Parents of children with disabilities and the COVID-19 pandemic

The COVID-19 pandemic prompted authorities and institutions around the world to adopt urgent measures of general application, including limiting social contact and shutting down public spaces to prevent spread of the virus. We now see clearly what had been insufficiently anticipated and planned for. Quarantine and other preventative measures often had painful consequences for those who already lead a more challenging life—the disadvantaged and the vulnerable, and those around them.

In the context of the pandemic, parents and caregivers of children with disabilities or complex chronic disorders faced unprecedented, at times insurmountable dilemmas. Schools and residential care facilities closed their doors; non-acute management was severely disrupted. Parents and carers had to decide on their own whether to take their children out of care and return them to the family home, or leave them in the usual living environment, where visits and other social contacts were drastically reduced or prohibited. In some instances, support for home care provision stopped and many aspects of daily life were put on hold for extended periods, with no promise of normalization. Restrictions on shopping, e.g. single, unaccompanied person, added to the multiplicity of challenges. These measures were rightly based on expert evidence, and they are indeed commonsense measures, but their application may have proved unmanageable for the families of disabled children.

The daily reality for these parents can lead to physical and mental exhaustion. The burden and responsibilities in normal times have become heavier and more complex. In addition to the hours spent teleworking and looking after confined siblings, they must take on the tasks of professional carers and educators, in home environments and with equipment that are often ill-suited for the job. In these situations, a child or adolescent who may have lost their bearings socially or emotionally requires constant attention. Family tensions can be exacerbated, especially when the usual support from grandparents and other relatives is lacking.

Parents report a latent sense of guilt about the difficulty of making choices and their inability to take on all these new roles. The social isolation they often experience in ordinary times has worsened. Fatigue is general. But they also talk about the many forms of helplessness they feel; recharging their batteries; managing daily life smoothly; accessing information that is understandable, targeted, and coherent on the measures that concern them; and finding existing resources for advice, support, and respite. Above all, most of them are unable to make themselves heard when they ask for the prevention system, which would account for their particular situation and needs, as well as those of their children and extended families.

The pandemic has exacerbated and highlighted the different realities and inequalities that exist within society. Coherent assessments and lessons for the future are now beginning to take shape, but slowly. The aftermath of the pandemic must lead to more in-depth reflection. On the one hand, on the mental and physical well-being of parents of children with disabilities, not only in times of crisis, but indeed across their life journey. And on the other hand, on the mechanisms for dialogue, support, and respite to which they must have access.

Health in all its aspects is one of the Sustainable Development Goals of the United Nations. Mental health is of course part of this, but it is far from receiving the attention it deserves. As an advocate for these goals, I particularly want to help raise awareness of the importance of mental health at the national and international level. The COVID-19 pandemic and the international response to it have opened our eyes to the need to end indifference and stigmatization, to promote empathy, and above all to ensure access to mental health support and care for all those in need.