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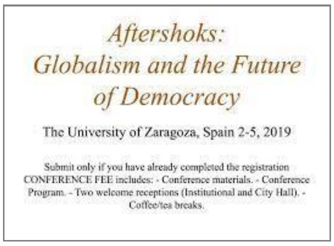

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The disability body as a social construction: between experience and formal normative

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Introduction

This paper provides an overview of a new approach proposed in Spain in 2006 by the authors of *The diversity approach* (PALACIOS y ROMAÑACH CABRERO, 2006).

In order to support this approach, a series of normative arguments and structural conditionings that support that discrimination, shall be proposed. They will be based on critic sociological theory, mainly based on Pierre Bourdieu and Michael Foucault ideas, although a broader development on these ideas may be found in: FERRANTE y FERREIRA (2007, 2008), RODRÍGUEZ DÍAZ y FERREIRA (2008) and FERRANTE (2008).

Functionally diverse (disabled) people have been systematically discriminated and undervalued along history. Sometimes, as it happened during the Nazi era in

Germany, they were murdered in a vane effort to remove their “imperfection”. Even nowadays, their reality is fully discriminatory and contemporary theoretical approaches to that reality have not proven to be enough to remove discrimination and to face the new bioethics challenges.

It is possible that this theoretical insufficiency might be partly due to the fact that not enough attention has been paid to a determinant aspect of functional diversity personal experience: the body. A body not defined as a biological reality, but as social control tool:: functionally diverse people embody domination logics through an specific *habitus* (BOURDIEU, 1991) in which *good, beautiful* and *healthy* normative is registered; on the other hand, the body is central to regulatory and political control issues that come from *Bio-politics* and *Normalization Technologies* (FOUCAULT, 1992; 1998).

Considering the body as an instrument that articulates domination logics, dualisms that generally cross disability analysis from a critic perspective are suppressed; as pointed out by HUGHES and PATERSON (2008), body omission in those analysis de-biologizes the problem and brings it to a political level, but at the same time it maintains the social and medical model dichotomy, reproducing it in cathegories used through a series of oppositions: body/society, nature/culture, medicine/politics, therapy/ empowerment, illness/oppression. Showing the social dimension of the body eliminates those oppositions revealing their arbitrariness.

Therefore, we propose a new approach to disability, with functional diversity as a starting point, and based on Human Rights, human dignity, bioethics and sociological theory.

A first model or approach could be named as the *cut out* approach. In this model, functional diversity is based on religious grounds and these different people are considered unnecessary due to different reasons: they do not contribute to community needs, because they are evil messages carriers, because they the result of gods anger or because they are disgraced and their life is not worth living.

As a consequence, society gets rid of functionally diverse people cutting them out of society through eugenic policies or by placing them in specific sites designed for *abnormal* and poor people, having a common treatment based on submission and dependency as it is done in the case of other people that need assistance or charity.

The second model is called the *rehabilitation* model. Under this conception, the origin and causes of functional diversity are not religious, but scientific. Functionally diverse people are not considered useless or unnecessary, as long as they are *rehabilitated*. In this model or approach the main goal is to *normalise* men and women who are different, even if it implies hiding the functional diversity's difference or making it disappear. It is basic to have the person rehabilitated and the success on this rehabilitation is valued according to the skills acquired by the individual. In this model, the body already appears as a central issue: *rehabilitation* is about trying to bring body abilities as close as possible to a standard (even in mental and intellectual diversities, rehabilitation acts on the body trough pharmacology).

The third model or approach is called the *social* (or Independent Living) model. In this approach, the origin of functional diversity, instead of providing religious or scientific reasons, is considered to have *social* reasons; furthermore functionally diverse people can contribute to society in the same way as the rest of men and women who are not functionally diverse, respecting their value as different people.

On this third model, discrimination based on the rehabilitation model body treatment, can be questioned. When the origin of functional diversity is moved from the person (corporal imperfection) to social structures (normative practices and definitions of the body), arbitrariness in the norm that regulates rehabilitation practices is revealed. "Imperfection" is not the result of a person's intrinsic deficit in relation to a universal standard, but it is a result of the arbitrary action of imposing a standard that is a result of historical, political, economical, and cultural processes, and provides services to determined interests. Different environmental conditions (habits, production activities, esthetic preferences, sport practices, cultural stereotypes, etc.) imply different perfection standards: the goal is not then to correct a person, according to the standard, but to correct the standard adapting it to people's reality in which it shall be applied. Those who rehabilitate should be rehabilitated in their perceptive and interpretative schemes and practices.

The result seems to be reassuring and modern occidental societies rest without fear developing social policies based on those models that are perceived as a benefit for society as a whole. Nevertheless, when analyzing social reality in our environment, mainly to Spain at the beginning of the XXIst century, barely visible incoherencies are detected that indicate how deep the *rehabilitation* model is established and the presence of an important discrimination that is hardly perceived. These incoherencies can be found in daily life, in juridical and bioethical contexts and also in the failure to abide what is established by laws that guarantee the rights of people who are discriminated on the grounds of their functional diversity.

In daily life many discriminatory facts can be found, but railway transport will be used as an example.

Railway accessibility is mandatory in the *Handicapped Social Integration Bill* (*Ley 13/1982, de 7 de abril, de Integración Social de los Minusválidos (LISMI)); Railway accessibility is stated in article 59 and Seventh Final Disposition of the Bill.*. This Bill was approved in 1982. Therefore, 25 years ago it was established by law that railway transport should have been fully accessible in 10 years (1993).

This discrimination can also be found in some other type of laws. The 9/1985 Bill on abortion introduced article number 417*bis* in the Penal Code. In this article, abortion is not punished in some cases. Those cases are: great danger to the mother's life, pregnancy by rape, and the functional diversity of the fetus. In the case of rape, the term on which abortion is allowed is 12 weeks. But in the case of a functionally diverse fetus, the term is extended from 12 to 22 weeks. This issues is not raised to promote discussion on abortion, but to point out that in countries like Spain, where abortion is not allowed as a rule, there exists a clear discrimination on the value of life of people with and without functional diversity, that is reflected in a difference the term in which it is permitted. This difference persists in the new that is actual proposal on abortion law that will be approved in Spain in 2010, even when all parlamentaries have been warned abuot this discrimination by spanish independent living activists.

We can also find discrimination of functionally diverse people in the bioethics field. As an example, the new genetics has raised many questions around functional diversity, and a new eugenics threatens our society.

This threat has been already studied by the functional diversity official NGOs. That study can be summarized in the following phrase: "We are threatened when Peter Singer, a professor of bioethics, writes: "It does not seem quite wise to increase any further draining of limited resources by increasing the number of children with impairments." DPI (DISABLED PEOPLE'S INTERNACIONAL) (2000) These statements are frequent in the bioethics field and they clearly discriminate the value of a person's life related to whether that person is functionally diverse or not.

But discrimination comes not only from laws or bioethical ideas: proof can be found in functionally diverse people's daily life and their personal experience. These experiences happen in personal relations with other people and with "experts" that "treat" them (mostly non functionally diverse), the existence of these experts indicates the primacy of the rehabilitation model in functionally diverse people's daily life. In first place, as it is generally understood that they are need, and second because it is generally accepted that they should mainly be doctors, psychologists and social workers.

Doctors categorize, classify and diagnose clinical forms of functional diversity according to a “universal” health standard. In this way functional diversity is automatically identified with disease and promoted actions are oriented to cure. Psychologists clinically categorize, classify and diagnose functional diversity according to a “universal” mental ability standard to assume a disease diagnosed by doctors and promote actions that are oriented to adaptation. Social workers clinically categorize, classify and diagnose functional diversity according to a “universal” special needs standard to be provided to people with more or less mental ability, according to psychologists, to assume a disease diagnosed by doctors and promoted actions are oriented to “dependency” logics.

In their relation with experts, functionally diverse people receive a triple normative categorization always that places them outside the regulation Standard (non healthy, non adapted, non independent). The starting point is a medical diagnosis centered on the body: a functionally diverse person is defined by having an unhealthy body, and it’s there where action should be taken to bring it back, as much as possible, to the health standard that defines him or her as ill.

ICF (WHO, 2001) has provided institutional validity to that normative foundation. (FERREIRA, 2008; RODRÍGUEZ DÍAZ and FERREIRA, 2008). Even though it accepts a contextual dimension in functional diversity definition, that is no longer an individual attribute, it still supports the idea that this is a *consequence* of a *health state*. ICF becomes then the expression of biopolitical regulation mechanisms (RODRÍGUEZ DÍAZ and FERREIRA, 2008).

As a result of this relation with experts, functionally diverse people assume their condition of unhealthy body owners. And that normative imposition is then moved to other personal relations. This happens because collective representation and its associated common practices are also regulated by that normalization that comes from experts discourse. Furthermore, this normalization is associated to ethic and aesthetic values: that unhealthy body is also perceived as ugly and bad. Health, beauty, and goodness are interweaved in our body representations (FERRANTE and FERREIRA, 2007), promoted by mass media and the success logic established by the market capitalist economy (in which ethics and aesthetics can be values themselves). Functionally diverse people social relations are then conditioned by this normalization discourse, applied to daily practices and representations. Labor and education discrimination is, to a great extent, the result of the general acceptance (including functional diverse people) of the idea of an imperfect body being insufficient to attain goals that can be reached by a healthy body. Many functionally diverse people families assume that they (functionally diverse people) will not be able to reach minimum education requirements, and they succeed in making it happen; many education professionals assume that functionally diverse people will not be able to stay afloat, and they act in a way that they succeed in making it happen; many employers assume that functional diverse people will not be efficient employees and they act in a way that they succeed in making it happen; many people will assume that a functionally diverse person will not meet the requirements to maintain an adequate personal relation and they act in a way that they succeed in making it happen; many functionally diverse people will assume the same things that their families, educators, employers and other people assume, and they will act in a way that will make those presuppositions happen.

Functional diversity discrimination is expressed and happens in daily experiences, because it is there where normative regulation that comes from experts discourse is valid, and that regulation is based in the idea of classifying the body as an unhealthy body. When this idea reaches collective representations and daily practices, that body is associated with the ideas of bad and ugly. As we shall see, this is the foundation where a very specific *habitus* (BOURDIEU, 1991) is generated, that will configure functionally diverse people's practices: the *disability habitus* (FERRANTE and FERREIRA, 2007, 2008; FERRANTE, 2008).

Under this perspective, it is assumed in first place, that material conditions exist that promote the social construction of disability as oppression and material conditions derived from strictly economical requirements as well as from the ideology that builds them in the capitalist system (OLIVER, 1990); and, in second place, that on top of that material base, non-material structures take place the are the ones that explain precisely *how* that social construction happens. Those structures act at the level of personal disability experience and imply social factors (SHAKESPEARE and WATSON, 1996) and also have effect at attitude level (FINKELSTEIN, 1980). From our perspective it is the body, as it articulates those social structures, that links the cultural and material planes, evidencing its mixture in personal experience. It is not necessary to choose a materialist or post-modern interpretation: both contain part of the "truth". We bring to evidence that both planes "get-together" in daily experience of disabled people, through certain specific techniques of power exercise (FOUCAULT,1992; 1998) and certain predispositions that have filled peoples heads in a lasting way (BOURDIEU, 1988; 1991; 1999) and that have the body as a subject of control and domination.

We think that our contribution is complementary to both perspectives and it brings complexity gathering both Analysis axis. As pointed out by BARNES (1998), a cultural version, as proposed by Shakesperare, may lead to a false universalism in relation to the insufficiency conception, and, at the same time, each may convert the disability phenomena in a mere product of thought. But, in a similar way, a strictly materialistic vision cannot explain subjective processes that those who structure promote to sustain themselves. We insist in suppressing the additional dualisms applied to disability analysis: the body is affected by economic and social processes and also by the structures linked to them: the body is society.

As it has been shown, using the current models on functional diversity has lead to discrimination in all fields, a discrimination that is not clearly perceived by society. For this reason, it becomes essential to find out what's missing in those models and propose solutions that will make discrimination disappear in the future.

Mistakes and solutions

The reality found today is based on a set of conceptual mistakes, many of which, although not all of them, are based on the scarce development of the social or Independent Living movement in this country (Spain).

One of the mistakes, as we have pointed above, comes from mixing two concepts: *illness* and *functional diversity*. Modern society keeps on perceiving functional diversity as illness, something to fix or cure through medical research. As a consequence, functional diversity is classified by organic differences, and administration certificates needed for social benefits are issued on the basis of a person's medical and functional reality. This is not just a conceptual confusion, but, as stated above, it also affects daily experience, through collective practices and representations, conditioning functionally diverse people's relations, educational, labor and affective opportunities. This confusion reveals the body as a central issue for domination, regulation and control in occidental societies.

On the other side, there has been a great progress concerning this issue in laws and international documents. In them, a functionally diverse person is considered to be discriminated, in an attempt to cooperate in a process called functional diversity *demedicalization.*

This *demedicalization* should lead to the development of policies and measures that would provide solutions for people with any kind of functional diversity, reaching that way a true *transversality*, in a way that proposed solutions would not be partial or specific for a type of functional diversity. Under this approach, in the case of trains, it would not be enough to make them wheelchair accessible, but it would require trains not to discriminate diverse intellectual, visual or hearing people too.

Nevertheless, demedicalization will not be fully effective until it reaches social representations and practices. Institutional measures can't be restricted just to legislation and policies; eradicating the concept of functional diversity as illness implies erasing its founding, the regulating norm that comes from medical expertise and has the body as a central issue. It should be noted that there exists no valid universal norm on health and that health and illness are relative concepts that vary according to existence conditions (they change with history, culture, economy, politics). This implies too transforming our conception on illness: health must be assumed, above all, as a human experience of the body, (not as a medical definition); the continuous perfect health is abnormal, as the experience of living includes illness, and overcoming it enriches our existence. Health and normality ideas are relativist and individualist, a consequence of emotive, active, sensory education (Canguilhem, 1970:123-125). In order to transform our health and illness conception, as a body extension, educational measures are needed, a broad cultural transformation of its associated values. Educational measures that will provide freedom, as they would act against domination, control, and regulation logics articulated around the body. Measures that are difficult to adopt, as that disciplinary logic is a powerful mechanism to sustain social order (many economic and political interests would be questioned).

There are also two concepts that are consistently mistaken: *moral autonomy* and *physical autonomy*. This confusion is also inherited from the *rehabilitation* model. The ability to perform physical tasks (eat, get dressed, run, etc.) has no relation whatsoever with the ability to make decisions concerning a person's own life. A person with a quadriplegia, as it is the case of one of the authors of this text, may not be autonomous to perform many tasks but, at the same time, be fully capable of making his or her own decisions. The institutionalization of persons with low physical autonomy and full moral autonomy is a consequence of confusing the two concepts. Institutionalized people have been therefore been deprived of carrying a life based on equal opportunities, a life for which they were prepared.

This second confusion is a direct consequence of the first one: the conception of functional diversity as illness, through medical normalization of the body, refers to physiological imperfection; but, as it has been pointed out before, in actual representations of the body nowadays, health, ethics and esthetics are intertwined in such a way that an imperfection in one of these issues is automatically extrapolated to the other two: lack of physical autonomy (that is translated to the health plane by medical criteria) is automatically associated to lack of moral autonomy. This means that a "defective" body is an expression of an integral person's defect, a constitutive insufficiency that affects all live spheres. Presupposing that a person that has no physical autonomy has no moral autonomy, considering both terms are equivalent, is an unquestionable symptom of domination, regulation, and submission operations exercised on the body, as a domination, regulation, and submission access point to a person.

From a certain point of view, functionally diverse people institutionalization due to the consideration that they have no moral autonomy is a "negation" operation: making those bodies invisible allows the persistence of a normative fiction of the healthy-beautiful-good body as a regulating norm, and at the same time a state of things is "naturalized", that in reality is the result of calculated strategies (the absence of people in society because they are disabled is assumed as natural, when it is the other way around, they are confined because they are considered disabled.

In order to avoid these discriminatory realities, a new approach to social policies that eliminate this confusion and promote *deinstitucionalization* of functionally diverse people of any age is needed. Furthermore, it will be necessary that those policies be accompanied by a profound change in functional diversity's common representation schemes; a change that implies questioning *symbolic violence* (BOURDIEU, 1988, 1997, 1999); an idea that supports domination logics that traverse actual normalized representations and practices of the body. In that way functionally diverse people will be able to develop community life, as stated in the UN Convention for people with disabilities (UN (2006): Art. 19: Living independently and being included in the community).

Diversity model, a new approach

Diversity model in relation to prior models

Following the tracks of the social model, from which it inherits a great amount of ideas and founding, the diversity model rejects the *cut out* medical, as it regards functional diversity as a part of the human diversity that enriches humanity and society. It therefore vindicates the right to live of functionally diverse people, and furthermore, it provides bioethical founding to maintain this vindication when facing new bioethical challenges (euthanasia, embryo selection, gene therapy, etc.), even beyond a Human Rights approach (ROMAÑACH CABRERO, 2009).

In the same way, the diversity model, as the social model, diverges from the medical model, as it considers functional diversity a social issue, related to Human Rights, on which it is based. It should be noted that the Convention on the rights of people with disabilities, that is part of the Human Rights system is itself based on the social model (PALACIOS, 2008). Therefore, it can be established that the diversity model is itself based on the social model, and rejects a medical perspective and approach as the unique way to describe and provide solutions to a far more complex issue, a human persistent reality of a group of people that have discriminated and whose lifes have been less valued through history.

The key issue is then what makes the diversity model different from the social model.

In a way, the new roots for the diversity model can also be found in an Affirmation Model of Disability (SWAIN, FRENCH, 2000) where a non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective, for disabled people grounded in the benefits of lifestyle and life experience of being impaired and disabled, is stated. Other authors (OLIVER, 1983; ZOLA, 1983) provided the idea that modern society failed to recognise or accommodate the human diversity associated with impairment. And other changes, such as wording change, have their roots in the idea that language matters (COLERIDGE, 1993).

Concerning the eternal and outdated debate on impairment/disability/handicap, and following some authors ideas (BARNES 1991) and a human rights approach, the diversity model considers there is only functional diversity (organs, minds, or bodies that perform functions in a different way) and social discrimination on those grounds. A discrimination similar to the one suffered by other groups such as women, children, migrants, differente races and, etc. that have been subject of specific human rights Convention.

Diversity and Dignity. Important shifts from social model.

Prior mistakes are a consequence of the scarce implantation of the social model in Spain, but changes have already been proposed and accepted, at least formally. Nevertheless, the diversity model proposes new and relevant changes or shifts.

The first change comes from language; words are a powerful tool to change ideas, and thoughts as stated by L.S. Vigotsky (VIGOTSKY 1985). The social model is not been able to shift away from a negative wording perspective of functional diversity human reality .

Colin Barnes accepts the UPIAS definition of disability as a part of the social model (Barnes 2007):

> “In contrast to previous definitions UPIAS had re-defined ‘disability’ as something imposed on top of people with ‘impairment’s’ lives, by a society that is intolerant of any form of biological flaw whether real or imagined (UPIAS, 1976).”

We can see in this text that, although the main idea of the social model provides a very important step, by making functional diversity a social problem - not a problem of the individual - the words “disability” and "flaw" still maintain a negative view of functional diversity. It accepts that ability is the core issue, in this case provided by an oppressive society, and that functionally diverse people have a flaw.

In the diversity model, the idea of imposition or oppression is substituted by discrimination, and the negative words are eradicated and the "flaw" or "impairment", are substituted by the words “difference" or "diversity".

Furthermore, the diversity model, although it maintains discrimination as a key issue of the model (it is based on external or legal dignity that implies same rights, non-discrimination and equal opportunities), it also sustains, as a key issue, the essence of diversity and the diversity within diversity, accepting different words for specific diversity types, e.g. visual functional diversity, physical functional diversity, intellectual functional diversity, etc. in this way one of the most common critics and pointed out critics of the social model is solved (SHAKESPEARE, T., WATSON, N. 2002).

The diversity model understands the different solutions must be provided for different diversity's, but that they all share a common discrimination.

The diversity model goes beyond the *ability* paradigm, whether it may depend upon society or the individual, as it is not useful for the new bioethical challenges and it has been imposed by prior models in a vane effort to become like the others.

The diversity model puts aside the *ability* paradigm, as a preliminary step to put aside medical normalization. The ability/dis-ability binomial is conditioned by presupositions on a determined universal standard way to function of the human body; but body abilities are defined in relation to historical contexts (economic, historic, cultural) in which the human being must live. Making *ability* a core issue would imply a debate on structural conditionings imposed to human body in determined existence conditions, and the outcome would be a great variety of conclusions, depending on contexts (specially national ones). On the contrary, diversity is a generic characteristic of most of the modern societies that includes many spheres (ethnic, cultural, religious, aesthetics, etc.)

In that way, diversity is accepted as a fundamental part of reality that provides richness to a society in this model. In the general context of the so called globalization, we have access to many manifestations of what we take as ours: different languages, cultures, ways of life, art movements, political models… difference, diversity, contact with what is supposed to be alien to us, enriches daily our experience, and we learn from it. The goal is then that functional diversity be assimilated as one more manifestation of that diverse and heterogeneous wealth of human coexistence. Functional diversity implies different ways (neither better nor worse; neither more capacity, nor less) to live daily; it expresses the creativity of those who must do daily things in a different way of what is considered standard, because they require non conventional tools (both human and technical).It expresses potential creativity of the group in a positive way; as long as all negative connotations, still associated to the conception of functional diversity as illness, are abandoned. In this case, the body is no longer a submission and control object, and becomes a potential innovation device, in a transformation, advance and improvement platform, that improves society.

We live in a society conformed by people who are functionally diverse during many periods of their own life. A society in which the number of people discriminated by their functional diversity increases as a consequence of the aging process. A society that also causes functional diversity due to its own peculiar way to function (traffic and labour accidents, malnutrition, poverty, wars… are factors that cause functional diversity): society not only hosts functional diversity, it produces it.

In the new model, the paradigm relies on diverse people's *dignity*, in this case functionally diverse people's dignity. A dignity that is inherent to all human beings and that is not linked to *ability*. In the concept of *dignity*, a key to nowadays incoherencies and discriminatory realities can be found.

In order to promote a change, it is indispensable to eradicate from language concepts related to *ability*, looking for a new term in which a person may find an identity that will not be perceived as negative. The proposed term in the *diversity model* is *people discriminated on the grounds of their functional diversity* or, in short, *people with functional diversity*. The term functional diversity (diversidad funcional) was prposed the first time by Manuel Lobato an Javier Romañach on may 12th, 2005. Since the day it was proposed, the term has disseminated fast and has generated a new identity in which diversity, and its inherent wealth, have become a key issue. In in January 2010, a search in Google of the term “diversidad funcional” (in Spanish) turned out with showed 68.600 references, whilst the same search done in February 2007 showed 26,000 references and in December 2005 showed 705.

The functional diversity concept has some analytical problems that should be analyzed. The “diversity” concept is too generic and could lead to non adequate assimilations with other different realities; this implies an analytical specification and singling out tasks. On the other hand the “functional” concept can be related to certain social science theoretical trends that would begin in Durkheim’s positivism, and it should be straightened and clarified that it is referred to an existence condition of a person (in his or her daily life) and not to an structural quality of the social system in which the person lives (as it would be derived from functionalist approaches).

Nevertheless it is a considerable advance, at least in two ways: first, it is a “positive” definition that breaks a tradition of defining in opposition and in a negative way this group of people; it is also an “inclusive” definition, as it describes an existence condition that is common to nowadays societies. Second, it has been decided and promoted by the same people the concept defines; it was born in the independent living movement in a spontaneous way; it has been a decision of the group, and is therefore an expression of their ability to control their own life. It is then a concept created outside the instances that exercise, through normalization strategies, institutional practices that create functionally diverse people discrimination. It is a concept that has the reflexive condition of naming a potentially creative reality, and is, at the same time, an expression of that creative potential.

The identity generated by the term has required, in a first approach, the analysis of the idea of dignity, a complex, polymorphous concept in which many dimensions, starting and end point, get mixed. Dignity is therefore many things, many perceptions, and above all, hard to simplify and apprehend.

Two types of dignity, two ways to defend dignity

In the diversity approach, a separation of the concept of dignity in two branches: *intrinsic dignity* and *extrinsic dignity*, is stated, and a different dialectical battlefield is chosen for each one. Dialectical battlefields where the instrumental strategies can be developed to allow a global defence, are proposed.

This is no random division, as it unifies two types of defence of disabled people's dignity that have not been completely successful so far.

In order to define *intrinsic dignity*, we follow María Teresa López de la Vieja:"«dignity» is synonymous of liberty, autonomy, integrity that deserves attention and respect. It is given to beings with an intrinsic value. A human being should be treated as a goal in itself, as stated in the Kantian formula. It indicates that human beings have a superior value that is independent of circumstances. That is why we usually speak about its «inviolability» or about an «inalienable» value. Those characteristics are reinforced in the «sanctity of life», a concept that has been used sometimes as a synonymous of «dignity of life». Although the first concept, sanctity, is more closely linked to the religious tradition of dignity" (LÓPEZ de la VIEJA, 2005:83).

In order to defend *intrinsic dignity* it becomes necessary to participate in the conceptual battlefield in which this concept is debated today: bioethics. The fight for dignity in this field is just started for people discriminated by their functional diversity.

Extrinsic dignity is a more instrumental than theoretical concept, and depends on the relation of a person with the rest of society, and therefore on the rights that each individual enjoys, taking as starting point the fundamental rights: Human Rights. Its conceptual battlefield can be found in *Rights and Law*,. in the chance to enjoy an exercise in equal conditions the fundamental rights.

The fight for dignity in this field has been going on for many years now but has not been a complete success for people discriminated by their functional diversity.

One of the main tools for this fight for rights is the new U.N. Convention on the Rights of Persons with Disabilities. Nevertheless, the fight to establish as a reality all that is written in laws, is still to be fully developed in Spain. It may be possible that once the *intrinsic dignity* is recovered through bioethics, people with functional diversity will find new energies to perform that task.

When people with functional diversity recover their *intrinsic dignity* and perceive themselves as equal, they will be better prepared to fight for the values that support both types of dignity.

To achieve that, both battlefields of debate must be used: bioethics and Law in a quest to obtain full dignity for all functionally diverse people, and by extension to everyone in society.

The need to work in the bioethical framework

The fight for Human Rights has been going on for some years now, as it was born with the social model, but the fight for intrinsic dignity in the bioethical framework has just started for functionally diverse people.

The vision of functional diverse people is not present today on the bioethics training curricula, especially in the Spanish-speaking world. There have been some slight advances in Europe, mainly in UK, where British Disabled People's Council started in 2004 the BCODP's Disability and Bioethics Training the Trainers Programme, to train trainers on bioethics and functional diversity, and some academic authors are addresing bioethics issues as Barnes and Goldbring in their new edition of their book "Exploring Disability". Also in Italy where since 2005 a module on bioethics and functional diversity is part of the "Master in Bioetica Generale e Clinica dell'Università Politecnica delle Marche". This lack of presence of the functionally diverse people's point of view on bioethics has already been stated by international experts like Gregor Wolbring, Professor of the Calgary University in his article "Disability Rights Approach Toward Bioethics?" (WOLBRING, 2003).

Furthermore, this point of view has been rejected by some "experts". Daniel W. Brock, a bioethics expert made a presentation at 10th Genetic Technology & Public Policy in the New Millennium symposium in the National Institute of Health stating: "Our notion of how good a person's life is [isn't] fully determined by their own subjective self-assessment" (BROCK, 2002).

On the bright side, in November 2005 the International Society Bioethics summoned a prize on "Disability and Society" that helped to promote reflection around bioethics and functional diversity, especially in the Spanish-speaking countries. Furthermore, in March 2007, for the first time in Spain, there was a roundtable with a title "Bioethics and functional diversity" in the XV Congress on Ethics and Political Philosophy organized by the Spanish Association on Ethics and Political Philosophy in Madrid.

There are several texts published from the point of view of functionally diverse people in Europe and in the rest of the world, mainly in English. As most of these texts are quite modern, documentation is organized through Internet. From the many resources available, two of them are especially relevant: the virtual community on Bioethics and Disability managed by Gregor Wolbring from Canada (http://groups.yahoo.com/group/Bioethics/), and the International Center for Bioethics, Culture and Disability (www.bioethicsanddisability.org). Both constitute the largest, but not the only source of document coordination from the point of view of functional diverse people.

In addition, functionally diverse peoples NGOs have also published documents on their positions concerning bioethical issues. Most of these documents come from the European and environment under the initiative of DPI Europe. Disabled Peoples International is a human rights organization committed to the protection of functionally diverse people's rights and the promotion of their full and equal participation in society. Established in 1981, DPI is represented through active membership of national organizations of disabled people in over 130 countries, including 29 in the European region (DPI Europe).

ENIL, the European Network on Independent Living has also shown an official concern on bioethical issues in the "Tenerife Declaration" (ENIL, 2003) in which there is a demand that says: "We demand EU to adopt the necessary measures to prevent discrimination against disabled people in future advances of genetics, science and technology."

There are two key documents that establish the position of functionally diverse people on bioethical issues: "Disabled People Speak on the New Genetics" (DPI,:-) and the "Solihull declaration: The right to live and be different" (DPI-Europe, :-).

The need to work on this field has been addressed by one of the authors of this text (ROMAÑACH CABRERO, 2009) that has compiled bioethics positions on several issues such as eugenics, euthanasia, abortion, clonation, biomedical research, sterilisation, new genetics, stem cell research, etc. These postions are based on equal dignity and therefore, equal value for all human present and future lifes, and clearly defend equal treatment on every bioethical issue; equality that is not granted on many of the issues adressed, as shown in the spanish legislation reviewed in the book.

As an example, functional diverse people would have a neutral position aabout stem cell research, but would firmly be against functionally diverse people sterilisation and genetic selecion only in the grounds of functional diversity.

The need to work in the Sociological Theory framework

Nevertheless, in order to strengthen the diversity model, these two battlefields are not enough. The fight against discrimination must use theoretical tools that specify and make visible the mechanisms that support them. And those mechanisms are installed in social reality, in daily experience of functionally diverse people. Developing a functional diversity Sociological Theory is therefore needed, a sociological theory on the experience of people that belong to the group that is able to explain why that experience is translated into oppression, marginalization, exclusion and discrimination. It cannot be, then, another kind of theory that a critical one. As stated before, the body can be a starting point. If we center on abstract issues (dignity, ability, autonomy, rights, citizenship), we forget that, in the end, we talk about "persons", specific persons that in their daily life experience in a certain way due to certain physiological qualities, because they have, we might say, a "singular body" (as we cannot forget that functional diversity has an objective physiological founding); what needs to be understood is why that specific condition is translated, in structural terms, in discrimination.

It is no less evident, as it has been pointed out, that the rehabilitation model is a medical imputation, and the reference object is the functionally diverse people's body: a body that is defined as ill by that imputation. In this case, it should also be explained how that normative definition is translated to functionally diverse people's daily life, and whether it is a factor to be taken in account when understanding if that experience implies discrimination. As indicated in prior sections, the medical imputation is relevant in daily functional diversity experience and discrimination.

Therefore, we take the body as central reference object, daily practices as the space in which they take place as the place where it must be observed, and the definition as healthy/ill derived from the medical normalization, as the articulation device. We must also take into account the articulation context: a market capitalist society in which the State still is the institution that has the monopoly of normative definitions.

It is in that economical and political context where science has been able to become an expert normalizing knowledge of our existence. And has been so through a historical process that Michel Foucault (1992) has analyzed, according to which, at the end of XVIII century, an adaptation of power exercise applied techniques took place: to the body centered power techniques that constitute disciplinary techniques, other types of techniques oriented to global population phenomena or biological processes of human masses were added; implantation of these new techniques would imply the creation of complex centralization and coordination institutions.

Power, through statalization of biological, takes in charge men and women as human beings: individual bodies can be surveyed, trained and punished. The new technology, called *bio-politcs* is oriented to a broad spectrum of people as a global mass, covered by specific life processes (birth, death, reproduction, illness). Knowledge objects and control goals will be then birthrate, mortality and longevity problems, and first statistical measures are adopted to observe procedures adopted by population in its relation to those phenomena (FOUCAULT 1992). Is there different goal for WHO when establishing and using international disability classifications?.

The application of these bio-political techniques leads to population "normalization" based on population body classifications, provided by medical science and its associated practices. We have already stated how these affect functionally diverse people (how expert knowledge acts on functionally diverse people's body and how its message invades their social environment).

But, how do these techniques become so efficient in daily experience? Pierre Bourdieu's theory provides some responses. We acquire our competence to cope in a social environment due to a set of predispositions that we inherit from the group we belong to; Bourdieu calls this the *habitus*. It is a predispositions structure for perceptions, the though and action that condition our actual possibilities beforehand (it determines beforehand what is possible or not, what is thinkable or not, what is adequate for us or not) guiding our actions in a not necessarily rational way. But when bringing *habitus* to practice, and as a result of the practical effects it produces we, inevitably, modify it: the predispositions structure evolves through our vital experience. Furthermore, we posses diverse *capitals* (economical, cultural, scholar, social, etc.) form which we try to make profit in different competence *fields* (the same: economical, cultural, scholar, social, etc.). Where a determined social space exists (a field) in which there is a valued property (capital) in dispute, there will be a complementary *habitus* shared by those who are involved in competition. There, a structural determination factor shall be found that will define, through that habitus a functioning logic of the field, the logic of practices that will take place inside it and to which all shall be submitted.

Is there a disability, functional diversity field, and as consequence, a specific habitus that conditions practices that take place in it? Our response is: yes, there is that field. Habitus predispositions structure that characterises that field, spins around the medical norm applied to the body, a normalization that classifies it as ill, unhealthy. As that normalization is a part of bio-politics, that body is *non legitimate*; nevertheless, through rectification practices, medical science offers a kind of legitimate promise, the possibility of acquiring a *non-legitimate legitimated* body. Consequentely we are speaking about a *symbolical* capital that qualifies the body. The inculcation of that habitus that comes from expert knowledge that monopolizes the disability field propels the search of that legitimacy, the acquisition of that symbolic capital that is just a struggle for a maximum approximation to “normality”, as defined by medical science. If a systematic presence of that habitus is detected in the functionally diverse people group, a practical mechanism will be stated, through which bio-political techniques get installed in daily experience, as predispositions, conditioning objective action possibilities of the group. Through several in depth interwviews it has been stated how, in the case of Argentina, interviewed narrations provide clear indication of the existence of that functional diversity or disability field (FERRANTE y FERREIRA, 2007, 2008).

The Independent Living Movement is just an attempt to create a new alternative field with a habitus that would not be oriented by the promise of medical legitimacy. In Spain its presence is small and the functional diversity world is still regulated by the hegemonic logic of medical science. To break that logic, besides the battles in the field of rights and bioethics, it is necessary to strengthen people’s daily life ability to evade conditionings imposed through disability habitus, a reconfiguration of their predispositions based on which daily practices could take place; unfortunately, legal norms and academic discourses do not contribute in a direct and effective way in that transformation. Therefore, the disability social theory must assume an educative function inside the functionally diverse people group.

Conclusions

At the beginning of the 21st century in Spain and in the majority of countries in the world daily, juridical, and bioethical reality discriminates functionally diverse people. Although theoretical models on functional diversity have changed from *cut out* to the *rehabilitation* model and then to *social* model, social policies based on those models still gave no effective response to contribute to the elimination of discrimination of this group of people.

In Spain, part of that mistake comes from the persistence of the *rehabilitation* model and the scarce presence of the *social* (or Independent Living) model. But even this last approach is not capable to provide answers to the new challenges that bioethics has brought up, related to new genetics, euthanasia, embryo selection, prenatal screening, etc.

As all prior models have accepted ability as the theoretical basis, transversality has not been adequately approached and policies have not been able to give responses to every type of functional diversity.

As a consequence, a new model is proposed in which the theoretical grounds on ability is substituted by a theoretical grounds on dignity. In this new model, the *diversity model or approach*, inherent human diversity is the starting point. Diversity amongst a person's life, and between different persons is accepted and valued. Furthermore, the diversity model states that every person with any type of diversity, in this case speaking of functional diversity, must have his or her dignity guaranteed.

In the *diversity model*, a deep analysis on the semantics of the word *dignity* is done through bioethical and juridical texts both national and international to come to the conclusion that dignity can be divided into branches: *intrinsic dignity* and *extrinsic dignity*. The first is related to the equal value of every human life and the second is related to equal rights for everyone.

The analysis done under this new model establishes that nowadays, society provides neither the same *intrinsic dignity* nor the same *extrinsic dignity* to functionally diverse people. Therefore, it becomes necessary to keep working and fighting in a double approach: on one side, to obtain the same rights, and in the other side, to develop new theoretical approaches that introduce in the bioethics debate a full support of intrinsic dignity for people who are discriminated on the on the grounds of their functional diversity.

For the first issue, a special defence, dissemination and implementation of the new UN Convention for people with disabilities must be developed.

For the second issue, a new bioethical approach born from the group of functionally diverse people, and based on their own reality and experience of life must be developed. In his way, the bioethical community will understand that they are not human beings that suffer for being different, but for being systematically discriminated or ignored due to their difference, and by the fact that their lifes have been systematically undervalued.

In this model, bioethics becomes a key tool for the future of functionally diverse people, and the presence of their point of view in the bioethical community is considered basic in order to obtain full dignity.

Furthermore, taking in consideration critic sociology proposals, discrimination mechanism, through which discrimination takes effect in functionally diverse people daily life (mechanisms based on bio-political power techniques, on medical normalization of the body and on the imposition on practices of a habitus oriented by those techniques and normalisation), are brought to light; consequently, the task of working deeper in that analysis becomes necessary in order to break domination logics (domination imposed through body, regulation, classification and submission) to provide the group theoretical tools needed to face their daily life in an alternative liberating way.

The analysis and proposals of the *diversity model* are, in fact, another tool to achieve what is written in the Universal Declaration of Human Rights, specially in it's articles 1, 22 and 23.3 (UN, 1948)[1], confirming that discrimination based on functional diversity is a Human Right's issue, a principle already established in the social or Independent Living model.

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[1] **Article 1**. 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.

Article 22. Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.

Article 23.3. Everyone who works has the right to just and favourable remuneration ensuring for himself and his family an existence worthy of human dignity, and supplemented, if necessary, by other means of social protection.

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