

Telehealth Learnings from the CMC CoIIN Family Focus Groups

The pandemic forced most health care to shift virtually, which caused families with children with medical complexity to switch to telehealth.

We spoke with families about their perspectives on the benefits, challenges, and areas of improvement regarding telehealth.



Benefits

- Provided comfort and accommodation for kids with sensory needs.
- Gave providers a window into the lived experience of CMC and their families.
- Decreased travel time to clinics.



COVID-19 and Telehealth

Challenges

- Structural barriers to telehealth can be difficult for families with poor internet service or older devices.
- Some families found telehealth impersonal, and preferred face-to-face conversations with providers.



Telehealth Quotes from Families

"[Telehealth] saves me a 40 minutes round trip . . . I feel like such a small thing as far as quality of life, but to get those minutes, to get those hours back in a week, has been huge."

"I still feel like I am constantly on the phone with telehealth and some things are getting answered and some things aren't... And I forget it, because there are so many other day-to-day things that I have to worry about that it just seems to, all of sudden, "oh, shoot, I was supposed to see this doctor four months ago".

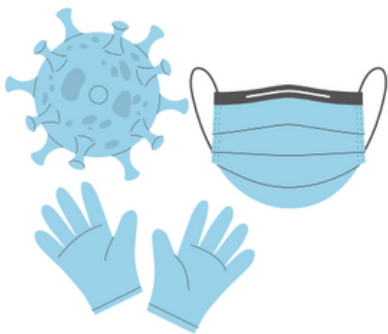
"I'm really loving telehealth therapy. I think I'm realizing that I had him overscheduled, because we would just go [to therapy] like 5 days a week... So, after this I will probably make some adjustments."

"I don't have to pull him out of school, I don't have to drive, I don't have to wait in the office, the appointments are on time... That's been helpful."



COVID-19 Learnings from the CMC COIN Family Focus Groups

The COVID-19 pandemic provided numerous barriers to access to care and changes for CMC families, including social isolation, loss of employment, changes in care, mental health concerns, and physical health concerns for their CMC. We spoke to families about their experience living through a pandemic as family caregivers for children with medical complexity.



SAFETY CONCERNS

"As soon as we were getting ready to interact with people, COVID hit. . . because it's respiratory, I had to quit my job. . . I wasn't able to go back, because it's just too dangerous, there's just too much risk."

CHANGES IN CARE

"[Child name] is transitioning now from pediatric to adult. I don't believe he had the level of support that he should've had from his care team. It's like, the pandemic came and then everybody kind of fell off."

"We really tried to make it clear that we don't want nurses that are working in other homes or other settings, that's kind of been a challenge, because it's hard to find a nurse that can work with one patient."

ADDED COMPLEXITY

He has sensory issues, he doesn't understand the mask and it like... its adds such a level of complexity to just our day, it's unbelievable."

Family Quotes about COVID-19's Impact



COVID THEMES

MENTAL HEALTH/ISOLATION

Family caregivers and children struggled with mental health and feelings of isolation during the pandemic. Some family caregivers experienced loss of employment, which exacerbated their situation.

TELEHEALTH

Families were forced to adjust to telehealth for their CMC needs. Most families appreciated the convenience and ease of telehealth, while some would have preferred in-person visits.

MEDICAL CHALLENGES

Many CMC families faced constant worry for their CMC children's health. Families with immunocompromised children feared going to hospitals or receiving in-home nursing care due to COVID.