Functional diversity, a new term in the struggle for dignity in the diversity of the human being

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Introduction

Men and women with functional diversity form a group that has traditionally been discriminated in a different way to the other groups that have also undergone or still do undergo discrimination (women, Negroes, immigrants, etc.).

This discrimination has also been found even within those other discriminated groups, which have also forgotten to include their own members with functional diversity as part of their struggle.

The limiting or derogatory terms used for describing the group of women and men with functional diversity play a fundamental role in bolstering underestimation and thus maintaining said discrimination.

This article attempts to propose a new term for denomiating the group of women and men - “women and men with functional diversity” - representing the most forgotten and discriminated ten per cent of humanity throughout the history of almost all human societies.

What need is there for a new term?

It is known that words or terms are associated with ideas and concepts and that these connotations are not something random, but represent culturally accepted values of the object or organism named. These values are conveyed over time using words as a vehicle. In time, if we wish to change ideas or values, we will have no alternative other than changing the words that support and give life to them.

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1 We are grateful for the remarks and contributions of members of the Independent Living Forum, in particular Mª Ángeles Sierra and Rebeca Gómez.

2 The aim of this article is the justification of the introduction of the term “functional diversity” to replace others with pejorative semantics such as “disability”, “handicap” etc.. It is used from the beginning because the authors are persuaded that this is valid.
There are many words widely used in different spheres for denoting the group of women and men with functional diversity. If we use the basis of our own personal experience, the most widely-used one in Spain is minusválido (handicapped): viz., car parking spaces reserved for the handicapped, pensions for the handicapped etc. Both on our television and on the radio, and in the streets, we form part of the menos válido (less valid) group, the people who are in other words “worth less”.

Apart from this aspect, such terminology still endures in legal texts in this country, with the use of terms such as disablement, disability, invalidity (partial, total, absolute, serious invalidity), handicap and dependency.

Even in the very recent Act 51/2003 dated 2\textsuperscript{nd} December, on equal opportunities, non-discrimination and universal accessibility of women and men with disabilities, article 1 “Goals of this Act”, in section 2, keeps up the terminology without making any effort to modify this:\textsuperscript{3}

\begin{quote}
2. For the purposes of this act, women and men with “disability” shall be understood to mean those with a degree of “handicap” equal to or over 33 per cent. In any event, any Social Security pensioners who qualify for a permanent “disability” pension in the degree of total, absolute or serious “invalidity” and civil service pensioners eligible for an old-age retirement pension or for retirement through permanent “disability” for service or “incapacity” shall be considered as being affected by a “handicap” to a degree equal or over 33 per cent.
\end{quote}

Certain bodies connected with the world of functional diversity, aware of the fact that language produces, modifies and guides thought, have attempted to define new terms, in the search for a new social vision of this group.

In its last attempt the World Health Organisation (WHO) promoted the so-called International Classification of Functioning, Disability and Health (ICF), adopted during the 54\textsuperscript{th} World Health Assembly, held in Geneva (Switzerland) from 14\textsuperscript{th} to 22\textsuperscript{nd} May 2001 (WHO, 2001), which proposes the following conceptual scheme to interpret the consequences of health disorders:

\begin{itemize}
\item \textbf{Functional impairment} (replaces the term “impairment” as this had been used by the previous International Classification of Impairments, Disabilities and Handicaps ICIDH, of 1980): this is the loss or abnormality of one part of the body or of a physiological or mental function. In this context the term “abnormality” is used to refer to a significant deviation from the statistical norm (for example, the mean of the standardised distribution of a population).
\end{itemize}

\textsuperscript{3} The inverted commas, italics and underlining are from the authors.
• **Limitation to activity** (replaces the term “disability” as this had been used in the ICIDH): these are the difficulties that a person may have in the performance of their activities. Limitations to activity may be classified in different degrees, depending on whether these entail a more or less significant deviation, in terms of quantity or quality, in the manner, extent or intensity in which the performance of the activity by a person without a health disorder would be expected.

• **Restriction in participation**: this replaces the term “handicap” as this had been used in the ICIDH): these are the problems that a person may undergo in their involvement in living situations. The presence of restrictions in participation is determined by comparing a particular person’s participation with the participation expected by another without a disability in a particular culture or society.

• **Barrier**: these are all the environmental factors involved in a person’s context which condition functioning and create disability. They may include aspects such as for example an inaccessible physical environment, the lack of appropriate care technology, women and men’s negative attitudes to disability, and also the non-existence of services, systems and policies fostering participation.

• **Disability**: in the ICF; this is an umbrella term which is used to refer to impairments, limitations to activity and restrictions in participation. It denotes the negative aspects of interaction between the person with a health disorder and the environment (contextual and environmental factors).

We must recognise that this search for new concepts is a praiseworthy attempt to shift the “problem” of functional diversity from the person to the environment. However, if we analyse the terms used, we will see that they contain the words impairment, limitation, restriction, barrier and disability.

In the authors’ opinion, none of these terms is positive or neutral, for which reason they prove a vain attempt to change a reality in which the very authors of the terms themselves fail to see the side of functional diversity that is, at least, neutral or positive.

**Towards a new model, beyond the medical model and the social model**

At the Independent Living Forum we understand that functional diversity has nothing to do with illness, impairment, paralysis, backwardness, etc.. All this terminology stems from a traditional vision of the medical model of functional diversity, in which a different person is presented as someone biologically imperfect who needs to be restored and “fixed” in order to reinstatetheoretical patterns of “normality”, which have never existed and which are not likely to exist in the future either, precisely due to medical progress.
We understand that women and men with functional diversity are connected with societies, which, whilst being intrinsically imperfect, have established a model of perfection to which no specific member of these has access, and which define the way of being physically, sensorially or psychologically, and the rules of social intercourse; and that this model is connected with the ideas of perfection and “normality” established by an extensive power-wielding sector and by the concept of merely quantitative majorities.

These majorities have endured for centuries, which is why attempts of terminological changes have had so few results, since these have mostly been made through the mental fog caused by years of oppression, discrimination and segregation.

The attempts to shift all or part of the problem to society, by proposing terms such as “restrictions to participation” have not been successful in the least because, after all is said and done, society continues to think and believe that a good deal of the problem lies within the subject with functional diversity. In fact, as a general rule, women and men with functional diversity themselves prefer the terms which designate their impairment directly such as deaf, blind, quadriplegic, etc., because they reflect a reality of their own lives and many of them no longer see the negative value in this.

The attempts to shift the “problem” fully to the person or fully to society have therefore not been a great success.

In this proposal we seek an intermediate area which does not shun the real situation. We, women and men with functional diversity, are different from most of the population, from the biophysical standpoint. Due to having different characteristics, and given the conditions of the context generated by society, we are forced to do the same tasks or functions in a different way, sometimes through third parties.

Hence, a deaf person communicates through the eyes and by signs or signals, while the rest of the population does so basically through words and hearing. However, the function that these perform is the same: communication. To move around, a person with a spinal injury customarily uses a wheelchair, while the rest of the population do so using their legs: the same function, but in diverse forms.

For this reason the term “functional diversity” corresponds to a reality in which a person functions in a different or diverse way from most of society. This term takes into consideration the person’s difference and the lack of respect of majorities, who fail to consider this functional diversity in their social and environmental constructive processes.
A matter of discriminating majorities

It should be taken into account that a person “joins” the group of women and men with functional diversity when she or he cannot perform the same functions in the same ways as the majority. If the majority of human beings, for example, would not see, we would be different to the way we are, and would probably have a much more highly-developed sense of smell and sense of touch. Furthermore, the environment created would be very different: computers would not have a screen, there would only be radio and no television, there would not be ink-writing and possibly relief writing would have been developed, and media for recording and reproducing sound would be much more highly developed.

Hence, the way we construct our environment depends on what we have been taught is “normal” in the statistical sense, and this “normality” changes with time. It should not be forgotten that what is considered “normal” is a statistical fiction whose nature is merely instrumental.

In this respect we have created a society in which the possibility of fully integrating diversity in all its spheres (education, work, building, transport, communication, information, leisure etc.) has not been contemplated.

Quite the opposite indeed, discrimination against everything that is different has been a dominant feature in building our social, corporeal and mental context, with attitudes of exploitation, exclusion, denial of rights being adopted, assignation of passive roles, of slavery and generation of conflicts. It is enough to think of the discrimination and abuses that have been suffered by American Indians, Negro women and men, women and men with no economic resources, women, children, etc..

From these layers of discrimination, which still exist today and which vertically stratify society, the last one to be revealed was that of women and men with functional diversity, around the late 1960s, when the Movement for Independent Living emerged at Berkeley University, the first in the struggle for human, social and economic rights of women and men with functional diversity.

This discrimination is what forces a different group, like that of women and men with functional diversity, to gather together and seek identification as a human group which has to fight to achieve full citizenship and effective equality of rights
and opportunities in society, to become a group of people whose diversity is appreciated as a value, and to find their place in this world.

Analysis of the term

The term women and men with functional diversity is a new one, and was proposed and started to be used at the Independent Living Forum⁴ in January 2005⁵. We understand that this is the first time in the history of the world that a change to a non-negative terminology for functional diversity has been proposed, and that this proposal comes exclusively from women and men with functional diversity. We attempt to go even further and avoid the social strategy of “deviationism”, the one that produces the “them” and “us” groups, to put forward that functional diversity is something inherent to the human being and that on many occasions it may be temporary or circumstantial, which is the reason for its emergence as a social conflict which directly, indirectly, temporarily or definitively affects us all.

The term consists of four words, and that initially makes it more complex to use than the term that it is intended to replace: people with disability. Experience has nevertheless shown that in a very short time women and men who accept the term use it fluently and naturally both in written and spoken language, the acronym PFD even having been coined from the initials of each word (Person with Functional Diversity).

The use of the words “women and men with” keeps up the previous tradition of stressing the concept that we are women and men and thus we ought and want to reinforce the dignity inherent to our essence as human beings who are born and desire to live with the same rights and dignity as all the others, as established by the UN⁶:

“All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.”

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⁴ The “Forum for Independent Living” is a virtual community, set up in mid 2001, constituting a venue for protest and debate in favour of the human rights of women and men with all kinds of disability in Spain. It can be found in http://es.groups.yahoo.com/group/vidaindependiente/. This philosophy is based on the Movement for Independent Living, which started in the U.S.A. in the late sixties.

⁵ Message 9622 of the virtual community of the Forum for Independent Living http://es.groups.yahoo.com/group/vidaindependiente/messages/9622

The word “diversity” is defined in Webster’s dictionary\(^7\) as:

**Diversity** n.
1. The state or fact of being diverse; difference, unlikeness.
2. Variety, multiformity.

Our aim by using this word attempts to reflect exactly that: difference, dissimilarity with what is usual in the statistical majority of the human race.

The word “functional” is defined as:

**Functional.** adj.
1. Of or pertaining to a function or functions

For this word we use the first meaning of the word function:

**Function** n.
1. The kind of action or activity proper to a person, thing, or institution.

We specifically refer to the first concept: action or activity proper to a person, the activities that human beings customarily perform as living creatures (for example, moving, seeing, communication, etc.). It should be noted also that functions are the result of actions of the organs or parts of our body (for example, eyes, ears, legs, brain etc.)

As we can see, the term is semantically correct in English and covers all the concepts that we wish to express, except for discrimination, but the traditional connection between human diversity and social discrimination means that including this aspect in the definition of the term is not necessary, as we are struggling for a time to come when discrimination disappears, and functional diversity is accepted as a further part of the wealth in the diversity of the human race.

As regards the order in which the terms diversity and functional are used, the following argument, expressed here by Carlos Egea\(^8\), could be put forward.

“*What I do not agree on, is the order in which the following two terms are used: “functional” and “diversity”. It is clear that the promoters of the use of this terminology wish to stress the fact that there are women and men who “function” (act, perform activities, interact, relate with each other, etc.) in a “diverse” (different, in another way, etc.) manner. I could not agree more with the root of the idea: there is a group of women and men in this society who function differently, or, to take it a little further, all of us, absolutely all of us, function differently.*

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\(^7\) Webster’s dictionary, 1989 edition.

\(^8\) Message n° 12,400 of the Independent Living Forum.
http://es.groups.yahoo.com/group/vidaindependiente/message/12400
The problem is that we have forgotten our grammar lessons on nouns (or subjects) and adjectives (or qualifiers). In the term whose introduction is being attempted, “diversity” is the noun that expresses, as the Dictionary reminds us, variety, unlikeness or difference, and the word “functional” is the adjective which, in the matter now concerning us, expresses belonging to or connection with biological or psychic functions.

That is, in the application of “person with functional diversity” we are expressing through the noun that the substantive part lies in the distinction applied to biological or physical functions. It would almost appear that we are undermining our own position.

But if the terms are turned around (as I have already done in some communications) we would be defining the intended change being put forward rather more accurately. If we talk of “women and men with diverse functionality” (it might look the same but the substantive and adjective elements are swapped) we are placing the emphasis on the fact that the substantive aspect is the functioning (functionality being the noun expressing the quality of the relative aspect of biological and psychic functions) and the adjectival part is the diverse aspect (expressing the different nature or form of the functionality that this qualifies).

Whilst accepting his reasons as fully valid, we nevertheless disagree with this recognised expert for three basic reasons:

- We do indeed wish to stress our difference, because this is a reality inherent to our lives, we are proud of it and find full dignity in this difference, which we do not deny.

- When it comes to coining a new term, how easy this is to utter and quick to assimilate are highly relevant matters. As we see it, “women and men with diverse functionality” is much more complex to pronounce than “women and men with functional diversity” and it would thus be more difficult and slower to be taken up.

- It should also be considered the possibility of exchanging this with the previous term: “disability”. For example, the conversion from “functional diversity” is direct: “Women and men with disability” -> “Women and men with functional diversity”, “Policies on disability” -> “Policies on functional diversity”, “Women and men with intellectual disability” -> “Women and men with intellectual functional diversity”, etc.. However, replacing this with “diverse functionality” seems less intuitive: “Women and men with disability” -> “Women and men with diverse functionality”, “Policies on disability” -> “Policies on diverse functionality”, “Person with intellectual disability” -> “Women and men with intellectual diverse functionality”.
Diversity within diversity

As has been stated at several points in this text, when it comes to considering the diversity of gender within the group, women and men with functional diversity, or men and women with functional diversity, should be used.

At the Independent Living Forum we understand that what makes the group a whole is not its internal diversity, but the social discrimination undergone everyday by women and men with functional diversity, including all those who are - circumstantially or provisionally - suddenly immersed in a hostile environment which denies them their citizenship.

We nevertheless understand that the solutions needed to eradicate this discrimination ought to take into account the specific diversity of groups of individuals, that we can group together and denominate as persons with: physical functional diversity, visual functional diversity, auditory functional diversity, mental functional diversity, intellectual functional diversity, organic functional diversity, circumstantial and/or temporary functional diversity, etc..

When tackling the linguistic diversity in the Spanish State we could coin terms such as “diversitat funcional” in Catalan, “diversidade funcional” in Gallego and “funtzionaltasun aniztasuna” in Basque.

Crossing our borders and taking advantage of the language knowledge of the authors, merely with a view to proposing and not imposing, as we have done in this whole document, we would venture to propose “functional diversity” in English, “diversité fonctionelle” in French and “diversità funzionale” in Italian.

Conclusion

In this article we have identified three elements which define the members of a group fighting for its rights as different:

- Bodies in which organs, parts or the whole body function differently because they are internally different.
- Women and men who, due to the different way their bodies function, perform their daily tasks (moving around, reading, gripping, dressing, going to the toilet, communicating etc.) differently. (We could say, women and men who function in another manner).
- A group discriminated against for any of the two reasons given above.
The way we at the Forum for Independent Living propose denominating this group, to which we belong, is **women and men with functional diversity**, as we understand that this is the first denomination in history in which the vision of a human reality is not given negative or medical connotations, and in which the emphasis is placed on its difference or diversity, values which enrich the world in which we live.