Leaving no one behind?

Special needs in times of COVID-19

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In the current COVID-19 pandemic, the rights and special needs of persons with disabilities are once again neglected dramatically. It is bitterly unsurprising that the topic arrived on the agenda of international policy makers only when UN special rapporteur on the rights of persons with disabilities, Catalina Devandas, criticized the lack of awareness and resulting inaction in mid-March. UNICEF was finally the first international organization to publish considerations on children and adults with disabilities and COVID-19 response measures a few days later; the WHO followed by the end of March. However, the current crisis amplifies everything that goes wrong already in “normal” times.

A particularly grim example not just of neglect but of outright discrimination are recently surfaced triage protocols like the one of the State of Alabama. These protocols prescribed that mechanical ventilator support should not be offered to patients with such conditions as “severe or profound mental retardation”, “moderate to severe dementia” and “severe traumatic injury” in the case of shortages. Alabama’s protocol had been incorporated into the state’s emergency preparedness plan in 2010 and was removed only recently due to severe criticism. According to an analysis by the Center for Public Integrity (a US NGO), 24 other US states adopted similar protocols. By attributing less value to the lives of persons with mental and intellectual disabilities such protocols violate not only the right of people with (cognitive) disabilities to the equal access to health care, Articles 25 and 9 of the UN convention for persons with disabilities (CRPD), but are an outright on assault on their dignity.

While the protocols are an especially horrid example of discrimination, there are other problems for disabled and institutionalized persons aggravated by the current pandemic. Disabled and institutionalized persons are oftentimes more vulnerable not only to the novel Corona virus, but also to the response measures taken by states. Of course, even in times of crisis, the 181 member states of the CRPD are not exempt from their obligations. Art. 11 CRPD even regulates the protection of persons with disabilities in situations of risk such as the current pandemic. According to a statement by the Committee on the Rights of Persons with Disabilities (the Committee), the obligation entails not only the protection against COVID-19 but also the protection against detrimental side effects of response measures. Due to past shortcomings in the implementation of disability rights, however, this is often impossible.

First of all, there is the problem of over-institutionalization. Fewer persons would be exposed to health risks posed by COVID-19 if more efficient measures of deinstitutionalization had been taken in the past. The Committee implicitly
recognized that by recommending to “accelerate measures of deinstitutionalization”. In permanent care facilities with a high percentage of risk patients, self-isolation measures are not feasible as the residents are often accommodated in large groups and depend on the assistance by care personnel. Once the virus gets inside a facility, it is almost impossible to protect the institutionalized persons within that facility from infection. Although deinstitutionalization has been a topic on the political agenda of many states, little has been done so far.

Moreover, many residents are cut off from their family and social environment as most institutions are subject to visit and entry restrictions. These restrictions interfere with Article 23, the right to respect for home and family, and Article 19 CRPD, the right to live independently and to be included in the community. As an alternative to physical visits UN High Commissioner for Human Rights Michelle Bachelet proposed social media. Regrettably, special support and training has not been provided in the past, so a great number of institutionalized persons is physically, emotionally or cognitively not able to take advantage of digital means. Moreover, many care facilities simply do not have the necessary technical equipment because of a lack of adequate funding.

Due to the absence of digital alternatives for work and schooling, the rights to education and work of persons with disabilities (Articles 24 and 27 CRPD) are also more severely affected than for other persons, despite their implementation being a key element for their social integration. Devandas also noted that the absence of visitors makes protection against abuse or neglect in permanent care facilities a lot harder for disabled persons. Although states are obliged to ensure that such institutions are monitored by independent facilities, Article 16(3) CRPD, the reliability of these monitoring processes is more than questionable given the frequency of human rights violations in such institutions even in normal times (see for instance here). During the current pandemic, these monitoring processes are additionally impeded by a lack of personnel and prohibitions of contact and entry.

However, not only past failures exacerbate the situation of disabled and institutionalized persons in the current crisis. States’ reactions to COVID-19 are often ignoring their special needs, confirming the trend that disability rights enjoy far too little priority in many states. For instance, only a few states have published relevant information about COVID-19 in minority languages, braille (embossed printing for blind persons), in sign and easy language, thus violating Art. 9 and 21 CRPD which guarantee access to information without discrimination. Additionally, emergency response laws were adopted that further weaken the rights of persons with disabilities, as e.g. in the UK, where the procedural standard for closed accommodation has been lowered.

In the current crisis, reminders that no one must be left behind are important. So far, however, we see that the gap between institutionalized persons with disabilities who had often already been left behind and the rest of society is only growing. There are two sides to every coin, though. This pandemic has the potential to raise awareness and build bridges to overcome this gap. Many of the digital alternatives that have been created because of the lockdown strategies enable many disabled and house-bounded persons to participate in social and cultural life for the first time, making the
rest of society understand the physical barriers disabled people face. The reactions to the unacceptable triage protocol of Alabama gives hope that awareness for the shortcomings and the still deeply rooted discrimination of persons with disabilities in our society is indeed growing.

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