

**RESPECT FOR HUMAN DIGNITY AS THE IDEA OF JUSTICE
FOR PERSONS WITH DISABILITIES AND THEIR FAMILIES:
THE MISSING GAZE**

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***Abstract.** This paper intends to analyze critical issues and prospects after adoption of United Nations Convention on the Rights of Persons with Disabilities (CRPD). The actual picture that emerges is certainly not reassuring. The medical model of disability is still prevalent. In most cases, path aimed at an independent living isn't considered. People with disabilities and their family members, family caregiver, siblings aren't adequately involved in decisions that affect them and they often are isolated. Adults with intellectual disabilities are considered as a separate topic. There are many abuses in support administrations that become cobwebs for beneficiaries themselves and their families. The paper purpose is highlighting the importance of human dignity. It is important to implement a cultural resolution to say enough to structures where people with disabilities are relegated. It is fundamental to break down barriers of all kinds: sensorial, architectural and, in particular, all mental barriers! The used research methods concern an analysis of reality, giving voice to experiences of people with disabilities and their family members, siblings, family caregivers and a comparative analysis with connection to disability studies. The results will highlight how important it is, and at the basis of every authentic cultural revolution to give voices to stories, to the person in all his dignity and how it is necessary to overcome fragmentation to authentically reconfigure social policies. The approach to disability must be based on human rights. The challenge of inclusion concerns entire human race and not a small minority. "Nothing about us without us!"*

***Keywords:** human rights, persons with disabilities, siblings, family caregivers, dignity of the person, UN Convention on the Rights of Persons with Disabilities (CRPD), inclusion, disability studies*

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Introduction and actuality. Giving the law a soul: this should have been, according to judge Livatino, killed by the mafia on the morning of 21 September

1990, the judge's primary task. The protection of the person and respect for human dignity are among the objectives of the "Let's give to the law a soul" Let's take action! Soul and courage! movement, Human Rights, law and disability studies Forum – study center “rEVOLution”. A society cannot be called civil if it does not take care of the most fragile people, of fragility which is power in itself. The movement, Forum - study center are the promoters the appeal “Stop segregating residences!”, “Stop institutionalization!” (Miccio, 2007, 2013, 2014, 2015, 2019).

This paper - in memory of the judge Livatino and of all the victims of every form of injustice, persons with disabilities and their families - intends to highlight the importance of human dignity, synonymous with human value. It should not be measured by any individual value. Recognition of the dignity of a person presupposes active respect for human rights (Nussbaum, 2002; Nussbaum, 2006; Barton & Armstrong, 1999; Lawson, 2005).

The paper highlights the critical issues and perspectives years after the adoption of the UN Convention on the rights of persons with disabilities and the enactment of other laws. The analysis of reality presents a picture that is certainly not reassuring. Most services are still based on the medical model of disability. Paths aimed at independent living are not considered. Adults with intellectual disabilities as well as children are considered as a separate topic or they are not considered. People with disabilities and their families are not adequately involved in decisions that affect them. Families, family caregivers, siblings must not be isolated! They must be included in tables where people talk about them. They can contribute to authentically improving society! What future for human dignity? Disability is a human condition that, during life, involves every individual. What future for all of us? It is fundamental break down barriers of all kinds: architectural, sensorial and above all mental barriers! It is important to give voice to stories, experiences, to the person, to human dignity. It is important to break down the dogma of hospitalization in facilities (Miccio, 2007, 2013, 2014, 2015, 2019, 2020, 2021; Parker & Clements, 2008).

It is important to say enough to a reality where the dignity of people with disabilities and their families is destroyed. It is important to act not in isolated sections. This paper intends to highlight how support administrations often become cobwebs for the beneficiaries themselves and also their families. Segregating logics disguised as virtuous examples must be unmasked. The approach to disability must be based on human rights. The new model of justice is based on social inclusion. Nothing about us without us! (Miccio, 2013, 2014, 2015, 2019).

Being the brother or sister of a person with a disability is a decisive experience, a gift that will accompany us during our lives (it is often forgotten that, in addition to our parents, there are also us siblings, the brothers and sisters of people with disabilities). It is difficult to describe the importance of this gift to those who do not experience it. Since we were very young, we siblings have known the difficulties and prejudices linked to the world of disability. It may seem strange but often we too, like our brothers and sisters, are the object of ridicule and prejudice. More than anyone else, we know about disability, above all, the joys and what it means to be a gift. Disability is then a stage of life that sooner or later

affects everyone and concerns everyone, without exception. We are all fragile creatures and fragility is inherent in each of us (Miccio, archive: "Let's give to the law a soul", from 2007 to today).

Research methodology. It is very important to give voice to humble and hidden heroics, to everyday heroes. Giving voice to those who are now tired, giving voice to stories, experiences of immense value and great example, destroyed by injustice. We need to start from the stories to rebuild! Who are we to draw a separation between people considered "normal" and not, between people considered healthy and people considered sick, frail? Frailty belongs to each of us - no exceptions! (Miccio, 2007, 2013, 2014, 2015, 2019).

The human person is the bearer of intrinsic, permanent and unconditional dignity. Dignity is not a principle that can be defined univocally. It must be thought of as a process rather than a definitive result. This leads to framing dignity in a relational perspective. Respecting human rights means protecting the dignity of the person. Disability is a human rights issue! It is necessary to move - thanks also to the contribution of Disability Studies (DS) (in general, for an introduction to DS should be consulted: Barnes & Mercer, 2004; Barnes, 2007; Charlton, 2000; Morris, 2000; Coleridge, 1993; Ingstad & Reynolds, 1995; Oliver, 1996; Priestley, 2003; Shakespeare & Watson, 2002; Shakespeare, 1994, 2002) - from the medical / individualistic approach where the focus is on the individual's impairment and the person is seen as the problem and treatments as the adequate response - to the social / contextual model of disability where the focus is instead on the social and environmental context and it sees discrimination/exclusion as the problem and the removal of barriers as the answer and then some rigidities must be overcome. In reality, the social model does not set aside the individual and pathological condition of the person and does not deny suffering and the need for medical care but it chooses to place emphasis on shared aspects (discrimination and the condition of social oppression).

It is necessary to implement emancipatory research work which is taking its first steps. Disability is a human rights issue. It's not about guaranteeing or maintaining privileges but it's about equality of opportunity, removing existing barriers/preventing discrimination. The United Nations Convention is not "special" but universal. At the basis of the UN Convention on the rights of persons with disabilities there is a new model of justice (Sen, 2009). Disability Studies are interdisciplinary, internal and external to the academic world. They are for (and with) people and not about people. The approach in disability studies is new. Disability Studies have provided the knowledge that informs the international legal framework for protecting the human rights of people with disabilities. Disability Studies provide jurists with a deeper understanding of the fact on which the legal rule is based. This new understanding requires an increase in awareness, a cultural change. It is a continuous process, it calls into question the already existing paradigms, it makes a different and more updated interpretation of existing laws necessary, it believes that the institutionalized discrimination that

emerges from the regulatory provisions oriented towards antiquated conceptions must be removed. Legal research and practice can benefit from Disability Studies to achieve the effective inclusion of people with disabilities. The focus "is no longer the physical impairment, but rather the lack of autonomy to which the jurist must find an adequate response. It is necessary to pay attention to one aspect. The limits of an anti-discrimination law also seem to emerge given the inevitability of "identifying the subjects deserving of protection, distinguishing them from those who are not subject to such protection. By establishing asymmetric protection, the law requires the adoption of a particular approach, which consequently creates, in fact, a specific right, different from the "common" one. A paradox emerges that is difficult to resolve and which seems to highlight the intrinsic difficulties of jurisprudence regarding disability. On the one hand the legal norm must inevitably "discriminate" in order to apply the legislative rules to protect a part of the population, on the other this protection itself becomes an instrument of "differentiation" and therefore partly of discrimination between those who are people with disabilities and who isn't, even if with the best intentions.

Terminological clarifications and analysis. "Person with a disability" has no synonyms. This is one of the fundamental indications that come from the "International Convention on the rights of persons with disabilities", made in New York on 13 December 2006 and which entered into force in Italy by law no. 18 of 3 March 2009.

It is today the most correct and shared definition and should not be replaced by others still in use such as "handicapped" or simply "the disabled" nor with the term "differently abled" or "diversable", loaded terms of ambivalences (and also, of a certain dose of do-goodism, of political correctness).

Law 227/21 carries a delegation to the Government for the reorganization of the current provisions on disability. It is one of the reforms envisaged by the PNRR (National Resilience Recovery Plan) in Mission 5, Component 2, a reform consisting of the creation of a Disability Framework Law with the aim of fully implementing the principles of the UN Convention on the Rights of Persons with Disabilities. The enabling law seems to be epochal given that it is the first time that recognition of the condition of disability has been introduced in a European country based on the definition of the Convention itself. The new legislative decree definitively approved on 15 April 2024 revises the terminology and evaluation procedures for Law 104 and civil disability. the decree modifies the definition of "disability condition". This definition replaces the concept of "handicapped person", now considered obsolete under international law.

The word "handicap" is everywhere replaced by the words "condition of disability", while the words "handicapped person", "person affected by disability", "disabled" and "differently able", wherever they occur, are replaced by the following: "person with a disability".

Will there really be a positive change after this law? Years after the adoption of the UN Convention on the Rights of Persons with Disabilities and the enactment of other laws, the picture that emerges is certainly not reassuring (Miccio, 2013,

2014, 2015, 2019). During the pandemic, criticism of the current welfare system has emerged both internationally and nationally. But did we need a pandemic to understand this? Did it take a pandemic to understand that people should not be placed into categories and there is no division between those who believe they are normal, healthy and those who are labeled as sick, as waste? During the pandemic, tragedies and problems that already existed and were deliberately not considered emerged. Just think of the many deaths that have occurred in places of segregation of the elderly and people with disabilities, of the most frail, fragile people. Based on the data made available by Istat on excess deaths (mortality statistics in Italy), it is clear that during the pandemic mortality in nursing homes and other facilities was truly high. A silent and hidden massacre. Research by the UK House of Commons based on the National Institute of Statistics survey found that 59% of residents with disabilities died in residential facilities/homes in England and Wales.

During the pandemic, the certainly not reassuring picture emerged in all its strength, what was not considered could no longer be hidden. Everything was evident without the need for words, everything that had been tried to hide had exploded in all its drama. People with disabilities, caregivers, elderly people were left even more alone. The great absentees: institutions, municipalities, schools, social workers, day centres too many times that they turn into "parking" centers where there is no real tendency towards independent living etc (Miccio, 2020, 2021).

Main results, considerations, discussion and conclusions. From a welfare system based on social protection that doesn't even function, it will be necessary to get to a welfare system based on social inclusion!

The logic of care that is not oriented towards inclusion is applied. Individual projects must overcome this logic to define individualized projects based on empowerment, on a community perspective, on rehabilitation and enabling in all fields, through the direct participation of interested parties. The definition of projects is poor and is often reduced to the definition of the resources to be deployed, losing sight of the person, the well-being of the person and their family members who come altogether abandoned. The relationship must involve all stakeholders in the field. Excessive fragmentation, the lack of coordination and continuity of services aimed at the most frail people and their families, caregivers.

Services often contain operators in every area who are unprepared and without any empathy. Zero careful checks and monitoring, lack of data, skills that are unrelated to each other. Suffice it to say that to date, for example, the Second Report (updated to December 2018) on the state of implementation of the law on "After of us", Law n.112/2016 ("Provisions regarding assistance in favor of people with serious disabilities without of family support") constitutes the latest "official" representation of the interventions pursuant to law 112/2016 that are concretely current at a territorial level. However, these are limited and incomplete data. In general, complete and constant monitoring is lacking.

What future if not built during us? There are many sore points in this law as in many others, for example that 6/2004 on support administration. As established

by the UN Convention of 13 December 2006, a person with a disability has the right to choose where, with whom and how to live (Parker & Clements, 2008; Koch, 2009; Flynn, 2011).

Empathy, preparation and training of operators etc. in every place regarding people with greater frailty and them family members are absent. Think for example also about the hospital. There is often a lack of connection between the hospital and the territory. Specific cards are needed where the rights of the most fragile people and their caregivers in certain cases are put down in black and white places? Or should it be the basis that operators in every area are trained especially towards people with greater frailty and their families?

Cards upon Cards, laws upon laws, tables, creations of figures upon figures for example of Guarantors, Specific ministries often produce even more fragmentation and acting in compartments without coordination where everyone wants to be the protagonist etc. Is the figure of the Guarantor really useful, for example at municipal level? Often people and especially people with disabilities and their families do not even know of the existence of such figures who remain inert, unknown, with the title only on paper (perhaps it only serves to enrich their curriculum vitae) and there is no authentic fight to see the rights of people with disabilities and their families affirmed (Miccio, 2019, 2020, 2021).

There is too much lack of information, incorrect or non-existent information, the unpreparedness of operators in every field, social workers, etc. regarding the rights of people with disabilities and their families. There is often non-existence, discontinuity, incompetence, poor coordination in services where everyone delegates responsibility to the other especially when the caregiver, the sibling, family member asks for explanations and in the end the caregiver, sibling becomes the guide, the mediator between these poorly managed services. Home care is full of gaps where services are only on paper and there is no serious control and monitoring.

Evaluation of activities in services is non-existent. The mediation between rights and the possibility of asserting them is often carried out by unprepared and indifferent operators, cooperatives with limited and frequent interventions segregating. Many lack knowledge and real training. Tense routes to independent living are not taken into consideration. There is a lack of controls. Home care is abandoned to itself where the caregiver is not considered or is isolated when she/he asks for seriousness in services and the caregiver, sibling is often forced to fight even more against walls of indifference, concealment, practices empty ones that are certainly not in the interest of the most fragile people and their families, their caregiver while the opposite is often shown by local health company, institutions, operators etc. to hide lack of real attention and non-compliance. Services are often wrapped in self-referential visions with operators at the centre. For example, home care for a very few hours will not allow interventions aimed at the full autonomy of the person with greater frailty. There are no serious long-term and truly calibrated evaluations for each person but the evaluation units plan similar interventions for everyone and sometimes in meetings the family member, caregiver is not involved (and they have to fight to assert the rights of their family

member with disabilities) and more frail people who don't have family members? Who fights for their rights and them? Who controls? This is really sad and serious. Often there is no coordination between the various parties, local health company, doctors, service managers, institutions. The caregiver ends up feeling even more abandoned, ignored and has to fight against walls of indifference, superficiality, etc. and very often he/she is even considered "responsible" for having questioned the dogma - which dies hard - of hospitalization in structures and "parking" centers for loved ones (Miccio, 2007, 2014, 2015, 2019).

The interventions each remain relegated to their own area without interconnection between them. It is necessary to overcome the scales used by the Regions which identify which services to direct people to.

It is important not to act in isolated compartments, each for himself in order to show hypocritical primacy and useless protagonism and underlying interests. Coordination, interdisciplinarity, multidisciplinary, competence, training, authentic experiences, monitoring, data, a common action aimed at implementing change first and foremost cultural and social aimed at a new concept of justice. Enough of the invasiveness of the structures, acronyms of various forms of residence, abuses in support administrations (Law 6/2004) which turn into cobwebs to the detriment of the beneficiaries themselves and their families, no more centres "parking places" which are wrapped up in self-referential visions with the operators at the centre, segregating logics and disguised as examples virtuous. In Italy the recognition of the family caregiver has not yet occurred. There is no national law yet. Siblings are not considered with the right attention. They can authentically bring about that much desired cultural change! (Miccio, 2007, 2014, 2015, 2019).

The caregiver is exposed to the so-called. Burden, which is a state of chronic stress. In 2009 in Stockholm to Elizabeth Blackburn was awarded the Nobel Prize for Medicine for her studies on the involvement of telomeres and telomerase in premature aging and reduced ageing life expectancy and poor health of family caregivers. The chronic stress to which the family caregiver is subject wears out telomeres, favoring the onset of very serious diseases. Chronic stress reduces the ability of cells to feed themselves. The more stressful situations continue over time, the more the length of telomeres and the activity of telomerase are reduced. It is clinically proven that family caregivers have an activity reduced by 50% and that the shortness of their telomeres causes an early death, ranging from 9 to 17 years compared to the normal population. Family caregivers live from 9 to 17 years less than everyone else! (Blackburn, 2004).

It is necessary - for a correct approach to disability and to create a new concept of disability - to move from the logic of help as a favor to the logic of help as a right of the person with disability for real inclusion in society and for an independent life (Parker & Clements, 2008). It is necessary to move on to the new concept of disability. I believe it is essential to build a global project. All universities should promote a new approach to the disability (Miccio, 2013, 2014, 2015, 2019).

The new model of disability that the Convention has produced must be made effective (Parker & Clements, 2008; Koch, 2009; Flynn, 2011). This model allows us to move from a welfare based on social protection to a welfare based on social inclusion!

It is necessary to highlight the effects and results obtained on a practical level from the laws currently in force, and their mechanisms of operation. To achieve this result, it is necessary to gather information about the type of anti-discrimination law, the criteria, practices and other obstacles that people with disabilities and their families continue to face in their daily lives. The more evidence there is that existing laws are incapable of offering adequate protection against discrimination, the easier it will be to persuade legislators to introduce reforms that are not an end in themselves and important will need to be seriously monitored.

Secondly, it is necessary to identify priorities. Finally, it is necessary to establish connections with other disadvantaged groups (that are not intended as separate categories. It is important to keep in mind that disability is a stage in life and affects everyone!) since the experience gained in those contexts can also be useful in reference to the disability. The establishment of common policies can be advantageous, given that all these policies tend to avoid exclusion and are easier for a broader base to reach a critical mass sufficient to justify specific legislative action not empty and an end in itself.

There would be so much more to say. I conclude with some thoughts taken from the testimony of a friend of mine who is physically blind but not mentally blind. "It would be enough to lend an ear, lend a hand, say a word, a smile, without implying any pietistic intent. This would be the real revolution capable of breaking down every barrier, cultural even before sensorial or architectural. In conclusion, although the events of recent years do not leave much room for hope, I still want to put my trust in others (...) Yes, I want to be confident and believe that, even if I have burned the sun, the dawn will come for me too" (Reale, 2017).

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