Telehealth for Children with Complex Needs:
What has the COVID-19 pandemic taught us?

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For discussion today…

- The “before” times: low level use of telehealth, barriers to use
- COVID-19 as a change agent
- Discoveries from parents, practitioners: opportunities to change the system!
- Needs to sustain the good parts; new opportunities, threats

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Prior to 3/15/2020…

- Most children with complex needs had 3-4 outpatient visits per year per specialist
- Evidence scant on “why” and ”how” of telehealth
- Telehealth infrastructure was expensive:
  - Software licensing
  - Equipment at the healthcare facility
- Regulatory barriers were common:
  - Licensing, malpractice insurance barriers across state lines
  - Few HIPAA-compliant systems
  - Payment (if any) was less than in-person
- Patients, families, providers inexperienced
  - Patient portals new
  - Usability, ?harms of video visits not well known

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A whole new world….

- March 2020: many clinics closed, PPE scarce, stay-at-home orders
- Children's complex needs did not go away
- Common viral illnesses vanished
- Scrambles to develop new care modalities
  - Telephone?
  - Messaging?
  - Video visits?
  - Need to educate millions of patients and millions of providers very quickly

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Response: rapid and robust

- Rapid investment by organizations in telehealth technologies, hardware, processes
- Government resources ($) made available
- Regulatory barriers suspended (licensing across some state lines for telehealth, malpractice, “official” HIPAA compliance of systems)
- Education of providers, teams, patients, family members
- Televisits 3%→25% in 3 months at our organization (<1000 to >10,000/month)
- Iterative, rapid learning!

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Telehealth learnings: benefits

- Safer for families (transport) and treatment teams (fewer people in same room)
- Less expensive to families (transport, missed work/school)
- Can replace some in-person visits without decreasing visit quality
- Families actually feel more connected (home environment)
- Easy for multiple family and team members (nurses, dietitians, psychologists, interpreters) to join visits

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From families

"If we can do a televisit, I don't have to take half a day or more off of work, spend an hour getting James and his equipment into the van, and drive in traffic an hour or more each way. James is less anxious and more comfortable. He'll let you look at his G-tube, where he won't in the office. And you can see us at home and meet our dogs!"

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Telehealth learnings: challenges

- Inherent limitations of remote visits: exam, procedures, immunizations
- Technological glitches (can you hear me now?)
- Unintended inequities:
  - Quality problems for video calls- especially rural and low-resource areas
  - Language barriers initially an issue (resolved with video interpretation)
  - Health/technological literacy (though not as much of an issue as anticipated)
- Need for personnel to teach families and staff calls- a new role, must be resourced
- Time for visits can be different
- Initial payment hiccups: billing, documentation

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What needs to stay

- Practice:
  - Up to 50% of follow-up visits; with newer technology, possibility for more complete exams
  - Behavioral Health follow-ups
  - Multidisciplinary visits less dependent on exam (nutrition, pharmacy etc)
  - Elicit and respect patient and family preferences for telehealth vs in-person (varies widely and unexpectedly)

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What needs to stay

- Payment:
  - Parity for televisits and in-person visits
  - Payment for all types and levels of visits
  - Funding for infrastructure, interpreters and other resources to maintain high quality telehealth presence
- Regulatory barriers need to remain low and decrease further
  - Already being re-imposed in some states as pandemic emergency ends (licensing etc)
- Continue investment in infrastructure for patients and families
  - Rural broadband
  - Affordable Wi-Fi and internet

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