

Creative Responses to the  
COVID-19 Pandemic:  
Shared Stories of Caregivers  
and Mental Health Practitioners

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## The context

The COVID-19 pandemic has affected all strata of society; and in this time, young people with developmental disabilities are a particularly vulnerable group. Ummeed Child Development Center was founded in 2001 by Dr. Vibha Krishnamurthy, as a not-for-profit organization, with the vision of helping children with developmental disabilities, aged 0-18 years, reach their full potential and be included in society. The team works towards this goal through four core areas of work – direct clinical services, training/capacity building, research, and awareness/ advocacy. Ummeed believes in care for all and hence, provides transdisciplinary services across all socio-economic sections. Furthermore, the principle of family centred care, which is the belief in collaborating with families underpins Ummeed's vision (Smith et al., 2015).

Working in partnership, the caregivers of young people with developmental disabilities, and the Ummeed mental health team have sought to respond to the COVID-19 pandemic in ways that offer glimpses of resilience, courage, and creativity. This commentary offers a reflection on the diverse experiences of both caregivers of young people with developmental disabilities and mental health practitioners, and what they have found both possible and useful during these times.

## Responding creatively to the COVID-19 pandemic

First reported in Wuhan, China in early 2020, the pandemic has spread rapidly across the globe, affecting large numbers of people, especially from vulnerable groups, and resulting in deaths. One of the responses to control the spread of the virus has been imposing lockdowns on populations, and this measure was announced in India in March, 2020. Mumbai, one of the most densely populated cities in the world, has struggled to flatten the curve of spread, despite severe lockdown. People are experiencing anxiety due to fear of infection, changing lifestyles, and isolation from loved ones. The suddenness of the lockdown did not allow caregivers of young people with development disabilities time to prepare. While the uncertainty and unpredictability of the situation has brought challenges, it has also opened up a myriad of possibilities.

In our work as mental health practitioners, caregivers, whose children with developmental disabilities access Ummeed services, have shared their constant fears, and anxieties related to themselves and their families, especially their children. For example, the fear of contracting the virus and what that would mean for caregiving responsibilities of their children. Other anxieties included their children's well-being, finances and meeting the basic needs of the family, and concern over the termination of therapy sessions and whether their child would regress. Specific difficulties related to their child included coping with the child's 'behaviours', engaging their children throughout the day due to an overwhelming workload at home and at work, and concerns related to their child's ability to keep up with school work and the increased use of screen. Caregivers expressed a feeling of isolation from being unable to connect physically with their community, which offers fundamental support in their lives. These conversations gave voice to caregivers' sense of helplessness; however, we also witnessed their resilience.

As mental health practitioners who engage in the practice of narrative therapy, we were keen to listen to stories that helped caregivers through these difficult times. (White, 2007). How were they managing the stresses in their lives? What were they doing to stay close to what was important to them? What were some of the things or people who supported them? Their responses offered stories of what the lockdown has made possible for them.

Spending time with families. Caregivers welcomed this time of lockdown to extend support to each other and redefine relationships. For example, the current situation made it possible for fathers to spend time playing with their children and be involved in their daily activities. Being able to support their children with attending online school also generated feelings of security and comfort for those children who had experienced increased anxiety during non-pandemic times (from bullying, sensory overload, keeping up with the teacher and classmates which can be hard when experiencing a learning disability). Experiencing less anxiety gave caregivers an opportunity to explore new skills of their children.

Discovery of skills. Caregivers used this time to uncover skills lost with time or engage in the development of new skills such as meditation, yoga, art, cooking, music etc. One family discovered making fun videos of themselves as a way of coming together.

Continuing therapy at home. During this period, caregivers shared how they figured out creative ways to engage children and simultaneously continue to work on their therapeutic goals. Caregivers reflected how including children in chores like cutting vegetables built on their skills for daily living and became a way to share the workload.

Prioritizing values. Another creative response to the COVID-19 pandemic came through finding a way to continue holding on to what they deemed important. For instance, prioritizing what they want to hold on to, their hopes and values as a family, allowed them to let go of things that were not as important and potentially coming in the way of realising those. For example, one mother of a young person with autism spoke about how maintaining peace in the house and everyone being happy was the most important to her, and so she chose to let go of the struggle of the use of additional screen time by her daughter. In this action of letting go, she felt a state of calm which was equally felt by the rest of the family.

The current situation has also called upon us, as workers, to develop creative ways to continue partnering with and supporting families. As mental health workers, the creative ways in which caregivers have responded to these new circumstances have inspired us to co-create and hold spaces to support these little and 'little

big' ways of navigating current times.

Making possible leisure spaces. An online format where young people experiencing developmental disabilities can come together and “chill” has seen enthusiastic attendance and been widely appreciated. Families come together to witness each other dance, play musical games, do craft and use colours; but most importantly, to connect with friends. The feeling of partnership and engaging with peers reduces the sense of being alone (Law et al., 2009), and in this space, children are able to put aside fear, share laughter, and feel uplifted. Caregivers have experienced support and reassurance that their children can connect with their therapists and other young peers.

Connecting caregivers. Caregivers have greatly appreciated spaces to explore leisure and connection with others through the opportunity to do something fun and relaxing with a group of caregivers who share a similar lived experience. In these caregiver groups, vibrant exchanges of ideas and “jugaad” on how to continue therapy goals using daily chores, how to get deliveries of food, who to contact for medications, or permissions for moving during lockdown are all explored.

Using books and social stories. Books support both children and caregivers in initiating conversations about what has been hard. They also make it possible to express things which may be hard to share (e.g., worries) and can provide newer possibilities for people to respond. Both children and caregivers have shared that being able to exchange information and understand a situation better, contributes to a sense of agency over the context. This brings a feeling of knowing what one's choices are, thereby reducing the sense of unpredictability.

Establishing new routines. The pandemic has offered many opportunities to re-evaluate old patterns and ways of being in the world. This has also been the case for caregivers of young people with developmental disabilities and Ummeed mental health practitioners. Routines have been shown to be helpful in supporting people's mental well-being (Rodger & Umaibalan, 2011). New routines have included having a fixed bedtime and meal times, a bath routine, creating family time to play together, involving each member in chores or assigning different

chores to each member of the home, and giving each member an opportunity to choose a movie or a fun activity for the day.

The creative responses offered by caregivers of young people with developmental disabilities and mental health practitioners as discussed in this commentary have been drawn from our experiences during the Covid-19 pandemic. While these are difficult times, nevertheless, we maintain that people have many skills and know-how, and are active participants in holding on to what is important to them in order to sustain their mental well-being.

## REFERENCES

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