

Future opportunities for the area of childhood disability in a post-COVID-19 Era

This document is a non-exhaustive list of lessons learned from the COVID-19 pandemic, with the focus on how we may turn a tragedy into an opportunity for a better future. This document can be seen as a first step towards raising the standards for users, caregivers, and professionals in the area of childhood-onset disabilities by identifying possible future opportunities. This document will be presented to all delegates of the EACD Europe 2021 Annual Meeting with the opportunity to respond with their ideas, comments, and suggestions.

Topics:

1) Minimal standards for health care (including mental health care), and opportunities for the future

- a. Access to healthcare is a right that all people have irrespective of background or demographic factors (e.g. disability, gender, race, ethnicity, age, religion, sexual orientation, or economic status). Therefore, all aspects of planning, delivery and review of services must reflect these values. All staff and volunteers must base their practice on these values, recognizing people's rights and aim to provide quality services that are patient-centered. This includes the implementation of policies and reasonable measures to ensure no one receives less favourable facilities or treatment on any of the grounds stated above with zero tolerance against any type discrimination and/or harassment, and asks for all to make sure that the implemented measures are set and followed.
- b. Considering that we live in a world that is ever changing and with the challenges and uncertainty that the COVID-19 pandemic brings, and considering that people with a disability are more likely to develop anxiety and stress-related complaints, it can be concluded that is important to build a supportive community for people with a disability. This requires a facilitating role from relevant authorities and organisations towards the set-up and maintenance of both informal and formal support networks and infrastructures. Furthermore, it needs to be acknowledged that for some this support just isn't enough. As such, children with any disability should be eligible for mental health services whenever appropriate, and mental health support needs to be at the core of any team supporting people with a disability.
- c. Considering that children with disabilities are more vulnerable and susceptible to medical complications due to frailty and instability, in all circumstances including but not limited to pandemics, war, and economic crisis. It can be concluded that in case of scarcity of healthcare resources, special attention has to be addressed toward care for this group as apparent small medical events are much more likely to result in major complications. Devoted pathways within hospitals should be developed for people with disabilities in order to prioritize access to this fragile population, either for medical (COVID or not-COVID related) or psychiatric assistance, in all possible circumstances.
- d. The COVID-19 pandemic forced services to be (re-)organised in more efficient and less time consuming deliveries, however it is important to keep in mind that this does not come at the cost of the quality of the service delivery. That is, to preserve the quality of the provided services a range of aspects need to be discussed and considered. This includes among other that professionals have to be trained to use optimally online platforms; that an alternation of remote support and live support may be important in order to keep strong links with patients; that a network between different contexts where the person with disability lives has to be set-up; that more space to psychological aspects



needs to be given, to discuss for example about social restriction and their consequences on the families; and that the needs and required services for every person with a disability are different.

- e. Lockdowns and other implemented measures and restrictions influenced negatively the mental health, the learning process (school skills) and the level of sedentarism of children with disabilities. Considering the well-known positive impact of a healthy lifestyle on one's physical and mental health, it can be concluded that the promotion of a healthy lifestyle and the promotion of healthy habits such as physical activity, appropriate sleep and healthy eating behaviour should be a priority for the upcoming years. This should not only be focused on the children but also on the family caregivers given their position as role model towards the children.
- f. Considering the wide variety in the use of the terms emergency care and non-deferrable care between different European countries during the COVID-19 pandemic, it became apparent that there is a clear need to define what is (and what is not) emergency care and non-deferrable care in relation to the care and treatment provided to children with a disability. A somewhat similar point can be made towards the variety across countries in the prioritization (or lack thereof) of vaccinating vulnerable young people with a disability.
- g. Considering the (in)direct effect of COVID-19 on children and adolescents augmented by the effect of trauma when it is faced at this developmental stage, governments and policy makers should implement mechanisms to detect early stressors of their social, emotional, mental and physical well-being in a pandemic situation. Governments and policy-makers should facilitate the providers to develop methods to help people connect during isolation. This begins with targeted communication and outreach. Technology/ social media could be tools to use during periods of isolation

2) Minimal standards of social protection (support), and opportunities for the future

- a. Considering that implemented austerity measures and disagreement over money between various layers of governance over the past decade has put the support of people with a disability under great pressure already prior to COVID-19 pandemic, it can be concluded that continuing along this path will lead to further exhaustion and overburdening of people with disabilities and informal caregivers, escalation of the problems faced by people in need of support and, as a result, higher costs for these people and for society. As such, a change in our approach is needed in which we ensure that social support in regard to care, participation, housing, school, mobility, work or meaningful daytime activities is offered based on the people's need of support instead of determined by the available budget. In this respect, such investments in social support could be expected to be cost-effective in the long-term as prevention is cheaper than cure.
- b. Considering that people with a disability have suffered greatly from laws and domains that do not or insufficiently connect with each other, due to legislation and regulations often not being focused on the person requesting support but on the parties providing support, it can be concluded that we should start putting needs of people at the forefront when assessing the required (social) support, irrespective of the type of support involved: work, school, housing, mobility, youth assistance, care or participation, and that we should start to work on the basis of trust in supporting people with a need for support and we should adjust legislation and regulations accordingly, in which we involve



people with a disability closely and actively within all the stages of policy decision-making processes.

- c. Considering that playgrounds have shown to be an important place for children with disabilities to play with their peers, it can be concluded that special attention must be made in their accessibility for children with disabilities in order to positively impact on participation in this group.

3) Access to high-quality education, and opportunities for the future

- a. Considering that compared to persons without disabilities, those with disabilities are less likely to ever attend school, more likely to be out of school and that they tend to have fewer years of education than persons without disabilities. And considering that persons with disabilities are also likely to suffer from multiple disadvantage with regard to access to education, for example the cumulative negative effects of being poor, living in a remote area and having a disability, it can be concluded that it is warranted for countries to respect, protect, and fulfil the right to education of people with disabilities, through the implementation of 'inclusive education'. Inclusive education recognizes the capacity of every person to learn, including people with disabilities, and acknowledges that each person has different strengths, requirements, and learning styles. Inclusion, therefore, takes an individualized approach with curricula, teaching, and learning methods that are flexible and adaptable. By taking into account differences among learners, inclusive education promotes respect for and value of diversity and seeks to combat discriminatory attitudes both in the classroom and society.
- b. Considering that the COVID-19 pandemic has highlighted the importance of education professionals and the fact that access to education cannot be taken for granted, it can be concluded that high quality education is not possible without highly-trained professionals provided with adequate resources. This would include the need for a minimum standard regarding for the proportion of teaching staff, in each institution, who have undergone specialist training regarding inclusive teaching practices and teaching children with disabilities specifically
- c. Considering that over the past year, our attention of the educational impact of the COVID-19 pandemic on children and young people has focused on the immediate to short-term effort to re-open schools, the quality of remote provision while they have been closed, and the longer-term challenge of recovering from the substantial disruption to schooling. It can be concluded that in doing so, this has drawn attention to a number of long-lasting, systematic education issues, such as among others the need for support of vulnerable pupils, inequality of educational outcomes, and school funding. Measures to address these issues and to support progress and educational outcomes for both vulnerable and disadvantaged learners are urgently warranted.
- d. During the COVID-19 pandemic it has become evident that the school is not only a place to fulfill curricula, but also a place to participate and have fun with peers, learn activities of daily living and develop values. As such, it can be concluded that a minimal level of social contact has to be warranted during similar situations, and maximal efforts should be taken to keep promoting tele-education as an extra tool, not only for educational purposes but also to facilitate social contact and interaction.



4) How to use telecommunication in rehabilitation context, and opportunities for the future

- a. Considering that more often than not, the main obstacles to successful telerehabilitation have to do with clinicians and patients adjusting to the technology, not with the bandwidth used or the equipment required for teleconsultations, it can be concluded that it is essential that service providers must receive adequate training in the clinical activities involved in telerehabilitation, and on how to adapt it to children's different needs.
- b. Considering that telerehabilitation care and service delivery can successfully meet client needs for certain clinical activities, it can be concluded that the quality of telerehabilitation care and service delivery should be assessed to the same standards as a conventional face-to-face rehabilitation setting. In addition, telerehabilitation care and service delivery should be individualised since it has been shown that some types of telerehabilitation settings do not work for specific people (e.g. people with a visual impairment, or more severe cases)
- c. Considering that telerehabilitation care and service delivery is not limited by travel barriers or restrictions, it can be concluded that telehealth could offer better access to care and services for people living in rural, isolated or remote areas. It promises health care services to become more accessible to a variety of people, including among others to families with many (other) children accessing child care for face-to-face appointment, and people with chronic fatigue where a journey may wipe them out for the day. Simultaneously it should be realized that telerehabilitation is not an alternative to creating an infrastructure and establishing clinicians in the regions in order to meet the population's needs either for medical (COVID or not-COVID related) or psychiatric assistance.
- d. Considering that technology may contribute to increasing training and treatment adherence, it can be concluded that the development and use of such new technologies and tools in rehabilitation context should be increased and facilitated.
- e. Considering the importance to adequately protect the safety and confidentiality of everyone involved when using any type of consultation, it is clear that it will be needed to set strict, clear, appropriate protocols and requirements for each tele-rehabilitation consultation based on the input from (hands-on) experts. The facilitating/supportive function of local employers and authorities are crucial in this regard to ensure such appropriate and clear protocols and requirements are set and followed.
- f. Considering that telemedicine is taking a more important place in the care for children with disabilities and their families, policy makers should support this way of consulting by enabling parents and professionals with secure and patient friendly platforms and being able to charge digital consultations. This accounts especially for people with different cultural or lingual backgrounds, and/or people with low-health literacy

5) How to support families, and opportunities for the future

- a. Considering that all users and families deserve and should experience quality care and support, it can be concluded that they should be fully informed and involved in all decisions affecting their treatment and care, and contribute to the planning and evaluation of services. This also includes that families and children should be fully informed at a regular basis on the status of the pandemic as well as on the impact on their disability (e.g. higher risk of getting infected, higher risk of mortality, etc.).



- b. Considering that parents and family members form the most important context for children with disabilities, and that all family members have individual and changing needs, it can be concluded that the needs of caregivers should be regularly assessed and addressed in order to support family members to form a solid base of support for children with disabilities. Lockdowns in different countries in Europe showed that this solid base of support is indispensable in the care for these children.
- c. Considering that parents and other family members can and often would like to play an important role in co-creating therapy opportunities and providing care for children with disabilities, it can be concluded that parents should be seen as partners in healthcare processes and should be enabled to do so. Considering the low-threshold communication possibilities using telerehabilitation, it can be concluded that telerehabilitation should be supported in rehabilitation and other healthcare processes
- d. Considering that during lockdowns families experienced an extreme burden, it can be concluded that awareness of families' situations have to be raise among professionals and with it preventive actions for similar situations when children with disabilities need to stay at home

6) How to support professionals, and opportunities for the future

- a. Considering that the COVID-19 pandemic has highlighted the importance of health care professionals and the fact that optimal care and service delivery cannot be taken for granted, it can be concluded that high quality care and service delivery is not possible without highly-trained staff provided with adequate resources.
- b. Considering that there are a lot of fears and worries by many professionals working with people with a disability, directly or indirectly linked to the COVID-19 pandemic, it is important to recognize that every professional working with people with a disability should be able to access (mental) support when needed. In this respect, the importance of social, more informal aspects of working in a team as health care professionals have become very clear, and it should be highlighted that attention should be paid to ensure that these more informal, unstructured contacts between colleagues/professionals are facilitated and organized at regular occasions where possible.
- c. Considering that communication is an essential element in the rehabilitation process, it can be concluded that health professionals should be allowed to dedicate sufficient time to this task, and should be encouraged and given the opportunity to train this crucial aspect at a regular basis
- d. Considering that (COVID-19) health care providers were in first-line contact with infected children and adolescents, were overwhelmed by media reports and news, and were facing long work hours, it can be concluded that the first-line health care providers during a pandemic episode should receive first-line transparent and crystal clear information at a regular basis. In addition, the well-being of the healthcare providers should be immediately supported by means of availability of extra personnel during a pandemic episode in order to avoid fatigue, stress and burn-out. Finally, they should receive support in care for their own family members wherever appropriate, in order to be available to deliver their best care where needed.