

Healthcare and Cultural life access for persons with disabilities during the pandemic: reflections of a researcher

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Abstract

The Covid-19 pandemic has put a strain on the health system, as well as the social, economic, and cultural ones at the Global level. After the pandemic, the risk is that the process of inclusion of persons with disabilities is grinding to a halt. But the chance is to find new ideas.

This paper will define a brief but significant framework of principles that should be taken into consideration in order to support strategies of inclusion of people with disabilities in the fields of health care and cultural life, especially through the research.

Keywords: health; cultural life; disabilities; inclusion.²

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² Received on May 31st, 2021. Accepted on June 24th, 2021. Published on June 30th, 2021. doi: 10.23756/sp.v9i1.615. ISSN: 2282-7757. eISSN: 2282-7765. ©Dario Imperatore. This paper is published under the CC-BY licence agreement.

1. Introduction

The Covid-19 epidemic has put a strain on the health system, as well as the social, economic, and cultural ones. Looking at the *Istat* (Italian Institute of Statistics) of 2019, there are over 3 million and 100 thousand Italians with disabilities (around 5% of the population), in a European context of about 100 million people with disabilities, as recently declared by The European Disability Forum. The current risk is to put first the interest in safeguarding "production" in favor of an economic recovery, without looking at the effective quality of social measures for people with disabilities and their families.

This paper would show some reflections on health and cultural life access (and other connections), during and before the pandemic, in order to define a brief framework of principles that should be taken into consideration on the basis of the UN Convention on the Rights of Persons with Disability

2. Health: The European Parliament's position against denial of care to people with disabilities

The Covid-19 pandemic found the world not ready to face such an emergency. States had to make decisions quickly, without the clear awareness of what was happening. Moreover, week by week the global situation was getting worse. We can reckon Italy as the first European member State that faced the pandemic. So, Italy's policymakers was not prepare to act over every national issue. Furthermore, the opposition in the Parliament did not allow a shared program of protection. So, the rights of people with disabilities risked being discriminated.

In this scenario, forgetfulness of the necessary protections can be seen, in fact, from the first Ministerial decree of the Prime Minister in 2020 - which indicates what is allowed or not allowed for citizens - that at a first has apparently forgotten to intervene on quarantine measures for families with people with disabilities.

In effect, at European level, the European Parliament³ noted that in some Member States, people with intellectual disabilities have been denied medical treatment, have been confined to institutions in conditions of social isolation, without being able to receive visits from family members or return to their respective families, and that discriminatory triage guidelines have been

³ The motion for a resolution 2020/2680.

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introduced. For many subjects, the forced blocking of rehabilitation treatments resulted in the partial nullification of the results obtained up to that moment.

3. Health: CRPD principles that to be translated into real facts during and after the pandemic

There is, therefore, a need to verify access to healthcare for people with disabilities in a pandemic period, starting from the provisions of Articles 25, and 26 CRPD⁴ (Health, Habilitation, and rehabilitation), also ratified by Italy, to overcome eventual mistakes and shortcomings, in order for planning improvement strategies, to promote the physical, cognitive and psychological recovery, rehabilitation, and social reintegration.

But in truth, the monitoring activity should be extended to a broader set of Fundamental Principles. In addition to articles 25 and 26, those of reference for this analysis are:

article 11: Situations of risk and humanitarian emergencies for the protection and safety of persons with disabilities in situations of risk, including situations of humanitarian emergencies and the occurrence of natural disasters;

articles 22 and 31: Respect of Privacy and Statistic and Data collection in order to protect the privacy of personal, health and rehabilitation information on an equal basis with others;

article 27: Work and employment in order to prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including safe and healthy working conditions.

Wanting to analyze the transversal impact of these principles, article 11 is a milestone since it undoubtedly recalls the pandemic situation. International and European policies, but also and above all national ones, should have immediately taken into consideration the needs of people with disabilities and their families to protect them from the pandemic.

Regarding the protection of privacy, this is an issue of increasing importance for strategic decision-making, also in consideration of the greater sensitivity of people, especially because their data are “particular” data - as more personal and sensitive than others. The Italian Privacy Authority urges the Data Controllers to identify adequate methods of protecting the particular data of people with disabilities but the pandemic situation has shown great fragility in

⁴The CRPD aims at building an inclusive society and entrusts national politics and legislation with the task of guaranteeing the enjoyment of human rights and fundamental freedoms to disabled people.

this sense, especially in consideration of patients with disabilities in the health sector.

As for article 27, in Italy, a double criticality emerges for people with disabilities regarding both the protection measures for the safety and health of fragile workers who continue to attend the workplace; and the danger of isolation and discrimination when the occupational physician establishes the preventive removal from the workplace due to the frailty of the disabled worker. A good note is given by the provision of a booking service for home vaccination for people with disabilities⁵. Here, however, further and transversal criticalities emerge. In particular two: the first is that the majority of people with disabilities need to be assisted at home because they have not autonomy and independence in mobility; the second, is the different approach to persons with disabilities in the field of health the very single regions of Italy.

In fact, in Italy, there is a system of regional autonomy in the health sector. The Regions, therefore, have exclusive competence in the regulation and organization of services and in the financing criteria of Local Health Authorities and hospitals. Consequently, there are sometimes considerable differences in terms of timing, quality and methods of providing services between regions and regions in the Italian territory, which cause territorial discrimination.

4. Cultural life: is time for new models of inclusion of people with disabilities

In the last 10 years, significant researches have been carried out concerning disability which shows the great value of cultural and leisure life for the inclusion of persons with disabilities.

But, after the Covid-19 pandemic, the risk is that this process of inclusion is grinding to a halt. The chance is to find new ideas through research supported by data collection on individual stories of life, good practices, regulations, and innovation in order to propose new models of inclusion.

5. Cultural life: CRPD principles to translate into real facts during and after the pandemic

The article 30 CRPD proposes the principle of participation in cultural life, leisure, tourism, and sport and asks States and privates to work together for

⁵Ceravolo MG, De Sire A, Andrenelli E, Negrini F, Negrini S. (2020), *Systematic rapid “living” review on rehabilitation needs due to Covid-19*. Eur J Phys Rehabil Med 2020;56(3):347-53.

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implementing policies of inclusion⁶. Despite the progress made in many member States, in Europe it is apparent that a lot remains to be done for truly equal and meaningful participation in cultural life⁷. In fact, even in the period before the pandemic participation was not the norm for persons with disabilities. Furthermore, the pandemic is increasing the difference between the Member States of the European Union, in terms of planning laws and policies, building norms and standards on accessibility (e.g. those on accessible services & technologies⁸, accessible tourism⁹, non-discrimination¹⁰, etc.), and the availability of expertise.

International research on the rights of individuals with disabilities is largely available, especially on the basis of the indicators of “accessibility” and “architectural barriers”. However, there is no academic consensus on the meaning of “inclusion”; and generally, there is no consensus on how inclusive leisure should be defined, then there is a poor perception of leisure as a right of inclusion¹¹. E.g., a swing at the playground is accessible if it allows a child in a wheelchair to play with it, but it can’t be defined inclusive if it is placed far from the other games: the child in a wheelchair will be excluded because he will not have interaction with other children. In this context, the role of the research should be to contribute to aggregate data in order to re-interpret the meaning of Cultural Life as a right of inclusion of persons with disabilities. It would consent to restart social life with a new comprehension of what inclusive leisure is, and why it is a right; how an inclusive leisure activity can be organized, and which are the benefits for all society, especially to break down old social barriers, and new ones.

⁶Raub, A.; Latz, I.; Sprague, A.; Stein, M. A.; Heymann, J., *Constitutional Rights of Persons with Disabilities: An Analysis of 193 National Constitutions*, Harvard Human Rights Journal, 2016, 29, pp. 203-240.

⁷UN Office of the High Commissioner for Human Rights (OHCHR), Professional training series no. 17: Monitoring the Convention on the Rights of Persons with Disabilities: Guidance for Human Rights Monitors, April 2010, HR/P/PT/17.

⁸Lawson, A., *Accessibility of information, technologies and communication for persons with disabilities*, Contribution to the Council of Europe Strategy on the Rights of Persons with Disabilities, 2017.

⁹Tatic, D., *Access for People with Disabilities to Culture, Tourism, Sports and Leisure Activities: Towards Meaningful and Enriching Participation*, Council of Europe Disability Action Plan, Quality life and full participation in society, 2015.

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6. Conclusion

To overcome all these limits, health and cultural life policies in Europe have to respect ethics and be implemented on a basis of equal opportunity. Policymakers should be inspired by a ‘Cultural Revolution’ that may raise awareness on priceless values, that are the result of social ties, such as inclusion¹². As well, it is desirable the cooperation of the Government, opposition parties, non-profit organizations (third-sector), and all civil society for a change to the independence and freedom of persons with disabilities¹³.

In the absence of a series of limits and corrective by the law, the risk is to expose the vulnerable part of society to marginality, with the consequent exaltation of the selfishness of society¹⁴.

Everyone should do his part, and the role of the research, in this scenario, is crucial.

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¹⁴ Perlingieri, P. (1994), *Prolusione letta al Congresso Nazionale dei Giuristi Cattolici Italiani*,. In effect, ethics is essential to match economic efficiency and of human rights or, in other words, to match market and democracy. Cf. Campanella, F. *Lo Stato e il mercato. Le idee e i miti di un passato più o meno prossimo*, in *Pubblico e privato nel sistema economico*, Beretta S. (ed.), Milano, 1992, p. 99.

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