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Quelles modélisations pour le corps social ?

Quels modèles pour l'inclusion des Personnes Handicapées ?

Patrick FARFAL

Cet article est la reprise, à quelques modifications près, d'une communicaion au Congrès WOSC (*World Organisation of Systems & Cybernetics*) 2020/2021, tenu à Moscou du 27 au 30 septembre 2021 : **Disability as a System Model in Social Sciences: Role of a 2-D Visualization**

Résumé

L'article propose une nouvelle représentation des différents modèles de handicap permettant de mieux comprendre la question du handicap, et en conséquence de mieux travailler dans le domaine de l'inclusion des personnes handicapées, grâce à la modélisation.

La modélisation fait souvent appel à la visualisation, qui complète la partie narrative pour faciliter l'étude du système.

Les modèles de handicap, individuels et sociaux, sont illustrés par des schémas qui permettent de comprendre les tenants et les aboutissants du handicap. Certains sont plus pertinents. Tous sont explicatifs et indispensables.

Cependant, pour mieux travailler dans le domaine de l'inclusion, il convient d'utiliser des modèles supplémentaires. Après avoir rappelé la dimension systémique du handicap, explicitement introduite en 1993 au Canada, et affirmée dans la loi française du 11 février 2005 sur le handicap, un modèle bidimensionnel est proposé : axe horizontal VIVRE - EXISTER, axe vertical PERSONNE - ENVIRONNEMENT, dans lequel une flèche vertueuse devrait aller de la gauche vers la droite.

Ce modèle bidimensionnel permet de mieux comprendre la supériorité du modèle social sur les modèles individuels. Des modèles élaborés existent, mais ce modèle bidimensionnel n'est pas très répandu. La visualisation en deux dimensions autorise une meilleure compréhension à l'intérieur de la communauté des personnes handicapées (en y incluant les personnes valides) et facilite la formation. Elle peut être étendue à d'autres domaines, tels que le transhumanisme.

Disability as a System Model in Social Sciences: Role of a 2-D Visualization

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Abstract

The paper aims at giving a novel representation of the different models of disability, making it possible to better understand the question of disability and therefore better work in the field of inclusion of disabled people thanks to modelling.

Modelling often utilizes visualization, which completes the narrative part to make the study of the system easier.

Disability models, individual and social ones, are illustrated by diagrams that make it possible to understand the ins and outs of disability. Some are better. All those diagrams are explanatory and essential.

However, to better work in the field of inclusion, additional models should be used. After reminding the system dimension of disability, explicitly introduced in 1993 in Canada, and asserted in the February 11, 2005, French law on disability, a two-dimensional model is proposed: horizontal axis from LIVE to EXIST, vertical axis from PERSON to ENVIRONMENT, in which a virtuous arrow should go from the left to the right.

That two-dimensional model helps better understand the superiority of the social model to the individual ones. Some elaborated models do exist; that two-dimensional model is not so widely used. 2-D visualization results in better understanding in the disability community (including able-bodied people), and facilitation of education. It can be extended to other fields, such as transhumanism.

Keywords:

Disability, Modelling, Visualization, Live, Exist, Person, Environment.

1 Introduction

Due to the high number of people with disabilities, and the complexity of the question (types of disability and actors in the field), disability can advantageously benefit from a systemic approach, whether or not this aspect is explicitly stated by the organizations in charge of disability. First, it is important to remind the role of the environment of people with disabilities, and what the "Disability System" is: it is from those concepts that we can build models that make it possible to work on solving the problems of people with disabilities.

Considering stereotypes and prejudices on disabled people, two types of models can be built, individual “charity” and “medical” models, and a social model; to achieve a full citizenship of the disabled persons, the latter highlights the role of the environment, which must adapt to the disabled person, in particular through compensation.

Models use diagrams of the interactions (flows, causations) between the elements of the system and between the system and its environment; for one given system model, several diagrams may have to be used, depending on which aspect we want to illustrate. In the case of “Disability System”, a 2-D visualization can explain which model best suits disabled people aspirations.

2 Role of the environment of people with disabilities in the “Disability System”

Taking into account the role of the environment in the consideration of disability as a social model is quite recent. Patrick Fougeyrollas' thesis [Fougeyrollas, P., 1993] is probably the first work on the subject. This work played a role in the development of an international classification of the consequences of illness and trauma.

The author illustrates the need for a systemic approach and analysis of the person-environment interaction to understand and act in the phenomenon of the production of disability situations. Here, the expression "situation of disability" is fundamental. The French law of February 11, 2005 [French law, 2005] undoubtedly owes much to this concept.

Patrick Fougeyrollas' model [Fougeyrollas, 1998] considers that it is the interaction between:

- risk factors and personal factors (organic systems: integrity or deficiency, aptitudes: ability or incapacity) on one hand

- environmental factors (facilitators or obstacles) on the other hand,

which determines the person's "life habits", i.e., the degree of social participation, more or less limited by the disability.

The notion of "Disability System" has been investigated [Farfal, P., 2014, 2015, 2017]. More precisely, the outlines of the "Disability System" have been defined. The "System" is not only made up of all people with disabilities, although there are interactions between other people with disabilities, but it is difficult to define a structure for it - if not the classification between the various disabilities, for example - let alone an organization, and it is difficult to define its aim (or finality). On the other hand, if we define the "Disability System" as the set of "elements" *directly* concerned by disability (disabled people, hospitals, integration bodies..., *interacting* with each other), in relation to the rest of society and the living environment (able-bodied people, living spaces, world of work...), we immediately identify a *structure* (and an organization), and an *aim*: inclusion and full citizenship of people with disabilities, which cannot be achieved by people with disabilities alone, even though they necessarily play a determining role in the inclusion process.

This definition of the "System" facilitates the approach and understanding of the "compensation" to be put in place, by all the stakeholders constituting the "System", i.e. the best accessibility to buildings, transport, care, communication tools, etc.

3 Back to the "Disability System” and its models

Because of many features of handicap, such as the number of actors and interactions, or the complexity of the field, disability must be considered from a system point of view and dealt with as any system. That makes it possible to build a comprehensive response to the question of the inclusion and full citizenship of people with disabilities, better than some fragmentary solutions often proposed.

3.1 *Reminder: Need for a systemic approach* [Farfal, P. 2017]

The complexity of the disability concept lies first in the questions of social link and citizenship, which mean many interactions between disabled and valid people (reciprocal interactions by definition), second in a few figures which give an idea of the extent of that matter [WHO, 2011]. Some figures for France are given below. Disability as a fact is far from being marginal.

Diversity, too, is well identified as a complexity factor; in the field of disability, diversity, differences, multiple singularities are recurrent terms: sensory and motor disabilities, psychic and mental disabilities, diversity of pathologies.

Maybe the best illustration of diversity is the definition of disability given by the French law n° 2005-102 February11th, 2005 [French law, 2005]: *"…any activity limitation or restriction of participation in social life suffered in her environment by a person due to lasting or final substantial deterioration of one or several physical, sensory, mental, cognitive, or psychic functions, to multi-disability or incapacitating health disorder* " That definition can be also found in [WHO, 2001].

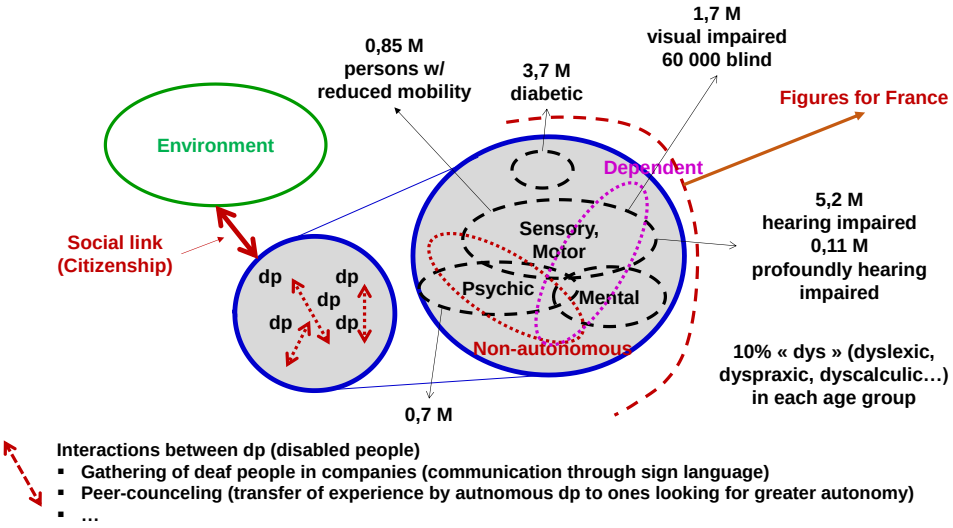

Fig. 1: Diversity of disabilities (France)

Diversity also addresses the high numbers of actors in the field of handicap: not only disabled people themselves, but also other ("valid") persons, and bodies in charge of disability: private & public sectors, associations; care & cure centers; financial bodies, with the result that, facing that inflation of bodies, people speak of "institutional jungle", in French "*maquis institutionnel*".

Definition of "Disability System"

As said before, the "Disability System" must not be reduced to disabled people, facing their environment, but extended to the whole of the "elements" *directly* concerned by disability (disabled people, hospitals, law, insertion bodies…, in *interaction* with one another), facing the rest of society and environment ("valid" people, city spaces, world of work…), each category (subsystem) more or less blurred, as in every system:

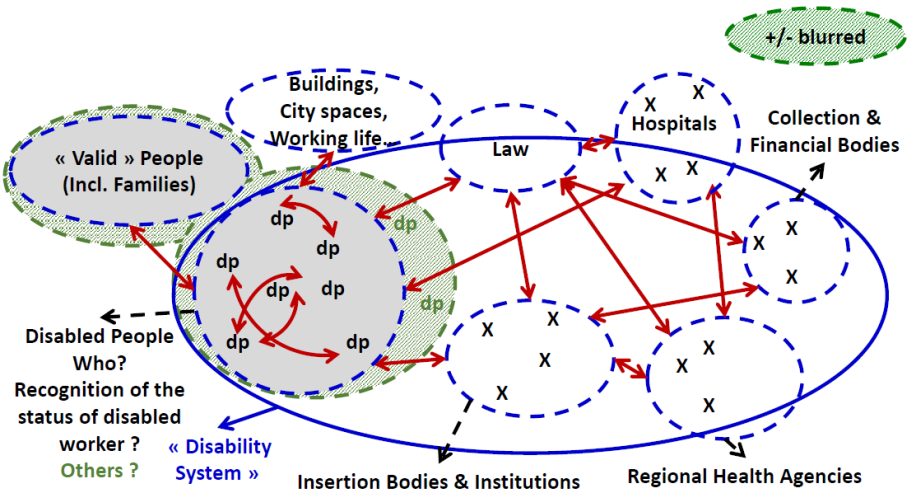

Fig. 2: Disability system extended to the whole of the "elements" directly concerned by disability

which probably is best suited to study the matter.

This is the well-known question of the system of interest in systems engineering: borders depend on which system of interest is considered.

Other properties of systems can be found, such as systemic loops:

- vicious (blocking) loops or positive loops: social exclusion, shame → deprivation of opportunities in social, economic, human development → lack of social, economic, cultural rights → reduced participation in decision-makings, deprivation of civic and political rights → social exclusion, shame → and so on (more that a simple systemic loop it is a limit cycle in the language of automatic control)
- virtuous loops or negative loops: e.g., changing the attention to disabled people; compensation: sensory or motor aid, desk fitting out, access to buildings, offices, shops, transports, communication; school aids, or support to children in schools, school life assistants (in French *Auxiliaires de Vie Scolaire*).

The existence of blocking loops (exclusion) and virtuous loops (compensations) emphasizes the systemic feature of the question.

Systemic treatment of disability

Disability treatment can opportunely take advantage from Systems Engineering principles, answering questions Why/For what/For whom? – What? – How/With what? which clarifies the way to do and prevents from directly skipping to solutions. Some cases have been recently tackled through a system approach: *Ageing disabled persons, Emotional and sexual life of disabled people and reproductive health* [LADAPT, 2016].

3.2 Disability models

Modelling is « building in one's mind » [Le Moigne, J.-L., 1990]: it is a necessary condition of intelligibility, an artificial representation, most of the time by a diagram and a system of symbols, of the interactions (flows, causations) between the elements of the system and between the system and its environment.

Several responses can be given to the previous question, according to the models chosen.

To arrive at the so-called "models" of Disability, it is necessary to introduce "attributes", judgments:

- on the disabled people: punishment of the gods (Antiquity), worthy of compassion, dangerous, subjects of medical interest, abnormal, and characterized by the stereotypes and prejudices of the "individual" model (without use of their limbs, in a wheelchair, deaf and/or blind, in crisis, unable to work, unable to move around, closed and aggressive, needing constant help)

- on the environment, highlighted by the social model: non-adapted buildings, inaccessible transportation, out-of-reach living spaces, discrimination in education, few employment opportunities, low income, isolated families, segregated attitudes, many prejudices.

In the "*individual*" model, which includes the "*medical*" model ("fixing what is broken" or "restoring normal functioning") and the "*charity*" model (which takes a compassionate look at people with disabilities and appeals to generosity), the disabled person is the problem to be solved, the "responsibility" for his/her disability lies with him/her; this model equates disability with impairment; social exclusion is seen as the result of the limitations imposed by impairments.

In the "*social*" model, [Fougeyrollas, P., 1993] [French law, 2005], it is the coupling of the disabled person with his or her environment that is the problem to be solved (the limits imposed on him or her by external and environmental barriers): there is a reversal of the burden of the process, which carries more potential. This model implicitly recognizes that disability is part of life; without refusing to consider the medical and medico-social aspects, it focuses on the elimination of barriers that prevent the full participation of disabled people and prevent them from fully deciding and controlling their own lives.

It is therefore the way in which the person is viewed that determines the model. The choice of a model is decisive, the social model being more about potentialities (potentialities: what to do (and for what?), with whom, with what?).

The models of disability have alternated throughout history and even prehistory:

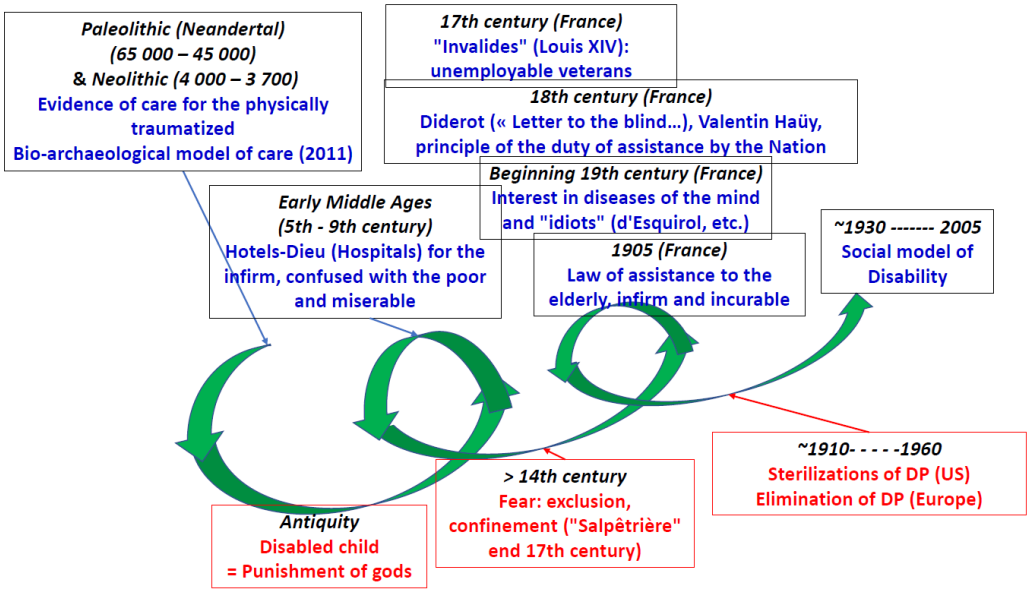

Fig. 3: Virtuous spiral of Disability

We note with surprise and satisfaction that the model of care (if not cure) seems to have existed in prehistoric times [Doat. D., 2015]: some people who have experienced serious accidents show that they have lived 35 to 40 years, that is to say as long as the rest of the population: they could not have survived without the care of their fellow human beings.

What is the purpose of the models? As we have said, to understand (to build in one's head), but also to analyze, to foresee, if necessary, to decide, to act. Understanding, analyzing, and

especially acting are the objectives we are interested in. A "good model" must make it possible to work, provided that it is built without losing sight of the purpose of the system (For What? For Whom?), and to allow us to answer the questions: What? and How? With whom? With what?

The answer to the three groups of questions is given below:

FOR WHAT? FOR WHOM?	FULL CITIZENSHIP FOR PEOPLE WITH DISABILITIES, INCLUSION
WHAT?	WELCOME, CURE & CARE, TRAINING, INSERTION, SUPPORT/ACCOMPANYING, FOLLOW-UP...
HOW? WITH WHOM? WITH WHAT?	DISABLED PEOPLE, LAW, ORGANIZATIONS, ABLE-BODIED PEOPLE, BUILDINGS, TRANSPORT, HELP/ASSISTANCE...

Table 1: Systems Engineering applied to Disability

4 2-D Visualization

Disability models, individual ones (charity model, and the so-called “medical” one) and social ones, are illustrated by diagrams that make it possible to understand the ins and outs of disability. Some are better. All those diagrams are explanatory and essential.

However, to better work in the field of inclusion, additional models should be used. It is easy to see that a purely linear diagram, even a chronological one, with back and forth as above,is insufficient: how to represent the aspirations of the disabled person and the model chosen to fulfill them?

The diagrams illustrating those models by insisting on the aspirations of the disabled person require a two-dimensional approach, as in other models in the social or religious sciences [Donnadieu, G., 2015]: a *PERSON-ENVIRONMENT* axis (the two terms on which the individual and social models oppose each other), and an "*INCLUSION*" axis, with the two poles: *LIVE* (in the sense of subsisting, or even surviving) - *EXIST* (in the sense of having importance, having value):

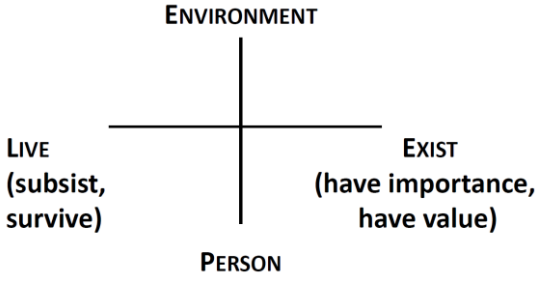

Fig. 4 a: 2-D basics for Disability models

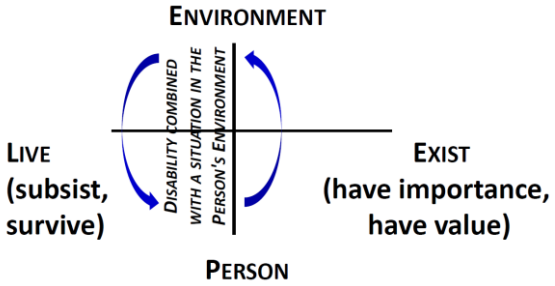

Fig. 4 b: 2-D basics for Disability models with interactions between Person and Environment

knowing that, of course, the aspiration of the person with a disability is to exist (despite his or her disability, which is the result of the interaction between personal and environmental factors), whereas we often only propose to live.

Let us see how the different models meet that aspiration:

- Charity model

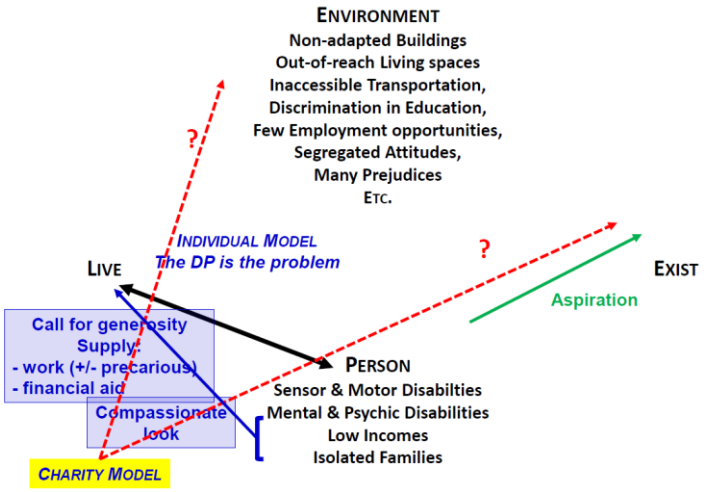

Fig. 6: Limits of the charity model

That model does not meet the aspiration of disabled persons.

- Medical model

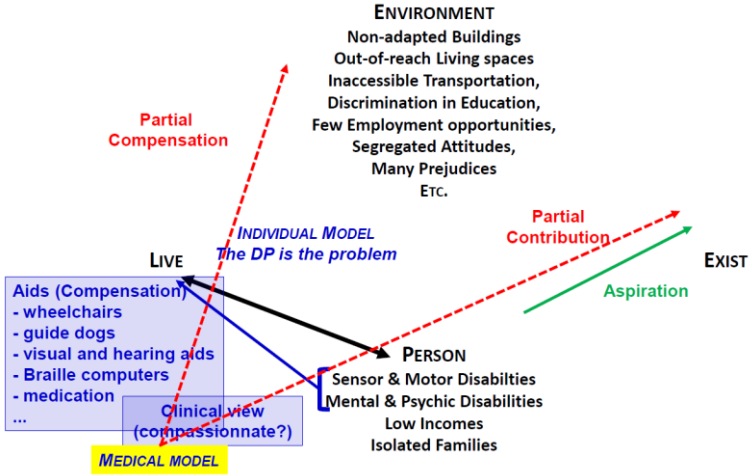

Fig. 7: Limits of the medical model

That model partially meets the aspiration of disabled persons.

- Social model

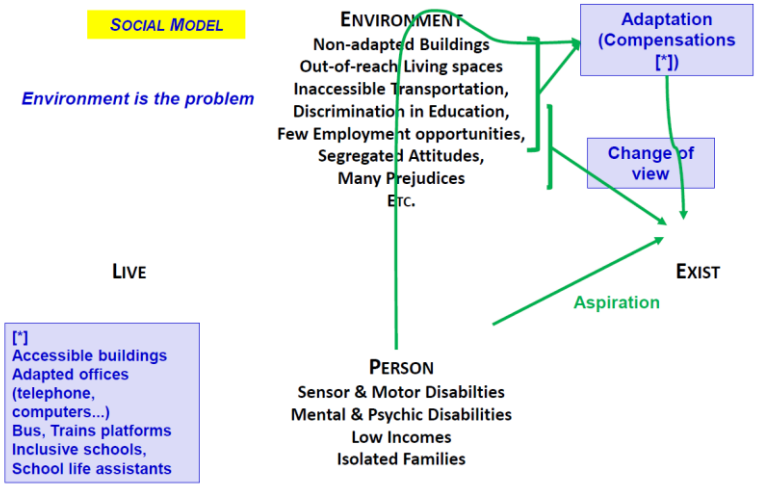

Fig. 8: Social model fulfilling Disabled People's aspirations.

Only the social model can fulfill the aspirations of people with disabilities.

5 Conclusion

This paper, starting from the extreme complexity of the world of disability, and reminding of what can be called the "disability system", has shown how models of the "disability system" are developed, and also how linear schemes, even with chronological content, are insufficient to describe how the models can represent the profound and actual aspirations of people with disabilities.

A two-dimensional model ENVIRONMENT-PERSON vs LIVE-EXIST, although that type of representation is little used, appears to be more satisfying, including both the aspirations of people with disabilities and the interactions between person and environment. It helps to better understand the pros and cons of the different models existing, and results in better understanding in the whole disability community, and facilitation of education.

As a methodological extension, that two-dimensional model ENVIRONMENT-PERSON vs LIVE-EXIST could be used to illustrate the relationship between person and environment in the field of transhumanism.

6 Summary

A sketch of the "Disability system" associated with systemic features, such as multiple interactions (between disabled people and between them and their environment) and system loops, has been presented in relation with several models: "individual" ones, and "social" model.

In the "individual" models, which include the "medical" model ("fixing what is broken" or "restoring normal functioning") and the "charity" model (taking a compassionate look at people with disabilities and appealing to generosity), the disabled person is the problem to be solved.

In the "social" model, the coupling of the disabled person with his or her environment is the problem to be solved. Without refusing to consider the medical and medico-social aspects, it focuses on the elimination of barriers that prevent the full participation of disabled people to satisfactory personal and professional lives. This is a reversal of the burden of the process, which carries more potential. It is therefore the way in which the person is viewed that determines the model.

"Natural" (linear, even chronological) illustrative model diagrams are facing a lack of completeness regarding the profound and actual aspirations of people with disabilities. A two-dimensional representation ENVIRONMENT-PERSON vs LIVE-EXIST makes it possible to better understand the superiority of the social model to the individual ones. That two-dimensional representation may result in better understanding in the disability community (disabled persons, nursing staffs, able-bodied people...) and facilitating education.

Such a 2-D representation can be used in other sections of social sciences.

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