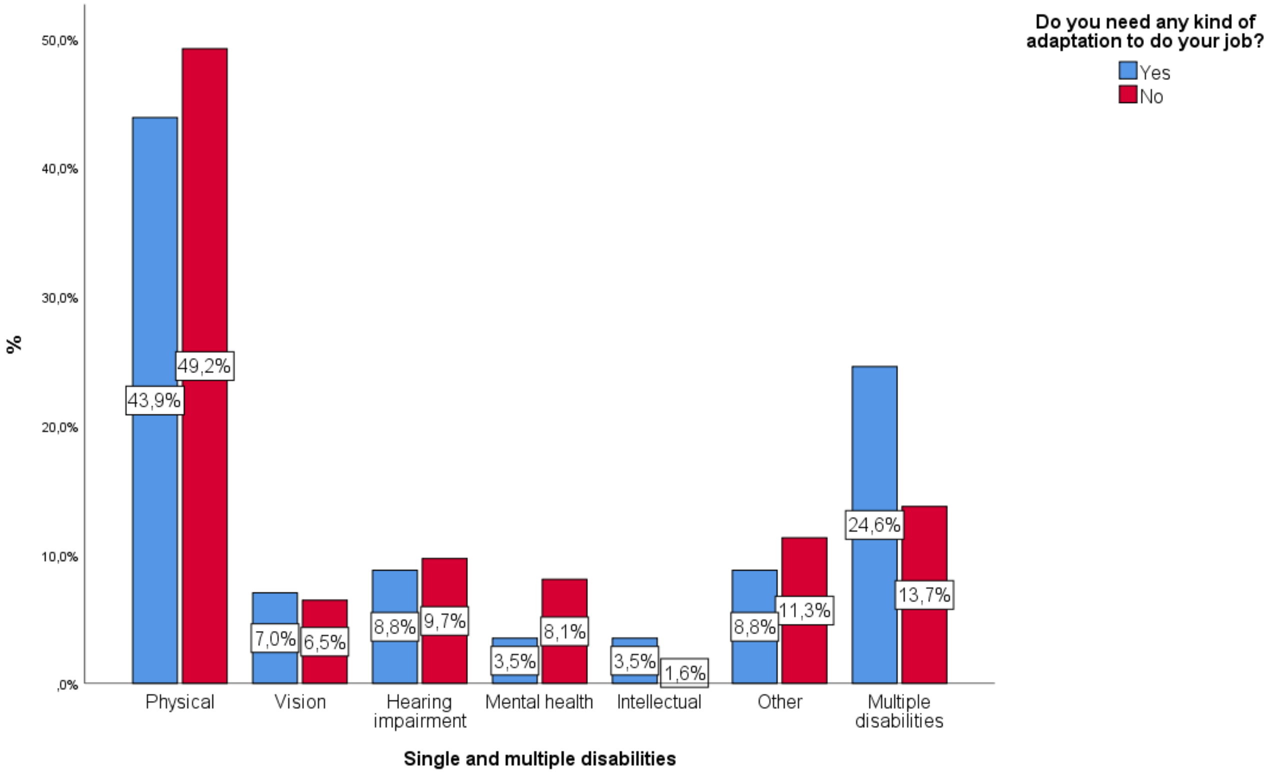

Figure 7. Distribution of the need for workplace accommodation according to type of disability.

Among the women with disabilities who require some form of workplace accommodation, in their open-ended response on accommodations, most of these were related to guaranteed accessibility and accessibility in the workplace itself (wheelchair-adapted desk, adapted toilet, screen readers or larger monitors, etc.). The same applies to working hours and the type of working day, for which a better reconciliation with personal circumstances and a greater emphasis on teleworking were called for. The need for a pleasant, calm and comfortable environment was also mentioned on numerous occasions, as well as the need for greater awareness of disability or greater sensitivity on the part of colleagues and the company's own administration. Cleanliness and adequate air conditioning were other requested accommodations, which would ultimately benefit all the people working in the same space.

Workplace accommodations vary widely, depending on the individual needs of each person, and are in any case rare. In most cases, they are not difficult and do not come at a great cost, and many other accommodations should be guaranteed by the universal accessibility, towards which societies must strive.

3.2. Information and communication technologies

Society must ensure that women with disabilities can interact with others through the use of information and communication technologies (ICT). However, in our study, when asked about the use of television, mobile phone or computer, 75% of respondents answered this question.

The results of the survey suggest that the women surveyed, although highly educated, are far from having solved the phenomenon of digital exclusion.

Among respondents, the mobile phone is the most widely used ICT (72.3%). In addition, a similar percentage use a computer at home (69.2%) and the Internet (69.4%). It is also common among these women to use e-mail (69%). The social network they use most is Facebook (53.1%), followed by Instagram (34%). Finally, 62.3% said that they watch television (Table 6).

Table 6. Use of ICT

ICT variables	% Yes (use)	% No (use)	% No answer
Mobile (for personal use)	72.3	2.5	25.2
Internet	69.4	5.4	25.2
Computer (for personal use)	69.2	5.6	25.2
Email	69.0	5.8	25.2
TV	62.3	12.5	25.2
Personal Facebook account	53.1	21.7	25.2
Radio	34.4	40.4	25.2
Personal Instagram account	34.0	40.8	25.2
Personal Twitter account	20.0	54.8	25.2
Skype personal account	16.5	58.3	25.2

3.3. Discrimination and violence

Despite international agreements[8], women with disabilities are often doubly discriminated against. This means that throughout their lives they face discrimination of all kinds and in different environments. To the question «have you ever felt discriminated against?», 17.9% of the women interviewed answered that they had never felt discriminated against. The women who participated in the questionnaire are able to recognise the types of discrimination they experience. Therefore, compared to the 17.7% of interviewees who have felt discriminated against for having a disability and the 9.2% who have felt discriminated against for being a woman, 27.1% of them feel the weight of double discrimination, which arises from the intersection between the stigma of being a woman and the stigma of disability (Table 7).

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[8] The Convention on the Rights of Persons with Disabilities and the Council of Europe Convention on preventing and combating violence against women and domestic violence (2011).

Table 7. Distribution of the feeling of discrimination

Variable	N	n	%
Have you ever felt discriminated against?	520		
Yes, as a woman		48	9.2
Yes, as a person with a disability		92	17.7
Yes, as a woman and as a person with a disability		141	27.1
Not		93	17.9
No answer		146	28.1

As regards the type of situations of discrimination and violence suffered by women with disabilities, the interviewees were able to clearly distinguish the different situations of discrimination. This is despite the fact that discrimination is not a concept that is objectively established by law, to the extent that the UN Convention on the Rights of Persons with Disabilities itself defines it very broadly[9].

The most common forms of discrimination that these women had suffered are invisibilisation (56.6%), psychological or emotional abuse (51.6%), labour exploitation (33.1%), over-care (27%), violation of privacy (27%) and neglect (25.6%). Obstetric violence (understood as contraception, sterilisation or forced abortion) is the least frequent discrimination (5%) (Figure 8).

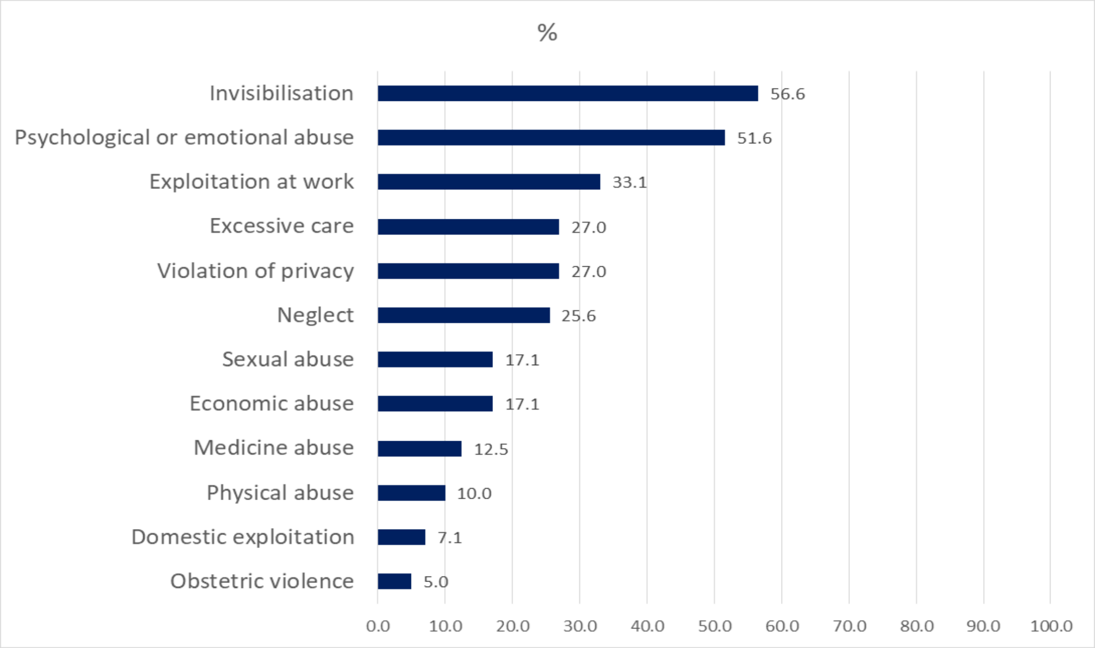

Figure 8. Discrimination.

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[9] Art. 2 of the UN Convention: any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field».

The most striking aspect of the discrimination suffered by women with disabilities is where it has occurred. The most common places where discrimination occurs are in the workplace and in the home. In general, their workplace is where they feel most discriminated against (48.2%), followed by their family (33.8%). Public institutions, training and leisure facilities were also mentioned at least one out of four times (29.6%, 26.4% and 25.6% respectively). It is also interesting to note the figure on virtual discrimination (11.4%) (Figure 9).

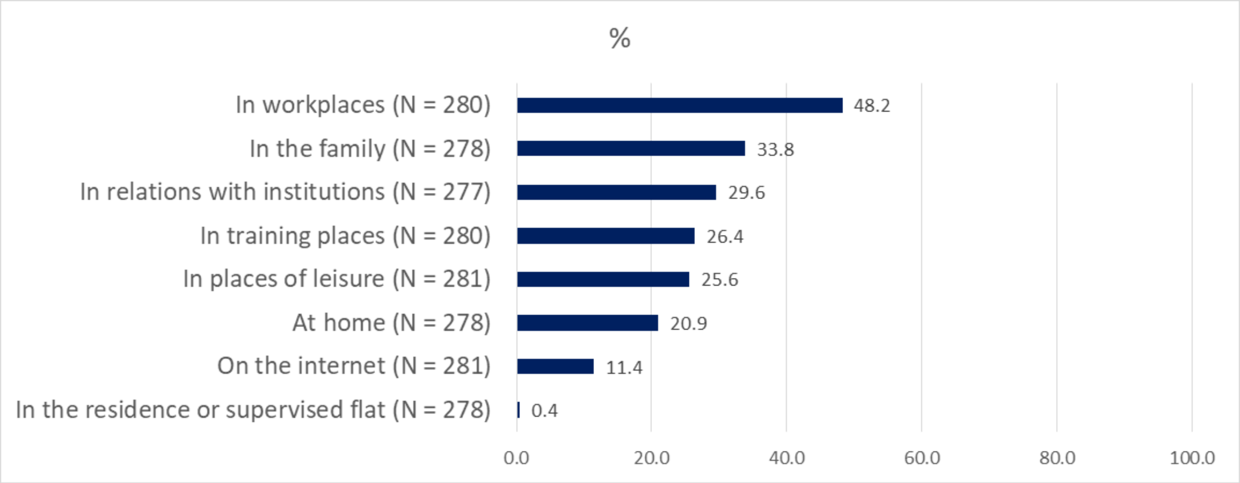


Figure 9. Where has discrimination occurred?

Invisibilization is a social mechanism widely used in Social Sciences to refer to the omission of certain people or social groups. From social anthropology it is generally understood that the understanding of the world comes through the assimilation of cultural representations, and therefore through the construction of an ‘us’ and an ‘other’. In the particular case of the relationship of the abled population with people with disabilities, the barriers that have been raised historically due to the medical-rehabilitating paradigm, the distancing and ignorance of disability, make the social value of diversity not recognized and the discourses and new cultural frameworks provided by the social model of disability (Palacios & Romañach, 2007, p. 39) are not yet taken into account. We are interested in invisibilization as a form of discrimination, due to our close relationship with people with disabilities, as we know that sometimes they are left aside or ignored, as well as their opinions and knowledge are not valued like the rest. Following authors such as Meekosha and Dowse (1997), who criticised the cultural and media treatment of disability at the turn of the last century, further progress must be made in adopting new social norms that are conducive to reducing discrimination against women with disabilities (see also Mendes & Silva, 2013; Shakespeare, 1994).

Surveyed women indicated that invisibilisation is the discrimination they experience most frequently. This occurs both in places of leisure, training, work and even in the home environment. One of the main demands of women with disabilities is for greater visibility. Feeling that they are heard and valued and that their opinions are taken into consideration in decision-making is fundamental for their inclusion and to avoid invisibilisation. Indeed, this need to be able to make their voice heard is an essential step towards their empowerment.

Psychological and emotional abuse also occurs more frequently in the family environment and in the workplace, in the form of abuse at work, bullying, or even harassment by men in positions of responsibility. Belittling and humiliation, which are mentioned among the forms of discrimination that occur in public institutions, are also very worrying and demonstrate a lack of sensitivity and training on the part of some civil servants and professionals. These situations prove that the societies in which the women surveyed live have not assimilated international norms and conventions with regard to disability. The Internet is also a place where psychological and emotional discrimination occurs, with hurtful comments and attacks on social media, especially towards those with more visible disabilities. Considering the age of the respondents, they may be the first generation of women with disabilities to experience discrimination in the virtual environment.

Many different types of discrimination occur in the workplace. In fact, after invisibilisation and psychological or emotional abuse, the most frequent discrimination is labour exploitation. This often appears as an excessive workload, as disruptive working hours or as wage exploitation, often legitimised or known, as in the case of the gender pay gap. There are also situations of discriminatory treatment, both because they are women and because of their disability, as well as a lack of consideration of their suggestions, as another form of invisibilisation. Finally, many report discriminatory situations in the recruitment processes themselves. The lack of diversity training for human resources staff also largely prevents them from accessing certain jobs.

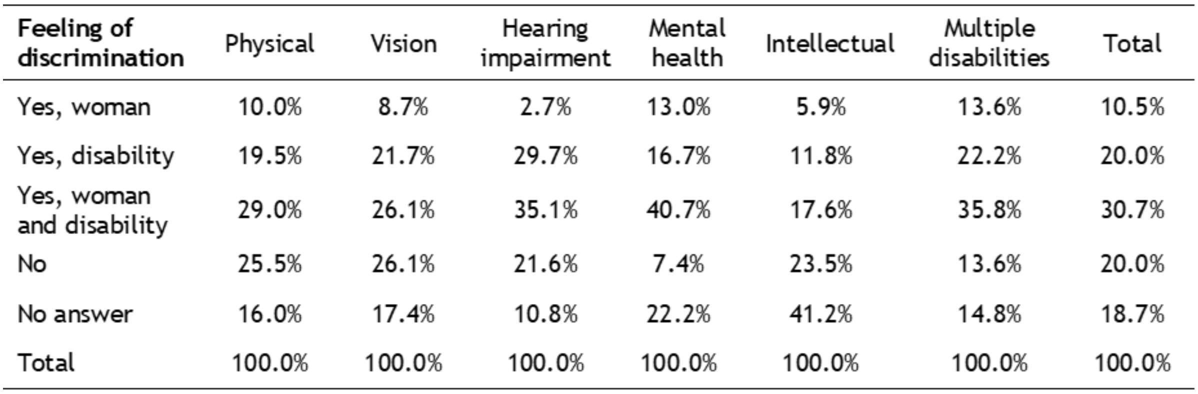
Over-care is often linked to the desire for autonomy, which is one of the main demands of people with disabilities. Paternalism, overprotection and this over-care are often experienced in the home. In the family nucleus we find that the moral autonomy of some women is not respected, because decisions that directly affect them are taken and imposed.

17.1% of the women surveyed stated that they had suffered mistreatment in the form of sexual abuse, repeatedly and also by people close to them. In addition, some reported difficulties in telling their families.

3.3.1. Association between discrimination and disability

The survey shows that women with mental health disability are particularly vulnerable, in line with the findings of several authors for people with mental health disability as a whole (Corrigan, 1999; Brohan *et al.*, 2010). Only 7.4% of the cases state that they have never experienced discrimination, showing that there is still a long way to go in terms of respect for disability (Table 8).

Table 8. Relationship of the feeling of discrimination and disability



Feeling of discrimination	Physical	Vision	Hearing impairment	Mental health	Intellectual	Multiple disabilities	Total
Yes, woman	10.0%	8.7%	2.7%	13.0%	5.9%	13.6%	10.5%
Yes, disability	19.5%	21.7%	29.7%	16.7%	11.8%	22.2%	20.0%
Yes, woman and disability	29.0%	26.1%	35.1%	40.7%	17.6%	35.8%	30.7%
No	25.5%	26.1%	21.6%	7.4%	23.5%	13.6%	20.0%
No answer	16.0%	17.4%	10.8%	22.2%	41.2%	14.8%	18.7%
Total	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Again, when analysing the relationship between discrimination and the type of disability, we find that women with mental health problems are those who have experienced the most discrimination. For example, among these women, 78.9% have experienced psychological or emotional abuse (higher than the overall proportion of 51.3%). Obstetric violence is less prevalent, but even so, among women with intellectual disabilities and mental health disability it amounts to 16.7% and 15.8%, respectively (the overall proportion is 5.1%). On the other hand, women with multiple disabilities have experienced psychological or emotional abuse in 65.5% of cases, labour exploitation in 44.8% and neglect in 39.7%. The latter two forms of discrimination are experienced by these women to a greater extent than the rest of women with other disabilities (overall proportions: 33.1% and 25.8%, respectively). Finally, focusing on women with visual impairment, we can see that they experience more situations of invisibilisation and domestic exploitation (69.2% and 15.4% respectively) (Table 9).

Table 9. Relationships between discrimination and disability

Discrimination		Single and multiple disabilities						Total
		Physical	Vision	Hearing impair-ment	Mental health	Intellectual	Multiple disabilities	
Drug abuse	Count	11	1	0	11	0	11	35
	% within Disabilities	9.4%	7.7%	0.0%	28.9%	0.0%	19.0%	12.7%
Excess of care	Count	36	4	5	13	0	12	73
	% within Disabilities	30.8%	30.8%	20.0%	34.2%	0.0%	20.7%	26.5%
Privacy violation	Count	23	5	3	17	1	20	75
	% within Disabilities	19.7%	38.5%	12.0%	44.7%	16.7%	34.5%	27.3%
Negligence	Count	26	4	2	10	0	23	71
	% within Disabilities	22.2%	30.8%	8.0%	26.3%	0.0%	39.7%	25.8%
Economic abuse	Count	13	2	2	16	0	15	48
	% within Disabilities	11.1%	15.4%	8.0%	42.1%	0.0%	25.9%	17.5%
Labour exploitation	Count	30	4	7	17	0	26	91
	% within Disabilities	25.6%	30.8%	28.0%	44.7%	0.0%	44.8%	33.1%

		Single and multiple disabilities						
Discrimination		Physical	Vision	Hearing impair-ment	Mental health	Intellectual	Multiple disabilities	Total
Domestic exploitation	Count	5	2	2	4	0	6	20
	% within Disabilities	4.3%	15.4%	8.0%	10.5%	0.0%	10.3%	7.3%
Psychological or emotional abuse	Count	45	3	18	30	0	38	141
	% within Disabilities	38.5%	23.1%	72.0%	78.9%	0.0%	65.5%	51.3%
Obstetric violence	Count	3	1	0	6	1	3	14
	% within Disabilities	2.6%	7.7%	0.0%	15.8%	16.7%	5.2%	5.1%
Physical abuse	Count	8	0	1	9	1	7	28
	% within Disabilities	6.8%	0.0%	4.0%	23.7%	16.7%	12.1%	10.2%
Invisibility	Count	63	9	16	20	0	38	155
	% within Disabilities	53.8%	69.2%	64.0%	52.6%	0.0%	65.5%	56.4%
Sexual abuse	Count	15	2	5	10	1	13	48
	% within Disabilities	12.8%	15.4%	20.0%	26.3%	16.7%	22.4%	17.5%

Table 10 shows the relationships between the spaces where discrimination occurs and the type of disability. Here we find that in general women with mental health problems have experienced more discrimination in different spaces. For example, among women with mental health problems, 60.5% have experienced discrimination at work and 52.6% in the family (higher than the overall proportions of 48.2% and 32.7%, respectively). Women with multiple disabilities report experiencing discrimination in their workplaces (58.6%). It is also worth noting that more than 35% of women with visual or hearing impairment experience discrimination in their educational establishments (38.5% and 36%, respectively; overall proportion: 26.3%).

Table 10. Relationships between places where discrimination and disability have occurred

		Single and multiple disabilities						
Circumstances		Physical	Vision	Hearing impair-ment	Mental health	Intellectual	Multiple disabilities	Total
On the Internet	Count	9	1	3	7	0	10	31
	% within Disabilities	7.7%	7.7%	12.0%	18.4%	0.0%	17.2%	11.3%
In leisure places	Count	29	2	5	13	0	18	70
	% within Disabilities	24.8%	15.4%	20.0%	34.2%	0.0%	31.0%	25.5%
In training places	Count	26	5	9	9	1	18	72
	% within Disabilities	22.4%	38.5%	36.0%	23.7%	16.7%	31.0%	26.3%
In workplaces	Count	48	6	12	23	0	34	132
	% within Disabilities	41.4%	46.2%	48.0%	60.5%	0.0%	58.6%	48.2%

Circumstances		Single and multiple disabilities						Total
		Physical	Vision	Hearing impairment	Mental health	Intellectual	Multiple disabilities	
In your house	Count	15	3	4	13	0	20	57
	% within Disabilities	12.9%	23.1%	16.0%	34.2%	0.0%	35.7%	21.0%
In your family	Count	35	4	4	20	0	19	89
	% within Disabilities	30.2%	30.8%	16.0%	52.6%	0.0%	33.9%	32.7%
In relations with institutions	Count	33	3	8	12	0	18	80
	% within Disabilities	28.7%	23.1%	32.0%	31.6%	0.0%	32.1%	29.5%

3.3.2. Preventing discrimination and empowering women with disabilities

When asked about possible solutions to discriminatory situations, respondents stressed the need for more training and awareness-raising on disabilities, irrespective of their type of disability. There is a demand for more understanding, listening and empathy from family members and professionals (whether in the field of health, education or other services), as well as from the rest of the public. Many advocate for a stronger focus on disability, sexuality and gender equality issues in education. Finally, economic autonomy is mentioned, through decent work that guarantees equal pay and accommodates each person's circumstances (both in terms of working hours and the work to be done), or through pensions adjusted to the physical and social reality of each individual. All of this alludes to empowerment, that is, the need to make and execute one's own decisions.

Among women with reduced mobility, there are two main complaints. The first concerns accessibility, which is essential in public spaces and services. The need to separate illness and disability in the collective imagination was also expressed. Among women with sensory disabilities (visual and hearing), as well as among people with intellectual disabilities and neurodivergence, one specific demand is the right to information. In the case of sensory disabilities, it should be conveyed both visually (photograph or text) and orally, so that no one is excluded. The information to be conveyed should be easy to understand in terms of its complexity.

Women with mental health problems, for their part, call for understanding and empathy. In addition, they advocate for the destigmatisation of mental health disability by making them visible and normalising them. They also want to see an improvement in primary mental health care.

3.4. Importance of and satisfaction with social aspects: Analysis of the relationship of what they consider to be most important and what they are most satisfied with

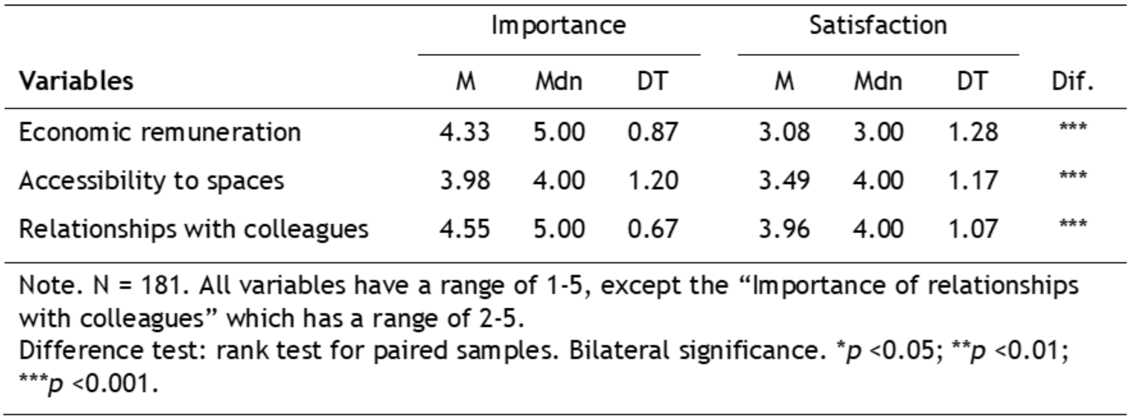
In this section we will focus on analysing the relationship between the importance of and satisfaction with different social aspects for women with disabilities. The analysis will focus on: working conditions, accessibility, social relations, and finally self-determination and representations of femininity.

3.4.1. Working conditions

While we reviewed access to employment for the women surveyed at the beginning of the study, we are now interested in what working conditions are like for women with disabilities. For this purpose, in our study we analysed 3 variables that measure different aspects of work.

The women surveyed attach greater importance to working conditions than to their satisfaction with them. This discrepancy is most pronounced in terms of financial remuneration and relations with co-workers. We also found statistical differences between the importance of and satisfaction with the accessibility of spaces for respondents (Table 11).

Table 11. Descriptive statistics of labour aspects



	Importance			Satisfaction			
Variables	M	Mdn	DT	M	Mdn	DT	Dif.
Economic remuneration	4.33	5.00	0.87	3.08	3.00	1.28	***
Accessibility to spaces	3.98	4.00	1.20	3.49	4.00	1.17	***
Relationships with colleagues	4.55	5.00	0.67	3.96	4.00	1.07	***

Note. N = 181. All variables have a range of 1-5, except the “Importance of relationships with colleagues” which has a range of 2-5.
Difference test: rank test for paired samples. Bilateral significance. **p* <0.05; ***p* <0.01; ****p* <0.001.

3.4.2. Accessibility

Inclusion of women with disabilities can be achieved through various social measures. One of these measures is to create public services that are accessible to these people. In our study we analysed 3 variables measuring: accessibility of public places, accessibility of public transport and accessibility of social and health services.

In Table 12, we can see that the women surveyed attach greater importance to accessibility and social and health services than to their satisfaction with them.

Table 12. Descriptive statistics of accessibility and social and health services

	Importance			Satisfaction			
Variables	M	Mdn	DT	M	Mdn	DT	Dif.
Accessibility to public places (institutions and leisure)	4.39	5.00	1.00	3.26	3.00	1.22	***
Public transport accessibility	4.32	5.00	1.15	2.99	3.00	1.35	***
Social and health services	4.67	5.00	0.73	3.39	4.00	1.18	***

Note. All variables have a range of 1-5.
Difference test: rank test for paired samples. Bilateral significance. **p* <0.05; ***p* <0.01; ****p* <0.001.

In general terms, women with an intellectual disability have a higher level of satisfaction with accessibility and social and health services. The women least satisfied with public services have a visual impairment and multiple disabilities. Here it is worth noting that visually impaired women were the least satisfied with the accessibility of public transport (Figure 10).

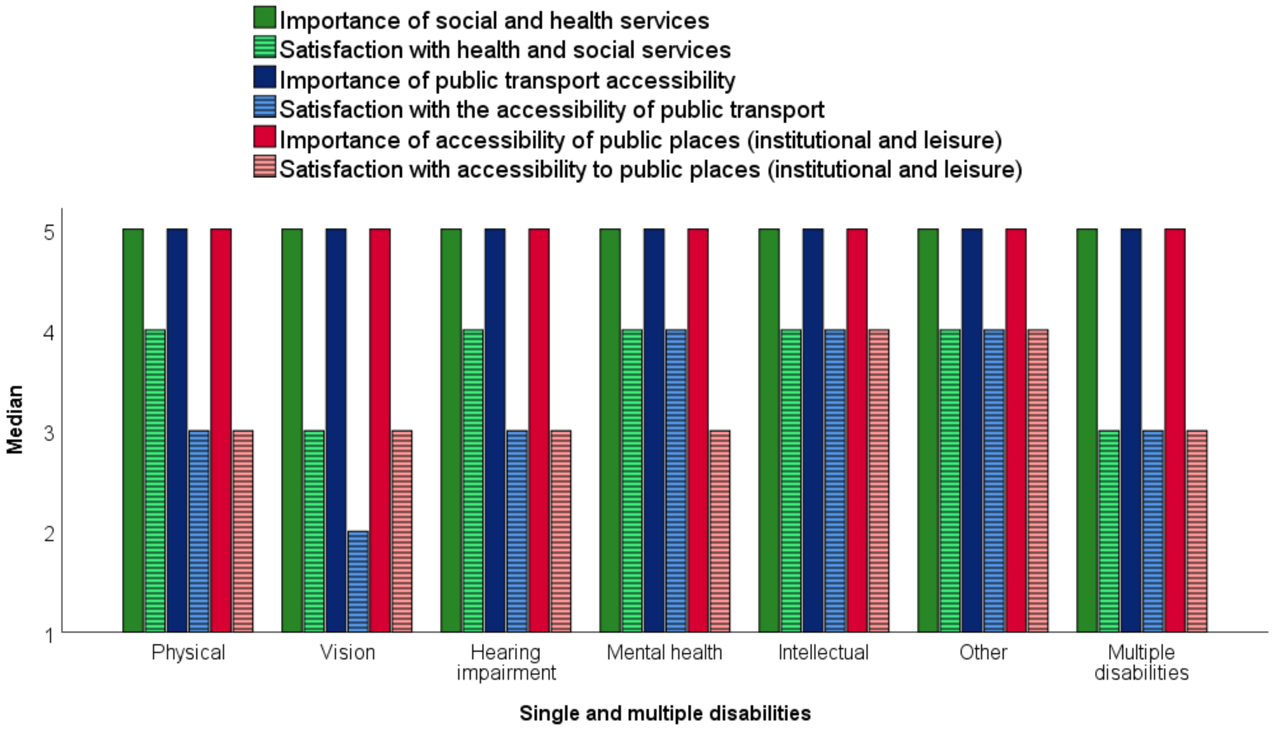


Figure 10. Accessibility and social and health services according to type of disability.

3.4.3. Social relationships

Social relations directly reduce the social exclusion of people with disabilities (Lepri, 2011). For this reason, in the study we asked the women surveyed about the interpersonal networks they have established or have managed to create throughout their lives as women with disabilities. In addition, we analysed 6 variables that represent different types of social relationships that can generate strong emotional ties.

Women with disabilities rate romantic, family and friendship relationships similarly in median terms (Median = 5 for importance; Median = 5 for satisfaction in all three cases). The rating decreases when we look at neighbourhood relations (Median = 4 for importance; Median = 4 for satisfaction). They are consistently less satisfied with their interpersonal relationships compared to the importance they attach to them. Notably, they are less satisfied with their sex life (Table 13). Of the respondents who answered the question on whether they are in an organization or association, 39.7% said yes. Although the degree of satisfaction with the association is lower than the importance of this institution for them, there is a direct relationship between the two variables. Generally, those who attach less importance to it are not very satisfied with being part of the association (Figure 11). On the other hand, the overall valuation of relationships in the association can be considered moderately high (Median = 4 for importance; Median = 4 for satisfaction) (Table 13).

Table 13. Descriptive statistics of social relationships

	Importance			Satisfaction			
Variables	M	Mdn	DT	M	Mdn	DT	Dif.
Family relationships	4.72	5.00	0.65	3.92	4.00	1.18	***
Friendship	4.53	5.00	0.80	3.76	4.00	1.18	***
Romantic relationships	4.39	5.00	1.06	3.34	4.00	1.51	***
Sex life	4.10	5.00	1.16	2.91	3.00	1.45	***
Neighbourhood relations	3.69	4.00	1.15	3.50	4.00	1.21	**
Participation in association	4.08	4.00	1.00	3.78	4.00	1.11	**

Note. All variables have a range of 1-5.
Difference test: rank test for paired samples. Bilateral significance. *p <0.05; **p <0.01; ***p <0.001.

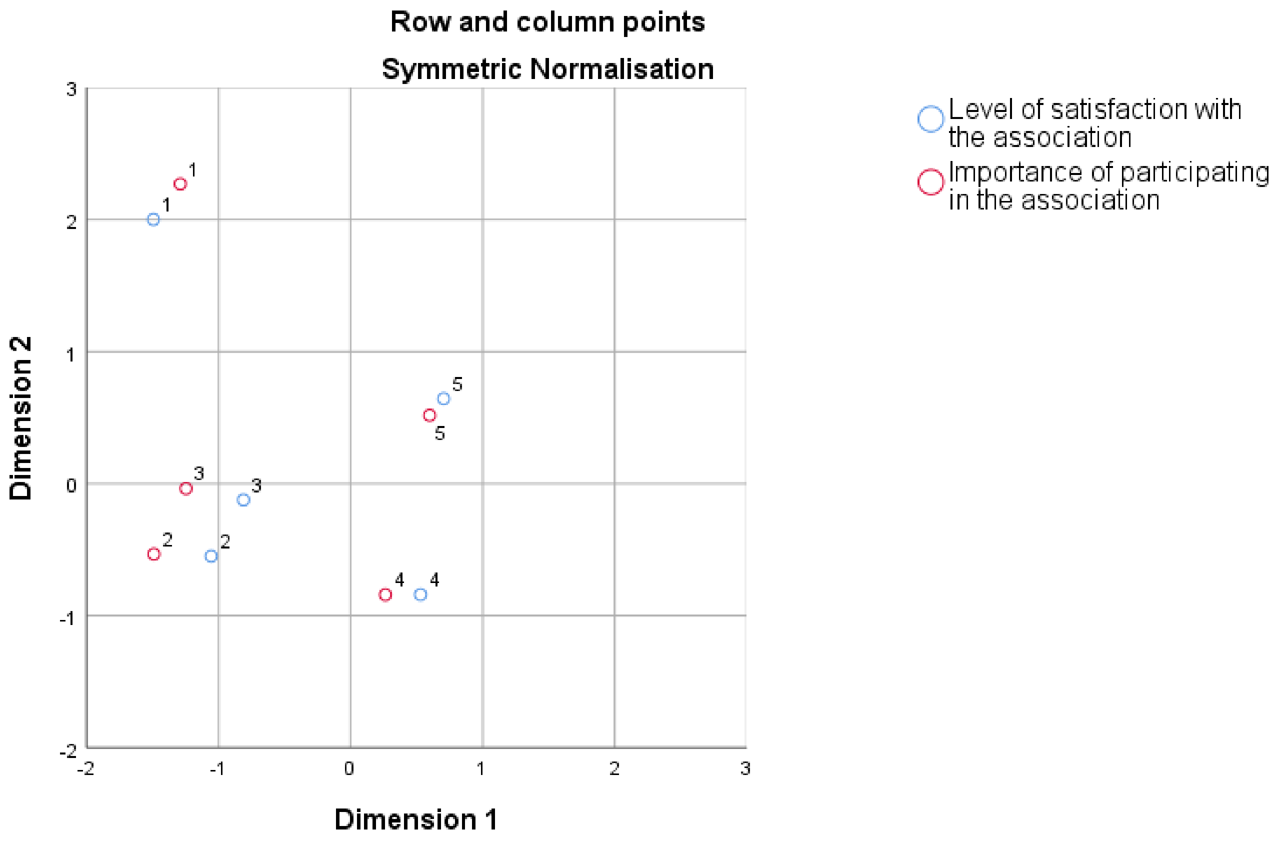


Figure 11. Relationship between importance and satisfaction with the association.

3.4.4. Self-determination and representations of femininity

The women surveyed were asked who has influenced aspects such as their self-image, their body image, their perception of their femininity, their ability to decide about their affective and sexual life, their desire to have a partner, their desire to have children, their choice of studies and/or work, their decisions about their autonomy and those related to their self-determination. The majority answer is ‘nobody’, except in their self-image, where they say that their family has had the most influence. It is interesting to note that a high proportion of women with disabilities shape their autonomy and self-determination by themselves (no one has influenced them: 60.2% and 64.5%, respectively). This may reflect a breakthrough in their role as protagonists in their own lives (Table 14).

Table 14. People who have influenced aspects of self-determination and femininity

	Influencers (N=332)					
Variables	No one	Family	Friends	Couples	Companions	Others
The image you have of yourself	28.4%	36.5%	14.7%	9.3%	2.7%	8.4%
Your corporeity	40.1%	23.2%	11.1%	14.2%	2.4%	9.0%
Perception related to your femininity	43.1%	17.2%	10.2%	20.8%	1.2%	7.5%
Choices related to your emotional and sexual life	50.5%	12.0%	6.3%	25.2%	1.8%	4.2%
The desire to have a partner	73.6%	8.7%	6.9%	6.3%	0.3%	4.2%
The desire to have sons or daughters	71.2%	10.8%	0.9%	12.3%	0.0%	4.8%
The choices of your study or profession	64.0%	22.8%	3.3%	3.0%	1.2%	5.7%
Choices for your autonomy	60.2%	28.0%	2.7%	4.5%	0.9%	3.6%
Choices for your self-determination	64.5%	22.7%	3.9%	3.9%	0.3%	4.5%

Finally, if we analyse the variables related to independent living, self-determination and representations of femininity, in general we can say that the women with disabilities surveyed attach much more importance to self-determination, autonomy and being able to choose their profession or studies (Median = 5, in all three cases). They also attach greater importance to their self-image (Median = 5). As mentioned above, this highlights the desire of women with disabilities to have the ability to freely choose fundamental aspects of their lives. On the other hand, they attach greater importance to the body, their self-perception of femininity, choices related to their emotional and sexual life than to their desire to have children and to be with a partner or partners (Figure 12).

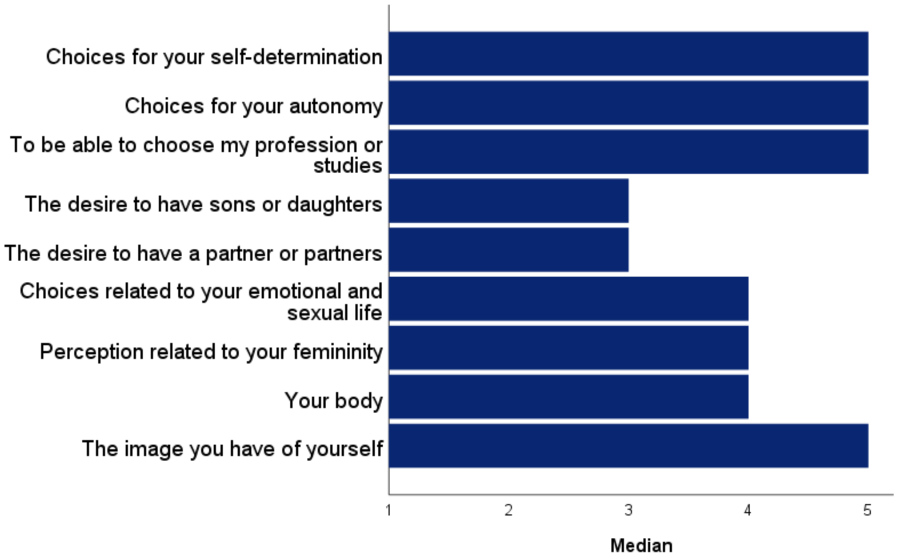


Figure 12. Importance of the variables of self-determination and representations of femininity.

4. Conclusions

Having provided this complex picture of the phenomenon under study, it remains to focus on the main elements of the phenomenon, in an attempt to provide interpretative frameworks, suggestions for further studies and guidelines for European policies in this area.

The study had four main objectives: firstly, to describe the problem in order to address the lack of quantitative studies in this field; secondly, to understand whether there are differences according to the type of disability; thirdly, to determine participants' levels of awareness and empowerment; and finally, to understand the degree and types of discrimination and violence to which women with disabilities are subjected.

The main socio-demographic elements studied include those relating to educational level, home and family nucleus and work.

As far as training and education are concerned, the women involved in our study have a relatively high level of education (high school or vocational training and university education are the most frequent levels). The importance of this data is evident, since — as mentioned in the introduction — education and professional training are fundamental elements both for the construction of a view of the world and its relationships and for a definition of one's own identity, in short, for the affirmation of their autonomy, independence and empowerment.

With regard to the elements related with the home and family nucleus, it is interesting to point out that most of the women live with the family nucleus they have established, while a good number live alone, thus indicating the strong proactivity of women with disabilities, contrary to a collective perception that sees them as incapable of being autonomous and independent. The marginal data on sheltered residences or apartments can be interpreted in the same way.

On the other hand, when women without children are asked about the influence of their disability on their decision to have them, 44% say that their condition has prevented them from doing so. Given that society seems to consider that women with disabilities would not be able to adequately care for their children, this prejudice is internalised by some of them and ends up discouraging them, despite the fact that 33% of the total number of women surveyed claim to have children.

In the employment sphere, we are faced with a complexity at the interpretative level as a result of the sociodemographic data. In some respects, these data seem to speak of a generally positive situation for women with disabilities. For example, approximately one-third of them are currently employed and only one fifth of these are not employed full time. In addition, the way of accessing the job was mostly autonomous, i.e. by sending a CV. Finally, relationships with co-workers is the variable to which they attach most importance and with which they are most satisfied.

> In the work environment, people with disabilities are not merely numbers to qualify for subsidies or to avoid fines for not complying with the LISMI[10]. They are people who want to develop professionally, who want decent pay, who do not want to feel watched, used or discriminated against in their working environment (ID: 323).

As this participant reports, not all employment-related issues are associated with positive aspects, highlighting the limits of state, labour and social organisation. In fact, as far as working conditions are concerned, the women surveyed are less satisfied with the aspects of work (which include financial remuneration, working hours, accessibility, relations with colleagues and facilities) compared to the importance they attach to them. More than half of the employed women reported that they had not been hired through the statutory quotas for people with disabilities[11], and only a quarter of the employed women had found work through associations and foundations for people with disabilities or through a special employment centre. Similarly, data on the qualifications of the women with disabilities show that almost half of the employed women say that their work does not correspond, or only partially corresponds, to their qualifications. In particular, we observe — in line with what generally happens with precarious workers, especially if they are highly educated and overqualified — that the highest proportion of women whose qualifications do not correspond to the work they are doing is found among women working part-time. In addition, companies' involvement in making workplace accommodations is low. One fifth of the sample is not at all or only partially satisfied with the accommodations made.

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[10] Law 13/1982 of 7 April 1982 on the Social Integration of the Disabled. Today, General Disability Law.

[11] In Spain under art. 59.1 of Law 7/2007, in Italy under art. 3 of Law 68/1999.

However, despite having a job, when analysing the discourse of the women surveyed, they tell us about the economic difficulties they face, either because of the high cost of care they have to face due to their disability or because of the few guarantees that their job offers them, with very low salaries and sometimes lower than those of their colleagues without disabilities. In general, the barriers and difficulties they encounter in the workplace are more related to the environment and its lack of accessibility than to their condition and capabilities. On the other hand, the accommodations requested by the women surveyed are mostly affordable and simply require a better understanding of individual needs and abilities. Employment is the tool through which people are given the economic independence to be able to make decisions freely. This requires a change in the way the company looks at disability. It is important for human resources managers to be cross-skilled and to take into consideration the value that diversity brings to the company. Moreover, the employability situation of women with disabilities may have improved over the last decades, but — as underlined in the European Parliament resolution of 10 March 2021 — it seems that there is still a long way to go. Indeed, labour inclusion is also one of the avenues for social inclusion and empowerment of women with disabilities (Scudieri *et al.*, 2019), and a principle that should guide public policies.

In terms of interpersonal relationships — emotional, sexual, family, friendship, work or neighbourhood — women place a high value on both their importance and their satisfaction. Here again, there is a significant difference between the levels of importance and satisfaction expressed by the respondents. In particular, the relationships most valued by the women surveyed are family, friend and romantic relationships, while the least important are neighbourhood relationships. Moreover, among all the relationships studied, the difference between importance and satisfaction is most pronounced in the sex life of women with disabilities. This is in line with what has been discussed in the literature.

With regard to accessibility, in our results we found that the importance attached to appropriate accessibility and quality of public services (such as accessibility to transport, public places, health and social services) is where we found one of the largest discrepancies between the degree of importance and satisfaction. Depending on the type of disability, the women who attach most importance to accessibility in public services and who are least satisfied with them are those with visual impairment and multiple disabilities. The low satisfaction of some of the participants sheds light on how far there is still to go in terms of accessibility and quality of public services for women with disabilities.

One of the main goals of our research was to study how and to what extent the phenomenon of discrimination affects women with disabilities, both discrimination that is recognised and punishable by law and discrimination that is more invisible. On this point, it should be noted that, although the questionnaire was not designed to study discrimination specifically, it does appear — as seen in the case of work — in a cross-cutting manner in the different areas of their daily lives. In fact, if we use a broad concept of discrimination — that is, any action or omission that causes unequal treatment of a group of people precisely because they belong to that particular social group — it is easy to discern suffering caused by society's dominant ableist paradigm (Medeghini & Valtellina, 2006) in the responses and words of the respondents («I want to be treated normally, to stop being treated as if I were a useless person. We have our needs but they shouldn't treat us like we can't do anything» ID: 209). This paradigm, making the independent, autonomous, productive and fully able-bodied individual the reference archetype upon which to base policies and regulations, has cemented the idea that people with disabilities are necessarily dependent, non-autonomous and unproductive, contributing to their symbolic, structural, cultural, economic, social and legal exclusion, thus justifying marginalisation, paternalism and discrimination. Considering this theoretical construction, we can say that there are other barriers (physical, cultural, communicative, etc.) behind the low satisfaction of some interviewees with different aspects of life created by relationships, spaces and services aimed at satisfying only the needs of people deemed to be able-bodied, and excluding people with disabilities.

Specifically, in the analysis we have seen how women with disabilities are affected by double discrimination. In fact, most of the interviewees feel discriminated against because of their intersecting status as women and as people with disabilities. Yet, despite the undoubted dominance of sexist and ableist cultural assumptions, there are also spaces in which forms of discrimination intersect with new aspects. Discrimination based on asymmetrical power relations in the areas of work and education can also be seen in the open-ended responses.

In addition, the women surveyed expressed that discriminatory situations such as overprotection, paternalism or invisibilisation affect or hinder their desire for autonomy as well as their social recognition. They also say that they regret that they are not listened to, both in terms of what they can contribute to and on issues that affect them directly. Sadly, almost one fifth of the women interviewed reported having suffered ill-treatment in the form of sexual abuse, repeatedly and by people close to them. In addition, some participants noted that it is difficult to talk about abuse within the family context. Even without knowing the cases in depth, this difficulty may be due — in line with the literature on the subject (Romito, 2008) — to a fear of not being believed, or an attempt to not to remember the traumatic experience or not to be victimised again. On the other hand, although the empirical evidence from other studies is stronger (Peláez Narváez *et al*. 2009; Carnovali 2018), our study shows that 5% of the women surveyed reported having experienced obstetric violence.

In terms of the association between types of disability and discrimination, we found that women with mental health problems have experienced the most discrimination. The discrimination these women suffer most is invisibilisation, psychological or emotional abuse and labour exploitation.

It is also helpful to briefly mention the most frequent places where discrimination has taken place. These, arranged in descending order, are work, family and institutions, i.e. the typical spaces where class, status, gender and (in this case) ability discrimination intersect. On the other hand, we have been able to observe how new forms of discrimination against women with disabilities (such as hate speech, cyber-bullying and body shaming) are appearing through digital media.

As mentioned above, one of the aims of this paper is to reflect on the empowerment desired and achieved by women with disabilities. In terms of the use of this concept — which is definable as a process through which individuals, organisations and communities gain greater control over life issues (Rappaport, 1987) — it is especially beneficial for studying both women and people with disabilities. As can be deduced from its definition, empowerment is a two-sided notion, i.e. it relates to individuals and to society. It is also a multi-level concept, as individuals and societies are engaged from different points of view. This means that, whether it refers to the individual or to society, empowerment, in some aspects, has a clearly personal value, linked to strengthening the individual's capabilities, competences, autonomy, independence and knowledge, and in others it has a public dimension linked to the acquisition of status and social power. However, the dynamic process of empowerment of women with disabilities is of great scientific interest, because only by promoting this aspect will it be possible to ensure their participation in all spheres of life and to tackle discrimination against them.

As we have seen with regard to training, housing, work and interpersonal relations, the issue of empowerment is addressed in the open-ended responses. However, where it appears most frequently is in the areas of autonomy, independent living and representations of femininity.

There are still women who express low satisfaction with autonomy and independence. For the women surveyed, it is important to have the ability to freely choose fundamental aspects of their lives (studies, profession, leisure management) as well as to define, without perceived influence, what their autonomy or self-determination should be like. Indeed, at least six out of ten of the women surveyed stated that no one has influenced them in their autonomy and self-determination choices.

As for the complex and controversial issue of representations of femininity, the responses are very striking. Indeed, here too, women generally attach a very high importance to the body, to their self-perception of femininity, to the choices related to their emotional and sexual life, and a medium importance to their desire to have children and to be in a couple or a couple. In other words, a person who is not resigned to the image of a subaltern representation of femininity, as can be appreciated by the fact that the participants give more importance to the corporal and individual dimension than to maternity and sentimental life. In addition, a high proportion of the women with disabilities define their autonomy and self-determination by themselves.

However, precisely because it is one of the ways to ensure the empowerment of women with disabilities (Morris, 1991), it is through the voices of the women interviewed, who willingly take the floor in the open-ended responses, that the most significant insights in this regard are obtained. From the analysis of these responses, despite the fact that in some cases there are women who seem discouraged and not very confident about the possibilities for change («Nothing can be done, the problem is that society does not see us as equals, they are scared of the unknown and react like this» ID:2130), it can be seen that the majority of these women, with strength and awareness, reach high levels of criticism and radicalism, in some cases connecting, in a clearly intersectional way, issues related to gender, class, race, and the way society and individuals are («legalised exclusion, negrophobia, xenophobia and racism [...] are entrenched and from all angles» ID:783).

In terms of the needs and determining factors that would promote a better quality of life, we have heard the voices of the participants who suggest ways of guaranteeing their effective participation in society, which in turn are key to their empowerment. One of the most frequently mentioned factors is economic autonomy. More and better job opportunities and sufficient pay are a guarantee of this economic independence in many cases. Of course, this must include flexible working hours, which can often mean a reduction in working hours, as well as reconciliation of work and family life or possible serious health problems («They must take into account the reconciliation of our work and family life» ID:149).

On the other hand, authorities should carry out an adequate assessment of disability, as well as the timing and amounts of the subsidies that provide people with disabilities with a certain degree of security and stability. Economic autonomy ensures that women with disabilities can develop a life plan of their own, and therefore emancipate themselves from the decisions that are often imposed on them by family members, health personnel or the administration itself.

In the discourse concerning their personal relationships, the respondents repeatedly mention the need to avoid unwanted loneliness in order to achieve subjective well-being («Company or activity to ease my loneliness» ID:387), as well as the wish to have more relationships between able-bodied people and people with disabilities. By having more contact, this would promote normalisation and therefore inclusion, as well as the necessary awareness of the general population («More awareness on the part of society»[12] ID:1198), as well as knowledge of disability and of issues that can facilitate communication and interaction. The need for greater understanding and empathy from the general population is also mentioned, as well as a greater emphasis on care, with strong and resilient neighbourhood support networks or neighbourhood communities («Mutually supportive relationships» ID: 412).

Love and respect from the people closest to oneself can be fundamental for self-esteem, which is also mentioned as one of the indicators for a better quality of life. This respect must always guarantee the physical and moral autonomy of the person, i.e. his or her ability to autonomously carry out whatever actions he or she can and to make his or her own decisions at all times («to be the master of my own decisions and choices» ID:1861). However, we have also

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[12] Translator's note: translated from the original in Italian into English.

seen how attempts by various actors during the course of their lives to increase their autonomy are rarely achieved, as many of them demonstrate their empowerment and autonomy by living in private flats, with relatives or on their own, as well as having a job and, most importantly, by their own accounts, which highlight self-sufficiency and independence as values that have helped these women to have a better quality of life.

As we have seen throughout the study, there are many factors that can contribute to greater inclusion of women with disabilities in all areas. In many of the situations analysed, cultural and environmental issues have a strong influence on the inclusion status of these women. On the other hand, our exploration reveals the figure of a woman who not only knows exactly what she wants, but also knows the ways and means to achieve it. In addition, some of the women who participated in the study try to break free from dominant representations of gender and disability by combating the stigma attached to these representations. Considering that one of the main assumptions of the empowerment approach is that marginalised individuals have experience in overcoming discriminatory factors, we can state that the women involved in the study are empowered.

Finally, considering the levels of satisfaction that the women feel with each aspect studied and the fact that the concept of empowerment envisages the involvement of both the individual and society, it seems that it is precisely the latter that does not live up to the expectations of women with disabilities. Despite the progress made, especially in the legal and institutional sphere, more needs to be done at all levels to ensure the inclusion and non-discrimination of women with disabilities.

5. Limitations

The work presented here is a pilot study within the framework of the RISEWISE project. For this reason, future research will expand and improve the qualitative and quantitative techniques used to study the social barriers of women with disabilities.

As this is a preliminary study, it is necessary to highlight the existence of several limitations ranging from representativeness to response rate. The limitations that we can highlight are:

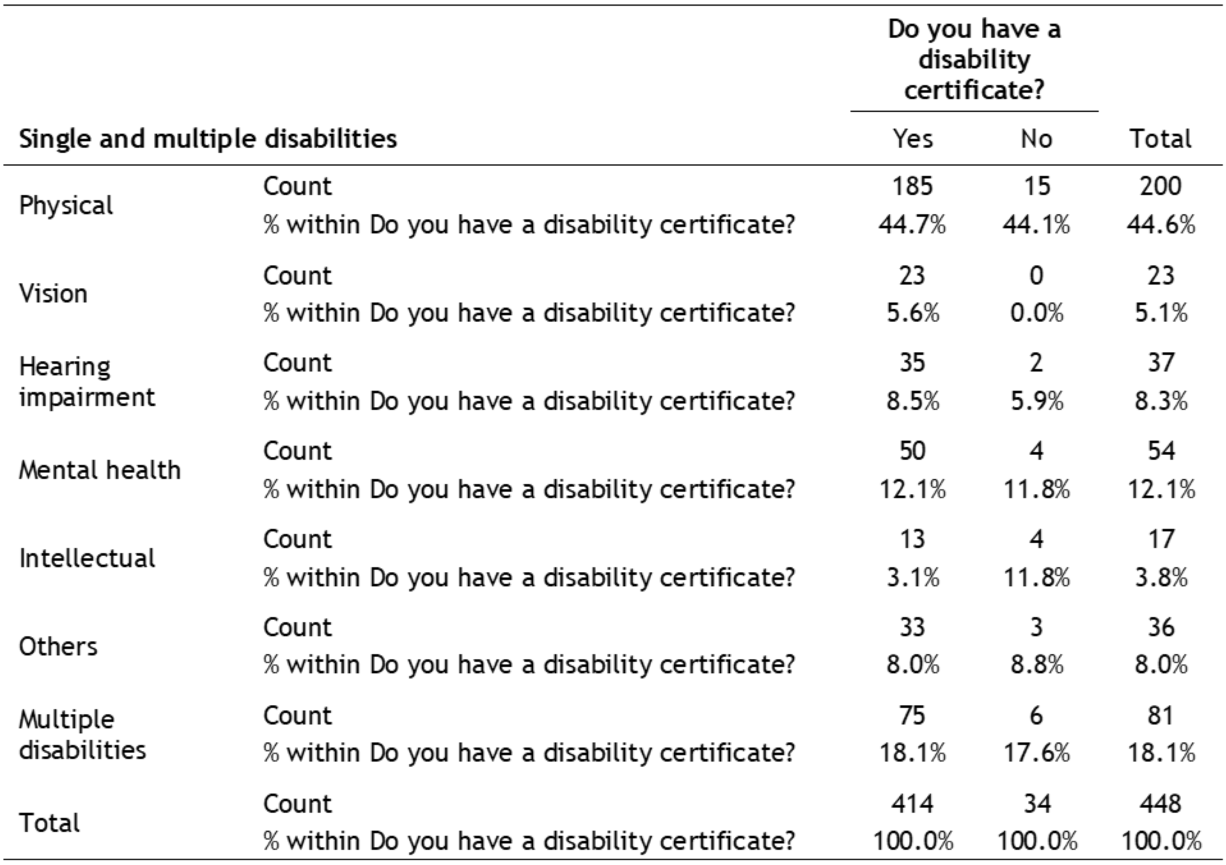
1. For some variables, the sample size was reduced because some of the respondents did not answer all the questions.
2. Related to the previous point, there was a high non-response rate across several questions. The valid size (n) was used in some results. Therefore, some results may not reflect the underlying distribution of some variables and may over/under-represent some proportions.
3. Most of the women surveyed have at least high school or vocational training (90.9%; 43.8% of them have high school or vocational training and 47.1% have university education). Therefore, results may be biased by the selection of the sample. It should be recalled that

the surveys were distributed, in part, in university settings. In any case, the results obtained in our study would not be representative of the population of women with disabilities.

4. The two-dimensional analysis was carried out with a new variable that measures whether a person has a single disability, and what type of disability, or whether he or she has several functional diversities. This reduced the maximum sample for analysis to 449 women with a valid response, whereas the use of the original variables would have provided a maximum sample of 462 women. However, the latter option would have required us to carry out the two-dimensional analysis with each of the functional diversities separately.
5. For the variable ‘Country’, missing values were imputed through the use of other variables in the questionnaire, their description in the study being purely indicative.
6. The sample includes a group of women who do not have an official disability certificate. There were 34 out of 520 (6.5%) women without an official certificate.

The relationship between disability and official certificate is presented in the table below:

Table L1. Relationship between «Single and multiple disabilities» and «Do you have a disability certificate?»



		Do you have a disability certificate?		
Single and multiple disabilities		Yes	No	Total
Physical	Count	185	15	200
	% within Do you have a disability certificate?	44.7%	44.1%	44.6%
Vision	Count	23	0	23
	% within Do you have a disability certificate?	5.6%	0.0%	5.1%
Hearing impairment	Count	35	2	37
	% within Do you have a disability certificate?	8.5%	5.9%	8.3%
Mental health	Count	50	4	54
	% within Do you have a disability certificate?	12.1%	11.8%	12.1%
Intellectual	Count	13	4	17
	% within Do you have a disability certificate?	3.1%	11.8%	3.8%
Others	Count	33	3	36
	% within Do you have a disability certificate?	8.0%	8.8%	8.0%
Multiple disabilities	Count	75	6	81
	% within Do you have a disability certificate?	18.1%	17.6%	18.1%
Total	Count	414	34	448
	% within Do you have a disability certificate?	100.0%	100.0%	100.0%

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Women's voices: empowerment, recognition and multidisciplinary work to prevent and tackle discrimination and violence against women with disabilities. The experience in Bologna

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Keywords: violence, discrimination, empowerment, women with disabilities

1. Introduction. Nothing about us without us[2]

Women with disabilities — Which gender identity? The premise from which we must start when talking about women with disabilities is what Simona Lancioni states in the preface to the Italian version of the *2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union*[3]: «Among people with disabilities, there is no habit of reflecting on the various aspects of life in terms of gender (it is as if the disability overwhelms and covers all the other characteristics of the person); nor is there the foresight, among women who grapple with gender issues (women and feminist movements), to cross this variable with that of disability».

It is precisely this assumption that has to be the departure point for reflection on the discrimination that women with disabilities face in being included in issues concerning gender, and even more so when it comes to gender violence. The constant denial of gender issues when talking about women with disabilities is a factor that gives concrete substance to multiple — or *intersectional*, to adopt K. Crenshaw's definition (Crenshaw, 1989) — and doubly dangerous discrimination, which is subtle and invisible due to the systematic lack of a gender-specific vision of disability.

Very often, political, social and cultural contexts at all levels disregard or even deny a gender perspective involving women with disabilities; and these entities include the very same movements that defend women's rights or those of people with disabilities.

Girls with disabilities — future women — are those who literally face the fallout of this specific denial on their own skin, primarily regarding the sphere of 'care' that starts from the body, from primary relationships, from the social context and from rehabilitation and education interventions that the presence of a disability entails. The result is a silent withdrawal when it comes to planning a future life: this process affects identity, as well as the choices for and the

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[2] For further details, refer to J.I. Charlton, 1998.

[3] 2nd Manifesto on the Rights of Women and Girls with Disabilities in the European Union. A toolkit for activists and policymakers, EDF, 2011.

opportunities of a conceivable future in terms of pleasure and fulfilment, and can turn into a permanent wound.

Only by giving voice to women with disabilities can the various expressions of these hidden wounds — that undermine a woman's most intimate image of herself and being part of the world — come to the surface and be recognised.

The determination to make these 'mute' aspects of the gender dimension in disability explicit brings out the violent facets that accompany the growth of girls with disabilities and enables the transformation of these denied and inhibited aspects.

Starting from reflection on the multiple discrimination that girls and women with disabilities face and its related challenges, the following sections describe our research within the framework of the RISEWISE[4] project and look more closely at aspects related to violence and discrimination, offering possible strategies to overcome these.

2. From RISEWISE to Voci di Donne ('Women's Voices')

To bring to light the existence of discrimination against women with disabilities, to raise awareness, to impact on local and national policies and, lastly, to respond to the challenges raised by the RISEWISE project, AIAS Bologna Onlus implemented, with support from the local bank foundation Fondazione del Monte, the project «Women's Voices».

The core to the project was the direct involvement of women with disabilities in the project activities. A working group of 7 women with disabilities was established to drive the project and, supported by AIAS staff, they featured both as 'investigators' and 'subject' of the research. Their motivation and participation were, as in the case of other women with disabilities, remarkable and demonstrated their need to express themselves, their feelings, their difficulties and their opinions on several issues often left outside mainstream research.

The United Nations has highlighted the lack of disaggregated data to enable a better understanding of the situation of girls and women with disabilities and to inform policies for their effective inclusion, the full realisation of their human rights and the need to translate the global policy within national contexts so as to reduce the inequalities that girls and women with disabilities face in society (UN Statistical Commission, 2019). To respond to this call for data, the first task addressed was construction of a questionnaire for analysis of the barriers women with disabilities face in everyday life. The barriers are not only those in physical and digital environments, which have been much discussed and addressed at national and European level through policies and projects aiming to improve the accessibility of public buildings, workplaces, digital spaces, and so on. To conduct full analysis of the challenges that people with disabilities,

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[4] *Risewise project – RISE Women with disabilities In Social Engagement*. Ref. Grant Agreement No. 690874 - H2020- MSCA-RISE-2015.

and particularly women with disabilities, are forced to face in everyday life, the less obvious barriers also need to be addressed. Thus the main feature of the questionnaire became its focus on discrimination, abuse, social relationships and sexuality.

As a result, 52 questionnaires were collected, filled out by women with disabilities from 13 different regions in Italy[5]. The main issue investigated by the questionnaire was whether women with disabilities feel discriminated against in some way or another. The results showed that 69% of the respondents stated they felt discriminated against as *persons with disabilities*. The causes reported were not just *architectural barriers*, but also *people's attitudes*: «Sometimes I feel looked at in a belittling way», «I'm not properly considered», «There's bullying at school», «I have difficulties in finding and keeping a job», «People who don't know me take a while to understand that apart from the wheelchair there is also a brain», were some of the reasons described.

Furthermore, 54% of the sample said they felt discriminated against as *women with disabilities,* especially in *access to health services* (e.g. «Difficulty in accessing appointments and diagnostic tests for cancer prevention»), in different *social contexts* (e.g. some reported not being taken into consideration or feeling psychologically humiliated, or being repeatedly marginalised), and in *personal relationships* (e.g. «Yes, they often tell me I'm a good friend and listener, but when it comes to going further, the man in question is frightened by my disability», «Yes, men prefer women without physical problems», «Women with disabilities are not considered sexually attractive or seen as future mothers or wives»).

Violence and maltreatment are closely connected with discrimination. Evidence illustrates that women with disabilities are more exposed to the risk of violence and abuse than other women, and although they are subject to particular forms of violence, women with disabilities are unlikely to be considered in the study of this occurrence. Maltreatment is in fact a critical topic that must be faced when talking about disability rights. There are however some open questions, such as: «What can be considered maltreatment?"; «What are its main causes?"; «How can it be prevented?". For the scope of the questionnaire, different categories of maltreatment were identified.

Considering the statistically small number of respondents (52 women), the data gathered in the research was remarkable. The form of violence documented most frequently among the responses was «psychological or emotional mistreatment», reported by 40.4% of the sample; 26.9% reported «violation of privacy», 23.1% «negligence», and the same percentage experienced «excesses in care». Some women also stated they had been victims of «exploitation» (15.4%), «financial abuse» (13.5%), «physical abuse» (11.5%), «sexual abuse»

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[5] The complete analysis and its analytical data can be found here (Italian version): https://www.aiasbo.it/PDF/voci-di- donne_Report_definitivo.pdf

(7.7%), or «drug abuse» (5.8%). The family environment turned out to be the place where women with disabilities were most exposed to the risk of violence, according to 32.7% of the sample.

Data was not only collected through the questionnaire: to give as much voice as possible to women with disabilities, face-to-face interviews were held, and freely composed writing and narratives were collected. Women with disabilities were asked to express themselves and to tell their stories, experiences and feelings.

What the working group aimed to achieve was a shared and participated pathway towards greater freedom. The women were therefore asked to propose actions, solutions and considerations. Some of the identified possible pathways for inclusion were:

- construction of a more stable, innovative and original *network with female and cultural movements*;
- *training of professionals* involved in every area of the disability condition, with a gender perspective, also employing in these paths women with disabilities who may have specific professional skills in this regard, for a reversal of perspective;
- construction of *peer networks of women with different disabilities* who work on self-image, rights, awareness of abuse or violence, and the ability to defend oneself and ask for help;
- in-depth work on cultural change, with *seminars and thematic workshops on gender identity and independence* proposed to the entities that work with people with disabilities, the social- rehabilitation structures and the sector associations;
- *improvement of accessibility of health services,* also in connection with gender medicine;
- *improvement of accessibility of places for protection of those who suffer violence*, not only of a sexual nature;
- *identification of new models of housing*, cohabitation and possible autonomies, also taking existing realities in other European countries as a starting point;
- *construction of housing contexts that favour the life choices of girls with disabilities* and outside the frequent family dynamics of overprotection and/or denial of the relational/affective/sexual dimension, with particular attention to defending aspects related to abuse and violence prevention, contraception and possible parenting;
- *identification of work-skills models* that foster economic independence and personal and career choices by women with disabilities.

3. Violence against women with disabilities

One of the topics that noticeably came to light through the questionnaire in the «Women's Voices» project was discrimination and violence. The topic of violence against women is now, fortunately, a much discussed issue and catches everyone's attention. This is not to be taken for granted if we consider that the first legally binding international instrument to tackle violence against women — the Council of Europe Convention on preventing and combatting violence against women and domestic violence, known as «the Istanbul Convention» — was only drawn up in 2011, and came into force in August 2014, with the European Union signing it only in 2017.

The UN Convention on the Rights of Persons with Disabilities (CRPD) recognises that women and girls with disabilities are subject to multiple discrimination (art.6) and invites its States Parties to take all appropriate measures to prevent all forms of exploitation, violence and abuse, by ensuring appropriate forms of gender and age-sensitive assistance and support for persons with disabilities, their families and caregivers, including through the provision of information and education on how to avoid, recognise and report instances of exploitation, violence and abuse (art.16).

A recent resolution by the EU Parliament[6] on the situation of women with disabilities invites States Parties to provide adequate training to health and education professionals for the prevention of discrimination and violence against girls and women with disabilities (art.43). The EU Parliament resolution also expresses concerns about the fact that women and girls with disabilities are more likely to become victims of gender-based violence, in particular domestic violence and sexual exploitation. Furthermore, women with disabilities are more likely to experience domestic violence, emotional abuse or sexual assault than women without disabilities (Ortoleva & Lewis, 2012), because of their condition. They may also feel more isolated and feel they are unable to report the abuse, or they may be dependent on the abuser for their care. Indeed, like many women who are abused, women with disabilities are usually abused by someone they know, such as a partner or family member (Barrett, O'Day, Roche & Carlson, 2009).

The resolution also insists that «gender-disaggregated data must be collected in order to identify the forms of intersectional multiple discrimination that are faced by women and girls with disabilities, in all areas covered by the Istanbul Convention and wherever relevant» (art.8).

In Italy, the latest report edited by the national institute of statistics, ISTAT, was published in 2014. It states that 6,788,000 women in Italy are victims of some form of physical or sexual violence in their lifetime (31.5% of the women between 16 and 70 years old). Among these, the situation of women with disabilities or those with health problems is critical: 36.7% of those with chronic diseases or long-standing health problems have suffered physical or sexual violence; 36.6% of those with serious limitations in activities; and 36.2% of those with minor limitations (compared to about 30% of those who have no health problems or functional limitations). In particular, the risk of suffering rape or attempted rape is more than double for women with severe limitations: 10.0% versus 4.7% for women without limitations or health problems. Psychological violence by the current or past partner also has higher values among women with health problems or functional limitations. Referring only to the current partner, 31.4% of women

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[6] Resolution of the European Parliament on the situation of women with disabilities, 29th November 2018 [2018/685(RSP)].

with disabilities suffer psychological violence versus 25.0% of women who have no limitations. The risk also increases in the case of stalking. 21.6% of women with severe functional limitations, 19.3% of those with minor limitations and 18.4% of those with chronic illnesses or health problems suffered persecution during or after separation from their long-term partner (compared to about 14% of those who have no limitations or health problems).

This data is nevertheless limited and requires integration through further analysis. An attempt was made with our «Women's Voices»[7] project (2018) and by FISH[8] at a broader national level in 2019, with the Vera (Violence Emergence, Recognition and Awareness) project[9]. Different aspects related to violence against women with disabilities that were not covered by other research and regarding which no previous data had been collected were investigated.

The data that emerged is worrying and confirms the need to take action at various levels: according to the Vera research, 65% of differently abled women have suffered some form of violence, although only a third recognise it as such. The most common types are insults, physical aggression and unwanted sexual advances. In 80% of the cases, the perpetrator was a known person: often a family member, and not necessarily a man. Only 37% of the women stated that they had put up resistance to the violence.

As a result of those studies, we know that women are more often blackmailed since they live in problematic structural conditions more often than men — i.e. they have less power in society. This is equally and perhaps even more true for women with disabilities: they are more frequently ignored because they live in problematic structural conditions and are victims of multiple factors of discrimination.

Gender-based violence in the context of women without disabilities refers to the violence perpetrated by a man against a woman. But in the case of disability, gender-based violence can also be expressed as violence carried out by female figures and more generally by people who carry out a support role, care for women with disabilities, or cohabit as family members. It is more difficult for a woman with disabilities to report this, especially when the violence is inflicted by the person taking care of her, and on whom her own survival depends. There is the fear of being alone, and helpless. In many cases, it is the differently abled woman herself who does not recognise the violence or discrimination as such.

Getting out of a 'family pattern' often means betraying a silent pact, an agreement in which everyone plays a specific role that must not be changed. This is even more true if it involves a woman with a disability who tries to get out of a role of dependency or submission. Those who

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[7] The project Voci di Donne – «Women's Voices»– was conducted by AIAS Bologna Onlus and co-financed by Fondazione del Monte, 2018.

[8] The federation represents the most representative organisations at the national level and intervenes to guarantee non-discrimination and equal opportunities for people with disabilities in every area of life.

[9] A project conducted by FISH in conjunction with Differenza Donna Onlus, 2019.

try to rebel are attacked, called to heel, debased. And if she does not ‘mend her ways’, she is punished and pushed out, making her believe that ‘outside’ she will never find anything better or different. But it is precisely from here that the courage to listen to oneself can stem and transform a fear of condemnation to loneliness into a force that creates new bonds.

4. An innovative centre for support to women with disabilities: the experience in Bologna

The *European Group of Experts on Action against Violence against Women and Domestic Violence* (GREVIO), in its evaluation report of the measures put in place by Italy to implement the Istanbul Convention and published on 13 January 2020, highlighted how concrete and targeted policies and actions are needed to protect women with disabilities from all forms of violence and multiple discrimination at a national level. It also pointed out: 1) the need to develop targeted campaigns, actions and information tools accessible to potential victims of gender-based violence and multiple discrimination; 2) the need to train the general services staff to better identify violence suffered by women with disabilities, assist victims and direct them to appropriate services; 3) the need to improve the accessibility of protection and support services for women with disabilities who are victims of violence, taking into account their specific needs.

In line with the GREVIO recommendations, continuing the work AIAS Bologna has been carrying out for over 20 years and within the framework of the RISEWISE project, a collaboration project encompassing various aspects of differently abled women’s lives started in Bologna in 2020. The project aimed to overcome the ‘watertight compartments’ way of working by the various single services, while the only feasible approach for combatting discrimination and violence was to consider an individual woman in her wholeness and specific identity.

The gap between the actual number of incidences of violence and the number of women who decided to report it and started a pathway out of it is huge. There are many reasons for this, among which the tendency to question the credibility of victims with disabilities, especially when the disability is cognitive, exposing the victims to further violence and inadequate or even inapplicable guidelines and caregiving pathways by the anti-violence centres.

To counter this gap, active collaboration between AIAS Bologna and an anti-violence centre in town has started, with the result that an accessible support centre has been opened. By merging the two organisations’ competences, a place can now be accessed by any woman with disability who may need to do so. The challenge posed was a large one: the classic model of risk assessment and responding services for women suffering discrimination and violence had to incorporate several variables, including disability; shared practices respecting a woman’s privacy, integrity and personal story — for instance, the need for support in communication, such as an ISL interpreter — had to be established; new pathways had to be found to overcome some customary procedures at the anti-violence centre and to increase awareness among the support services so that there were adequate tools, training and places to enable support that takes into account the woman's whole living environment and any significant figures connected with her. The teamwork between the two entities turned out to be a key factor in ensuring a multidisciplinary and flexible response that considers the entire ecosystem of relationships around women.

Two of the first steps in the collaboration were mutual training to share knowledge between the two organisations, and the involvement of external experts to share experiences and best practices. A multidisciplinary team was created and a network with other local entities (other associations, social services, policy makers) was set up. Some customary tools were updated, taking into account the specific aspects of contexts involving women with disabilities (e.g. different forms of violence, various figures who can be the perpetrators, presence of a caregiver network or support services). New methods were created, such as 'second-level consultancy' for professionals (educators, assistants, etc.), periodic focus groups with experts and stakeholders at the local level, and periodic joint supervision.

The composition of the team — an expert in gender violence working together with an expert in disability — enables observation of the different needs and better analysis of each woman's situation. Both operate as mediators should the women have difficulties in talking about themselves for reasons closely linked to their own disabling condition, and are able to build effective pathways for dealing with the reported situations.

Furthermore, awareness and recognition of violence and factors of discrimination affecting women with disabilities are essential elements for combatting the violence itself. It is therefore necessary that women with disabilities themselves have greater awareness of their gender identity, their body, their needs, and their rights in terms of friendly, emotional and sexual relationships. This type of empowerment is the essential starting point to ensure that situations of violence and discrimination are recognised and addressed.

Parallel actions to facilitate the recognition of violence or situations of discrimination were thus undertaken, directly addressing women with disabilities. A five-meeting programme was launched and this actively involved women with disabilities in reflecting on their identity, on their experiences with their body and on the strategies that can be used to assert their rights.

Lastly, again to encourage recognition of situations of violence and to build more effective support for the victims, specific training sessions including social services, professionals, law enforcement and the community were held.

The work done and the communication strategy were very successful. Many women with different characteristics and living conditions have asked for support: during the last year, women with physical, cognitive, psychiatric or sensor disabilities, living alone or in residential structures have all come to the centre. The collaboration with local services has been very positive. A strong network with other associations has been established and positive results have been obtained at policy level: the disability variable has officially been included in the data collected by all the anti-violence centres in the metropolitan area of Bologna, the topic of gender and disability has been included on the political agenda and a policy group working on this topic has been created.

5. Empowerment, recognition and awareness as key factors for equal rights

Reading the United Nations Convention on the Rights of Persons with Disabilities, it emerges that empowerment, the right to choose and awareness are essential factors. Therefore, it is vital that the greatest effort should be made to develop the following in women with disabilities, from an early age: being aware of themselves, of their needs and their desires; being able to accept that they are very often dependent on others' support, without however giving up the fight for their dreams and desires; knowing how to ask, be with others and be able to measure oneself in relationships; feeling capable of giving and not just receiving, due to the presence of a disability.

For this reason, the 'most genuine questions' posed by a woman who lives the experience of disability must be placed at the centre of our attention. Although these are often unexpressed or denied, they are not unlike the topics raised by others: a house, some friends, exclusive affections, a job, entertainment, the right to live in an urban area, money to live on, and freedom to speak and express oneself. The struggles that emerge are much greater than those of people who do not have to deal with disability; thus, being helped to understand the risks and how to decide for oneself becomes a vital path to pursue.

We know that the gender dimension is intrinsically part of the identity of each individual. Why should it be different for a woman with a disability? Only by fully participating in building up our own lives we can transform possible limits into the pride of our complete identity; the identity of each person is not such if awareness of one's rights remains excluded. To foster this, we should reiterate and remind everyone that «nothing about us without us» must fully become a project of responsibility and shared choices, also in terms of gender and disability. We should encourage in everybody the ability to tolerate 'non-healing', and for this very reason learn not to choose for the other but to build together, starting from the needs of each. If we incorporate the gender perspective theme within our reflection, we can take care of a person in her or his entirety and complexity. The body and the right to desire are two of the main areas of denial in women's subjectivity.

'Moving the will' makes us active subjects and helps us to choose to become 'unanticipated subjects' instead of 'voiceless individuals'. For a long time, no one envisaged that women with disabilities could express wishes of their own. In female disability, the body is still the place of revolution, sometimes, in spite of ourselves. The choice is to make it an opportunity for dignity and freedom.

For women with disabilities, the quest for the specific form of their freedom can help create the cultural and material conditions so that the path to freedom is no more difficult than that of women without disabilities — or that of men, with or without disabilities.

6. Conclusions

Women with disabilities suffer from conditions and feelings in which the unspoken prevails over the body, sexuality, falling in love, affections and desires. A shadow of denial and often real violence has always fallen on motherhood, on the very meaning of the future and on bonds. Very significant and painful analogies come to the surface. Torture, for example, has its deepest core in sexual frustration and humiliation of the body. 'The weaker subject' seems to carry a violable body; being historically unequal can make a woman weak and therefore an easy target.

All this requires willingness to listen to women with disabilities and to be involved. It implies self-questioning to ask whether we are willing to really listen to their voices. However, we have to be very careful because talking mainly about violence can be reductive and risks producing further discrimination regarding women with disabilities. There is the risk of involuntarily increasing 'segregation', creating a boomerang for their emancipation. Victimised women risk being placed, by others or even by themselves, in a situation of inferiority. Seeking freedom from stereotypes instead empowers those involved to move beyond the 'victim' model.

Generally speaking, a more active attention could be generated to enable a fundamental change both in terms of a model of designated 'victim' — since girls and women with disabilities are often imagined as less able to choose for their own lives — and in terms of stereotypical imagery that portrays 'female' disability as a further threat to the lives of those living alongside a woman with disabilities, be it as a partner, a child or any other significant bond.

Girls with disabilities indeed have the right to be guided to envisage an independent life, respectful of their gender identity and beyond stereotypes. It is already known that the direct consequences of this approach have a significant influence on the prevention of many forms of violence and abuse. Abuse and negligence at body level, and the emotional and relational impact can all be reduced, creating the scope to foster a greater ability to recognise and defend against sexual harassment, to which women with disabilities fall victim between two and five times more frequently than women without disabilities.

One way to take power away from the conditions or people that sustain situations of violence or abuse is to be helped to choose to no longer be a victim. And thus it is important to remind every woman who has the power to choose to disarm the cultural contexts responsible for violence, that she has the power to never again be a victim, not even of herself. The importance of telling stories of redeeming women who can choose in their lives is considerable. We need to instil a new perspective in which women are not only victims, passive, frightened or weak.

An identity that can also speak of its own fragility, and that can recognise it as such, does not necessarily have to lead to victimhood. Being fragile, knowing how to talk about one's own vulnerability, and also recognising it by seeing oneself in others, have nothing to do with being a victim and instead transform these weaknesses into freedom. This becomes a wealth that can be passed on to others.

It is a matter of finding the meaning and the courage of the shared word, of that vision of rights from a perspective of intersectionality, because particular discrimination, oppression or valorisation can be recognised by comparing the realities of different groups and identities. We could say, basically, that no person and therefore no woman recognises alone his or her origins, identity or denied rights, except in comparison with and in the struggles of other communities that are victims of discrimination.

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Exploring female MS patients' social engagement in Sicily

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Keywords: barriers, mixed methodology, MS patients, social engagement, accessibility

1. Introduction to the study

During summers 2017 and 2019, we spent a month exploring the social engagement of female multiple sclerosis patients in Sicily, focusing on the everyday difficulties and barriers that hinder their full participation in diverse environments, such as social life, public representation, studies, career building and work. Our research idea was based on listening to the direct voices of persons engaged with the challenges of MS disease and therefore, we interviewed female AISM patients, social workers and volunteers, instead of recurring to literature on the subject.

External experts were inquired about the structural, legal and institutional aspects of female MS patients' life in the insular context. We also performed direct and participatory observation during our secondment in Sicily, attending sports events for disabled persons, participating in cultural activities and visiting public organisms, acquiring insights about the architectural barriers that difficult MS patient's access to diverse activities. Our exploration included several visits to tourist offices In Palermo area, to request information on adapted tourist attractions, as well as taking walks in the diverse neighbourhoods to observe the pavement conditions that can hinder wheelchair mobility.

These fieldwork activities and the data analysis that followed had an explorative and qualitative nature, and to systematize data, we used templates for the interviews and focus groups. The results obtained were classified on the basis of the barrier typology.

We also found fieldwork diaries and notes very useful for the participatory and direct observation activity. The information we gathered was organized into categories according to the type of barrier, context and environment, following the guidelines established in Risewise Deliverable 1.2. Analysis of Barriers (Fuentes, D'Antonio, Leone, Pavón & Bencivenga, 2017).

The barriers include a wide range from plain architectonic, technological and transport difficulties to legal and communicational ones, and to more complex aspects related with attitudes, gender, maltreatment, etc. These barriers can be further classified in terms of a larger contextual framework wherein they belong, including social, economic, mediation, psychological, legal, accessibility as well as violence and discrimination dimensions.

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Women with disabilities (WwD) often need to tackle with barriers wherever they go, no matter whether they move in the environments of home and daily care, education, work or social life, and they even encounter trouble within the healthcare system. The fieldwork results can contribute to a better understanding of the female AISM patients' local context and of their particular difficulties, also aiming to gain larger public awareness of the problems. This awareness among policymakers and civil society organizations may lead to design better tailored assistance strategies and foster infrastructural improvements that would improve the social engagement of female SM patients in Sicily. Nevertheless, due to the geographic and sample size limitations of the study, the results cannot be generalized and offer only a partial view on the overall barriers faced by women with disabilities.

2. Framework for the study: UN Convention on the rights of persons with disabilities

United Nations Convention on the Rights of Persons with Disabilities (CRPD) was used as a guiding framework for designing the current study, especially for the fieldwork key research questions. This Convention and its' Optional Protocol, adopted in 2006 as the first comprehensive human right treaty of the 21st century, entered into force on May 2008 (CRDP, 2008). It offers a worldwide common frame for the protection of disabled persons, the Conference of the State Parties (COSP) being the largest and most diverse international disability meeting in the world, aimed at advancing human rights and fostering the social inclusion of persons with disabilities. Countries that have joined the Convention engage themselves to develop and carry out policies, laws and administrative measures for securing the rights recognized in the Convention and abolish laws, regulations, customs and practices that constitute discrimination (Article 4).

In our explorative study on female MS patients social engagement in Sicily, we found that in many cases, the underlying factors that hindered women with disabilities' full participation in social life and professional environments were often related to discrimination and psychological barriers, though more attention is usually drawn to the directly observable legal, architectural and technological barriers.

Several articles of the Convention deal with broad issues related with non-discrimination of disabled persons, and Article 8 specifies the countries' obligation to combat stereotypes and prejudices towards them. Other chapters referring to discrimination include article 5 on equality and non-discrimination, article 10 on right to live in equal conditions as others, article 17 on the protection of integrity of the person. Article 6 deals with gender issues, a key aspect for the present research, and article 7 covers the protection of children. These are stated as follows in the UN brief:

- Countries are to recognize that all persons are equal before the law, to prohibit discrimination on the basis of disability and guarantee equal legal protection (Article 5).

- As a change of perceptions is essential to improve the situation of persons with disabilities, ratifying countries are to combat stereotypes and prejudices and promote awareness of the capabilities of persons with disabilities (Article 8).
- Countries are to guarantee that persons with disabilities enjoy their inherent right to life on an equal basis with others (Article 10), ensure the equal rights and advancement of women and girls with disabilities (Article 6) and protect children with disabilities (Article 7).
- Countries must protect the physical and mental integrity of persons with disabilities, just as for everyone else (Article 17) (CRDP, 2008).

As a conclusion, the Convention emphasises the importance of mainstreaming disability issues as an integral part of relevant strategies of sustainable development, and recognises also that discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person. The CRDP document offers an operative definition for discrimination:

> Discrimination on the basis of disability means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation (p. 4).

Therefore, changing negative or uncaring mind sets among diverse stakeholders is key for tackling discrimination and stopping negative behaviours that are the consequences of these attitudes.

3. Secondment findings

3.1. 2017 research secondment findings

During summer 2017, our team carried out a research secondment at Associazione Italiana Sclerosi Multipla (AISM) in Palermo, where we had a first-hand opportunity to get to know the functions and daily routines of the organization. The following results are based on AISM volunteer, social workers and staff interviews, as well as direct observation in public transport, public organizations and around tourist attractions.

As a conclusion, we would underline that when it comes to barriers of MS patients, women find different difficulties depending on their social condition, as poverty has a multiplying effect on their situation. In those neighbourhoods that are socioeconomically less developed, women expressed that they experience bigger obstacles because traditional social norms apply, meaning that especially elder generation disabled women basically stay at home and don't develop professionally. The life of many women is highly limited to their homes and housekeeping, and in extreme cases, women are even hidden or actively hiding from social contact, often unaware of the assistance they are entitled to receive.

When the illness does not have external manifestations, patients, especially highly educated women, have what they call normal lives. If the situation worsens, women find more difficulties keeping their jobs, or in the other extreme, getting pension for incapacity can be difficult. Personal relations often suffer as young women do not dare to risk to have a relationship, due to fear of the evolution of MS, and sometimes, husbands might leave their wives when these get ill. Architectonic and transport barriers are also relevant because subventions for adapting houses are no longer available and moving around in public transport can be difficult for women of reduced mobility.

In terms of tourism, we made direct observations on Palermo area transport and surrounding tourist area accessibility and information. Strolling around in Cefalù, a well-known seaside town and holiday spot, we found hardly any adaptation for persons with reduced mobility, no ramps to main sea view points, monuments or museums. The beaches do not have any access for wheelchairs and generally, the natural stone pavements make it hard to move around. Many of the trains that operate in the area do have accessibility signs, but these do not always operate correctly, and the same happens with buses, where the driver often jumps out to help people in wheelchairs to get aboard. The 'attention buttons' for disabled persons are very visible at the train station in Cefalù and Palermo, but mostly the assistance is not real, as there is not enough personnel to attend the people requiring assistance.

Most of the tourist attractions and view spots do neither have any audio guides or braille texts nor any other adaptations. In many sightseeing spots, the information is only accessible for those who have smartphones and can use QR-codes, as very little written *in situ* information is provided. The airport is well equipped, with a special service point for disabled persons, like most international airports in Europe, though we did not have an opportunity to test the efficiency of the facilities.

In the following, we will have a closer look at the main results of the focus group and interviews, organized by type of barriers.

3.1.1. Most relevant barriers according to interviewees

The interviewees mention attitudinal, inter-relational and architectonical barriers in first place. In small communities, people are not very open to issues related with MS and therefore, some women hide, do not speak up and participate, which generates a greater social problem and isolation. Even the women that have active professional lives have problems at work as MS has many invisible symptoms. In terms of accessibility, Palermo is not a very accessible city, though improvements have been made recently. Many MS patients live in old houses that are not restored and made accessible, many have economical scarcity and cannot adapt their homes.

3.1.2. Technological barriers matter

The interviewees underline the disinformation on technological gadgets to assist MS patients, even though they mention the existence of a service called *Auxilioteca*, entity of Palermo community that offers assistance for all kind of situations of disability. However, many women do not know about the assistance they could get or the availability of technical equipment and feel discriminated at workplaces. There are no accessibility managers in the companies where female MS patients work. They mention the example of a pharmacist who was working, got MS and started to feel fatigue, lack of balance and concentration, and finally, she had to leave her job.

3.1.3. Architectonical barriers found all over

This kind of barriers can be found all over, in different environments. These include ramps that do not work or you cannot access, the interviewees mention the examples of a public building ramp totally blocked and surrounded by plants, or a clinic without accessible bathrooms.

Women sometimes feel prisoners of their houses as physical access to several buildings and outdoor activities is hindered. They face architectonical barriers in Palermo historical centre, public buildings and neighbourhood services. During holidays, they find that access to the sea and going to the beach is often very difficult. The interviewees argue that one of the main reasons for this kind of barriers is the lack of *culture of accessibility*, not so much lack of means, but willingness to adapt the environment. Also, when it comes to adapting houses, there are specific requirements and a permission is needed from the community of neighbours.

3.1.4. Legal barriers limit access to services

Related to the before mentioned possibility to improvement and adaptation of houses, the interviewees mention that there was a law on regional funds for house adaptations, but (due to the crisis), it does not exist since 2009. The interviewees mention another law from 1992 (Legge 104/1992) that defines the grade of disability from 1-3 (where 3 means more serious) and according to the individual’s degree of disability, assistance is available or not. Reduction in automobile taxes, special parking permissions and general services for disabled persons are available, but can be difficult to access.

3.1.5. Workplace and social context related barriers

As mentioned in the introduction, women with MS often suffer discrimination at workplaces. Right in the beginning of the employability process, there can be discriminative work position descriptions (related to disabilities) that force WwD to seek jobs in a different place in case they do not fit the post requirements. Also, the women we interviewed mention that many companies have actions related with integration and diversity that are not real, companies sometimes just fulfil the minimum requirements, but it is not real integration. Also, in the streets, when moving around, WwD can be affected by discrimination because of the curiosity of the people, who often do not know about MS and the external manifestation of the illness, or are not used to dealing with people in a wheelchair, so people get confused and stare…Therefore, discrimination can become worse in small towns and villages, where MS patients are more afraid of telling about their condition and speaking about it.

3.1.6. Attitudinal discrimination

The interviewees agree that attitudinal discrimination highly depends on the culture and context of the person. Women that live in culturally and socially less developed neighbourhoods, as mentioned before, do not know the possibilities they might have. The situation is totally different for women that work in banking, education or other white collar or technical positions. As long as the disease is invisible, women can conduct a rather normal life. When it comes visible, women basically have two choices: avoid social contact or face the situation and become an example for other disabled women. The interviewees expose sad situations where, if the wife develops the MS disease, the husband might disappear. This is nowadays changing for better, but 20 years ago MS always meant finishing in a very severe condition, often followed by a divorce. Still, even today, many women do not want to have a relationship as they are afraid of the future.

3.1.7. Gender differences linked to old role models

In opinion of the female MS interviewees, disabled women are treated in a different way than males, though during the last years the situation has improved a lot. They remind us that Sicilian women are very passionate, ready to explore new things… and now they dare more. Still, in Southern Italy, very often women stay at home and perform housekeeping tasks. Lately, there are changes in the roles, but men do mostly very little at home, women do most of the housekeeping.

3.1.8. Transport barriers cause great difficulties

«Great difficulties», express the interviewees when asked about public transport. Transport remains one the main barriers that hinder WwD’s social engagement in Sicily. There are big contradictions between the information provided by the transport companies and the actual services they offer. For example, many buses have ramps, but these are often broken, so the driver and peer travellers must jump out and help the persons in wheelchairs, with baby trollies, etc. In theory, and according to the official information, train stations offer discounts and assistance for person with disability, but in the practise it does not work out. In the city of Palermo, it is difficult to move around as there are not many adapted taxis and some streets are in bad conditions or have too deep pavement edges, not suitable for wheelchairs. Palermo city administration offers special services for students and disabled persons that are residents and also, organisations such as AISM offer transport service -they have two adapted vans with ramps- but this is not enough. Many entities that offer transport service charge for it and add also the waiting hours to the fee. At the airport, special assistance and adapted premises are provided.

3.1.9. Communication barriers and mental refuge

The interviewees mention that in fundraising events, people often do not want to know anything about AISM. They find that only very few people are open minded or have curiosity for knowing more, because people do not think MS is something that could happen to them. People use disinterest as ‘a mental refuge’. We find lack of information for both the affected persons as well as other publics, there is not enough discussion on MS. In this sense, AISM tries to get large visibility at events, clinics and other places, and to communicate and be available for people. Events are found to be a good way to mobilize the media and get more press coverage for MS and AISM. Volunteers mention the importance of networks, AISM often functions in collaboration with other organizations. Regional organizations do not have communications management, so this makes it harder to reach media. Communication with the family is also important, they need assistance in order to adjust their life to MS. In resume, general awareness campaigns are necessary, providing suitable information for all publics. Interviewees mention a service called *Spotello* (telephone information and help desk) which they find useful.

3.2. 2019 research secondment findings

During summer 2019, we wanted to know more about female MS patients’ social engagement in Sicily and renewed our research stay at AISM, where again, as happened the first time, we received a very warm welcome by the volunteers and coordinator who assisted and co-organized the group interviews to MS patients. This time, the interviewees were mainly young women at the early stages of MS. We used the same methodology proceedings as during the 2017 secondment, completing the interview findings with direct observation, reinforced by a photographic memory of the whole secondment. We mainly did observation and participated in activities in Mondello and Palermo, but also visiting other cultural and sightseeing spots on the island.

This time, we would underline the importance of the attitudinal barriers that hinder people’s understanding of the MS patients’ situation, especially in the early stages when the illness is still invisible. Naturally, these psychological dimensions together with the social and legal ones can contribute to the discrimination and social isolation of SM patients, but also, purely physical architectonical and transport barriers keep causing great difficulties for persons with reduced mobility in Palermo area. Compared with the previous visit in 2017, we saw no substantial improvements. In some areas, such as Mondello (where the AISM is located), the streets are literally unpassable for wheelchairs and very risky for persons with reduced mobility or/and vision.

The relative lack of knowledge of SM disease among citizens causes social difficulties at work and at the university, whereas legal barriers make it difficult to get appropriate assistance. The most striking of the results this time was that the women we interviewed experienced no gender based discrimination and expressed no gender related barriers in terms of people’s attitudes towards SM patients. Quite the contrary, they found that being a women can be empowering when you fall ill, as they argued women have more resilience and strength to undergo this kind of situations. This might be due to the attitudinal changes and gender equality perceptions among younger generations.

In the following, we will share the main results of the interviews, organized by type of barrier.

3.2.1. Attitudinal barriers and the invisibility of MS at early stages of Illness

In general terms, the interviewees repeat that their disease is invisible, especially when there are not external signs of the illness. They look perfectly healthy in the early stages of SM and therefore, it is more complicated to explain how they feel, for example when they have cycles of tiredness or react to the medication. In this sense, they find the illness more discriminatory than some other illnesses with more visible symptoms. Sometimes they need more time or need to do the things in a different way. At work, patients must ask their employer for permission, even when attending the basic therapy related with the disease. When working, they may require more time to run the activities and complete the tasks, because of the fatigue or the lack of concentration. This is not always seen as result of the illness and therefor, they often feel misunderstood. They feel the same way also when studying, but they do not necessarily inform about the disease at the university or educational center, because they find it would not make much difference.

When the symptoms become visible, especially in terms of reduced mobility, sometimes people do not know how to react and can make discriminatory comments. In extreme cases people may relate the illness to mental problems or ignore the SM patient, for example not talking directly to the person and speaking to the accompanying person instead.

As a conclusion, they think that at school, at the university, at work… within the society in general, there should be more knowledge about this disease. More communication and conscience about MS is needed to raise awareness. Also, more volunteers and means are necessary.

3.2.2. Legal barriers related to economic barriers

Only one of the interviewees benefits from the assistance granted by law (Legge 104). They exclaim that it is difficult to prove that you are ill when the disease is still invisible. Also, the recognition of disability is difficult to get by legal means and even if you get the legal status, it does not necessarily mean any social or economic benefits for the patient. These are only included when the law recognizes a very high level of disability. Many times, economic barriers are related to legal requirements or directly caused by legal obstacles. The governmental assistance is very scarce and does not pay for all the specific needs of disabled persons. In the before cited law, there are some points referred to rebuilding and adapting the interiors of the house or for acquiring some devices, but this is clearly not enough for making homes entirely accessible. The interviewees find the law discriminatory.

3.2.3. Transport barriers still persisting

To drive a vehicle, WwD have to obtain a special driving license which costs about 200 euros and must be renewed every 2-3 years, the cost is not refunded. In fact, one of interviewees said that usually the people who are affected by a certain disease try to hide it in order to avoid paying for this kind of frequent renewal of license, even though the interviewees agree that the license is important for carrying out normal lives. The neurologist report is not enough, and the renovation of the license takes several months.

When it comes to public transport, the women argue that it is not accessible and there are very few means of transport that are equipped with the right resources. When it comes to railways, there is only one train line on the island and it doesn't arrive to all the places. They don't know if it has accessibility. Some of the local trains are marked with accessibility signs, but we found that no ramps appear for getting onboard. Buses are mainly not accessible, even if they have ramps, as these seldom work properly. The offices for attention of disabled persons seem mostly to work only on paper. The interviewees mostly depend on private transport. AISM provides some adapted transport, but only in Palermo region.

3.2.4. Tourism and therapeutic passports

At early stages of the illness, the interviewees don't find any kind of problems for travelling, except for some cases when going to isolated areas far from health services. They need a therapeutic passport to take the pills (or injections) with them whenever crossing the borders. «You just need to be quite near to medical services, sometimes it can be tricky to do the injections», reclaims one of the women.

Even faraway destinations are feasible (Australia, Peru, etc.) and you just need to adjust, «the only thing I could not do, was to climb Machu Picchu». When the disease advances, travelling gets more difficult.

3.2.5. How does a woman's life change when she finds out that she is affected by multiple sclerosis?

«It depends on the person, but I can say that the disease completely upsets a normal person life. But this doesn't mean that you cannot do the things you've done before anymore. You can continue doing what you've done a lifetime ago, the only thing that changes, is the way you do it», quotes one of the interviewees and the others nod in agreement. The women find that gender does not make any difference in the disease itself. They surprise us affirming that being a woman is in itself an empowering element, they find females often stronger than men, more capable of adaptation and fighting the disease. Women are also expected to be the caretakers, which is not so often the case of men. This can cause some difficulties in couples where the women get ill, but it also means that women can take better care of themselves.

Some of the interviewees mention that they had already found some signs of the illness before being diagnosed by the neurologist. Also, they mention they sometimes feel sad and need to redefine some of their future projects.

4. Conclusions and limitations of the study

In this occasion, we found the SM patient interviews to be the most fruitful technique for exploring the multiple dimensions and contexts of barriers faced by women with disabilities, as it offers a direct look into their lives, understanding how different stages of MS imply different challenges and how much courage and effort it takes to tackle the barriers, physical and mental ones. Listening to their voices gave us insights that would have been outside of the scope of our research otherwise.

Still, it is important to bear in mind that the sample we used in the study was small and Sicilian-context bound, so these results are exploratory and express the opinions of the interviewees, enriched by insights from direct observation and previous experiences of the researchers.

Through the fieldwork, we found that the approaches to find solutions to improve WwD's life conditions and social engagement are sometimes simple. For example, amending architectural barriers, such as lack of street tramps or useless, too high ramps, requires medium or low cost public investment at local level, but has immediate effects on the city centre accessibility. Tackling this kind of tangible barriers — architectonic, technological, transport and even legal — often seems rather a question of political good will, of strategic policy making and of budget priorities than an insuperable, out of reach challenge.

As the focus is often in these directly observable dimensions of disability, discrimination and psychological aspects are often ignored while they can form bigger walls for understanding and act as underlying, silent or silenced factors that hinder women's full participation in social and professional life. Polishing outdated attitudes, opening doors to flexibility and openness are required not only from the policy makers and local administration, but also from the civil society, businesses, education system and researchers.

We learned from the experience of the interviewees that different stages of MS imply different challenges and responses. It takes a lot of courage and effort to tackle barriers, both physical and mental ones. It is important to foster patients' independent life and their right to decide about personal life, equal opportunities to study, form a family, study and work.

The socioeconomic condition does matter and can make a difference in WwD's lives, often the elements in the intersection of gender, poverty and disability may determine the basic opportunities for the social engagement of disabled women. And so do the attitudinal barriers in their living context, the people they interact with, as well as the psychological aspects related to their self-reliance and self-confidence.

If we were only going to keep one of the ideas that emerged during the research, it would be that many women with MS find being a woman an empowering element, as they find that women are often stronger and more capable of adapting to the disease and fighting it. But, as these brave women say, this is something that all women have in common, ill or not.

Building ramps and removing architectural, transport and legal barriers is relevant, but constructing *bridges for understanding* is key for enabling larger changes happen. In this sense, the EC freshly published Union Equality: Strategy for the Rights of Persons with Disabilities gives new hope as it enhances equal participation and non-discrimination and sets out key initiatives around three main issues:

- **EU rights**: Persons with disabilities have the same right as other EU citizens to move to another country or to participate in political life. Building on the experience of the pilot project ongoing in eight countries, by the end of 2023 the European Commission will propose a European Disability Card for all EU countries that will facilitate mutual recognition of disability status between Member States, helping disabled people enjoy their right of free movement. The Commission will also work closely with Member States to ensure the participation of persons with disabilities in the electoral process in 2023.
- **Independent living and autonomy**: Persons with disabilities have the right to live independently and choose where and with whom they want to live. To support independent living and inclusion in the community, the Commission will develop guidance and launch an initiative to improve social services for persons with disabilities.
- **Non-discrimination and equal opportunities**: The strategy aims to protect persons with disabilities from any form of discrimination and violence. It aims to ensure equal opportunities in and access to justice, education, culture, sport and tourism. Equal access must also be guaranteed to all health services and employment (EU, 2021).

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Disabilità, lavoro e prospettiva di genere

Luciana Guaglianone[1]

Disability, work and gender perspective

Keywords: women with disabilities, work inclusion, intersectionality, regulatory framework, limits

1. Una breve premessa: inseguendo l'obiettivo dell'inclusione lavorativa

Si parla poco di disabilità, pochissimo di donne con disabilità e, difficilmente, si affronta il nodo donne con disabilità e lavoro.

Le motivazioni anche se diverse tra di loro sono tutte riportabili ai limiti esistenti nella nostra società che tende alla normalizzazione della persona ed alla rimozione delle differenze. L'oscuramento del binomio donna-disabilità è un fenomeno che accomuna società civile e diritto; quest'ultimo è refrattario a riconoscere l'attraversamento dei confini tra varie categorie sociali, nello specifico donne e donne con disabilità e, di conseguenza, restio a tutelarne i diritti.

In particolare, la scarsa importanza che si dà alla disabilità è determinata da un processo di parziale rimozione della tematica che la relega a studi specialistici. Il mancato riconoscimento della rilevanza della questione di genere, invece, deriva dalla non considerazione dell'impatto negativo che si determina quando il fattore disabilità ed il fattore genere si incontrano.

L'invisibilizzazione del problema stride fortemente con la grande rilevanza numerica che riveste il fenomeno. Le donne con disabilità sono il 16% della popolazione femminile europea (percentuale calcolata sul totale della stessa popolazione attualmente di 250 milioni): ciò significa che nella UE ci sono circa 40 milioni di donne (e ragazze) con disabilità alle quali non viene riconosciuto il diritto di avere una doppia identità (donna e disabile).

L'interrelazione negativa che si determina dall'incontro tra disabilità e genere raggiunge una delle sue massime espressioni per quanto riguarda l'inclusione lavorativa. Nel 2015, secondo la statistica dell'*Equality Index* (EIGE)[2], nell'Unione Europea lavorava solo il 18,8% delle donne con disabilità contro un 28,1% di uomini con disabilità. Stereotipi e pregiudizi, non diversamente da quanto succede per le donne cosiddette 'normali', hanno un peso determinate nell'ostacolare l'accesso al lavoro a parità di condizioni e di opportunità.

Non sembra inopportuno, quindi, parlare anche con riferimento alle donne con disabilità, dell'esistenza di un *gap* di genere. Se prendiamo il lavoro come uno degli elementi principali per l'inclusione, l'elevato tasso di disoccupazione rende più facile che le donne con disabilità vivano

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[2] Si può leggere in https://eige.europa.eu/it/in-brief.

condizioni di vita disagiate e che soffrano maggiormente di esclusione sociale[3]. Il mancato o poco soddisfacente inserimento lavorativo (v. par.3.1), determinato da difficoltà storicamente e culturalmente incrostate, implica una situazione di vulnerabilità sociale che trova le sue cause proprio nella società. La disabilità, e specialmente quella femminile, si costruisce, quindi, anche come fenomeno sociale, nutrito da stereotipi e pregiudizi che, in quanto combinano tra di loro quelli relativi al genere ed alla disabilità, incrementano la loro potenza.

Da quanto detto, risulta abbastanza chiaro che cogliere una sola dimensione del problema, solo genere o solo disabilità, non fa comprendere i reali meccanismi che dovrebbero essere alla base di un corretto processo di inclusione lavorativa, né fa individuare gli interventi idonei a garantire un'effettiva eguaglianza di opportunità tra uomini e donne con disabilità (Schiek, 2015; Barrere & Morondo, 2016, p. 169).

Esempio chiarissimo di come la neutralità di una norma possa, sostanzialmente, nascondere una lesione del principio di eguaglianza sostanziale è il sistema italiano. La disciplina legislativa, finalizzata a promuovere l'inclusione lavorativa delle persone con disabilità (v. par.3.2) (per molti aspetti estremamente meritoria), quando si tratta di donne con disabilità, non raggiunge (del tutto) questo obiettivo. Al 2018 gli occupati erano 360 mila di cui il 58,7% uomini e il 41,3% donne[4]; nonostante che il 54,6% delle persone con disabilità sia composto da donne in età lavorativa[5] il differenziale occupazione si colloca al 17,4.

In sintesi, con numeri e percentuali differenti, le linee di tendenza della situazione lavorativa delle donne con disabilità e delle donne cosiddette 'normali'. sono esattamente le stesse. Con riferimento a queste ultime, l'*Equality Index* (EIGE) si ricorda che il *gap* di genere italiano, per quello che si riferisce all'indice di occupazione, è di 8 punti superiore alla media europea (UE 10%, Italia 18%)[6].

2. Legislazione antidiscriminatoria e Convenzione ONU sulle persone con disabilità: il nodo della multidiscriminatorietà[7]

Auspicare che il legislatore tenga in conto il peso negativo della compresenza di genere e disabilità significa aprire una finestra sul problematico e complesso tema della multidiscriminatorietà. Scivoloso terreno di confronto e riflessione di studiose e studiosi di

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[3] Riporta uno studio ISTAT del 2019 che il 19,2% di uomini con disabilità si dichiara soddisfatto della sua vita quotidiana mentre la percentuale di donne è del 17,2, in https://www.istat.it/it/archivio/235774.

[4] Si veda il Rapporto Istat 2019, https://www.istat.it/it/archivio/235774.

[5] Al 2018, sempre secondo dati ISTAT, erano presenti circa 27 milioni di donne in età lavorativa, dato più alto del 7,4% rispetto a quello degli uomini.

[6] Al 2019 nella UE il tasso di disoccupazione era del 7% per quanto riguarda le donne e del 6,4% con riferimento agli uomini il 32,1%. Il tasso di inattività, per quanto riguarda l'Italia, oscilla tra il 32,1% del Nord Italia (uomini il 14,8%) e il 59,9% del Sud Italia (uomini il 28,4%) https://www.istat.it/donne-uomini/bloc-2b.html

[7] Multidiscriminatorietà è il termine presente nella documentazione europea.

differenti discipline, finalizzato a individuare la possibilità di immaginare un ombrello protettivo più ampio di quello che deriva solo dal divieto di fattori di discriminazione unici[8].

La tematica — che trova una delle sue motivazioni nella ricerca di una forma più avanzata di eguaglianza sostanziale — ha molteplici risvolti ed alcuni mettono in discussione i punti focali della costruzione del diritto antidiscriminatorio. Le posizioni espresse, di conseguenza, sono contradditorie. L'Unione europea, ad esempio, nella redazione dei suoi atti normativi, utilizza un approccio «*single axis*» (Smith, 2016, p. 73), senza prendere in considerazione ipotesi discriminatorie che lavorino su binomi (genere/razza; genere/età; genere/discriminazioni). Dedurre dalla tecnica di redazione delle norme europee una totale mancanza di condivisione da parte dell'Unione della rilevanza di queste tematiche, però, non sarebbe corretto. La consapevolezza del peso discriminatorio che ha la multifattorialità è espressa nei considerando, sia della Direttiva 2000/43/CE (punto 14), sia della Direttiva 2000/78/CE (punto 3), anche se, almeno lessicalmente, questo interesse è manifestato sotto forma di constatazione «la Comunità deve mirare, conformemente all'articolo 3, paragrafo 2, del trattato CE, ad eliminare le ineguaglianze, nonché a promuovere la parità tra uomini e donne, soprattutto in quanto le donne sono spesso vittime di numerose discriminazioni»: quindi senza valore vincolante nei confronti degli Stati.

È la stessa Unione Europea, tuttavia, che, in un momento successivo e con più decisione, sottolinea l'evidente inadeguatezza di un sistema giuridico che limita la sua sfera di azione a fattispecie uniche. Nella recente Strategia Europea sulla disabilità dopo il 2020 (P9_TA (2020) 0156)[9], il Parlamento Europeo riconosce che le precedenti iniziative non sono riuscite a tutelare i diritti delle donne con disabilità, in quanto queste si trovano ad affrontare discriminazioni multiple (v. considerando 'O'). Sollecita, quindi, la Commissione a presentare una Strategia europea sulla disabilità globale a lungo termine, per il periodo successivo al 2020, che riconosca ed affronti le forme molteplici e trasversali di discriminazione e salvaguardi l'integrazione della dimensione di genere (punto 5 lett. f e lett. h).

A differenza di quanto detto in relazione all'ordinamento antidiscriminatorio europeo, la Convenzione Onu sui diritti delle persone con disabilità riconosce la presenza della multidiscriminazione. Il testo dell'art. 6 (*donne con disabilità*) non solo contiene un'esplicita constatazione della soggezione delle donne e delle ragazze alle discriminazioni multiple, ma va oltre, impegnando gli Stati a prendere «misure per assicurare il pieno ed uguale godimento di tutti i diritti umani e delle libertà fondamentali da parte di donne e ragazze con disabilità». Il momento meramente descrittivo, pertanto, si accompagna all'assunzione di uno specifico obbligo finalizzato al superamento della situazione discriminatoria. La norma, quindi, non solo si

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[8] Una riflessione organica dovrebbe necessariamente prendere spunto dai dubbi sull'attualità ed efficacia di una nozione chiusa di discriminazione.

[9] https://www.europarl.europa.eu/doceo/document/TA-9-2020-0156_IT.html

propone come articolazione e specificazione del principio generale di eguaglianza (di cui all'art. 5 della stessa Convenzione), ma fornisce gli strumenti per il raggiungimento dell'eguaglianza sostanziale, antidoto alla non discriminazione.

Come è noto, con decisione del Consiglio dell'Unione Europea (2010/48/CE del 26 novembre 2009) la Convenzione è stata approvata a nome della Comunità ed è stata successivamente ratificata il 23 dicembre 2010. Ai sensi dell'articolo 216, paragrafo 2, del Trattato sul Funzionamento dell'Unione Europea, «gli accordi conclusi dall'Unione vincolano le Istituzioni dell'Unione e gli Stati membri». Le disposizioni della Convenzione ONU sui diritti delle persone con disabilità entrano quindi a far parte del *corpus juris* dell'Unione Europea, divenendo obbligatorie per tutti gli Stati membri. Non diversamente da quanto è successo con la nozione di discriminazione per disabilità, anche quella di discriminazione multipla, quindi, avrebbe potuto essere adottata, anche se in via interpretativa dalla UE. Allo stato, il risultato dell'omessa considerazione delle discriminazioni multiple implica che in questo ambito la UE abbia ceduto, il ruolo di promotrice di eguaglianza al legislatore internazionale (Xenidis, 2018, p. 41).

I motivi socio-politici, sicuramente, non sono stati gli unici ad avere ostacolato l'introduzione della nozione di discriminazione multipla. A questi si affiancano perplessità giuridiche, in particolare sull'uso giudiziario della nozione (Xenidis, 2018; Fredman, 2016)[10]. Il dubbio principale riguarda l'individuazione di un comparatore idoneo per la verifica del trattamento discriminatorio (Fredman, 2016; Yuval-Davis, 2006, p. 199)[11]. Tuttavia, se ci riferiamo specificamente alla causale della disabilità, questa perplessità potrebbe, forse, essere legittima nel caso in cui, il comportamento che si vuole denunciare come discriminatorio, interessi una presunta discriminazione diretta (anche se, si ricorda, la normativa antidiscriminatoria prevede la possibilità di fare ricorso quale comparatore ad un soggetto ipotetico). Non trova, invece, nessun fondamento nei casi in cui il trattamento differenziato faccia ipotizzare la presenza di discriminazioni indirette. L'obbligo di raccogliere dati disaggregati, finalizzati ad «identificare e rimuovere le barriere che affrontano le persone con disabilità nell'esercizio dei propri diritti», di cui all'art. 31 della Convenzione ONU sui diritti delle persone con disabilità dovrebbe, se rispettato, determinare la costruzione di Banche dati ai cui contenuti attingere per costruire prove statistiche. Il rispetto della previsione (art. 4 c. 1 della Convenzione ONU), posto sia carico degli Stati che l'hanno ratificata sia, di conseguenza, della UE, al momento è

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[10] Xenidis, 2018, osserva che la legislazione UE ha molti ostacoli strutturali che rendono difficili i ricorsi giudiziari per motivi di intersezionalità. In particolare osserva che ci sono quattro ragioni tra di loro correlate. Per primo le causali discriminatori sono contenute in differenti atti normativi, poi le diverse direttive hanno scopi differenti e le giustificazioni e le eccezioni differiscono a secondo della causale protetta. Da ultimo non c'è possibilità di un ampliamento delle causali indicate senza un esplicito intervento legislativo.

[11] Fredman, S., *2016,* sottolinea la necessità di potere individuare un comparatore che sia adeguato alle diverse situazioni.

complessivamente disatteso[12]. È l'inadempienza, di conseguenza, che rende difficile/impossibile il corretto uso della normativa non le regole in tema di onere della prova.

2.1. L'intersezionalità[13] come metodo di analisi da proporre ai policy makers e al legislatore

La nozione di disabilità contenuta nella Convenzione[14] deriva dalla compresenza di più elementi alcuni (quelli fisici, psichici, sensoriali) tradizionalmente riconosciuti come componenti (unici) della nozione di disabilità; altri non predefiniti né tipizzati, la cui esistenza deve essere verificata caso per caso.

Questa modalità definitoria ha il merito di avere spostato il centro di attenzione dal solo modello medico (disabilità=presenza di patologie fisiche o psichiche o sensoriali) a quello sociale (la disabilità deriva dall'interazione delle patologie fisiche o psichiche o sensoriali con l'ambiente esterno e la società) e, di fatto, utilizza un approccio intersezionale (Bello, 2015, p. 54)[15]. La verifica della presenza di comportamenti discriminatori avviene, infatti, utilizzando un mezzo di analisi finalizzato a comprovare se il trattamento diseguale, sofferto dai soggetti portatori di disabilità, sia il prodotto di un'intersezione tra ragioni storiche, sociali, culturali, politiche che si materializzano nei campi elencati dall'art. 2 della Convenzione (Verloo, 2006, p. 211). L'ineguaglianza di trattamento si verificherà quando un soggetto, indipendentemente dal genere, razza, età, orientamento sessuale o opinione politica, sia portatore di patologie fisiche o psichiche o sensoriali che creano svantaggi (anche) a causa delle interazioni sociali.

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[12] Come si legge nel parere *La condizione delle donne con disabilità [parere esplorativo richiesto dal Parlamento europeo (SOC/579) del 2018,* https://eur-lex.europa.eu/legal-content/IT/TXT/?uri=CELEX%3A52018AE1639], il Comitato economico e sociale europeo chiede che gli Stati adottino un approccio più sistematico nelle loro attività, in relazione alle persone con disabilità e alla condizione di queste persone nel mercato del lavoro e nella società. Tale approccio dovrebbe tenere conto in particolare della situazione delle donne e del fatto che l'intersezionalità può portare a molteplici forme di discriminazione. Allo stato la UE e i suoi Stati membri non dispongono di dati omogenei e comparabili né di indicatori del rispetto dei diritti umani per quanto riguarda le donne e le ragazze con disabilità, e neppure di studi/ricerche sulla condizione di queste due particolari categorie nell'Unione.

[13] Si utilizza questo termine in quanto, per riportare le parole di Bernardini, 2018, p. 281, è quella che definisce la tecnica che consente di analizzare la specifica condizione in cui si trovano determinati soggetti in ragione del convergere di plurime forme di discriminazione e oppressione.

[14] L'articolo 2 della Convenzione utilizza per definire la discriminazione per disabilità un metodo teleologico: l'espressione «Discriminazione sulla base della disabilità indica qualsivoglia distinzione, esclusione o restrizione sulla base della disabilità che abbia lo scopo o l'effetto di pregiudicare o annullare il riconoscimento, il godimento e l'esercizio, su base di eguaglianza con gli altri, di tutti i diritti umani e delle libertà fondamentali in campo politico, economico, sociale, culturale, civile o in qualsiasi altro campo…».

[15] Il testo del punto P) del Preambolo esprime la consapevolezza che le persone con disabilità «sono soggette a molteplici o più gravi forme di discriminazione sulla base della razza, colore della pelle, sesso, lingua, religione, opinioni politiche o di altra natura, origine nazionale, etnica, indigena o sociale, proprietà, nascita, età o altra condizione».

La componente intersezionale, tuttavia, anche se non è esplicita come criterio di indagine, è presente tutte le volte in cui si utilizzano analisi di tipo 'sociale' (Hern, 2017)[16]. Nella giurisprudenza della Corte di Giustizia Europea l'adozione (o l'aspirazione all'adozione) di una nozione di discriminazione per disabilità psico-sociale ha implicato una valutazione delle situazioni, non solo giuridiche, ma anche socio ambientali che influiscono (o potrebbero farlo) sul trattamento differenziato che si chiede provare. Si ricorda, ad esempio, che nella sentenza *Conejero* (C-270/16) la Corte per esaminare la proporzionalità dei mezzi di cui all'art.52 lett. d) dell'*Estatuto de los trabajadores* indica tra i criteri di valutazione anche «il rischio cui sono soggette le persone disabili, le quali, in generale, incontrano maggiori difficoltà rispetto ai lavoratori non disabili a reinserirsi nel mercato del lavoro e hanno esigenze specifiche connesse alla tutela richiesta dalla loro condizione»[17].

Se l'analisi intersezionale, in maniera esplicita, ovvero implicita, è utilizzata dai giudici europei (e non solo), è molto più difficile che venga adottata dai *policy maker,* dal legislatore europeo e da quello nazionale come guida per vagliare l'idoneità delle politiche del lavoro per facilitare/promuovere l'inclusione lavorativa delle donne con disabilità. Questa carenza, denunciata da più parti ed allo stato irrisolta[18], è sicuramente una delle origini del pessimo saldo occupazionale delle donne europee con disabilità.

3. Il sistema del collocamento obbligatorio: meritorio ma da aggiornare

3.1. Ragioniamo sui dati

Uomo, tra i 50 e 59 anni, residente al Nord Italia, impiegato (Fondazione Studi Consulenti del Lavoro, 2020). La lapidaria espressione fotografa il prototipo classico del lavoratore con disabilità. La descrizione, non sorprendentemente, coincide con quella del lavoratore tipo senza disabilità, a partire dal quale si è strutturato il diritto del lavoro delle origini. L'archetipo dell'uomo «*breadwinner*», unico percettore di reddito, intorno al quale ruota la costruzione sociale della divisione dei ruoli, domina il mercato del lavoro (Foster, Wass, 2012, p. 74).

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[16] Potremmo dire che nelle analisi di tipo sociale, nello sviluppo delle politiche o delle identità, storicamente l'intersezionalità c'è sempre stata, che fosse visibile o meno.

[17] Sentenza CGUE C/270/16 punto 51) https://curia.europa.eu/juris/document/document.jsf;jsessionid=EFF30CDBCE337866337F4CC1D332315D?text=&docid=217624&pageIndex=0&doclang=IT&mode=lst&dir=&occ=first&part=1&cid=80770; nello stesso senso v. HK Danmark, C-335/11 https://curia.europa.eu/juris/liste.jsf?num=C-335/11&language=IT e C-337/11, punto 91) https://curia.europa.eu/juris/liste.jsf?num=C-335/11&language=IT e sentenza Z C-363/12 https://curia.europa.eu/juris/liste.jsf?language=it&num=C-363/12.

[18] L'Unione europea, sistematicamente, non ha integrato la dimensione della disabilità nel ventaglio delle sue politiche, dei suoi programmi e delle sue strategie in materia di genere, né ha adottato una prospettiva di genere nelle sue strategie in materia di disabilità.

Del resto, quando ci si addentra nell'analisi della condizione lavorativa delle donne con disabilità ci si rende conto che lo svantaggio occupazionale, tanto nell'accesso quanto nelle condizioni di lavoro, è una condizione che accomuna le donne, indipendentemente dalla loro situazione. Non diversamente da quanto accade con riferimento al mondo del lavoro 'normale', esiste un disavanzo occupazionale in sfavore delle donne con disabilità. Al 2018 erano quasi 360 mila i lavoratori con disabilità, di questi il 58,7 % uomini ed il 41,3% donne[19]. Detto in modo più chiaro il 43,3% degli uomini lavorava contro il 29,4% delle donne: non solo, ma le donne alla ricerca di occupazione erano il 16,6% (contro il 25,1% degli uomini) ed il tasso di inattività delle donne con disabilità era il 53,9%, mentre quello degli uomini il 31,6%.

Un'interessante chiave di lettura del disavanzo occupazionale ce lo fornisce l'ISTAT (2020). La differenza nel tasso di occupazione tra i due sessi non è imputabile al minore numero di donne che si iscrivono al Collocamento mirato (sul punto v. par. 3.2), complessivamente, eguale a quello degli uomini, ma si manifesta successivamente, al momento dell'avviamento al lavoro. Nonostante la presenza di una forte normativa antidiscriminatoria, la selezione del personale utilizza criteri che non sono neutri e, inoltre, sono anche le stesse norme in materia di collocamento mirato che facilitano questo approccio. Punto debole del sistema è la possibilità che le assunzioni avvengano anche utilizzando un sistema nominativo (sul punto v. par. 3.2.), cosa di per sé positiva, ma che ha un forte potenziale discriminatorio.

La verifica della rischiosità di questa scelta la troviamo in un recente rapporto sulla disabilità, redatto dalla FISH (Proietti & Zucca, 2020) in cui si sottolinea la grande differenza tra il settore pubblico e quello privato per quanto riguarda il numero delle occupate. Il 49,9% delle donne (contro il 38.5% presenti nel settore privato) lavora nel settore pubblico[20], a cui, come è noto, si accede per concorso pubblico, modalità che lo rende immune, al momento della selezione, da valutazioni estranee a quelle che riguardano le competenze professionali.

Al contrario, il settore privato è particolarmente propenso ad inficiare le politiche di selezione con meccanismi discriminatori e ad agire in base ai pregiudizi[21]. La lavoratrice disabile è estranea, in quanto donna, alla costruzione dell'organizzazione del lavoro, storicamente cresciuta intorno al lavoratore uomo, e contrasta, in quanto disabile, con la dominate idea abilista che si ha del lavoratore (Jones, 2016)[22].

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[19] I dati sono tratti dal rapporto della Fondazione studi Consulenti del lavoro, *op. cit*. A livello europeo i dati differiscono e si attestano su una percentuale del 50,6% per quanto riguarda gli uomini e del 44,77% per quanto interessa le donne.

[20] Si veda Fondazione studi consulenti del lavoro, *op. cit*.

[21] Proietti, Zucca, 2020, riportano che circa il 65% delle donne con disabilità che lavorano riporta di avere subito una qualche forma di pressione negativa.

[22] Un'ulteriore difficoltà che spiega il divario di occupazione è la circostanza è che la domanda di lavoratori con disabilità è condizionata dalla produttività percepita di tali dipendenti e dalla discriminazione.

Lo stigma che accompagna la donna con disabilità, tuttavia, non incide solo sul momento della selezione, ma condiziona la qualità e i rapporti di lavoro: sono le donne che soffrono il *gap* salariale[23], che sono meno soddisfatte della conciliazione vita-lavoro (Eurofound 2021)[24], che vivono la di segregazione occupazionale[25], che si lamentano maggiormente della mancanza di prospettive di carriera. Lo *status* di disabilità, quindi, pur non influendo sulla tipologia di disagio lavorativo, né sulle cause, sempre imputabili al genere, opera come moltiplicatore di effetti svantaggiosi.

Da ultimo, un altro dato sul quale riflettere è l'alto tasso di donne inattive. Il tappo che si crea al momento dell'ingresso nel mercato del lavoro e l'alta percentuale di donne inattive hanno quale comune terreno di coltura l'esistenza di difficoltà che, in quanto originate da un insieme di motivazioni, trovano difficilmente rimedio (o se lo trovano è insufficiente) nelle regole giuridiche così come sono redatte (v. par. 4.3.), molto focalizzate ad agire sul singolo problema, senza mettere in discussione l'attuale struttura sociale, che è una delle cause.

Queste osservazioni risultano più chiare se si ricostruiscono le ragioni dell'inattività, originate da una molteplicità di motivi che hanno diversa natura. Il primo è la minore scolarizzazione delle donne con disabilità; il 17,1% delle donne contro il 9,8% degli uomini è senza titolo di studio (nel resto della popolazione le quote rispettivamente, sono 2% e 1,2%) (ISTAT 2020)[26]. La mancanza di un titolo di studio, non crea solo danni in sé ma, sempre secondo il Rapporto ISTAT del 2020, influisce negativamente sulla valutazione soggettiva delle proprie condizioni di salute. La salute percepita, come ci ricorda l'OMS[27], è un indicatore importante del complessivo stato di benessere psicofisico e del livello di integrazione sociale. Percepire uno stato di salute peggiore rispetto a quello oggettivo, è un elemento che determina l'autolimitazione delle proprie attività. Inoltre — come si legge sempre nel rapporto ISTAT — è molto forte l'associazione tra limitazioni di attività e morbilità cronica: non a caso la diffusione delle malattie croniche interessa l'11,1% delle donne in età lavorativa contro il 7,9% degli uomini.

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[23] Le donne guadagnano sistematicamente di meno degli uomini e sono meno presenti nelle fasce medio-alte di reddito (1500€ in su), in cui troviamo il 42% dei lavoratori e il 23% delle lavoratrici. È lecito ipotizzare che, quanto si osserva nella popolazione in generale, sia valido anche nel caso delle lavoratrici con disabilità, ossia la presenza di discriminazioni salariali e minori compensi a parità di mansione; o anche la discriminazione nell'accesso alle mansioni con corrispettivi salariali più elevati.

[24] Problema che, logicamente, è presente tra le donne disabili in quanto direttamente collegato alle dinamiche sociali di divisione di ruolo che sono indipendenti dallo status di disabilità.

[25] Le attività lavorative più comuni nel pubblico impiego sono le mansioni impiegatizie (+5 punti percentuali) e l'insegnamento (+4 punti percentuali), anche le più diffuse tra le donne. Le motivazioni di questo differenziale, in parte, sono collegate alla segregazione occupazionale.

[26] Si veda rapporto ISTAT, *op. cit.*

[27] La salute percepita, ovvero la valutazione soggettiva delle proprie condizioni di salute, rappresenta ormai un importante indicatore di salute a livello internazionale. È infatti in grado di cogliere il più ampio concetto di salute, inteso come «completo benessere fisico, mentale e sociale», secondo le raccomandazioni dell'OMS.

Incomincia a delinearsi, quindi, l'assoluta indispensabilità di interventi, anche normativi, trasversali che valutino il differente impatto che le norme producono sui gruppi di destinatari, anche in relazione al loro sesso (v. par. 4.).

In Italia, tuttavia, l'interesse per i *Disability studies*, è un tema di nicchia e la scarsezza di dati pubblici, cosa della quale sono responsabili anche le istituzioni, contribuisce a tenere il tema sottotraccia. La massima espressione del disinteresse normativo, non a caso, è la sistematica violazione da parte del Governo dell'obbligo (art. 21 L. 23/3/1999 n.68) di fornire al Parlamento, con cadenza biennale, una relazione sullo stato di attuazione della normativa sul collocamento obbligatorio mirato (par. 3.2.). L'ultima comunicata, pur risalendo al 2018, utilizza dati aggiornati al 2014-2015. Non solo, ma la tematica della disabilità di genere, inglobata, come succede nel caso delle matrioske, nella generale nicchia della disabilità suscita ancora meno interesse e i dati disaggregati riguardano pochissime voci.

3.2. La cornice normativa del sistema del collocamento obbligatorio

Non è questo il luogo per approfondire le complesse dinamiche del sistema italiano di collocamento obbligatorio[28]: è necessario, però, introdurre alcuni punti fondamentali, da utilizzare come guida nelle valutazioni e riflessioni successive.

L'Italia ha una lunga tradizione in tema di promozione dell'attività lavorativa delle persone con disabilità che si concretizza, soprattutto, nell'istituto delle 'quote di riserva'. I datori di lavoro, sia pubblici sia privati, con percentuale variabile in relazione alla loro dimensione (legge n. 68/1999 per quanto riguarda il settore privato) — previa verifica della percentuale d'invalidità posseduta che si accerta tramite procedure mediche/amministrative — hanno l'obbligo di assumere una quota di personale con disabilità[29]. Lo scopo che il legislatore intende raggiungere è duplice: assistenzialistico, in quanto i datori di lavoro godono di incentivi economici per l'assunzione di personale disabile[30]; ma anche solidaristico perché è un potenziale e forte strumento di inclusione lavorativa. Nel tempo, la funzione solidaristica si è accentuata. La forza inclusiva che possiede il meccanismo delle quote di riserva si è potenziato con il passaggio da una tecnica di individuazione dei lavoratori da avviare, basata, essenzialmente, sul

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[28] Disciplinato dalla legge n.68/99, modificata nel 2012, con la legge n. 92 — cd. legge Fornero — nel 2015 e nel 2016 con i decreti attuativi del *Jobs act*.

[29] Condizione perché sorga il diritto all'assunzione tramite collocamento mirato è l'esistenza di percentuali d'invalidità (superiore al 45%) che incidano sulle capacità di lavoro. Per le persone con minorazioni fisiche, psichiche o sensoriali e per i disabili intellettivi, la «riduzione della capacità lavorativa» deve essere superiore al 60 per cento.

Il numero dei lavoratori con disabilità da assumere dipende dal numero dei lavoratori già presenti in azienda ed oscilla da un minimo di 1 (azienda da 15 a 35 dipendenti) ad un massimo del 7% del personale nelle aziende con oltre 50 dipendenti.

[30] Si veda art. 13 L. n. 68/99.

collocamento numerico[31], a regole che utilizzano un sistema nominativo[32], secondo una procedura non differente da quella esistente nel mercato del lavoro ‘ordinario’.

Il risultato di questo mutamento consiste in un deciso cambio di paradigma[33]; attualmente, l’incontro tra domanda ed offerta è regolato dalla corrispondenza tra attività lavorativa disponibile e capacità lavorativa. Il metro che orienta la selezione diventa la capacità della persona, non più i suoi limiti (disabilità), come avveniva in base alle regole precedenti in materia di collocamento.

Il senso del cambiamento è dato non solo da un parziale cambio di denominazione, collocamento, sì obbligatorio (quote di riserva), ma «mirato», ma anche dalla predisposizione di una serie di strumenti, tecnici e di supporto, funzionali ad aiutare gli Uffici all’avviamento delle persone con disabilità (art. 2 l. n.68/99). Con un metodo espositivo un po’ caotico, nel testo di legge l’analisi dei posti di lavoro si affianca alle forme di sostegno, alle azioni positive, alla ricerca di soluzioni di problemi connessi all’ambiente di lavoro ed alle relazioni interpersonali sui luoghi di lavoro. Elementi eterogenei, ma tutti finalizzati ad adeguare il disposto legislativo agli obblighi europei ed internazionali

L’ultimo tassello nell’evoluzione del sistema del collocamento obbligatorio «mirato» è il d. lgs n. 151/2015, temporalmente successivo all’introduzione nel nostro sistema normativo del divieto di discriminazione per disabilità (D. Lgs. 216/2003), nonché alla ratifica da parte del Governo italiano della Convenzione Onu in materia di diritti delle persone con disabilità (2009). Le tracce di queste due disposizioni sono ben visibili, peccato, però, che le linee guida per potere applicare le disposizioni del D.LS n. 151/2015 non siano mai state emanate.

Rimangono, così, solo intenzioni la revisione della nozione di disabilità alla luce dei criteri di valutazione bio-psico-sociale; l’istituzione di un responsabile dell'inserimento lavorativo nei luoghi di lavoro; l’individuazione di buone pratiche d’inclusione lavorativa dei disabili.

Senza nessuna pretesa di esaustività si segnala che il 31 dicembre 2021 è entrata in vigore la legge n. 227/21 che delega il Governo ad emanare quelle che, sulla carta, sembrano essere consistenti modifiche in materia di disabilità. In particolare potrebbe introdurre nel nostro ordinamento, in via definitiva, la nozione psico-sociale di disabilità; in maniera esplicita la

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[31] Si veda L. n. 462/1968.

[32] Ai sensi del d. lgs n. 151/2015 le assunzioni nominative sono estese a tutti datori di lavoro privati e agli enti pubblici economici per l’intera quota e non ci sono più limiti di percentuale per le richieste nominative. La percentuale di residua capacità lavorativa richiesta si diversifica in relazione alla tipologia di disabilità; rimane al 60% per le persone affette da disabilità fisica o sensoriale e diminuisce al 45%, per la disabilità psichica/intellettiva (art. 4 d. lgs n. 151/2015).

[33] Condizione perché sorga il diritto all’assunzione tramite collocamento mirato è l’esistenza di percentuali d’invalidità (superiore al 45%) che incidano sulle capacità di lavoro. Per le persone con minorazioni fisiche, psichiche o sensoriali e per i disabili intellettivi, la «riduzione della capacità lavorativa» deve essere superiore al 60 per cento.

delega obbliga il Governo ad adottare «una definizione di ‘disabilità’ coerente con l'articolo 1, secondo paragrafo, della Convenzione delle Nazioni Unite sui diritti delle persone con disabilità». L’obiettivo, in assoluto, lodevole potrebbe, però, essere vanificato da due cose. La prima è insita nel meccanismo giuridico, la delega, che dovrebbe garantire l’attuazione del dettato legislativo: appartiene alla storia italiana la non attuazione di deleghe ovvero il loro travisamento. La seconda, del tutto interna alla costruzione dell’atto normativo, è collegata al meccanismo immaginato per la verifica della condizione di disabilità, momento in cui attualmente prende corpo l’idea medica della disabilità grazie alle indagini basate (quasi) esclusivamente sugli *impairment* fisici. La nuova procedura, organizzata in due tempi, ipotizza una prima fase «valutativa di base» obbligatoria per tutti per accertare la condizione di disabilità e le necessità «di sostegno intensivo o di restrizione della partecipazione della persona ai fini dei correlati benefici o istituti». A questa segue una seconda ed eventuale valutazione, attivata su richiesta della persona interessata, che la legge definisce «multidimensionale» con lo scopo di «realizzare il progetto di vita individuale, personalizzato e partecipato». In apparenza la duplicità delle valutazioni e, soprattutto la differenziazione tra gli obiettivi da raggiungere, e quindi, realisticamente, la diversità dei contenuti e parametri di indagine è in contraddizione con lo scopo di adeguare la nozione nazionale di disabilità a quella di derivazione internazionale. Resta da valutare, tuttavia, il ruolo che può avere nell’omologazione delle procedure valutative il richiamo alla Classificazione internazionale del funzionamento, della disabilità e della salute (International Classification of Functioning, Disability and Health ICF) che si concretizza nell’uso di una pluralità di indicatori alcuni riportabili alla sfera psico-sociale.

3.3. I limiti del sistema collocamento obbligatorio: rivisitando l’alfabeto «del diritto della disabilità»

L’espressione «diritto della disabilità» è presa in prestito da Sanlorenzo (2018)[34] che la utilizza per sollecitare un cambio di rotta nella concezione di disabilità che sposti l’attenzione dai limiti alla valutazione delle capacità.

Il sistema del collocamento obbligatorio ‘mirato’, teoricamente, come abbiamo già detto, è ispirato a questa logica. Il valore della persona, in quanto lavoratore/lavoratrice, non è più dato dai suoi limiti, ma dalle sue capacità. Parametro di misura diventa il contenuto della prestazione lavorativa che dovrà essere idonea alla «residua capacità lavorativa»: ma anche in linea, sia per qualità che per quantità, con quelle dei colleghi non disabili che prestano la stessa attività. Fino a qui tutto assolutamente condivisibile. Peccato che l’espressione «residua capacità lavorativa» tenga conto solo di un’equivalenza matematica tra la percentuale d’invalidità e la capacità di

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[34] Per Sanlorenzo la costruzione di un «diritto della disabilità» che muova dall’approccio basato sulle capacità e dunque sulla universale dignità umana, non è solo frutto di una teoria morale fondata sui valori, ma, come insegnano gli studi di Martha Nussbaum, rappresenta una dottrina politica che concerne i diritti fondamentali. La Convenzione Onu si ispira a questa dottrina.

lavoro, indipendentemente dalle mansioni concrete che vengono attribuite alla persona disabile. Si può verificare, così, ad esempio, che persone con disabilità molto gravi, ma il cui tipo di disabilità non incide minimamente sulla loro produttività, vengano valutate solo in base alla loro condizione medica. Questo scollamento tra capacità reale e capacità presunta contribuisce al pregiudizio negativo sulla produttività delle persone con disabilità con pessime ripercussioni sul saldo occupazionale.

In una qualche misura, però, il pregiudizio viene anche fomentato dalla storica scelta del nostro sistema legislativo di destinare la maggioranza dei fondi pubblici a sostenere sistemi che incentivino i datori di lavoro ad assumere, piuttosto che investire in misure destinate a rendere le persone con disabilità più appetibili per il mercato del lavoro. Il prototipo di lavoratore ‘normale’, in funzione del quale sono state costruite le regole ed in funzione del quale è strutturata l’organizzazione del lavoro, riappare come aspirazione, anche se ben occultato dalle parole delle disposizioni normative.

Quello fatto è solo un esempio di come il sistema collocamento obbligatorio mirato sia, di fatto, refrattario alle profonde e sostanziali modifiche che sono imposte, non solo dalla normativa italiana, ma anche dalle disposizioni internazionali. Un sistema per molti aspetti, autoreferenziale che non riesce a farsi amico di nozioni quali quella di «accomodamenti ragionevoli»; né di concetti come discriminazione di genere, che sente come un corpo estraneo. Il sistema di collocamento obbligatorio mirato, ripiegandosi sui suoi limiti e non sfruttando le sue potenzialità, diventa esso stesso un riproduttore di diseguaglianze che si manifestano sia tra lavoratori con disabilità e lavoratori ‘normali’ sia tra lavoratrici con disabilità e lavoratori con disabilità (v. par. 4.)[35].

I dati che riguardano il disavanzo occupazionale, ad esempio, costituiscono il caso più evidente della discrasia tra situazione giuridica e situazione. L’osservazione acquista maggiore peso alla luce della norma (art. 1 D.LGS n. 216/2003) che riconosce, anche se non in maniera del tutto esplicita, la multidiscriminatorietà data dalla compresenza dei fattori sesso e disabilità[36]. Quale conseguenza di questa qualificazione tutti gli strumenti di tutela, offerti dal diritto antidiscriminatorio in tema di disabilità, possono/debbono essere finalizzati anche al superamento del *gap* di genere. In particolare, si pensi all’obbligo posto a carico dei datori di lavoro di «accomodamenti ragionevoli». Cioè, (usando le parole della Convenzione Onu), di «tutti gli adattamenti necessari ed appropriati» per garantire alle persone con disabilità la piena

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[35] Questa tendenza, purtroppo, non accenna ad invertirsi. La legge n. 227/21 che delega il governo ad emanare provvedimenti in materia di disabilità che dovrebbero ‘rivoluzionare’ quasi completamente l’impostazione dell’attuali disposizioni e nozioni (v. par. 3.2) non fa alcun accenno al problema del genere, nonostante uno dei suoi scopi sia quello di adeguare l’ordinamento italiano alle disposizioni contenute nella Convenzione Onu sui diritti delle persone con disabilità.

[36] Questa interpretazione trova una forte sponda nel testo dell’art. 6 della Convenzione ONU sui diritti delle persone con disabilità.

eguaglianza con gli altri lavoratori. Dall'obiettivo che ha l'obbligo di accomodamenti ragionevoli deriva che se, come è esplicitato dalla stessa norma, le donne con disabilità, a causa della compresenza dei due fattori di discriminazione, soffrono di discriminazione multiple, lo stesso obbligo dovrà plasmarsi anche sulle specifiche esigenze femminili. In caso contrario ci troveremmo di fronte ad una violazione del principio di eguaglianza sostanziale. Gli accomodamenti ragionevoli, per l'ampiezza di contenuti che caratterizza questa nozione e, per la vastità delle difficoltà che marcano i percorsi lavorativi delle lavoratrici con disabilità[37], avrebbero tutte le potenzialità per rivelarsi il rimedio più idoneo al riallineamento dei diritti. Tuttavia, è dubbio che l'obbligo di l'accomodamento ragionevole entri in campo prima dell'ingresso della lavoratrice nel luogo di lavoro. Si rende, così, necessario incidere sulle regole di accesso al mercato del lavoro, nonché sulle condizioni socio-ambientali che si ripercuotono negativamente proprio sulle possibilità di accesso.

Su questi aspetti potrebbero intervenire le azioni positive. L'art. 2 L. 212/3/1999 n. 68 attribuisce al collocamento obbligatorio «mirato» la facoltà di introdurre azioni positive con lo scopo di facilitare l'inserimento delle persone disabili nei posti di lavoro. Anche se la norma è bidirezionale — operando sia in favore di lavoratori con disabilità, sia di lavoratrici con disabilità — di fatto, la situazione di svantaggio numerico che penalizza le donne la rende una tecnica di promozione del lavoro di queste ultime. Particolarmente adatte, inoltre, perché potrebbe essere finalizzata a regolare mercati del lavoro locali ovvero iniziative dedicate a specifiche realtà lavorative, cosa estremamente attraente al momento di puntare ad un'operazione di riequilibrio occupazionale.

A livello nazionale, invece, la possibilità di adottare azioni positive è contenuta nel D.Ls. 11/4/2006 n. 198 (Codice delle pari opportunità) che disciplina. In questo caso il fattore esplicitamente protetto è il sesso e le azioni positive per la loro legittimazione richiederebbero il confronto tra gli indici occupazionali delle lavoratrici 'normali' e quelli delle lavoratrici con disabilità. Come si è visto, anche in questa ipotesi, non ci sarebbe nessun problema di prova, data la sottorappresentazione che interessa le donne con disabilità.

In via interpretativa, inoltre, lo svantaggio occupazionale delle donne con disabilità può essere interpretato, per quanto già detto, come un fenomeno di discriminazione multipla. In questo caso il confronto potrebbe avvenire tra il gruppo dei lavoratori uomini con disabilità e quello delle donne con disabilità. Accogliere questa interpretazione consentirebbe di intervenire sulla riserva di quote per l'accesso al lavoro. Una percentuale dei posti riservati a tutto il gruppo

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[37] Già abbiamo evidenziato come siano le donne a soffrire maggiormente all'interno dei luoghi di lavoro di condizioni svantaggiose, la mancanza di prospettive di carriera, il gap salariale, l'insoddisfazione della loro conciliazione vita-lavoro sono solo alcuni esempi.

di persone con disabilità potrebbe essere riservata solo alle donne con disabilità[38], gruppo decisamente sottorappresentato.

In sintesi, non è la mancanza di strumenti normativi la responsabile (o perlomeno non lo è in parte consistente) del permanere delle situazioni di svantaggio, ma è la lettura neutra che si dà di questi.

Le nuove parole del diritto della disabilità non trovano legittimazione, il risultato è un innesto mal riuscito tra innovazione normativa e tradizione giuridica. Il sistema italiano, nonostante le premesse teoriche, purtroppo, non riesce a cambiare pelle.

4. Se il metodo di costruzione delle leggi cambiasse?

Siamo sempre più consapevoli che viviamo in un mondo interconnesso. Conosciamo e riconosciamo l'importanza che hanno le reti siano esse, tecnologiche, informative, amicali, sociali. Il sistema di produzione normativo, invece, in maniera un po' atemporale, continua ad utilizzare una modalità di riproduzione che segue linee mono dimensionali. Si pensa per singoli temi, al massimo per isole di problemi, senza costruire collegamenti tra tematiche. Questa modalità di intervento determina, in molti ambiti, un grande scollamento tra effetti reali ed effetti potenziali, con la conseguenza che indebolisce la stessa forza della norma di legge.

Le disposizioni in materia di genere rappresentano un chiaro indice di quanto detto. La mancata comprensione di come la disparità di condizione tra generi sia determinata dalla costruzione complessiva e patriarcale della società e di come sia irrisolvibile/inattaccabile, agendo solo su singoli aspetti, comporta che, anche normative eccellenti, non riescano ad intaccare, realmente, la disparità.

L'insegnamento che si ricava da questa situazione è che la risoluzione di (gli interventi su) problematiche che trovano origine in modelli e condizionamenti socioeconomici non possa essere affidata a leggi settoriali.

Del resto, già dalla fine degli anni '80, sia a livello internazionale sia europeo, ci si era resi conto che la diseguaglianza tra sessi era sistemica e che era necessario aggredirla in maniera trasversale. Diventa così indispensabile, per raggiungere questo obiettivo, introdurre procedure che valutino le diverse implicazioni che ha — per usare le parole del Consiglio economico e

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[38] L'UE e i suoi Stati membri devono mettere a punto azioni, sia di carattere generale che positive, mirate a questa specifica categoria e intese a promuovere la formazione, i collocamenti al lavoro, l'accesso all'occupazione, il mantenimento del posto di lavoro, la parità di retribuzione per uno stesso lavoro, le pari opportunità di percorso professionale, gli adattamenti sul posto di lavoro e l'equilibrio tra vita professionale e vita privata. Le donne con disabilità devono avere il diritto, alla pari con tutti gli altri, a condizioni di lavoro eque e favorevoli, incluse le pari opportunità e la parità di retribuzione per uno stesso lavoro (Parere del Comitato economico e sociale europeo su «La condizione delle donne con disabilità» [parere esplorativo richiesto dal Parlamento europeo] (2018/C 367/04).

sociale delle Nazioni unite — «ogni azione pianificata, compresa la legislazione, le politiche o programmi, in tutti i settori e a tutti i livelli», allo scopo di raggiungere la parità tra i sessi.

Traduce queste indicazioni l'art. 4 del D.LS. 11/4/2016 n. 198, che introduce l'obbligo di tenere presente l'obiettivo della parità di trattamento e di opportunità tra uomini e donne nella formulazione e nell'attuazione «a tutti i livelli ed a opera di tutti gli attori di leggi, regolamenti, atti amministrativi, politiche e attività». Quella che, sulla carta, è una disposizione molto avanzata e costituisce un obbligo preliminare all'introduzione di disposizioni di qualsiasi natura, in realtà, non è mai stata utilizzata ed è stata anche molto poco pubblicizzata. In quanto vigente, però, potrebbe rivitalizzarsi e valere anche con riferimento alla disabilità. Inoltre, come già prospettato, l'art. del 1 D.LGS n. 216/2003 riconosce, pure se non in maniera del tutto esplicita (anche alla luce dell'art. 6 della Convenzione ONU sui diritti delle persone con disabilità), la multidiscriminatorietà della compresenza dei fattori sesso e disabilità. Le situazioni di svantaggio che colpiscono le donne con disabilità hanno, quindi, natura di discriminazione multipla; da questa qualificazione deriverebbe la soggezione di tutti gli atti siano legislativi, amministrativi, o di indirizzo politico, al rispetto della parità di trattamento e della parità di opportunità tra uomini e donne.

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Accessibility and inclusion in higher education in Turkey

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1. Introduction

One of the main aims of education is being inclusive to all groups that are present in the society. Ensuring that individuals with disabilities have access to educational institutions and receive a high-quality education in an inclusive environment should be the primary responsibility of all countries and educational systems. The aim of this chapter is to present the current situation in Turkey regarding the educational opportunities of individuals with disability and the accessibility studies conducted in higher education (tertiary level education) institutions. In discussing the current status of individuals with disability, firstly their educational participation is presented. In the second section of the paper, the barriers they face are discussed. The third section of the paper focuses on the institutional support provided to individuals with disabilities. The last part of the paper draws conclusions regarding the issues individuals with disability face in tertiary education in Turkey and makes suggestions for the future.

2. The current situation in Turkey

Based on the figures supplied by the OECD and the European Union (EU), in the world, there are roughly one billion individuals with disability which make up nearly 15% of the world's population. One of the priorities and the main moral obligation of societies is to offer solutions that integrate the individuals with disabilities in social life and to offer their potential for the benefit of the public. This being the case, role of education in accomplishing this endeavor becomes important. As tertiary education is the main path to enter professional life, having the opportunity to earn a university degree becomes a high priority for individuals with disability.

A study conducted by the Turkish Ministry of Family, Employment and Social Welfare in 2016 estimates that 16,2% of the population consists of people who experience constant difficulty coping with basic life activities. This study also demonstrates that women with disability outnumber men with disability. Of the total number of people with disability, 8,4% experience visual, 5,9 auditory, 0,2 speech, 8,8% orthopedic, 29,8% mental, 3,9 emotional, 29,8% health

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related, and 18% multiple disabilities (Republic of Turkey, Ministry of Family, Labor, and Social Services, The General Directorate of Family and Social Services, 2018).

Turkish Statistical Institute reports that in 2019 in Turkey, active employment of all adults is 53% where 72% constitute men and 35% constitute women. However, when individuals with disability are considered, this proportion decreases to 35,4% for men and 12,5% for women leading to a total of 22,1% employment of individuals with disabilities. These figures reflect that employment rate of people with disability is lower than the employment rate of people without disability.

In the OECD countries, 40% of the employed individuals with disability have received primary and secondary education while this proportion is 20% among individuals without disability. In EU countries, the dropout rate after primary school is 25% whereas it is 60% in Turkey. In Turkey, observing that only 22,1% of the population of individuals with disability are employed encourages us to question the extent to which such individuals are educated not only at primary and secondary levels but also at tertiary level.

Another point worth noting is that for the year 2021, Special Education Department of the Turkish Ministry of Education is receiving only 1% of the total of the budget allocated to the Ministry of Education. The situation for people with disability seems to be worsened after the COVID-19 pandemic in Turkey. In July 2020, Turkish Statistical Institute reported that while participation in the workforce is 49,5% for the whole population, it is only 22% for people with disabilities; that is, only 22% of the disabled people were employed in the post-COVID-19 era. Based on official figures, while 78% of people with disabilities are unemployed, this figure is 13% for the general population. The number of unemployed women with disability has also increased after the pandemic: unemployment is 16,3% for women without disability and 32% for women with disability.

Another striking finding reported by the Confederation of Persons with Disabilities in 2020 is the violence experienced by women with disability. This recent report indicates that 32% experience violence from their husbands, 16% from their fathers, and 11% from their children. Forty-four percent of the women with disability report needing psychological support while 93% express not being able to receive the support they require. These findings demonstrate that women with disability experience discrimination in multiple domains due to gender and disability related biases.

According to the figures announced by the Turkish Council of Higher Education in 2020, there are nearly 7,5 million students enrolled in tertiary education in Turkey and only 47,751 (6,4%) of them have reported having at least one disability. Of the students with disability, the nature of the disability is not known for 38,895. Among the individuals for who the disability is known, 2,705 have a physical disability, 2,031 have visual and 1,103 have auditory impairment. The number of students with autism and cognitive disability is very limited in Turkish universities perhaps due to the competitive high stakes university entrance screening system. Only 119 students are reported to have mental disability while 58 are diagnosed with autism and 21 are diagnosed with Asperger syndrome. In Atatürk University 4,760, Istanbul University 1,670, and Ankara University 247 students with disability are enrolled. When the type of university is considered, 42,062 of the students with disability are in open university programs. Five thousand are in formal education programs while 515 are in distance education. Of the total number of 47,751 students with disability, 32,944 are men (Council of Higher Education, 2020). The disproportionate representation of women with disabilities in higher education is striking.

As of March 2020, the global COVID-19 pandemic has caused an education emergency of unprecedented scale. According to the World Bank Report of 2020, at its peak, the pandemic caused more than 180 countries to mandate temporary school closures, leaving 85 percent of the learners (approximately 1.6 billion children) out of school for close to 11 weeks as of June 30, 2020. Interruptions in face-to-face instruction have multiple direct impacts on learners as schools offer structure and routine, peer group contact, friendships, support, and safety. This observation regarding the multidimensional effects of school closure applies also to tertiary education where a similar situation is observed since March 2020. Today, an announcement made by Turkish Council of Higher Education reports that approximately 7,5 million university students in 207 universities have been obliged to migrate to emergency online instruction since the outset of the pandemic in March 2020. As outlined in the World Bank Report 2020, COVID-19 pandemic has further deepened the stark inequalities in our world. There is a real threat that persons with disability, who have traditionally been among the most vulnerable and marginalized populations, are likely to be most influenced by the negative consequences of the pandemic. From an educational standpoint, the main concern is that students with disability are least likely to benefit from remote learning solutions as the necessary assistive technologies are usually scarce.

3. Factors that contribute to inclusive higher education experiences

Identifying and removing obstacles that make life difficult for people with disabilities are one of the important study topics in the field of disability. In addition to the difficulties arising from disability, environmental conditions become prohibitive in many cases where reasonable accommodations are not made for the special needs of persons with disabilities. As stated in the World Report on Disability prepared jointly by the World Health Organization (WHO) and the World Bank (WHO, 2011), persons with disabilities face many obstacles including the health system, rehabilitation, education, and working areas.

Across the world, a growing number of studies have been conducted to explore how various factors within university settings (or context) contribute to the success or failure of students with disabilities. According to the United Nations Convention on the Rights of Persons with Disabilities (2006), the difficulties faced by persons with disabilities can be defined as discriminatory if they negatively affect an individual's equal and full participation in social life in accordance with human rights principles. In addition to the problems faced by individuals with disabilities in terms of health, education, work, and accessibility, it is stated that attitudes towards persons with disabilities also make life difficult, cause discriminatory behaviors (Ajzen & Fishbein, 2005), negatively affect equal access and participation (Paul, 2006), and in many cases, changing negative attitudes is much more difficult than removing social and economic barriers (Shakespeare, 2014).

Attitudes motivate us to act and respond to others. Precisely, attitudes are tendencies to act in a stereotypical and predictable way to other individuals who are part of a certain group (McCaughey & Strohmer, 2005). The current view on the concept of attitude emphasizes its multidimensionality. Attitudes have components such as memory and judgment (Albarracin, Wang, Li, & Noguchi, 2008) and are related to beliefs, emotions, and behaviors (Antonak & Livneh, 1988; Albarracin, Johnson, & Zanna, 2005). According to the study of Ajzen and Fishbein (2005), there is a reciprocal relationship between attitudes and behaviors, and certain behaviors are shaped in line with the beliefs, attitudes, and intentions of the person. Altman’s (1991) study has also shown that attitudes towards people with disabilities can affect the individual's (with disability) development of a positive self-perception and socialization.

At the tertiary level of education, studies conducted with students regarding their attitudes toward students with disabilities have revealed inconclusive findings. Paul (2006) found that the duration of contact with people with disabilities, and the relationship type are related to the attitudes of undergraduate and graduate students towards people with disabilities. In another study, it was observed that the students had a positive approach to the social engagement with people with disabilities; however, they were uncomfortable with spending time with them, and beliefs that people with disabilities are different in nature compared to people without disabilities were common (Naami & Hayashi, 2012). In the same study, the level of interaction with disabled people was not found to be related to the attitudes. In another study, no significant relationship was observed between the frequency of interaction with disabled individuals, the perceived level of knowledge about disability, social work lessons, age, gender, and attitudes towards people with orthopedic disabilities (Haskell, 2010). In a study examining the explicit and implicit attitudes towards the people with disabilities among undergraduate students, it was revealed that students have implicitly negative but explicitly positive attitudes, and male students have more overt negative attitudes than female students (Chen, Ma & Zhang, 2011). In one of the review studies, Boer, Pijl, and Minnaeart (2012) found that students generally hold neutral attitudes towards their peers with disabilities. Nevertheless, students’ attitudes are influenced by gender, age, type of disability, experience with inclusive education, and knowledge about different types of disabilities. Indeed, lower misconceptions about disabilities mediated the relationship between increased contact with individuals with behavioral disabilities among undergraduate students. Students who hold more positive attitudes toward individuals with disabilities are more likely to be education majors (Barr & Bracchitta, 2008), and women students with more hands-on experience demonstrate more positive attitudes (Folsom-Meek, Nearing, Groteluschen, & Krampt, 1999).

Standing against the discrimination and implementation of supports provided by the universities are key factors for inclusive tertiary education. During the implementation of supports in university settings, faculty members' attitudes, beliefs, and actions regarding students with disabilities and their perceptions about the use of auxiliary aids such as teaching and exam accommodations are critical. Overall, results of several studies have indicated that most of the faculty members have positive perceptions about students with disabilities, but they underline a need for training to accommodate them. In one study, female nontenured faculty within the college of education who had previous disability focused training experiences have reported more positive attitudes toward providing accommodations and adopting universal design principles (UDP) (Lombardi & Murray, 2011). At the heart of UDL are three core principles for instructional design: multiple means of engagement, multiple means of representation, and multiple means of action and expression (Rose & Meyer, 2002). The employment of UDP enabled inclusion of accessibility concepts beyond the physical environment and provided varied, accessible, and engaging teaching and learning opportunities for all students. Overall, the framework of UDP aimed to remove discriminatory practices while fostering development of positive attitudes.

Other related studies show that people who have been working as lecturers for less than 5 and more than 26 years expressed discomfort in communicating with people with disabilities (Kjellerson, 2009), and the increase in the frequency of interaction with the persons with disability is associated with the decrease in negative attitudes (Aaberg, 2010; MacMillan, Tarrant, Abraham, & Morris, 2014). Empirical evidence also indicates that previous or current experience of teaching students with disability is associated with having more positive attitudes (Emmers, Baeyens, & Petry, 2020). Hence, the frequency of contact with people with disabilities along with teaching and training experiences appear to connect with more favorable attitudes towards inclusion in higher education.

Students with disabilities often perceive that faculty and administrators are mostly resistant to their accommodation requests (Farone, Hall, & Costello, 1998) and have difficulty obtaining reasonable accommodations (Dowrick, Anderson, Heyer, & Acosta, 2005). Hartman-Hall and Haaga (2002) examined the undergraduate students' reactions to hypothetical scenarios in which faculty reacted negatively or positively to a request for an accommodation. The study revealed that negative reactions from faculty negatively affected students' decisions to seek further assistance while positive reactions from faculty led to greater willingness to seek further assistance. This finding implies that faculty are particularly important figures in influencing students' decisions to seek support for their disabilities.

When university staff undergo a disability-focused extensive training, they become more sensitive to the needs of students with disabilities (Murray, Lombardi, & Wren, 2011). Other studies have also indicated that faculty who receive support from their departments about teaching students with disabilities and have prior disability focused in-service and pre-service training predict faculty’s willingness to provide teaching and exam accommodations (Bourke, Strehorn, & Silver, 2000; Bigaj, Shaw, & McGuire, 1999; Murrey, Lombardi, Wren, & Keys, 2009). Even providing five hours of group instruction for faculty members on the use of universal design learning principles and teaching strategies increases the implementation of those strategies (Davies, Schelly, & Spooner, 2013). These findings suggest that preventive measures can stimulate positive attitudes and perceptions among faculty, which can potentially promote positive and inclusive educational experiences among students with disabilities at the tertiary level.

When the impact of COVID-19 on education is considered, we realize that, while reliable figures on students with disabilities are not yet available, the current crisis has further affected their exclusion from education. As the United Nations Policy Brief on the «Impact of COVID-19 on Children» released in April 2020 indicates, students with disabilities are least likely to benefit from distance learning solutions. Lack of support, access to the internet, accessible software and learning materials are likely to widen the learning gap for students with disabilities. In a study conducted with Turkish women and girls with disabilities, participants reported that during the COVID-19 pandemic, they had difficulty to access to remote learning and could not benefit equally from their right of education (ENGKAD, 2021). Even before the pandemic, this situation has been emphasized by the faculty at higher education level. Though scarce, the available literature indicated that due to their limited experience at making online accommodations, most of the faculty were unsure whether they had the knowledge, technology, and support to handle online accommodations (Phillips, Terras, Swinney, & Schneweis, 2012). To conclude, previous challenges exist in higher education along with problems in providing assistive technology to people with disabilities (e.g., lack of supply, demand mismatches for products, inadequate numbers of trained personnel, limitations in innovation systems and processes) are largely observed and created additional challenges in the COVID-19 pandemic (Smith, MacLachhan, Ebuenyi, Holloway, & Austin, 2021).

4. Support provided to individuals with disabilities

Access to education is right for all individuals and it is known that, in Turkey, less than 3 percent of young people with disabilities have graduated from universities (State Institute of Statistics Prime Ministry Republic of Turkey, 2002). In Turkey, higher educational institutions are mandated to provide the necessary individual learning supports to enable students with disabilities to participate in education equally. In accordance with the articles 11 and 12 of

«Regulations on the Solidarity and Coordination of the Individuals with Disabilities in the Institutions of Higher Education» (2010, amended 2013 & 2014), Disability Support Offices (DSO) are responsible to provide this support and higher education institutions are required to implement reasonable accommodations to address physical, social, academic, and attitudinal barriers in learning environments. In fact, the law on «People with disabilities no. 5378 article 15» (2005, amended 2012, 2013 & 2014) mandated that universities are responsible to establish disability support offices to provide students with disabilities equal access to the facilities and services of university. Students with disabilities have varying needs, thus the support provided by the universities are varied. Nevertheless, based on the law and regulation, universities are required to provide ramps for wheelchair access, elevators, toilets, parking, signaling systems, tactile ground surfaces (guide strips, warning indicators, etc.), accessible classroom and lecture halls, Braille prints, sign language translators, recorded lectures, caption videos, scribes, note-takers, extension for assignments and exams, and course substitutions.

Similar legislations exist in North America, Australia, and many European countries to support tertiary students with disabilities (e.g., Bunbury, 2020; Emmers, Baeyens, & Petry, 2020; Fossey, Chaffey, Venville, Ennals, Douglas, & Bigby, 2017; Fowler, Getzel, & Lombardi, 2018). In those countries, some of the more common accommodations provided by the disability support offices are note-taking, extended time for assignment and testing, tape recording, preferential seating, taking exam in quiet place, priority registration, use of assistive technologies, and course substitutions. Like in Turkey, in many countries, the accommodations and need for special services are determined on case-by-case basis by the Disability Support Offices. Moreover, higher learning institutions are not required to identify and diagnose disability. It is the responsibility and preference of the student to document and disclose his/her disability (Singh, 2019).

A small body of research demonstrates that reasonable accommodations and support provided by disability support offices can be effective in increasing academic success of tertiary students with disabilities (Simpson & Ferguson, 2014; Schreuer & Sachs, 2014). However, one of the qualitative studies conducted with disability support office staff and students about implementing and using reasonable accommodations at two tertiary institutions in Australia indicated that support is not easily accessible and simply provided. Often, students with disabilities need to negotiate on reasonable adjustments and requesting adjustment is perceived as a student responsibility (Fossey, Chaffey, Venville, Ennals, Douglas, & Bigby, 2017).

Although providing reasonable accommodations ensures success, lack of clarity about roles and processes related to implementing reasonable accommodations can sometimes complicate this issue in higher educational settings. This is quite problematic when accommodating students with invisible disabilities. For instance, the number of students with learning disability and psychiatric disabilities has grown dramatically over the years. According to some sources, these students represent the largest group of students with disabilities in higher education institutes (Gargiulo & Metcalf, 2017). Faculty encounters students who have diverse disabilities (e.g., learning disabilities, Asperger's syndrome, psychiatric conditions, speech and language disorders, attention deficit and hyperactivity disorder, traumatic brain injury, orthopedic impairments such as spinal cord injuries, spina bifida, and cerebral palsy; hearing impairments, visual impairments; other health impairments such as asthma, diabetes, epilepsy, fibromyalgia, cancer, arthritis, cardiac problems and HIV) and accordingly diverse needs in their classrooms (Singh, 2019). In fact, the empirical evidence obtained recently suggests that some faculty members struggle to accommodate students with disabilities because of lack of knowledge, training, and awareness of disability (Bunbury, 2020). It was also reported in another recent study that faculty feel less confident in designing learning tasks to accommodate the individual needs of students with disabilities (Emmers, Baeyens, & Petry, 2020). Likewise, another qualitative study in a higher education institution has indicated that academic staff still needs training in increasing disability awareness and implementing inclusive instructional practices, and there is a need to move away from making individual reasonable accommodations to inclusive education for all (Collins, Azmat, & Rentschler, 2019). Moreover, having an inclusive curriculum and switching focus to the social model of disability can minimize the need to make reasonable accommodations in higher education institutions (Bunbury, 2020).

5. Conclusions and recommendations

People with disabilities still encounter barriers to quality education due to discrimination, lack of reasonable accommodations, and inaccessible buildings, and teaching. Social inclusion, community participation, and empowerment are crucial concepts guiding policies, legislation, and services for people with disabilities. Existing legislations and support systems are guaranteed educational rights of individuals with disabilities. Nonetheless, in practice, the situation is not what it looks like. For instance, in Turkey, according to the Turkey Disability Survey results (State Institute of Statistics Prime Ministry Republic of Turkey, 2002), in total population with disability under the age of 25, the total illiteracy rate is 36.37%, and the illiteracy rate of females is three times higher than that of males. The similar trend is observed throughout the educational levels. The proportion of primary school graduate individuals with disability in total is around 40.97% but only 2.42% of them have graduated from a higher education institution. In the group of young people with disabilities, university graduate females' ratio is even more thought-provoking. Of the university graduates, only 1.45% of them are women with disabilities in comparison to 3.10% of men with disabilities. The underlying reasons of this situation can be related to many factors including society's perception and attitudes toward disability, lack of knowledge, gender-role biases, and inadequate inclusive educational practices. In fact, a qualitative study with elementary school teachers and counselors in Turkey demonstrated that school staff had positive beliefs about educating students with disabilities in regular schools but in classroom practice, students with disabilities are far from being fully included (Sakiz & Woods, 2014). This empirical evidence is particularly important when we think about the number of students with disabilities that drop out the formal school system before reaching the tertiary education. From the earlier studies, it is known that teacher skill and attitude are critical variables in the success of inclusive education. Therefore, these findings suggest that teacher training programs should be modified in the direction of including more inclusive teaching practices with enhancing awareness of preservice teachers regarding negative attitudes and stereotypical thinking that exist in society. Thinking and acting inclusively may also foster teacher candidates' motivation to educate students with disabilities which in turn may impact on the educational aspirations of students with disabilities.

A recent research shows that mobility, employment, and educational status are crucial factors of community participation of people with disabilities (Akyurek, Bumin, & Crowe, 2020). Society and its range of systems need to be stimulated to think and act inclusively to increase community participation of people with disabilities. Furthermore, tertiary education is one of the main paths to enter professional life and to a better future. Hence, all the staff in tertiary education institutions should take part in the process of disability inclusion and campus-wide inclusiveness should be implemented (Lyner-Cleophas, Swart, Chataika, & Bell, 2014). Empirical evidence reveals that faculty become more knowledgeable and feel more confident in designing learning tasks to meet the individual needs of tertiary students with disability when they learn practical strategies based on the universal design principles (Emmers, Baeyens, & Petry, 2020; Lombardi, Murray, & Dallas, 2013). Thus, universal design provides effective support and ensures accessibility to students both with and without disabilities. As Patterson (2018) emphasizes, to promote the educational expectation of students with disabilities, encouragement received from the faculty has the potential to make a difference. More supportive and appropriate level of challenge can facilitate learning. Moreover, to address the diverse needs of students at higher education, inclusive curriculum including the course content, teaching, and assessment methods should be designed to minimize making individual accommodations (Fossey, Chaffey, Venville, Ennals, Douglas, & Bigby, 2017).

Furthermore, university disability support office staff should plan training programs to faculty as well as to administrative staff. Based on an empirical evidence it was recommended that disability support staff can plan large training event, but simultaneously the training content should be delivered in small modules online or in print materials. This strategy seems beneficial because university staff may access the resources according to their time and needs, and same information can be disseminated across multiple formats. It was also suggested that using scenarios in trainings can be beneficial to provide more hands-on experiences to faculty and administrative staff (Fossey, Chaffey, Venville, Ennals, Douglas, & Bigby, 2017).

For inclusive tertiary education, the role of assistive technology should not be overlooked. Based on the experience of COVID-19 pandemic, there is a need to focus on the required systemic and systematic changes to ensure inclusive assistive technology services to all people.

As suggested, these services should be delivered according to rights-based approach, should be accessible, affordable, and address to disability related needs of individuals. Additionally, assistive technology users' participation is required to plan inclusive and effective services (Smith, MacLachhan, Ebuenyi, Holloway, & Austin, 2021).

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Guías de diversidad para apoyo al profesorado de la educación superior

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Diversity guidelines to support the teaching staff of the University

Keywords: diversity, student, inclusion, teachers, university

1. Introducción

En la actualidad, se está produciendo un cambio del concepto de integración al de inclusión, si bien la inclusión en realidad no se implementa aún en todos los centros de enseñanza superior.

Hoy en día, coexisten tres enfoques, tal como, se presenta en la tabla 1. El primer enfoque, el de la 'exclusión' se identifica la diversidad con los grupos que se diferencian de la sociedad dominante, por lo cual, se consigue que la persona asimile esta cultura. Se produce un proceso de asimilación, que resulta de negar el derecho a la diferencia. En el sistema educativo se identifica al estudiantado y se establecen medidas de exclusión. El enfoque de la 'integración' supone el reconocimiento de la convivencia de diferentes grupos que coexisten, donde la interacción es escasa y predomina el respeto mínimo o la tolerancia pasiva. Y, por último, el enfoque 'inclusivo' defiende un planteamiento que supone la aceptación de las diferencias, el desarrollo de valores que favorecen la convivencia y la comprensión de la diversidad. Por lo tanto, supone un planteamiento inclusivo en el que todos y cada uno son diferentes, por lo cual deben plantearse métodos, estrategias y recursos variados de acuerdo con las diferencias individuales de los grupos de estudiantes (Giménez, 2012; Jiménez y García, 2013).

Ello cambiará en función de las características del contexto social, en conocimiento de la diversidad y las medidas del contexto educativo. En esta clasificación, la equidad está enmarcada en el enfoque inclusivo y en el de integración.

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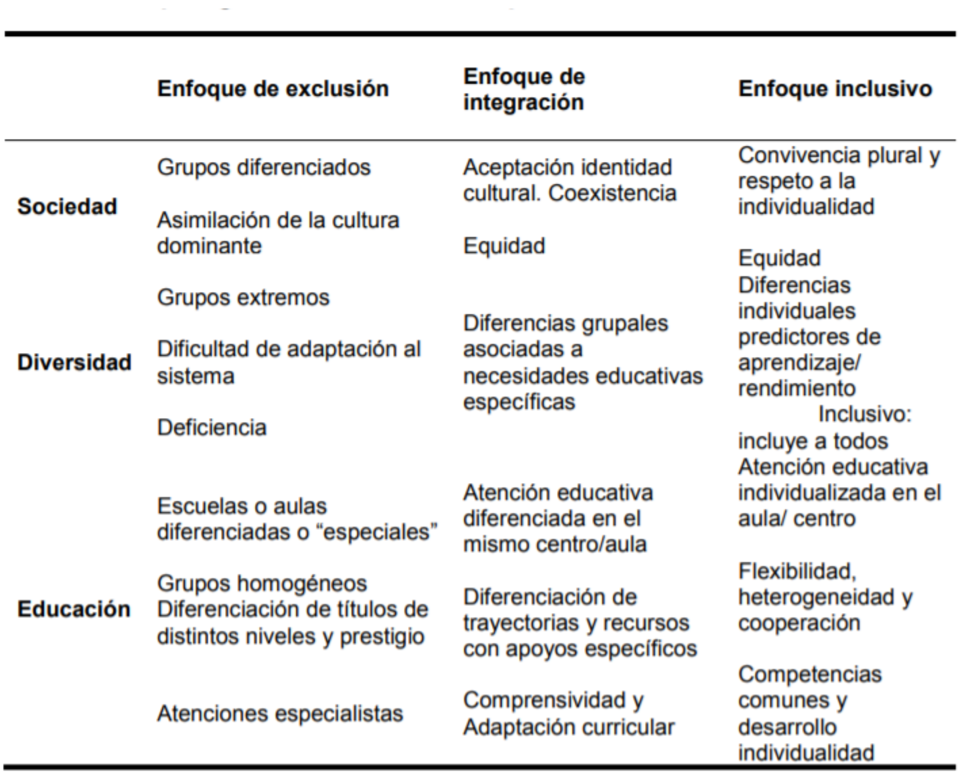
Tabla 1. Enfoques educativos



	Enfoque de exclusión	Enfoque de integración	Enfoque inclusivo
Sociedad	Grupos diferenciados Asimilación de la cultura dominante	Aceptación identidad cultural. Coexistencia Equidad	Convivencia plural y respeto a la individualidad Equidad
Diversidad	Grupos extremos Dificultad de adaptación al sistema Deficiencia	Diferencias grupales asociadas a necesidades educativas específicas	Diferencias individuales predictores de aprendizaje/ rendimiento Inclusivo: incluye a todos
Educación	Escuelas o aulas diferenciadas o "especiales" Grupos homogéneos Diferenciación de títulos de distintos niveles y prestigio Atenciones especialistas	Atención educativa diferenciada en el mismo centro/aula Diferenciación de trayectorias y recursos con apoyos específicos Comprensividad y Adaptación curricular	Atención educativa individualizada en el aula/ centro Flexibilidad, heterogeneidad y cooperación Competencias comunes y desarrollo individualidad

Fuente: Madrid, Sánchez, García y García (2011).

En la Agenda 2030 para el Desarrollo Sostenible, en el objetivo 4 sobre educación exige que se promueva y se haga hincapié en una educación inclusiva y equitativa, fundamental para la educación, un aprendizaje de calidad.

En este sentido, la «Guía para asegurar la inclusión y la equidad en la educación» (UNESCO, 2017) está destinada a ayudar a los países a incorporar la inclusión y la equidad en las políticas educativas. El objetivo es generar un cambio en el sistema para superar los obstáculos a una educación de calidad, y para asegurar que el estudiantado sea valorado y participe en igualdad de condiciones.

2. De la inserción laboral e integración a la inclusión social

El concepto de inserción laboral aparece también en Francia, en la época de los ’70. En un primer momento, el concepto hizo referencia a las medidas de formación laboral que se adoptaron tras la crisis económica de esa etapa. Estas medidas contemplan la creación de nuevos perfiles profesionales: formadores, agentes de empleo, coordinadores o supervisores (Urteaga, 2009; Sánchez y Jiménez, 2013).

Se busca favorecer la incorporación al mercado laboral de los jóvenes que eran las personas más afectadas por el desempleo.

Con posterioridad, se amplió la definición al concepto de inclusión. El escenario de desempleo genera situaciones de falta de perspectivas, falta de viviendas, aislamiento social o de las redes familiares. Por esto, «el concepto de inserción necesita ser ampliado, ir más allá de la inmersión en el mercado laboral, poniéndose entonces en uso un nuevo concepto, el de inclusión» (Sánchez y Jiménez, 2013, p. 140).

Los procesos y los resultados promovidos desde el concepto de inserción se centraban en el contexto laboral. Por ellos se comenzó a trabajar en el concepto de inclusión como «proceso de incorporación de las personas en riesgo de pobreza y /o exclusión social a la vida normalizada» (De Lucas, 2010, p. 84). A partir de esta nueva concepción de la inclusión social se comienza a estudiar la posible implantación de nuevas políticas centradas en el desarrollo personal, la reconstrucción de las redes sociales o el acceso a viviendas, con el objetivo de facilitar la autogestión y la autonomía de la persona.

A la debilidad económica, se pueden sumar otras categorías de desigualdades sociales como ser migrante, mujer, persona con diversidad funcional o trabajador con contrato discontinuo. Estas categorías suponen una situación de desigual de acceso a servicios, protección social, oportunidades laborales o educativas. En este aspecto, el concepto de inclusión social trasciende la mera igualdad relativa a los recursos económicos.

Por tanto, la inclusión es un proceso que asegura a las personas el aumento de las oportunidades y recursos, necesarios para la participación plena y el acceso a sus derechos fundamentales como ciudadanos. Continuando con lo anterior, en el «Informe Conjunto sobre la Inclusión Social» de la Comisión Europea (2003), se indica que hay que responder al reto de la exclusión social, ya que aparece como un fenómeno multidimensional complejo y dinámico. La pobreza es una más de las características de la condición significativa en la que se encuentra la persona, que tiene que afrontar problemas y retos, para llevar un proyecto de vida accesible.

3. De la inclusión social a la inclusión educativa

La inclusión social implica fundamentalmente una mayor inclusión en la educación, con una respuesta a la diversidad de necesidades de aprendizaje. Supone un desarrollo educativo de los estudiantes con independencia del origen social, cultural o características individuales.

Desde esta perspectiva, la UNESCO (2005) define la educación inclusiva como «un proceso orientado a responder a la diversidad de los estudiantes incrementando su participación y reduciendo la exclusión en y desde la educación» (p. 13), por lo tanto, la inclusión educativa se percibe como una estrategia hacia la igualdad de oportunidades. Un sistema educativo que apuesta por la inclusión considera la educación como un derecho, y no como un privilegio. La población en riesgo de exclusión social no tiene mecanismos de selección ni discriminación, y transforma su funcionamiento y propuesta pedagógica para integrar la diversidad del estudiantado. Se favorece la cohesión social, que es una de las finalidades de la educación (UNESCO, 2008). Tal vez cabe, preguntarse si la educación superior favorece el desarrollo de una comunidad más inclusiva, o si, por el contrario, como señalan Bourdieu y Passeron (2001), se reproducen los mecanismos de la exclusión social recreando diferentes formas de discriminación en su seno.

En relación con el desarrollo de una educación inclusiva que tenga en cuenta a los estudiantes con diversidad hay que plantearse una serie de interrogantes, que hay que saber gestionar ¿Cómo conseguir un mayor interés de este tipo de enseñanza? ¿Cómo garantizar el derecho de los estudiantes con mayores dificultades de aprendizaje a estudiar con sus compañeros, pero también a aprender al máximo de sus posibilidades? (Marchesi, 2014). La educación inclusiva tiene que responder a una educación de calidad, que garantice el acceso al conocimiento, en las mejores condiciones, a todos los estudiantes. Se evita la exclusión y segregación mediante la convivencia e interacción con estudiantes de diferentes capacidades, origen social o cultural.

Para conseguir una educación inclusiva es necesario analizar las causas familiares, sociales, económicas o laborales, así como los perfiles de los estudiantes en riesgo de exclusión, con el fin de obtener los recursos que permitan su permanencia en el sistema educativo.

De este modo, la Estrategia Europea 2020 cuenta con el apoyo de las Naciones Unidas, la UNESCO, organizaciones internacionales y países que abogan por un cambio hacia la educación inclusiva (Unión Europea, 2017). Entre sus principales objetivos la educación y la formación de la comunidad, como un elemento clave para el desarrollo de la persona. Para ello, se trabaja en las políticas educativas, investigación y análisis acerca de las prácticas inclusivas, en el progreso académico de todos los estudiantes, inmersos en el sistema educativo inclusivo.

4. Inclusión en la educación superior

La diversidad puede presentar un desafío para la educación superior, pero no la inclusión de todas y todos lleva a la perdida de talento. Es por ello, por lo que la comunidad universitaria, en especial el profesorado, debe tener formación suficiente para adaptar las clases para todas y todos. Como indica Carlos Andradas, el que fuese rector de la Universidad Complutense de Madrid, siempre que un grupo queda excluido, toda la sociedad, en nuestro caso la universidad, pierde. Por tanto, es necesario mantener inclusión educativa desde una mirada holística que contemple soluciones desde variadas perspectivas en la que la formación en diversidad del profesorado tiene una prioridad esencial (Martín, 2018; Miguel, 2014; Miguel, Cury, Astray y Fernández, 2019; Miguel, Medina y Ramos, 2019).

Las instituciones universitarias europeas han sufrido cambios en los últimos años, debido a los avances científicos, tecnológicos y económicos. Sin olvidar que hay que dar respuesta a las necesidades del entorno social y a la diversidad de la población que se forma en sus aulas. Un hecho que obliga a redirigir la orientación académica y el apoyo al estudiantado. Las universidades tienen que aumentar su capacidad para vivir en la incertidumbre, para innovar y provocar el cambio. Además, tienen que atender las necesidades sociales, fomentar la solidaridad y la igualdad de oportunidades.

En el sistema educativo se ha venido utilizando el término «integración» para trabajar con las barreras del aprendizaje. Sin embargo, actualmente se utilizan los términos «educación inclusiva y atención a la diversidad». Este modelo genera espacios de igualdad de oportunidades para una sociedad diversa, independientemente de las condiciones personales, sociales o culturales. El concepto de educación inclusiva se asocia a la respuesta que desarrollan las universidades a la diversidad de necesidades de todo el estudiantado. En un sentido más amplio, tiene como finalidad impregnar la cultura de la gestión organizativa y a la comunidad universitaria en general, así como las políticas y prácticas educativas (Ainscow, 2005; Bausela, 2002; Booth y Ainscow, 2015; Booth y Ainscow, 2002; Echeita, 2008; Echeita, Martín, Sandoval, Simón, 2016; García-Cano, Buenestado, Gutiérrez, López y Naranjo, 2017; Jiménez y García, 2013; Onrubia, 2004; Solla, 2013).

Por ende, la educación inclusiva promueve el respeto a ser diferente y garantiza la participación del estudiantado en el proceso educativo dentro de una diversidad humana y cultural. Con este modelo se trasciende lo estrictamente académico y curricular, para enfocarse en los aspectos sociales. La educación inclusiva representa un valor y un principio fundamental. Así, la inclusión es una cuestión de derechos, que ha de garantizarse sin discriminación o exclusión, y ha de ser el futuro del modelo de educación (Ainscow, 2001; Casanova, 2016; Jiménez y García, 2013). En la actual sociedad globalizada, la diversidad del estudiantado en los centros de enseñanza superior es una realidad presente en las aulas.

Por las razones que hemos citado, la universidad se ve avocada al compromiso de facilitar el acceso a estudiantado perteneciente a diversos grupos minoritarios como, por ejemplo, las minorías culturales, grupos desfavorecidos o personas con diversidad funcional. A tal efecto, la universidad proporcionará recursos sociales y educativos, que faciliten la superación de obstáculos en el desarrollo de los estudios en ese nivel y permitan el desarrollo de las capacidades y talentos de los grupos minoritarios del estudiantado, según se recoge en la «Conferencia Mundial sobre la Educación Superior» (UNESCO, 1998).

Esto puede ser interpretado como un aprendizaje, que conduce a analizar las motivaciones y el talento para desarrollar las capacidades del estudiantado y asegurar el principio de igualdad de oportunidades. La educación inclusiva genera espacios de igualdad de oportunidades para una sociedad diversa. Dentro del contexto universitario español se encuentran publicaciones desde 1995, fruto de las jornadas celebradas en Salamanca sobre la inclusión del estudiantado con diversidad funcional en la universidad. En ellas, se debatieron los procesos educativos, la eliminación de barreras arquitectónicas, los productos de apoyo, los programas específicos para la inclusión, así como el voluntariado social y la integración laboral del estudiantado con diversidad funcional (ASPER, 1997). Con posterioridad, se trabajó en el principio de igualdad de oportunidades de la diversidad y de adaptaciones curriculares en el ámbito universitario (Alcantud, 1997; Miguel, Medina, Ramos y Durán, 2020; Rivas 1997).

Las universidades deben asegurar que los apoyos ofrecidos respondan a las necesidades de todo el estudiantado, incluidos los que presentan algún tipo de diversidad funcional para desarrollar plenamente las competencias profesionalizantes. Por ende, en el acceso a la enseñanza superior no se podrá admitir ninguna discriminación fundada en la raza, el sexo, el idioma, la religión, la diversidad funcional o consideraciones económicas, culturales o sociales. En otros términos, la inclusión es contraria a la competencia y a la selección centrada en el modelo de logro individualizado, es una cuestión de derecho y de equidad, es decir, de lucha contra la desigualdad (Arnaíz, 2003; Dalmau, Llinares, y Sala, 2013).

Por último, las universidades españolas están realizando un esfuerzo importante por implementar un modelo inclusivo. En este sentido, se crea el Área de Atención a la Diversidad y el Área de Inserción Laboral en la Red Universitaria de Asuntos de la Conferencia de Rectores de las Universidades Españolas, en la que participa la Red SAPDU. En concreto, la Universidad Complutense de Madrid desde la Oficina para la Inclusión de Personas con Diversidad (OIPD de UCMd+I) apuesta por la formación, y por su importancia en la inclusión social y educativa. Por tanto, hemos estimado desarrollar una acción accesible fundamental que se está implementando en el contexto universitario, las guías de diversidad de apoyo al profesorado de la Educación Superior en la Universidad Complutense de Madrid.

Esta experiencia significativa, colabora también a la Universidad de Génova y de Brescia, y se encuentra incorporada en las buenas prácticas del Proyecto Europeo RISEWISE.

5. Objetivo

El objetivo de esta publicación es dar a conocer la guía de apoyo al profesorado, recomendaciones prácticas para el profesorado, que tiene estudiantes con diversidad funcional y/o necesidades especifica de apoyo educativo. Asimismo, como su publicación en español, italiano e inglés.

6. Población destinataria

La población destinataria es el profesorado universitario, que debe estar informado de los recursos y necesidades que tiene el estudiantado con diversidad funcional y con necesidades específicas de apoyo educativo.

7. Desarrollo de la experiencia

El presente documento es el resultado del trabajo realizado por el equipo de la Oficina para la Inclusión de Personas con Diversidad de la UCMd+I, Universidad Complutense de Madrid en el 2012. Se retoma en el marco de buenas prácticas del proyecto europeo RISEWISE en el año 2020.

El equipo está integrado por los grupos de trabajo de la Universidad Complutense de Madrid, en colaboración con la Universidad de Génova y Universidad de Brescia.

Las Guías de diversidad de apoyo al profesorado que se están actualizando y traduciendo son:

- Guía para diversidad auditiva
- Guía para diversidad visual
- Guía para diversidad física/orgánica
- Guía para dislexia y trastorno por déficit de atención con y sin hiperactividad (TDA-H)
- Guía para los problemas de salud mental
- Guía para Síndrome de Asperger

Estas guías, en la fase de revisión, constan de los siguientes apartados en los cuales se está trabajando: Definición y pautas generales, interacción en el aula, aspectos docentes, programación y metodología, tutorías, trabajo en el aula, evaluación de trabajos, procedimiento de evaluación, recursos técnicos y tecnológicos, y el listado de coordinadores de la Delegación para la Diversidad e Inclusión, referencias bibliográficas y recursos e información de interés, (véase anexo I), recomendaciones prácticas para la inclusión del estudiantado con problemas de salud mental en las aulas.

Se propuso una metodología de revisión de actualización de las guías de diversidad de apoyo al profesorado del 2012, que incluyó el apoyo de coordinadores de la Delegación para la Diversidad e Inclusión, profesorado, becarios, estudiantes y egresados coordinados por la responsable de la OIPD de UCMd+I. Esta variedad de profesionales y estudiantado colaborador logra cumplir el objetivo, considerando la importancia del trabajo colaborativo e interdisciplinario en el ámbito de la educación inclusiva.

En una segunda fase, estas guías serán validadas por los equipos de las universidades de Génova y Brescia y, posteriormente en una tercera fase, traducida al italiano e inglés.

En esta publicación presentamos los resultados de la primera fase de la experiencia significativa enmarcada en RISEWISE.

8. Resultados

En los resultados obtenidos, debemos tener presente que para que este estudiantado pueda concurrir en igualdad de condiciones que el resto de sus compañeros/as. Según se recoge en la Ley Orgánica 4/2007, del 12 de abril, de Universidades, que regula los principales principios que las universidades deben adoptar en materia de inclusión de las personas con discapacidad, así como los programas específicos de ayuda, apoyos y adaptaciones en el régimen docente.

Queremos hacer hincapié en que, estas adaptaciones en modo alguno pueden significar que el estudiantado no alcance los objetivos de la asignatura o que la prueba no tenga el mismo nivel de dificultad que la realizada por el resto de sus compañeros/as de clase.

Es buena práctica que, el profesorado adelante con suficiente antelación todo el material con el que va a trabajar en la clase. De esta manera, favorece que el estudiante con alguna diversidad se pueda preparar la asignatura y podrá seguir la clase con más facilidad comprobar si necesita apoyo en el aula para la toma de apuntes. Puede que, en algún momento, el estudiantado llegue un poco más tarde o tenga que salir unos minutos antes de clase para recibir apoyo sociosanitario.

Actualmente, la actualización de las guías de la diversidad para el profesorado está en proceso de la última revisión. Se tiene previsto finalizar en este curso académico, para ser traducida al italiano e inglés como experiencia significativa en el contexto del proyecto RISEWISE.

9. Conclusiones

En lo referente a los temas de educación y accesibilidad en la Estrategia Europea sobre Discapacidad 2010-2020, figuran como líneas de actuación, la promoción de una educación y un aprendizaje inclusivo permanente para el estudiantado. Por otra parte, también se subraya la necesidad de que haya un apoyo a las actividades destinadas a fomentar la accesibilidad y a eliminar las barreras actuales, sin olvidar la mejora de los recursos y las tecnologías de apoyo.

Ello supone el reconocimiento y la garantía de los derechos de estas personas y cumplir con el artículo 24 de la Convención Internacional sobre los Derechos de las Personas con Discapacidad. Al mismo tiempo que se trabaja con los Objetivos de Desarrollo Sostenible, el objetivo 4 señala que se quiere lograr una educación inclusiva y de calidad para todos, la educación es uno de los motores más poderosos y probados para garantizar el desarrollo sostenible.

Desde una perspectiva de futuro y contemplando la política institucional, hemos percibido que existen condiciones propicias para que esta experiencia significativa sea extrapolable a otras universidades europeas.

Con la utilidad de estas guías, consideramos se facilita la incorporación de este perfil de estudiante en la enseñanza superior. Es un avance hacia la inclusión, la diversidad y la igualdad de oportunidades, por la que apuestan universidades como la Universidad Complutense de Madrid. Con recursos como este, no solo se trabaja desde el modelo de los Derechos Humanos, sino también, con el modelo de la diversidad en las nuevas políticas sociales y educativas y la Agenda 2030. En relación con esto y junto a RISEWISE, ha sido posible el conocimiento de esas guías y la incorporación en otras universidades italianas.

A modo de conclusión, podemos considerar que, en líneas generales, este recurso favorece las políticas sociales y educativas universitaria. Al tiempo que es necesario seguir adaptando los servicios, los recursos y los modelos pedagógicos de aprendizaje a las necesidades cambiantes de la población de estudiantes en la universidad.

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Anexos

Anexo I. Modelo de guía de apoyo al profesorado.

UNIVERSIDAD
COMPLUTENSE
MADRID

GUÍA DE APOYO AL PROFESORADO

RECOMENDACIONES PRÁCTICAS PARA LA INCLUSIÓN DEL ESTUDIANTADO CON PROBLEMAS DE SALUD MENTAL EN LAS AULAS UNIVERSIDAD COMPLUTENSE DE MADRID

OFICINA PARA LA INCLUSIÓN DE PERSONAS CON DIVERSIDAD

A tener en cuenta

- Establecer un plan de tutorías o un primer acercamiento para conocer las particularidades del/la estudiante
- Algunos/as estudiantes pueden tener dificultades o pánico escénico que les reduce la capacidad a la hora de comunicarse

- Puede ser conveniente realizar las exposiciones orales/exámenes en un aula aparte de sus compañeros/as
- Flexibilidad en la entrega de trabajos y posible adaptación del tamaño de los grupos. Asegurarse que la persona tiene un grupo con quien trabajar
- Planificación. Avisar de cualquier cambio con suficiente antelación a través de múltiples medios (clase, Campus Virtual...)
- Anticipación. Una buena organización docente y comunicación, así como materiales de apoyo y bibliografía suficiente
- Descomponer las tareas largas y abstractas con metas intermedias, para favorecer la autoestima
- Es posible que se produzcan faltas de asistencia en períodos de descompensación

Para ampliar información consulte la página web: https://www.ucm.es/recursos-y-enlaces

Sguardi dalla periferia.
Riflessioni a margine di una ricerca su disabilità e professioni delle arti performative

Mariella Popolla, Chiara Bersani[1]

Views from the periphery. Reflections on the sidelines of a research on disabilities and performing arts professionals

Keywords: disabilities, performing arts, emotional labor, care labor, ableism

1. Premessa

Il presente contributo si basa su un lavoro di ricerca sulle intersezioni tra disabilità e lavoro nelle arti performative che ho condotto tra il 2019 e il 2020 (e in parte ancora in corso). La metodologia utilizzata è stata quella etnografica e le tecniche implementate, ad oggi, sono state l'osservazione partecipante e, in alcune fasi, lo *shadowing* (cfr. Cerulo, 2016; Quinlan, 2008; Czarniawska, 2007; McDonald, 2005, Paskiewicz, 2002; Cardano, 2011; Marzano, 2006). La scelta è stata quella di seguire il lavoro di Chiara Bersani, autrice e performer, e i campi osservati sono stati molteplici. I primi, due festival a Berlino e a Ostrava, sono stati inseriti nella ricerca proprio grazie al prezioso contributo del progetto Risewise ed è a questa prima esperienza che è dedicato quanto segue.

1.1 Dialogo. Parte prima

Forse se un giorno Mariella mi avesse scritto chiedendomi di poter fare questo lavoro seguendo per un periodo la mia compagnia in tour le avrei detto di no. Le avrei risposto con cortesia ovviamente, credo che le avrei scritto che in quel momento non avrei potuto prendermi cura di lei, che il tour era faticoso e altre argomentazioni molto lucide ma anche poco ragionate. La verità è che non avrei nemmeno capito con precisione cosa mi chiedeva. La verità è che non sono una scienziata e tutto passa attraverso la mia pelle.

E la pelle ha regole tutte sue.

Invece è andata in un modo diverso. Io e Mariella ci siamo conosciute qualche mese prima a Bari e per una serie di coincidenze abbiamo condiviso due giornate in cui già esplodevano come bombe tutte le questioni che ci avrebbero accompagnate nei mesi successivi. In quei giorni io

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[1] Il saggio è il risultato comune del lavoro delle autrici, tuttavia, in termini formali, si segnalano le seguenti attribuzioni: i paragrafi 1, 2, 2.2, 3, 3.2, 3.4, 3.5 e 4 sono di Mariella Popolla (University of Genoa); i paragrafi (segnalati col titolo 'dialogo ') 1.1, 2.1, 3.1, 3.3 sono invece di Chiara Bersani (Performer).

vivevo esperienze di affaticamento, dolore e violenza causate da una cattiva gestione delle modalità di lavoro che il festival che mi ospitava aveva messo in atto.

Mariella, che si avvicinava per la prima volta alla mia persona e al mio team, entrò con noi nella bufera. Non perse l'orientamento, non sparì nell'emotività ma ci aiutò a navigare nella tromba d'aria ed uscire senza lesioni.

Di quelle giornate ricordo lo spettacolo in chiusura del festival, un pubblico commovente e lei, seduta in prima fila, che mi regalava un disarmato sguardo d'accoglienza.

Ecco perché quando Giulia Traversi, la manager e curatrice dei miei lavori, mi ha parlato della proposta di collaborazione arrivata da Mariella ho detto subito sì.

Non posso dire che avevo capito di cosa si trattasse, nemmeno quando Mariella mi ha spiegato con precisione. Non capivo perché non era lì che mi volevo soffermare, io volevo solo continuare qualcosa che era già iniziato, anche se nemmeno sapevo di cosa si trattasse.

Da quel momento in avanti Mariella ha iniziato a dare i nomi alle cose e io a spostarmi di lato per guardare il mio mondo dalle periferie.

2. Dove tutto è (ri)iniziato

«05/11/2019, Bologna, aeroporto:

Tempi di attesa prolungati, [nome compagnia rimosso] rispetto ad altre compagnie fa salire le persone con disabilità per ultime. Dato il generale viavai, e la scarsa attenzione al proprio corpo nello spazio tipica deu passeggeru negli aerei, questo implica alcune difficoltà a Chiara e assistenti che spostano di continuo la sedia nel corridoio stretto. Non mi pare una scelta astuta. Implica anche che gli occhi di tuttu u passeggeru siano addosso a Chiara. Invisibilizzazione vs ipervisibilità corpi con disabilità. Il pieno controllo sul proprio corpo che definisce una persona come indipendente è visibile solo quando viene meno (controllare dove lo avevo letto… forse Shildrick???). Lo spazio è stretto, pensato per le persone abili che sono abituate ad abitarlo in un certo modo; quanti voli prende Chiara in un mese? Quante volte succede tutto questo? Come si sente lei? Si stanca e poi lavora comunque?» (nota di campo, 05 novembre 2019, Volo Bologna-Berlino).

2.1 Dialogo. Parte seconda

No, non te ne rendi conto subito.

Ho iniziato a viaggiare sola da giovane, giovanissima. Prima in aereo e poi in treno.

Per ogni nuovo mezzo che esploravo non erano mai pensieri su accessibilità o l'accoglienza ad abitarmi ma sempre e solo paure. Paure di farmi male. Paure di perdermi. Paure di sbagliare e dover tornare a dire a quei genitori a cui chiedevo indipendenza «avevate ragione voi, da sola non posso».

Io, per ogni nuova rotta aperta, ho avuto paura. Io, appena sotto la pelle, ho sempre paura. Sono costantemente impegnata a controllare la paura, ad evitare che mi divori e mi paralizzi.

Come posso concentrarmi su altro?

Come posso, se sto provando a non andare in frantumi, rendermi conto che quella gentilezza degli assistenti è una toppa malmessa su una mancanza?

Come posso riflettere sugli sguardi delle altre persone?

Posso, ma non subito.

Lo faccio quando Viaggiare diventa abitudine. Per un po' mi sembra di stare bene, la paura è controllata e si può fare tutto. Poi lo sguardo si apre, solitamente lo fa all'improvviso, e allora arrivano come lame negli occhi tutti questi atti di quotidiana violenza.

Certe volte dimentichi.

Certe altre non pensi di essere realmente autorizzata.

Alcuni giorni vedi, sai, ma non hai l'energia.

Altri giorni invece ti infiammi.

2.2 Situarsi

Con le parole citate all'inizio del paragrafo si apre una delle prime pagine del mio diario di campo: la mia ricerca sulle intersezioni tra disabilità e lavoro nelle arti performative stava avendo ufficialmente inizio. Sono, per me, parole piene, ancorché acerbe, già dense delle riflessioni che mi (ci) avrebbero accompagnata nei mesi a seguire e che, almeno parzialmente, introdurremo nel corso di questo contributo. Ma sono anche rivelatrici di quanto il mio sguardo, in quel momento, cercasse di ancorarsi alle dimensioni che percepivo più afferrabili della disabilità, più osservabili e, in qualche modo, dimostrabili: quelle relative all'accessibilità fisica, quelle materiali, quelle dei corpi. Eppure, nei mesi in cui io e Chiara abbiamo attraversato un pezzo di percorso insieme, quella dimensione ha assunto centralità solo quando sono riuscita a leggerla all'interno di un processo co-costitutivo che la metteva in relazione con determinate organizzazioni sociali e con la loro normatività (cfr. Ferrucci, 2004). In altre parole, la dimensione fisica, di organizzazione degli spazi e gli eventuali ostacoli all'autonomia di movimento, erano importanti in quanto manifestazione pratica e tangibile di, e al contempo giustificazione per, un ordine sociale che marginalizza le persone con disabilità.

Quanto appena dichiarato non vuole essere un mero esercizio di posizionamento teorico all'interno di una o un'altra corrente tra quelle più accreditate all'interno dei *disabilities studies*; tanto più che ritengo che le diverse interpretazioni (purché distanti dal modello medico) possano concorrere a illuminare di volta in volta aspetti peculiari dei processi di costruzione sociale dei soggetti con disabilità. Il fatto di leggere la disabilità come relazione sociale ha, difatti, informato il modo in cui la ricerca è stata svolta e le tecniche utilizzate, ha sollevato interrogativi e stimolato quella riflessività che dovrebbe definire e caratterizzare la ricerca etnografica e, ancor più, sottende la peculiarità di questo contributo che, difatti, è frutto di un dialogo tra me e Chiara.

I temi su cui X e io abbiamo riflettuto nel corso della ricerca, affioravano di volta in volta dall'osservazione sul campo e venivano esplorati insieme, quando possibile, 'a caldo', vale a dire nel primo momento disponibile (compatibile con gli impegni lavorativi di Chiara) immediatamente successivo alla loro emersione. Nel caso della prima "tappa" della ricerca, quella formalmente inserita all'interno del Progetto RiseWise, due sono i nodi critici che hanno interessato il nostro dialogo: la questione del ribaltamento del concetto di cura e del lavoro emozionale richiesto e quella, inestricabilmente collegata, della mia presenza sul campo, a cui stiamo cercando di dare spazio, preservando la cifra stilistica dei nostri scambi anche in questa fase di scrittura.

3. Una cura di direzione inversa, o del lavoro emozionale di Chiara

La prima tappa della ricerca prevedeva che seguissi Chiara a Berlino, per il No Limits DISABILITY & PERFORMING ARTS FESTIVAL, per poi proseguire verso il Norma Festival di Ostrava.

Il fatto che il primo campo da osservare fosse proprio un festival che metteva a tema il focus della mia ricerca, ai miei occhi, aveva il pregio di permettermi un ingresso 'morbido' nel campo. Davo per scontato che, rispetto alle altre organizzazioni che in qualche modo avrei intercettato nel corso della ricerca, vi fossero una serie di questioni affrontate 'a monte e a priori', che le dinamiche e le pratiche di lavoro riflettessero queste consapevolezze pregresse, che fossero prive di residui abilisti, aiutandomi a comprendere con più rapidità dove orientare lo sguardo una volta spostata altrove. In altre parole, che questa occasione mi potesse agevolare nel definire una sorta di standard sufficientemente buono a cui raffrontare le pratiche organizzative e lavorative in quelle realtà che, invece, si ponevano verso l'esterno (per nome, focus tematico, promozione pubblica) senza un posizionamento esplicito rispetto alla disabilità.

3.1 Dialogo. Parte terza

Quella fu la mia prima tournée dopo il viaggio di nozze.

Ricordo l'adrenalina di andare a Berlino, la confusione sempre presente di quando da un'esperienza di grande intimità (un viaggio con la persona amata) si passa alla tournée, il disagio al pensiero di dover tornare a prendersi cura del team, e Mariella che per la prima volta partiva con noi. Ricordo di aver realizzato tutto questo mentre il pick up ci portava dall'aeroporto all'albergo e ricordo di aver pensato «ed è pure un festival sulla disabilità».

No, non era un pregio per me ma non avevo voluto dirlo subito a Mariella.

Chissà perché mi sembrava che l'avrei delusa — salvo scoprire molto presto che le erano bastati pochi sguardi per notare subito le prime lacune della manifestazione.

Conoscevo uno dei direttori artistici, un coreografo con disabilità di cui stimo il lavoro e il pensiero. Lui aveva fortemente desiderato la mia opera nel programma della manifestazione e per me la sua presenza era garanzia di qualità per l'intero evento. Non potevo, tuttavia, non sentirmi a disagio a partire già dal titolo.

No Limits.

Cosa mi stai chiedendo?

Di quali limiti stiamo parlando?

Perché partiamo da lì?

Perché prendiamo in prestito il titolo dal linguaggio abilista?

E poi la domanda che non avrà mai risposta in me: perché ci serve un festival 'solo per noi' ma organizzato da persone tra le quali quelle disabili sono una minoranza?

Perché vogliamo un giardino protetto?

Perché non possiamo buttarci nel mondo?

Riflettere sull'essere artista disabile necessita porre la disabilità al centro o può anche significare semplicemente usarla come metodo d'analisi del mondo?

Si può aprire ad un pubblico disabile senza aver prima guadagnato la fiducia di queste singole comunità emarginate?

E se al pubblico disabile quel nostro cartellone non piacesse?

Vogliamo attrarre audience o vogliamo permettere a tutte le persone di fruire liberamente del maggior numero di contenuti artistici presenti?

Quest'ultima domanda è perché da artista italiana e quindi nata e cresciuta in un paese in cui gli investimenti sulla cultura e sul sociale sono profondamente carenti, mi domando a cosa mi serva andare al festival di un paese ricco, scoprire le sue soluzioni articolate e costose per l'inclusività (termine problematico ma qui preso in prestito per semplicità), valutare al primo sguardo che non sarà mai possibile portare questo modello nel luogo in cui lavoro maggiormente e quindi andarmene. Cosa porto con me oltre a una frustrazione rinnovata?

Siamo sicuri che il cambiamento arrivi dalle soluzioni applicate indiscriminatamente? Da un'imitazione poco ragionata di questo tipo di modelli?

3.2 Tempi, corpi, imprevisti

Già scorrendo il sito del festival appare chiara, quanto ovvia, l'attenzione all'accessibilità degli spazi così come, ma ci torneremo a breve, delle performances. Dal punto di vista degli spazi due elementi attirano la mia attenzione: il primo è che, in realtà, l'accesso ad alcuni spazi sarebbe impossibile senza una persona che accompagni Chiara dal momento che le porte sono estremamente pesanti da aprire ma, ancor più interessante, è il fatto che sul sito accanto alla descrizione fisica dei luoghi venga sempre riportata la frase «Gli utenti su sedia a rotelle sono pregati di registrarsi in anticipo al numero [...]». Niente di più logico, è necessario organizzare gli spazi e i tempi in modo da garantire un accesso privo di difficoltà alle persone con una sedia a rotelle; eppure la mia mente non smette di pensare «tempo, organizzazione del tempo, cambi di programma dell'ultimo minuto... IMPREVISTI».

Pur comprendendo le ragioni dietro a una tale richiesta non posso che riflettere su come le persone con disabilità, in qualche modo, non siano previste, siano un'eccezione anche come audience e di come questo le obblighi a una gestione del tempo e perfino del desiderio (in questo caso di assistere a una performance) meno immediato: niente può essere lasciato al caso, neppure assistere a uno spettacolo. Mi chiedo quanto questa dinamica, in fondo, non abbia innanzitutto un effetto dissuasivo sulla potenziale audience e, allo stesso tempo, quello di sottolineare a gran voce il fatto che «tu non sei previstu».

Questa stessa riflessione, in realtà, può essere applicata all'accessibilità delle performances; prendiamo come esempio la traduzione nelle lingue dei segni. Nel caso specifico del NO LIMITS Festival, questa veniva offerta per tre spettacoli (alcuni, come quello di Chiara, non prevedevano dialoghi) ma in un caso la disponibilità era vincolata a una richiesta esplicita e anticipata. Dal confronto avvenuto in seguito con alcunu artistu, è emerso che nel contesto italiano molte istituzioni lamentano il fatto che quando hanno offerto questa possibilità in sala non c'era neanche una persona sorda e che, di conseguenza, si era trattato di una sorta di 'spreco di risorse'. In taluni casi era stata richiesta la prenotazione ma la persona che l'aveva richiesto non si è poi presentata; in altri l'interprete era presente *a prescindere* dall'effettiva presenza in sala di persone sorde. Come conseguenza, secondo una valutazione costi-benefici, in moltu hanno deciso di non offrire la traduzione con continuità o come servizio integrato nella prassi. La questione della presenza nell'audience di persone con disabilità andrebbe problematizzata e approfondita (cfr. Lancaster 1997; Tozer 2014; Hadley 2015) ma, ai fini del presente contributo, questo passaggio ci è utile per illuminare un ulteriore aspetto rispetto alla gestione del proprio tempo: la responsabilità che una persona con disabilità ha verso le altre persone con disabilità. Alla persona con disabilità che decide o meno di andare a uno spettacolo viene implicitamente richiesto di valutare le conseguenze delle proprie scelte dal punto di vista delle ricadute sulla più ampia comunità di persone con disabilità; nel caso non ci si presenti in sala, questa assenza potrà essere utilizzata come indicatore della superfluità dei servizi offerti per garantire l'accessibilità che divengono, dunque, un costo immotivato da sostenere. Si crea, dunque, una sorta di cortocircuito che, di fatto, va a minare la possibilità di accesso agli spettacoli.

Nel sito del NO LIMITS Festival, per proseguire nel nostro percorso, vengono evidenziate altre misure atte a garantire e promuovere l'accessibilità delle performances: i cosiddetti spettacoli rilassati (per un'analisi critica si veda Fletcher-Watson, 2015), sedute comode e reclinabili, descrizione audio, l'ingresso anticipato (o pre-ammissione) e, di nostro interesse per le riflessioni emerse sul campo, il tour tattile. Con tour tattile si intende la possibilità per le persone cieche di entrare materialmente in contatto con la scenografia e gli abiti di scena prima della performance.

Durante il NO LIMITS questo processo veniva gestito da una persona, P., che abbiamo avuto modo di incontrare nel bar dell'Hotel dove alloggiava Chiara la sera prima della replica. P. ha spiegato a Chiara i vari passaggi del tour tattile e le ha suggerito che il vestito venisse fatto toccare *prima* di essere indossato. Per esperienza personale, ha raccontato, molte persone potrebbero, anche inavvertitamente, toccare il corpo della performer rendendo l'esperienza più 'intima'.

Qualche minuto prima P. aveva definito la performance di Chiara (Seeking Unicorn) come seducente; è interessante notare che questo aggettivo è forse quello che più ho sentito pronunciare dalle persone che parlavano del lavoro (e) di Chiara nel corso della mia ricerca. Chiara è una donna ed è una donna con disabilità; il tema della sessualità è, a parer mio, sempre presente, proprio per gli eccessi di significazione che i processi sociali di costruzione delle sessualità impongono sia ai corpi femminili in generale che a quelli con disabilità.

In quanto donna con disabilità, il corpo di Chiara è attraversato da sguardi che lo posizionano su due piani opposti eppure coerenti: deve sempre, difatti, rappresentare in qualche modo un'eccezione/eccezionalità. Citando Liz Emmens (2009), non possiamo che far riferimento alla desessualizzazione normativa che esclude le persone con disabilità dalla sfera intima; la costruzione sociale delle loro sessualità le situa costantemente in un altrove stigmatizzante che ci parla da un lato di asessualità e dall'altro di perversione, ipersessualità, devianza (Shakespeare *et al.*, 1996), di «sexual excess» o di «sexual lack», per richiamare il lavoro di McRuer e Mollow (2012). Nel pensare a questi processi, che sono anche discorsivi, una considerazione della filosofa Iris Marion Young ha guidato il mio pensiero: «Being used [in questo caso da me inteso come 'sessualizzate'] is oppressive, yet not being used is also a problem» (1990, p. 53).

Il suggerimento dato da P. sul tour tattile ha offerto a me e a Chiara l'occasione per confrontarci sulle dinamiche che investono i corpi, su come un corpo disabilitato possa o meno creare situazioni di intimità legate più a una serie di contingenze che a una reale profondità di rapporto (ma di questo parlerò in altra sede); inoltre, questi corpi che vengono immaginati come fortemente medicalizzati per questa stessa ragione sembrano divenire in automatico 'accessibili', disponibili. A interessarci, di questa riflessione, è però un altro punto. Chiara, infatti, racconta di una certa stanchezza (ma sottolinea verso le situazioni e non verso le persone) nel dover accogliere la paura che l'altru potrebbe provare verso il suo corpo, nel dover rendere il suo corpo comprensibile e intelligibile, nel farsi carico di mettere le persone a proprio agio. Nuovamente, emerge un carico di lavoro classificabile come di 'cura', di presa in carico di situazioni e interazioni, un vero e proprio lavoro emozionale ed emotivo (Hochschild, 1979), secondo il quale le emozioni costituiscono un aspetto specifico del lavoro e la loro mercificazione e commercializzazione sono condizione necessaria per il lavoro stesso e, in questo caso, per le relazioni al lavoro connesse.

La centralità che questo punto assumerà per la mia ricerca richiede, in qualche modo, di non proseguire questo contributo con l'analisi del NO LIMITS Festival ma di spostarmi verso il secondo campo che ho potuto osservare nell'ambito del progetto RiseWise: il Norma Festival di

Ostrava. Più precisamente, a portare nuovamente in superficie questo tipo di lavoro emozionale implicitamente richiesto a Chiara sono stati due momenti che, in realtà, precedono la nostra presenza nella sede del Festival: il viaggio in treno da Berlino a Ostrava e l'arrivo in hotel.

Per poter raggiungere il vagone ristorante, situato molto distante da dove ci avevano assegnato i posti, abbiamo dovuto attraversare dei corridoi che erano pieni di persone sedute sul pavimento. Molte di loro avevano le gambe allungate, rendendo difficoltoso l'attraversamento di quel tratto, spesso diventava necessario scavalcare. Questo tipo di esperienza è, in effetti, comune sui treni, soprattutto su quelli caratterizzati da un alto tasso di passeggeru pendolari. Tuttavia, nel nostro caso, la buona volontà non poteva essere sufficiente: per poter passare era necessario che u passeggeru, quantomeno, piegassero le gambe o si alzassero in piedi per permetterci di proseguire. Con mia grande incredulità, non abbiamo incontrato la minima collaborazione da parte di molti passeggeri che si ostinavano a conservare la loro posizione nonostante la nostra più che evidente difficoltà o le esplicite, per quanto cortesi, richieste di permesso. Personalmente, provavo rabbia e sconcerto ma sapevo che non erano le mie emozioni a contare, avevo bisogno di osservare le reazioni di Chiara e il suo modo di gestire la situazione. Chiara appariva imperturbabile, il suo tono rimaneva calmo e gentile anche dopo l'ennesima richiesta di farci spazio, il viso appariva disteso. Ero sicura, per come fino a quel momento l'avevo inquadrata, che non si trattava di inconsapevolezza su ciò che le stava accadendo, né, tantomeno, di una forma di abilismo interiorizzata che la facesse sentire in qualche modo causa del problema. Nel frattempo, u suou collaboratoru sembravano avere un atteggiamento che oscillava tra un agire distaccato rispetto alle persone che rimanevano immobili (per esempio, spostando le valigie altrui di propria iniziativa) e l'utilizzo di un tono di voce alto e severo per chiedere che facessero spazio. Una volta raggiunto il vagone ristorante non abbiamo parlato dell'accaduto; Chiara si è limitata a spiegare che di solito i posti assegnati au viaggiatoru con disabilità e aglu accompagnatoru sono ubicati in prossimità del ristorante. Ho ipotizzato che questa chiusura dell'argomento così 'chirurgica' fosse una delle modalità scelte da Chiara per gestire situazioni simili; una prassi lavorativa consolidata (e qui ritorna il lavoro emozionale, in questo caso orientato a 'sopprimere' la manifestazione delle emozioni) e condivisa dau collaboratoru che, difatti, non hanno approfondito la questione.

3.3 Dialogo. Parte quarta

Essermi accanto quando non ho le energie per combattere è complesso.

Tutto oscilla tra il rispettare la mia stanchezza, proteggermi dal disagio, gestire la frustrazione che, in determinate situazioni, colpisce anche chi semplicemente divide vita o lavoro con la persona disabile.

Quel giorno io ero stanca. Volevo solo mangiare e passare un tempo tranquilla. Ho visto le persone accanto a me mettere coperte sulle bombe che avevano nel petto. L'ho apprezzato. Lo apprezzo quando succede.

Ma ne conosco il prezzo.

3.4 Ostrava

Ad attenderci a Ostrava una nuova difficoltà: nonostante la persona che si occupa della logistica per Chiara invii delle indicazioni precise sulle caratteristiche che dovrebbero avere gli spazi per non interferire con la sua autonomia, la stanza assegnata non era in alcun modo accessibile. Lo spazio era stretto, il bagno era piccolo e aveva una vasca da bagno inutilizzabile da Chiara. Alle proteste sollevate dalla manager, presenza costante e centrale per il lavoro di Chiara, la receptionist ha risposto che tutte le stanze accessibili erano occupate da altri ospiti. Questo incidente, in un contesto di stanchezza per le tappe ravvicinate del tour, non poteva che creare appesantimento nel gruppo. Chiara non vedeva riconosciuto il suo diritto all'autonomia e al contempo lu collaboratoru venivano investitu di un ruolo che non necessariamente apparteneva loro e che alla lunga avrebbe potuto causare stanchezza e frustrazione. Le pratiche lavorative e i rispettivi ruoli, in qualche modo, venivano modificati e informati da dinamiche esterne all'organizzazione da me presa in esame.

Siamo poi tornate su questi due episodi durante l'intervista fatta il giorno seguente a Chiara e per rendere conto di come sia stato messo a tema l'accaduto, riporterò stralci della nostra conversazione, in modo da dare più spazio possibile alle sue stesse parole:

Chiara: «... una cosa che io sto notando è che più si va verso paesi che vengono considerati strutturalmente più idonei alla disabilità, e la Germania è uno di quelli, più l'eccezione non viene mai accolta [...] Per me è sempre molto complicato perché quando siamo in situazioni come quella, che comunque mi trovo appunto a confrontarmi con persone che non prevedevano di incontrarmi come passeggera di un treno, io faccio fatica ad arrabbiarmi, perché penso che non conosco il loro background e non conosco neanche come il loro paese va incontro alla disabilità, quindi ho sempre dei problemi ad arrabbiarmi, cioè la mia lucidità non vuole arrabbiarsi perché sa che io non ho i mezzi per sapere se ho il diritto di arrabbiarmi per quella cosa lì e dall'altro lato c'è tutta la parte invece istintiva, fragile, umana, che resta sempre un po' ferita, no?»

Mariella: «Cosa hai provato?»

Chiara: «Eh, lì era molto... è un equilibrio fra queste due cose, quindi un continuo anche dire "No, dai, non urlare", non urlare perché... la voglia che nessuno si arrabbi perché appunto, per la cosa che dicevo prima, perché non sappiamo se per loro è veramente una cosa inaccettabile, cioè una cosa veramente non prevista, e dall'altro lato però anche una feritina che sta lì sotto, che si riapre, che tu pensi: "Va beh, adesso non è il momento, devo arrivare dall'altra parte del treno, quindi non è proprio il momento di entrare nello psicodramma, cioè pragmatismo", e allora anche lì per me diventa una cosa quasi di sopravvivenza, quindi va beh, strategia [...] è molto animale, è controproducente per la nostra sopravvivenza, quindi: cortesia…»

Mariella: «Ma è faticoso per te fare questo lavoro? Implica che tu faccia un lavoro sul corpo o, cioè... la mia domanda è questa: te dici che è una cosa molto animale, quindi abbastanza immediata, ma è diventata immediata perché tu hai affinato questa cosa nel tempo?»

Chiara: «Sì, ho affinato una strategia. È animale ma nell'ottica dell'apprendimento, boh, quindi che apprendi davanti... davanti a delle difficoltà apprendi una strategia che poi metti in campo molto rapidamente, però, per esempio, per me è faticosissima, cioè io arrivo veramente stanca, stanca mentalmente, è proprio faticoso anche perché poi io sento molto la responsabilità, cioè... ho la fortuna di lavorare con persone con cui ho un fortissimo legame di amicizia e di amore e quant'altro, e questa è anche una responsabilità però, enorme. È una grande responsabilità nel senso che poi io so che tutte queste cose vanno anche su di loro emotivamente, con però il fatto che loro non ci si relazionano da 35 anni, io sì. Loro ci si relazionano da due anni, tre [...] poi arrivi e c'è una seconda fase in cui in realtà io non mi prendo davvero un tempo per una decompressione personale perché subito sento che per loro questa cosa diventa più grande di quello che è, e quindi c'è un momento di cura, che passa dal parlarne se han bisogno di parlarne al fare la cazzona parlando d'altro al... boh, passa attraverso varie fasi. [...] Poi è ovvio che c'è stato un concatenamento di cose difficili ieri, perché poi arrivati qua, è stato difficile anche l'albergo. [...] Io sono una delle prime artiste disabili che girano freelance, che girano come sto girando io, e che girano senza avere alla spalle una struttura grande, le famose compagnie inclusive, sono tutte compagnie super finanziate e quindi che, laddove vengono in un paese che ha pochi soldi, in un festival che ha pochi soldi, lì compensano loro; se io vado a un festival che ha pochi soldi, mi attacco [...] Io lo vedo quando... lavoro adesso con questa compagnia svedese, compagnia inclusiva, li vedo quando vengono nelle residenze in Italia, cioè comunque loro sono in centro, nei grandi alberghi o nei grandi appartamenti e l'ultima volta era emblematico, cioè io e la loro coreografa eravamo in residenza insieme, loro avevano una casa e io ero in ostello, io ero lì coi soldi italiani, loro ufficialmente erano lì coi soldi italiani, ma evidentemente c'era stato qualcuno che ha compensato, che ha integrato, perché altrimenti non c'era... quindi, tornando a monte, io mi ritrovo in un festival che non è abituato ad avere artisti disabili, che ha comprato me facendo grande fatica, e comunque che è importante che io sia qui, e quindi sì, spiego che c'è stato un errore, al tempo stesso io non voglio avviare quel meccanismo per cui se rendo la mia esperienza troppo difficile poi non chiamano più artisti disabili».

Mariella: «Quindi un senso di responsabilità per chi arriva dopo…»

Chiara: «...so che incazzarsi è fondamentale per riaccendere un dibattito sul diritto, per far capire che non possono gestire un'artista disabile come gestiscono un’artista abile, al tempo stesso so che non voglio che risulti che questa cosa è così pesante da essere infattibile perché, se risulta questo, l'apertura che loro hanno invitando me avrebbero una giustificazione per non averla più, che sarà anche una giustificazione buona eh, anche tipo "guardate abbiamo capito che non abbiamo i mezzi per..." eh, però, non va bene neanche quello».

3.5. Ripensare la direzione della cura; riconoscere l'interdipendenza

Ai miei occhi, il lavoro di implementazione e incorporazione di tali strategie da parte di Chiara risponde perfettamente alla definizione di lavoro emozionale sopracitata e diviene una tecnica lavorativa che va a comporre quel saper *gestire* e il saper *fare* delle pratiche organizzative. Ancor più, indica un ribaltamento rispetto ai concetti di cura e di caregiver così come affrontati nel dibattito riguardo le persone con disabilità. A ben vedere, infatti, vi è un lavoro di cura di 'direzione inversa', così potremmo definirla perché agita dalla persona con disabilità verso l'altru, e un carico mentale non riconosciuto che viene messo in atto sia all'interno di relazioni e interazioni di prossimità (amicu, collaboratoru e via dicendo) che nei confronti della più ampia comunità di artistu con disabilità. Riconoscere questo tipo di dinamica può essere utile per andare a decostruire l'immaginario di dipendenza, che vede la disabilità come qualcosa che porta a un bisogno dell'altru *unidirezionale*, e a recuperare quello di interdipendenza, vulnerabilità e instabilità (Shildrick, 2012), troppo spesso represso e negato ma che in realtà contribuisce alla definizione dell'esperienza umana e delle interazioni tra soggetti e tra soggetti e ambiente come co-costitutive.

4. Conclusioni (premature)

Ci sembra prematuro parlare di conclusioni; il nostro lavoro di ricerca e il nostro dialogo non sono ancora conclusi. Queste riflessioni che hanno visto la luce all'inizio del nostro percorso insieme conservano ancora una loro validità; le esperienze che sono seguite a questa prima 'tappa' hanno confermato quanto restituito in questo contributo ma ci sono altri nodi critici che si sono imposti al nostro sguardo e che inevitabilmente informano tutto il percorso, anche retroattivamente.

Abbiamo osservato molte cose dalle periferie del mondo che stavamo attraversando e abbiamo dato altrettanti nomi alle cose; in questa sede ci è parso importante dare spazio e riconoscere quello che abbiamo chiamato lavoro emozionale e di cura inverso. Inverso rispetto alla percezione sociale che lo riconosce esclusivamente come appannaggio delle persone senza disabilità e che dipinge quelle con disabilità con una postura di dipendenza e di bisogno.

Inoltre, pur consapevoli della sua inusualità, abbiamo tentato di dare a questo contributo la forma riflessiva e dialogante che ha caratterizzato la ricerca, di restituire quel passo di lato così come lo abbiamo fatto noi, insieme.

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Mujeres con discapacidad y sexualidad: una investigación empírica en el marco del «feminismo de la diversidad funcional»

Laura Scudieri[1]

Women with disabilities and sexuality: an empirical research within the framework of the spanish functional diversity feminism

Keywords: women with disabilities, sexuality, spanish functional diversity feminism, sexual assistance.

> Eres mujer, tienes una discapacidad: ¿qué más te falta para que te omitan? (…) ¡Olvídate! Tú ni vas a tener una vida sexual ni una vida reproductiva [paraplejía, 28 años, universidad, 18/02/2018].
>
> Es que vives a través de estas personas, y si estas personas [asistente personal y asistente sexual] no existen, no vas a vivir jamás esa realidad [invalidez del 85% — artrogriposis múltiple congénita, 46 años, residencia, 10/10/2017].

1. Introducción

A través de un enfoque metodológico narrativo (Kohler Riessman, 2008; Poggio, 2004), que busca entrelazar la orientación del *feminismo «de y desde» la diversidad funcional* (Arnau Ripollés, 2005a, 2020b) con las «historias de vida» de mujeres con discapacidades certificadas de diverso tipo (motoras, sensoriales, orgánicas, intelectuales, psíquicas) y los relatos de algunos «asistentes íntimos/sexuales»[2], toda/os residentes de la capital española donde he llevado

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[1] Laura Scudieri (University of Genoa).

[2] Agradezco a todas las mujeres (treinta por las entrevistas en profundidad, y al menos el doble en total) y a los tres asistentes sexuales/íntimos (dos hombres y una mujer) que me han donado su tiempo y sus historias. Agradezco también a los responsables de las diferentes asociaciones madrileñas dedicadas a las personas con discapacidad y a los gestores de los 'lugares' de asistencia sexual escuchados en calidad de testigos calificados. Un agradecimiento especial, por diversos motivos, es para María del Carmen Crespo Puras, Maria Giulia Bernardini, Isabel Fanlo Cortés, Nuccia Gianelli, Susanna Pozzolo, Julieta Agustina Rabanos y, finalmente, a Soledad Arnau Ripollés (1971-2021), a la memoria de quien están dedicadas estas páginas.

adelante numerosos periodos de investigación en el marco del proyecto europeo[3], me propongo indagar algunos núcleos temáticos hasta ahora poco investigados por la reflexión feminista y sólo parcialmente tomados en consideración por la perspectiva interseccional.

En particular, es en el terreno de la sexualidad que hoy parece encenderse de nuevo la relación problemática entre *Feminist Studies* (FS) y *Disability Studies* (DS). Las dos corrientes teóricas, aunque unidas por tener ambas origen en las batallas por los derechos civiles llevadas adelante por dos grupos de diferentes niveles y título (género, en el primer caso, y discapacidad, en el segundo) 'incapacitados' dentro de la sociedad, han dejado al margen a los sujetos femeninos con discapacidad afectadas tanto por el dispositivo sexista como por aquel capacitista (Bernardini, 2016).

Los *Feminist Disability Studies* (FDS), con el objetivo de dar visibilidad a esta «tierra de nadie» (Cerrato Calero *et al.*, 2017) y de reivindicar los derechos de los «sujetos imprevistos» que la habitan (Lonzi, 1974), han intentado hacer dialogar a las dos corrientes señaladas (FS y DS), poniendo la atención en los estereotipos y en las formas de opresión y de discriminación múltiple interseccional, causadas por varios factores que interactúan entre sí, que atenazan a las mujeres con discapacidad (no a las otras mujeres, y no a los hombres con discapacidad), y con algunas discapacidades más que otras. En este sentido, el «feminismo de la diversidad funcional» (FDF) español sin duda puede ser considerado como parte de la amplia corriente

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[3] Las entrevistas se llevaron a cabo en Madrid en el arco de más de dos años (junio 2017-septiembre 2019); los períodos de investigación en la capital española fueron realizados en el marco del proyecto europeo RISEWISE (RISE *Women with disabilities In Social Engagement; EU project under the Agreement No*. 690874). Para las entrevistas a las mujeres con discapacidad, he adoptado el método del así llamado muestreo de avalancha (o de bola de nieve), partiendo de algunos contactos de la asociación AFADIS *Asociación de familiares y amigos de personas con discapacidad*, partner española del proyecto europeo, y la técnica de la «historia de vida», que pertenece a la categoría más amplia del enfoque biográfico. «El muestreo por bola de nieve, recordémoslo, pertenece a a la categoría de los muestreos no probabilísticos: aunque significativos, los resultados obtenidos no pueden ser completamente generalizados» (Prina, 2019, p. 102 – la traducción es propia). En relación con la pregunta fundante de la entrevista en profundidad, he optado por la siguiente: «Me gustaría que usted/tú me contara/s su/tu historia, partiendo desde donde usted/tú prefiera/s: de la infancia, de aquello que está/s viviendo en este momento, de un momento que le/te viene en mente; para mí es totalmente indiferente. La técnica de esta entrevista prevé que usted/tú hable/s libremente y que yo intervenga poquísimo. Si ahora usted/tú me da/s su/tu consentimiento, grabaré la entrevista con el fin de poder luego reflexionar mejor sobre sus/tus palabras, que naturalmente citaré — si lo hago — de forma anónima» (cfr. Bichi, 2002). Un par de mujeres prefirieron enviarme un relato escrito acerca de sí. También para las entrevistas a los asistentes sexuales, rastreados siguiendo los indicios dejados por las historias de vida, me decidí por un nivel bajo de directividad y de estandarización, aunque con una consigna/estímulo inicial circunscrita/o: «Me gustaría que usted/tú me contara/s su/tu experiencia como asistente sexual». Los extractos de entrevista citados en el texto se encuentran acompañados de la información siguiente, en el caso de las mujeres: tipo de discapacidad, edad, país de origen (si no es España), lugar y fecha del encuentro; y para la/os asistentes sexuales: género, profesión 'primaria', fecha y lugar del encuentro, pertenencia a los dos canales de asistencia sexual identificados (un centro físico y uno virtual/plataforma).

teórica de los estudios feministas sobre la discapacidad, pero ésta no se trata de la única afiliación del movimiento feminista surgido en España.

En este sentido, el *feminismo de la diversidad funcional* (FDF) está ligado, por un lado, a los movimientos LGBTQI+ — en particular, a la/os teórica/os del *Queer* que más han contribuido a descompaginar las teorías sobre el cuerpo y sobre la sexualidad (Arnau Ripollés, 2016, p. 53; García-Santesmases Fernández, 2017; McRuer, 2018) — y, por el otro lado, al movimiento filosófico-político por la vida independiente, originado en los Estados Unidos al final de la década de 1970 y promotor del conocido *motto* «*Nothing about us without us*»: eslógan que se traduce en una participación (así llamada) activa-emancipadora de las personas con discapacidad también en el plano de la investigación teórica y empírica (Marra, 2018; Arfini, 2013, p. 489), vivida justamente como investig*acción* (Arnau Ripollés, 2020b).

La versión española del Foro de la Vida Independiente[4], cofundada por Soledad Arnau Ripollés (la principal teórica del feminismo de la diversidad funcional), acuñó en 2005 la expresión «diversidad funcional» (Lobato, Romañach, 2005), la cual también ha sido objeto de encendido debate (Moscoso Pérez, 2011, 2019). Un debate que parte del uso problemático de la expresión (como sucede con la categoría de vulnerabilidad) con referencia, contemporáneamente, a una condición universal de los seres humanos — todos, al menos en algún sentido, funcionalmente diferentes y todos, con seguridad, potencialmente discapacitados — y a una condición particular de un grupo de individuos — la minoría 'calificada', casi 'etnificada' (Moscoso Pérez, 2013), constituida por personas con discapacidad/diversidad funcional — discriminado dentro de la sociedad (Palacios, Romañach, 2006, pp. 108, 114-115, 183).

La alianza estipulada por el feminismo de la diversidad funcional (FDF), doctrina que encuentra su génesis literaria en concomitancia con la del neologismo «diversidad funcional», es cuanto menos sorpresivo, si se consideran algunas corrientes históricamente poco *gender sensitive* expresadas por el *Independent Living Movement* y anunciadas ya en su acrónimo, que evoca un concepto mitológico de independencia fuertemente puesto en discusión ya por la primera 'ola' feminista. Por otra parte, la alianza insólita parece coherente con la referencia que hace la misma Convención Internacional sobre los Derechos de las Personas con Discapacidad (en adelante, CDPD), ratificada por España en el 2007, al *living independently* (art. 19), y tampoco choca con las posiciones de otros enfoques feministas contemporáneos de matriz neoliberal (es el caso del controvertido *choice feminism*: Hirshman, 2006; Casalini, 2018; Verza, Vida, 2020) con los cuales, en una inspección más cercana, el FDF muestra algunas asonancias significativas justamente en el plano de las reivindicaciones en materia de 'libertad sexual'.

Uno de los objetivos polémicos principales del feminismo de la diversidad funcional, así como lo fue para el feminismo negro y postcolonial de fines de la década de 1960, es el así llamado

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[4] Marcadas por la experiencia franquista: García Alonso, 2003, pp. 259-281.

feminismo *mainstream*. Este último sostendría un discurso etnocéntrico-capacitista con implicaciones marginadoras en relación con las mujeres con discapacidad.

En realidad, sólo algunas de las mujeres con discapacidad y de la/os asistentes sexuales que entrevisté se reconocen abiertamente como parte del feminismo de la diversidad funcional y/o del movimiento por la vida independiente español, rebautizado en 2009 como *Foro de la Vida Independiente y Divertad* (FVID): el cambio de nomenclatura pretende remarcar el nacimiento de un «modelo cultura de la diversidad», una superación definitiva de los viejos modelos médico y social, también éste inspirado por la CDPD y basado en la conjugación de los derechos de dignidad y libertad para las personas con discapacidad (Rodríguez-Picavea, 2013; Palacios, 2008). Tal modelo «busca poner en valor la riqueza de la diversidad humana y defender la igualdad en base a la dignidad intrínseca del ser humano, no a unas supuestas capacidades extrínsecas» (García-Santesmases Fernández, 2016): una suerte de paradigma *disability blind* con ecos (nuevamente) neoliberales, que propongo adscribir mejor a un paradigma intermedio.

A pesar de que falte un reconocimiento explícito, buena parte de las entrevistadas se identifica con las interpretaciones principales del feminismo de la diversidad funcional en relación con los mecanismos de segregación y de exclusión que afectan a las mujeres con discapacidad, y también con las instancias conjuntas de los dos movimientos (FDF y FVID) en relación con la esfera de la sexualidad como ámbito esencial en el que se expresa el derecho humano universal a la salud, de acuerdo con la versión de la «Declaración de los derechos sexuales» compuesta en 2014 por la *World Association for Sexual Health* (Arnau Ripollés, 2020a), así como con algunos discursos iusfilosóficos recientes (de Asís, 2017, Suárez, 2020). Entre esas instancias, se destaca la del reconocimiento de la figura del asistente sexual, entendida de diferentes maneras, para las personas con discapacidad. El debate acerca de accesibilidad y asistencia sexual pone de relieve algunos de los cabos sueltos dentro del pensamiento feminista *mainstream*, lanzando un desafío a la reflexión feminista en general.

2. El «feminismo de la diversidad funcional»: la crítica al feminismo mainstream entre «paredes de cristal» y estereotipos 'faltantes'

Soledad Arnau Ripollés (2005a), también cofundadora de la *Oficina de Vida Independiente* (OVI) de Madrid de la cual fue coordinadora, fue la ideóloga y la exponente con más autoridad del feminismo de la diversidad funcional. El movimiento nació de la toma de distancia, por parte de un grupo de estudiosas y activistas con discapacidad (con competencias a menudo certificadas en el ámbito de la sexología), de las corrientes feministas percibidas como hegemónicas: de las blancas, 'estructuradas' académicamente, occidentales, cisgénero, heterosexuales, normocapaces, de clase o de edad media, de «aquellos feminismos, dominantes y excluyentes, que dejan a muchas mujeres en los márgenes» (Arnau Ripollés, 2015). No sintiéndose representado por las voces y los discursos de estos feminismos, el grupo se afilió primero a los «feminismos periféricos» (Rodríguez Martínez, 2011) para luego dar vida a un posicionamiento autónomo (Mañas Viejo, 2009) desde los márgenes (Casalini, 2013, p. 315), transformados con el tiempo en instrumentos de *empowerment,* medios a través de los cuales resignificar y reivindicar las diferencias (Arnau Ripollés, 2016, p. 58; Moscoso Pérez, 2016).

Como teórica y militante, en diversas ocasiones Arnau Ripollés ha reprochado al feminismo *mainstream* el no haberse comprometido con la deslegitimación del patriarcado en relación con el así llamado capacitismo (Campbell, 2009; Friedman, Owen, 2017; Brown, Leigh, 2020), que en su opinión es el dispositivo principal de discriminación, opresión y exclusión de las mujeres con discapacidad. Incluso en la larga entrevista que me ha dejado[5], no deja de denunciar esa laguna que le adscribe:

> Yo nací con el feminismo, entonces de repente me dio un subidón y decir “¡guau, este es maravilloso!, hasta que me dio un super bajón porque dije: “oh, no nos quieren a las mujeres con diversidad funcional”. Por lo menos en España, no nos quieren. Eso no se arregla de hoy para mañana, esto es un proceso largo. Es que quienes tienen las voces hegemónicas, quienes estén en los proyectos de investigación, quienes hacen libros, todas son idénticas, ese es el problema, y están institucionalizadas, o sea, que tienen sus cátedras en las universidades, están en el ayuntamiento o no sé qué, pero todas son blancas, todas son de clase media, de mediana edad, ninguna ha sido cuidadora, por ejemplo, y han estado en las mesas de negociaciones de los cuidados, pero no son las cuidadoras (…) El feminismo — yo creo — que se ha dedicado a deconstruir el patriarcado, pero no se ha preocupado jamás de deconstruir el capacitismo, y por tanto el feminismo está sesgado por el capacitismo. Ellas (las feministas) quieren mujeres con muchas capacidades como el resto del mundo. Claro, después obviamente existen pluralidades de feminismos y los feminismos más disidentes, menos hegemónicos, van creando alianzas. Claro, desde la marginalidad vamos creando alianzas, pero no tenemos las voces hegemónicas.

El discurso del feminismo ‘clásico’ se encontraría inervado por una lógica capacitista: daría por descontadas, o pretendería, una serie de capacidades en cabeza de las mujeres, no teniendo seriamente en cuenta de las exigencias y de las dimensiones disímiles que plasman sus vidas materiales (Cruz Pérez, 2004). Por lo tanto, éste no sería capaz de comprender y defender las instancias de sujetos femeninos que no satisfacen algunas expectativas o que no se encuentran disponibles para un «ajuste extra» (Iglesias Padrón, 2007). Para Arnau Ripollés, así como para otras estudiosas, esto no significa automáticamente que las mujeres con discapacidad no hayan tenido o no puedan tener lugar en las reivindicaciones feministas, sino más bien que sus voces no

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[5] Soledad Arnau Ripollés me había expresado la voluntad de renunciar al anonimato: sin embargo, aparte de las declaraciones ya expresadas en numerosas intervenciones orales y escritas, he decidido respetar el pacto general de entrevista, volviendo anónimas sus referencias, así como lo he hecho con las otras mujeres entrevistadas.

han sido y todavía no son escuchadas adecuadamente, dado que en cierta medida resultan disonantes con respecto a algunas de las premisas y objetivos del proyecto feminista *mainstream*:

> al movimiento feminista, que tradicionalmente ha establecido relaciones más fluidas con otros colectivos de mujeres como las migrantes, se le presenta una ocasión de oro para tender puentes con el amplio colectivo de las mujeres con discapacidad. Sin duda esto les exige buenas dosis de humildad y reconocer que el patriarcado es una experiencia que va más allá de las situaciones que su discurso ha enseñado a ver como opresivas, y le urge a revisar la categoría de mujer desde la que elaboran su reflexión, demasiado parecida a la de los discursos dominantes a los que se opone (Moscoso Pérez, 2014).

Sin embargo, es innegable que la reflexión feminista tiene *ab origine* una relación problemática con la ‘discapacidad’ y con su bagaje simbólico — compuesto por palabras altisonantes como deficiencia, carencia, ausencia, inferioridad, pasividad, dependencia — ya que las mujeres han sido consideradas por largo tiempo (y, en algunos contextos, lo son todavía) como sujetos discapacitados (las mismas mujeres con discapacidad a menudo se perciben como ‘doblemente discapacitadas’), es decir no capacitadas para llevar a cabo determinadas tareas y a ocupar ciertas posiciones (reservadas a los hombres) por ser débiles físicamente, frágiles emocionalmente, inmaduras cerebralmente, y por tanto relegadas a funciones presuntamente connaturales al sexo femenino, que requerirían más instintos que capacidad, como aquellas de cuidado de maridos, hijos, ancianos y (otros) discapacitados.

Con estas premisas, la ‘primera ola’ feminista comprensiblemente apuntó a desacreditar el patriarcado, revelando sus mecanismos incapacitantes-sexistas en relación con las mujeres, en aquella fase consideradas como un grupo social homogéneo, con el fin de primero que todo rehabilitarlas como sujetos capaces a la par de los hombres y, por tanto, merecedores de los mismos derechos fundamentales reconocidos a estos últimos. En particular, en el plano de las políticas del derecho, el esfuerzo de las primeras teóricas liberales fue en la dirección de una igualdad que considerara jurídicamente irrelevantes los factores de sexo y género.

Desde la posición de las mujeres con discapacidad, la operación emancipadora no ha considerado al capacitismo en sí mismo como un sistema masculino-opresivo, haciendo que las diversidades humanas y especificades femeninas terminaran siendo consideradas obstáculos para el logro de los objetivos establecidos. El abultado bagaje neutralista habría así determinado la remoción sustancial, de la reflexión feminista, de algunas cuestiones centrales que tampoco las olas sucesivas (aunque más atentas a la diferencia sexual y entre mujeres, a las oportunidades iguales más que a las capacidades iguales) habrían sido capaces de sacar a la luz y profundizar.

Entre aquellas removidas por este bagaje, se encontrarían comprendidas:

- las políticas generalizadas, también en el derecho, de corte eugenético (piénsese a las pruebas diagnósticas prenatales, aborto terapéutico, aborto de fetos discapacitados[6], contracepción forzada, esterilización forzada[7], suicidio asistido selectivo, *wrongful life actions*[8]);
- la violencia sistemática contra las mujeres con discapacidad (Iglesias Padrón, 2007; Arnau Ripollés, 2005b), ejercida no pocas veces en lugares domésticos o de cuidado por parte de otras mujeres *care-givers* y normatizada como si fuera parte necesaria de 'su cuidado' (Wadiwel, 2018, p. 58);
- la cuestión irresoluta del asistente personal, «contrapuesto [por los *disability studies* y las feministas de la diversidad funcional] a la figura del *care-giver*» (Casalini 2015), evidentemente también un instrumento necesario para la construcción de una vida de relación en general (art. 19 CDPD), e íntima en particular (sin el asistente personal, algunas personas no podrían ir al trabajo, hacer las compras, tener hobbies o salir para conocer a otras personas);
- las dificultades, en último lugar, que experimentan las mujeres con discapacidad para acceder a aquellos roles 'tradicionales', novias, esposas, madres (Keith and Morris, 1995; Mun Man Shum *et al*. 2006, pp. 39-40), por los cuales las mujeres 'normales' se sienten generalmente oprimidas y de los cuales se habría visto por tanto forzada a tomar distancia la primera corriente feminista. El hecho de que los estereotipos femeninos típicos no apliquen de la misma forma a las mujeres con discapacidad que a otras mujeres, hecho que es acompañado por una relación casi completamente inversa en el plano de los derechos reproductivos «positivos» y «negativos» (Medina, 2017), lejos de constituir necesariamente una fuente de liberación, paradójicamente se vuelve motivo de ulterior marginación (Viñuela Suárez, 2009, p. 40).

En palabras de algunas entrevistadas:

> Por ejemplo, mis amigas se quejan mucho de que cuando van a reuniones familiares siempre les preguntan: "y el novio, ¿cuándo vas a tener novio?" Y cuando tiene novio, "bueno, y ¿cuándo te casas? Y cuándo te casas, "bueno, y ¿cuándo tienes hijos?" A mí nunca me lo ha

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[6] Cfr. al menos Arnau Ripollésl, 2012, pp. 196, 215.

[7] Cfr. al respecto almenos la relación de Cermi Mujeres, 2018. España puso finalmente fin a la práctica con la «Ley Orgánica 2/2020 de modificación del Código Penal para la erradicación de la esterilización forzada o no consentida de personas con discapacidad incapacitadas judicialmente».

[8] Se trata de acciones legales dirigidas a obtener un reconocimiento del daño por vía de un nacimiento, y por tanto de una vida no deseada. Las acciones son generalmente interpuestas contra médicos y profesionales sanitarios responsables de no haber predicho o evitado el nacimiento de la persona con discapacidad. A veces, en cambio, son dirigidas contra los progenitores del/la hijo/a discapacitado/a por parte del tutor de éste/a.

> preguntado mi familia, y entonces, pues, mis amigas se quejan de eso y yo me quejo de que no me lo preguntan [discapacidad física-genérica, 36 años, sede asociación, 25/10/2017].
>
> Yo, cuando era jovencita, pues, había pensado tener familia numerosa, porque nosotras éramos seis, yo quería casarme, tener hijos, familia numerosa, ni un hijo ni dos, quería familia numerosa, pues quería tener hijos, y ya poco a poco he visto que eso ya… tenía que renunciar a eso. (…) Muchas veces pensé también al miedo que tengo yo al rechazo, y sobre todo de una pareja, yo tengo miedo porque yo ya he visto que sí que es verdad que te rechazan y como se pasa muy mal, ¿sabes? [trastorno bipolar, 44 años, casa, 31/01/2018].
>
> ¡Olvídate! Tú ni vas a tener una vida sexual ni una vida reproductiva, desaparece esa faceta (…) Ellos piensan, primero, que yo no voy a ser capaz de tener hijos, y segundo, que si al día de mañana quiero tener hijos: primero, un embarazo — yo creo — que lo obvian por completo, y sería sí obviamente por adopción, porque — yo creo — que como que no se tiene pensado en un formato de una mujer en silla de ruedas embarazada… es muy triste, me da pena [paraplejía, 28 años, universidad, 18/02/2018].
>
> En aquellos tiempos la gente con artritis no tenía familia, las mujeres se esterilizaban porque después de tener el embarazo, después de dar a luz, sueles tener un brote que te puede dejar en silla, entonces la mayoría de las mujeres que yo veía en la consulta del médico, el reumatólogo, se habían esterilizado o me decían que me olvidara de tener familia (…) Es que el tener un hijo es una experiencia, y que te quiten esa experiencia… porque si eliges tú, vale, que alguien te esterilice y te quite esa experiencia — yo creo — que no es justo, porque si yo me hubiera quedado en silla no me hubiera importado, porque mis hijas es lo mejor que me ha pasado en esta vida, entonces no me hubiera importado [artritis reumatoide, 57 años, bar, 27/10/2017].

Arnau Ripollés sugiere que, así como el patriarcado tiene un referente ideal (varón, adulto, blanco, cisgénero, heterosexual, sano, normocapaz, de clase burguesa y tradición cristiana), también el feminismo tiene uno, consolidado e igualmente opresivo, incluso si no es tan evidente como el primero, que admite a las mujeres con discapacidad sólo hasta un cierto nivel. Un límite — anclado en un núcleo duro capacitista, que posee capacidades preestablecidas — que marca un confín, alza una «pared de cristal» entre las mujeres con discapacidad y las otras mujeres: una pared que, con cada alejamiento del modelo, se multiplica exponencialmente (Arnau Ripollés, 2005a, p. 22; 2015, p. 3).

La pared de cristal es tan invisible como el conocido *glass ceiling*, y quizás más resistente que éste, en la medida en que constituye un ‘no dicho’, otro «problema sin nombre» o, peor, un ‘asunto privado entre mujeres’. Muchas mujeres con discapacidad perciben el discurso feminista *mainstream* como dispuesto a incluirlas y a representarlas bajo la condición de responder positivamente al llamado de volverse *capaces*, es decir, a alcanzar niveles predeterminados de autonomía, control, calidad/dignidad de vida; más aún, a demostrar habilidades extraordinarias, a volverse heroínas en una lucha personal dirigida al logro de la pretendida y reconfortante (para las normales) normalidad:

> Yo acabo de meterme en todo esto de la diversidad funcional, pero no desde un punto de vista victimista que es lo que yo veo más aún abundante, eso de: “pobrecita, tienes mucho merito, eres una valiente, eres una luchadora”. A mí eso no me gusta, me parece muy paternalista (…) Tenemos que hablar de igualdad con nuestras diferencias… o, pues, lo que se reclama desde el punto de vista de más activistas de la diversidad funcional, hay gente muy radical, pero, bueno, es que somos igual de diferentes todos. No necesitamos alguien que te diga: “pobrecitos”, sino que se adapte la vida, o las cosas, a nosotros, pero, que tengo el mismo derecho, todo esto viene del Foro de vida independiente [física-genética, 36 años, sede asociación, 25/10/2017].

> Solo tenía que creer en ella misma y dedicar más tiempo, más esfuerzo y tener más motivación que aquellas personas que no tuvieran lámpara [sordera, 29 años, relato, 5/7/2018].

En este sentido, el feminismo de la diversidad funcional (FDF) parece proponer nuevamente la crítica hecha por la ‘segunda ola’ (en particular, del feminismo cultural), y después retomada y rearticulada por el feminismo radical (del cual la abogada Catharine Mackinnon puede ser considerada su principal exponente), contra la posición teórica de la primera ola, responsable de haber caído en la red asimilacionista al incorporar en la caja de herramientas para la emancipación femenina algunos instrumentos generadores de desigualdad o, al menos, de mantenimiento del *status quo*. Muchas feministas habrían interiorizado el capacitismo con la ilusión (quizás) de poder corregirlo con el tiempo.

La expectativa heroica feminista fortifica a aquella sostenida por el resto de la sociedad en relación con las personas, y en particular las mujeres, con discapacidad, agudizando la distancia entre mujeres presuntamente *normales*-capaces-titulares de derechos y *desviadas*. No sorprende, por tanto, que en todas las entrevistas se destaque la trama de la conquista ardua de la normalidad, que incesantemente requiere un comportamiento de superación a las mujeres con discapacidad, combativo contra la ‘discapacidad-enfermedad-límite’, así como habilidades sólidas de «negociación»:

> Estoy contenta con mi vida y mi forma de ser, pero a veces te sale la rabia: no puedo hacer una vida como una chica normal, es que es eso “¡no eres una chica normal!”. ¿Por qué yo no voy a ser una chica normal? Ay, tonterías, pero es lo que te establece la sociedad, que te obliga a pensar que tú no eres una chica normal, es que, por estar en una silla de ruedas, no te consideres normal. ¿Qué es normal también? Pero la sociedad es muy cruel, establece cosas que no son justas [paraplejía, 28 años, universidad, 18/02/2018].

> O sea, yo no me veo como una persona con discapacidad, igual debería verme, porque limitaciones tengo, pero no me veo en mi cabeza, no soy capaz de verme (…) Era un espectáculo andante, no te puedes imaginar, que la gente me miraba, es claro: el hecho de estar en continuo temblor, la gente te mira sí o sí. ¡Es que a parte de lo que tienes, lo que hay que aguantar es la gente! (…) Si hago una cosa, quiero hacerla con normalidad [discapacidad subsecuente a cáncer de colon, celiaquía, bar de su barrio, 20/01/2018].

> La práctica no normaliza (…) Tienes que demonstrar la normalidad continuamente, demonstrar continuamente que tú eres normal entre comillas (…) Tienes que demonstrar que eres normal todo el rato: ¡cuesta, eh! (…) Tienes que negociar también, tú vas negociando [parálisis cerebral, 34 años, bar de su barrio, 30/01/2018].

«La práctica no normaliza»: justamente, las heroínas siguen siendo ejemplos excepcionales.

Así habla, un asistente sexual entrevistado, de la mujer con parálisis cerebral con la que ha tenido relaciones sexuales:

> Es una mujer extraordinaria, yo le digo: “eres mi heroína”, porque es que tiene fuerza de voluntad, de gana de vivir, yo me pongo en su lugar y yo me querría morir (…) No me voy a enamorar de ella evidentemente, lo que te quiero decir es que cuando estoy con ella hablamos de cosas, hasta de política, es una persona encantadora, yo le digo: “eres mi heroína, me pareces una mujer extraordinaria, porque muchas mujeres en tu situación estarían…”. No sé, tiene una gana de vivir impresionante [hombre, arquitecto, parque, 29/06/2018, plataforma].

No sólo las heroínas no son susceptibles de normalización real (Pozzolo, 2019, p. 31) sino que además sus biografías extraordinarias, a menudo publicitadas por los medios de comunicación masiva, corren el riesgo de reforzar el modelo capacitista: las verdaderas mujeres, con discapacidad o no, son aquellas que se sacrifican y se esfuerzan, que soportan (silenciosamente) el dolor, que no se dan por vencidas ante la adversidad. En resumen: que lo logran, siempre.

Además, las heroínas refuerzan estereotipos y prejuicios relacionados con otras mujeres con discapacidad, que son consideradas, por ejemplo, como usualmente negligentes o inoperantes en el plano productivo-laboral («menos productivas, pasivas, comodonas, que se cansan más»: Leyra Fatou *et al.*, 2019, p. 114), lo cual constituye el plan capacitista y de segregación por excelencia: el «suelo pegajoso» (Harlan e Bertheide, 1994; Perez Oroz, 2014) que caracteriza el mercado del trabajo confina a las mujeres a sectores y posiciones medio-bajas y, a las mujeres con discapacidad, a sectores y posiciones bajísimas. Estos estigmas luego son fácilmente internalizados por las mujeres con discapacidad y ‘consumidos’ en todos los planos (mucho más allá del laboral, que ya de por sí ejerce una fuerza centrípeta y osmótica en la construcción de la identidad), dejando poco lugar a la expresión de las diferencias, y menos aún a la afirmación del principio de «igualdad en las diferencias», recordado en uno de los extractos de entrevista.

El fenómeno de la internalización de los estereotipos contribuye a volver aún más pegajoso al suelo, e inexpugnables a las paredes entre mujeres, favoreciendo un verdadero cortocircuito que puede impedir la persecución de rutas comunes.

En cambio, el énfasis en la ‘capacidad de superación’, en el compromiso y en las responsabilidades individuales, es parte de las retóricas más abusadas por el matrimonio entre neoliberalismo y «capitalismo emotivo» (adecuada expresión de la socióloga franco-israelí Eva Illouz, 2007) para deslegitimar las voces disidentes, ocultar las discriminaciones y, al mismo tiempo, reducir problemas estructurales a meros problemas actitudinales individuales (Moscoso Pérez, 2013, p. 177)[9]; es decir, en el fondo reducirlos a cuestiones de tipos psicológicos que, según la conocida distinción del sociólogo Talcott Parsons (1952), se pueden calificar como activos o pasivos en relación con la capacidad (de nuevo) de acción y control en circunstancias críticas.

El discurso capitalista neoliberal (Fraser, 2013) con gusto recurre a las narraciones discapacitado-heroicas, de imágenes resilientes, para ejercer control moral sobre la entera sociedad (en tal sentido, se habla de «biografías terapéuticas»), quizás invocando el sentido cívico y/o el valor de la solidaridad, al mismo tiempo que exime de responsabilidad a los actores institucionales con respecto a la cultura incapacitante que justamente constituía el objetivo polémico de los primeros teóricos del modelo social.

En este marco, la ya mencionada académica Moscoso Pérez (2016, p. 914) pregunta: «¿No será la discapacidad heroica la mejor de las excusas para desentenderse de las limitaciones de todos?».

3. Los cuerpos ‘impertinentes’ de las mujeres con discapacidad: estereotipos específicos

El de la heroína discapacitada es sólo uno entre los estereotipos ‘específicos’ insidiosos que conciernen a las mujeres con discapacidad (y no a las otras).

Los estereotipos que conciernen a las personas con discapacidad atraviesan todas las áreas de la vida socio-relacional y afectan en mayor medida a las mujeres (Mun Man Shum *et al.*, 2006, pp. 34-35), legitimando de hecho — y, en ocasiones, también de derecho — prácticas opresivas hacia ellas: basta pensar a la plaga de la esterilización forzada ya señalada, a la cual España sólo recientemente puso fin con la *Ley Orgánica* 2/2020 (Scudieri, 2021).

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[9] Como señala la académica, se trata de un mecanismo particularmente evidente si pensamos al que se volvió el *motto* de los Juegos Paraolímpicos: «The only disability in life is a bad attitude». Cfr. también Russo, 2020, p. 116.

Para las mujeres, las dificultades ligadas a la discapacidad se entrelazan con aquellas inherentes al cumplimiento de las expectativas del rol (femenino), en el caso en que estas expectativas existan o que en cualquier caso hayan sido interiorizadas como socialmente importantes:

> También es que soy muy feminista, entonces, claro, cuando juntas una cosa con la otra, estalla y la gente te dice: “no quiero nada de esto”. Te juntas con chicos, que hacen comentarios, me salen venas, no puedo con este machismo: “pues, mujer, tienes que tener hijos, te tienes que casar” y tengo alrededor gente que me dice (…) ¿Por qué no puedo ser feliz a lo mejor con mi vida, con un trabajo, disfrutando al cine, a conciertos, a música? ¿Por qué, por ser mujer, me tengo que casar y tener hijos? Tu ambiente es como que te lo condiciona [paraplejía, 28 años, universidad, 18/02/2018].

Los esfuerzos que las mujeres realizan para no defraudar tales expectativas, esto es para seguir las normas de género, corren el riesgo de comprometer ulteriormente su condición, como es evidenciado en el relato de una mujer con discapacidad que trabaja en una asociación que se ocupa de personas con artritis:

> Es que (las mujeres) siguen trabajando en casa, y es que el trabajo en casa es muy duro, supone un esfuerzo tremendo, y si tienes que retorcer y tienes que hacer cosas con artritis es muy complicado. Los hombres dicen, muchísimos dicen: “es que tengo muchísimas cosas que hacer”, pero tienen que ir al hospital a llevar no sé qué cosas, a ver a su madre a no sé qué otra, a este porque tienen que llevar no sé qué papel. Entonces, son otros tipos de funciones, totalmente distintas la mujer: la mujer se queda en su casa barriendo, limpiando, fregando. El hombre: yo no conozco a ningún hombre que le hayan dado una incapacidad y se haya quedado en su casa barriendo, fregando, limpiando, cepillando, no lo conozco, ¿sabes? Todo lo que conozco es que tiene muchas cosas que hacer, pero es porque van a ayudar a la madre o a acompañar a la madre o a la suegra o al suegro al hospital, a no sé qué, y van a llevar, a acompañar, al hijo a… porque tienen una mujer en casa o consiguen alguien que lo haga [artritis reumatoide, 55 años, sede asociación, 18/01/2018].

En este sentido, se habla de «doble discriminación» o, más a menudo, de «discriminación múltiple», basada en dos o más componentes: a género y discapacidad se pueden agregar el color de la piel, la edad, la clase social, el idioma, la fe religiosa, la orientación sexual, el origen étnico, la posición política, etc. Dado que generalmente los dos o más componentes no se limitan a sumarse, sino que interactúan entre ellos influenciándose mutuamente (volviendo difícil discernir y evaluar el peso de cada una de las dimensiones opresivas), la discriminación también es eficazmente denominada «interseccional». El término, como es sabido, fue acuñado por la jurista Kimberlé Williams Crenshaw (1991, 1993) — estudiosa de referencia para el FDF — que lo volvió la llave para la asunción de una perspectiva innovativa en la lectura de la dimensión cualitativa (y no meramente cuantitativa) de la experiencia opresiva sufrida por los «sujetos no paradigmáticos» (Bello, 2020; Bernardini, 2020). Para el feminismo de la diversidad funcional, hasta ahora la reflexión feminista no parece haber sido capaz de afrontar el desafío lanzado por el enfoque de la interseccionalidad en su versatilidad; por el contrario, ha contribuido no a evidenciar las potencialidades de este enfoque, sino más bien a evidenciar sus límites. Tal como desde hace tiempo las feministas negras denuncian el debilitamiento del enfoque a causa de su «blanqueamiento», entendido como la 'apropiación indebida' por parte de estudiosas blancas de un instrumento originariamente elaborado por activistas negras con el fin de evidenciar la interacción sistemática entre sexismo y racismo, las mujeres con discapacidad reprochan la consideración escasa y estereotipada que se reserva a la intersección género-discapacidad y que habría contribuido a condenarlas a la invisibilidad:

> Primero, eres mujer, que ya te encuentras un paso por debajo; segundo, eres discapacitada, tienes una discapacidad, y allí te encuentras otro paso por debajo y: ¿lo tercero qué es? ¿Que también te omitan de cualquier cosa que quieras hacer? En un libro había una expresión que me gustaba mucho que era, lo comparaban con el béisbol: strike uno, eres mujer; strike dos, tienes una discapacidad; ¿cuál es tu tercer strike para que te eliminan de la vida? ¡Y es verdad! [paraplejía, 28 años, universidad, 18/02/2018].

Para el feminismo de la diversidad funcional, el feminismo *mainstream* es reacio a renunciar a un modelo de mujer normo-capaz, dotada de un grado más bien elevado de autonomía[10]. En este sentido, percibiría algunas instancias de las mujeres con discapacidad como una amenaza para las arduas conquistas feministas, temiendo una ola *cripwashing*[11] en un momento histórico en el cual, por otra parte, el riesgo de un retroceso cultural y jurídico (especialmente, en el campo de los derechos) es más real que nunca.

Para las feministas de la diversidad funcional, tal comportamiento contribuye a la alimentación de una cultura patriarcal-capacitista, que niega necesidades, emociones y derechos a las mujeres con discapacidad. Y la reivindicación de los derechos que pertenecen a la esfera de la sexualidad, quizás la más empapada de (hetero)normo-narraciones, ha asumido un rol de primer plano en la estimulación del debate entre mujeres y discapacidad. En tal campo, los estereotipos y los prejuicios se encuentran muy bien consolidados y se irradian a partir de aquello que muchas consideran como el más grande tema borrado de la reflexión feminista: el cuerpo.

Si, por un lado, las estrategias discursivas recurrentes en torno a la separación de cuerpo y mente y a las distinciones biológico/social (como sexo/género, déficit/discapacidad) en sus

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[10] Ciertamente, como surge en diversas ocasiones, el feminismo de la diversidad funcional no parece tomar en consideración buena parte de las reflexiones feministas sobre la autonomía, en particular sobre la «autonomía relacional», el cual se limita a contraponer una concepción de independencia.

[11] «Cripwashing refers to the practice of using the rights protections of one group to conceal abuses towards other groups» (Moscoso y Platero, 2018).

inicios funcionaron a los fines de desacreditar el modelo médico, de la apertura del debate político y del reconocimiento de algunos derechos fundamentales de las mujeres con discapacidad, por otro lado, terminaron por volverse en contra de ellas en el momento en el cual decidieron apelar a otros derechos sobre la base de las diferencias (funcionales) anteriormente normalizadas al precio (caro) de la invisibilidad.

El 'cuerpo discapacitado' tiene, al menos, tres peculiaridades significativas. En primer lugar, la exposición tendencialmente continua a la mirada (crítica) y/o al toque (asistencial) de otros. En segundo lugar, la sensación frecuente de ser un extraño que habita ese cuerpo. En tercer lugar, el hecho de constituir la cifra de la diferencia entre las diferencias, en el sentido de volver a la minoría constituida por personas con discapacidad sustancialmente diferente a otras minorías (entendidas aquí como grupos desventajados), por ejemplo, religiosas o sexuales, a través de la *quota* biológica que impone. En los otros grupos minoritarios, con menos visibilidad y poder, en efecto la diferencia tendría un carácter prevalentemente 'cultural'. Ciertamente, algunas mujeres con discapacidad grave entrevistadas me dijeron que sentían mucha empatía por las minorías sexuales debido a su corporeidad no conforme. Sin embargo, para las minorías sexuales la opresión cultural parece pesar más que aquella biológica, en la medida en que pueden desembarazarse de esta última de manera relativamente más sencilla (por ejemplo, cambiando sexo). Por otra parte, también es significativo que la 'comunidad sorda' — percibida desde afuera como una minoría con una discapacidad sensorial, y por tanto portadora de una diferencia que puede decirse física — se haya en cambio a menudo autodefinida (emerge también de mis entrevistas) como un grupo cultural, notablemente etno-lingüístico; una minoría, en resumen, *by will* (Fanlo Cortés, 2016).

Indudablemente, el cuerpo está destinado a permanecer en la intersección de transformaciones culturales y reivindicaciones identitarias que, en el caso de las mujeres con discapacidad, lidian con las expectativas presentes o frustradas sobre la pertinencia sexual y sobre la adecuación estética de sus cuerpos (Cruz Pérez, 2004, pp. 157-158).

Las mujeres con discapacidad (especialmente, si es física) son percibidas como indeseables, privas de «capital erótico» (Hakim, 2012), ya que habitan cuerpos que se alejan de los estándares de feminidad y belleza: cuerpos *erróneos*, los define una entrevistada; cuerpos *rotos* al punto de no ser considerados 'de mujer', lamenta otra en la narración citada abajo. Estos cuerpos fracturados, no hegemónicos, lejanos de los cánones propuestos por la sociedad, «fuera de la industria del sexo» (como afirma Arnau Ripollés, 2018), serían capaces de atraer únicamente *devotees*, personas que se considera que sufren trastornos parafílicos, para quienes el deseo (morboso) sería suscitado en realidad por el déficit y/o por los auxilios (silla, muletas, dispositivos varios) utilizados por la persona[12].

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[12] Sobre el así llamado «devotismo», cfr. al menos Mora, 2016.

Al mismo tiempo, las mujeres con discapacidad son percibidas como no deseantes, hiporeactivas, como niñas eternas privas de intereses y estímulos sexuales o, por el contrario (en este caso, especialmente si se encuentran afectadas por una discapacidad intelectual o psíquica), como monstruos hiperactivos/hiper-sexuados, sexualmente incontinentes; características que las volverían también víctimas menos creíbles en caso de denuncia por abuso o violación (Steele, 2018, especialmente p. 86):

> Es el canon de belleza que estipula la sociedad y, como tú no entras en ese canon, ya te humillen (…) Una silla de ruedas para mucho a la gente, y a los chicos más…porque queda muy mal decirlo, pero muchos chicos buscan a una chica guapa, a una chica con un buen cuerpo, muchos chicos buscan a lucir a su novia, y en mi caso no… (…) Algo que a mí me dejó y me tocó muchísimo es que (ella) me dijo que es que nos ven como que si estuviésemos rotas… y, en verdad, es que la gente te ve así, te ve como si estuvieras rota y te sigue manteniendo como si fueras una niña. O sea, en todo momento, nadie te ve como en plan “eres una mujer” [paraplejía, 28 años, universidad, 18/02/2018].
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> Mis compañeras en el colegio no querían salir conmigo porque daban por hecho que tenían que ser como mi niñera: saliendo conmigo, bueno, según ellas, no podían conocer a chicos (…) De allí también viene ello de mi inseguridad, de no sentirme deseable (…) Hay casos que yo tenga siempre mucho complejo de fea, de gorda, de poco inteligente, y todo también de mi padre: “no le vas a gustar a nadie, si alguien está contigo es por pena o por aprovecharse de ti” (…) Mi sueño también es ponerme un vestido, y además me hace mucha ilusión, pero como mi madre dice: “con ese culo tan gordo que tienes, con esas piernas que tienes, ¿cómo te vas a poner un vestido? ¡Que horror!” (…) Al final acabé hablando de validar el error, el cuerpo erróneo, de este cuerpo que es mío, que en realidad, pues, puede llamarse un cuerpo erróneo, y también empaticé mucho con las personas transexuales que están en un cuerpo que no es erróneo para ellos [física-genética, 36 años, sede asociación, 25/10/2017].
>
> Se suele ver un discapacitado como un ser asexual… no es así… Lo que pasa es que las circunstancias no son tan fáciles [parálisis cerebral, 34 años, bar de su barrio, 30/01/2018].
>
> ¿Qué ocurre con esas personas que tienen esas necesidades? ¿Qué hacen con ellos? “Ah no, son angelitos, son angelitos que no sienten”. Eso es lo que dice mucha gente: “no, ellos no sienten”. ¡Cómo que no sienten! ¿Que no sienten en la pierna porque están parapléjicos? Sí, pero tienen cabeza, y tienen cerebro y tienen memoria [asistente, mujer, masajista, 29/11/2018, centro].
>
> Esta mujer lo único que quiere es gozar, disfrutar, es lo único que quiere. Ella no piensa en novios. Sus mensajes de WhatsApp son hasta pornográficos. Ella habla de sexo de una manera desinhibida totalmente [asistente, hombre, arquitecto, parque, 29/06/2018, plataforma].

> Nos encontramos con gente como que siente atracción, pero no es una filia, o sea es una atracción por personas que tengan, pues a lo mejor, amputaciones, entonces que se encuentren en silla de ruedas, y a mí eso me genera tanta curiosidad, o sea, me encantaría conocer a alguien que tuviera ese tipo… se llaman devotees y son hombres y mujeres, pero lo que más suele haber son hombres, que sienten atracción por personas con discapacidad, unos son por personas a que les falta un brazo o a que les falta una pierna, que se encuentran en silla de ruedas, pero yo mi pregunta es: ¿sienten atracción por ellos, por la situación? ¿O sienten atracción por ellos por el cuidado y la dependencia que les pueda generar? ¿Sabes algo a que me refiero? Porque hay muchas personas que es en plan que les encanta ejercer el rol del cuidador, que alguien dependa de ellos. Entonces, a mí no me apetecería estar con una persona que le guste estar conmigo porque le satisfaga el ser mi cuidador [paraplejía, 28 años, universidad, 18/02/2018].

El último extracto de entrevista es particularmente significativo: si, por una parte, la mujer joven denuncia el estigma proveniente de la sociedad que consideraría a la atracción por personas con discapacidad como una perversión, por otra parte, no puede dejar de preguntarse si tal deseo está dictado por el placer obtenido del saber-poder sobre otro dependiente de sí, como sucedería en algunas relaciones de cuidado, y en consecuencia sea de cualquier modo insano.

Desde una perspectiva de género, la conexión puede incluso adoptar tintes más oscuros cuando el sujeto dependiente es automáticamente pensado en femenino mientras que el gratificado, independiente, con capacidad de control, es imaginado en masculino: la fantasía patriarcal en efecto habla de cuerpos disponibles, pasivos, vulnerables (Amy Elman, 2001).

La entrevistada misma pone entonces en discusión la autenticidad del involucramiento, aunque varias veces en el transcurso del relato se aprecia la conciencia de que la duda no es sino el producto de la internalización de una barrera interna («yo soy la primera, yo, que me pongo la traba») que le impide pensarse en una relación de pareja (que el sentido común querría que fuera, a lo sumo, con otra persona con discapacidad), incluso antes que sexual, ya que son es mujer con discapacidad.

La duda se vuelve relevadora de otro mecanismo discriminador interseccional cuando la muchacha, que se autodefine como feminista, piensa en la cinematografía. Entonces se da cuenta de que las pocas películas que conoce, que tienen a personas con discapacidad como protagonistas, escenifican románticamente la transformación de una relación de cuidado en una relación amorosa, cuyos intérpretes son siempre una asistente personal normo-dotada y sensible y su atractivo (físicamente y/o por su estatus) asistido:

> Es que lo que hay es el hombre, que además siempre, o sea, la tontería es que normalmente es un hombre que le ha ido bien en la vida, quien ha tenido recursos, quien se ha ido moviendo bien, y de repente le pasa, tiene un accidente, se queda en silla de ruedas y, por bien de la vida, conoce a una chica, quien es la persona que le cuida, y esa chica se enamora de él y pasa de ser su cuidadora a ser su mujer y cuidadora también, y, claro, yo me pongo

> mal, la vida real no es así: porque tú cuidas a una persona no te vas a enamorar de ella [paraplejía, 28 años, universidad, 18/02/2018].

En efecto, incluso en la película que es considerada un punto de quiebre en tema de sexualidad de las personas con discapacidad, la célebre *The Sessions* (dirigida por Ben Lewin, 2012), es una asistente femenina normo-capaz — en este caso, sexual — que se enamora de un poeta famoso con una discapacidad grave. Y no se trata de una única representación estereotipada propuesta por la película.

The Sessions presenta la historia verdadera del poeta Mark O'Brien que, paralizado a causa de la poliomielitis, descubre la sexualidad gracias al encuentro con una mujer — interpretada por Helen Hunt — quien se ofrece como terapeuta sexual y *partner* subrogada, aunque luego pide la interrupción de las sesiones debido a los sentimientos que en interín comienza a tener hacia el hombre. Falta el final romántico a la *Pretty Woman* (la asistente está casada y tiene un hijo, el asistido encontrará otra mujer que será su pareja hasta su muerte pocos años después), pero permanece el retrogusto amargo de la historia desgastada entre un cliente fascinante normal, o en cualquier caso normalizado, y una desviada semi-prostituta (Garofalo Geymonat, 2014, p. 405). Quizás una prostituta 'buena', menos alejada de la mujer normal lombrosiana — la terapeuta es una esposa y madre atenta que elije ocuparse de las personas con discapacidad, confirmando actitudes de ciudado ancestrales —, que sin embargo necesita ser redimida. Ambas protagonistas femeninas venden sexo y aprenden el amor: a través de la relación con el protagonista masculino de turno se domestican, revisan su «actitud hacia el sexo» — como la llama la protagonista de *The Sessions* — realineándose al binario de género correcto que las quiere románticas y morigeradas en la esfera emotiva-sexual. Al final de ambas historias, uno tiene la impresión de que son dos hombres quienes salvan a las mujeres perdidas (Giomi, Magaraggia, 2017, pp. 38, 117-133), a pesar de que al menos la protagonista de *The Sessions* no abandona el papel de terapeuta sexual.

En este marco, a pesar de ser innovadora e invocada como fuente de inspiración por la única asistente sexual [mujer, de más de cuarenta años] que he entrevistado, la película tiene el límite de no lograr conducir el mensaje de 'liberación' afuera de las jaulas de género, terminando por legitimar, a su pesar, una visión todavía estereotipada de las relaciones. Es bastante llamativo, por ejemplo, que la terapeuta, pensando en las primeras sesiones, subraye que él (el cliente): «no puede evitar verme como una mujer multifuncional: madre, hermana, amante».

Por otra parte, al hombre, incluso si con discapacidad, se le reconoce (casi siempre) el derecho a una sexualidad activa e incluso dominante-penetrativa: de nuevo en la película, después de las primeras 'sesiones exploratorias', el objetivo de los encuentros se vuelve explícitamente aquel de lograr el organismo mediante la penetración profunda, como si se trata del único modelo de relación sexual que vale la pena vivir o experimentar. Ésta me pareció también la perspectiva de los dos asistentes hombres entrevistados y, en parte, también de la asistente mujer, la cual me aclaró inmediatamente que tenía relaciones 'completas' sólo con el marido mientras otra colega — agregó —

> ella sí que ha hecho todo, todo absolutamente todo con cualquier tipo de discapacidad, esa persona sí que es excepcional de verdad: el quería todo... besos en la boca, penetración, momento íntimo sexual completo, nosotros lo llamamos completo aquí [asistente, mujer, masajista, 29/11/2018, centro].

Uno de los hombres me dijo abiertamente que entendió a la asistencia sexual como la consumación de una relación completa, es decir, que incluye la penetración (aunque la plataforma online en la cual está registrado promueva otro modelo de asistencia sexual), y que cualquier cosa diferente, según él que se detenga antes de la penetración, equivale a «no verdadero sexo», sino directamente a una forma de tortura para la mujer con discapacidad (para usar una expresión utilizada por el entrevistado).

La presunción en torno a una sexualidad necesariamente genital(-productiva) y falocéntrica está siempre en el centro de la crítica lésbico-feminista y, más recientemente, de las contra-narraciones del porno *queer* y feminista (Comella, Popolla, 2019), en los cuales las feministas de la diversidad funcional han encontrado ideas para una alianza fecunda tanto en el plano teórico como en aquellos de la investigación empírica y del activismo político:

> la sexualidad tiene muchas prácticas bonitas y placenteras, por lo que la penetración no es la única opción ni la que siempre apetece (Arnau Ripollés, 2018).

Volviendo a las representaciones cinematográficas — es posible colocar, junto a *The Session*, al menos el documental *The Special Need* de 2013 y la serie de televisión *The Special* (Rinaldi, Strizzolo, 2020) — es entonces plausible afirmar, en consonancia con los temores expresados por la entrevistada, que éstas no logran explorar la sexualidad de las mujeres con discapacidad (la excepción es el documental *Because of My Body*, que elige a una protagonista femenina), ya que se trata de algo que todavía hoy se esfuerza por ser pensado como emoción antes que como práctica. Las mujeres con discapacidad son de verdad *inessential* (para retomar el eficaz adjetivo de Spelman, 1988) en la medida en que se les quita la emoción sexual antes que su ejercicio práctico, la inteligencia emotiva (Nussbaum, 2004) antes que la competencia en la respuesta sexual:

> Me leí y vi un montón de películas, y de cosas, y no había nada acerca de como se veía a la mujer en el ámbito sexual, nada, y sigue sin haberlo, o sea, me da mucha pena, porque no se reconoce, es que estamos completamente invisibilizadas: en día de hoy tú te pones a hablar con una persona y no sabes cómo mantener una relación [paraplejía, 28 años, universidad, 18/02/2018].

Según el feminismo de la diversidad funcional, la 'invisibilización' es una consecuencia directa del capacitismo, que lleva a calificar como inexistentes o inadecuadas las expresiones sexuales que provienen de personas incapacitadas, y a mayor razón si son mujeres, en cuanto históricamente consideradas como objetos y no sujetos del deseo sexual.

Algunos estereotipos en materia sexual están tan cristalizados que incluso conducen a lo/as profesionales de la salud a asumir comportamientos estigmatizantes y, todavía más, a negar a las mujeres información y exámenes vitales:

> En vez de hablar conmigo, cuando yo soy la interesada, (el médico) se lo está contando a mi padre (…) Pero, aunque yo le cuento al médico lo que me pasa, el médico, lo que le remite, se lo remite a mi padre, no a mí, no (…) ¡A mí nunca un ginecólogo me ha preguntado si yo he mantenido relaciones sexuales, con 28 años! Nunca me ha preguntado… mira solo los resultados de tu analítica. Nunca me han ofrecido si hay algún taller: no, no, no. Nunca te van a preguntar si quieres tomar precauciones, o sea, ellos te ven como si fueras una niña, una niña que va al ginecólogo porque, a lo mejor, ha tenido un problema con la regla, o ha tenido un problema con no sé qué, pero no es ni: "¿te quieres cuidar?" o "¿tienes pareja?" o "¿tienes pensado tener relaciones sexuales?". No, nada, nada [paraplejía, 28 años, universidad, 18/02/2018].

> (El médico) está hablando sobre ti y le está preguntando a tu madre: ¡cuando tú tienes 20 o más años! Mi madre viene siempre (…) — "¿Me has puesto más cantidad u otra cosa distinta?" Porque el cuerpo no asimila uno y otros de la misma manera. — "No, no, no" y me quedé cambiando tema — "Te estoy hablando. Si me vas a hacer otra cosa distinta, dímelo porque yo me conozco". Y ella como sorprendida, ella al principio iba probando cosas distintas. — "No te preocupes, que a los tres meses te ha pasado" — "¡Cómo no me voy a preocupar de algo que afecta mi cuerpo! ¿Te sorprende? Me vas a inyectar algo: ¡no sé lo qué es!" [parálisis cerebral, dislexia, 34 años, bar de su barrio, 30/01/2018].

> Mi trastorno mental a veces es infravalorado por algunos profesionales sanitarios (yo creo sinceramente que hay un poco de desconocimiento y falta de experiencia acerca de este trastorno, y que por cierto, es uno de los trastornos de la personalidad que más sufrimiento genera, dentro de los trastornos de la personalidad) por lo cual no he tenido mucha puntuación en las valoraciones de mi centro base [41 años, 45% de invalidez a causa de un trastorno de la personalidad ansiosa y de un trastorno articular y tendinoso, 13/02/2018].

Los médicos infantilizan a las pacientes cuando no les reconocen el derecho de auto representarse, dirigiéndose durante una visita médica al acompañante (progenitor/a, amigo/a, asistente personal, intérprete) como si se tratara del único interlocutor adulto. En general, según algunas entrevistadas, tienden a identificar a la persona con discapacidad con la condición física o mental particular, omitiendo todas las otras características, incluso aquella de mujer: alguna/os ginecóloga/os, según los relatos, no parecerían tomar en consideración que las pacientes con discapacidad puedan tener una vida sexual y reproductiva, y por tanto que puedan necesitar informaciones puntuales sobre aquellos aspectos; ni que también puedan enfermarse de tumor en el seno o en el útero, y que por tanto necesitan someterse a exámenes oncológicos preventivos de detección como las otras mujeres. Y, en el campo médico, el enfoque deshumanizador y 'sectorial' puede dar lugar a diagnósticos extemporáneos de enfermedades importantes: en efecto, las mujeres con discapacidad tienden a obtener diagnósticos tardíos relacionados con los así llamados tumores femeninos, que afectan al seno y a los órganos reproductivos (Informe España 2019 — Fundación CERMI Mujeres, p. 60), elementos característicos de una corporeidad femenina ignorada, a veces, hasta las consecuencias más extremas.

Se trata de aspectos acerca de los que la medicina de género tiene el mérito de haber introducido una perspectiva inédita, que promete un impacto revolucionario a largo plazo (Valls, 2020). Sin embargo, en todas las entrevistas a las mujeres con discapacidad surgió de forma abrumadora el malestar, y no pocas veces la rabia, ligados a la preclusión de los medios para, y en sustancia del derecho a, tomar decisiones informadas en el área de la salud psico-física (en general) y reproductiva y sexual (en particular). Un derecho que al menos se deriva de la Convención de 1979 sobre la eliminación de todas las formas de discriminación contra la mujer.

4. Sujetos de deseo y ciudadanía sexual: prácticas de resistencia

El feminismo de la diversidad funcional está involucrado de diversas maneras en las operaciones de deconstrucción de los estereotipos mencionados anteriormente y de conquista de los derechos sexuales negados. Sin embargo, muestra una predilección por el uso de los instrumentos y del lenguaje de la sociología visual (imágenes, audiovisuales, fotografías) considerados más eficaces a los fines del logro de los objetivos establecidos.

Tres años después de la aparición de la recordada *The Sessions*, el movimiento feminista (FDF), en línea con el enfoque participativo-emancipador, se volvió promotor, junto con el rebautizado *Foro de Vida Independiente y Diverdad* (FVID), del documental español *Yes, We Fuck!*[13] — en el cual participaron algunos exponentes acreditadas interpretándose a sí mismas —, así como de campañas mediáticas como *Yo me masturbo*, programas de radio como el seguidísimo *¡Acuéstate conmigo*! y, en general, de seminarios (muy populares) en todo el territorio nacional sobre temas de sexualidad y de asistencia sexual.

Tales iniciativas habrían permitido, sin caer en la trampa 'tokenista' de siempre que termina por poner en escena *freak shows* (Moscoso Pérez, 2011, pp. 89-90), dar voz a las mujeres con

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[13] Dirigido por el activista Antonio Centeno y Raúl de la Morena, 2015. En 2015 también apareció el cortometraje post-porno *Habitación*, dirigido por Irene Navascués Cobo y Rosario Ortega Amador, con protagonistas como Teo Valls, Kani Arkada y Soledad Arnau Ripollés. Al año siguiente, 2016, apareció otra película exitosa, *Vivir y otras ficciones*, dirigida por Jo Sol y con Antonio Centeno revistiendo el rol de protagonista. Centeno también fue director y actor del documental post-porno *Nexos*, del 2014, y más recientemente de la serie de televisión *Trèvols de 4 fulles* (2018).

discapacidad respecto de cuestiones no consideradas como prioritarias, sino incluso silenciadas, en la agenda política feminista *mainstream*.

En particular, el documental mencionado habla de personas con discapacidad, que finalmente también son de sexo femenino y con emociones sexuales, como sujetos de deseo (no patológico), guiados por un asistente sexual hacia el descubrimiento del propio cuerpo *sexuado* y del placer. El asistente sexual está presente sólo cuando sirve una «herramienta» para explorar el cuerpo. Para desacreditar uno de los estereotipos mencionados en la sección anterior, en el cortometraje se pone en escena una relación sexual entre una mujer con una discapacidad grave y su pareja normo-dotada. El mensaje es luego reforzado por la presencia de 'otras sexualidades no (hetero)normativas' (García-Santesmases Fernández, 2016).

Una intención explícita del documental es «mostrar no sólo qué puede hacer la sexualidad por las personas con diversidad funcional, sino también qué puede aportar la realidad de la diversidad funcional a la sexualidad humana»[14], en particular a la sexualidad femenina, que en muchos aspectos es todavía un 'lugar prohibido', un espacio a recuperar.

Como sugieren las palabras del asistente sexual protagonista del cortometraje posterior *Moi, asistente sexuelle* (dirigido por Stefano Ferrari, 2016), lo que conviene repensar el tiempo de la sexualidad. El espacio y el tiempo del placer, para el 'cuidado' de sí y del otro/a, es quizás el código más importante compartido por los aspirantes a asistentes y clientes en el marco del proyecto del *feminismo de la diversidad funcional*.

Las mujeres con discapacidad — subrayan diversas entrevistadas — están acostumbradas a ver representaciones mediáticas en las cuales se mueven cuerpos y se consuman relaciones en las cuales no pueden identificarse[15]:

> Lo que tú ves en las películas, yo veo películas y en esas películas se están teniendo unas relaciones sexuales que yo no puedo vivir para empezar. No tenemos las mismas corporalidades, entonces mi primer imaginario es que eso no va conmigo [invalidez 85% — artrogriposis múltiple congénita, 46 años, residencia, 10/10/2017].

La fuerza de los estereotipos específicos y pasados por alto hace que las mujeres con discapacidad sientan que no tienen 'ciudadanía sexual' en la sociedad en la cual viven. Y el etiquetamiento condiciona fuertemente sus auto-percepciones como sujetos deseantes y deseables:

> Yo pensé: "¡así que este chico tiene poder de elección, tiene capacidad de decir que no!", "¡o sea que yo he sido una elección!". Sigo manteniendo el contacto y me sigue haciendo gracia que tontee conmigo, me se insinuó de una manera también sexual y a mí me hace ilusión… Era

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[14] https://yeswefuck-blog.tumblr.com/ima-ge/119014053814

[15] Como sucede además para otros grupos no conformes, pero también presumidos como 'normales'.

> un tío súper generoso, súper paciente y muy respetuoso, y muy bien, a mí me hizo crecer como ser deseante y ser deseable [física-genética, 36 años, sede asociación, 25/10/2017].

> “Es que me pareces una chica fenomenal, noto mucha alquimia contigo, yo te quiero conocer” (…) “¿Y qué más da? No me molesta la silla, y es que a mí eres una persona que me está atrayendo mucho”, y entonces me dijo: “me he puesto a investigar y no encuentro nada acerca de cómo poder mantener una relación contigo mas allá de… me estaba informando y no hay nada en cuanto a sexualidad” [paraplejía, 28 años, universidad, 18/02/2018].

Las pocas medidas, incluida la asistencia sexual, pensadas para acceder al cuerpo, conocerlo y gozar de éste, satisfacer su deseo (el o la asistente sexual trabaja, según el FDF, sobre el cuerpo ‘olvidado’), parecen ser casi exclusivamente a medida de hombre:

> Hay médicos que te enseñan cómo tener una relación íntima para que pueda, para que haya una fecundación, qué postura hay que hacer, cuándo hay que hacerlo, porque claro ellos no son personas como los demás, ellos no eyaculan como los demás, ellos no saben cuándo van a venir, ellos no sienten, sienten de otra forma, que es todo visual, cerebral, pero no a nivel físico de sentir allí [asistente, mujer, masajista, 29/11/2018, centro físico].

> Leí un montón de documentación, y lo único que era, era acerca del hombre (…) Todos los libros, te ponías a mirar, y lo único que encontraba era cómo recuperar que el hombre volvía a tener su función eréctil para poder tener hijos o dar placer a una mujer… y era en plan de pasaba las paginas tú decías: “¡muy bien!”. Pues, al hombre se le pinchaba creo una especie de hormonas y entonces volvía como a tener una función eréctil, y pasaba páginas, y tú decías: “¿y ellas? ¿Y dónde están?” Y, de repente, era en plan de… se acabó… era en plan de: “¿dónde estoy? ¿Dónde hay algo para mí? ¿Qué pueden hacer (las mujeres)?” (…) Para el hombre está pensado cómo devolverle su vida (…) hasta muy poco tiempo solamente ha habido asistentes sexuales para hombres, porque lo que importa es él, es que él tenga el placer [paraplejía, 28 años, universidad, 18/02/2018].

Según el testimonio de la segunda muchacha entrevistada, si para los hombres se habría siempre puesto en marcha estrategias para que les sea posible tener una vida sexual o restituirles aquella perdida (a través de la medicina, pero en última instancia recurriendo a la prostitución), en lo que respecta a las mujeres, se podría encontrar como único joven antepasado de la asistencia sexual un ‘servicio’, no pedido, prestado por auxiliares de hospital a niñas hospitalizadas con la intención de sedar y, al mismo tiempo, castigar su deseo, como si se tratara de una culpa que debe expiarse:

> En España no había hombres que prestaban ese servicio para mujeres, lo que ponían muchos libros — que a mí eso me parece algo alucinante — es auxiliares de hospitales que prestaban ese servicio a mujeres. No sé si me explico, pues, por ejemplo: cuando hay muchas niñas que empiezan a conocer su cuerpo y a estimularse no sé qué, según los libros que había, por

> ejemplo, en este del 1984, castigaban el que una niña se pudiera conocer, entonces lo que preferían era que un auxiliar del hospital fuese a esa niña y como que la masturbase [paraplejía, 28 años, universidad, 18/02/2018].

Desde la perspectiva del feminismo de la diversidad funcional, el asistente sexual constituiría por tanto una figura de verdad revolucionaria, sobre todo para las mujeres.

Según Soledad Arnau Ripollés (2020a), teórica del feminismo de la diversidad funcional, el asistente sexual constituye una herramienta, una 'extensión humana', — en este sentido, parangonable al así llamado asistente personal — para la satisfacción del derecho humano al propio cuerpo y, como tal, debería encontrar legitimación dentro del plan ensalzado de la «accesibilidad universal» (*Design for all*). En línea con la filosofía por la vida independiente, y de nuevo como para el asistente personal, debería tratarse de una persona elegida por la persona con discapacidad y con la cual instaurar una relación contractual.

> Para mí de algún modo es sencillo y, claro, porque yo tengo asistentes personales, yo vivo día a día gracias a que existe esta otra figura laboral, entonces para mí es como una extensión, que conviene que estratégicamente no sean los mismos (asistente personal y asistente sexual), pero realmente que el enmarque de esa profesión tiene que ser la filosofía de vida independiente. Quiero decir, al igual que el asistente personal, no debería existir en un contexto de cultura asistencialista, pues, también un asistente sexual no debería existir en un contexto de cultura asistencialista. ¿Entonces cómo lo concibo? Bueno, para empezar, yo interpreto que deba ser alguien obviamente, pues, que cojas tú, como igual cojamos las otras personas asistentes personales, tendría que tener formación sobre todo en el enfoque de vida independiente, porque entendiese por qué yo me he planteado tenerle a él o a ella, en primer lugar, y bueno a partir de allí, bueno, una serie de mínimos, de resolución pacífica de conflictos… cuestiones, pero no atención socio-sanitaria, al revés, en todo caso, soy yo la que tiene que aprender, es que yo creo que las personas que usamos la figura laboral de asistente personal tendríamos la obligación y el deber de formarnos en vida independiente [invalidez 85% — artrogriposis múltiple congénita, 46 años, residencia, 10/10/2017].

> Luego están los asistentes sexuales por las personas que deciden… por cualquier persona, bueno, que decide que tiene derecho a enamorarse, que tiene derecho a incluso tener relaciones sexuales sin amor, como lo puede tener cualquier otra persona, o a acariciarse o a masturbarse. Quiero decir: si tú no puedes mover las manos, no puedes hacer nada, necesitas un asistente sexual que te coja la mano y que te la lleve a donde tú digas que quieres que te la lleve, entonces yo también me sentiría identificada [física-genética, 36 años, sede asociación, 25/10/2017].

El trabajo profesional sexual (remunerado) del asistente debería limitarse a facilitar el autoerotismo y/o a apoyar a la persona con discapacidad en la relación sexual con una pareja con discapacidad que también requiera apoyo, salvo acuerdos diferentes — libres, pero no reivindicables como derechos — entre las partes (Arnau Ripollés, 2014). En opinión de Arnau Ripollés, la/os asistentes sexuales no serían por tanto asimilables a 'prostituta/os especiales', aunque ella piense que la prostitución que llama 'inclusiva' sea un recurso que debería ser implementado.

La ideóloga del FDF se coloca en la misma línea que el activista de Barcelona Antonio Centeno (2020), según el cual la asistencia sexual debería ser formalizada como servicio específico (y no especial-segregativo) para personas con diversidad funcional, como la asistencia personal y el interpretariado en lenguaje de signos, un servicio que en todo caso debe entenderse como complemento de servicios generales-inclusivos, entre los cuales podría eventualmente también entrar la terapia sexual.

Por otra parte, este modelo «autoerótico», del cual el propio Centeno (que también se encuentra entre los fundadores del *Foro de Vida Independiente*) es considerado el principal defensor, es criticado por el hecho de dirigirse casi exclusivamente a una clientela con discapacidad física (Branco de Castro Ferreira, García-Santesmases Fernández, 2016, pp. 21 ss.)[16]. La crítica es compartida también por el gestor del centro que ofrece asistencia sexual que tuve la oportunidad de encontrar, el cual agrega que, en su opinión, se trata de un modelo de asistencia híper-simplificador que tiende a reducir la cuestión de la sexualidad de personas con discapacidad a un mero problema de acceso a la masturbación, como atestiguan campañas del tipo *Yo me masturbo*.

Aunque moviéndose dentro del modelo del colega catalán, Arnau Ripollés deja en realidad la puerta abierta a prácticas sexuales diferentes — respecto de aquellas autoeróticas — siempre que sean explicitadas en el 'contrato libre' entre asistente y asistida/o. Además, amplía el horizonte de la reflexión a cuestiones de diferente naturaleza: de los contenidos concretos de la formación del asistente a las condiciones de la relación contractual, a la configurabilidad del así llamado sexo a domicilio, hasta la moralidad de la transacción sexual-económica, empujando a repensar las categorías del debate y a remodelar la perspectiva de análisis de forma realmente inclusiva de los sujetos no paradigmáticos. Sin embargo, le parece que buena parte de los interrogantes todavía están destinados a permanecer sin respuesta por largo tiempo, debido a la cultura capacitista también abrazada por el feminismo *mainstream* que se arrogaría el derecho de hablar por las otras. Finalmente, del mismo modo que otra/os entrevistada/os, mujeres y asistentes, está convencida de que la propuesta acerca de la asistencia sexual, en todas sus formulaciones, sigue encontrando resistencias fuertes a causa del estigma que el «trabajo sexual» porta con sí (Arnau Ripollés, 2014, p. 36; Gómez Bernal, 2017):

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[16] En realidad, la plataforma española que analicé contempla el caso de la 'diversidad intelectual' y, como para el centro físico, se requiere la mediación de un tutor, con la diferencia de que en el caso del centro virtual no se asegura ninguna forma de verificación.

> por ejemplo, ahora mismo está lo de los asistentes sexuales que se está promocionando en muchos sitios, y todavía hay mucha gente que siente reparo porque lo ven como uno estilo de prostitución, cuando no lo es [paraplejía, 28 años, universidad, 18/02/2018].

5. Los modelos españoles de asistencia sexual: *the whore stigma*

La asistencia sexual para las personas con discapacidad constituye un tema controvertido bajo diferentes perfiles incluso en los países tanto europeos (Holanda, Alemania, Dinamarca, Suiza alemana y francesa: Garofalo Geymonat, 2013, 2019) como no europeos (Canadá, Australia: Wotton, 2017) en los cuales la figura del así llamado asistente sexual (*sexual assistant, sex surrogate, caresseur, lovegiver, acompañante sexual*) ha encontrado hace tiempo regulación *ad hoc* o, al menos, modalidades de reconocimiento y regulación parcial de la profesión.

En otros contextos de Europa, como el italiano, francés y español, aunque no han faltado iniciativas de sensibilización, formación[17] y también legislativas[18] sobre el tema, muchas veces el debate político encalló en la cuestión del favorecimiento y la legitimación de una «transacción sexual-económica» (Tabet 2002, 2004, 2014; Selmi, 2016; cfr. Wagenaar, Jahnsen, 2017). Apoyándose en tal aspecto, significativamente no tomado en cuenta cuando lo que está en discusión son relaciones sexuales consideradas legítimas (Trachman, Tabet, 2009), también la academia y la opinión pública se dividió, como sucede cuando se trata de prostitución, entre abolicionistas y regulacionistas 'pro-derechos' del así llamado *sex work* (Crowhurst, Garofalo Geymonat, 2019). Este último término — es bueno recordarlo — es fruto de las batallas, llevadas adelante por tantas activistas que aspiran a obtener la inscripción de la actividad de prostitución en el catálogo de oficios a todos los efectos, aunque sin por esto necesariamente considerarla 'una profesión como cualquier otra'.

Justamente como sucede en relación con el tema de la prostitución (Abbatecola, 2018, p. 12; Garofalo Geymonat, 2014, pp. 624 ss., 2019, p. 215), el *affair* encontró tonos todavía más divisivos en el ámbito del pensamiento y del activismo feminista (Garofalo Geymonat, 2019, p. 215). En efecto, una parte vio en los pliegues de las propuestas sobre la asistencia sexual la sombra de una relación patriarcal, de un intercambio claramente asimétrico, que involucraría mujeres (prevalentemente) en la figura de asistentes sexuales y hombres (prevalentemente) en

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[17] En los tres países mencionados (Italia, Francia, España), han sido activados cursos de formación para asistentes sexuales.

[18] En Italia, se presentaron ya tres proyectos de ley (del diputado del *PD* Sergio Lo Giudice, de la diputada del *PD* Ileana Argentin, y de la diputada de *Forza Italia* Elvira Savino), y un cuarto (promovido por el diputado del *Movimento 5 Stelle* Aldo Pena) está en proceso de elaboración. Todos están, en diferente medida, inspirados en la propuesta del *Comitato per l'assistenza sessuale per le persone con disabilità* institutido, en enero de 2013, por la férrea voluntad de Maximiliano Ulivieri, presidente del comité y responsable del proyecto «LoveGiver». Ulivieri (2014) es curador, además de uno de los autores del texto de referencia del movimiento italiano por la asistencia sexual: el libro contiene la propuesta de Lo Giudice (pp. 93-98).

la figura de sus clientes, reforzando la posición de estos últimos como titulares de derechos sobre los cuerpos femeninos: cuerpos todavía percibidos como connaturales a una sexualidad 'de servicio' — una suerte de dote de la cual otros disponen y gozan — y, por tanto, expuestos a prejuicios inveterados y nuevos[19]. Para esta parte del feminismo, la asistencia sexual es otra expresión del patriarcado, una manifestación de la violencia contra las mujeres que en este caso asume una forma todavía más retorcida — respecto de la prostitución o pornografía, objeto de diatribas históricas — en la medida en que instrumentaliza las discriminaciones sistemáticas sufridas por las personas con discapacidad para su obra de opresión y, en última instancia, deshumanización femenina. En cierto sentido, se podría incluso decir que la asistente sexual representa la síntesis ideal del modelo patriarcal, uniendo en una única figura sus expectativas de objetivación de las mujeres 'hechas para el cuidado y para el sexo'.

Para otra parte del feminismo, en cambio, dentro de la práctica de la asistencia sexual, justo como sucede en el ejercicio 'libre' de la prostitución y de la producción de material pornográfico, se juega uno de los partidos más importantes para la emancipación de las mujeres del patriarcado y para la afirmación de la liberación sexual femenina.

La marcada reducción binarista del discurso (abolicionista o pro-*sex work*), facilitada por la tendencia coriácea de los estereotipos de género evocados, de hecho ha obstaculizado una confrontación constructiva en el plano de la elaboración de políticas de promoción de los derechos de las personas con discapacidad a expresarse a través del sexo y no sólo a no ser víctimas de abusos y violencias sexuales (como víctimas, parecen sujetos más creíbles), sin por otra parte hacer avanzar la comprensión (weberiana) de los «mercados del sexo» [20] y menos aún en el campo de la tutela de las *sex workers* (Martínez Moreno, 2020; Guamán Hernández, 2020) donde es verdad que «no existe todavía país en Europa en el cual la/os *sex workers* no estén sujeta/os a formas de discriminación, violencia y estigmatización» (Garofalo Geymonat, 2014, p. 45).

Si el debate no logra liberarse del «whore stigma» (Pheterson, 1993, 1996), tendiendo a polarizarse alrededor de la admisibilidad o no de prácticas consideradas de prostitución, en cambio las praxis de la asistencia sexual se mueven en dirección a la constante diversificación y evolución: educación en la afectividad, en la corporeidad y en la emoción sexual[21]; terapia

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[19] Ésta, por ejemplo, es desde ya hace décadas la posición de la asociación francesa *Femmes pour le Dire, Femmes pour Agir* (FDFA): fdfa.fr/position-sur-les-aidant-e-s-sexuel-le-s/.

[20] Como señala varias veces Abbatecola (2018), el interés casi pruriginoso acerca de la cuestión de la elección termina por obnubilar las antinomias presentes en los sistemas de mercado en los cuales ésta se realiza. Acerca de los «modelos de prostitución» adoptados por los Estados, se reenvía nuevamente a Garofalo Geymonat, 2014, pp. 1046 y ss.

[21] En esta dirección va la propuesta italiana del comité *LoveGiver* de un O.E.A.S., acrónimo de «operador de emotividad, afectividad y sexualidad».

sexual[22]; acompañamiento en el autoerotismo; facilitación de la relación sexual con la pareja con discapacidad; apoyo en las actividades ciber-sexuales; subrogación sexual (el/la asistente actúa como un verdadero *partner* sexual).

Algunas propuestas prevén la combinación de varias de las formas mencionadas, y todas responden a la definición amplia formulada por la *European Platform Sexual Asisstence* (EPSEAS)[23].

La mayor parte de las propuestas acerca de la asistencia sexual, si bien de diferente manera y en diferente medida, contempla cursos de formación para la/os aspirantes a asistente. Cursos que, según las mujeres con discapacidad entrevistadas que han tocado el tema, deberían estar dirigidos también a la/os potenciales clientes, especialmente femeninos, las cuales tendrían menos oportunidad de recibir una educación sexual 'positiva' adecuada, a menudo a causa de la actitud híper-protectora de las familias de origen (que, para muchas, terminan por ser las únicas familias). Con 'educación sexual positiva' se hace referencia no tanto al aprendizaje de sistemas de prevención de malatías de transmisión sexual y de embarazos no deseados — si bien, también desde este punto de vista, las mujeres con discapacidad se encuentran menos preparadas que las mujeres sin discapacidad y que los hombres con o sin discapacidad — sino a la adquisición de conciencia respecto del funcionamiento del propio cuerpo en relación a la emoción, a la expresión y a la satisfacción sexual, puntos centrales también para reconocer y denunciar la violencia en esta área. En los últimos años, indudablemente creció la atención puesta en el derecho humano de las mujeres a no ser víctimas de abuso y violación, pero todavía es bajo el compromiso contra la «disviolencia» y, aún más, permanece bajísima la consideración por la tutela del derecho humano a la expresión sexual: como se ha visto, las mujeres con discapacidad en general no son consideradas como sexualmente activas y, por tanto, no se encuentran previstas prestaciones concretas (ni siquiera de tipo informativo) aptas para permitirles llevar adelante una vida sexual.

Sin embargo, no todos los modelos de asistencia sexual son aplaudidos por el feminismo pro-*sex work* en general, y por el feminismo de la diversidad funcional en particular, especialmente allí donde reenvían a los macro-modelos médico o incluso religioso (imbuidos de paternalismo), como sucedería con los así llamados *therapy approach, care approach, charity approach* — a veces, entrelazados — que atraviesan algunas de tales propuestas. A tal tipo de modelo asistencialista mixto cuidado-caridad podría reconducirse el ejemplo japonés proporcionado por la ONG *White Hands*, que propone un servicio de eyaculación asistida prestado de forma voluntaria principalmente por enfermeras profesionales o, en cualquier caso, por mujeres con una formación sanitara de base (*sex volunteer*). Se trata de enfoques que, teniendo subyacente

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[22] En relación con el modelo terapéutico, cfr. al menos el texto clásico de referencia: Masters, Johnson, Kolody, 1977.

[23] http://www.epseas.eu/en/page/181

una concepción de la sexualidad de las personas con discapacidad como algo que ajustar y/o a lo cual mostrar un comportamiento misericordioso, no pueden tener espacio en el modelo de la *divertad*, ni tampoco en la fórmula de *The Sessions,* dado el modelo explícitamente terapéutico adoptado por la protagonista de la película. Por otra parte, el mero hecho de considerar a la prestación solicitada en términos asistenciales, al menos literalmente (la observación vale también para el así llamado «asistente personal»), reconduce el debate al área médica, sin lograr desvincularlo del todo de sus presupuestos; carácter que confirma la dificultad de hablar de un nuevo paradigma cultural de la diversidad — como querrán también las teóricas del feminismo de la diversidad funcional — y mi percepción, en cambio, de un enfoque (todavía) intermedio 'bio-social'. Por lo demás, una investigación empírica reciente muestra que la misma cultura profesional de quien forma a la/os asistentes sexuales estaría impregnada de un enfoque asistencialista-terapéutico-rehabilitador (Alonso Sánchez, 2021, p. 11) que, como se verá en la sección siguiente, en efecto parece haber sido asimilado también por la y los asistente/s sexual/es entrevistada/os.

En lo que respecta a España, siguiendo la reconstrucción propuesta por Carolina Branco de Castro Ferreira y Andrea García-Santesmases Fernández (2016) a la luz de una investigación etnográfica, es posible distinguir al menos tres modelos de asistencia sexual, que no han sido nombrados expresamente por la/os entrevista/os (mujeres y asistentes) pero sí evocados: el modelo de la prostitución especial, el modelo de la «conexión erótica», y el así llamado modelo autoerótico.

El primero reivindica al servicio de asistencia sexual como un elemento característico de la actividad de prostitución, y es reivindicado de este modo por un grupo nutrido de prostitutas.

El segundo y el tercero, en cambio, prevén la introducción de una nueva figura profesional: el asistente sexual. Sin embargo, divergen en relación con sus tareas y modalidad de participación. El segundo se fundaría sobre una emoción sexual compartida (aunque presumiblemente diferente) entre asistente y asistido/a, que desemboca en una relación que involucra a ambos cuerpos. El tercero se focaliza en el acceso, por parte de la persona con discapacidad, a su propio cuerpo a través del cuerpo del asistente (en general, de sus manos), cuya intimidad permanece inaccesible.

Volveremos sobre el segundo y el tercero. En relación con el primer modelo, no profundizado en este trabajo, las autoras remarcan que la instancia también tiene una motivación estratégica, en la medida en que finalmente podría abrir el camino a la legitimación y a la tutela del trabajo sexual. Según las dos estudiosas, entran en el primer paradigma: la asociación Aprosex (*Asociación de Profesionales del Sexo*); la octogenaria Lydia Artigas, conocida como «Madame Rius de moral distraída» (Peiró, 2013), gestora de uno de los burdeles más conocidos en Europa (en un momento frecuentado por algunos de sus amantes famosos, como Dalí, Cela, Belmondo, el rey Faisal, Orson Welles); y la *escort* independiente Montse Neira, pionera en el ámbito de la oferta de asistencia sexual a personas con discapacidad.

Las feministas de la diversidad funcional actualmente parecerían moverse entre el segundo (prevalentemente) y el tercer modelo, aunque, mirando favorablemente a las experiencias en otros países[24], auspician la elaboración de un arquetipo mixto, tendencialmente abierto, de prácticas que pongan en el centro, como ya mencionado, la dimensión del placer del/la cliente con discapacidad y, al mismo tiempo, del asistente. Uno de los puntos centrales del proyecto de asistencia sexual, así como imaginados por las feministas de la diversidad funcional (que, en este sentido, intentan mediar dentro de la «guerra del sexo»), justamente está en la atención puesta en la figura del asistente cuya tutela debería ser igual a aquella otorgada a la persona con discapacidad. Y es con el fin de garantizar la autodeterminación de ambos, persona asistente y persona asistida, que la mayor parte de las proponentes hipotetiza, quizás influenciada por la larga ola neoliberal, una relación de tipo contractual capaz de vincular a la/os dos estipulantes al respeto de un conjunto de normas (a definir), así como sucede, o debería suceder, siempre según el feminismo de la diversidad funcional (FDF), en la relación que vincula al asistente personal y a la persona con discapacidad. En cuanto a la regulación, tanto algunas feministas como las mujeres con discapacidad y la asistente sexual (mujer) entrevistadas sostienen que sería deseable la participación de las organizaciones sindicales, mientras que, de los dos asistentes hombres, uno piensa en un servicio de base informal y el otro, en una intervención estatal orgánica en relación con la tutela del «trabajo sexual», se exprese ésta en prostitución o en asistencia sexual a las personas con discapacidad.

Si el panorama general en relación con la formalización hipotética de la asistencia sexual todavía parece confuso, me parece que en la atención especial dedicada al asistente se ve uno de los frutos más maduros del encuentro entre *Disability* e *Feminist Studies*. En todo caso, la cuestión de la regulación del trabajo sexual, comenzando por la prostitución, sigue siendo crucial para imaginar soluciones operativas.

6. Los ‘lugares’ de la asistencia sexual y la posición de algunos asistentes íntimos

El tema de la prostitución en efecto ha surgido de modo espontáneo en todas las entrevistas (aunque sean pocas, por las razones que se mencionan a continuación) efectuadas a los asistentes sexuales: dos sobre tres son hombres, de nacionalidad española[25], de edad

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[24] Véase, por ejemplo, el modelo de la *BodyUnity* suiza: Garofalo Geymonat, 2019; Garofalo Geymonat, Macioti, 2016.

[25] Como ha sido destacado en investigaciones relativas a otros contextos, los datos sobre sexo y nacionalidad son particularmente significativos si se ponen en relación con el mercado más general del sexo que también en España involucra prevalentemente mujeres de origen extranjero.

comprendida entre los 40 y 55 años, sin experiencias precedentes en la así llamada industria del sexo ni del ciudado de personas con discapacidad.

En concreto, he entrevistado a un hombre y una mujer (masajistas 'de profesión') pertenecientes a un centro físico de apertura reciente — el primero, y hasta hace poco tiempo atrás, único en España[26] — del cual son casi los únicos empleados ocasionales, y un hombre (arquitecto 'de profesión') contactado a través de una plataforma *online* española.

Los dos canales, ambos activos desde hacía poco más de un año al momento de las entrevistas, me parece que pueden considerarse como exteriorizaciones de los modelos mencionados arriba de conexión erótica (la persona con discapacidad entra en relación con el cuerpo del asistente) y del autoerotismo (la persona con discapacidad entra en realidad sólo con su propio cuerpo a través del asistente).

El centro ofrece acompañamiento íntimo — además de masajes terapéuticos y un mostrador de asesoramiento sexológico — en las instalaciones de la estructura, equipadas para responder a exigencias multiformes en términos de accesibilidad. En cambio, la plataforma funciona como una 'vitrina virtual' para facilitar el encuentro entre la/os asistentes proponentes y personas con discapacidad, con la advertencia para la/os usuaria/os de que «esta web intenta crear una comunidad basada en la confianza mutua y no dispone de los medios para comprobar la veracidad de la información que proporcionan las personas que se anuncian. Se recomienda prudencia, cualquier dato podría ser inexacto, falso o incluso malicioso. Si has detectado cualquier problema contacta con nosotras».

Para hablar, en pocas palabras, de las otras características de los dos 'lugares' de asistencia sexual, ambos promotores de la *Filosofía de Vida Independiente*:

- El centro físico contempla un curso obligatorio de formación, que dura 12 horas y cuesta 80 euros, dirigido a los aspirantes a asistente cuya relación con las personas con discapacidad es supervisada constantemente por algunas psicológicas/psicoterapeutas/sexólogas; cada sesión, generalmente precedida por un encuentro preliminar recomendado entre asistente y cliente, se lleva a cabo en las instalaciones equipadas del centro y prevé un costo de 200 euros, independientemente de qué actividad se desarrollen[27] (comprendidas las relaciones sexuales 'completas'[28]), previamente acordadas con la persona con discapacidad y con su eventual tutor/a; cuando

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[26] En Valencia se encuentra ahora activo otro centro para la asistencia sexual a personas con discapacidad.

[27] En todo caso, asistente y asistida/o deben primero certificar la ausencia de enfermedades de transmisión sexual.

[28] La asistente mujer ha afirmado que, en el pasado, pidió menos de 200 euros porque no tiene relaciones completas con los clientes (a diferencia de una colega), pero después agregó que el centro necesita ese dinero para llevar adelante la actividad, que lamentablemente no se beneficia de otras subvenciones.

la persona no pude expresar su consentimiento o manifestar el placer verbalmente, son utilizados algunos instrumentos como por ejemplo un abecedario o una tableta.

- En relación con el segundo lugar de asistencia, el centro virtual, los asistentes registrados en la plataforma (respecto de los cuales no hay ninguna forma de selección o control) no están obligados a realizar cursos de formación, pero son frecuentemente invitados, a través de una *newsletter*, a seminarios e iniciativas sobre el tema de la asistencia sexual, eventos a los cuales también yo tuve ocasión de participar durante mis períodos de investigación en la capital española.

La plataforma promueve un concepto de asistencia en línea con la definición mencionada antes por Arnau Ripollés y por algunas mujeres entrevistadas. En efecto, se habla de «apoyo para acceder al propio cuerpo, no al del/la asistente», se subraya que «se trata de un trabajo sexual, de carácter instrumental, no educativo ni terapéutico[29], que concretiza el derecho al propio cuerpo» y que explícitamente se remite al «modelo teórico de la diversidad» (Palacios, 2008).

Las sesiones se llevan a cabo en la casa de la persona con discapacidad o, probablemente con más frecuencia, en hoteles donde es posible procurarse un espacio-tiempo privado: en general, mujeres y hombres con discapacidad viven con sus familias de origen o en residencias en las cuales difícilmente tienen una habitación toda para sí (e, incluso cuando tienen una habitación propia, es más bien común que la puerta se deje abierta para permitir que la/os *care-giver* 'cuiden y vigilen').

Con base en los perfiles de la/os asistentes, se puede calcular un costo medio de 60 euros, a los cuales se suman los gastos de viaje y eventualmente del hotel.

A fecha 23 de junio de 2018, había 131 registrados, de los cuales 48 eran mujeres y 83, hombres: dato que, aislado, parecería desmentir las previsiones preocupadas de una profesión prevalentemente femenina. Por otra parte, es en cambio elocuente que las reivindicaciones en términos de profesionalización conquisten atención en el momento en el cual la actividad se vuelve prerrogativa (incluso predominante) masculina[30].

De los 131, 35 — 24 hombres, 7 mujeres y 4 perfilados como «otras opciones» — ofrecían asistencia sexual en la capital española al momento de mi investigación[31]. Sólo 3 de los 35 — a

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[29] La propuesta italiana, por ejemplo, va en cambio en esta dirección.

[30] Cuando inicié a realizar las entrevistas, el caso del primer asistente sexual masculino, el catalán de origen griego Dimitri Zorzos (que se hace llamar Dyon Baco en el ejercicio de la profesión), comenzaba a suscitar en España un interés grande y aparentemente genuino, es decir, no viciado del prejuicio que en cambio acompañó las causas análogas llevadas adelante por Montse Neira (líder del grupo en el cual se formó el Zorzos mismo) y por Silvina Peirano.

[31] Un año después, el número creció a 52; y dos años después, a 55.

todos los contacté usando la dirección de correo electrónico que aparecía en sus perfiles — se pusieron inmediatamente a disposición para una entrevista[32].

Es significativo que las dos personas del centro físico ofrezcan asistencia, respectivamente, la mujer a hombres y el hombre, a mujeres, mientras que de la plataforma surge un panorama más variado[33].

Los tres entrevistados, dos hombres y una mujer, declaradamente heterosexuales, dan por descontado el vínculo de la asistencia sexual con la orientación sexual; esto es, piensan que sea natural que las sesiones se lleven a cabo entre personas físicamente atraídas la una con la otra:

> Yo he tenido una asistencia íntima con este chico, porque, bueno, además físicamente era una persona que me atraía, porque también es lógico te tiene que atraer un poco la persona que vas a hacer…, tiene que haber un feeling entre ambas personas, tanto yo le tengo que gustar a esa persona, como a mí él, porque vas a hacer cosas íntimas con él (…) Yo solo para hombres, porque sí que hay mujeres que pueden ser lesbianas que estén en silla de ruedas, pero yo en principio con mujer no, no, no me se ha planteado tampoco. Hay hombres para mujeres y mujeres para hombres. (…) Es un campo muy abierto y hay que tener de todo, tanto personas que sean heterosexuales como bisexuales [mujer, masajista, 29/11/2018, centro físico].

> Yo pienso que cuando te acuestes con alguien también tiene que haber atracción física (…) Yo por ejemplo no lo haría con un hombre. Yo soy heterosexual, claro vamos a ver: a mí dar placer a una mujer no me cuesta nada a nivel mental pero por ejemplo a un hombre me costaría, yo no sé si es una cuestión cultural pero... a parte que al hombre le gustaría que también se lo hiciera una mujer [hombre, arquitecto, parque, 29/06/2018, plataforma].

Sin embargo, los dos hombres, inicialmente sorprendidos por mis preguntas sobre este tema, parecen dispuestos a considerar la posibilidad de prestar asistencia a otros hombres (haciendo alarde de ser personas con una mente muy abierta).

Entre la/os teórica/os de la asistencia sexual, no se aclara este aspecto. La mayoría, incluida Arnau Ripollés, parece sugerir la irrelevancia de la orientación sexual para la realización del servicio de asistencia (neutral respecto de sexo, género y orientación), presumiblemente también para legitimarlo como ocupación moderna y desengancharlo así del fantasma del «oficio

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[32] Se trata de dos hombres, de los cuales uno fue efectivamente entrevistado mientras que el otro luego me ha comunicado que no tenía experiencia y no renovó su disponibilidad (es más, en los días inmediatamente sucesivos a mi petición, su perfil fue eliminado del sitio), y una persona registrada con la etiqueta «otras opciones», también ella sin experiencia en el ambiente, que finalmente no me confirmó la cita.

[33] Se puede señalar lo siguiente: de 24 hombres, 15 ofrecen asistencia a mujeres, 5 a ambos sexos, 1 a ambos sexos y a personas transexuales, 3 (que no muestran la cara) a hombres; de las 7 mujeres, 6 ofrecen asistencia indiferentemente a mujeres y hombres; de las 4 «otras opciones», 2 ofrecen asistencia a todos los géneros, 1 (que se autodefine como de género no binario) sólo a mujeres y, en relación con la última, con discapacidad, la página no resulta activa.

más antiguo del mundo» culturalmente relegado a un mero saber instintivo. Estereotipo, este último, que las socias de la *Asociación de Profesionales del Sexo* (Aprosex) consideran fruto de la así llamada «putofobia» y que en consecuencia llevan años intentando desacreditar, incluso a través de la promoción de cursos remunerados de prostitución, como aquellos impartidos en diversas ediciones por la psicóloga clínica Cristina Garaizábal y por la terapeuta sexual y prostituta Conxa Borrell, en cuyos programas de base sin embargo no parecen incluir atención a las discapacidades[34].

Como anticipado en el principio de la sección, el tema de la prostitución ha sido tocado en todas las entrevistas.

Dos de los asistentes entrevistados, pertenecientes a los dos canales de referencia, han resaltado con fuerza que no se consideran prostituta/o, inmediatamente tomando distancia de una actividad que en opinión de ambos tendría objetivos y características profundamente diferentes. La mujer, en particular, puso repetidamente el acento sobre la formación como elemento característico y distintivo del servicio de asistencia sexual, considerando su falta como la principal causa de las experiencias humillantes vividas por alguna/os asistida/os del centro con prostituto/as. La formación implica el aprendizaje de conocimientos teóricos, médicos y psicológicos en relación con la discapacidad, la salud y el *embodiment* sexual, y también conocimientos operativos, relacionados con las técnicas de movilización del/la asistido/a y de gestión de las problemáticas vinculadas con la discapacidad específica (falta de control de esfínteres, espasmos, insensibilidad genital):

> A veces me han preguntado qué diferencia hay entre esto y ser, por ejemplo, un prostituto o no sé, la prostitución. Bueno, yo creo que hay diferencia. Yo no me considero para nada un prostituto, esto no es mi trabajo, yo tengo mi trabajo, mis cosas, yo esto lo hago porque creo que es maravilloso ayudar a la gente, sobre todo si no te cuesta nada [hombre, arquitecto, parque, 29/06/2018, plataforma].

> Es que hay gente que lo ve como "ah sexo": es un puticlub o una prostitución, no, no tiene nada que ver con la prostitución, aquí hay gente formada, aquí hay gente que ha hecho sus formaciones, sus cursos. ¿Qué tiene que ver con la prostitución? Es que no tiene nada que ver (…) Los centros les han llevado al prostíbulo, eso sí es malo para ellos porque hay quien se han reído de ellos, que se le han robado, se aprovechan de que es una persona que está mal, entonces se ríen de ellos, le roban, o incluso no le hacen nada y le dicen "ya ha pasado la hora, ahora vete y págame". Eso no puede ser, ahí sí que tienen un problema. Necesitan un centro donde haya personas que estén formadas, que tengan una sensibilidad especial y que tengan ese corazón para poder dar este servicio a estas personas, que no sean especialistas en prostitución, vamos a ver: yo no soy prostituta, ni lo he sido nunca, yo tengo mi familia, mi vida normal y corriente, pero entiendo que estas personas necesitan eso. ¿Qué importancia

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[34] http://www.aprosex.org/

> tiene el tocar un aparato genital a una persona porque yo esté casada? Es decir, yo lo que tengo que conseguir es que esta persona sea feliz y que él esté feliz en ese momento, y yo no quiero, no me considero una prostituta porque haya hecho algo así, ni me considero una prostituta, ni me considero infiel a mi marido, porque lo haya hecho. Es algo consensual entre todos, y es algo que yo me he formado para ello y que hay que verlo desde el punto de vista del discapacitado, desde la diversidad funcional que es importantísima, que tiene muchos problemas psicológicos. ¡Ha habido casos en que los hijos se lo piden a las propias madres! Una madre dice: "¿Cómo voy a hacer yo una cosa así a mi hijo lógicamente?" ¿Qué madre hace eso a un hijo? Pero hay hijos que lo necesitan y que lo piden (…) Pero yo tengo familia, hijos y tengo que seguir viviendo, trabajando [mujer, masajista, 29/11/2018, centro físico].

Al marcar las diferencias que separan a la asistencia sexual de la prostitución (Garofalo Geymonat, 2019, p. 215), los dos enfatizaron su normalidad cotidiana, constituida por otro trabajo y otras relaciones sexuales; en particular, la mujer no dejó de enfatizar que era esposa (¡fiel!) y madre (véanse las partes puestas en cursiva en el extracto apenas citado).

También el tercer asistente destacó la importancia de la formación, pero luego se centró más en la necesidad de que el Estado avance rápidamente hacia la legalización de la actividad de asistencia sexual a favor de los «bípedos» normales (así se refiere a la prostitución) y de las personas con diversidad funcional, en este sentido asimilando ambos servicios.

Muchas veces, advertí la existencia fuerte por parte de la mujer de defender su reputación sexual, de la cual siente que depende su reputación social, alejando el espectro de la prostitución (como la terapeuta de la película ya citada, *The Sessions*[35]). Los dos hombres, en cambio, aunque tomaron distancia de la prostitución, parecían sentir menos amenazada su reputación social (después de todo, menos en riesgo que aquella femenina) e incluso ven a su experiencia con las mujeres con discapacidad como motivo de alarde en sus currículums sexuales.

Todos los asistentes entrevistados consideran, como cualidades esenciales para la realización de la asistencia, la mente abierta, la generosidad («el corazón grande»), la especial sensibilidad y empatía, el deseo (auto gratificante) de ayudar y de ver al/la otro/a satisfecho/a, elementos que, en conjunto con la formación, en cambio no serían necesarios para la actividad de prostitución.

En particular, los asistentes hombres motivan su elección de dedicarse a la asistencia ante las discriminaciones y las violencias sufridas por las mujeres en general, y por las mujeres con discapacidad en particular, en el ámbito sexual.

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[35] Apenas llegada a casa del cliente, la terapeuta aclara: «no tengo nada en contra de las prostitutas, pero no soy una prostituta, es otra cosa, no me debes pagar por anticipado, la prostituta quiere transformarte en un cliente habitual, yo no, por esta razón el número de sesiones es limitado».

Finalmente, dos de los tres asistentes entrevistados (aquellos pertenecientes al centro físico) consideran que el servicio de asistencia — muy costoso, considerando que las personas con discapacidad, entre ellas sobre todo las mujeres, difícilmente reciben o rédito o un subsidio adecuado — debería encontrarse cubierto en todo o en parte por el sistema sanitario nacional y/o por aquel de la seguridad social. En cambio, el tercero piensa debe seguir siendo un servicio retribuido pero prestado a voluntad. Al mismo tiempo, todos parecen ser conscientes de alguno de los interrogantes con los cuales, según Arnau Ripollés (2014, p. 36), ha tenido que enfrentar el desarrollo de la actividad de asistencia, especialmente en lo que concierne a la definición y a la gestión de los límites de la relación entre asistente y asistida/o. El temor principal de la asistente y de los asistentes entrevistados es el excesivo involucramiento emocional por parte de la/os clienta/es. A los tres, en efecto, les ocurrió al menos una vez que tuvieron que interrumpir la relación de asistencia por esta razón.

7. Concluyendo: libres de no elegir la asistencia sexual

> Si yo no sé usar un asistente no le voy a sacar partido, pero, no solamente no le voy a sacar partido, sino, como es un humano, voy a generar problemas, porque tampoco entenderé los límites, ni los míos ni los suyos, y que es una relación laboral. (…) Esta persona está simplemente para apoyarte. Yo creo que es un apoyo, nada más, tampoco creo que sea la solución [invalidez 85% — artrogriposis múltiple congénita, 46 años, residencia, 10/10/2017].

La cuestión de los límites, planteada por asistentes y asistidas, lleva de nuevo al hecho de que la asistencia sexual, al menos desde la perspectiva del feminismo de la diversidad funcional, debería ser configurada como un instrumento de apoyo: un medio y no un fin en sí mismo, insiste Arnau Ripollés (2013), y aun así, «un apoyo que traspasa lo meramente sexual» (Alonso Sánchez, Muyor Rodríguez, 2020).

Su eventual formalización debería ser pensada como una suerte de acción positiva, de medio alcance, para acceder al propio cuerpo y vivir un aspecto importante de la vida, no un remedio universal y permanente para la resolución de las dificultades que encuentran experimentadas por las personas con discapacidad, en particular por las mujeres, en el ámbito de la sexualidad:

> Yo lo tengo muy claro y yo no quiero que un asistente sexual me resuelva mi vida sexual a mí, a ti no te la resuelve nadie, la sociedad no te resuelve tu vida. ¿Por qué me lo tiene que resolver a mí? No, yo creo que lo que tenemos que hacer es que tú y yo estemos en igualdad de condiciones, nada más, a partir de allí tendremos que recibir mucha educación sexual [invalidez 85% — artrogriposis múltiple congénita, 46 años, residencia, 10/10/2017].

Como sugerido en este extracto, y como aparece también en las entrevistas a las otras mujeres y a los asistentes sexuales, el objetivo a largo plazo debería ser el de rediseñar una sociedad globalmente inclusiva a partir de la educación, de la condena a las estructuras segregadoras, de la desinstitucionalización.

Sería por tanto reductivo y deshumanizante mirar a la asistencia sexual como a una medida autónoma o aislada, desvinculada de los otros aspectos de la vida en sociedad y de relación:

> por un lado, yo necesito horas de asistencia personal para vivir con normalidad: necesito salir a la calle, necesito poder ir a tomar copas, como otras personas van y toman copas, y a lo mejor es cuando ligan o intentan ligar, pero, a lo mejor, esas horas son las dos de la madrugada. Yo también quiero estar a las dos de la madrugada, como el resto del mundo, y no quiero estar con un chándal y a las seis de la tarde llamar por teléfono a alguna agencia y decir: "oye, traerme un asistente sexual que tengo un apretón que me muero". No, yo no quiero a las seis de la tarde, no, yo creo que eso no es humanizante. (…) Yo creo que lo que hay que darles es alas para volar para que esa persona aprenda a volar, tiene que aprender a volar [invalidez 85% — artrogriposis múltiple congénita, 46 años, residencia, 10/10/2017].

Si la asistencia sexual puede quizás encontrar espacio en un plano de reequilibrio de las oportunidades, su estabilización en cambio correría el riesgo de obtener el efecto perverso de los taxis o de las escuelas especiales, avalando una cultura marginalizante de las personas con discapacidad percibidas como «individuos que viven en la sociedad, pero que no con ella» (Merton, 1957) pues no pueden compartir los canales 'normales' de la socialización. Como ya fue destacado por otras estudiosas y estudiosos, la asistencia puede entonces constituir (y, de hecho, constituye) un instrumento educativo y de socialización sexual no sólo para quien la recibe (Arfini, 2010): la/os asistentes sexuales, sus familias, las sexólogas y las mujeres con discapacidad involucradas en los proyectos de asistencia sexual españoles se han vuelto promotora/es de campañas de sensibilización en las escuelas, en las plazas físicas y virtuales, en las instituciones políticas.

En la dirección del *feminismo de la diversidad funcional*, la reflexión acerca de la asistencia sexual debe empujar a repensar las categorías del cuerpo, del deseo, del placer — y del derecho de cada uno a estos — a partir de la deconstrucción de la estructura social y cultural que preside estas categorías. Investigar las raíces socioculturales significa pensar en una sociedad a medida de la «diversidad funcional», al mismo tiempo tomándose en serio la asimetría de género y los estereotipos discriminatorios que están en la base del duradero sistema patriarcal. En este sentido, el marco del feminismo de la diversidad funcional supera quizás sus propias expectativas, recordando la necesidad del diálogo entre feminismos (Arnau Ripollés, 2020b) y en el fondo sugiriendo que se debe lograr que las mujeres estén en condiciones de *no* elegir la asistencia sexual, ni como asistidas ni como asistentes.

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Programa expresivo-corporal: la barrera corporal como elemento de análisis en la mejora de calidad de vida en personas con esclerosis múltiple

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Body language programme: the physical limitations as elements of analysis in the improvement of quality life in people with multiple sclerosis

Keywords: body image, multiple sclerosis, body language, empowerment

1. Introducción

El presente trabajo se desarrolla en el marco del Proyecto Europeo Women with disabilities in Social Engagement (Risewise) en la Universidad Complutense de Madrid, cuyo foco de atención se centra en la investigación sobre el colectivo de mujeres con discapacidad dentro de una perspectiva multidisciplinar.

El estudio se realiza en la Asociación Italiana de Esclerosis Múltiple con sede en Palermo, cuyo centro social ofrece servicios de atención a personas con esta enfermedad incluyendo trabajos de apoyo como, atención domiciliaria, transporte en vehículos equipados y desarrollo de actividades formativas entre otras intervenciones. La asociación cuenta con la colaboración de jóvenes voluntarios que ayudan temporalmente a través del Servicio Civil en el centro, participando en cualquier actividad donde sean necesarios.

Durante la estancia se aplicaron un conjunto de acciones de carácter formativo y de investigación orientados, por un lado, a los usuarios de la asociación y por otro a las personas voluntarias. En ambos se trabajó la importancia de la conciencia corporal, a través del estudio de la imagen corporal y de la proyección y actitud del cuerpo frente a distintas situaciones que están presentes en la vida diaria. La formación fue dirigida a cada colectivo según los diferentes objetivos a perseguir. En el caso de las personas con esclerosis múltiple, se trabajó sobre la conciencia de la barrera corporal y las posibilidades de afrontar obstáculos desde un análisis de futuras acciones de mejora en su calidad de vida. Y en el caso del voluntariado para saber manejar e interactuar corporalmente con los usuarios, ofreciendo una mejor ayuda en las intervenciones.

En definitiva, el estudio se articuló en torno a los dos siguientes objetivos.

- Conocer la imagen corporal percibida por las personas con esclerosis múltiple con la intención de identificar barreras que se encuentran en la vida cotidiana.

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- Conocer la opinión del voluntariado relativa al desarrollo del seminario formativo para la adquisición de herramientas de apoyo profesional hacia personas que presentan esclerosis múltiple.

2. Marco teórico

La esclerosis múltiple (EM), es una enfermedad crónica del sistema nervioso central que tiene un gran impacto en la salud y en la vida cotidiana de las personas. Puede causar una gran cantidad de impedimentos para el funcionamiento del cuerpo, limitar las actividades diarias y restringir la participación en la sociedad (Kierkegaard, Einarsson, Gottberg, von Koch y Holmqvist, 2012).

La calidad de vida es un constructo multidimensional, que tiene estrecha relación con la participación social (González Casas, 2018; González Casas, Ducca Cisneros y García Román, 2020). Debido a que el concepto puede estar sujeto a múltiples definiciones, tomaremos de la desarrollada por Verdugo, Schalock, Arias, Gómez y Jordán de Urríes (2013), que la definen como

> Un estado deseado de bienestar personal compuesto por varias dimensiones centrales que están influenciadas por factores personales y ambientales. Estas dimensiones y la incidencia del apoyo social comunitario en la calidad de vida de personas con discapacidad, son iguales para todas las personas, pero pueden variar individualmente en la importancia y valor que se les atribuye. La evaluación de las dimensiones está basada en indicadores que son sensibles a la cultura y al contexto en el que se aplica (p. 446).

En 2001, la Organización Mundial de la Salud elaboró un documento para abordar la Clasificación Internacional del Funcionamiento, de la Discapacidad y de la Salud, ampliando el concepto de discapacidad, incluyendo diferentes ámbitos de la vida de las personas, centrándose tanto en las funciones y estructuras corporales como en las actividades y el grado de participación en la sociedad (OMS, 2001). Este documento, que pretende ser utilizado entre otras cuestiones para guiar la intervención y tratamientos con personas con discapacidad, da importancia tanto a las capacidades y limitaciones del funcionamiento del cuerpo, como a la participación en las actividades cotidianas y en la sociedad. En las últimas investigaciones disponibles, se está reconociendo la participación como uno de los objetivos deseados en el proceso de rehabilitación (Hidalgo, Perarnau, Fasulo y Rovella, 2021; Craig y Bigby, 2015; Yorkston, Kuehn, Johnson, Ehde, Jensen y Amtman, 2008).

Durante el tratamiento de personas con EM participan numerosos profesionales que atienden a diferentes aspectos. Sin embargo, últimamente se está reconociendo la necesidad de contar con la perspectiva de las personas con discapacidad, ya que esta presenta una mirada más completa y holística, que incluye los aspectos objetivos y subjetivos, no centrándose solamente en los impedimentos y posibilidades físicas sino en las consecuencias sociales de los mismos. (Abal Rey, Canosa Domínguez y Pousada García, 2021; Yorkston, Johnson y Klasner, 2005).

La participación es un concepto polisémico, que varía según el contexto y las personas o instituciones que lo definen. Sin embargo, existe un acuerdo en abordarlo como requisito básico para la inclusión social de las personas en la sociedad. Como ya se ha mencionado, las políticas públicas tienen como objetivo la inclusión social de las personas con discapacidad, dando de este modo una importancia fundamental a la participación en los diferentes ámbitos: personal, familiar, laboral, comunitario (Milner y Kelly, 2009). Por lo tanto, los programas de tratamiento de personas con EM deberían tender a dar protagonismo a la persona que padece la enfermedad, atendiendo no solamente a los aspectos físicos sino a los sociales y subjetivos.

Sin embargo, las habilidades e impedimentos corporales tienen estrecha relación con las posibilidades y limitaciones al participar en los diferentes ámbitos (Kierkegaard, Einarsson, Gottberg, von Koch y Holmqvist, 2012). Es aquí importante destacar la importancia de considerar la imagen corporal que las personas con discapacidad poseen de sí mismos, ya que sus vivencias y percepciones condicionan la forma de participar en la sociedad (Martínez-Espejo, Limiñana-Gras, Patró-Hernández, Meca Lallana, Aznar Robles y Márquez Rebollo, 2021).

La imagen corporal es un concepto multidimensional asociado a la percepción que se tiene del propio cuerpo y sus partes, así como los pensamientos, sentimientos y conductas que se manifiestan a partir de las cogniciones y sentimientos que se experimentan (Raich, 2004). Se articula en torno a tres componentes. Un componente perceptivo, asociado a las dimensiones del cuerpo de manera global y segmentaria. Otro componente cognitivo-afectivo de carácter subjetivo en el que se incluyen aquellas valoraciones respecto al cuerpo y los sentimientos, actitudes y cogniciones que genera. Finalmente, un componente conductual en el que se incluyen aquellas conductas que se generan a partir de los sentimientos que producen esas conductas (Thompson, 1990).

Cuando esta imagen es negativa se pueden producir efectos que pueden derivar en problemas psicológicos y de interacción social (Raich, 2004). Además, la satisfacción o insatisfacción de su percepción también depende de la percepción de la imagen proyectada y la necesidad de obtener la aprobación social (Botero y Londoño, 2015).

En el caso de las personas que presentan esclerosis múltiple, la autopercepción influye de manera determinante en su calidad de vida, ya que habitualmente pueden presentar una disminución cognitiva (Cáceres, Vanotti, Rao y Reconem Workgroup, 2011). De hecho, en estudios como los de Bora, Özakbaş, Velakoulis, y Walterfang (2016) y Cotter *et al.* (2016) se comprueban alteraciones en la cognición social, así como en la capacidad para reconocer emociones. Profundizar en esta línea de investigación facilitará una mayor comprensión en cómo afecta al desarrollo de su vida diaria en sus interacciones sociales, así como potenciar el desarrollo de programas concretos para la mejora de estas habilidades (Leiva, Margulis, Micclulli y Feeres, 2017).

Hay muchas maneras de hacer partícipes a las personas de su tratamiento y no todas ellas se basan exclusivamente en la expresión oral. Existen numerosas experiencias que consideran el arte como herramienta de comunicación y expresión que permite captar otros discursos, generar conciencia crítica y fomentar el bienestar personal. Así mismo, las actividades artísticas pueden constituir y propiciar una mayor participación en la sociedad, tanto mediante la mera expresión de opiniones y miradas de personas que generalmente están excluidas de la sociedad como para ser objeto de sensibilización de la sociedad en general (Huss y Bos, 2018).

En este sentido, existen técnicas basadas en la expresión corporal como las dramatizaciones o prácticas teatrales que pueden aportar bajo enfoques adecuados y contextualizando de manera coherente las circunstancias para las que son dirigidas identificando el cómo, el porqué y el para qué de las intervenciones (Vieites, 2015). Además. existen técnicas basadas en el teatro del oprimido como las generadas por Paulo Freire y Augusto Boal que buscan la transformación social a partir de la identificación de problemas sociales tanto a nivel intrapersonal como interpersonal, por lo que este tipo de prácticas se configuran como una estrategia de participación social y transformación comunitaria en el entorno en el que se vive convirtiéndose en ciudadanos más críticos y concienciados (Motos-Teruel y Navarro-Amorós, 2012).

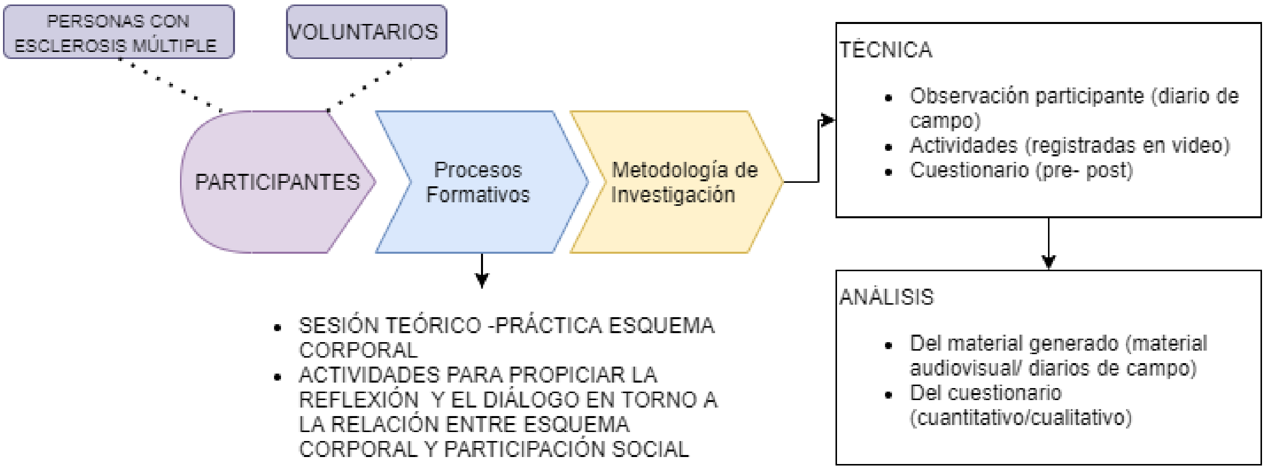
En consecuencia, con todo lo expuesto anteriormente, resulta necesario profundizar en el uso de estas técnicas basadas en la expresión corporal con personas con esclerosis múltiple que nos permitan obtener información para poder generar mejoras tanto a nivel personal como colectivo.

3. Marco metodológico

3.1. Características de la investigación

El presente trabajo se configuró como un estudio de caso desde un paradigma cualitativo para obtener información para comprender la realidad desde la perspectiva de sus protagonistas tomando en cuenta la atribución de significados personales que dan a partir de sus percepciones (Sandin, 2003).

En el siguiente esquema se resume la metodología utilizada:



Esquema 1: Resumen proceso de investigación

3.2. Participantes

La muestra está formada por voluntarios/as de La Asociación Italiana de Esclerosis Múltiple (Onlus). En ella se reconoce la importancia de su aportación como ciudadanos/as partícipes en la vida comunitaria y en la cultura de solidaridad. Es un grupo formado por quince personas de las cuales el 47% son mujeres y el 53 % hombres cuyas edades están comprendidas entre los 20 y 30 años. Su participación en la asociación es promover el bien común a través de la atención al otro y su mejora personal tanto en el campo afectivo como social. Estos jóvenes que cumplen servicio civil deben respetar los valores que se incluyen en la Carta Ética (adoptada por la Oficina Nacional del Servicio Civil del CSNU), en favor de la paz y solidaridad. Los años de voluntariado cumplidos por estas personas varían en función de la edad, pero generalmente van desde uno a seis años, sin embargo, el tiempo de voluntariado con personas con esclerosis múltiple es menor, siendo entre seis meses y un año de permanencia.

Trabajamos a la vez con personas de la asociación con esclerosis múltiple formada por tres mujeres y dos hombres. Aunque el grupo era más amplio en otras actividades desarrolladas por la propia asociación. Estas personas tienen perfiles diferentes dentro de la enfermedad, sobre todo en relación con su estado de movilidad. Sus edades eran distintas, comprendidas entre los 20 y los 60 años.

3.3. Implementación del proceso formativo

Objetivos en el proceso formativo llevado a cabo en la investigación

El proceso formativo realizado tanto al voluntariado como a las personas con esclerosis múltiple tenía un formato parecido. A todos ellos y ellas, aunque en formaciones diferentes se les explicó de forma teórica el concepto sobre el cuerpo y su relación con el control emocional, la imagen corporal y el lenguaje corporal. Se habló de la importancia de tener conciencia de todos estos focos de interés desde la dimensión cognitiva, afectiva y conativa. Estas pinceladas teóricas tenían objetivos diferentes y las ejemplificaciones cambiaban según fueran dirigidas al voluntariado o a las personas con esclerosis múltiple.

En las siguientes tablas queda reflejada de manera sintética la información relativa a la implementación realizada a ambos grupos:

<table>
<tr><td colspan="3">DESTINATARIOS: Voluntariado (nº: 15)
Duración del programa:10 horas
Metodología:
• Desarrollo de sesiones que favorezcan una participación activa.
• Exposiciones teóricas y experienciales basadas en role-playing
• Reflexión y debate a partir de la exposición de conceptos, experiencias y visionado de materiales audiovisuales.
• Desarrollo de tareas de análisis y reflexión de casos.</td></tr>
<tr><td rowspan="2">CUERPO-CONSCIENTE</td><td>Objetivo</td><td>1. Conocer y reconocer la importancia que tiene el cuerpo y la imagen corporal propia para generar seguridad en las personas con esclerosis múltiple como para identificar en otros las señales corporales.</td></tr>
<tr><td>Contenidos</td><td>➢ El cuerpo y el control emocional
➢ La imagen corporal (dimensión cognitiva, afectiva y conativa)
➢ Lenguaje corporal</td></tr>
<tr><td rowspan="2">CUERPO-SOCIAL</td><td>Objetivo</td><td>2. Generar estrategias para manejar situaciones cotidianas aumentando el nivel de consciencia ante el control de situaciones</td></tr>
<tr><td>Contenido</td><td>➢ Gestión emocional en situaciones de apoyo
➢ Control corporal y motor en situaciones de apoyo</td></tr>
</table>

<table>
<tr><td colspan="3">DESTINATARIOS: Personas con esclerosis múltiple (nº: 5)
Duración del programa: 10 horas
Metodología:
• Desarrollo de sesiones que favorezcan una participación activa.
• Exposiciones teóricas y experienciales basadas en role-playing
• Reflexión y debate a partir de la exposición de conceptos, experiencias y visionado de materiales audiovisuales.
• Desarrollo de tareas de análisis y reflexión de casos.</td></tr>
<tr><td rowspan="2">CUERPO-CONSCIENTE</td><td>Objetivo</td><td>1. Conocer el propio cuerpo y las múltiples manifestaciones que se da en él para analizar la competencia percibida, sobre sus fortalezas limitaciones desde un punto de vista consciente.</td></tr>
<tr><td>Contenidos</td><td>➢ El cuerpo y el control emocional
➢ La imagen corporal (dimensión cognitiva, afectiva y conativa)
➢ Lenguaje corporal</td></tr>
<tr><td rowspan="2">CUERPO-SOCIAL</td><td>Objetivo</td><td>2. Reflexionar sobre las diferentes experiencias vividas en situacione cotidianas con las personas de apoyo</td></tr>
<tr><td>Contenidos</td><td>➢ Identificación y reflexión sobre las emociones en situacione de recepción de apoyo
➢ Cuerpo y movimiento en situaciones de apoyo</td></tr>
<tr><td rowspan="2">CUERPO-RETO</td><td>Objetivo</td><td>3. Analizar las situaciones cotidianas experimentadas identificándola fortalezas, limitaciones y el control emocional de cada momento</td></tr>
<tr><td>Contenidos</td><td>➢ Retos y dificultades personales cotidianos</td></tr>
</table>

Objetivos sobre el marco conceptual (CUERPO-CONSCIENTE)

El objetivo principal con el voluntariado iba dirigido a que se conocieran de la importancia del cuerpo y la imagen corporal, tanto para percibir en otros las señales corporales y poder ayudar mejor, como conocer la propia suya para dar seguridad a las personas con esclerosis múltiple.

El objetivo más importante en las personas con esclerosis múltiple iba encaminado a conocer su propio cuerpo y las múltiples manifestaciones que en él se dan, para poder analizar la competencia percibida, sobre sus fortalezas y limitaciones desde un punto de vista consciente. Cuerpo que piensa, siente y en consecuencia actúa, siendo así más eficaz en la atención en el proceso de su enfermedad.

Una vez trabajados los conceptos referenciales de la formación, se consideró establecer debates incluyendo sus perspectivas particulares, haciendo ejemplificaciones aclaratorias de hechos, momentos, sentimientos o acciones que repercutían directamente sobre el tema que estábamos tratando del cuerpo, y la importancia que tenía tanto en su ámbito de ayuda en el caso del voluntariado, como en personas con esclerosis múltiples en su vida cotidiana.

Consideramos interesante incluir diferentes actividades donde los participantes trabajaron sobre la conciencia corporal como es en el caso de los/as voluntarios/as, realizando un análisis corporal entre compañeros a partir de unas variables previamente explicadas que tenían que valorar, conocer y evaluar. Este análisis se hacía a través de la visualización de un video donde cada voluntario/a hablaba sobre ella o él mismo. Era importante comentar sobre los gestos, tono de voz, actitud corporal, lenguaje del cuerpo, formas de expresión, miradas, etc.

También se hizo un análisis sobre situaciones de la vida cotidiana que se dan con frecuencia, donde tenían que observar desde las tres dimensiones ya explicadas en la parte teórica, como afectaba las acciones diarias en ellos y ellas. De ahí podían reflejar de forma consciente la cantidad de errores que se cometen por no hacer caso a alguna parte del proceso.

Se establecieron debates muy interesantes sobre la realidad en su ciudad y los problemas y barreras que encuentran a la hora de trabajar en condiciones con las personas de esclerosis múltiple, referían sobre todo la falta de medios, concienciación, y sensibilidad ciudadana.

Objetivos a conseguir por el voluntariado en el desarrollo de actividades prácticas (CUERPO-SOCIAL)

Los objetivos más importantes que se pretendían con la práctica de actividades con el voluntariado fueron: la capacidad de conocer y controlar las situaciones cotidianas para poder mejorar sus futuras actuaciones, tomar conciencia del propio cuerpo cuando se someten a situaciones cotidianas que necesitan revisarse por la actuación inadecuada, poco eficaz, o poco controlada del momento y ser conscientes de verbalizar los sentimientos y problemas que surgen cuando ejercen su labor de voluntariado y sentirse comprendido por el grupo.

En cuanto a las actividades realizadas en la formación con las personas con esclerosis múltiple, consideramos interesante que el voluntariado también estuviera con ellos/as. Por lo tanto, las prácticas las realizaron juntos, en ellas se trabajaron actividades de concienciación corporal, en un intercambio entre parejas de percepciones sobre el cuerpo. Logrando establecer feedback entre ellos y hablar sobre distintos focos de atención relacionados con el cuerpo y la conciencia corporal. Se realizaron también dramatizaciones, donde se ejemplifican situaciones que ellos utilizaban como problemáticas, dando solución a estos momentos utilizando estrategias de cambio que ellos y ellas elaboraban para resolver eficazmente el problema. Por lo tanto, había un previo análisis entre todos de la situación, la escenificaban representando los problemas y posteriormente concluían con un debate. Podemos decir que los debates eran muy interesantes, ya que había una participación y colaboración a la vez de asentimiento de todo lo que se expresaba. Los debates eran dirigidos por los formadores, poniendo énfasis en los focos de interés de la formación.

Objetivos a conseguir con las personas de esclerosis múltiple, en el desarrollo de actividades prácticas (CUERPO-RETO)

Los objetivos a conseguir con las personas con esclerosis múltiple en todas estas actividades era el de que fueran conscientes de sus actuaciones diarias, y que pudieran analizarlas. El reto de enfrentarse a la vida diaria y conocer de forma ajustada sus limitaciones y fortalezas reales, y controlar emocionalmente cada momento de superación personal. El valor de ser entendidos y de establecer espacios donde poder expresar todos los problemas a los que se enfrentan, conocer los problemas de otros e ir por el mismo camino del conocimiento personal en todas sus dimensiones es lo que permite el debate como actividad interesante.

3.4. Instrumentos

3.4.1. Cuestionario para el análisis de la percepción previa del voluntariado sobre la importancia del cuerpo y la emoción en el trato con personas con esclerosis múltiple

El cuestionario ha sido realizado por las propias formadoras (profesoras de la Universidad Complutense de Madrid), que han impartido las jornadas, cuya experiencia es extensa tanto en el campo de la imagen, corporal y lenguaje corporal, como del control emocional a través del cuerpo todo dentro de ámbitos sociales y diversidad.

El objetivo principal por el que se aplicó este cuestionario fue, para ver el nivel de percepción del voluntariado sobre la importancia que tenía el cuerpo y el control de emociones en el trato con las personas con esclerosis múltiple.

El cuestionario está formado por nueve preguntas en escala de Likert, de uso frecuente en cuestionarios donde las respuestas van (1-5), significando el uno (muy en desacuerdo) y el cinco (muy de acuerdo).

Se consideró importante dividir el cuestionario en tres apartados, donde en cada uno de ellos estaba presente tres focos de interés:

- Imagen corporal
- Lenguaje corporal
- Manejo de emociones

En cada apartado se pone énfasis en:

- Primer apartado (si consideran importantes estos focos de interés).
- Segundo apartado (si en el trato con estas personas, el tener en cuenta estos focos determina la relación cuando ejercen su función).
- Tercer apartado (si son conscientes de estos factores en la labor como voluntarios).

Además de estas preguntas, se consideró importante incluir previa a ellas, los años de experiencia que tenían como voluntarios/as, y los que llevaban con las personas de la asociación. Además, fue de interés también dejar reflejados los motivos por los que dedican su tiempo al voluntariado.

3.4.2. Cuestionario para el análisis de la percepción sobre la formación realizada en cuanto a la metodología, organización y conocimientos adquiridos

Este cuestionario también fue de realización propia como el anterior. El objetivo principal fue el conocer la repercusión de la formación en varios aspectos:

- Los relacionados con la estructura y organización del seminario y el grado de comprensión de este.
- Lo que han sentido, han conocido y la utilidad de la formación.
- El conocimiento global del nivel de satisfacción percibido tras la realización de la formación.

Los relacionados con la estructura y organización del seminario y el grado de comprensión de éste

Formado por 12 preguntas de escala Likert (1-5), donde el 1 significa (muy en desacuerdo) y el 5 (muy de acuerdo).

Lo que han sentido, han conocido y la utilidad de la formación

En este apartado ha sido de interés conocer la repercusión y las sensaciones que han tenido los voluntarios/as durante el proceso de formación. Con preguntas semiabiertas divididas en tres partes:

- Emociones sentidas durante la formación
- Conocimientos adquiridos
- Utilidad para el futuro

El conocimiento global del nivel de satisfacción percibido tras la realización de la formación

Formado por 10 preguntas, cuyo propósito era conocer la satisfacción global por parte del voluntariado de la formación tras haberla realizado. Se presenta en escala de Likert como las anteriores del (1-5).

3.4.3. Rejilla de observación sobre el análisis corporal

En el análisis sobre las imágenes visualizadas. El objetivo principal, era trabajar a través de grupos combinados (voluntarios y personas con esclerosis múltiple), para que fueran capaces de representar situaciones que se daban en la vida real difíciles de resolver. Por tanto se establecieron cuatro grupos de 5 personas cuya finalidad era dramatizar momentos claves del día a día donde se generaban conflictos de difícil solución. En cada grupo había un representante de esclerosis múltiple, los demás eran voluntarios/as.

En esta primera parte de escenificación cada grupo hacía una representación del caso, y los otros grupos a través de una rejilla de observación veían los aspectos más relevantes que se presentaban teniendo en cuenta:

- El tipo de lenguaje gestual que intervenía
- Las formas comunicativas que se daban en cuanto a calidad y cantidad
- Los aspectos de dificultad física que surgían según la situación
- El tipo de sentimiento que afloraba en cada momento

En la segunda parte del proceso, una vez visualizado en el video todos los grupos y teniendo en cuenta la rejilla con los items analizados. Debían de nuevo representar la misma escena solucionando el problema y resolviendo la situación. Era importante que pusieran énfasis en los puntos mencionados con anterioridad.

A través del debate que se realizó después de la primera y segunda escena impulsado por los docentes, pudieron comprobar cómo podemos mejorar las actuaciones, cuando somos conscientes de dónde se producen los focos conflictivos y cómo entre todos podemos ayudar a mejorar y cambiar esas situaciones adversas.

3.4.4. Debates reflexivos

Se consideró de interés trabajar en puestas en común a lo largo de la formación. Donde el voluntariado pudiera expresar sus sensaciones, sentimientos, sobre su práctica en la labor de voluntariado.

Los debates fueron aplicados cuando finalizaban las actividades para poner en consenso ideas, conocimientos y sensaciones sobre la práctica realizada. Los debates se desarrollaron tras:

- El desarrollo de una práctica escrita en grupos
- Puesta en común final de puntos claves de la formación

Tras el desarrollo de una práctica escrita en grupos

En este debate el objetivo fue poder conocer cómo cada grupo había trabajado de forma conjunta una tarea en la cual tenían que analizar situaciones reales de la vida cotidiana a través de las tres dimensiones explicadas en la formación. Conciencia corporal sobre el proceso de pensamiento de esa acción, el sentimiento o emoción que se despertaba, y en consecuencia las acciones que se sucedían.

Puesta en común final de puntos claves de la formación

Un debate final donde se expusieron los sentimientos que habían aflorado durante el curso de formación, además de expresar la utilidad de las jornadas para su futuro profesional.

- Instrumentos aplicados con las personas con esclerosis múltiple

3.4.5. Debates con las personas de esclerosis múltiple

Básicamente, en la formación a las personas con esclerosis múltiple, se trabajó a través de debates que se realizaron tras diferentes actividades:

- Dramatización
- Debate sobre la emoción
- Debate sobre el interés y utilidad de la formación realizada

Dramatización

Tras una dramatización sobre la acción de una situación cotidiana de conflicto donde se contextualiza todos los agentes que intervienen y las reacciones de éstos. Debían discutir y debatir sobre las posibles estrategias de cambio que se podían dar para mejorar la acción y ser más eficaces.

El objetivo era que tanto el voluntariado que estaba formando parte de esa dramatización como las personas con esclerosis múltiple, fueran capaces de expresar la acción, analizarla en todo su proceso y que juntos pudieran ser capaces de resolver el conflicto, y abrir diferentes caminos de actuación para mejorar estas situaciones comprometidas.

Debate sobre la emoción y las barreras a las que se enfrentan las personas con esclerosis múltiple

Fue importante abrir un debate sobre la demostración de emociones en estas personas, y verbalizar donde la emoción está más presente y cuando el control de la emoción se hace necesario. El objetivo del debate consistió en expresar cuáles son las barreras a las que se enfrentan y qué emociones despiertan éstas.

Se desarrollan diferentes preguntas guiadas sobre:

- Dónde encuentran las barreras principales
- La emoción que despiertan ciertas situaciones cotidianas
- Los traumas que generan esas situaciones
- Estrategias de mejora

Debate sobre el interés y utilidad de la formación realizada

Se estableció un debate final guiado sobre la aportación de la formación y la importancia de sus contenidos, donde las personas con esclerosis múltiple estuvieron expresando sus sentimientos y valoraciones del curso. Los temas tratados fueron:

- Utilidad de lo aprendido
- Interés del cuerpo-consciente y su importancia en la vida
- Importancia del exteriorizar la emoción

3.4.6. Diarios reflexivos

Los diarios reflexivos de las investigadoras, reflejaban el hacer diario y las percepciones captadas que surgían tras desarrollar la formación:

- Emociones sentidas
- Anécdotas
- Problemas surgidos
- Puntos de interés relevantes durante la práctica

Reflexión del investigador externo

Fue interesante incluir una investigadora externa para poder observar cómo había ido la formación. Donde se trató:

- Puntos fuertes y débiles de la formación
- Estructura de la metodología
- Control de la temporalización de las actividades
- Fluidez en la comprensión de los contenidos

4. Resultados

4.1. Cuestionario para el análisis de la percepción previa del voluntariado sobre la importancia del cuerpo y la emoción en el trato con personas con esclerosis múltiple

Uno de los primeros pasos en nuestra investigación, fue aplicar un cuestionario al voluntariado antes del comienzo de la formación, donde entre los objetivos prioritarios estaba el de conocer las ideas previas que ellos y ellas tenían sobre el cuerpo y la imagen corporal en su labor como voluntarios. De ahí se desprenden datos que nos ayudan no solo a comprender cómo interactúan sobre el control de sus emociones, sino sobre la importancia que le dan a la imagen y el lenguaje corporal cuando trabajan con personas con esclerosis múltiple. También se les preguntó por el cuerpo en relación a la imagen corporal, y son la mitad de los participantes que consideran no creer que la imagen del cuerpo determine la interacción con estas personas, sin embargo, hay otra mitad en su mayoría mujeres que sí que entienden que la imagen corporal tiene cierto protagonismo. Se preguntó sobre las emociones y el manejo de éstas en la función del voluntariado y fue posiblemente la respuesta más contundente entre ellos y ellas de forma afirmativa, donde entendían que la emoción está presente continuamente en cada acción que realizan con estas personas y que repercute en el modo de actuar de forma clara. Se consideró que el manejo de emociones es de vital importancia sobre todo cuando están ejerciendo la labor de voluntariado, puesto que ayuda claramente como refuerzo en la comunicación verbal. Es interesante comprobar que cuando ponemos el foco de atención sobre el nivel de conciencia que tiene el voluntariado respecto a la imagen corporal, el manejo de emociones y el lenguaje corporal, a la hora de trabajar con estas personas coinciden en que suelen ser más conscientes de los gestos que realizan, que de la imagen que proyectan. Sobre todo, se acentúa en los hombres esta idea, aunque a nivel general consideran que la emoción siempre está presente en la interacción con personas con esclerosis múltiple, no perciben que sean conscientes de un modo habitual en ella, salvo en situaciones puntuales donde una determinada acción ha tenido repercusión directamente en la emoción.

- En su introducción este cuestionario pedía conocer los motivos por los que utilizan su tiempo en este voluntariado. De lo que se desprendió las siguientes consideraciones:

Fue importante poder conocer directamente del voluntariado cuáles son los motivos por los que quieren ayudar a personas con esclerosis múltiple. Y casi todas las personas expresan en sus respuestas, la necesidad de dedicar su tiempo a una causa tan importante como es esta, además de sentirse muy bien por poder ser útil a la sociedad. Ellos y ellas hacen su labor de voluntariado con mucha ilusión y entusiasmo, reconocen que son experiencias que enriquecen y son muy gratificantes. Sienten que colaborar en la asociación también les hace crecer a nivel profesional y personal.

4.2. Cuestionario para el análisis de la percepción sobre la formación realizada en cuanto a la metodología, organización y conocimientos adquiridos

Una vez realizado el cuestionario sobre la percepción del voluntariado tras la formación realizada, han considerado que es un aprendizaje que les valdrá para su vida profesional de forma importante, más que para su vida personal. Que les habilita para tener instrumentos que les ayuden a trabajar con más seguridad en la práctica con estas personas. Las actividades les han parecido muy exitosas e innovadoras, por aportar temáticas muy diferentes a las que acostumbran. A pesar de que el idioma ha dificultado la comunicación, parecen haber recibido un curso donde ha habido claridad en la exposición y una buena organización de contenidos, así lo expresan en sus respuestas dando valores altos al estar de acuerdo con la afirmación que presentamos. Además, en las actividades se han sentido cómodos y han considerado que han sido formuladas claramente, siendo posible crear un espacio confortable y de distensión. Entienden haber recibido una formación provechosa que podrá ser muy útil en el desempeño de su profesión y que enfatiza sobre la importancia que tiene el cuerpo como foco de atención sobre la ayuda a estas personas, junto con la importancia de controlar sus emociones cuando desempeñan el voluntariado.

- En cuanto a la percepción de los conocimientos recibidos en la formación consideran:

Que el cuerpo y el lenguaje corporal tienen una función fundamental en la relación con las personas con esclerosis múltiple. Sobre todo, en los momentos de ayuda cuando ejercen la labor de movilización o de traslados, saben que un gesto, una mirada o una actitud determinada corporal, representa una información complementaria que se está dando en cada intervención en la que tienen que ayudar. Trabajar la gestión de la emoción es otro punto que han destacado, tanto en el control de la emoción personal, como en la gestión emocional de otros, ya que es fundamental en este tipo de voluntariado, entienden que cada persona gestiona su emoción de una forma diferente y por ello la relación que se establece es distinta. Por lo tanto deben estar atentos no solo a aspectos gestuales y de intervención manual (agarres, ayudas, etc), sino que también deben tener un repertorio de herramientas y recursos para mejorar su intervención y labor profesional a la hora de tratar con la emoción. La comunicación asertiva también ha sido un tema de interés entre los voluntarios/as, ya que es importante proyectar seguridad a nivel corporal y a nivel comunicativo. Coinciden que hay personas que reclaman la ayuda de un voluntario determinado, porque con él o ella se sienten más seguros, es entonces cuando son conscientes de la importancia de estos aspectos a tener en cuenta en este tipo de colaboraciones. Tras esta formación reconocen haber conocido más de su cuerpo y de sus posibilidades, y el hecho de que cada acción tiene determinada repercusión en el otro, por ello la importancia de saber cómo actuar y ser conscientes de que las relaciones que se establecen son de vital importancia para el buen abordaje de estas intervenciones.

- En cuanto a la parte emocional de la formación que se pregunta sobre los sentimientos que han tenido:

Se puede resaltar que los sentimientos experimentados en la formación, han sido muy diversos, desde tener vergüenza a la hora de representar escenas frente a los demás, hasta sentirse muy satisfechos por poder superar las presentaciones en público y hablar de forma serena y tranquila sobre su persona. Valoran el haber tomado conciencia de lo importante que es analizar la actitud corporal y las percepciones que tenemos de nosotros mismos cuando somos grabados en video. Consideran necesario que a veces se trabaje de forma introspectiva y se analicen las emociones que surgen en diferentes situaciones. La expresión de sensaciones como ansiedad, nerviosismo, vergüenza, tanto como aquellas relacionadas con el interés, curiosidad, alegría y divertimento, han sido reflejadas en sus escritos en relación con lo vivido en la formación. Se han dado numerosas situaciones de complicidad y satisfacción al comprobar que los sentimientos son muy parecidos entre ellos y ellas cuando se analizaron secuencias o situaciones. Las palabras que han estado presentes al finalizar la formación han sido de enriquecimiento, interés, ganas de saber, y agradecimiento por toda la formación recibida.

- En cuanto a los debates realizados con las personas con esclerosis múltiple

Consideran que aún hay muchas barreras por resolver y estas provocan en ellos y ellas en muchos casos sensaciones traumáticas que obstaculizan su normalización en la vida diaria. En toda la formación y sin duda cuando hemos trabajado en los debates, sobre todo con las personas con esclerosis múltiple. Hemos podido observar en ese diario de control de las sesiones por parte de los formadores que estas personas presentan muchas barreras a lo largo de su vida. Barreras que son traumáticas porque continuamente sienten encontrarse con obstáculos en su vida diaria. Desde que se descubre la enfermedad, ya comienza a ser traumático el sock de poder entender lo que les está pasando y lo que en el futuro acontecerá. Hasta conseguir determinar si es esclerosis u otra enfermedad se dan momentos de incertidumbre por la divagación en el diagnóstico, se habla de incertidumbre, no solo cuando se diagnostica la enfermedad, sino de cómo se presenta el futuro de incierto. Se convierte en trauma el no saber cómo responderá el cuerpo, lo que se podrá hacer cuando el proceso de la enfermedad avance, los proyectos de futuro se disipan, manteniendo la duda en el presente. Consideran que no solo existe problema en los diagnósticos en la medicina, sino que tampoco encuentran equipos interdisciplinares de forma accesible y rápida para empezar a actuar de forma holística tempranamente. La familia es otra de sus grandes preocupaciones, porque consideran que desde que descubren la enfermedad su comportamiento varía, pasan a ser sobreprotectores y tener miedo de cada cosa que realizan de forma autónoma. De alguna manera limitan su proceso de vida, obstaculizan la evolución, entienden que sea normal, pero interrumpen las posibilidades de crecimiento. El peso de tener una familia preocupada y en muchos casos sobre todo en mujeres que pasan de ser cuidadoras a ser cuidadas, supone un trauma por la impotencia de no poder realizar las tareas de antes. También supone una barrera el diseño de las ciudades, la poca sensibilización sobre la arquitectura de los edificios, las calles, la inaccesibilidad a espacios culturales, artísticos, y la poca cultura urbanística sobre aquellos que tienen limitaciones en los accesos. Provoca en estas personas gran malestar e incluso frustración por no sentirse incluidos socialmente como seres humanos. A nivel social encuentran obstáculos, porque las personas no están sensibilizadas, y es como si fueran invisibles ante los demás, desde el poder pasar por una carretera y que las personas tengan calma, hasta, las ayudas en la vida cotidiana. La manera de ayudar, en muchos casos el tratamiento infantil, o de pena por tener una mirada distorsionada sobre lo que es la enfermedad y quién la padece. Son muchos los obstáculos que estas personas encuentran y sumado a todo ello, el tener que convivir con un cuerpo que no reacciona como antes, que no responde a las expectativas que se tenían. Un cuerpo que lucha por superar retos, que lucha por vivir desde el lugar que le corresponde. Un cuerpo expresivo, que comunica desde su posición y que no es comprendido como debiera. Por lo tanto, todas estas situaciones hacen que la persona sienta una carga emocional-afectiva y una impotencia complicada en su vida para seguir adelante.

Durante el grupo de discusión y en los ejercicios de role playing, los participantes han identificado varios ámbitos en los que encontraban dificultades, teniendo en cuenta la dimensión participativa en cada uno de ellos. Entre las esferas de sus vidas que se mencionan como fundamentales para su participación en la sociedad, se encontraban la familia, las amistades y el ocio y tiempo libre, el trabajo y los estudios. A ello sumaban una esfera pública que tenía como principal obstáculo la falta de empatía y educación de la sociedad en general.

Entre las barreras mencionadas por las personas con EM se encontraban aquellas relacionadas con las limitaciones derivadas de la enfermedad, pero las dificultades de participación social cobraban una importancia fundamental en sus posibilidades de bienestar personal. Al buscar soluciones posibles al problema, las mismas se dirigían hacia la concienciación de la sociedad en general y no tanto a las modificaciones arquitectónicas o mejoras en el tratamiento médico. Es importante destacar que, aunque la necesidad de participación no se encontraba entre las preguntas formales, la misma surgió durante los relatos y vivencias.

Si bien reconocían que sus capacidades físicas influyen en su imagen corporal y las reacciones de los demás, las mismas se veían afectadas por las reacciones de las familias, las instituciones y la sociedad en general. Ponían especial hincapié en la necesidad de mejorar la información que posee la sociedad acerca de la EM y en tener un papel más activo en este proceso de concientización.

- En cuanto a la percepción global de la formación y las reflexiones del voluntariado

La apreciación generalizada ha sido muy positiva, porque todo lo aprendido será de utilidad no solo como voluntarios sino para su futuro profesional. Han destacado la importancia de ser conscientes del cuerpo y todo lo que representa éste cuando interactúa con los demás. Han agradecido el conocer nuevas temáticas que ayudan a mejorar su labor como voluntarios y tomar conciencia sobre la comunicación y expresión corporal. La formación les ha parecido muy práctica a la vez que divertida por todas las actividades que han realizado.

- En cuanto al evaluador externo se identifican las siguientes cuestiones

Como puntos fuertes del programa se destaca el desarrollo satisfactorio de las actividades y el cumplimiento de los objetivos de sesión previstos. Como puntos débiles de la formación se identifica las dificultades comunicativas que supone el desconocimiento de un idioma común, aunque a través del lenguaje no verbal y recurrir a una tercera lengua (inglés), se ha suplido esta carencia. Por otro lado, nos hubiera gustado poder desarrollar nuestro programa de forma más amplia para que los contenidos trabajados se consolidasen más.

En relación con la temporalización de las actividades, la carencia de tiempo mencionada se ve también condicionada por el retraso en el inicio de las actividades por causas ajenas aunque justificadas y respecto a la estructura metodológica se ha podido percibir que ha sido la adecuada. Finalmente, respecto a la comprensión de los contenidos, estos son adquiridos, aunque en algún momento, y como ya se ha comentado, se producen algunos problemas que dificultan la comunicación, y por lo tanto la comprensión.

5. Conclusiones

Es necesario considerar que la participación en la sociedad contribuye al bienestar general de las personas. Dado que la legislación vigente tiene en cuenta la promoción de la ciudadanía, la intervención social debería apuntar a la defensa de la igualdad de oportunidades para la accesibilidad y la participación comunitaria (Díaz Velázquez, 2018).

Además, la participación no tiene que ser contemplada solamente como un derecho o una acción que contribuya al bienestar de las personas con EM. Las vivencias, puntos de vista y conocimiento acerca de la enfermedad y sus consecuencias pueden contribuir a un enriquecimiento de la sociedad en general (Inza Bartolomé, Bergantiños Franco y Rivera Escriban, 2014).

El análisis de esta investigación se centró en considerar diferentes perspectivas que nos facilitasen una información más rica y completa de la situación y cuyos resultados permiten concluir que

- las personas con esclerosis múltiple han adquirido un mayor nivel de conciencia corporal que les permitirá desenvolverse con mayor soltura en diferentes acciones cotidianas con incidencia en una mejora de la calidad de vida, y a pesar de las diferentes barreras que expresan encontrarse diariamente muestran una gran capacidad de lucha y superación;
- el voluntariado percibe de manera muy positiva el proceso de formación recibido y reconocen la utilidad de los aprendizajes adquiridos tanto para su quehacer cotidiano con las personas con esclerosis como para su futuro profesional.

Respecto a las limitaciones encontradas, somos conscientes de que un mayor tiempo de permanencia en el campo, permitiría obtener una información más completa. No obstante, como nuevo desafío, sería interesante que la sociedad haga esfuerzos para que las personas con esclerosis múltiple sientan que hay cambios reales que hagan que mejore su calidad de vida y expectativas de futuro.

Para finalizar, expresar que hemos sentido de cerca la importancia de complementar este tipo de formación relacionado con el cuerpo e imagen corporal, que tan innovadora es por un lado y que tanto ha podido beneficiar a todo el equipo de voluntariado y a las personas con esclerosis múltiple de la asociación. Fue interesante vivir la experiencia, en primer lugar porque estábamos en un contexto desconocido para nosotras, por un lado una temática nueva pero transferible a nuestra formación. El idioma también pudo obstaculizar en algún momento todos aquellos contenidos que queríamos transmitir en su justa medida. Las sensaciones y la emoción estuvo muy presente ya que estás tratando con personas que asumen vivir en una situación de lucha constante. Es todo un aprendizaje poder admirar el valor de superarse día a día, y a la vez te da conciencia del privilegio de vivir con salud. Emociones encontradas de alegría por poder compatir experiencias de vida y establecer lazos de unión para ayudar en la medida de lo posible a mejorar la calidad de vida de estas personas. Emociones de impotencia al ver como la sociedad no está atenta en escuchar un colectivo que sufre, y que no es considerado. Valorar la importante labor del voluntariado y las ganas de aprender cosas nuevas para mejorar como personas y también como profesionales. A su vez la capacidad de escucha e implicación en los debates expresando sus ideas y sentimientos, ha sido crucial para enriquecernos como formadoras y llevarnos una experiencia de gran valor.

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Perception and multiperception in architecture

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Keywords: representation of architecture, theory of multiperception, multisensoriality, accessibility, inclusion, teaching of architecture

1. Introduction

The contribution aims at tracing a path that extends from visual perception to include the other senses for a cognition of space intended as accessible in both its functional and aesthetic dimensions.

Perception permits an awareness of reality through various sensorial sources. It is the plurality of the characteristics of people, and their perceptions, that can suggest how to overcome the idea of a single, unitary perception channel to interpret and live spaces in architecture.

We want to illustrate a process of disciplinary development of architectural representation aimed at explaining to aspiring architects not so much the ways to eliminate architectural barriers, but how to give more attention to the configuration of spaces that considers people's diversity.

In the vastness of the categories of disabilities, we have chosen to exemplify the field of difficulties in visual perception, as this offers a particular challenge in the context of the aesthetic dimension, and represents the occasion to experiment the help of synesthetic principles and the consequent extension to the Theory of Multiperception.

For this reason, we started depicting the theorical frame of visual perception and what it offers to the awareness and knowledge of space. Then we moved into architectural theories that deal with the multisensorial perception and described the way we proposed these topics during a course of Representation in the Architecture master's degree of the University of Genoa.

2. Perception and multisensoriality

Studies on perception until the end of the second half of the twentieth century only paid attention to vision. The first applications of spatial design as a function of vision can be traced back to ancient times with the optical aberrations of the Parthenon mentioned by Vitruvius Pollione in the 1st century B.C. (Panofsky, 1991). The subsequent developments in this thematic

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area were decisive in the scientific discoveries concerning the perspective and the definition of laws that regulate the relationship between the observer and the subject (Gombrich, 1960; Elkins, Fiorentini, 2020).

In our studies we considered the interaction between space and observer in ecological context, with a total integration and indistinctness of the two cited elements, as supposed by Gibson (1979). In this text we will mention some episodes of the history of perception paying attention to the physiological and cognitive spheres; for a global dissertation we refer to some texts dealing with the history of visual perception with behavioural and phenomenological contributions (Palmer, 1999) also in their current applications in the field of architectural representation (Migliari, 2003; Casale, 2018).

The multidisciplinary approach is fundamental for the contemporary development of theories relating to perception. Merleau Ponty (1964) underlines how the perceptual process involves all the senses, and the whole body, especially in the case of people with visual impairments.

This concept is fundamental in the neuroscientific field: Harry Francis Mallgrave (2013) demonstrates the role of mirror neurons that are activated during perceptual activities, defining the neurological relationships that are established in the observer during the process of interaction with space. This evolution has contributed to define the multisensory theory of architecture (Pallasmaa, 2014; Robinson, Pallasmaa, 2015), which relates body, mind, and space, and broaden strictly retinal architectural studies. These theories find practical confirmation, for example, in the projects by Steven Holl inside the Chapel of St. Ignatius (1997, Seattle, WA, USA), an olfactory space has been designed which includes a layer of beeswax to cover the walls (Holl, 2000, p. 31).

The multisensory approach makes possible to amplify the possibilities of finding useful information for the perception of space, considering it as a relevant component for all types of users, especially in the case of disabilities. Tommaso Empler (1997) underlines how some environmental and design factors play a fundamental role in the reception of the message. A topic is also studied through the testimony of people who live these experiences in first person, as in the case of the blind artist Marta Telatin (2019), as can be seen below.

The heterogeneity that distinguishes this sector can lead us to identify architecture as the discipline capable of combining the different characteristics of perception in order to dialogue in a multisensory way with the different kinds of people.

Architect Juhani Pallasmaa (2014) emphasizes that multisensoriality is the aspect that allows architecture to take on poetic meaning, thus granting its aesthetic characteristics to be fully appreciated. The multiple characteristics of people show that there can be no univocal interpretation. The stimulation through other senses, in fact, allows to enrich the possibilities of perception of spatial information while allowing the accessibility of the architectural space to be implemented. It is also necessary to specify how the identification of the multisensory components is not limited to the aspects related to the five senses but provides for the addition of at least two other aspects: balance and proprioception, components that contribute to the identification of one's position in the environment (Figure 1) (Robinson, Pallasmaa, 2015).

The kinesthetic component is crucial in the process of dynamic perception of space: the exploration of an environment becomes a bodily activity that involves bones, muscles, and tendons (Pallasmaa, 1994, p. 36). The ability to identify one's position within a given context is fundamental in various fields. Italo Calvino (1995, pp. 2-3) describes an interesting proprioceptive process, which refers to the identification of the sea as the main determining point of reference for subsequent dynamic actions, whether it is a real or imaginary movement.

In order to understand these aspects, it is necessary to mention essential knowledge about the physiology of vision, such as the functioning of the eye and the main characteristics of binocular vision (Figure 2a). It is curious to note that, for the reading of details, the field of vision is reduced to an amplitude of 2°-5° (Figure 2b-c), so it is necessary to resort to a constant movement of the eye to be able to explore the whole context. To monitor these ocular dynamics, it is possible to use the digital eye tracking tool, which can extrapolate data that relate perceptual activities with dynamic ones.

The eye tracking tool was initially developed in the marketing field to identify the best sale strategies for the sale and promotion of consumer products; proved to be an effective instrumentation, the areas of interest have expanded and involve the figurative arts, including architecture. The interest in spatial design is determined by the possibility of identifying useful parameters for perceptual studies, such as the degree of fixation, the period in which the eye remains stable on a specific object, and the quantitative data of the saccades, the jumps that the eye makes between one fixation and another: both factors are analyzed to extrapolate data that allow to identify the areas of greatest interest (Malgoretza, 2020). It is important to note that the eye is particularly attracted to specific architectural forms, such as elements with an oblique direction (Lee *et al.*, 2015).

In addition to the physiology of vision, it is also necessary to define some notions regarding the theories of interpretation of the process of visual perception. The Gestalt theory, or theory of form, allows us to illustrate the seven principles regarding the correct composition of images: Proximity, Similarity, Figure- Background, Closure, Common fate, Experience and Good figure (Figure 3). Particularly interesting is the third principle (Figure-Background) (Figure 3c), because it permits to introduce the theme of the ambiguity of the image with the well-known example in which the appearance of two white faces positioned one in front of the other on a black background can be interpreted as a black vase on a white background.

The theme of ambiguity is extensively treated in the field of representation theory and the Müller-Lyer illusion (1889, Franz Carl Müller-Lyer) (Figure 4a) is an interesting example: segments of the same dimensions appear different because of the direction of the arrows. This happens because the two ends of the arrows determine a perspective direction that triggers a three-dimensional interpretative process.

In architecture, examples of the use of perspective rules to create illusory spaces are frequent; relief perspectives, for example, are effective in allowing simulation of the spatial depths of an environment (Leopold, 2019). The choir of *Santa Maria presso San Satiro* (Milan, 1478-1482, Donato Bramante) fits into this context, which, thanks to the use of the relief perspective simulates a choir in only one meter and twenty. In this illusionary space is very important the correct position of the point of view (Rossi, Mele, Buratti, 2019): the building, viewed from a central position, is perceived as a Latin cross plan, consisting of three naves, a large transept and a deep choir behind the altar (Figure 5a); the perception is completely changed when the point of view leaves the centrality of the nave, and the accidental view of the altar shows the perspective fallacy (Figure 5b).

In the reading of images and illusory spaces, culture context plays a decisive role (Baglioni 2016). In this regard, we can cite the suggestive room of Adalbert Ames Jr. (1946) that shows how perspective can generate confusion and strong contradictions. The design of the room is based on the vision from a specific point of view that allows you to bring the room back to a regular parallelepiped (Empler, 2018). As a result of the optical illusion created by the distorted room, a person standing in one corner appears to the observer to be significantly larger than a person standing in the opposite corner while the room appears to be a normal rectangular shape (Figure 6).

These examples of interpretable spaces highlight the importance of spaces appearances; architectural projects often privilege the formal aspect, ignoring the factors capable of making it intuitive and easy to understand, thus generating a gap that is very often bridged by the presence of signs that try to fulfill this task. This is a problem studied extensively in the context of complex buildings such as airports, where the role of space and distribution is fundamental for the functioning of the structure, and which finds one of the first examples at Schipol Airport in Amsterdam (1990), where Paul Mijksenaar (2008) has managed to define a multisensory language. He used shapes and colours but also sounds to facilitate orientation inside (Figure 7). Making the space more intuitive allows to a more independent navigation, a fundamental prerogative especially when referring to complex environments and to people with disabilities.

Including aspects that are not only visual amplifies the possibilities of perceiving spatial qualities, including a wider typology of people; in this regard, Peter Zumthor's multisensory attitude regarding the importance of sound is interesting: «Listen! Every space works like a great musical instrument that collects the sound, amplifies and transmits it» (Zumthor, 2007, p. 27). Sound contributes considerably to the perception of space in the use of materials and in the consideration of their interaction with people's movements. The importance of sound is therefore fundamental in defining the message transmitted by architecture, also for people with visual disabilities, which through sound can define the space that surrounds them (Empler, 1997).

The interesting example described by Marta Telatin (2019, p. 39), blind artist and writer, highlights how the loss of the sense of sight can change perception; the famous film by Walt Disney, Dumbo (1941), is an interesting example because, as we known, the protagonist is mute, and he communicate through facial expressions. Watching this movie without the aid of sight completely reverses its perception: Dumbo becomes a background actor, while Timothy Q. Mouse, his faithful companion, turns into the protagonist.

Based on the multisensory aspects mentioned, we thought interesting and effective within the RiseJam event (15/06/2020) to present how a cave (Figure 5a) can arouse different moods depending on the sound associated with the exploration activity. We showed two videos: the first featured a soundtrack that evoked an exciting exploratory opportunity and the second portrayed the same cave, but with a music from a horror movie capable of transmitting anxiety. A similar effect can be obtained thanks to the use of colour: anguish can be defined by shades of black and white (Figure 8a); on the contrary the use of bright colours can be more reassuring (Figure 9b).

These are considerations that allow us to highlight the importance of multisensory factors in the perceptive field and how they permit the transmission of more complex and useful information about space to people with or without disabilities.

3. Inclusion in architectural teaching

Considering the topics just described about the importance of the multisensoriality in architecture, we asked ourselves a question about our role: what can we do to develop inclusivity as architects and teachers?

Bill Hillier (1983) — one of the founders of the architectural movement of Space Syntax — stressed the importance of Architecture as a tool to shape the society which we live in. So, we think it is important to teach how to give to architecture a useful shape to transform it into an appropriate scenography for an inclusive society.

This was one of the goals for the course of «Representation Methodologies for the Architectural Project» in the master's degree of Architecture at University of Genoa. During the academic year 2019/20 we offered a starting off exercise to simulate temporary disabilities by the students themselves. We did something similar the year before thanks to Paula Trigueiros (University of Minho, Portugal) that visited our University during an Erasmus Programme. We stressed the importance to develop an empathic attitude and we make a 360° video during the starting off exercise proposed (Figure 9).

It is well known that spatial perception differs between individuals, because of various characteristics and experiences, or gender, but it seems that most of architects often go on ignoring this. But, as José Saramago said, «*The time always comes when we discover that we knew much more than we thought*» (*Ensaio sobre a Lucidez*, 2004) and we believe it would be better if this time arrives during the training period. This is the reason why we discussed in depth what we called the Theory of Multiperception during a cycle of lessons about "Multisensory and Inclusion".

We have proposed insights into the new social and legislative perspectives in the field of disability (Bernardini, 2016; Clarkson et al., 2003). One of the fundamental requests was to pay attention to the orientation within the space, interior or outdoor, but also to the knowledge of spatial characters through different perceptual channels. We have therefore provided useful information about the significant references of a place based on the wayfinding theory.

We have analysed the elements that favour the legibility of space, as suggested by Kevin Lynch (1960), who mentions paths as characteristic components, but also other elements such as edges, districts, and nodes, and, above all, the landmarks, that is the emerging entities that play the role of a local polar stars. We have illustrated the stages of the wayfinding process: 1) recognition of one's own position and of the destination to be reached; 2) choice of a path and its monitoring; 3) achievement of the destination (Golledge, Stimson, 1997).

We have also cited some research carried out in the context of the aforementioned Space Syntax, defined as a set of theories, methods and tools aimed at describing the phenomena of relationship between space and society (Hillier, 1996, ed. 2007). We have considered the links between architecture and neurological and cognitive domains (Dalton Conroy, *et al.*, 2015). We have also illustrated the characteristic of the dynamic use of architectural space, inspired by the taste for flânerie (Empler, Quici, Valenti, 2015), with particular attention to increasing accessibility and multisensory variety. A summary was carried out in a cycle of lectures published together with some students' outcomes (Càndito, 2020). The fundamental concept is that architects should not solely be concerned with the functional accessibility of architecture, but also with allowing all the people to enjoy its spatial characteristics (Càndito, Meloni, 2022).

Space is naturally recognizable both in visual and tactile ways; we all know that a stick can allow a blind person to identify a vertical surface, to obtain functional information: the edge of the sidewalk. Referring back to what was expressed in the previous paragraph, sound sensations help in the knowledge of further spatial qualities: for example, in an urban space, the sound of footsteps or traffic is reflected differently as a function of the extension of vertical surfaces (Figure 10). In this way, one can discover the formal characteristics of the space useful for building a cognitive image of it, not only with the sight.

We also considered the importance of the connection between music and architecture. Among the countless testimonials about this, we can remember Ezio Bosso, a well-known composer and orchestra conductor who died in 2019 at the age of 48. We often cite him for his clear vision of disability shown by his famous statement: «I am a man with an evident disability among many men with an unseen disability», but Bosso should also be recalled for his poetic view and his capacity to explain it to everyone. About the music and its influence on spatial perception, he stressed the impact generated by the position of the different instruments in the space and by their way of producing their power of sound. Sound, therefore, allows to recognize space and to imagine it, and this also happens not only to blind people, if only one pays careful attention! The cultural overturning of the concept of disability from a personal limit to a problem of relationship between person and environment (Clarkson *et al.*, 2003) was interpreted in our proposal as a transformation of the person with disabilities from subject in need of help to a useful human sensor for a refinement of perceptual potential.

With this in mind, we proposed to our students an exercise of architectural representation in an area of the historic centre. In particular, we asked the students to conceive a pavilion that had the purpose of introducing the passage from the city to the place that houses the Department of Architecture and Design, projected for people of all kinds, including individuals with difficulties, temporary or stable, in the motor, sensory or cognitive field.

Parametric modelling techniques have been adopted capable of permitting variations on configurations efficient of be adapted to different places, people, and functions. Some exercises focused on the aspects of the materials used for the flooring and their capacity to produce a variation of sound generated by the footsteps of people walking along them or by the crawling of the cane of blind people, who can deepen a formal knowledge but also a cognitive relationship of the space (Figure 11). Other spatial configurations have been characterised by spatial limits and their dynamically changing with variations that are perceptible visually, but also in a tactile way (Figure 12). The well-known supports of tactile maps and written texts, accessible both for the blind (in braille and in black) and for the deaf, constitute a set of a communicative complex aimed at integrating the perception needs of as many people as possible. The illustration of these projects was always performed in accessible terms, with the aid not only of images, but also of videos with audio description and subtitles, and scale physical models aimed at illustrating the salient details of the spatial suggestion.

The final presentation of the projects took place in the presence of a commission of teachers with a blind person, who recognized the effectiveness of the effort made in the task to consider not only the physical characteristics of accessibility, but also the perceptive ones, thanks to multisensory contents.

4. Conclusion

Even if sight is the fundamental means for spatial knowledge, other perceptions also concur to providing information. In this contribution we analysed perception in its different forms and characteristics, initially focusing our attention on the main role of sight, describing its relevant characteristics. To understanding of the mechanisms that are activated during perceptual processes reveals the importance of bodily involvement in interaction with the environment; this feature has allowed us to analyse the multisensory architectural theory, which permits us to expand the possibilities of receiving the spatial information that characterizes an environment.

We have pursued a perspective for which disability is considered not as a disadvantage, but as a peculiarity to identify some modalities that allow everyone to be able to enjoy spaces, not only at a functional level; in this way we wanted to demonstrate that an architect should be able to design integrating these principles with their own expressiveness. Another consequence is that a blind person, for example, becomes the guide for a modality in which the mental image of space is also built through the echo of footsteps, which reveals the presence and the characteristics of walls and ceilings, or through the tactile variation of walls or flooring materials, which denote the passage between different environments. In this perspective, the consideration of multisensory factors represents an enrichment at many levels: for functional purposes, but also for the enjoyment of an architectural space in a global sense.

Acknowledgements

The authors actively participated in the RiseWise project also through secondment periods. In particular, Cristina Càndito had contacts with the Spanish, Portuguese and Swedish units and Alessandro Meloni participated in the preparation of the final RiseJam event collaborating with the Swedish unit carrying out activities related to the accessible transformation of video content through the introduction of accessible multimedia elements. This study has been partially conducted also with funding from the «Inclusive architectural representation» project (University Research Projects 2019, University of Genoa), which involves both authors. The contribute is the result of the collaboration between the two authors, but the paragraph *Perception and multisensoriality* was written by Alessandro Meloni, while *Inclusion in architectural teaching* is written by Cristina Càndito.

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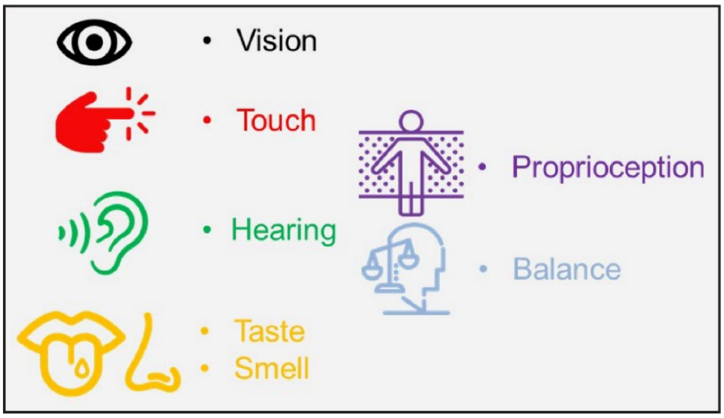

Figure 1. The seven senses: Vision (black), Touch (red), Hearing (green), Taste and smell (yellow), Proprioception (violet), Balance (light blue).

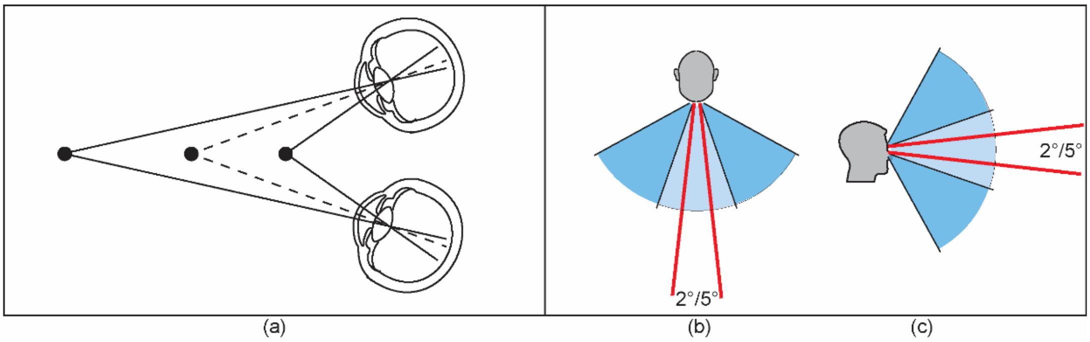

Figure 2. The physiology of vision: a) The main characteristics of binocular vision; b-c) the field of vision (light blue), peripherical view (dark blue), two red lines identify the amplitude of 2°-5°.

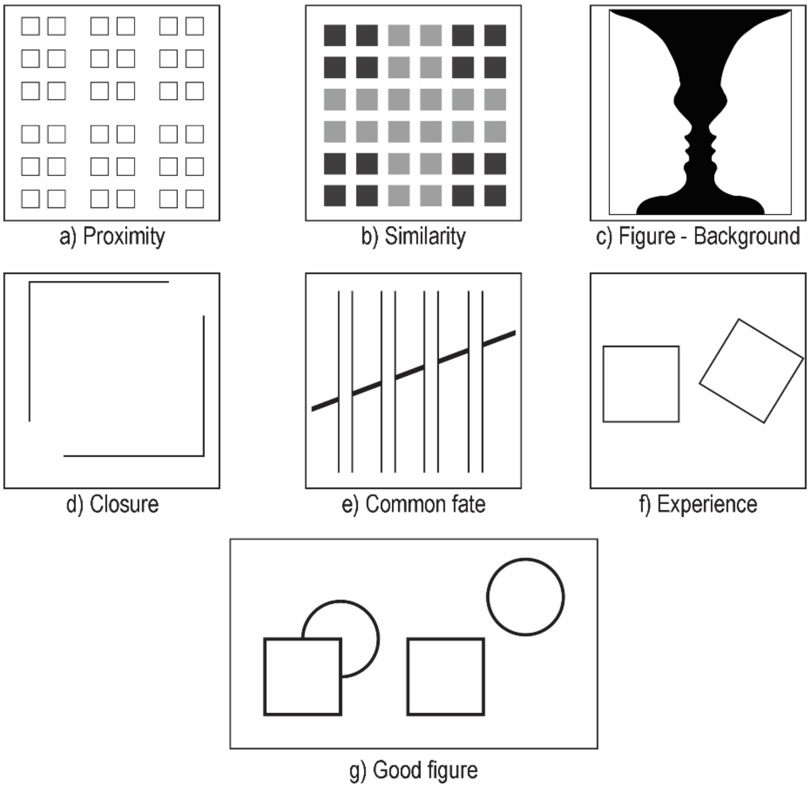

Figure 3. Principles of Gestalt theory.

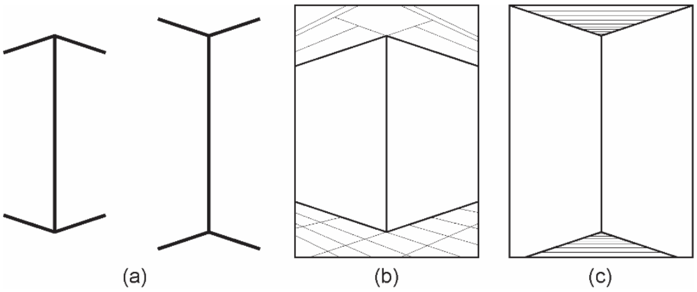

Figure 4. Illusion and ambiguity: a) Müller-Lyer illusion; b-c) Relation with perspective and architecture.

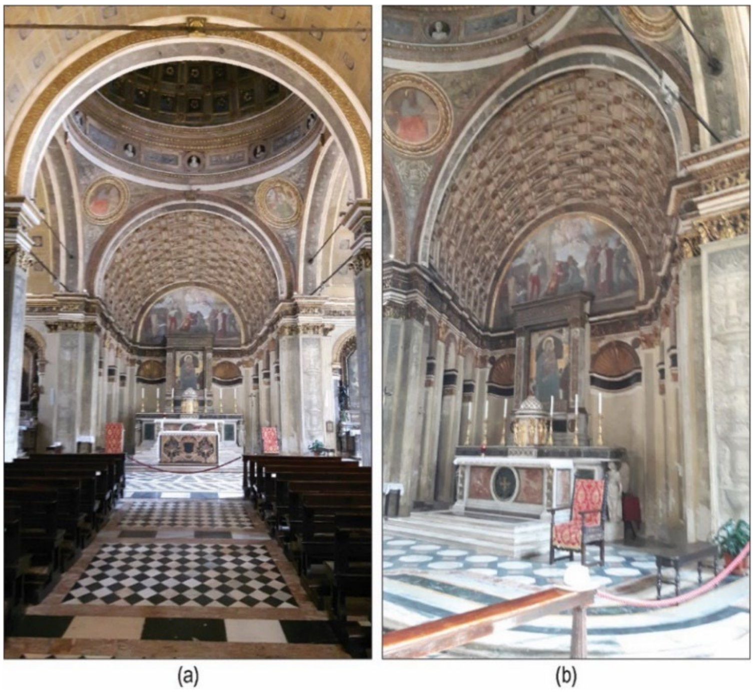

Figure 5. The choir of Santa Maria presso San Satiro (Milan, 1478-1482, Donato Bramante): a) Central view; b) Accidental view (Photo by Cristina Càndito).

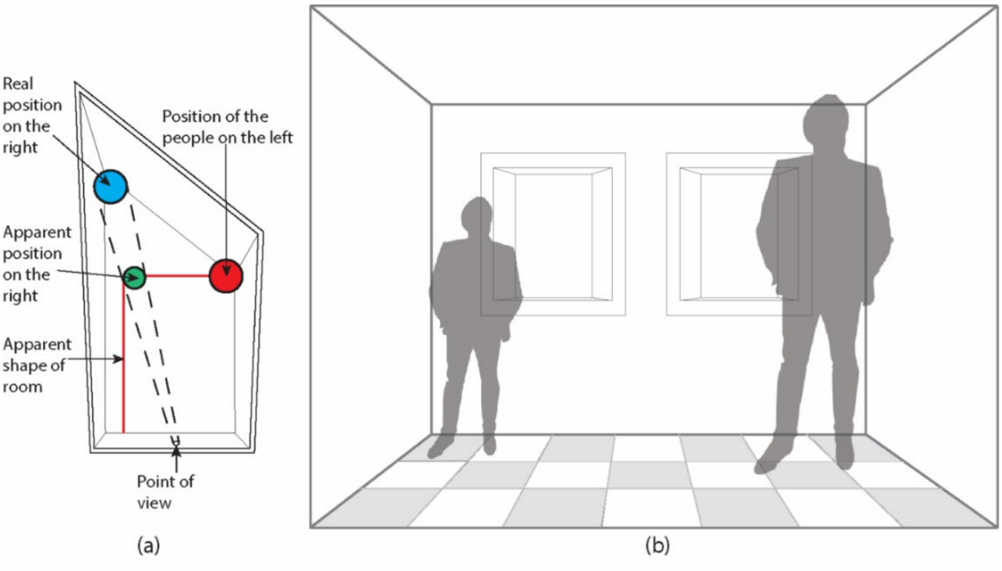

Figure 6. Ames room (1946, Adalbert Ames): the space appears as a normal parallelepiped and the person on the right seems to be much taller, because of the perspective illusion.

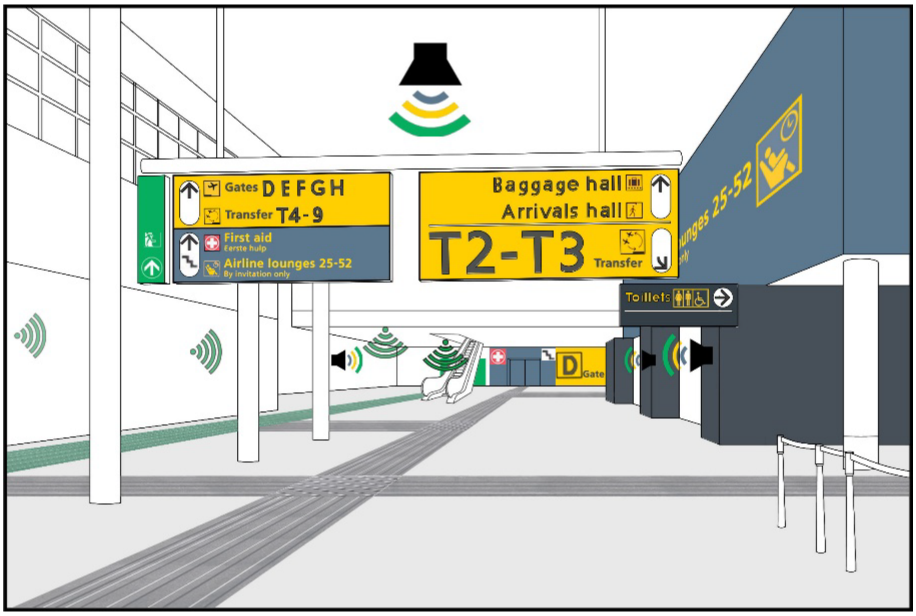

Figure 7. Schipol Airport in Amsterdam (1990), Paul Miijksenaar: the importance of visual elements to allow to a more independent navigation and the integration with sound.

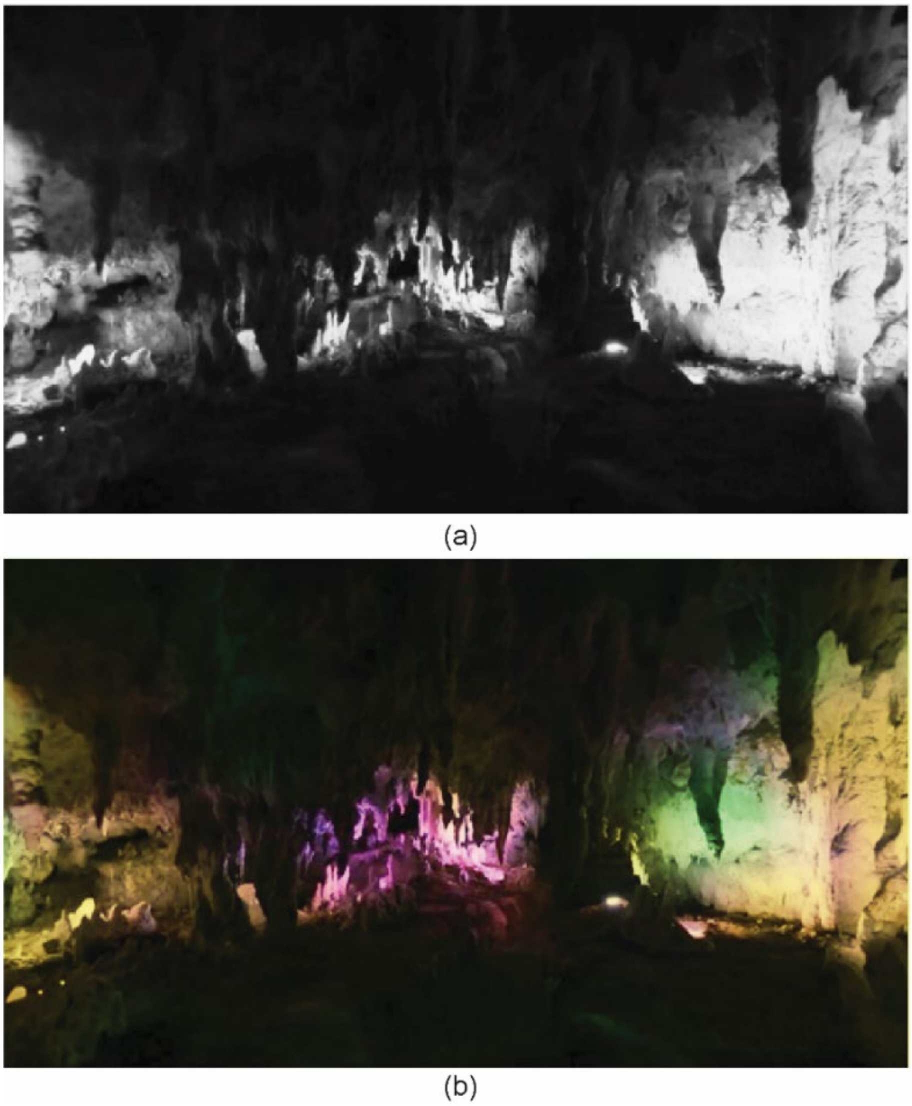

Figure 8. The coloured cave (b) seems to be a safe and nice place.

Figure 9. Portrait in a frame of a 360° video of the disability’s simulation experience in the course of «Representation Methodologies for the Architectural Project» (Master’s degree in Architecture, University of Genoa, 2019/20).

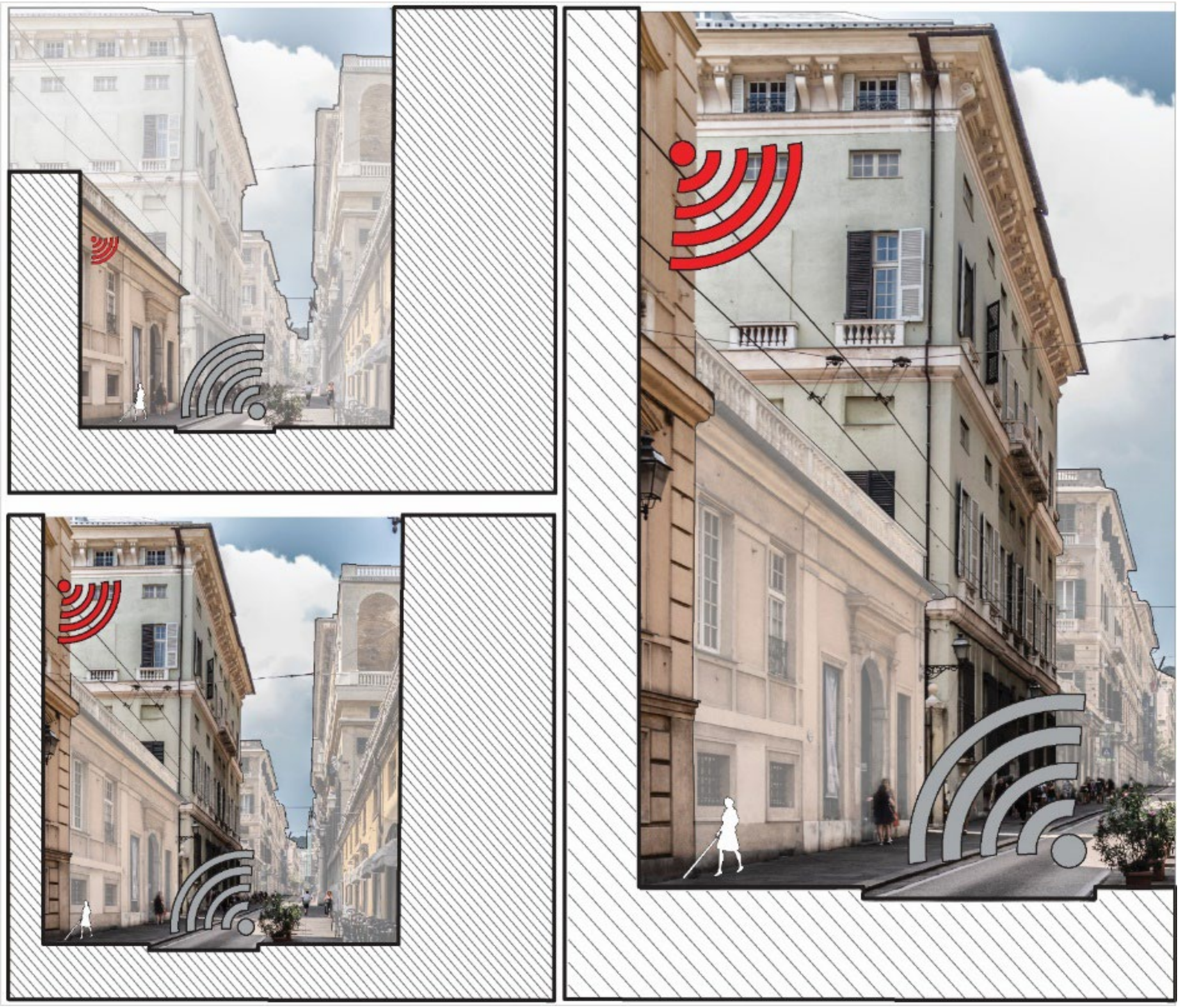

Figure 10. Sounds and tactile clues for the knowledge of space.

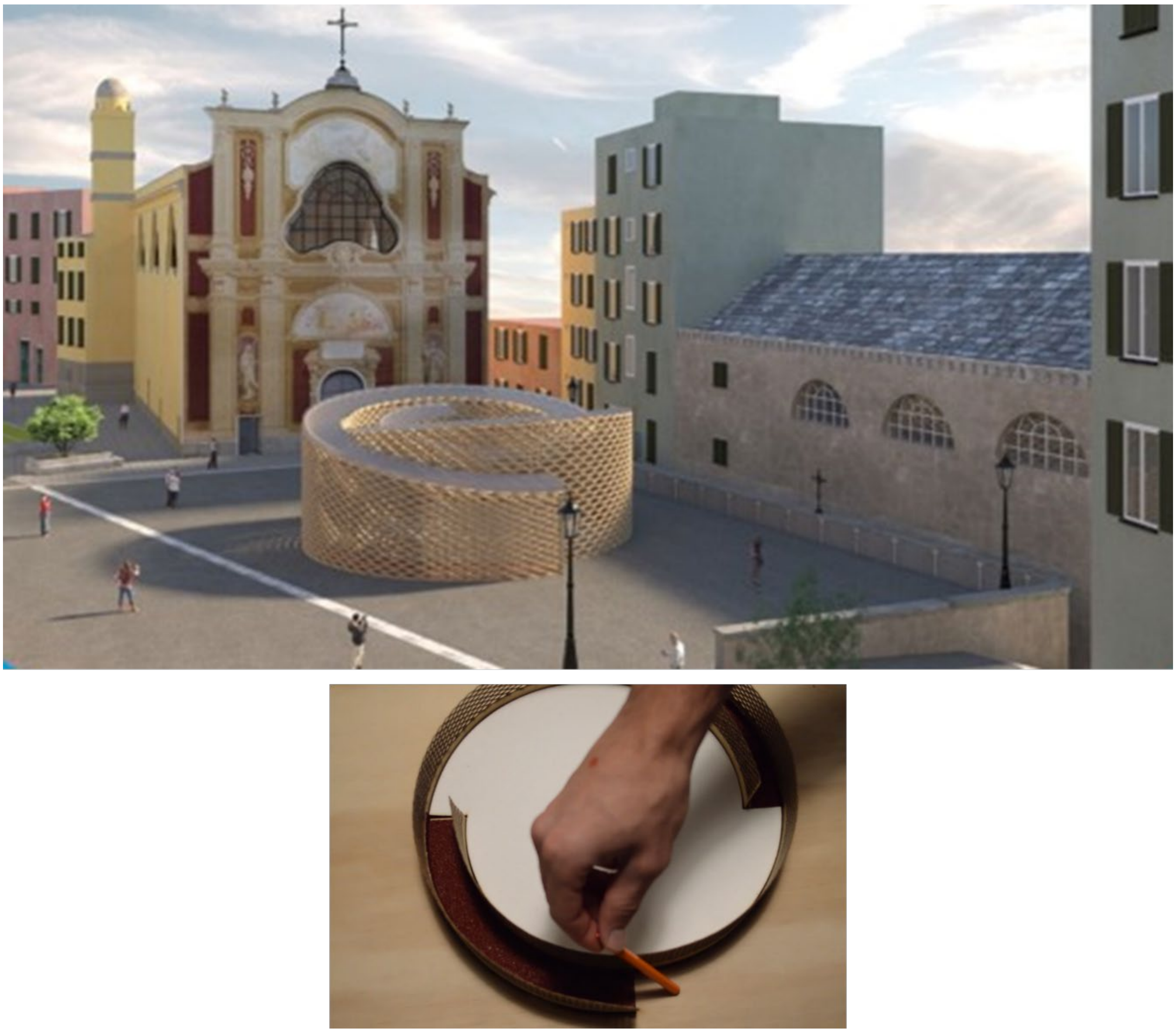

Figure 11. The «Sounding spiral» with its floors and walls characterized by different textures. «Representation Methodologies for the Architectural Project» (Master's degree in Architecture, University of Genoa).

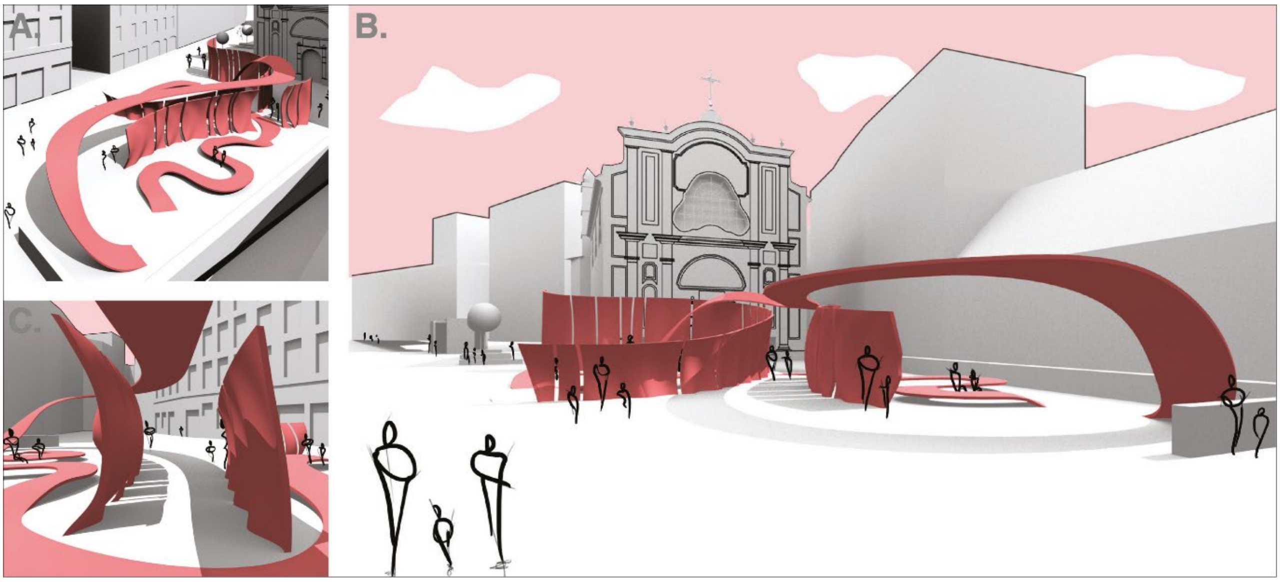

Figure 12. The «Fluid pavillion» with moveable limits. «Representation Methodologies for the Architectural Project» (Master's degree in Architecture, University of Genoa).

Welcome to museum.
Approaches for inclusive museums

Sabrina Armenio[1]

Keywords: museology, inclusion, cultural heritage, accessibility

1. Introduction

«The matter of museum accessibility (still)remains, nowadays, a debated topic. It is a structured issue that should take in to account the different aspect of usability and heterogeneity of the audience, considering the public's changing needs and expectation» (Schichter, 2020).

As Lidia Schichter (2020) states, changes in society have led to an opening and a change on the part of the museum, which has allowed it to develop a new process of communication towards its public. Universal accessibility, in fact, from a physical, sensorial, and cultural point of view, is today a very important issue. An accessible museum, therefore, inclusive, is a place open to its community, in which it seeks to listen and involve its public. Now a day, it is possible to find that there is not just one type of visitor but different types, and each lives the 'museum experience' in a personal and different way (Clarelli, 2018). For this purpose, museums, cultural installations, and archaeological areas are called upon to eliminate their barriers. Generally, the concept of accessibility is indicated with «the implementation of projects, initiatives and the construction of infrastructures with the aim of making the museum truly accessible to everybody»[2]. This concept, from a theoretical and practical point of view, is not rigid, but it is extremely flexible, because it must embrace all the different types of disabilities. The criteria to be applied to evaluate the accessibility of a public place, a building or a service cannot be the same for everybody, because everyone's needs are very different. Therefore, the museum must be able to interact correctly with the public, designing museum strategies that adapt to certain needs requested by the visitor. Apart from physical access to the museum and the existence of dedicated sanitation facilities, there are other problems related to the museum visit. For example, in the halls, the space between the display cases is often not sufficient for the passage of wheelchairs and strollers. Moreover, the height of the displayed specimens does not permit easy observation by people with a low field of view, and the same problem occurs for the explanatory supports (captions, panels, etc.). Finally, the height at which multimedia devices are stationed is often prohibitive or difficult for wheelchair users and so on. However,

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[1] University of Genoa.

[2] Official definition of IMS: Integrated Museum solution, https://soluzionimuseali.com/il-museo-accessibile/.

the accessibility of a museum is not measured only by the tools it makes available to people with disabilities to break down physical, architectural, and sensorial barriers, but also by the sensitivity and competence of the staff who work within the structure. Some studies show that the services offered by the museum are also important in the visiting experience. According to the study carried out by the Spanish Ministry of Culture, there is an important relationship between the time dedicated to the exhibition and the quality of the visit. Being able to choose multiple activities, plan the visit, be able to rest in a relaxing place (cafeteria, relaxation area, etc.) converts the museum experience into a more complete experience that facilitates and proportions its educational function[3].

In this research I tried to deepen and understand the definition of accessibility museography, analyzing all the areas of change in museums (accessibility, interpretation and communication, social participation) in the perspective of stimulate the reality of the museum and promoting advantageous synergies between the cultural and society sectors.

Thanks to the Risewise project, I had the opportunity to get in touch with various European organizations working in the disability field and dealing with the issue of accessibility from different perspectives.

2. Secondment at AFADIS UCM in Madrid

My project is centered on the theme «Museum and Accessibility», to answer the problem of accessibility inside the museum. With my proposal I would like to make an analysis of the condition of museums in Madrid. The Spanish society is increasingly aware that the inclusion of people with disabilities, in the various spheres of social life, is a fundamental requirement for the full respect of human rights. The Spanish Government has established a fine which says: «this implies the hypothesis that the means must be available so that all citizens, regardless of the obstacles and limiting conditions affecting them, see their needs covered in conditions of equality»[4]. One of the most decisive actions is to promote universal accessibility, including the removal of barriers and design for all[5]. In compliance with the principles of accessibility and universal design established in the Royal Decree[6], the Spanish Ministry of Culture has as its main objective that of making the Spanish cultural heritage accessible to all, starting from museums,

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[3] Public study in museum of the Ministry of Culture of Spain: «laboratorio permante de Publico de Museos» https://es.calameo.com/read/0000753353c6f6cc139ef.

[4] Law 13/1982, of April 7, on the Social Integration of the Handicapped.

[5] Ministry of Culture and social policy and Equality of Spain.

[6] Decree 1494/2007 of 12 November. Law approving the Regulation on the basic conditions for the access of people with disabilities to technologies, products, and services. Ministry of Culture and social policy and Equality of Spain.

archaeological areas, and cultural installations. Working in collaboration with various associations the ministry has funded many projects with the aim of helping and integrating people with disabilities in the social and professional world. One of these Spanish realities, that collaborates with the Risewise project, is called AFADIS-UCM, an association of family members and friends of people with disabilities. This association is based in the Faculty of Medicine of the Complutense University of Madrid, in collaboration with the OIPD[7], offering help and guidance for the future disabled student enrolled in university. During my secondment, which lasted for one year (2018-2019), I collaborated with this association. In addition to developing my project, I collaborated in the activities carried out by the association: it aims to promote and implement all activities aimed at improving the quality of life of people with disabilities, aiming at full integration into the social and working life of the latter.

3. Methodology strategies

The methodology used for the realization of this study has seen different parts of development. A first part saw a theoretical study of the topic, through the study of the state of the art and projects (implemented and in progress) concerning the topic. Thanks to the help of AFADIS, which put me in contact with various subjects with whom he collaborates, it was possible to create meetings and focus groups. We have tried to involve as many people as possible- people who collaborate with AFADIS and UCM students — to understand the real needs and problems they may encounter during their experience in museums (Figure 1). Based on the choices and artistic tastes of the interviewees, it was decided to take into consideration museums of different themes and types in Madrid. The main difficulty encountered in this work was obtaining an immediate response from the selected museums. With the assistance of AFADIS we contacted by e-mail 20 museums in Madrid, but only 4 of them showed interest: Museo Geominero de Madrid, Casa-Museo Sorolla, Museo de Antropologia, Museo del Traje de Madrid. The second part of the project was based on carrying out interviews with museum directors, or educators, asking questions about how they deal with the problem within their facility (museum information, disabilities, architectural barriers, communication, cultural activities, gender difference in work and more). After having received an initial official response, it was decided to carry out a direct inspection of the building. Based on the studies carried out, the spaces must be reformed to ensure total and easy mobility, considering the needs and safety of people. Considering: Accessibility of the building, information and communication of the plants, cultural activities for people with disabilities. Based on these concepts, our work has tried to verify the real difficulty that people with different disabilities can encounter in museums. Through AFADIS, have been

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[7] Office for the inclusion of people with diversity of UCM.

organized guided tours, with small groups of people with different disabilities, inside the selected museums. The objective was to see how the 'museum experience' is perceived and their reaction.

Figure 1. Focus group and meeting with participants and collaborators of the Risewise's Project.

4. Analysis of the museum

In this report, will be presented my comments on the condition of the museums that have been analysed. Based on the answers obtained from the directors and from the personal inspection, it has been possible to find that the situation is different in every museum. Some these have set up their spaces with structures suitable for different types of disabilities, especially the most recent buildings, while others do not.

As for the 'adapted' structures, it is possible to consider two museums: the Museo del Traje and the Museum of Anthropology.

The Museo del Traje (costume museum), dating back to 2004, it was created to bring together all the collections concerning Spanish fabrics, costumes, and fashion over the time. The building was built in 1973 in Moncloa and initially used as an ethnographic museum, only to be renamed years later (1975) as the Museo Español de Arte Contemporaneo, exclusively private and not open to the public. Only in 2004, the museum was modified, and was created a structure that enclosed the ethnographic collections and the history of Spanish costume. Device from the beginning as a museum, the building is perfectly designed for this function, with its multipurpose rooms, the ease of internal circulation and the flexibility of its design. From the point of view of physical accessibility, the building meets the essential requirements: large entrance with access ramp, double reception desk; the permanent exhibition of the Museum and most of its spaces for public use are on the same floor, without any type of difference in height and suitably large rooms.

In addition, the museum features services for visitors with different disabilities. For example, the creation of the Multisensory Didactic Area (Figure 2 image below right). This space has been designed following the principles of universal design and with the necessary support to ensure accessibility and autonomous visit[8]. The lighting in the exhibition halls is very low, which makes the perception of the pieces difficult, especially for people with visual impairment. The new space ensures that even people with visual impairments can enjoy the museum. The tour begins at the point where the Permanent Exhibition speech ends and runs parallel to it. It begins with a succession of replicas of the most representative costumes that can be found in the shop windows followed by a series of busts that take as models the same pieces of the replicas of the costumes and that offer a presentation of the evolution of clothing and of the silhouette from the XIX century.

Moreover, the museum allows the active participation of people with visual and deaf impairments in the activities of the museum. Promoting specific guided tours also thanks to the help and the presence of various associations that deal with the theme of disability (ORANGE, ONCE etc…). Nevertheless, the museum has devices that facilitate access to information (simplified audio guides) and that allow people with hearing disabilities to participate in the activities of the museum, such as magnetic rings and sound amplifiers[9]. The Museum also offers people with visual impairments a brochure with general information in Braille and macro fonts, which can be requested at the box office[10].

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[8] Project set up by Luciana Llorente Llorente(2014-2015) responsible for the collection of textiles and flat fabrics; http://www.ibermuseos.org/pt/recursos/boas-praticas/area-didactica-multisensorial-del-museo-del-traje/

[9] Thanks to the ORANGE foundation and in collaboration with the FEAM (Spanish Federation of Friends of Museums) and the Ministry of Education, Culture and Sport, they have helped to create devices for the Traje museum that help people with hearing disabilities to participate in the activities of the museum: magnetic rings at the museum, customer service desk, library and cafeteria, meeting room and on the catwalk; individual magnetic rings intended for users of hearing aids or cochlear implants; and individual audio amplifiers connected to portable wireless equipment for people with hearing difficulties; both devices can also be connected to audio guides.

[10] Project promoted by ONCE.

Figure 2. Museo del Traje.

The Museo Nacional de Antropologia, was the first museum dedicated to this science created in Spain. Inaugurated in 1875 by King Alfonso XII as an Anatomical Museum, years later, at the behest of the Higher Council for Scientific Research, it became a museum of cultural anthropology. The original collection over time has been expanded with objects acquired during the various anthropological expeditions organized by Spanish scientific institutions in the last years of the nineteenth century and thanks to donations and acquisitions already made by the Directorate General for Fine Arts, Cultural Heritage, Archives and Libraries, on which the institution depends since the 1960s. The museum structure is easy to access, during the visit it was possible to see that the museum guarantees adequate assistance for people with disabilities. The museum has a dedicated entrance for people with physical disabilities and reduced mobility on the side of the museum. The exhibition is divided into several levels, the exhibition space is very large and allows adequate walking (even in a wheelchair) and guarantees access to the upper floors thanks to a very large lift. The museum has an adequate audio guide and the possibility of taking a guided tour. Furthermore, for people with hearing disabilities, magnetic 'holes' are made available that allow people with hearing disabilities who use technical aids to obtain a clearer acoustic signal, without interference from external noises[11]. Instead, a tactile and Braille path has been built for blind people to facilitate their visit. However, the lighting of the display cases is too high, and the descriptions of the pieces are written too small, not allowing adequate reading.

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[11] Project promoted by the ORANGE and Feam association (Spanish federation of friends of museums).

The museum is part of the state circuit of the «*Plan de museos + sociales*» promoted by the secretariat of the Spanish State of Culture, which has as its fundamental principle the creation of a museum that is 100% accessible and that adapts to the needs of all citizens and specific to those groups who have greater difficulty during the visit and who may be at risk of social exclusion. The museum, in addition to making the building accessible, create temporary exhibitions and open activities that are inclusive and for all.

Figure 3. Museo de Antropologia.

The situation of the other two museums is different: the Geominero Museum and the Sorolla House-Museum. Both are important historic buildings, the former headquarters of the Spanish Mineral and Geological Institute in 1925 and the latter was a private home of the painter Sorolla from 1900 to 1925, and as a historical asset they are under the jurisdiction of the cultural superintendency and the city hall of Madrid. Precisely for this peculiarity, there are constraints that limit changes to buildings on a structural level.

As regards the Geominero Museum, various difficulties were encountered during the visit. First, the structure does not have an entrance adapted to people with physical disabilities; the only entrance has a large historic marble staircase. In recent years, thanks to municipal concessions, it has been possible to add an elevator that allows the disabled visitor to reach the first floor of the museum, where the main collection is exhibited.

The museography consists of a permanent collection on the first floor which explains the minerals and geology of the Iberian Peninsula and the territory of Madrid, while the remaining floors deal with various geological issues of the world.

A first obstacle encountered during the visit was the limited circulation inside the museum. The permanent collection, on the first floor, is characterized by a long row of large chest of drawers; due to their width, small circulation corridors are created in which, at times, a wheelchair cannot pass (Figure 4). Continuing the visit, it was found that the visitor with mobility difficulties (disabled or not) cannot access the collections on the upper floors because they can only be accessed by spiral staircases. The impossibility of modifying the building does not allow the installation of elevators. Another problem was found in the unevenness of the floor (also historical) which does not allow the addition of a tactile path for the blind people.

Aware of the limitations of their structure, the didactic staff (under the guidance of the director Dra. Ana Rodrigo Sanz) has developed an alternative accessibility plan to their collections. Thanks to the collaboration with ONCE, were created copies of the original pieces of materials and fossils, placed outside the display cases, with signs in Braille and macro characters for blind or visually impaired people. In addition, one is provided explanatory brochure published in Braille of the Museum, its collections and the recommended route to access the contents of the exhibition.

Figure 4. Museo Geominero.

The Sorolla House-Museum, home of the homonymous painter until his death, has several architectural barriers. The visit to this property brought up several problems: the building is accessed from a single main entrance where there are two steps. There are no fixed ramps for wheelchairs as the building cannot be changed, but a mobile ramp can be added upon request. Once inside, the visitors enter in the beautiful garden, even here the path is hindered by the presence of small steps and needs to ask for the addition of mobile ramps. The path is narrow due to the presence of large flowerbed and fountains, which does not facilitate the passage of a person in a wheelchair (Figure 5). The exhibition itinerary unfolds in several levels of the building: on the ground floor it is possible to visit the kitchens, while on the first floor the exhibition itself is divided, since there are the private rooms of the painter Sorolla and the places where the rest of the family. However, accessibility to the first floor is rather limited; people with physically disabilities and reduced mobility cannot access it, because it is not possible to install a lift or a load lift. In the rooms the floor is very irregular and the museum layout of the collection, at times, makes the path not very accessible. Furthermore, the structure does not have itineraries created especially for people with visual and hearing disabilities, so a visit would not be possible without adequate assistance.

Figure 5. Casa Museo Sorolla.

5. Conclusion

The cultural heritage, belonging to the entire community, is accessible in a very different way from subject to subject. For many people, in fact, participation in cultural life is extremely reduced, due to the impossibility of entering in the places of culture, identified by the same subjects as inaccessible places. Inclusive museums should allow full accessibility to the environments and pieces of art they hold. The importance of creating inclusive museums lies not only in the fact that they are usable by people with different deficits, both in terms of structure and content, but that they also allow able-bodied visitors a different approach to works of art.

Through a significant sample examination in terms of accessibility and inclusion — considering the different types of disabilities (sensory, physical, cognitive, but also cultural) — I tried to identify different problems and consequent approaches used within the museums of Madrid.

Despite the presence of some rules and laws on the subject, not all museums are equipped and struggle to accommodate people with disabilities.

In fact, in this work I could see that the situation of each museum is very different, some already advanced in the management of the theme, while others still have many problems to solve. In some cases, the directors of the museums considered are themselves aware of the limitations of their structures (such as the inaccessibility of some parts of the museum and the lack of specific signage). Although, limited by the impossibility of being able to apply structural changes, they have tried to manage and confront with another form of accessibility, which is also important: cognitive and cultural accessibility. In fact, some of the museum analysed showed the use of a museography that seeks to improve the understanding and meaning the pieces inside the museum. Some structures have specialized support staff able to help and make the works more understandable, also thanks to the collaboration of volunteers from various specialized associations.

The Geominero Museum, for example, not being able to remedy the problems related to physical accessibility, has focused on a museography aimed at trying to 'solve' sensory and cognitive accessibility: through the creation of specific audio guides with a very simple and explanatory language, he has created a tactile path for people with visual disabilities, in which not only the object is described in braille but it is possible to touch it in all its parts; in addition, it organizes various activities aimed at making the collection known and involving people with intellectual disabilities.

Although few museums have responded and decided to address the issue directly, I think that the work can represent a starting point for deepen this theme and study the evolution of the role of museums as publicè and social union space. There can be many solutions to the problem of accessibility in museums, but essentially, I think it is important and necessary to create adapted and specific routes within museums that can help not only people with disabilities but all the public visiting the museum. In addition, the fundamental element for the success of the visit is the presence of qualified and trained staff to guide the visitor (disabled or not) who knows how to interact in a simple and adequate way.

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«We live in a plural world»: A framework for rapid interdisciplinary and community engagement

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Keywords: interdisciplinary research, inclusive design, participatory design, action research, community involvement

1. Introduction

RiseWise was a large European project that focused on understanding the experiences of women with disabilities with a view to improving their quality of life and their participation in society. It promoted staff exchange and collaborations among its partner universities and associations across six countries, who collectively comprised a range of expertise relevant to its goal of empowering women with disabilities. These staff exchanges involved individuals being seconded to partner institutions abroad, with cross-pollination between academic and non-academic environments; in other words, academic staff were seconded to Non-Governmental Organizations (NGO) and vice-versa. Secondments were typically self-directed according to individual interests, with some support and guidance provided by the host institution.

The opportunity for the work described in this chapter originated from four RiseWise secondments in Guimarães, Portugal, which overlapped with each other for just under two weeks. These four RiseWise secondees were from three European countries and represented different fields of expertise and levels of experience. Although they were seconded to Fraterna, a local non-profit community association, they were also hosted by researchers from the University of Minho, some of whom were involved in RiseWise. This group make up the authors of this chapter and will henceforth be referred to either collectively as RiseWisers or by their initials, as appropriate. The RiseWisers ranged from postgraduate students to senior members of staff, from various disciplinary backgrounds. This posed an initial challenge of identifying a shared research problem, where this diversity could converge and truly be an asset to collaboration. For this, we needed a real-world problem.

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Through conversations with Fraterna’s staff about the local community and their needs, it was agreed that the work would focus on understanding the experiences of older adults with Information and Communication Technologies (ICT) and how these can contribute to improving their lives in a meaningful way. This is a prolific and multifaceted research topic (Knowles & Hanson, 2018), which has seen a shift towards deeper involvement of older people in efforts to understand their genuine needs and design solutions that meet them (Fondevila Gascón *et al.*, 2015; Greenhalgh *et al.*, 2013; Pradhan *et al.*, 2020; Rogers *et al.*, 2014). Underpinning these participatory approaches is a call to recognize the wisdom and the diversity of older adults beyond any stereotypes concerning an age-related decline in abilities (Durick *et al.*, 2013; Lindley *et al.*, 2008; Neves *et al.*, 2018; Vines *et al.*, 2015). Huppert notes that, while ageing can precipitate a decline in abilities, disabilities can become more evident when a person is faced with new, demanding or complex situations (2003). However, the same author argues that the majority of older adults today comprise a large group of people with slight disabilities who are keen to maintain their independence and contribute to the community. Older adults are also living longer and therefore often live with and manage long-term health conditions as part of their daily lives, which adds to the homogeneity of this sector of the population (empirica *et al.*, 2010).

The aim of this chapter is to broadly describe and critically reflect upon the work that we carried out in Guimarães and, in doing so, provide a framework for rapid interdisciplinary and community engagement. The remainder of the chapter is divided into five interconnected sections. We begin with a brief consideration of interdisciplinary collaborations and different approaches to community engagement in research, drawing mostly on design and social sciences literature. The next section details the participatory engagement framework and circumstances of work undertaken, followed by a section on the evaluation of this work by the RiseWisers. In the final two sections, we reflect on the process as a whole and conclude by articulating a future research agenda that builds upon the work described here. In this, we contribute towards breaking down perceived barriers that hinder the adoption of interdisciplinary and participatory approaches in research.

2. Ways of working

2.1 Across disciplines

Societal challenges are by nature compelling and complex. While much academic research purports to work towards this end goal, understanding how to achieve effective and sustainable societal impact remains an ongoing ambition for many. Involving various disciplines in research, as well as external collaboration with decision-makers, has long been identified as key in this pursuit (Wowk *et al.*, 2017). Addressing complex problems in all their relevant dimensions requires a variety of competencies and toolsets. Thus, combining different perspectives, based on different disciplines, allows partial understandings to be counteracted and knowledge synergies to be established (Lowe & Phillipson, 2009). In fact, at the intersection of seemingly unrelated knowledge domains and the unexplored connections between them lies the potential for innovation, ranging from new explanations and solutions to old problems, methodological innovations, to new questions and ideas (Mazzocchi, 2019). Moreover, collaboration across disciplines can also personally benefit those involved through motivational factors, such as social relations, personal development, and intellectual curiosity, as well as through its inherent creative potential (Siedlok & Hibbert, 2014).

Collaboration across disciplines can take several forms, the most familiar of which are multidisciplinarity, interdisciplinarity, and transdisciplinarity. A principal distinction between these forms of collaboration is that in multidisciplinary research disciplinary boundaries are still maintained; in interdisciplinary research there is some integration across these boundaries so that parts of the original disciplines are combined into a shared approach; and transdisciplinary research takes it a step further so that disciplinary boundaries become irrelevant or are radically reshaped (Mazzocchi, 2019; Siedlok & Hibbert, 2014). Despite these varying levels of involvement across disciplines, persistent barriers to effective collaboration remain. On the one hand, these are attributed to institutional factors such as a lack of appropriate structures and incentives, the existence of deterrents such as performance metrics that fail to contemplate societal impact (Wowk *et al.*, 2017), and ill-prepared systems of research funding and rewards more generally (Mazzocchi, 2019). On the other hand, difficulties can arise at the interpersonal level, including disciplinary differences in language and terminology (Burrows *et al.*, 2016), research strategies and methodologies, and overall work practices (Mazzocchi, 2019). With these relational challenges in mind, a comprehensive review of the literature identified seven essential attributes of successful interdisciplinary research teams: team purpose, goals, leadership, communication, cohesion, mutual respect, and reflection (Lakhani *et al.*, 2012). Some of these attributes overlap with existing models for interdisciplinary collaboration (e.g. (Bronstein, 2003), but we found the literature lacking in terms of process-driven frameworks for this purpose.

2.2. With communities

«Nothing for us without us» is a frequently used affirmation in Inclusive Design, attributed to no person in particular but the maxim of many (most notably among disability rights activists and advocates). Although Inclusive Design is often understood as designing *for* diversity, in reality it aims to design *with* diverse communities and to encourage users themselves to steer the design process (Langdon *et al.*, 2014). This is in line with recommendations to actively include users through dialogue and knowledge co-production to address complex societal challenges (Wowk *et al.*, 2017), while also striving for diverse representation and inclusion. Inclusive Design therefore takes a user-centred design (also known as human-centred design and person-centred design) approach, which means actively involving users in the design process alongside multidisciplinary teams with appropriate expertise and technical skills (Maguire, 2001). The benefits of user-centred design are widely acknowledged, ranging from more accessible and relevant design outputs to more ethical and transparent relationships between developers and consumers. Nevertheless, certain misconceptions about user-centred approaches, namely that it can be costly and time-consuming, perpetuate barriers to its widespread adoption (Chamberlain, 2010).

In reality, user-centred design can go from relatively swift interactions with users, such as usability testing, to more prolonged and participatory approaches. Participatory Design envisions users participating in all phases of the design process and argues for power to be shared amongst all stakeholders involved in the design process (Bratteteig & Wagner, 2014). This positions Participatory Design towards the top end of Arnstein's (1969) ladder of citizen participation, where citizens are empowered through partnership, delegation of power, and ultimately ownership and control. The impact of Participatory Design can in turn be augmented by Action Research, which seeks transformative change by focusing on local solutions to local problems (Hayes, 2011; MacDonald, 2012; Moreira da Silva, 2019). On the matter of democratic community engagement, Corbett and Le Dantec (2018) suggest that *setting the table* is an important practice whereby stakeholders are assembled and power is distributed amongst them in decision-making processes (p. 6). Setting the table has also been used elsewhere as a metaphor for inclusive design (Nicolai, 2019). There are various tried and tested techniques for achieving this type of open, democratic, and inclusive forum, although some of these can be highly specialized and require time. The World Café is an engagement process pioneered by Brown and Isaacs in 1995 (2005), whereby the café metaphor is leveraged to create a space where anybody is able to talk about things that matter to them. Of particular relevance to our work in [*city*] is that the World Café has been effectively used across different cultures, age groups, for various purposes, and in diverse types of communities and organizations, and is not particularly resource-intensive.

3. Setting the table

3.1. Context

In late September and early October 2019, Fraterna hosted four people on RiseWise secondments from three European countries Fraterna is a Public Interest Cooperative with Limited Liability, equivalent to a Private Social Solidarity Institution, based in Guimarães, Portugal. It was established in 1999 through the initiative of Guimarães City Council and a group of private entities, with the aim of contributing to the municipality's offer in terms of promoting social development. Fraterna's sphere of intervention includes various actions and services, with a particular focus on children, young people, and seniors.

One of Fraterna's initiatives is the Arca Social, which comprises recreational and training activities aimed at older adults and people who are unemployed. This project aims to fill an occupational void, by promoting personal development and social interaction among its community participants. In partnership with the Associação de Moradores Nossa Senhora da Conceiçao (AMNSC), the Arca Social hosts training sessions in the use of technological devices, such as computers, smartphones and tablets, and relevant software such as Microsoft Office. These sessions are run by an external facilitator in a room provided by the AMNSC, which has some computers available. There are between 15 and 20 regular participants from the community.

This infrastructure and the pre-existing activities provided an opportune context for interdisciplinary and participatory work within the scope of RiseWise. On the one hand, the conditions for organizing and carrying out any such activities were readily available; on the other hand, this established real-world setting would allow for sustained collaboration with the local community, including the co-creation of design solutions (e.g. to improve the accessibility of apps, accessories, and other forms of technology), the involvement of local students in tech support and training initiatives, and other appropriate measures to foster the digital inclusion of such communities. Staff from Fraterna and the University of Minho therefore decided to organize activities that aligned the interests of those people involved in the Arca Social training sessions with the broader objectives of the RiseWise project. The agreed focus was on taking an interdisciplinary approach to digital inclusion, aimed principally but not exclusively at older women and those in vulnerable situations, in line with calls for academia to address complex societal challenges (Wowk *et al.*, 2017).

3.2. Two communities

This work brought together two distinct communities, which can be broadly distinguished as being academic/institutional and non-academic/non-institutional. The former comprised members of the RiseWise project who were on secondment and who were based at the University of Minho, as well as other University of Minho researchers and Fraterna staff. Although not everyone in this group was part of RiseWise, for brevity and clarity they shall be referred to as RiseWisers in this chapter. The latter comprised local community members of the Arca Social activities, some of whom (but not all) participated in the training sessions in the use of technological devices. Participants in these activities had low digital literacy and, in line with the focus of the RiseWise project, were predominantly older women. However, it was decided that all people who regularly take part in the Arca Social activities would be invited, to maintain the natural dynamics and symbioses; for example, several women usually attended these activities with their husbands. This second group, henceforth referred to as Residents, was recruited through Fraterna by its staff and the Arca Social activity facilitators. Written informed consent was obtained from all Residents prior to any data collection.

3.3. Participatory engagement framework

The challenge of this work was two-fold: first, to encourage collaboration across the different disciplines and levels of experience amongst the RiseWisers; and second, to foster engagement between the RiseWisers and the Residents, which would generate meaningful and fruitful outcomes for both communities. Crucially, there was only a short timeframe in which all stakeholders would be present in Guimarães to complete the work. In order to achieve the desired efficient and empathic participatory process, a framework comprising multiple relationship-building stages was designed. This framework is illustrated in Figure 1, with the stages involving only RiseWisers represented in red and the stages involving both communities represented in purple.

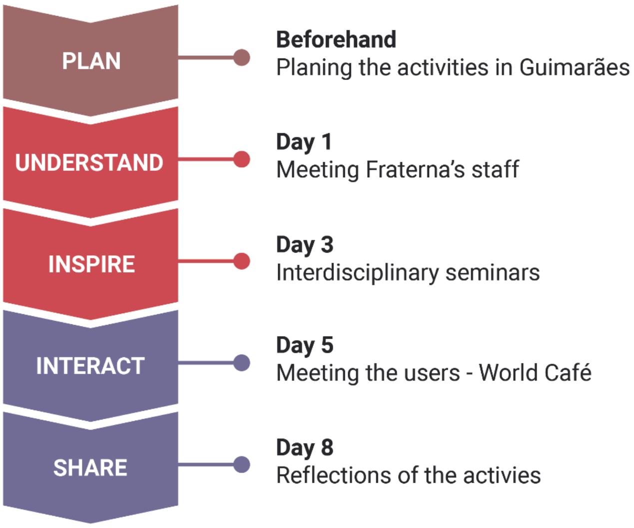

Figure 1. Participatory engagement framework with stages and timing.

PLAN: The preparation of these activities began between May and July 2019, a few months before the planned secondments. At this point, it was known that several RiseWisers intended to be seconded in Guimarães, between September and October 2019. During this planning phase, the four-stage participatory engagement framework described here was developed by AB and PT and reviewed by SMB and ARM. AB and PT discussed possible topics for an inspiration workshop around different ways of empowering women with disabilities and made the necessary arrangements for the planned activities. This stage involved RiseWisers only.

UNDERSTAND: One preliminary visit to Fraterna helped to gain an overview of its operation and to inform the planning of subsequent stages. During this visit, SMB, NG, FI and PT met Fraterna staff, familiarized themselves with the space available (e.g. size of the rooms, accessibility of the venue for wheelchair users), and learned about the regular activities hosted there to better understand who might take part in the planned interactions with the local community. This stage involved RiseWisers only.

INSPIRE: To provide a shared perspective from which to begin our research, a half-day 'inspiration' workshop was held with invited speakers who presented a range of perspectives pertinent to the themes of disability and gender (Figure 2, left). MG and PT gave an introductory talk about the RiseWise project and the remaining speakers were all women, from different backgrounds and some of whom had disabilities. The themes of the talks and subsequent discussions included: empowerment through design, empowerment through technology, empowerment through social engagement, empowerment through work, empowerment through research, empowerment through policy and legislation, and empowerment through arts and leisure. It was anticipated that this event would help shape and refine ideas for the following stage. This stage involved RiseWisers and invited speakers only.

Figure 2. On the left, photo of the Inspire stage; on the right, photo of the Interact stage with RiseWisers and Residents.

INTERACT: The first participatory interaction between RiseWisers and Residents took the form of a World Café at Fraterna. The familiarity of this space to Residents made it particularly appropriate and the available rooms were set up so that participants were seated around tables as recommended (Brown *et al.*, 2005), to create an environment that encouraged open and meaningful conversations. After written informed consent was obtained from the Residents, they were asked to fill in a brief questionnaire about their demographic and background information. The 21 Residents were arranged into four groups of four to five people and each group was assigned to a table, where they would remain for the duration of the World Café event (Figure 2, right). The RiseWisers were assigned either the role of Reporter or of Listener. The Reporters (AB, RA, BD, PT) were responsible for asking the questions, facilitating discussions amongst the participants, taking notes (either in English or Portuguese), and reporting back to their assigned Listener. The Listeners (SMB, NG, FI) supported the Reporters and ensured the discussions were kept on topic, suggesting additional questions and prompts when appropriate. In addition to these roles, there was a Photographer (MO), who moved between tables to take photos of the discussions, and a Timekeeper (ARA). The RiseWisers were split into four teams comprising a Reporter and a Listener (except for one group), each of which was responsible for one of the following discussion topics relating to technology use: (a) current use of mobile phones and tablets, (b) dreams and aspirations, (c) relationship with ICT, and (d) support. An overview of RiseWisers' roles and distribution during the World Café is provided in Figure 3.

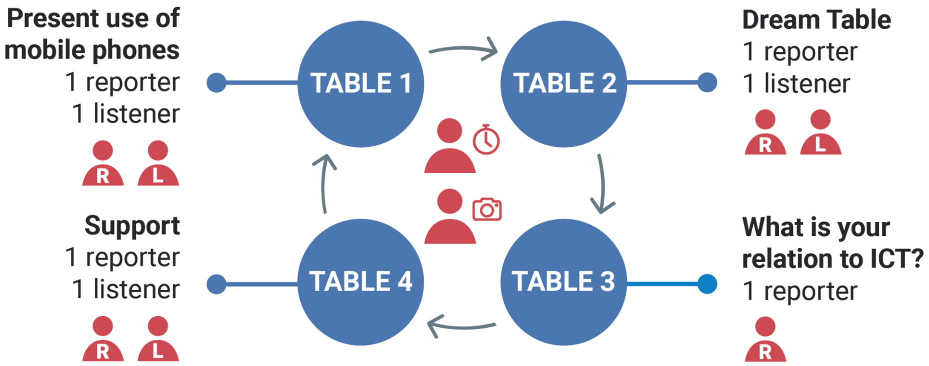

Figure 3. World Café plan and RiseWisers' allocated roles.

Residents remained seated at their group's table, while the RiseWisers rotated around each table sequentially. Upon arrival at a table, the Reporter had approximately 2 minutes to introduce their topic of discussion and present a summary of discussions from tables they had visited previously. The group then had 15 to 20 minutes to discuss the topic, following a topic guide to stimulate initial conversations. This process was repeated four times, so that every Reporter-Listener team visited each table and all four Residents' tables discussed all four topics. Table discussions were audio-recorded (with prior consent from each Resident) by the team Listener, for use by the RiseWisers for data transcription and analysis purposes only.

SHARE: In the following days, the RiseWisers had a few work sessions to collate and analyse the data gathered during the previous stage. ARA, RA, SMB, NG, FI and PT took a reflexive thematic analysis approach (Braun & Clarke, 2006) by carefully reading and critically discussing the data, then identifying key themes through inductive coding. (Figure 4, left). Through this process, four strategic areas of intervention were identified for subsequent interventions. These results are beyond the scope of this chapter and will be reported elsewhere.

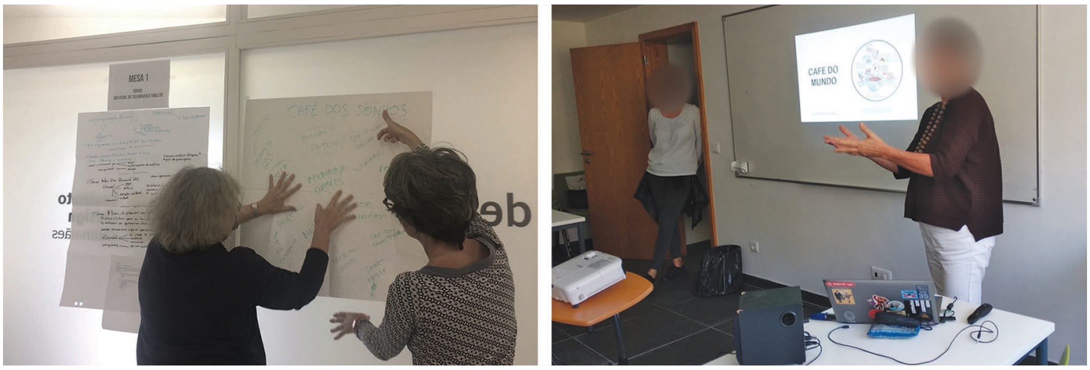

Figure 4. On the left, photo of the data analysis session; on the right, RiseWisers presenting the outcomes of the work at Fraterna.

ARA, RA, SMB and PT re-visited Fraterna to share and discuss these results with the Residents (Figure 4, right). This was an informal and celebratory event, which began with a presentation by the RiseWisers, followed by a feedback from the Residents, and ended with a tea party involving everyone. This iteration with the Residents helped to validate the findings and inform the planning of future interventions that would be meaningful to them and that would also continue to build the relationship between Fraterna and the University of Minho. These results are beyond the scope of this chapter and will be reported elsewhere.

Other: There were final in situ meetings amongst the RiseWisers to reflect on the outcomes of the secondment and to discuss directions for future work. The continuation of this work was cut short by the COVID-19 pandemic at the start of 2020, which made any in situ collaboration between RiseWisers and Residents untenable. Further meetings amongst RiseWisers were held through videoconferencing and focused mainly on dissemination of results. A number of shared online documents were also created, to allow discussions and iterations of this work.

4. Capturing the RiseWisers' experiences

The framework and associated work described above were evaluated by the RiseWisers, using a questionnaire designed specifically for this purpose by AB, ARA, SMB and PT. A questionnaire approach was deemed most appropriate for three key reasons: first, it would allow RiseWisers to respond easily, in their own time and place; second, even though the questionnaire was written in English, RiseWisers were encouraged to respond in the language of their choice (i.e. English, Portuguese, Italian or Spanish); third, the questionnaire permitted a certain degree of anonymity and it was anticipated that this would encourage RiseWisers to be candid about their experiences. The questionnaire was created in Google Forms and comprised three main sections: (i) background and expertise of the respondent, (ii) reflections on the activities carried out, and (iii) impact of this experience on subsequent work. The questionnaire was based on multiple choice questions, some of which were supplemented by open-ended questions where respondents could explain their previous answers.

The responses were collated and analysed by AB and PT. Given the small sample size, responses to multiple choice questions were summarised in frequency tables and no further statistical analysis was performed. The qualitative material in the open-ended responses was coded independently, then these codes were discussed and refined in data analysis meetings until no new codes were identified. A descriptive summary was developed based on these findings, to provide explanation and a deeper understanding of RiseWisers' experiences. The results are reported below.

4.1. RiseWisers' characteristics

The RiseWisers group comprised 11 people, all of whom completed the evaluation questionnaire. Their areas of expertise included four people from design backgrounds, one from architecture, one from adapted physical activity and technology, one from ICT, one from computer science, one from human-computer interaction, one from information sciences, and one from social integration. Table 1 summarises the RiseWisers' characteristics in terms of occupation, previous experience of collaborative work, and previous experience of community-based research.

Table 1. Summary of RiseWisers' characteristics

Occupation	**Number**
Senior researcher	4
Junior researcher	1
Researcher in training	2
Practitioner	1
Other	3
Previous experience of collaborative work	**Number**
Yes	9
No	2
Previous experience of community-based research	**Number**
Yes	6
No	5

Of the nine people who had previous experience of collaborative work, six reported collaborating within their discipline or field of work, seven had done multidisciplinary or interdisciplinary collaborations, three had collaborated in a new field of research, seven had participated in non-academic collaborations such as working with members of the public, and one collaborated with NGOs on research. Examples of effective ways in which collaboration had previously been achieved included in-person approaches (e.g. meetings, seminars, workshops, ice-breaker and team-building activities) as well as sustained communication through digital means such as online platforms and instant messaging apps. One respondent mentioned that an initial conversation to allocate responsibilities, plan data access, and manage expectations is key to a healthy professional collaboration.

All six RiseWisers who reported having prior experience of community-based research were involved as a researcher and none reported having experience as a participant in such type of research. Nevertheless, cited methods that had been used for working with members of the public showed the value placed on understanding people's experiences (e.g. interviews, questionnaires, user evaluations, generative workshops) and establishing empathy (e.g. personas, scenarios, storytelling). One respondent highlighted the importance of conducting such activities in places that are comfortable for participants.

4.2. Evaluation of the framework

Three RiseWisers took part in every stage of the aforementioned work. One RiseWiser took part in only one stage of the work (Interact) and the remaining seven took part in three or more stages. These results are summarised in Table 2.

Table 2. Number of RiseWisers who participated in each stage of the framework

Framework stage	Number
Plan	7
Understand	6
Inspire	9
Interact	10
Share	7
Other	8

Results of the evaluation (Figure 5) show largely positive to very positive reactions to each of the stages. There was consensus among the seven, six, and nine RiseWisers who respectively took part in the Plan, Understand, and Inspire stages that these were very useful. In the RiseWisers' opinions, the Plan stage was fundamental to getting to know each other's backgrounds and establish common interests, to share expectations, to agree on an agenda, to discuss logistics, and overall to support coordination across disciplines, levels of experience, and geographical distance. The Understand stage was described as valuable to understanding the context of Fraterna, its stakeholders and its users. In particular, RiseWisers mentioned that face-to-face meetings at this stage were important for building strong relationships and extracting meaningful information. They commended Fraterna's staff for their openness and generosity with their time and resources. The workshops of the Inspire stage were deemed especially stimulating for their multidisciplinary approach, for showing how academia and NGOs can collaborate towards shared goals, and for presenting women's experiences in their own voice and from a range of perspectives, including women from various backgrounds and women with disabilities.

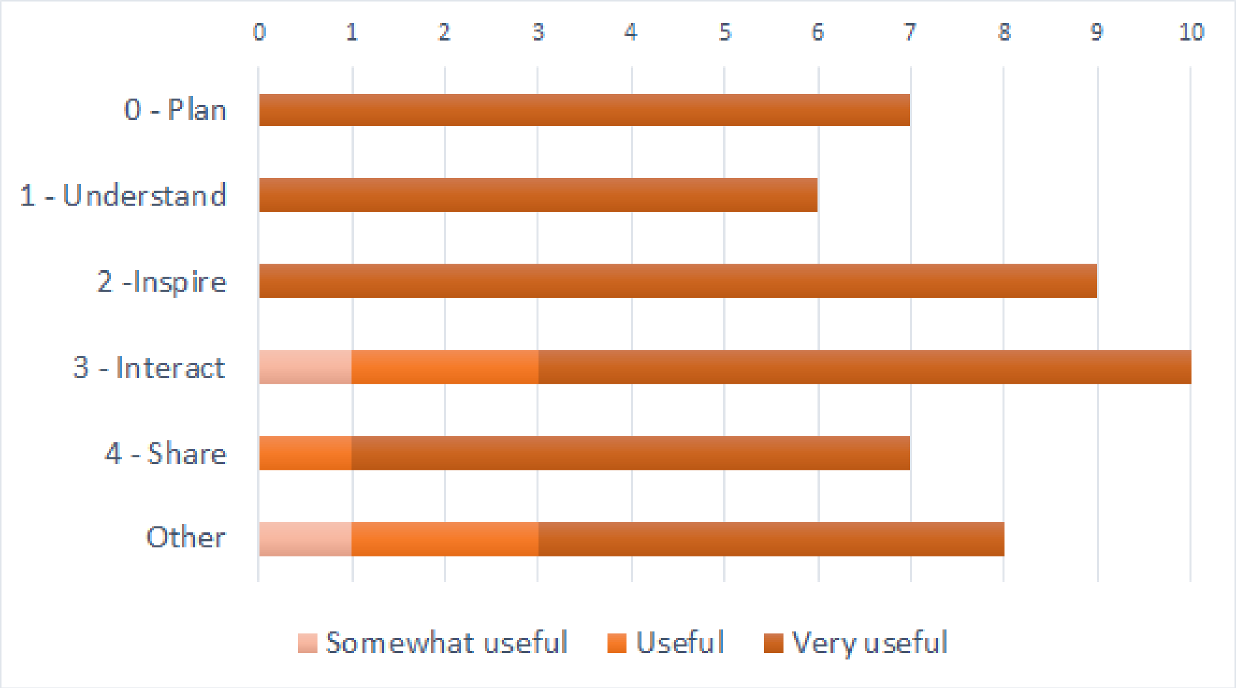

Figure 5. Results indicating how useful RiseWisers rated each stage of the framework.

The Interact stage, comprising the first interaction between RiseWisers and Residents, was seen as essential and one RiseWiser even described it as ‘the whole point’. RiseWisers responses indicated they enjoyed working with other RiseWisers who brought different expertise and cultural inputs to the table, but also found it rewarding to hear directly from the Residents about their experiences, opinions, and concerns. One RiseWiser noted that this activity allowed the Residents to feel that there were people who were motivated to listen to their views and find appropriate solutions for them. The World Café process was perceived as a dynamic technique that generated quite a lot of information in a relatively short period of time. It was effective in ensuring that Residents were actively engaged in the conversations and that all RiseWisers were involved in some way, even if they were not experienced in participatory research. However, several RiseWisers felt that the time allocated for this activity was too little, considering the language barriers and that it was the first time anyone was conducting a World Café. There were some communication difficulties, namely that conversations with the Residents needed to be interrupted so that information could be translated by Reporters (Portuguese speakers) to Listeners (non-Portuguese speakers), which sometimes resulted in difficulties resuming the momentum of conversation with the Residents. Also, one RiseWiser thought that the fast-paced conversations and rotation to new topics without breaks may have been quite tiring for the Residents. The overall success of this activity was attributed to the participants’ positive attitude towards the event, which was in no small part due to Fraterna’s staff’s strong and friendly relationship with the Residents and RiseWisers.

The Share stage was a welcome opportunity to provide feedback to the Residents, providing (in the words of one RiseWiser) a «reality check of what went right or what went wrong during the activities». In their open-ended responses, the RiseWisers noted the Residents enthusiasm and interest in discussing the outcomes of the World Café. It was also observed that despite its ethical imperative, this type of sharing and discussion of results with participants is often neglected by researchers. In fact, such a stage in the framework was identified as a potential contributing factor to ensuring sustained engagement with the community and eventual implementation of solutions. However, another RiseWiser felt that the time allocated for this stage was not enough and suggested there was need for a common debriefing schema to collect data.

Feedback about the activities that fall under the Other stage of the framework highlighted the disappointment that the planned work was interrupted by the sudden occurrence of the COVID-19 pandemic. This meant that no further interactions between RiseWisers and Residents were undertaken, and indeed interactions amongst the RiseWisers were mostly held online. One RiseWiser felt there was a decline in commitment and enthusiasm once they were no longer able to meet and work together in person. Nevertheless, it was during this phase that reflection, planning and decisions about how to continue the collaboration took place, which ultimately led to the writing of this chapter.

4.3. Impact on the RiseWisers

When asked to list up to three benefits or best things and up to three challenges or negative aspects about the work carried out in Guimarães, all 11 RiseWisers provided at least one example for each category. A summary of the main themes to emerge from these questions is presented in Table 3.

Table 3. Summary of best things and negative things about the work according to RiseWisers

Best things about the RiseWise work done in Guimarães	**Number**
Working across disciplines	6
Understanding real-world problems	6
Working with the community	5
Establishing partnerships for future collaborations	4
Productivity and structured approach of the work	4
International collaboration	3
Working with non-academic institutions	2
Diversity and empowerment of community members	2
Learning	2
Negative things about the RiseWise work done in Guimarães	**Number**
Short duration	5
Unfulfilled plans due to the Covid-19 pandemic	4
Language barriers	3
Disciplinary differences	2
Lack of resources (e.g. human resources)	2
Competing responsibilities (for local RiseWisers)	2
Not enough women with disabilities involved	1
Not enough exposure	1
Transforming academic knowledge into practice	1
Timekeeping when talking with the Residents (World Café)	1

Best things outnumbered negative ones by roughly a third, with 34 and 22 examples given respectively for each. Answers given for best things tended to concern the personal benefits and experiences of the RiseWisers. Understanding real-world problems and working with the community were among the most cited benefits, but nobody mentioned outcomes of the work related to the digital inclusion of older adults. Nevertheless, two respondents mentioned the diversity of the Residents and their empowerment as positive aspects of this collaborative work. Four RiseWisers praised the structured approach of the work and a resulting sense of productivity. In contrast, negative aspects had a lot to do with the short duration of the work as well as plans being interrupted due to the COVID-19 pandemic. Some communication barriers and disciplinary differences were experienced, but they were not the most prevalent drawbacks mentioned.

When asked whether they felt this collaborative experience had changed the way they did their research or work, eight out of nine responses were affirmative; the other response explained that the experience had served as a «reminder of the local nature of any participatory action». Examples of new perspectives included enhanced empathy with users and real-world contexts, collaborating with experts beyond academia, and a better understanding of how to conduct their own research project. All respondents (10 responses) felt that the experience of working with researchers from other disciplines in Guimarães had contributed to their professional development and could be useful for future work. Specifically, these responses showed that this had been an opportunity to learn new perspectives, approaches, and methods, and to expand knowledge more broadly (e.g. by working with more experienced researchers).

5. Looking back on our experience

The aim of this work was to develop an inclusive and efficient way for RiseWisers and Residents to work together in addressing a meaningful real-world challenge. It therefore positions itself within recommended best-practices of interdisciplinarity and external collaboration with decision-makers and end users (Wowk *et al.*, 2017). The RiseWisers were a group of researchers and practitioners from various disciplines, with varying levels of experience, and from different European countries who convened in Guimarães in the autumn of 2019; the Residents were a diverse group of older adults who were regularly involved in training and vocational activities provided by Fraterna, a local NGO partner of the RiseWise project and host to the seconded RiseWisers. This work involved many challenges inherent to working across disciplines and with communities, with the added constraint of a short time frame when all the seconded RiseWisers would be in Guimarães. To address these, a multi-stage framework for participatory engagement was created and used to inform the work carried out in Guimarães. A subsequent evaluation of the framework showed that each stage was mostly perceived as useful or very useful for the work. RiseWisers' responses suggested that it was a valued and beneficial approach, conducive to long-term relationship-building and feelings of productivity. Interestingly, positive feedback from the RiseWisers focused more on the collaborative process and its personal benefits to them, than on the wider societal impacts of addressing the challenge of digital inclusion of older people. This is in line with evidence that motivational factors are a key benefit of working collaboratively with other disciplines (Siedlok & Hibbert, 2014).

Despite abundant evidence in favour of participatory and user-centred approaches, misconceptions about their costs and logistics often prevent their application in real-world settings (Chamberlain, 2010). Here, we have demonstrated that it is possible to work collaboratively with diverse communities on matters that concern them, using relatively few resources and in a short period of time. Much of the success of this work can be attributed to the involvement of Fraterna as a trusted community mediator. Activities within the participatory engagement framework were planned well in advance with input from Fraterna staff, who were able to advise on the community and thus help to establish an appropriate local problem for which to seek change (Hayes, 2011; MacDonald, 2012; Moreira da Silva, 2019). Fraterna was also instrumental in providing a space that was familiar to the Residents and therefore encouraged candid conversations (Brown *et al.*, 2005). One foreseen challenge for such conversations was the language barrier, given that four RiseWisers did not speak Portuguese and the Residents only spoke Portuguese. Consequently, for the Interact stage, the World Café method (Brown *et al.*, 2005) was adapted so that RiseWisers who spoke Portuguese could act as a bridge between non-Portuguese speaking RiseWisers and the Residents. While this was not entirely successful, in part due to the short amount of time allocated for each discussion, we feel that it can be refined in future iterations of this work.

Reflecting on the work, we have identified some strengths and limitations that need to be considered when interpreting this work. Most notably, and evidenced by the frustrations reported by RiseWisers (see Table 3), we were not able to continue the work as planned due to the advent of the COVID-19 pandemic around the time when the next steps were to be taken. Nevertheless, we argue that the initial work described here constitutes a relevant first step that merits reporting, as it lays out a demonstrably effective process for commencing interdisciplinary and community engagement. We acknowledge that the RiseWisers were naturally drawn to the ethical argument for inclusion encompassed by the RiseWise project and that about half of this group had some experience of community engagement, which may have been contributing factors in facilitating this process. Additionally, we note that Residents were not directly involved throughout all stages of the framework and, as a result, could not be involved in its evaluation. Instead, the RiseWisers included Fraterna staff who acted as a proxy for the Residents interests in the Plan and Understand stages. Moving forward, we feel that there is scope to further extend decision-sharing between the two communities in future iterations of this framework, following recommendations in the literature (Bratteteig & Wagner, 2014; Corbett & Le Dantec, 2018).

In conclusion, the framework provided structure to the secondments and generated welcome opportunities for continued collaboration. Although RiseWisers reported some challenges related to language barriers and disciplinary differences, these did not prevent fruitful collaborations and an overall enjoyment of the process. It is likely that being together physically and in pursuit of a shared vision, a unique opportunity afforded by our involvement in the RiseWise project, was a fundamental success factor. We believe that our framework represents a significant step towards understanding how to create inclusive and efficient engagement across disciplines and with the community. In doing so, it has the potential to positively advance the relationship between academia, NGOs, and local communities.

6. Looking forward

The process of working across disciplines and with a local community of older adults was not without challenges, but it was a rewarding and productive endeavour in many respects. The rapidly established engagement between RiseWisers and Residents has laid the foundations for future work involving both these communities, but also created a blueprint for collaborative work with other communities and in other contexts. Continuing the planned work between RiseWisers and Residents will help determine the applicability of this framework for sustained collaboration across disciplines and with the community, and allow it to be refined accordingly. Replication of this work with different user groups and applied to other real-world challenges will help to further establish the framework's value as a mechanism for inclusive and meaningful innovation. These are challenges we hope to address moving forward. We also hope that the insights we have gained through this experience will encourage others that participatory approaches need not be reserved for specialists or those with an abundance of time in which to conduct their work.

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European research projects as a driving force for growth

Cinzia Leone[1]

Keywords: cultural bias, gender and disability, inclusion, research projects, EU funding

1. Introduction

European research and cooperation projects are drivers of the social, cultural and economic growth of the European Union and, at the same time, offer a concrete tool for inclusion, thanks to specific planned actions that seek to overcome the cultural gaps and bias that exist in our society, particularly as concerns disability and diversity.

This article explains how the European RISEWISE — RISE Women in Social Engagement — project offers evidence of the above, constituting a prototype to be replicated so as to increase the project's impacts.

The activities pursued by the project over the four and half years for which it ran, for many aspects, were breakthrough in nature, breaking down the invisible barriers between dialogue and knowledge transfer and exchange between the academic world and the tertiary sector, between public and private, between researchers and social care professionals, between men and women, between people with and without disabilities and between grass-root movement activists and policy-makers.

The success of the capillary dissemination and the large number of people who listened to, frequented and monitored the project activities, bear witness to the fact that it is indeed possible to implement change in the institutional activities of entities of very different cultures, sectors, origins, countries and languages and, in doing so, to form a prototype for change and inclusion, above all to increase the inclusion of women with disabilities in research, cooperation and inter- and transnational, as well as inter-sectoral, exchanges.

After a brief introduction to European Union funding for research and innovation projects in recent years under the scope of the Framework Programmes for Research and Technological Development and specifically as regards the recent planning period called «Horizon 2020» («H2020», which covered the years 2014-2020), a more specific analysis will be provided of this project, seeking to outline the most innovative, break-through aspects that the RISEWISE project has represented and continues to represent on the European scene, as well as on a national level for the individual countries that have played an active part in the project: a varied community

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[1] Cinzia Leone (University of Genoa).

of European countries with clear geographic, historic, social and cultural differences, going from Turkey through to Sweden.

The topic discussed, that of women with disabilities is without doubt one of interest and one that the project has pursued holistically, covering all aspects. It is my opinion, as author of the project proposal, that this type of approach is what has made it a winning one. A holistic approach that does not merely analyse specific aspects of the life of women with disabilities, thereby circumscribing the analysis and action of the project to specific areas or sectors or aspects, but rather which inserts the topic into an extensive context, embracing all aspects of the everyday life of people with disabilities, paying particularly close attention to the female universe and deliberately lesser so to the medical aspects of disability.

As far as I am aware, RISEWISE was the first research project financed by the European Union that focussed on women with disabilities as the protagonists of the project itself and not as the ‘object’ of study, analysis and research. The women with disabilities who were therefore the focus and fulcrum of RISEWISE were both the subject and the object of the project; they were the artifice and the parties responsible, with, as mentioned, a holistic approach, where no aspect of everyday life, politics and social policies was neglected.

The mandatory cooperation between the academic and non-academic sector formed the basis for the projects financed under the scope of the RISE type Horizon 2020 framework programme, taking a trans- and international approach.

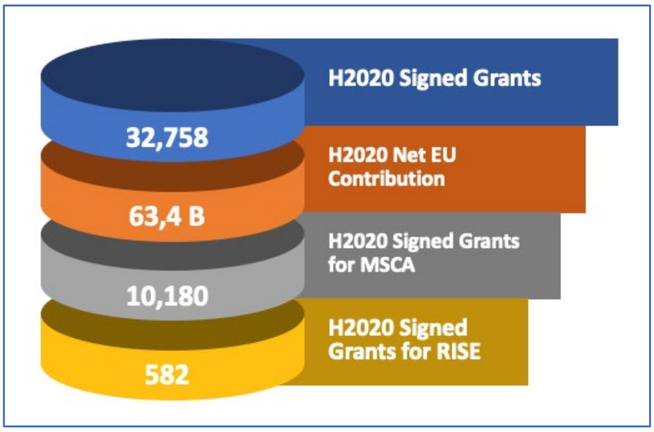
These elements, coupled with the distinguishing characteristics of the RISE projects, have meant that the physical and virtual exchange, made up of travel and exchanges and visits, events and initiatives at all levels, has been a harbinger of positive, unexpected results. At a time when the lives of all Europeans appeared to be relegated to the virtual world of on-line activities only, the importance of RISEWISE becomes even more appreciable, because heading to a location, gaining experience and physically reaching out and touching are still key aspects for the stable constitution of an international network of practitioners and professionals in the sector of interest.

This contribution therefore submits various concrete elements that justify the positioning of RISEWISE as possible driver for change and prototype that can be replicated and implemented further in new European and national projects, which finally put women with disabilities at the centre, listening to their voices and not only the voices that talk about them. *Nothing about us without us* (Charlton, 2000).

2. The european projects

Thanks to the Horizon 2020 Dashboard that the European Commission has openly made available, it is today possible to obtain a great deal of data about the European projects of interest. The figure below gives some brief figures allowing for a better overview of the size to which reference is made when we talk about research and innovation projects financed under Horizon 2020.

Figure 1 Horizon 2020 Projects Data



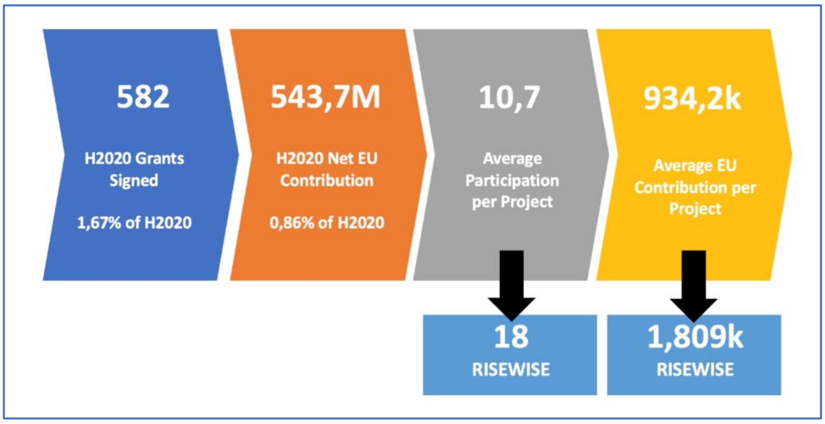
Source: H2020 Projects Dashboard. https://webgate.ec.europa.eu/dashboard/sense/app/93297a69-09fd-4ef5-889f-b83c4e21d33e/sheet/erUXRa/state/analysis. Retrieved 18 April 2021. Own processing.

With a contribution of more than 63 billion euros, the Horizon 2020 project has financed a total of 32,758 research and innovation projects, of which 10,180 come under the family of the Marie Sklodovska Curie Actions (MSCA), of which Research and Innovation Staff Exchange (RISE) type projects and the RISEWISE project are a part.

As we can see, continuing to query the extremely up-to-date data given on the above website, MSCA account for almost a third of all projects financed during the programme period, which runs from 2014 to 2020, whilst the RISE only account for 1.67%, with a total grant of just 0.86% of the entire Horizon 2020. Ultimately, therefore, RISE projects are the youngest children of a very vast family, where the lion’s share consists of Individual Fellowships (with almost 8000 signed grants), followed by ITN projects (1021 signed grants).

The figure below summarises the H2020 data for RISE projects.

Figure 2 RISE data for Horizon 2020 compared to RISEWISE



Source: H2020 Projects Dashboard. https://webgate.ec.europa.eu/dashboard/sense/app/93297a69-09fd-4ef5-889f-b83c4e21d33e/sheet/erUXRa/state/analysis. Retrieved 18 April 2021 and RISEWISE Project. Own processing.

The project with which we are concerned, clearly, differed somewhat from the average programming regarding the RISE projects. It was a far more vast project in respect of the number of participants and the grant assigned. In addition, its duration was four years, thereafter extended as a result of the COVID-19 pandemic for a further six months, making for a total duration of four and a half years.

RISEWISE was a complex, articulated project, both in terms of the number of partners and the amount of the loan, and the varied make-up of the partners.

The following countries were involved: Sweden, Italy, Spain, Austria, Slovenia, Turkey and Portugal. The partners came from the world of academia and the private sectors, embracing both non-governmental organisations and charities, as well as businesses, balancing half scholars and half from the private world. During the project life, a couple of partners alternated, with some new ones joining, in particular also involving Slovenia, a country of great interest to the topic at hand.

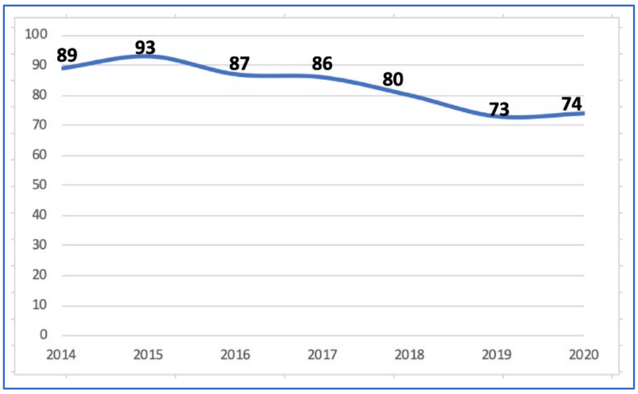
The project then gave rise to other initiatives and new projects that are still in progress, which are definite elements of exploitation, continuity and sustainability of RISEWISE.

In general, RISE projects are a new feature for the Horizon 2020 programming and the above figures bear witness to just how much this type of project has not gained extremely successful standing on the European projects scene. Difficult to manage and with little money available, the RISE as per the project in question — because there were different types, albeit all very similar — were mainly intended for those who truly believed in the value of international and inter-sectoral mobility and focussed very much on the value of knowledge transfer and international networking.

The various calls for proposals that the European Commission issued from 2014 to 2020, have seen a decreasing number of RISE proposals submitted and projects approved and we can hypothesise that the reasons are close to those explained above, regarding the difficult management and little in the way of funding, together with a general decline to the number of proposals presented during the life of the framework programme for any type of call.

The graph below shows the performance of signed grants in the history of RISE in all the Horizon 2020 programming.

Figure 3 RISE Grants under H2020



Source: H2020 Projects Dashboard. https://webgate.ec.europa.eu/dashboard/sense/app/93297a69-09fd-4ef5-889f-b83c4e21d33e/sheet/erUXRa/state/analysis. Retrieved 18 April 2021. Own processing.

Already at first glance, we note how, after some initial success, RISE projects have thereafter declined constantly. This trend differs considerably for what has been the case for many other project types, particularly if new introduction, where at first, in the initial calls, the number of proposals and projects funded was lower, before then growing over time, as familiarity increased and there was a gradual spread of awareness of the new project model. In addition, the lesser number of project proposals and signed grants is not explained if the success rate is compared with the high levels, always remaining at an average of around 20-25% (in the first call, in 2014, it was 34%). This above all where for other types of project, the success rate has been constantly low, even below one percent, and in a trend that has seen the success rate diminish constantly, starting from the Framework Programme 7 (FP7 2007-2013) until completion of Horizon 2020, going from an average success rate of 21.2% for FP7 to 11.94% for H2020 (EC, 2018; SERI, 2018). Therefore, even if the hopes for success were higher, the partners did not appear to be curious or interested in submitting a high number of applications for RISE projects.

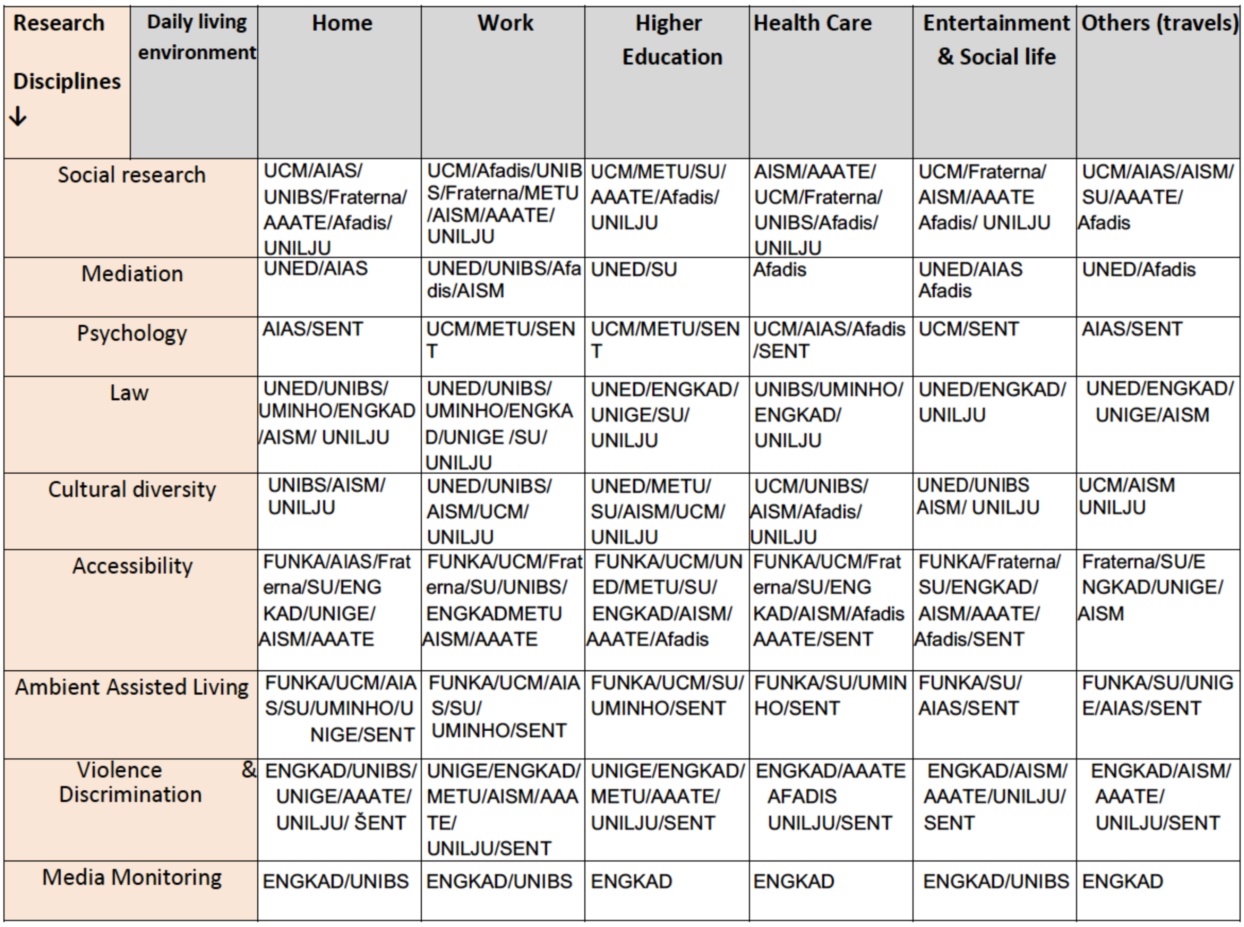
As then concerns the funding of European research projects about disability or, specifically, women with disabilities, the European Commission search engine containing all data about projects financed, CORDIS, returns a result of 636 H2020 projects financed that include the word ‘disability’ in the title, description or teaser. The vast majority of projects relate to medicine or technology, which today are the most widespread approaches taken internationally to the topic of disability, both in theoretical terms and in regard to research (Bencivenga & Tinti, 2011). In various cases, the matter of ageing as the bringer of possible disabilities, is analysed. As regards intellectual disability, various projects have been pursued regarding both autism and other types of mental impairments. None of the projects on the list would appear to be dedicated to women with disabilities, neither entirely nor in terms of the topics faced in everyday life, analysing more than one aspect that is not that of health, of a specific illness, of a topic already defined, such as, for example, social work, caregivers, domestic work, assistive technology and others. In addition, there is rarely specific discussion of women with disabilities.

The exception on the list is the project in question, RISEWISE, and its spin-off, the project *MILIEU: Women, Disability, and Inclusion. Scientific Excellence in Bulgaria*, a project written mainly by the author of this contribution and which represents a sort of evolution of the analysis of the topic of women and disability with a particular focus on a country of eastern Europe.

3. Risewise as a driver for change

The RISEWISE project is a winning one, therefore, right from the focus, which is not only concentrated on a specific aspect of disability and with an inter-sectional observation (Crenshaw, 1989), which has made it possible to avoid ‘unpacking’ a complex topic, but rather to address it, inserting it into environments and dimensions that intersect, as in a matrix, where the project partners pool their competencies, applying them in different aspects of the everyday life of women with disabilities.

Table 1 Multi-disciplinarity applied to different environments of daily living, and partners' expertise



Research Disciplines ↓ Daily living environment	Home	Work	Higher Education	Health Care	Entertainment & Social life	Others (travels)
Social research	UCM/AIAS/UNIBS/Fraterna/AAATE/Afadis/UNILJU	UCM/Afadis/UNIBS/Fraterna/METU/AISM/AAATE/UNILJU	UCM/METU/SU/AAATE/Afadis/UNILJU	AISM/AAATE/UCM/Fraterna/UNIBS/Afadis/UNILJU	UCM/Fraterna/AISM/AAATE Afadis/ UNILJU	UCM/AIAS/AISM/SU/AAATE/Afadis
Mediation	UNED/AIAS	UNED/UNIBS/Afadis/AISM	UNED/SU	Afadis	UNED/AIAS Afadis	UNED/Afadis
Psychology	AIAS/SENT	UCM/METU/SENT	UCM/METU/SENT	UCM/AIAS/Afadis/SENT	UCM/SENT	AIAS/SENT
Law	UNED/UNIBS/UMINHO/ENGKAD/AISM/ UNILJU	UNED/UNIBS/UMINHO/ENGKAD/UNIGE /SU/UNILJU	UNED/ENGKAD/UNIGE/SU/UNILJU	UNIBS/UMINHO/ENGKAD/UNILJU	UNED/ENGKAD/UNILJU	UNED/ENGKAD/UNIGE/AISM
Cultural diversity	UNIBS/AISM/UNILJU	UNED/UNIBS/AISM/UCM/UNILJU	UNED/METU/SU/AISM/UCM/UNILJU	UCM/UNIBS/AISM/Afadis/UNILJU	UNED/UNIBS AISM/ UNILJU	UCM/AISM UNILJU
Accessibility	FUNKA/AIAS/Fraterna/SU/ENGKAD/UNIGE/AISM/AAATE	FUNKA/UCM/Fraterna/SU/UNIBS/ENGKADMETU AISM/AAATE	FUNKA/UCM/UNED/METU/SU/ENGKAD/AISM/AAATE/Afadis	FUNKA/UCM/Fraterna/SU/ENGKAD/AISM/Afadis AAATE/SENT	FUNKA/Fraterna/SU/ENGKAD/AISM/AAATE/Afadis/SENT	Fraterna/SU/ENGKAD/UNIGE/AISM
Ambient Assisted Living	FUNKA/UCM/AIAS/SU/UMINHO/UNIGE/SENT	FUNKA/UCM/AIAS/SU/UMINHO/SENT	FUNKA/UCM/SU/UMINHO/SENT	FUNKA/SU/UMINHO/SENT	FUNKA/SU/AIAS/SENT	FUNKA/SU/UNIGE/AIAS/SENT
Violence & Discrimination	ENGKAD/UNIBS/UNIGE/AAATE/UNILJU/ ŠENT	UNIGE/ENGKAD/METU/AISM/AAATE/UNILJU/SENT	UNIGE/ENGKAD/METU/AAATE/UNILJU/SENT	ENGKAD/AAATE AFADIS UNILJU/SENT	ENGKAD/AISM/AAATE/UNILJU/SENT	ENGKAD/AISM/AAATE/UNILJU/SENT
Media Monitoring	ENGKAD/UNIBS	ENGKAD/UNIBS	ENGKAD	ENGKAD	ENGKAD/UNIBS	ENGKAD

Source: RISEWISE Project — GA 690847.

As can be seen, the partners taking part in the project make their investigation skills and potential for innovation in very different disciplines available, applying them to selected daily living environments, embracing the entire existence of women with disabilities. Various disciplines were involved, ranging from sociology to engineering, from law to psychology and from computing to political sciences and so on. The inter-sectional vision accompanied the entire life of the project and yielded excellent results in different fields and sectors, which can be seen in the table given in the last paragraph of this essay.

And thus we have the first breakthrough aspects outlined, which gave the project its positive start, built up all around the matrix structure outlined above.

Another key, innovative element was, without doubt, the direct involvement of women with disabilities in the project activities. We know only too well just how much constant discrimination women with disabilities suffer, recalled explicitly by the UN Convention on the

Rights of Persons with Disability (2006). The project, in evolving from the social model, chose to put the person at the centre, and not their deficit (Oliver, 1990; Griffo, 2014); the woman before her disability (Morris, 1991; Garland-Thomson, 2005).

Many women with disabilities therefore took part in the activities of RISEWISE, with many having travelled and spent time with the partners. It may seem obvious, but we know how difficult it is, even today, for someone with disabilities to embark on travel or organise a long stay abroad. And it is even less of a given to assume that an active part can be played in research and innovation by a) those not coming from the academic world; b) women with disabilities not included in the category of researchers or university lecturers (Bencivenga, 2020). There is a wealth of events organised directly by women with disabilities: in the latter part of this contribution, I will strive to provide a rapid overview of what has been successfully implemented throughout the long life of RISEWISE.

Just a short while ago, I mentioned the academia-surrounding world dialogue that was the focus of RISE projects, also aiming to identify specific social needs to which academia can respond, and this is what RISEWISE did. In the last two years, the debate concerning ableism in academia was finally started, seeking to investigate and theorise experiences of disabilities in higher education (Brown & Leigh, 2020), striving to overcome and express the paradigm of ableism in which the academies continue to be involved. RISEWISE has entered this debate fully, including from a conceptual and theoretical point of view and, amongst others, round tables have been organised and scientific publications on the topic.

The public/private and inter-sectoral dialogue, which has always been at the base of RISEWISE and which represented an obligation for RISE projects has, in fact, once again contributed to making sure that universities opened up from their ivory towers to dialogue with professionals and practitioners in the sector of disability. Dialogue was productive and has brought the two worlds very much closer, yielding sustainable, lasting results that will be better explained shortly.

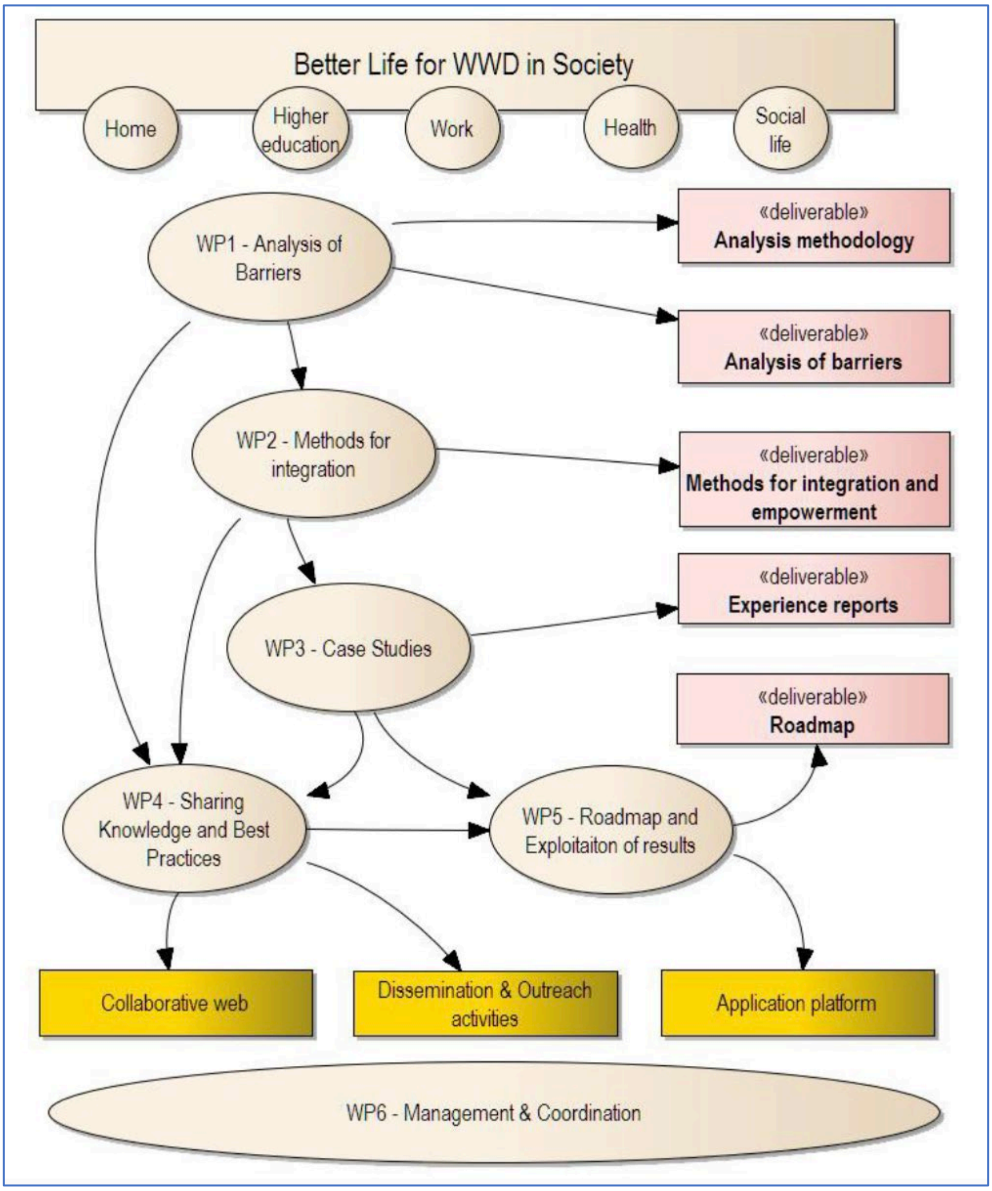
Another innovative element that assured the success of the RISEWISE project was the constant dialogue between men and women, between those with and without disabilities, with constant attention paid to the differences and needs of all. For example, each partner, in order to better understand the differences present in the project, prepared a welcome kit to help guide them both in the new country and at the host partner, together with an information exchange procedure aiming to facilitate the welcome and respond to special needs before they became incumbents. We can therefore talk about a project that is accessible to everyone and attentive to the needs of the individuals.

If we consider that in four and a half years of project, 157 people have travelled for RISEWISE to 18 different partners (later reduced to 16) in seven countries across Europe, we can perhaps start to imagine the flow of exchanges and knowledge transfers produced by the project and borne out by the large number of performed outreach actions.

And there was no shortage of best practice exchanges and dialogue opportunities with policy-makers, where considerable interest was seen throughout in respect to the project topics and the project itself.

The project was constructed with the following structure and work flow:

Figure 4 RISEWISE Workplan structure and main results



Source: RISEWISE Project — GA 690847.

The figure above shows the general structure of the work flow and plan of RISEWISE and has proven well able to produce the expected results, where the project, hinged on cooperation and continuous exchanges, was always monitored and assessed throughout.

4. Results

Merely by way of example, below are some of the results of RISEWISE, which just go to show how much European research and innovation projects can truly represent a driver for change on a global level and not only in the sector of interest.

On the centrality of women with disabilities, we would recall just some of the initiatives organised in Bologna, Genoa and Brescia (Italy), Ljubljana (Slovenia), Guimaraes (Portugal, Madrid (Spain) and in many other cities outside the consortium and beyond, where women with disabilities organised events, told their stories, were interviewed, starred in themed workshops and conferences, with huge social media and press coverage.

Project partners have reported 260 actions in total with a good distribution between communication, dissemination and outreach.

For example, following table resumes communication at conferences

Table 2 RISEWISE Communication and Dissemination Tool — Communication — Extract

Activity Code	**Performed activities: short description**	**Year**	**Location**	**Stakeholders target (if relevant)**
C4 — Communication at conferences or workshops	Invited speaker at Chamber of Deputies Coordinator Cinzia Leone	2017	UNIGE Genova (Italy)	Government exponents, Ministries for Work and for Education, Policy makers, exponents from unions, entrepreneurs
C4 — Communication at conferences or workshops	Workshop on WWD by side of «Women voices» (AIAS) + Invited speaker Cinzia Leone	2017	Bologna (Italy)	Stakeholders, citizens, policy makers
C4 — Communication at conferences or workshops	Invited speaker — Evert-Jan Hoogerwerf Presentation of RISEWISE	2017	Genova (Italy)	Stakeholders, citizens, policy makers
C4 — Communication at conferences or workshops	Accesibilidad y diseño universal.Inclusión social de la mujer con discapacidad	2017	Madrid (Spain)	University students and researchers

Activity Code	Performed activities: short description	Year	Location	Stakeholders target (if relevant)
C4 — Communication at conferences or workshops	Presentation «Disability And Women In Portugal» at Biblioteca Municipal Raúl Brandao de Guimaraes	2017	Guimaraes (Portugal)	The Disability Forum of Guimaraes
C4 — Communication at conferences or workshops	RISEWISE Panel	2017	Avila (Spain)	General public, major associations and institutions on gender and disabilities in Spain
C4 — Communication at conferences or workshops	Presentation of RISEWISE at the AIAS Annual National Assembly — 28th April 2018	2018	Massa Carrara (Italy)	Presidents and Representatives of all the local AIAS
C4 — Communication at conferences or workshops	Promotion of RISEWISE and the Questionnaire «Women and technology» between the participant of the conference at the Annual EASPD International Conference	2018	Barcellona (Spain)	Service providers from all over Europe
C4 — Communication at conferences, workshops and seminars	7th National congress of Social Work with international audience, Slovenia, Moravske Toplice, Title of the Congress: Humanism and Ethics in Social Work. The Symposium: Women, Disability And Human Rights Moderator; Cinzia Leone. Speakers: Zaviršek Darja: The importance of social norms for the technology of normalisation and the reproduction of normalcy and de-normalisation of disabled women in professional services; Bezjak Sonja: Women with disabilities in rural Slovenia in the perspective	2018	Moravske Toplice (Slovenia)	Social work educators, social workers, NGO's working with persons with disabilities, people with disabilities themselves

Activity Code	Performed activities: short description	Year	Location	Stakeholders target (if relevant)
	of greater risk of being discriminated; Leone Cinzia: Women, disability, normality; Siri Anna: Normality and disability across cultures.			
C4 – Communication at conferences or workshops	Speech and presentation of the video «If you were not like this» at the conference organised by UIC (Italian Union of blind people) titled «Women with disabilities, between double discrimination and opportunities», by one of the women working internally in AIAS for RISEWISE topics.	2018	Italy	Citinzenship, academia, NGOs, politicians and administrative staff
C4 – Communication at conferences or workshops	Presentation of RISEWISE at the AIAS Annual National Assembly – 28th April 2018	2018	Massa Carrara (Italy)	Presidents and Representatives of all the local AIAS
C4 – Communication at conferences or workshops	Promotion of RISEWISE and the Questionnaire «Women and technology» between the participant of the conference at the Annual EASPD International Conference	2018	Barcellona (Spain)	Service providers from all over Europe
C4 – Communication at conferences or workshops	Presentation «La inclusión universitaria como modelo abierto» at VIII Congreso Iberomaricano de Pedagogía (Buenos Aires, 14-17/08/2018)	2018	Buenos Aires (Argentina)	Academia
C4 – Communication at conferences or workshops	RISEWISE workshop «GROWING THE FUTURE – Empowerment of people with disabilities in the sport sector»	2018	Guimaraes (Portugal)	Institutions, citizenship, academia, NGOs, politicians and sports professionals Guimaraes

Activity Code	Performed activities: short description	Year	Location	Stakeholders target (if relevant)
C4 — Communication at conferences or workshops	Participation in the working group on: Sexual and reproductive rights. In the Conference «Rights of women with disabilities and the 2030 agenda» María del Carmen Crespo	2019	Madrid (Spain)	General public, Associations, Profesionals, Private Organisations, Academia, People with disability
C4 — Communication at conferences or workshops	«Deaf women´s knowledge of pap tests in europe». Presentado en: Conferencia Mundial de la Association of Medical Professionals with Hearing Losses (AMPHL) 2019, Ana Isabel Sanz Lledó, María del Carmen Crespo Puras, Laura Scudieri.	2019	Baltimore (EEUU)	General public, Associations, Profesionals, Private Organisations, Academia, People with disability
C4 — Communication at conferences or workshops	«Study on knowledge of the Pap-test for deaf women who use Sign Language. Presentado en:» 18th World Congress of the World Federation of the Deaf (WFD 2019) Ana Isabel Sanz LLedó, María del Carmen Crespo Puras, Laura Scudieri	2019	Paris (France)	General public, Associations, Professionals, Private Organisations, Academia, People with disabilities
C4 — Communication at conferences or workshops	«La visibilidad de la discapacidad en el deporte: cobertura informativa de los Juegos Paralímpicos de Pekín 2008, Londres 2012 y Rio de Janeiro 2016 por la RTVE», by Olga Kolotouchkina, Carmen Llorente Alonso, María Luisa García-Guardia, Juan Pavón, presented at VII Congreso Internacional de la AE-IC, Comunicación y Diversidad.	2020	Valencia (Spain)	Academia, Associations, Professionals

Activity Code	Performed activities: short description	Year	Location	Stakeholders target (if relevant)
C4 — Communication at conferences or workshops	Presentation of the paper «Disability narratives in sports communication: Tokyo 2020 Paralympics' best practices and implications», by Olga Kolotouchkina, Carmen Llorente-Barroso, María Luisa García-Guardia and Juan Pavon, at a European Communication Research and Education Association (ECREA) conference.	2020	London (England)	Academia, Associations, Professionals
C4 — Communication at conferences or workshops	Presentation of the Progress of the Survey of Women with Functional Diversity of the European RISEWISE	2020	https://risewisejam2020.wixsite.com/risewisejam2020	General public, persons with disabilities, association of persons with disabilities, social services

This demonstrates clearly the real capacity of the consortium to trigger communication.

Dissemination activities have been extremely relevant and promising. Several networking actions and collaborations with external stakeholders have been initiated.

In the following table a selection of dissemination initiatives is reported.

Table 3 RISEWISE Communication and Dissemination Tool — Dissemination Extract

Activity Code	Performed activities: short description	Year	Location	Stakeholders target (if relevant)
O1 — Public talks/lectures/discussions	Computational Sustainability for Smart City Design	2016	Savona (Italy) Campus UNIGE	Researchers, PhD students, professors
O1 — Public talks/lectures/discussions	Speaker at a conference related to disability	2016	Italy	General public, citizenship, researchers, professionals

Activity Code	Performed activities: short description	Year	Location	Stakeholders target (if relevant)
O1 — Public talks/lectures/ discussions	Conference «Retos de empleo de personas con discapacidad» (Universidad pontificia) (Davide Filippi)	2017	Madrid (Spain)	Stakeholders, citizens, policy makers
O1 — Public talks/lectures/ discussions	Seminar «Gender from the perspective of knowledge»	2017	Ankara University (Turkey)	Stakeholders; University students
O1 — Public talks/lectures/ discussions	Public seminar. Speakers: José Usero and Rita Bencivenga	2017	UNIBS, Law Department, Brescia (Italy)	Researchers, PhD students, professors, technical personnel
O1 — Public talks/lectures/ discussions	Seminar «Nessuno può volare. Un libro, un tour, un documentario per raccontare la disabilità oggi attraverso la storia, l'arte e la cultura». Key speakers Simonetta Agnello Hornby e George Hornby	2017	Brescia (Italy)	Students, citizenry
O1 — Public talks/lectures/ discussions	Conference «III encuentro entre investigadores en salud mental, pacientes y familiares» (Instituto de salud Carlos III) (Davide Filippi)	2017	Madrid (Spain)	Researchers, practitioners, stakeholders
O1 — Public talks/lectures/ discussions	Gala Plena Inclusion Madrid (CAIXAFORUM) (Davide FIlippi)	2017	Madrid (Spain)	Researchers, practitioners, stakeholders
O1 — Public talks/lectures/ discussions	Learning Workshop on «Women and disability»	2018	Bologna (Italy)	Families and professional operators
O1 — Public talks/lectures/ discussions	Seminar: Supported Employment done by Esther Mercado and Luis Mariano García during secondment	2018	Guimarães (Portugal)	Organisations, technical personnel

Activity Code	Performed activities: short description	Year	Location	Stakeholders target (if relevant)
O1 – Public talks/lectures/ discussions	International Colloquium – Lecture @University of Ljubljana: Disability as a litmus test for democracy. The International colloquium with the presentation of the publication Sledi v zraku/ Tracings Out of Thin Air (2018, published by Forum slovanskih kultur/ International Foundation Forum of Slavic Cultures, Ljubljana) is organized by Marina Gržinić (ZRC SAZU, Ljubljana) and Darja Zaviršek (Fakulteta za socialno delo, Ljubljana). Presenters: Cinzia Leone, Univ. of Genova: Disabled or Citizens:Is this Dilema Still Exist? Darja Zaviršek, Univ. of Ljubljana: The mystery of the delayed deinstitutionalization in postsocialist countries: case study Slovenia	2018	Ljubljana (Slovenia)	Dissemination within UL and invited Slovenian and International stakeholders
O1 – Public talks/lectures/ discussions	Participation – Incontro «Accessibilità. Concetti fondamentali e possibili applicazioni» ("Accessibilità digitale" – Federica Imperiale)	2019	UNIGE Genova (Italy)	University staff
O1 – Public talks/lectures/ discussions	The public Guarantee Committees and the prevention of discrimination related to disability	2019	Rome (Italy)	Public entities, National institute for insurance against industrial injuries, professionals, private enterprises,
O1 – Public talks/lectures/ discussions	Seminar at EASSW International Congress, Madrid 2019 – Anna Siri, Darja Zavirsek, Sonja Bezjak, Cinzia Leone	2019	Spain	Academia, Associations, Social Workers, Professionals, Private Organisations

Activity Code	Performed activities: short description	Year	Location	Stakeholders target (if relevant)
O1 — Public talks/lectures/ discussions	Presentation: *Perception and Perceptions in Architecture*, by Cristina Candito e Alessandro Meloni.	2020	Stockholm /online	Participants of RISEWISE JAM/ Online — Public
O1 — Public talks/lectures/ discussions	POSTER SESSION. Title: RISEWISE — SPECIAL NEEDS — Networking Sport and Technology to support Women with Disability by Sabrina Dapino, University of Genova	2020	Stockholm /online	Participants of RISEWISE JAM/ Online — Public
O1 — Public talks/lectures/ discussions	Risewise Jam: Organised full day program with abstracts, two presentation tracks, posters and an extensive accessible video exhibition and a website. All performed online in June 2020 with almost all partners in Risewise. Planned for 1.5 years	2020	Stockholm /online	Participants of RISEWISE JAM/ Online — Public
O1 — Public talks/lectures/ discussions	Writing master's thesis in DIGITAL HUMANITIES on the RISEWISE project, title «RISEWISE project: multidisciplinary research in the field of sport and rehabilitation». Discussion March 2021.	2021	Genova (Italy)	Academic

These have already resulted in new partnerships for new research paths, with close attention paid to ensuring that RISEWISE can be exploited on a long-term basis. For example, new project proposals have been submitted for research and innovation projects. These have been prepared in collaboration with NGOs and private businesses, with the aim of reaching out and physically touching the contexts needed and where research is called to help in a sort of co-creation process, where everyone is responsible for producing the common good and special needs are heard and assigned forefront importance, with stakeholders and professionals invited to take part in the creation and innovation process, according to the principles of RRI (Responsible Research and Innovation).

New research and innovation projects have been initiated as a result of the synergies and mutual better knowledge among partners, beyond the already above mentioned MILIEU H2020 project. Some other proposals have been also submitted in connection to the RISEWISE topics and overall partnership that may materialise during 2021 and beyond.

Performed outreach activities are in line with planning and have taken advantage of some specific assets of project partners including: the strong link with associations of women with disabilities, the close relationship with municipalities and local/national public authorities and the transversal expertise of project staff in the addressed domain. One example of this was the hearing at the Italian parliament, to which the project coordinator and author of this contribution was invited in October 2017 to speak about the topic of women and disabilities and employment policies in Italy.

Above is just a small part of the tireless work carried out externally, which the RISEWISE project has performed, also and despite the pandemic, which has naturally put a stop to public and in-person events and initiatives, as well as mobility exchanges between participants.

The Communication Reporting Tool of RISEWISE has been designed to collect all data and avoid any losses; it has proven to be an effective and user-friendly tool by which to gather information on regular basis and allow monitoring the progress of activities. Its effectiveness relies on the capacity of partners to track events and report data/information and on the conformity to the Key Performance Indicators used as a project reference. Covering 54 months, RISEWISE partners have implemented a wide range of actions to promote the project results, engage stakeholders and spread outcomes within and beyond the target users' community. The key performance indicators show that most of the activities have been properly triggered in order to cope with the mission of fostering and transfer the knowledge generated by the project.

All of the above shows how European projects can be strong drivers for change, aimed at facilitating the cultural change of the societies in which they are implemented, but only where they manage to create a strong bond with the local citizens, with those not in charge of works, with those who are not already informed about or active in the topic. Nor should the extent to which RISEWISE has worked to bring the scholars out of their ivory towers be underestimated, and have them enjoy permanent, extraordinary dialogue with the private sectors and associations. The best results stem precisely from what are classed as 'non-typical' projects, just like RISEWISE was both non-typical and innovative, bringing together different sectors and disciplines, which even stand on opposing shores, cultured people of different origin and educational backgrounds, far-off countries and varied personal situations, thereby reaching thousands of people.

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University of Genoa: Cristina Càndito, Isabel Fanlo Cortés, Nuccia Gianelli, Cinzia Leone, Laura Scudieri.

University of Brescia: Luciana Guaglianone, Paola Parolari, Susanna Pozzolo.

This book offers a complex and multifaceted understanding of disability by recounting and reflecting the experiences gained within the European project RISEWISE: Women with disabilities In Social Engagement, Horizon 2020, MARIE SKŁODOWSKA-CURIE RESEARCH AND INNOVATION STAFF EXCHANGE (RISE) 2015. By collecting a multidisciplinary set of contributions, many of which are conceived and developed adopting a gender perspective, it shows how the goal of full citizenship is still a challenge for many disabled people, especially women. At the same time, however, it aims to propose new reflections, methods and spaces for the inclusion of these people, starting from the recognition that disability is not a destiny, but rather the product of the interaction between personal impairments and contextual (i.e. social) conditions.

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