

# Expert Interview: COVID-19 and the Rights of People with Rare Diseases in the EU

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The interview was conducted by Dipl. Jur. Anna Kohte with Dipl. Jur. Lara Schmidt[\*]

## 1. COVID-19 and the rights of people with rare diseases

**Question:** People with pre-existing medical conditions are among the most affected groups in the pandemic. Many are at increased risk of a severe course of infection and are at the same time particularly affected by pandemic-related restriction measures. What difficulties do people with rare diseases face specifically?

**Answer:** *The impact of the Covid-19 pandemic has arguably caused great difficulties for all those affected by a chronic disease, especially those living with a rare disease. A disease is considered to be rare if it affects no more than 5 in 10,000 people in Europe. It is estimated that there are about 30 million people affected across the EU. Even before the pandemic, those affected were particularly vulnerable not only medically, but also from a social and economic point of view. This is even more the case when one considers that rare diseases are often genetically caused and therefore many children are affected. As a result of the pandemic, people living with rare diseases are now in a situation that goes far beyond the individual risk of suffering a severe or even life-threatening Covid-19 infection. They are particularly exposed to structural problems in the health care system: These diseases are often medically very complex, and due to a lack of qualified specialists, these patients have no established pathway through the national health system. This is reflected in their overall quality of medical services, from diagnosis to treatment and care. Hence the healthcare of people with rare diseases already poses a significant challenge under normal conditions for all involved. The effects of the pandemic on the health care structures lead to major additional health risks. This even applies to those affected living in Germany and Europe, whose medical care situation is quite good compared to the world's average. In particular during the first year of the pandemic important treatment measures were cancelled and check-ups not performed because capabilities were reserved for the pandemic. Professional care providers were also unable to carry out their work due to a lack of personal protection equipment and care materials. Consequently, these activities had to be performed by private caregivers – mostly by family members who were already under great stress. In short: All the system deficiencies revealed by the pandemic have in one way or another affected those who are living with a rare disease. These extra burdens are indeed related to the pandemic. But there is also a systemic cause: people with rare chronic diseases are unfortunately still often forgotten in political decision-making. In Germany, for example, caregiving relatives were initially not adequately considered in the prioritization of vaccinations. Those affected were also left alone with regards to information on the general possibility of vaccinations for a rather long time. Recently, there is a fear that those affected who*

cannot be vaccinated for medical reasons will be once again forgotten, or excluded, as those that have not been vaccinated or recovered from an infection can be refused entry and service in Hamburg, for example.

## 2. A response at EU level

**Question:** The primary legal competence in the field of health protection falls to the Member States. To what extent can EU institutions (e.g. the European Commission) nevertheless contribute to safeguarding the rights of people with rare diseases in the pandemic?

**Answer:** *The EU's objectives in the field of health do not always correspond to a sufficient legal competence in the area, which was also noticeable in the pandemic. In any case, there are no provisions for legal harmonisation in the area of health, not even for a pandemic. The Union's legal competence in the health sector is explicitly limited to complementary measures, see Art. 168 TFEU. Nevertheless, the interdependencies caused by European integration are stronger than one might think at first glance. Particularly in the field of rare diseases, the quality of healthcare has improved greatly as a result of Union activities. As early as the end of the 1990s, the EU launched a health policy action programme with a focus on rare diseases, which has drawn a lot of attention to the „rare community“. A 2009 Council Recommendation then initiated National Action Plans for people with rare diseases in the Member States and led the path for medical centres of expertise and European reference networks. The EU regulation to promote the market introduction of so-called „orphan drugs“, i.e. medicines specifically for rare diseases, was also important. With regards to EU actions in the COVID-19 crisis in particular, everything that helps to combat the pandemic and its negative effects on health care systems and improves the medical as well as the socio-economic and social situation of those affected is, in general, welcomed. For example, there have been concrete attempts by the European Commission to improve the availability of scarce medical equipment in Europe by means of non-binding solicitations. There is also hope, that the “NextGenerationEU” reconstruction programme will improve the management of the economic fallout from of the pandemic and enable the Member States to invest in their health systems. In any case, I am interested to see whether and how the debate about more EU legal competences in the field of health, which has been brought up during the pandemic, will have an impact in the future. What it has brought so far is a public debate on options for action by the Union in a globalized world.*

**Question:** With regard to people who are disabled as a result of their rare disease, the UN Convention on the Rights of Persons with Disabilities of 2006, which is the first global treaty under international law to specify the rights of people with disabilities, is particularly important.

In addition to all EU Member States, the EU itself has also ratified the UN Convention on the Rights of Persons with Disabilities. What does this independent ratification of the Convention by the EU mean in practice, especially in times of pandemics?

**Answer:** According to the UN Convention on the Rights of Persons with Disabilities (UN CRPD), people with chronic illnesses are first of all “impaired”. They are furthermore considered “disabled” if they also encounter barriers and the interaction of impairment and barrier “may hinder them from full and effective participation in society”. Therefore, not every person with a rare chronic disease is automatically disabled. However, in practice the vast majority of those affected will be.

The fact that the EU has ratified the UN CRPD independently is remarkable in itself, as it is the first time that the EU has become a party to an international human rights treaty. In terms of disability policy, the ratification marked a change of paradigm towards the understanding of the term „disability“ in a social and human rights context at a European level. This had a signalling effect beyond the borders of Europe. From a legal perspective, EU actors are directly obliged to implement the contents of the Convention and to uphold the human rights specified. Considering the distribution of legal competences between the EU and the Member States, an independent ratification by the EU was also necessary in order to ensure the comprehensive validity of the Convention in Europe.

Of course, what is important for practical implementation is that EU legal acts potentially have to be measured against the UN CRPD and that the Convention becomes justiciable through the ECJ. Still, the independent ratification has also had an influence on the interpretation of EU primary law, in particular Art. 26 CFR. The Union must also submit an individual report on the status of implementation of the Convention. This will help to generate meaningful data about the situation of people living with disabilities in Europe. Future reports will certainly also address the implementation of Conventions rights in the pandemic period. In this context, the guarantee of the highest possible level of health and corresponding access to health services, as guaranteed in Article 25 of the UN CRPD, will be especially noteworthy.

Still, it can be said that the practical enforcement of the Convention in Europe faces the same difficulties as in Germany. Due to the Convention’s high level of abstraction and the high density of regulations at the same time, there is hardly any room for a direct application of the Convention. Only when it comes to discretionary decisions can the UN CRPD influence legal interpretations. In German law on aids and appliances, this is the case with „basic needs“. The provision of assistive devices in accordance with the Convention must aim at full participation in society and must not be geared solely towards compensating for disabilities. In this area, German courts already explicitly recognise the importance of the Convention.

**Question:** Criticism was voiced in Germany in particular over the fact that people with certain pre-existing conditions were not sufficiently prioritised in the vaccination campaign. For example, people who have trisomy 21 were assigned to the second priority group despite the fact that the risk of a fatal outcome is just as high as for people over 80. What opportunities are there at the European level to work towards inclusive national vaccination strategies?

**Answer:** *Indeed, especially at the beginning of the pandemic, the German vaccination management did not prioritise all chronically ill people according to their real risk of becoming severely ill with Covid-19. In fact, people living with trisomy 21 were only included in priority level 2 in the German draft of the vaccination regulations if they lived in an institution for people with disabilities. Relatives providing care and other assistants were also not sufficiently prioritised at first. Fortunately, this later changed, also thanks to strong civil engagement and advocacy. However, this could not always prevail, for example when priority groups were opened up for certain professions at short notice at the expense of people with high health risks. So there were potential reasons for EU influence. A possible approach could have been the joint vaccination strategy of the EU and the Member States. The European Commission had spoken out in favour of such a strategy early on and pushed it forward. However, the focus was on the procurement of vaccines and simultaneous access to vaccines for the Member States. Within the framework of this voluntary cooperation, the EU should also have created steering effects on prioritisation issues and worked towards a consistent implementation in the Member States. The same applies to barrier-free access to vaccinations. Here, the EU should have acted more as a multiplier.*

### **3. Disability Mainstreaming as a solution?**

**Question:** The German Institute for Human Rights recently published a position paper in which it calls for „consistent disability mainstreaming“ in pandemic response. This is defined as the systematic consideration of people with disabilities in all pandemic response measures. At the global level, António Guterres, Secretary-General of the United Nations, has already called for disability mainstreaming in the pandemic. How can we imagine such disability mainstreaming in practice? Are there already examples of this?

**Answer:** *In the mentioned position paper of the DIMR, it was already criticised that the persons affected were not sufficiently consulted in political decision-making processes during the pandemic. However, the political participation of people living with disabilities is an indispensable component for realising a non-discriminatory and self-determined existence in all aspects of life. Participation is both a goal and an instrument for disability mainstreaming. Art. 4 para. 3 of the UN CRPD therefore rightfully obliges the states parties to structurally include people living with disabilities in legislative processes. Representative organisations of people living with disabilities play an important role in this regard. This applies even more to the area of people who live with a disability due to a rare disease. In this field, a unique expertise is concentrated in disease-specific self-help organisations. They offer affected individuals and their relatives a platform for exchange and networking. “Rare people’s” organisations are also often the first point of contact on the way to diagnosis as well as therapies and are excellently networked with specialized doctors and therapists. They are also able to reliably identify and promote the needs and interests of their members to the public. Health-related self-help makes those affected visible. Self-help is empowerment and serves participation. In this way, self-help also provides the preconditions for disability mainstreaming. Politicians have understood that health-related self-help groups are indispensable consultation partners. However, the*

*representation of affected people as a whole still lacks reliable financial resources that correspond to its responsibilities. Given the mentioned obligations under the UN CRPD, this is not a satisfactory situation. Europe also needs to get involved here. The EU has to make full use of its possibilities in the field of engagement policy.*

**Question:** Can such disability mainstreaming actually be expected to improve the situation for people living with disabilities because of their rare disease?

**Answer:** *To consistently involve people living with disabilities in decision-making processes has the potential to prevent barriers from arising in the first place, instead of having to correct deficient decisions or their effects in retrospect. If implemented in a realistic way, this can be expected to lead to a considerable improvement in the situation of people living with disabilities. Holistic „disability mainstreaming“, however, requires a profound change in the way our whole society thinks. Personally, I think it is important to recognise that in many areas there may not be a simple and cost-effective „one fits all“ solution. And yet these efforts must be made, because inclusion is not a favour, but a right. What I would like to see for people who live with a disability due to rare diseases is greater visibility. As a potentially multi-marginalised group, they are particularly in need of an inclusive process aimed at equal opportunities and participation.*

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