



**HHSC: Policy Council
for Children and
Families, July 13th,
2020**



The [Policy Council for Children and Families](#) works to improve the coordination, quality, efficiency, and outcomes of services provided to children with disabilities and their families through the state's health, education, and human services systems. Members are listed below. Since new members have been added the list is not complete.

Chris Masey, Chair

Family Representative
Austin

Margaret McLean, MSN, Vice-Chair

Family Representative
Dallas

Lisa Brodie

Family Representative
Deer Park

Sara Daugherty-Pineda, MSN

Community Services Representative, Blue
Cross Blue Shield of Texas
Coppell

Nicole Dilts, PhD

Family Representative
San Angelo

Cynthia Guiton

Family Representative
Missouri City

Julie Ivey-Hatz, PhD, LSSP

Mental Health Expert Representative,
Baylor University, Baylor Autism Resource
Clinic
China Spring

Mary Klentzman

Faith-based Representative, Cornerstone
Ranch
Plano

Nicolas Morales

Youth Representative
San Antonio

Jessica Ochoa

Family Representative
Mission

Leah Rummel

Family Representative
Austin

Josette Saxton

General Expert Representative, Texans
Care for Children
Austin

Lee Sonnenberg, MA, CPP

Family Representative
Lubbock

Janis Townsend, MA

Family Representative
Coppell

Elizabeth Tucker

Advocacy Organization Representative,
EveryChild, Inc. Austin

Silvia Vargas

Family Representative
El Paso

Laura Warren

Organization Providing Services
Representative, Texas Parent to Parent
Austin

Welcome and introductions. The meeting was convened by the Chair, Chris Masey.

Review and approval of meeting minutes from February 28, 2020, meeting. The minutes were approved as written.

Review and approval of Bylaw amendments.

- A seat at the table for a representative for Autism Services
- There will most likely be a statement about Autism in the bylaws which could be voted on at the next meeting

Discussion was tabled until the next meeting.

Election of Chair.

Council members shall:

- Elect a chair; and
- Review the duties of the chair as established in the bylaws

Proposed election process:

- The Council will elect a Chair from among the appointed family member representatives.
- If a member is nominated by someone else, ACCO will verify that they are willing to accept the nomination.
- Candidates will have an opportunity to inform members of their qualifications for presiding office.
- A roll call vote of members will be taken and the votes will be announced. The candidate with the most votes will be elected Chair.
- In the event of a tie between two candidates, the floor will be open for any additional member discussion.
- A second vote will take place in the same manner as the first.
- In the event of another tie, the chair will be determined by the flip of a coin.

Chair:

- The Chair of the council shall be nominated and elected by the membership. The Chair will serve as presiding officer.
- The regular term of office for a presiding officer is two years, with the Chair serving until December 31st of each odd-numbered year.
- The Chair will serve no more than two consecutive terms.
- The Chair will remain in their positions until the Council selects a successor; however, a presiding officer may not remain in office past his or her membership term.

Responsibilities of the Chair:

The role of the Chair is to:

- Provide reports to HHSC;
- Participate in agenda planning and preparation for Council meetings;
- Provide leadership in conducting Council meetings;
- Promote, maintain, and encourage a participatory environment;
- Identify the need for, and work with Council Liaison, to call meetings to accomplish the work of the Council;
- Ensure the Council adheres to its charges;
- Call for the establishment of subcommittees (if applicable and with approval of agency staff); and

- Confer with HHS staff to acquire the support needed for Council operations.

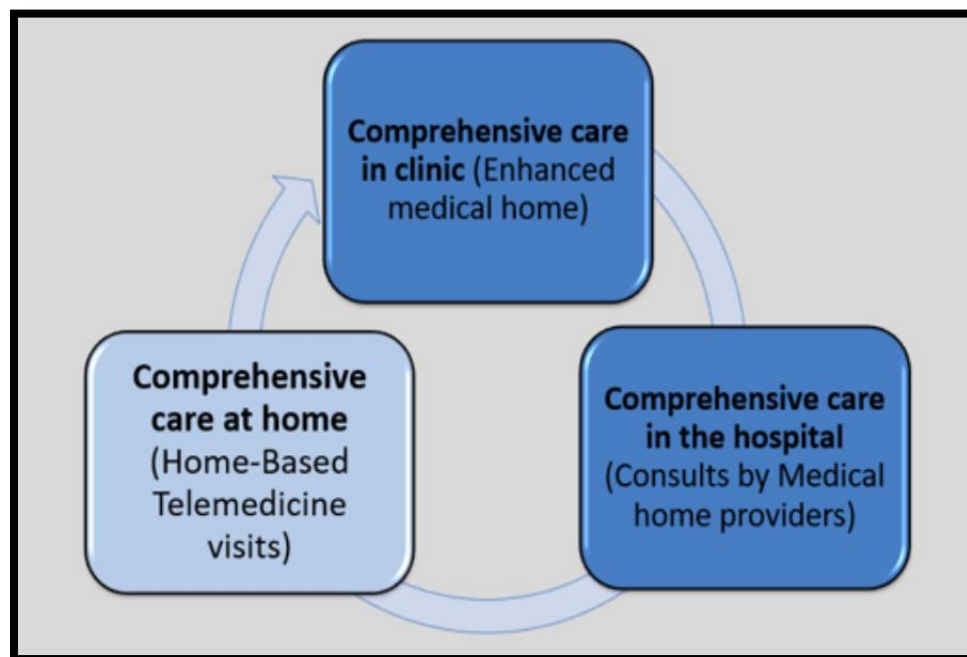
Roll call vote procedure for election was approved. There were two people nominated who accepted the nomination.

Results of Roll Call Vote: Margaret McClean was elected as the new Chair. Ms. McClean assumed the Chair.

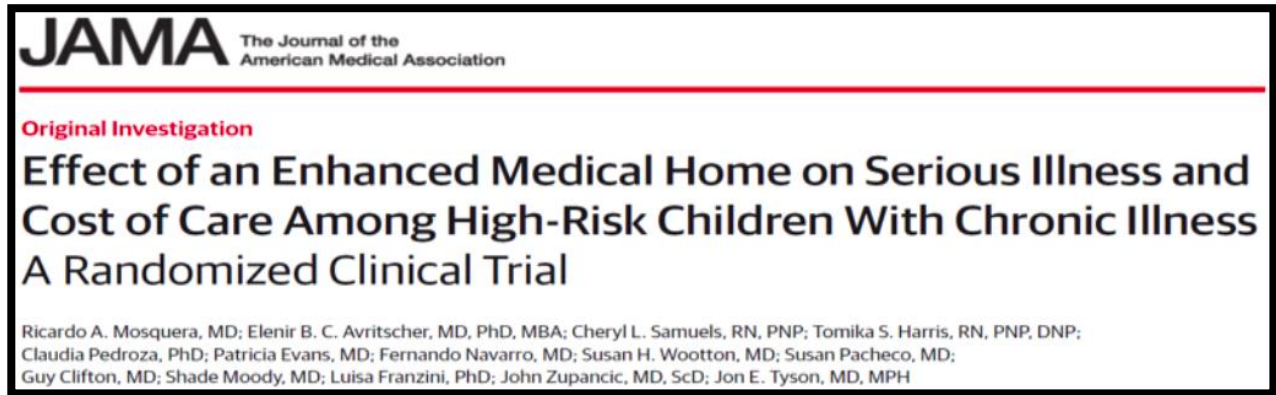
Presentation: Telemedicine in high risk children. Managing Children with Medical Complexity (CMC) at Home: A Clinical Trial of Telemedicine as Part of a 360 Degree Approach to Improve Their Outcomes. Ricardo Mosquera, MD, MS; Elenir Avritscher, MD, PhD, MBA; Claudia Pedroza, PhD; Kyung Lee, PhD; Tomika Harris, PNP; Julie Eapen, MD; Michelle Poe, PhD, RN; Supriya Ramanathan, MD; Maria Caldas, MD; Diana Martinez, BS; Aravind Yadav, MD; Madelene Ottosen, RN; Jon E. Tyson, MD (underscored names made the presentation).

Children with medical complexity comprise less than 1% of the population but consume 30% of pediatric healthcare costs. They also consume 55% of all inpatient pediatric costs and 85% of all 30-day pediatric re-admission costs.

A 360-Degree Approach to Improve Outcomes for Children with Medical Complexity with Benefits Outcomes Demonstrated by RCT.



Comprehensive Care Clinic



In this RCT comprehensive care (**CC**) reduced ED visits, hospital admissions hospital days, PICU admissions, PICU days & serious illnesses by **47-69%**. CC was LAO associated with systematically **higher parental ratings of care**. Health system costs (conservatively estimated) reduced by **\$10,258/child-year**

Comprehensive Care in the Hospital. An RCT of Inpatient Consultations for CMC from Their Outpatient Comprehensive Care Providers

We found that an inpatient consultation service from outpatient comprehensive care providers had a:

- 95% likelihood of decrease in **total hospital days**.
- 80% likelihood of **parental rating of 9 or 10 (highest values) for inpatient providers**.
- 94% probability of a **reduction in mean total health system costs**.

Comprehensive Care at Home by Home-Based Telemedicine Visits.

- *"...Patients spend most of their time away from the health care system and the focus has to be on managing their health literally where they live with more wireless monitoring, electronic and phone visits, at-home care, and patient engagement." - Hoffman and Emanuel."*
- Likely benefits of telemedicine: Convenient and easy for patients and families, proactively and promptly treating problems day or night, and avoiding exposure to infections and costs of clinic or ED visits and hospitalization.

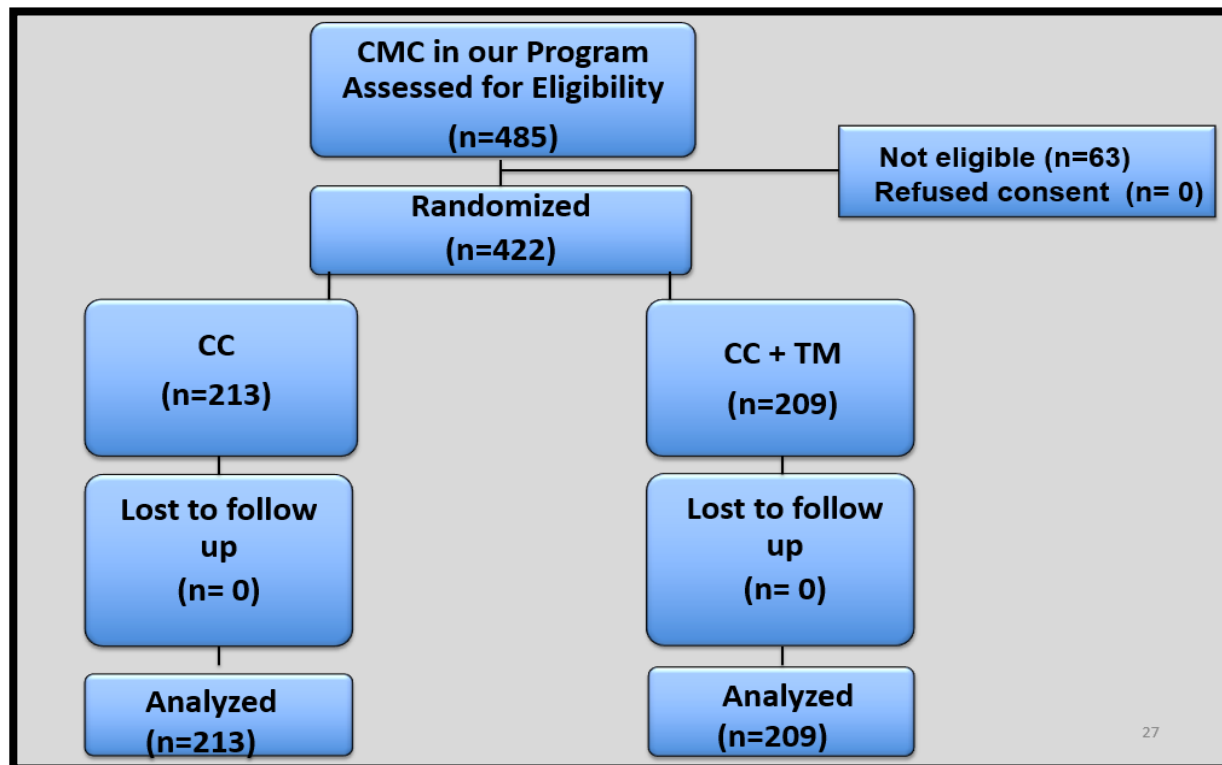
The objective of telemedicine RCT is to assess whether the addition of home-based telemedicine to comprehensive care reduces the need for clinic visits and hospitalizations, and the costs for children with medical complexity. Eligibility includes CMC in our outpatient comprehensive care (CC) program, which enrolls high-risk chronically ill children with ≥ 2 hospitalizations or ≥ 1 pediatric ICU admission in prior year and a $>50\%$ estimated risk for

hospitalization at enrollment. There are exclusions for children with DNR status and unrepaired congenital heart disease.

They use Zoom for Healthcare platform for telemedicine. With our clinic already equipped with a smart television, web cameras, and an emergency iPhone, no additional equipment is required. With help from clinic staff, families are randomized to telemedicine download a free Zoom application to any smartphone when they are in clinic. TM has been used:

- During clinic hours for: 1) calls to PCPs during clinic hours from parents who seek medical advice or appointments for their sick child, and 2) selected calls to parents from PCPs as needed to schedule follow-up appointments.
- At night and on weekends, following initial contact from parents, telemedicine visit has been performed based on physicians' judgement.

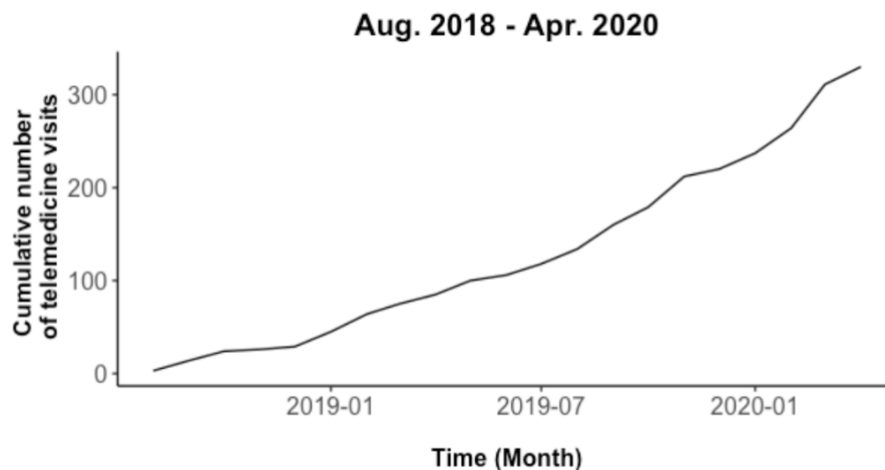
Patient Selected through RCT



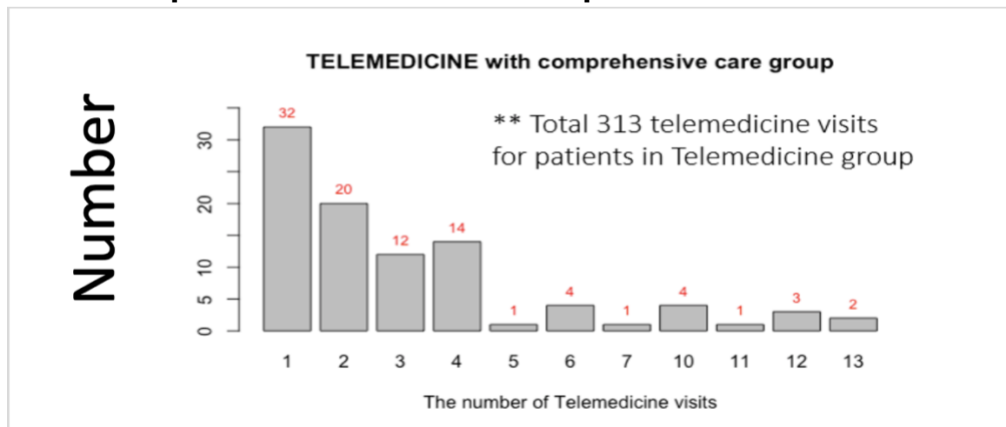
Patient Baseline Characteristics

Characteristic	CC (n=213)	CC + TM (n=209)
• Age in years , mean (SD)	5.7 (4.5)	6.2 (5.4)
• Male , No. (%)	117 (55)	121 (58)
• Race/Ethnicity , No. (%)		
a. African-American	82 (38)	56 (27)
b. Non-Hispanic White	21 (10)	21 (10)
c. Hispanic	88 (41)	109 (52)
d. Other	22 (10)	23 (11)
• Clinical Risk , No. (%)		
i. Level I (mechanical ventilation)	52 (24)	52 (25)
ii. Level II (\geq expected median risk)	70 (33)	67 (32)
iii. Level III (< below expected median risk)	91 (43)	90 (43)

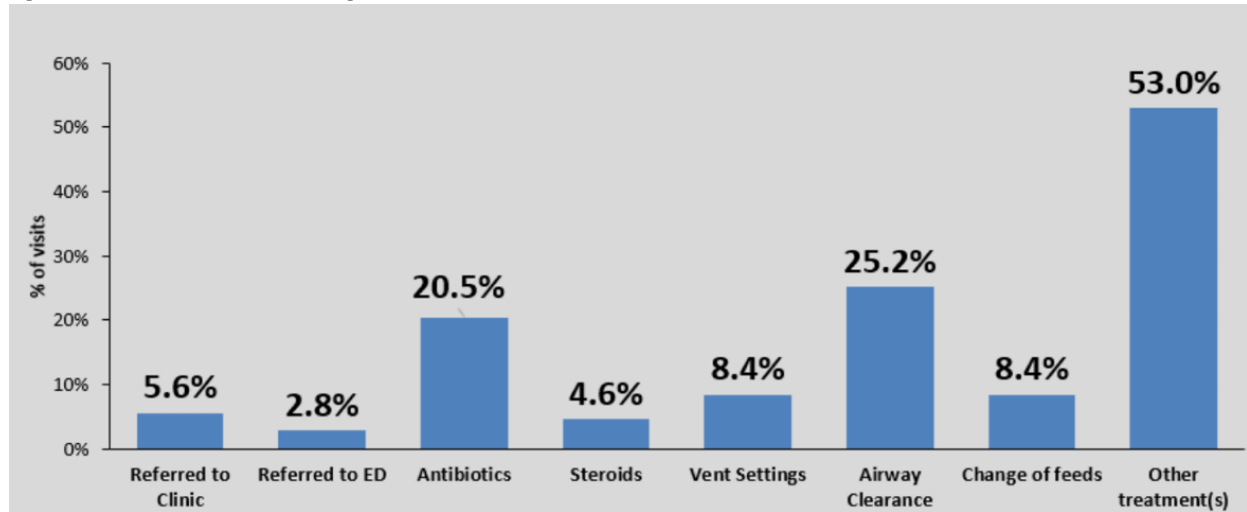
Total TM Visits in the CC+TM group

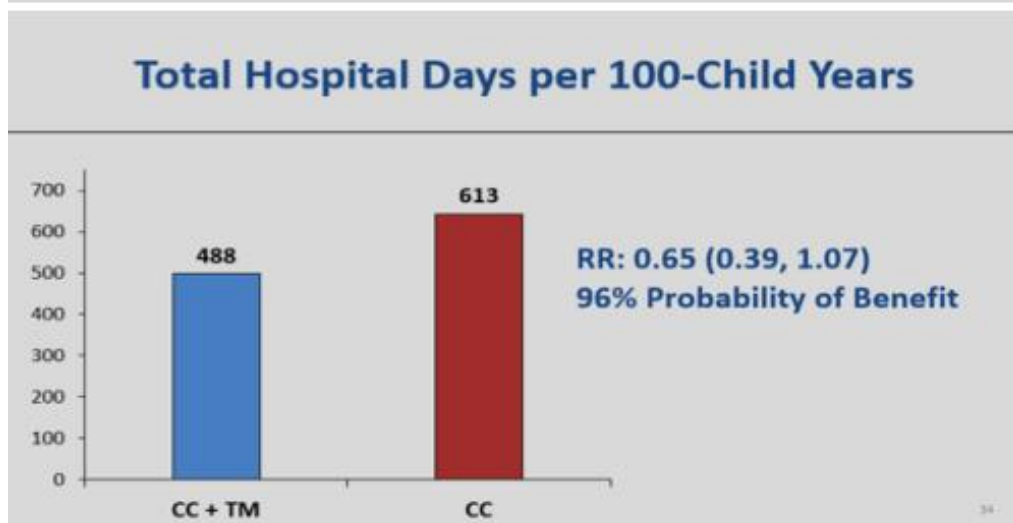
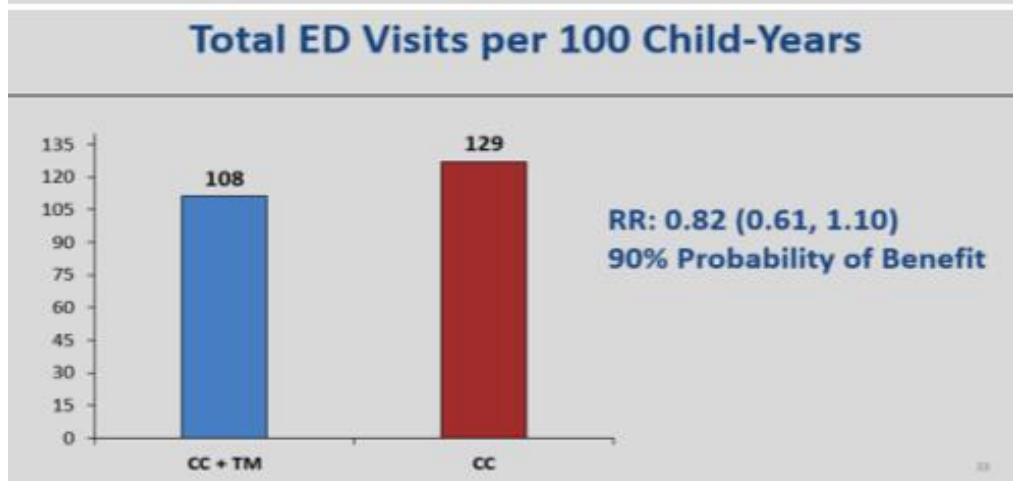
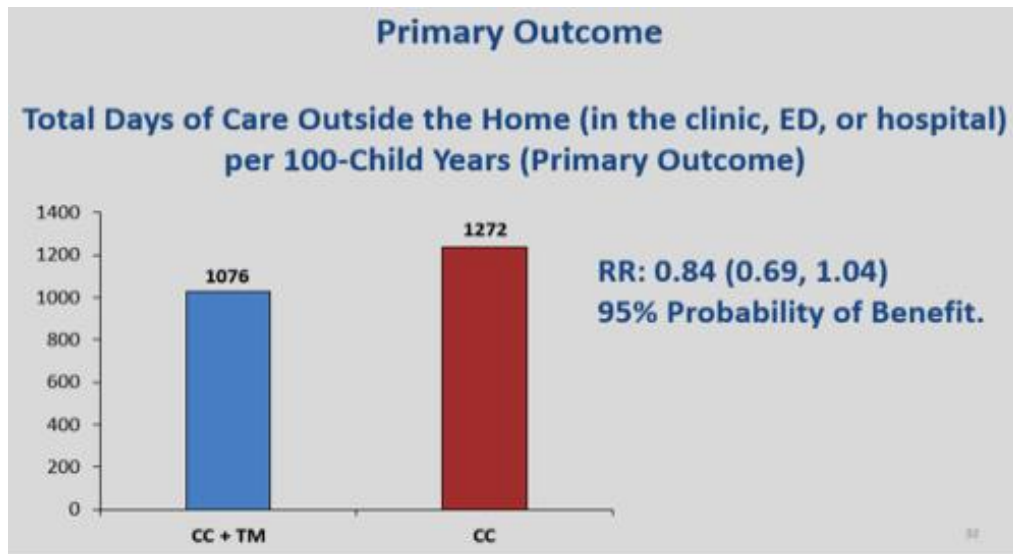


Total Visits for TM patients in the CC+TM Group



Specific Interventions per 100 TM Visits





Other Outcomes				
	Telemedicine with Comprehensive Care Rate/100 Child-Years	Usual Comprehensive Care Rate/100 Child-Years	Rate Ratio (95% CI)	Probability of Benefit
Children with Serious Illnesses (Death, length of hospital stay >7days, or PICU admission)	31	38	0.62 (0.33, 1.17)	93%
Admissions	84	94	0.84 (0.62, 1.14)	87%
PICU Admissions	32	37	0.67 (0.43, 1.06)	96%
30-day re-admissions	17	21	0.67 (0.27, 1.65)	81%
Office visits (excluding well-child checks)	525	588	0.89 (0.76, 1.05)	91%

Why replacing a clinic visit for a telemedicine visit decreases hospital utilization.

About 10% of patients who are seen in our clinic for non-sick visits have a sick visit within 15 days after the initial non-sick visit in clinic and the medical intervention resulting from a telemedicine visit is given sooner than a clinic visit.

Since the end of the telemedicine trial on 3/23/2020, all patients have been offered telemedicine, 80% of our CMC visits are now served by telemedicine, and for our children the total days in the ED or hospital have fallen 60-70%. While conventional TM may work well for most children, an enhanced TM program is likely to be especially important to reduce exposures and care outside the home for high-risk CMC particularly while COVID-19 is surging or becomes endemic.

Enhanced Telemedicine includes:

- Use of FDA-approved, HIPAA compliant, mobile devices in the home to visualize the skin, throat, & ears, auscultate the heart & lungs, and measure temperature & oxygen saturation (TytoCare™).
- Trial Design: In the first 12 months of the trial, our patients will be initially randomized to receive either enhanced telemedicine or conventional telemedicine. In year 2, all patients will receive enhanced TM.
- We are applying for grants to cover the expenses of the TytoCare devices and platform.

Interim findings indicate between 93% to 96% probability that home-based conventional telemedicine decreased total days of care outside home, total hospital days, and serious illnesses for CMC. Our findings also suggest a possible reduction in hospital costs (financial data is currently being analyzed).

Choosing the right platform is key for the successful operation of telemedicine. (Easy to use and accessible at anytime and anywhere).

Promote interventions that provide care at home (home visits, phone visits, telemedicine, enhanced telemedicine).

Healthcare facilities can be expected to be one the worst places to be during a pandemic. And as such families should avoid clinic visits as much as you can.

Questions/Answers/Comments

In response to a question about reimbursement, **the speaker stated** that reimbursement was an issue before the pandemic and then there was an increase in telemedicine payment due to the pandemic.

In response to a question concerning the family experience, **the speaker stated** they have been collecting data from parents. Prior to the pandemic, people wanted in-patient/face-to-face encounters. Now they are comfortable with telemedicine.

In response to a question concerning the next study publication, **the speaker stated** that the paper draft has been completed; maybe in two or three months.

In response to a question concerning comfort of families with telemedicine and follow-through, **the speaker stated** that they did not have problems with follow-through. There were no problems with compliance.

In response to a question concerning adjustments of equipment, **the speaker stated** that they were able to see real-time what was going on with the patient so adjustments could be made.

In response to a question concerning medical reimbursement for telemedicine and cost of equipment, **the speaker stated** each device with supplies cost \$350 per patient. They had to pay the company to get the support and \$50,000 for support of the system. This comes to about 700 dollars per patient per year.

In response to a question concerning access to equipment for families, **the speaker stated** that most patients have a smartphone and they can access the services through the smart phone.

We should support Medicaid paying for these services and making licensure adjustments after the pandemic provisions are ended.

The speaker asked the group for assistance in accessing grant funding for the project.

2020 Workgroup Report.

1. Workgroup 1: Transition Care Clinics for adults

Policy Issues:

- Lack of access/availability/funding to expand transition care clinic across Texas. Currently there is only one transition clinic in Texas and it only serves a small geographic area.
- Lack of payment model that can pay for care co-ordination between providers and MCOs.
- Lack of training resources to build provider capacity.
- Lack of knowledge/experience by adult medical practitioners in order to care for patients with a chronic childhood disease or disability.

Proposed Recommendations:

1. Ensure funding to maintain and expand access to transition care clinics. The following goals will be achieved by expanding transition care clinics:
 - a) Preventing urgent healthcare crises, reducing emergency room visits and reducing overall healthcare costs.
 - b) Minimizing the impact of a shrinking social support network to patients and families, who rely on the pediatric system.
 - Help patients and their caregivers access adult medical care.
 - Help navigate the adult healthcare system.
 - Maintain or identify alternative social services that are critical for their well-being.
 - c) Fund pilot program for areas and to see its impact.
 - d) (Funding presently is from DSRIP and they suggest continuing this until more secure funding can be found).
2. Provide flexibility in the Medicaid payment model to support care coordination in the transition clinic model.
 - a) Paid for by cost savings from reduced hospital admissions and re-admissions.
 - b) Provide flexibility in payment for telehealth services in rural area (flexibility of video platform or audio call reimbursement in case of lack of access of appropriate technology in rural areas).
 - c) Identify performance measures for transitions from the pediatric to the adult healthcare system and tying quality to payment.
3. Resources to build the provider capacity and training are needed to develop transition care in multiple areas across the state.
 - Paired pediatric & adult team for hand-offs and consultation.

The speaker stated that there is a supporting document that supports the funding of transition clinics; DSRIP funding; and other funding issues.

The speaker asked for assistance in identifying data sources to support the need. There is a large children's survey that provides online data that might be helpful.

Regarding provider training, we are not training the next generation of physicians. We have Dr. Peacock's clinic that takes physicians into training as well as social workers. Statistics were presented related to transitions services. Recommendations include:

- Continued funding for Dr. Peacock's Clinic.
- Continue to allow telemedicine beyond the COVID Pandemic.
- Continue funding for a similar project to Project Echo which is a continuing education project.
- Establish a CPAN-like program (Child Psychiatrist Access Network), pairing adult physicians with pediatric experts.
- Increasing funding for teaching hospitals in the area of transition service needs.

There are other recommendations from other advisory groups that could be coordinated to be more powerful. (STAR Kids and other groups).

2. Workgroup 2: Medicaid Buy-In for children and adults

Medicaid is a lifeline for families of children with disabilities. Not only does it provide critically necessary health coverage to children with complex health care needs, it is the payor of long-term services and supports that allow children with disabilities to grow up in their homes and communities.

Policy Issues:

- Long wait for community-based waivers and Medicaid
- One of the highest rates of uninsured children in the country
- Texas families of children with special health care needs who have insurance report their insurance is inadequate

Texas has several options to offer both uninsured and privately insured families the extra help they need in paying for their child's care through Medicaid.

Goal: Improve access to Medicaid for children with disabilities by allowing more families to contribute to the cost of Medicaid premiums and by improving access to lower cost waivers for children who meet an institutional level of care thereby reducing the need for a more comprehensive community-based waiver and reducing home and community-based waiver interest lists.

Recommendations:

1. Reduce the MDCP interest list by allowing children who have SSI and meet nursing facility level of care to receive waiver services with no wait, and fund waiver services for approximately 575 children without SSI or Medicaid to receive the waiver services

2. Align the Texas Home Living waiver's financial eligibility requirements with the other Texas home and community-based services waivers so children can access the lower tiered waiver in lieu of a more comprehensive waiver, and also remove the requirement that children with related conditions have an IQ below 75.
3. Apply the Family Opportunity Act's family income limit of 300% Federal Poverty Level to the Texas Medicaid Buy-In for Children program and improve outreach so that more families can contribute to the cost of their children's care.
4. Institute a Tax Equity Fiscal Responsibility Act (TEFRA) option for children who meet an institutional level of care to prevent placement in a facility.

3. Workgroup 3: Reducing Medicaid Waiver Interest List and promoting Independence

It is the policy of the state to strive to ensure that basic needs for safety, security, and stability are met for each child in Texas. A successful family is the most efficient and effective way to meet those needs.

Policy Issue: In order to continue the success of Texas' Promoting Independence Plan and Texas' Permanency Planning and Family-Based Alternatives initiatives, continued funding of Medicaid waivers for children to move from nursing homes, group homes, large institutions and General Residential Operations (GRO) licensed by the Department of Family and Protective Services (DFPS) is necessary.

Goal: Ensure children with disabilities grow up in well-supported families instead of facilities.

Recommendations:

1. Fully fund Promoting Independence transition and diversion waivers to allow children to move from all institutions to families and be diverted if at imminent risk of admission.
2. Provide legislative direction and funding through an appropriation's rider for HHSC to amend the Medically Dependent Children Program waiver to create reserved capacity for crisis diversion slots for a targeted group of children who are determined to be medically fragile and at imminent risk of nursing facility admission.
3. Provide legislative direction and funding through an appropriations rider for HHSC to amend the Texas Home Living waiver services to create a set aside number of slots for a targeted group of children graduating high school.
4. Increase funding to support a 10% reduction of Medicaid waiver interest lists.

Questions/Answers/Comments

- Trauma-informed care should be included in Recommendation 2,
- Include neuropsychology work and adolescent brain development and the need to continue services (beyond graduation).

- Three of the four are familiar because they have been recommended previously. Regarding number 3, it is important to have post-graduation services beyond the age of 22.
- The state has approved interest list assessments through telehealth (due to COVID-19). We need data on how this is working. (See recommendation in Group Five.)

4. Workgroup 4: Crisis Intervention and Respite Care

Policy Issue:

Children with IDD with significant behavioral support needs and/or co-occurring mental health conditions are at an increased risk for abuse and out of home placement. To avoid the placement of children in expensive long-term out of home options, a comprehensive system of community services and supports are necessary. These supports must include short-term out of home crisis arrangements for children at imminent risk of facility admission as well as increased access to respite.

Goal:

Improve access to mental health, trauma-informed care and crisis services for children with developmental disabilities to ensure children are supported to live in families in lieu of costly long-term institutions.

Recommendations:

1. Develop and fund child focused, small, community-based emergency short-term out of home respite options for children of families who are in crisis. Services must include:
 - Thorough assessment of the child and his/her support needs
 - Development of appropriate supports for the child to return home or move to another family-based alternative.
 - Supports needed to care for children with complex behavioral support needs including additional staff if needed.
2. Fund and expand the Texas START programs to additional counties and allow current START facilitators to serve as mentors to facilitators in the newly added counties.
3. Create a funding mechanism for the emergency short-term out of home respite, assessment, and facilitator services, within the Texas Medicaid waivers as well as through the Medicaid State Plan and general revenue.
4. Assign a Level of Need (LON) 6 in the HCS waiver to children with complex support needs leaving long-term facilities such as a lengthy state hospital admission, DFPS facilities, nursing facilities and ICF/IID's for the first year of their transition.

Goal: Increase access to respite services for families of children with disabilities to strengthen and support families to remain together.

Recommendations:

1. Reinstate the In-Home and Family Support program as a mechanism to fund respite services for families whose children do not have Medicaid.
2. Ensure access to non-educational funds for children at risk of residential placement through improved outreach, service benchmarks for LEAs, and an increase in the amount of funds designated for schools to allow schools to fund respite for families in need.
3. Provide an additional 30 to 60 days of respite per year in the HCS, CLASS, YES, Texas Home Living and DBMD waivers.
4. Increase access to respite for families of children in the Youth Empowerment Services (YES) waiver by enhancing the provider base to make it a viable resource for families.
5. Allow HCS host families to access respite services outside of the daily rate assigned to the family to promote placement stability for the child.

5. Workgroup 5: Disaster and Emergency Preparedness- COVID-19

Proposed Recommendations:

Continuity of Member Care Emergency Response (COMCER)

1. The COMCER plan should include a process for pandemic, and environmental/natural disasters for MCOs.
2. COMCER plan should address issue of extension and flexibility (even eligibility component) not on monthly basis but for extended period.
3. Identify some commonality amongst MCO requirements.
4. HHSC should identify important elements that MCOs should report on during disaster.

Identify best practices to communicate and educate families, providers and MCOs

1. MCO communication to members through website, through advisory committees within MCO, and service coordinator available to educate families.
2. MCO communication through texting to patient which will direct them to the MCO website for resources; creating standard communication.
3. Require Managed Care plans and/or waiver programs to develop with children and their families a communication support plan that can go with them to the hospital in the event they are separated by their primary caregiver. Plans must include at a minimum:
 - Communication techniques of the individual
 - Likes and dislikes of the individual
 - The way the person prefers to be cared for
 - Diagnoses, medications, food allergies, food preferences, etc. of the individual
 - Emergency contact information

Changes to MDCP waiver

1. Extend MDCP plans of care that expired during the COVID-19 pandemic by 12 months as allowed in Texas' CMS approved Appendix K.
2. Amend the MDCP waiver to allow for a reserved capacity of nursing facility diversion waivers for children with medical fragility that are at risk of facility admission and do not require a nursing facility stay.
3. Allow for the MDCP initial assessments and annual reassessments to be conducted via telehealth.

Expansion of Telemedicine

1. Identify technology that is user friendly across Texas.
2. Instead of authorizing telemedicine benefit in 30-60-day increments, consider 6 months to one year to allow services for goals related to long-term therapy needs to continue without interruption.
3. Authorize telehealth for intermittent nursing services (in addition to therapy) that can be performed via telehealth via video and audio media. (Example: assessing patient status through parent questioning, patient observation, troubleshooting, and parent/family caregiver teaching).
4. Recommend that telehealth become a standard alternative during times of pandemic/disaster.

Questions/Answers/Comments

- We should touch on broadband and expansion to rural areas.
- Be specific in the language to emphasize the ability to utilize telemedicine due to technological and resource issues.
- Perhaps use of the school nurse staff and their telecommunication capabilities could be an access point for families.
- Use service coordinators to guide families to resources for hardware and other support equipment and resources. The MCOs do value-added services and this might fit in there.
- Funding for diagnostic tools should be included.
- Add behavioral health in number 3.
- Providing the diagnostic tools to the school nurse would increase their shelf life.
- Not every school has a school nurse.

Extension and flexibility for services and supports placed due to COVID-19. The recommendations just discussed address the need for extension of the COVID-19 flexibilities related to telehealth. People may be missing therapies because of the lag time. This should be extended for private insurance and Medicaid as well. Ms. Tucker stated that the STAR Kids Advisory Committee has addressed this as has the IDDSRAC. A letter should be sent especially as we head into cold and flu season.

There was consensus that a group would be pulled together to develop a letter addressing this issue. They will also review the draft letters of other groups.

Ms. Tucker stated that we should look at this flexibility beyond telehealth and we should include those other extension issues as well.

Legislative Report planning and timeline.

- **July 13th:** Review draft recommendations from workgroups.
- **August:** Finalize draft and format editing.
- **September 10:** Full Council Meeting: Present final report. Take public comment from stakeholders. Approve final report. Discuss report education and follow up.
- **September–October:** Report follow-up and format editing.
- **November 1:** Final report due to the legislature (Distributed by Chair).
- **November 16:** Full Council Meeting: Meet to discuss report education and follow-up.

Mr. Blanton stated that a lot of good work has been done and the group is on track to submit the report timely. This is the report of this group, not HHSC, so there is some flexibility. There is much work still to be done. The council appears to be ahead of past councils at this point.

The next meeting is scheduled for September 10th and that will be confirmed with the meeting support office.

Public Comment.

A mother and grandmother of individuals with disabilities stated that one child is in foster care and asked how much the foster parent is being trained and how much money she is getting from the state. (The question was out of the scope of this council. Ms. Marx stated she would connect the person with the appropriate resource.)

Linda Litzinger, Texas Parent to Parent, stated she appreciates the letter on telehealth and has an issue about therapists in the house. Texas Parent to Parent offered to help with these efforts.

Action items for staff and/or member follow-up.

- Look at a letter related to extension of telehealth and other flexibilities
- Election of a vice chair
- A writing committee will be established
- Bylaws approval
- Data that has been requested by the workgroups
- STAR Kids recommendations incorporated as discussed
- Neuroscience data and extension beyond 18 years
- Include the bandwidth issue in telehealth and the diagnostic equipment discussed



- MCO information on COVID-19 experience

Adjourn. There being no further business, the meeting was adjourned.

This summary contains supplemental information from third-party sources where that information provides clarity to the issues being discussed. Not every comment or statement from the speakers in these summaries is an exact transcription. For the purpose of brevity, their statements are often paraphrased. These documents should not be viewed as a word-for-word account of every meeting or hearing, but a summary. Every effort has been made to ensure the accuracy of these summaries. The information contained in this publication is the property of Texas Insight and is considered confidential and may contain proprietary information. It is meant solely for the intended recipient. Access to this published information by anyone else is unauthorized unless Texas Insight grants permission. If you are not the intended recipient, any disclosure, copying, distribution or any action taken or omitted in reliance on this is prohibited. The views expressed in this publication are, unless otherwise stated, those of the author and not those of Texas Insight or its management.
