Texas Policy Council for Children and Families
Recommendations for Improving Services for Children with Disabilities

As Required by
H.B. 1478, 77th Legislature,
Regular Session, 2001

Health and Human Services

November 2020
About This Report

This report was prepared by members of the Policy Council for Children and Families. The opinions and recommendations expressed in this report are the members’ own and do not reflect the views of the Texas Health and Human Services Commission Executive Council or the Texas Health and Human Services Commission.

The information contained in this document was discussed and voted upon at regularly scheduled meetings in accordance with the Texas Open Meetings Act. Information about these meetings is available at https://hhs.texas.gov/about-hhs/leadership/advisory-committees/policy-council-children-families

Report Date

November 2020

Contact Information

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1. Letter from the Chair

To the Texas Legislature and Health and Human Services Commission (HHSC)
Executive Commissioner Cecile Young:

The Policy Council for Children and Families (PCCF) (formerly the Children’s Policy Council) submits the following biennial legislative report according to the traditions and the duties assigned to the Council by the HHSC Executive Commissioner.

This biennial report is the culmination of approximately two years of research, analysis, public input and feedback on issues of importance to children and young adults with disabilities and their families.

PCCF members have leveraged and prioritized their own lived experiences, drawn upon the expertise of professional members, and sought input from subject matter experts to identify areas of significant concern impacting children with disabilities and their families in Texas. Subsequently, the PCCF formulated recommendations to bring attention to these critical issues and identify solutions to improve the care and well-being of this exceedingly vulnerable population of children.

Stakeholder input is invaluable in public policy. Public input was requested and received continually, which created a much more robust, useful and inclusive product.

This report contains recommendations specific to:

- Supporting and expanding transition care clinics across Texas;
- Increasing the threshold allowance for Medicaid Buy-in for Children and Adults to 300 percent of federal poverty level;
- Reducing the Medicaid waiver interest lists;
- Ensuring access to Promoting Independence waiver slots;
- Expanding crisis intervention and respite services;
- Improving crisis intervention, respite, and early childhood intervention services; and
- Strengthening disaster and emergency preparedness planning to ensure continued access to vital services during natural disasters, pandemics or other large-scale events affecting children with disabilities and complex medical needs.
The positive or negative life-trajectory of child with a disability depends on the choices made by lawmakers and policymakers. These choices have far ranging impacts that will either support or limit our children’s well-being and quality of life.

Over the past year, we have seen how the SARS-CoV-2 pandemic has exposed the cracks and amplified deficiencies in the medical delivery support systems and educational systems meant to provide essential care and resources to Texas children with disabilities and their families. Authorizations for care, medicines and equipment have been delayed or have faced critical shortages. Families have seen the landscape of medical care as well as on-medical services altered. All of these have contributed to child instability and negative outcomes. It is not more important than ever to reassess and recommit to the care and services provided to our most vulnerable population.

Implementing these recommendations will make it possible for our children with disabilities in Texas to be actively engaged, contributing members in their communities and grow up to live fulfilling, meaningful lives.

The Council respectfully requests your serious consideration of and support for the recommendations included in this report.

Respectfully,

Margaret McLean- Chairperson for Policy Council for Children and Families
Message from the Family Members of the Policy Council for Children and Families

Figure 1. The Urbina-Patlan family: A family of children with disabilities.

According to council member, Lori Urbina-Patlan, her family’s beginning was much like many others. They were a loving and growing family who knew little of what was to come on their journey ahead. Her family, pictured in Figure 1, began as an ordinary typical family and they were given no manual or guidance as far as managing all that comes with having a child with a disability. They faced many obstacles and dealt with many challenges along their journey, and while none were easy, they divided and conquered! Each family member serves an important role in the development of the individual with a disability. Disability changes the way one views the world and it motivates those affected by it, to make a difference in the world. Families do this because of pure love and compassion. We, the family, will support our children with disabilities in every way possible so that they may reach their fullest potential in life.

As mentioned before, every family member serves a role in improving the quality of life for an individual with a disability. Just as we all carry a role, there are also
professionals/representatives in many capacities who positively impact the lives of individuals with varying exceptionalities. Moreover, our elected Texas representatives have a direct correlation to the Texas state policies which profoundly impact the lives of children and families with disabilities. With this being said, we would like to take this time to inform our legislators of what encompasses raising a child with a disability.

- Disability knows no boundaries. It is non-partisan, non-discriminatory and cuts across lines of political party, income, race, religion, and culture.
- One must be committed to create change so that Texans with disabilities and their families are fully included and thought of in their communities.
- One must be committed to increasing the self-determination of your child so that one day they exercise control over their own lives.
- One must ensure that your child with a disability have access to information and a voice in the policymaking process.
- Commit to promoting disability-related advocacy so self-advocates, family members of Texans with disabilities, and other representatives can influence the policymaking process.
- Promote the implementation of Inclusion and research based effective strategies in a public school system.
- Promote and raise awareness of mental health since individuals with disabilities are at greater risk for abuse and suicide.
- Encourage and advocate for the use of community funding or other alternative modes of funding to support families with respite care.
- Request additional resources and supports for families and individuals in crisis.
- Plan and prepare for emergency situations such as natural disasters.
- Be committed to educating key decision-makers about the impact their decisions can have on the lives of Texans with disabilities and their families.

Thank you for your dedicated time serving as our elected officials!
2. About the Council

Since its creation in 2001, the Policy Council for Children and Families (PCCF), formerly known as the Children’s Policy Council (CPC), has worked to improve services for children with disabilities and their families. The PCCF has historically focused on the following principles:

- All children should grow up in families
- Institutionalization of children is costly and negatively impacts all areas of the child’s development. We must provide the services and supports families need to prevent the institutionalization of children with disabilities
- Medicaid home and community-based services are the safety net that keeps children in families
- Services during childhood can prevent higher costs in the future by addressing behavioral and medical issues in their early stages

The recommendations made by the PCCF will bring Texas closer to realizing the conditions where all children can achieve their potential.

Policy Council for Children and Families
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Ex Officios
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Greg Mazick, Subject Matter Expert Representative
Leah Rummel, Subject Matter Expert Representative

Acknowledgements
The council would like to thank Greg Mazick, Leah Rummel, and Ivy Goldstein for their many contributions as a subject matter experts.

We would also like to thank the families and individuals who consented to have their stories and photos included in this report.
3. Executive Summary

The Policy Council for Children and Families (PCCF) serves as a strong voice for the families of children with disabilities in Texas. As the population of Texas continues to grow, so will the need to provide supports that empower children with disabilities to achieve a good life and to give families the tools to help them along their path to success.

In 2001, the Executive Commissioner of the Health and Human Services (HHS) system established the Policy Council for Children and Families (PCCF) which 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 as required by House Bill (H.B.) 1478, 77th Legislature, Regular Session, 2001.

The Committee has released several reports since its establishment in 2001. The last biennial report, written in 2018, included recommendations on access to care, network adequacy, long-term services and supports, special education, safe schools, therapies, Early Childhood Intervention (ECI), STAR Kids, medical transition, and mental health. These recommendations informed discussion and legislation when the Texas Legislature met in 2019.

Building on its 2018 report, the Committee’s second biennial report includes the following recommendations (see below), all adopted without a dissenting vote, to offer good faith solutions to help Texas continue to advance high quality, efficient care for families raising children with disabilities, particularly for those in the Medicaid and the Children’s Health Insurance Program (CHIP).
4. Policy Issues and Recommendations

Policy Issue: Continued funding of The Transition Clinic at Baylor College of Medicine / Texas Children Hospital and funding mechanism for the development of additional transition clinics across Texas

There is a lack of access and funding for medical transition care clinics across Texas for adolescents with disabling conditions and special health care needs that can provide continuity of care as they transition from the pediatric medical model to the adult medical model. These children and adolescents are those that “have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally”.

Medical transition clinics are essential in bridging the gap between pediatric and adult healthcare systems. Whereas the pediatric medical model is family-centric and relies on significant parental guidance with decision making, the adult medical care is patient-centric and requires autonomous patient input and decision making and often lacks many of the interdisciplinary resources found in pediatric healthcare.

Adult health care systems are not typically structured to adequately address the medical complexity and costly needs of children with special health care needs as they become adults. Adult medical care is fragmentated and often lacks the medical expertise, psycho-social support and care coordination needed to support the myriad of medical, nursing, mental, dental and physical needs to ensure continued health, wellbeing and aging of this population.

There is currently a lack of sufficient payment model to support multidisciplinary medical care and coordination of services for these adolescents as they transition into adulthood. The Policy Counsel for Children and Families (PCCF) is asking for continued financial support for the sole transition clinic in Texas and provide

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funding mechanism(s) to develop the infrastructure to expand transition clinics into other areas of Texas to meet the growing demand for this population of patients.

**Recommendations**

Ensure continued funding to maintain the one and only transition clinic in Texas (The Transition Clinic at Baylor College of Medicine /Texas Children’s Hospital in Houston, TX) and provide flexibility in the Medicaid payment model to support the framework needed to develop additional transition care clinics in other major metropolitan areas of Texas which will expand access to medical homes that provide comprehensive care for children with disabling conditions and special health care needs as they transition into adulthood.

A. Continue use of Delivery System Reform Incentive Payment (DSRIP) funding until it is no longer available. This includes continued DSRIP funding to the current Transition Clinic which provides enhanced patient care, continuity of care and better outcomes for this complex population.

B. Develop a start-up funding source for Transition Clinics in all the major metropolitan areas of the state and include enhanced patient care and proven outcomes for this complex population. Look to develop Transition Clinics in conjunction to or in addition to existing pediatric complex care clinics.

- Funding options for continued operations of the Transition Clinic in Houston and development of new transitions clinics could include:
  - Transition DSRIP funding to managed care with goals aligned through a direct payment model. The directed payment model should be based on the Missouri Medicaid Access to Physician Services (MAPS) program, which includes quality reporting and monitoring activities.\(^3\) The size of the funding pool will be determined before each capitation rate year and will be based on factors such as anticipated utilization and the expected rate increase for certified Transition Clinics. MCO will pay providers contracted rates, and then quarterly incentive payments from the pool (calculated by the state based on actual utilization). Actuaries calculate the final capitation rates based on actual utilization data following the fourth quarter of the rate year.
  - Create a “capacity building pool” similar to the North Carolina 1115 Waiver pool, which will fund infrastructure and system start-up costs for new Transition Clinics for the first two years of the pilot program.\(^4\)

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\(^3\) [https://dss.mo.gov/mhd/cs/health-homes/](https://dss.mo.gov/mhd/cs/health-homes/)

In addition to the capacity building and directed payment pools, the pilot program can include alternative payment model strategies tied to quality outcomes, such as shared savings for reductions in inpatient admissions.

C. Develop in-house shared service coordination models with health plans to provide better health outcomes. This can include:

- Includes face to face visits with health plan service coordinator to provide better coordinated care.
- Include weekly case conferences to identify any barriers.
- Includes coordination with other health plans on coordination of benefits; coordination with other case managers; and alignment with networks.
- Follow-up with specialty physicians and other providers to get pre-authorizations completed.
- Serves as resource for clinic including any training needed such as covered benefits, transitioning for members aging out, etc.
- Monitor member outcomes.

**Background**

There are approximately 1,191,876 (16.5%) children in Texas who have special healthcare needs and require specialized medical care with multiple specialists, regular & comprehensive needs assessment, triage for urgent health crisis and coordination of community-based services. Transition clinics typically serve the needs of patients diagnosed with developmental delay, neuromuscular disorders, spina bifida, autism, chromosomal abnormalities, cerebral palsy, multi-system congenital anomalies, wide range of genetic & metabolic disorders, technology dependent children and children with function limitations in walking /eating /learning, complications of prematurity, to name a few.

Due to advances in medical technology, children born with a chronic or disabling condition will often live into adulthood but are at risk of deterioration if there is not a smooth transition. Nearly 69,000 youth with special needs transition to adult health in Texas each year.

As these children turn 18 and transition from pediatric medicine to adult medicine, they often lose their medical home and comprehensive care. Adult medicine is often fragmented, lacks the social services needed to coordinate care and physicians may lack the clinical expertise needed to address the complex specialty care and care

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5 Child Health data - https://www.childhealthdata.org/browse/multiple-indicators/title-v-national-outcome-measures-nsch-2016-20170
coordination required to maintain the health and wellness of this population of patients. The issues young adults experience as they transition between pediatric and adult medicine include the following:

- Lack of adult physicians who are willing and knowledgeable of pediatric conditions
- Poor reimbursement for services rendered
- Lack of training for medical providers to care for those with complex medical needs
- Difficulty meeting psychosocial needs of the patient and family
- Differences in culture between pediatric and adult health care models
- Fragmented care with patients seeing multiple specialists each treating different aspect of care and lack of interdisciplinary communication and coordination of care
- Less social work and case management services

Children with disabling conditions and special health care needs are representative of all racial and ethnic groups, ages, and income levels but there are still disparities and minorities are disproportionately affected. Children and adults of color are more significantly impacted than their peers. Per the 2017-2018 National Survey of Children Health, the lack of medical transition between CSHCN and their non-CSHCN peers is apparent. When asked “Has this child’s doctor or other health care provider actively worked with this child to understand the changes in health care that happen at age 18, age 12-17 years?” CSHCN with more complex health care needs responded 74% of the time that their health care provider did not discuss changes in health care compared to CSHCN peers with less complex health care needs and non-CSHCN peers (43% and 48% respectively). A further look at the American Community Survey from 2017 shows a greater proportion of minorities with a disability compared to Caucasian individuals.

Functional levels for these individuals vary and span the spectrum from rarely affected by their conditions to severely affected. Regardless of their functional level, they share the consequences of their conditions - reliance on medications or therapies, special educational services, assistive devices, specialized equipment, mental health care, vision and dental care. Due to their complexity, they need comprehensive, coordinated, community-based, family-centered and accessible (able to accommodate wheelchairs, stretchers, walkers, etc.) medical homes. Given this, transition clinics are staffed with specially trained physicians, nurses,

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pharmacists, dietitians, dentists and clinical social workers to address these health needs and help navigating the healthcare system. Despite this, many families and individuals (~24%) report at least one unmet health need. This unmet need worsens as they transition to adult medicine.⁸

### Table 1: Race and Ethnicity of Texans with and without Disabilities, 2017

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Total</th>
<th>With a Disability</th>
<th>Without a Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percent</td>
<td>Number</td>
</tr>
<tr>
<td>White</td>
<td>9,785,157</td>
<td>1,458,647</td>
<td>14.9%</td>
</tr>
<tr>
<td>African American</td>
<td>3,427,511</td>
<td>465,919</td>
<td>13.6%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>11,160,594</td>
<td>1,088,776</td>
<td>9.8%</td>
</tr>
<tr>
<td>Asian</td>
<td>1,350,337</td>
<td>73,058</td>
<td>5.4%</td>
</tr>
<tr>
<td>Other</td>
<td>2,580,997</td>
<td>260,605</td>
<td>10.1%</td>
</tr>
<tr>
<td>Total</td>
<td>28,304,596</td>
<td>3,347,005</td>
<td>11.8%</td>
</tr>
</tbody>
</table>

*Note: 2017 ACS summary table data. Percentages indicate the portion of each race/ethnicity category with and without disabilities. The race and ethnicity categories are mutually exclusive and include: Hispanics of one or more races, White(exclusive), Asians (exclusive), and other (more than one race not including Hispanic).*

In Texas, there is only one transition clinic that provides comprehensive medical care, social services and coordination of care for adolescents and young adults - the Transition Clinic in Houston which is a collaboration between Texas Children Hospital and Baylor College of Medicine and headed by Dr. Cynthia Peacock. This clinic is the first of its kind in Texas and serves as a model of excellence. However, this clinic faces many challenges, among them are funding - “more than 80% of the patient have Medicaid as their insurance source, 65% have an intellectual disability, 41% use a wheelchair and most have more than one medical diagnosis”.⁹

“The goal of the [transition] clinic is to prevent an urgent healthcare crisis and to minimize the impact of a shrinking social support network that these patients and families have come to rely on in the pediatric healthcare system. This includes

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⁹ Berens, John C. and Peacock, Cynthia. Implementation of an Academic Adult Primary Care Clinic for Adolescents and Young Adults with Complex, Chronic Childhood Conditions’. 1 Jan. 2015 : 3 – 12.
helping them overcome obstacles encountered in both adult Medicaid and private health insurance systems”.

Given the above, The Transition Clinic in Houston can only handle a limited number of patients and there is a geographic limitation to patients accepted. It is not feasible to see patients beyond their geographic range due to inability to respond quickly for crises.

Besides availability and access to a transition clinic, funding is the other essential issues facing further expansion of transition clinics. The BCM/TCH Transition clinic is primarily funded by Waiver 1115 through DSRIP (Delivery System Reform Incentive Pool) which is slated to end in 2021 without a plan to replace. When established, the Centers for Medicare and Medicaid Services (CMS) was clear that the pool was intended to build capacity, not to provide an ongoing funding stream for health care operations. Funding also comes from grants and fund raising but not enough to sustain long term viability of the clinic. Only a small portion of the BCM/TCH Transition clinic is funded by commercially insured patients.

Currently, Texas has the 2nd highest population of disabled persons in United States (only behind California). If looking at school data in Texas, there are approximately 209,823 non-institutionalized youths aged 16 to 24 with disabilities according 2017 data. This population is not evenly disturbed and mostly conjugated in the counties of Harris, Bexar, Dallas, Tarrant, Hidalgo, Travis, El Paso, Collin, Denton, and Cameron.

Table 2: Total Numbers of Individuals with Disabilities by County, Texas (2017)

<table>
<thead>
<tr>
<th>Local Texas Workforce Development Area</th>
<th>Total population of county</th>
<th>Total # of individuals with any disability</th>
<th>Approximate % of population (rounded)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Panhandle</td>
<td>437,985</td>
<td>57,618</td>
<td>13%</td>
</tr>
<tr>
<td>South Plains</td>
<td>434,744</td>
<td>61,565</td>
<td>14%</td>
</tr>
</tbody>
</table>

10 Baylor Medicine - Transition Care Clinic  
https://www.bcm.edu/healthcare/specialties/internal-medicine/transition-medicine-clinic  
<table>
<thead>
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<th>Local Texas Workforce Development Area</th>
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<th>Total # of individuals with any disability</th>
<th>Approximate % of population (rounded)</th>
</tr>
</thead>
<tbody>
<tr>
<td>North Texas</td>
<td>220,528</td>
<td>40,861</td>
<td>19%</td>
</tr>
<tr>
<td>North Central</td>
<td>2,846,279</td>
<td>274,083</td>
<td>10%</td>
</tr>
<tr>
<td>Tarrant County</td>
<td>2,054,475</td>
<td>215,313</td>
<td>10%</td>
</tr>
<tr>
<td>Greater Dallas</td>
<td>2,618,148</td>
<td>261,072</td>
<td>1%</td>
</tr>
<tr>
<td>Northeast Texas</td>
<td>283,772</td>
<td>46,188</td>
<td>16%</td>
</tr>
<tr>
<td>East Texas</td>
<td>860,334</td>
<td>132,738</td>
<td>15%</td>
</tr>
<tr>
<td>West Central</td>
<td>328,919</td>
<td>53,317</td>
<td>16%</td>
</tr>
<tr>
<td>Borderplex</td>
<td>865,822</td>
<td>106,293</td>
<td>12%</td>
</tr>
<tr>
<td>Permian Basin</td>
<td>476,304</td>
<td>55,452</td>
<td>12%</td>
</tr>
<tr>
<td>Concho Valley</td>
<td>159,608</td>
<td>23,285</td>
<td>15%</td>
</tr>
<tr>
<td>Heart of Texas</td>
<td>366,026</td>
<td>57,393</td>
<td>16%</td>
</tr>
<tr>
<td>Capital Area</td>
<td>1,226,698</td>
<td>103,634</td>
<td>8%</td>
</tr>
<tr>
<td>Rural Capital Area</td>
<td>1,011,224</td>
<td>112,066</td>
<td>11%</td>
</tr>
<tr>
<td>Brazos Valley</td>
<td>352,634</td>
<td>39,928</td>
<td>11%</td>
</tr>
<tr>
<td>Deep East Texas</td>
<td>383,784</td>
<td>71,917</td>
<td>19%</td>
</tr>
<tr>
<td>Southeast Texas</td>
<td>398,485</td>
<td>67,197</td>
<td>17%</td>
</tr>
<tr>
<td>Golden Crescent</td>
<td>197,376</td>
<td>31,672</td>
<td>16%</td>
</tr>
<tr>
<td>Alamo</td>
<td>2,587,905</td>
<td>388,045</td>
<td>15%</td>
</tr>
<tr>
<td>South Texas</td>
<td>294,318</td>
<td>33,118</td>
<td>11%</td>
</tr>
<tr>
<td>Coastal Bend</td>
<td>596,853</td>
<td>86,298</td>
<td>14%</td>
</tr>
<tr>
<td>Lower Rio Grande Valley</td>
<td>946,699</td>
<td>139,727</td>
<td>15%</td>
</tr>
<tr>
<td>Cameron County</td>
<td>423,725</td>
<td>56,047</td>
<td>13%</td>
</tr>
<tr>
<td>Texoma</td>
<td>205,481</td>
<td>33,073</td>
<td>16%</td>
</tr>
<tr>
<td>Local Texas Workforce Development Area</td>
<td>Total population of county</td>
<td>Total # of individuals with any disability</td>
<td>Approximate % of population (rounded)</td>
</tr>
<tr>
<td>---------------------------------------</td>
<td>-----------------------------</td>
<td>------------------------------------------</td>
<td>------------------------------------</td>
</tr>
<tr>
<td>Central Texas</td>
<td>488,128</td>
<td>78,748</td>
<td>16%</td>
</tr>
<tr>
<td>Middle Rio Grande</td>
<td>173,630</td>
<td>32,025</td>
<td>18%</td>
</tr>
<tr>
<td>Gulf Coast</td>
<td>7,064,712</td>
<td>688,191</td>
<td>9%</td>
</tr>
</tbody>
</table>

Note: Data is based on the definition of a disability being reported by the individual if they have serious self-care, hearing, vision, independent living, ambulatory, or cognitive difficulties on the 2017 American Community Survey (ACS). This report may not include those individuals with psychiatric disabilities and the ACS is based on samples and produce data that approximate the size of the population.12

Given the above data, the State of Texas should look into developing transition clinics in these counties. One option would be to partner with current pediatric complex care clinics and/or State of Texas academic health care centers. Current pediatric complex care clinics in Texas, include the following:

- Children’s Comprehensive Care at Ascension Health Dell Children’s Hospital in Austin (Dr. Rahel Berhane) in Austin
- Children’s Health & UT Southwestern Complex Care Clinic in Dallas
- Texas Tech Physicians with clinic in Lubbock (Dr. Latisha McLaurin)
- University Health Clinic in San Antonio (Dr. Glen Meddellin)
- UT Houston (Dr. Ricardo Mosquera)
- UTMB in Galveston (Dr. Christine Murphy)13

Now more than ever, it is important for Texas to lead the nation and establish additional medical transition clinics to meet the needs of disabled children and children with special health care needs. Only about 1 in 5 adolescents with special health care needs and disabilities successfully transition into adult health care.14


By funding and supporting the infrastructure needed to develop additional transition clinics, these patients will have continuation of a comprehensive medical home, medical providers to mitigate urgent healthcare crisis that can result in unnecessary ER visits, hospitalizations and a decline in health & function, reduction in overall healthcare cost by more efficient utilization of resources and limitation of duplication of care, minimization of the impact of the loss of the pediatric social support network as the patient transitions into the adult medical model, resources to navigate adult healthcare system to better coordinate care with improved health outcomes, maintenance and identification of additional services that are critical to health and functional status, and reduction healthcare disparities.

Transition Clinic - Christy’s story

Christy Travis’ first appointment with Dr. Cynthia Peacock at the Transition Medicine Clinic (TMC) in Houston, Texas was 12/13/2012. Prior to that, Christy was hospitalized an average of 2 times per year at Texas Children’s Hospital Pediatric ICU (PCU) for an average of 9 days per stay for pneumonia. Since starting care with the TMC, Christy has been hospitalized only twice since 2012, once for pneumonia and one overnight stay for dehydration. The TMC has kept us out of the hospital by treating Christy at home before she gets sick enough to go to the hospital. In the 8 years Christy has been under the care of Dr. Peacock and her team at the TMC, she has saved 2 hospital visits per year 9 days each (minus the 18 days for the 2 hospitalizations) for an average savings of 126 hospital days at PCU intermediate care level. This savings through reduction of hospitalizations is what the funding sources for additional transition care clinics should be looking at. What 126 hospital days saved means to Christy and our family:

- Christy has been healthier overall in the past 8 years than she was before starting care at the TCM.
- Not having 2 months of recovery time to get back to baseline health after each of the 16 hospital stays - so 32 months of recovery is saved. It takes Christy a long time to recover and more equipment/treatments to recover - suction machine, oxygen concentrator, nebulizer, vest treatment machine. Our home looked like a hospital room for a long time after we returned home from the hospital.
- Our family life wasn’t put on hold for 126 days while one parent stayed in the hospital 24/7 and one parent stayed home with the other 2 children to take care of them.
Transition Clinic- Tyler's Story

Tyler is a 24-year-old young man, who has Down Syndrome and Autism. He is an active and loving part of his family, who loves to eat out at restaurants and travel together. Tyler is a connoisseur of mochas and will argue that McDonald’s mochas are sweeter and better than the competition! He also loves birthday celebrations, especially with his family, and has become a big fan of birthday parades that have become a popular trend during the COVID-19 Pandemic.

As an infant, Tyler was diagnosed with Hirschsprung's (HIRSH-sproongz) disease. It was undetected and disguised by other problems until he was 8 months of age and was diagnosed largely due to his mother’s research and persistence in trying to help him. Throughout his childhood, Tyler had several illnesses requiring emergency room visits. By the age of 18, Tyler’s behavior had begun to deteriorate rapidly and then as he began doubting over in pain, it was discovered that he had an intestinal malformation. He had 7 surgeries in one week, became septic, and was in the ICU for 21 days and in the hospital for a total of 5 ½ months. He got better but by ages 21 and 23, he’d experience additional difficulties requiring hospitalization and surgical intervention. Fortunately, by age 19, he had begun receiving care at the Baylor Medicine Transition Medicine Clinic in Houston. It was at the Transition Medicine clinic where Tyler received comprehensive care for his complex medical needs and was able to transition to adult care providers who understand his
complex needs. When asked about their experience in the clinic, Tyler’s mother expressed that she did not realize the inadequacy of care her son received until he got to the Baylor clinic. She also stated that the providers at this clinic establish relationships with their patients, are extremely proactive, and coordinate services as needed.

Tyler also receives essential services and supports through the Texas Home Living (TxHmL), a Texas Medicaid waiver program. These services include day habilitation, respite, attendant services, therapies, and many more, which are an invaluable resource to help him live at home and also remain active in his community. Tyler is considered nonverbal and can become overstimulated in highly sensory environments, so having access to caring, trained individuals to help him navigate his community and enjoy his favorite activities is very important to his family. Without this support and access to these services, Tyler’s life may likely look very different than it does today.

![Tyler, a young adult who receives services at the Baylor Transition Medicine Clinic in Houston.](image)

**Transition Clinic - Ellie’s Story**

Ellie is a 19-year-old young lady with Down Syndrome who just graduated high school and is excited to begin her journey into adulthood and embark on new adventures! Ellie is active in her community, participates in Special Olympics, loves art, music and dancing, and enjoys watching Houston professional sports. Fortunately, she has had access to many support services through her CLASS
Medicaid waiver program and recently began receiving care at the Baylor Medicine Transition Medicine Clinic in Houston. These programs are not widely available to her peers and friends with special needs across the state and Ellie’s family cannot imagine the challenges other families will face as they navigate the transition of their child with special needs into adulthood. They believe it is unfair that our state does not provide equal care and support for all individuals. Therefore, Ellie and her mother have become advocates in fighting for the rights and services for all individuals with disabilities and their families.

Ellie’s pediatrician referred her to the Baylor Medicine Transition Medicine clinic after her 19th birthday. The process was efficient, with excellent communication and care during each call and visit, despite the ongoing pandemic. At her first visit, she was approached with great respect and was given the opportunity to ask questions and be involved in her care. Staff ensured that she had access to all available services, was proactive in coordinating care and referrals as needed and discussed future steps for appropriate planning. While Ellie and her mother left the clinic feeling confident and pleased, the visit felt like more of a privilege than a standard level of care. Many more families could benefit from this great level of care if Texas would prioritize healthcare and funding for children and adults with disabilities.

Figure 4: Ellie, a young adult who receives services at the Baylor Transition Medicine Clinic in Houston.

**Policy Issue: Building Provider Capacity and Training for Adult Transition Clinics**

Many adolescents and adults with disabilities experience poor access to adult health care once they age out of pediatric services. Those individuals who continue
through adulthood with pediatric providers receive incomplete services for age-based screenings, as well as during times of disease exacerbations, particularly those requiring hospitalization. These adults struggle with the fallout of a system where 90% of children born with a disability will survive to adulthood, but the training of adult care clinicians in their disease-specific care has not kept pace.\(^{15}\) Additionally, the high level of resources required to care for adults with disabilities, coupled with low reimbursement rates of public payors, result in an even smaller pool of clinicians providing care – leaving many adults with disabilities without a medical home of any kind.

Texas is unique as it is the home to one of the few dedicated Transition Medicine Clinics in the nation, and currently the only one in Texas. Located in Houston, adults under the care of this clinic utilize the ER less than their comparable counterparts. Here, they receive age-appropriate screenings and healthcare, coupled with developmentally- and disease-appropriate assessments of special medical and social needs. However, not every adult with disabilities will be able to travel the distance required to attend this clinic, and transportation for this group is notoriously more challenging than an otherwise healthy adult. Additionally, it is the only clinic in the State dedicated to training students of many disciplines in the special care of these individuals and their families.

If Texas is to be home to healthy citizens, we must provide training for clinicians already in practice to bridge the knowledge gap from training to practice for adults with disabilities. Texas already participates in a collaborative-learning program for physicians already in practice to access support for child psychiatry services known as the Child Psychiatry Access Network (CPAN). CPAN links disease-specific experts, namely child psychiatrists, with primary care physicians across the state to deliver real-time answers to clinical questions about diagnoses, management, and resources. CPAN increases the fund of knowledge for clinicians out of formal training, provides appropriate psychiatric care for children in underserved areas, and keeps children and families within their home communities. Texas adults with disabilities would reap benefits of a similar collaborative network to promote care for their needs within their home communities, as it would improve access to high-quality care through improved clinician real-time education.

**Recommendations:**

1. Ensure continued funding for the only transition clinic as a means to continue one-on-one education of future medical professionals.

2. Allow telemedicine consultative services to continue beyond the COVID-19 pandemic as a way to improve access to health care providers specializing in treating children and adults with disabilities, possibly reducing wait times for new patients from referral time to time of first visit.

3. Increase capacity to train providers already in practice.
   a. Provide funding to create programs similar to those found in child psychiatry to assist local medical providers currently in practice with access to resources and education in real-time.
      i. Establish Project ECHO (Extension for Community Healthcare Outcomes) for Pediatric to Adult Care Transitions
         (1) Project ECHO originated in 2003 at the University of New Mexico Health Science Center and was formed to allow dissemination of knowledge from academic centers to rural area providers.
         (2) Incorporate CME of interest to both adult and pediatric care providers for this patient population in a virtual context.
         (3) Establish a mentoring forum for providers interested in providing/receiving such training.
   b. Establish a CPAN-like network for complex care access centers.
      i. Assist with assessment and treatment of medical illnesses related to or complicated by underlying chronic conditions.
      ii. Assist with identifying community resources for those impacted by complex medical needs.
      iii. Provide didactic information to providers with regards to details related to congenital or childhood-onset chronic illness.
      iv. Provide these services within a real-time setting, affording local medical care providers the ability to request consultative services with a complex care specialist at the time of need.
         (1) Services are requested by phone call made to main network hotline during regular clinic hours.
         (2) Trained staff are available for information and/or consultation within minutes to answer the incoming request(s).
            (a) Staff include:
               (i) Network coordinator to answer basic questions and triage calls.
               (ii) Social work specialists to provide information on access to programs and other social networks/benefits for individuals with special needs.
               (iii) Clinician (physician, nurse practitioner, etc.) to provide guidance on clinical management inquiries.

4. Increase capacity to train providers in training
a. Increase funding to teaching hospitals to provide more training positions (or develop new programs) for Internal Medicine-Pediatrics Residency Programs.

b. Consider special funding to Family Medicine Residency Programs who include added competencies regarding congenital and childhood-onset chronic conditions in their training programs.¹⁶

Background

Identifying the need

The need for well-trained adult care team staff to accept adults with disabilities transitioning to adult care is well established. Nationally, roughly 750,000 children with special health care needs transitioned from pediatric to adult care in the United States based on a 2014 study by Davis et. al, a number unlikely to change given advances in medical technology improving childhood survival rates for previously fatal conditions.¹⁷ Unfortunately, too often, transition to adult services result in the loss of a physician specifically trained in childhood-onset disabilities and the disease-specific resources required for high quality care. These adults are too often left without an appropriately trained provider or team to transfer care.

The difficulty with transitioning to adult care

Adult health care providers have long established medical competency limitations to providing appropriate care for adults with congenital and/or childhood chronic conditions, despite the increasing numbers of children with these conditions surviving to adulthood. In 2009, a survey sent to 2000 physicians registered with American Board of Medical Specialties cited lack of medical competency in congenital and childhood chronic illnesses as a major concern for accepting patients with medical complexity.¹⁸ Similar concerns were cited in a later study in 2014, which also reported a lack of training and availability of social, medicolegal, and care coordination resources to provide care for adults with these conditions.¹⁹

¹⁹ Berens J. C., Steinway C., Szalda D., Jan S. Transition to Penn Medicine: a survey of adult providers assessing the needs and barriers surrounding a seamless transition process.
Unfortunately, this trend has no evidence of improvement in sight. In 2020, the National Resident Matching Program reported a total of 37,256 open training positions across the nation. Internal Medicine-Pediatrics Residency positions represented a mere 1% of those slots. Strikingly, there were a total of four Neurodevelopmental Disabilities positions open across the U.S. in 2020. These numbers were generally static to 2019 available positions.\textsuperscript{20} Texas must invest in the training of our adult physicians both currently in training and already in practice.

Poor access to care for young adults with disabling chronic conditions is well established, made worse by insurance benefits loss and changes, as well as overall few adult providers accepting new patients with Medicaid compared to the number of pediatric providers.\textsuperscript{21}

In fact, greater than 66\% of young adults in this population reported poor health care access in the form of delayed or missed care due to high cost, and 45\% of this group had no usual source of care. These percentages were 6 to 8-fold higher for young adults who were no longer covered by SSI benefits.\textsuperscript{22}

**Impact of health care access on health outcomes**

Poor access to health care generates poor health outcomes. While long-term data is lacking for persons specifically with neurodevelopmental disabilities, information can be extrapolated from several disease-specific studies, as well as the outcomes that are known when access to primary care services are reduced for a specific region. Robust data exists for the impact of poor access on chronic, complex disease-specific outcomes. As noted by Prior, et al, health declines during the pediatric to adult care transition are pervasive, and findings well-described in literature include obesity, increase in complications of sickle cell disease, and loss of renal transplants.\textsuperscript{23}


\textsuperscript{23} Prior, M., McManus, M., White, P., Davidson, L. Measuring the “Triple Aim” in Transition Care: A Systematic Review. Pediatrics 2014;134;e1648
Impact of transition of care on health outcomes

Currently, there are few studies examining the impacts on mortality rates at transition of care in young adults specifically with neurodevelopmental disabilities, in part because of the relative recency of the need to transition patients at adulthood related to improved pediatric survival rates. As such, there are no published reports monitoring this population for more than 2 years after transition. However, an increase in morbidity after transfer among adults with other chronic diseases has been documented. In Western Australia, one study found for adults with type 1 diabetes mellitus, mortality peaks for both genders at 25-29 years of age. In another study focusing on patients with sickle cell disease, 6 of 7 deaths occurred after 18 years of age, with a median time from transfer to adult services of 1.2 years.\textsuperscript{24}

Literature also supports the importance of access to primary care services. According to an article in JAMA Internal Medicine, between 2005-2015, every 10 additional primary care physicians per 100,000 population was associated with an increase in life expectancy by 51.5 days for that population.\textsuperscript{25}

Transition Clinics Matter

Transition programs are important and have been found to improve quality of life for patients receiving these services. Because these clinics are relatively new, many studies lack a unified, validated evaluation approach to consistently assess patient and family experience, cost, and population health. However, many programs found positive value to the intervention.\textsuperscript{21}

Texas is fortunate to be home to one such clinic. The Transition Medicine Clinic in Houston is a beacon of hope for many families in the region with adolescents reaching the age of transition. With limited resources, including mainly DSRIP and private philanthropic resources, this clinic provides training for 12-16 adult providers per year, as well as students in medicine, nursing, social work, and dental schools.


Training providers already in practice

Hands-on training is ideal, but areas in East, West and South Texas are notoriously underserved, and the Transition Medicine Clinic’s ability to train highly qualified clinicians annually is limited. Additionally, this type of training fails to address the knowledge gap of clinicians already in practice. Real-time continuing medical education in the form of a network similar to CPAN or Project ECHO, as well as a component to provide lecture-based events is imperative to training clinicians ready to accept these adults now. Addressing knowledge gaps in clinicians in practice would increase access to care much more quickly than with training students. Additionally, this training may reduce the risk of long-term complications at transition, thereby reducing Medicaid spending, as well as costs of transportation to receive specialty care outside of their home community. This model has been proven to “develop specialty expertise over time, provide care...[that] is as safe and effective as that of a specialist, [and] demonopolizes specialty knowledge”.

Texas adults with disabilities have a right to access to local high-quality, age- and disability-appropriate care. We must act now to provide training and resources to create this future.

Policy Issue: Improve Access to Medicaid Insurance for Children with Disabilities

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. The receipt of supports in the home prevents costlier institutional admissions. Since 2002, the number of children living in large institutional settings has decreased by approximately 62%. If Texas is to sustain this trend, the state needs to ensure families have access to lower cost preventative services and long-term services and supports that allow children to remain healthy and allow families to remain intact as well as comprehensive waiver services for children who need support to move from an institution to a family. Currently children and families are waiting years for the support they need not only threatening the health of the child, but the well-being of the entire family.

Texas has one of the highest rates of uninsured children in the country. According to 2018 data from the US Census Bureau, Texas leads the country in the number of

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26 University of New Mexico School of Medicine. Project Echo Model. https://echo.unm.edu/about-echo/model/
uninsured children under the age of 19 at 11.2% or 873,000 children. According to Joan Alker, the executive director of Georgetown University’s Center for Children and Families in Washington, D.C., "No other state is even in double digits".\textsuperscript{27}

In addition, according to the US Department of Health and Human Services 2017-2018 data from the National Survey of Children’s Health 33% of Texas families raising children with special health care needs who have health insurance report their insurance is inadequate. It does not pay for all the services their children need, does not provide access to the providers their children need, and the out-of-pocket expenses are not reasonable. Medicaid offers children better benefits with much lower cost-sharing, but access to Medicaid is limited because of family income restrictions.\textsuperscript{28}

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

\begin{table}[h]
\centering
\begin{tabular}{|p{\textwidth}|}
\hline
\textbf{Research has identified that parents of children with disabilities have lower incomes and higher out-of-pocket costs related to their children’s care needs compared to parents of other children.} \\
\textbf{Average out of pocket expenditures paid directly by the family of a child with special health care needs were two times higher than the out of pocket health care expenses of families without children with special health care needs.}\textsuperscript{29} \\
\hline
\end{tabular}
\end{table}

**Recommendations:**

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.

1. Reduce the Medically Dependent Children Program (MDCP) interest list by
   a. allowing children who have SSI and meet nursing facility level of care to receive Medically Dependent Children Program waiver services with no wait; and

\textsuperscript{27} https://www.texmed.org/TexasMedicineDetail.aspx?id=51858 \\
\textsuperscript{28} https://www.childhealthdata.org/browse/survey/results?q=6953&r=45&g=731. \\
\textsuperscript{29} Newacheck, P. W., & Kim, S. E. (2005). A National Profile of Health Care Utilization and Expenditures for Children with Special Health Care Needs. ARCH Pediatric Adolescent Medicine, 10 - 17.
b. funding of MDCP waiver services for the approximately 575 children who do not have SSI or Medicaid and are waiting for critical medical and long-term supports for their children.

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 cost tiered waiver in lieu of a more costly 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.

Background

MDCP and SSI Children

The Medically Dependent Children Program (MDCP) waiver provides services to children with significant medical complexities as a cost-effective alternative to the institutionalization of children in nursing homes. Many children in the waiver utilize life sustaining medical technology. MDCP services include respite, minor home modifications, adaptive aids, and flexible family supports. The individual cost of services is capped at less than 50% or less than half of what is paid to a nursing facility.

As of May 31, 2020, 6,386 children were on the interest list for the MDCP waiver. Of that number 2,544 children have SSI. Unlike the STAR+PLUS home and community-based services waiver that allows adults who have Supplemental Security Income (SSI) access to the waiver with no wait, children who have SSI and meet MDCP eligibility criteria cannot access waiver services until their names come to the top of the interest list. The wait for services is approximately two to three years.

Currently eligibility for MDCP is determined when the child’s name reaches the top of the list and receives a waiver offer. The average percentage of children who are determined eligible for and accept MDCP when they reach the top of the interest list is between 11% to 15%. HHSC refers to this as the uptake rate. Applying the more conservative 15% uptake rate to the total number of children on the list means that only 958 of the 6,386 children currently on the interest list will likely be determined eligible and/or enroll in services.
Based on current data approximately 40% of the 958 children likely to be determined eligible and enroll in the waiver have SSI (382). The remaining 60% or 576 children do not have SSI or Medicaid. Given these facts, if children with SSI are granted access to waiver services with no wait then funding of waiver services for the remaining 576 children becomes economically feasible. The state could also choose to prioritize waiver services to those 576 children without access to any Medicaid services. Texas has an incredible opportunity to make a significant difference in the lives of families with medically fragile children.

**Texas Home Living Waiver**

The Texas Home Living waiver (TxHmL) is Texas’ lowest individual cost-cap waiver. It was first authorized in March 2004 to provide essential community-based services and supports to individuals with intellectual and developmental disabilities living in their own homes or with their families. Texas financed the waiver by taking General Revenue typically used to pay for respite and other safety net services to draw down federal match. The premise was strong, but because Texas limited eligibility to only those who have Medicaid, many children and some adults who were engaging in supported employment were deemed ineligible and lost some
of the General Revenue funded services they had been receiving. The yearly individual cost cap for the waiver is $17,000.

Aligning TxHmL waiver eligibility to be the same as other Texas Medicaid waivers would allow children to access a base level of service while reserving comprehensive waivers for those with more significant long-term support needs. It is a cost-effective strategy Texas could employ to significantly reduce the Medicaid waiver interest lists as well as a strategy to strengthen and support families.

**Family Opportunity Act and Medicaid Buy-In for Children**

In 2005, the federal government passed The Family Opportunity Act as part of the Deficit Reduction Act. The Act allowed states the opportunity to create a Medicaid buy-in program for families of children who meet the federal SSI disability criteria and whose family income is below 300% of the Federal Poverty Level (FPL). This option allows families of children with a disability determination to pay a premium to access Medicaid. Texas is one of only a few states that used this Act to create a Medicaid Buy-In option for children. Texas’ program was passed by the Texas Legislature in 2009 and was estimated to initially support 2,000 children. The Texas legislation had bi-partisan support in both the house and the senate and is a program that has received positive attention on both a state and national level.

While the federal legislation allows states to set the financial eligibility at up to 300% of the FPL, Texas has chosen a lower financial eligibility of 150%. Texas could increase eligibility to 300% of adjusted gross income as have other states like Colorado. Eligibility for Colorado’s program is 300% after income disregards.

In addition, when the Texas legislation was passed in 2009, the state and legislature estimated the program would initially support 2,000 families to contribute to the cost of their children’s care by paying a premium for Medicaid. The fiscal note stated that the intent would be for the program to increase over time to approximately 6,000 to 7,000 families. The number of children served in 2020 remains at 2,000. Given the high percentage of uninsured children in Texas, improved outreach is warranted.

**TEFRA**

The Tax Equity Fiscal Responsibility Act (TEFRA) was passed in 1982 under the leadership of President Ronald Reagan. Section 134 of Public Law Number 97-248 allows states to provide Medicaid coverage to children with severe disabilities younger than 19 who require a level of care that could be provided in a hospital, skilled nursing facility, or an intermediate care facility for individuals with intellectual disabilities.
The TEFRA option is often referred to as the Katie Beckett provision named after a young girl in Iowa who in the early 1980s contracted encephalitis at the age of 5 months and required extensive medical care. Her family wanted their baby to grow up at home with them instead of in a nursing facility. Her story caught the attention of the Reagan administration who advocated on her behalf.

Currently 18 states and the District of Columbia have a TEFRA state plan option. In addition, two other states, New Hampshire and Arkansas have TEFRA look alike programs bringing the total number who participate to 21. According to a policy brief written by Boston University’s Catalyst group both the Family Opportunity Act and TEFRA:

- Help ensure children with complex health needs receive medically necessary services
- Prevent family financial hardship, medical debt, and bankruptcy by reducing families’ out-of-pocket expenses
- Bridge gaps in the scope, amount, and duration of health services covered by private insurance
- Pay for health care services that private insurance only partially covers, like durable medical equipment, or may not cover at all, for example, skilled nursing services
- Remove incentive for families to leave the workforce or decline raises in order to keep household income low enough for a child with complex health needs to qualify for Medicaid, which in turn means all children in the household qualify for Medicaid
- The majority of children with disabilities will continue to have private insurance as their primary source of coverage under both these options; Medicaid as payer of last resort covers co-pays, deductibles and uncovered services, not the full cost of a child’s health care needs.30

Policy Issue: Ensure Children with Disabilities Grow Up in Families instead of Institutions

It is the policy of the state to strive to ensure that the 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. Local communities and the state must work together to provide encouragement and support for well-functioning families and ensure that each child receives the benefits of being a part of a successful permanent family as soon as possible.

Well-established factors that contribute to healthy development that are embedded in most families are missing in even the best congregate care.\(^{31}\)

Institutionalization can negatively impact a child’s physical, cognitive, neurodevelopmental, and social-psychological health.

Setbacks are most pronounced when children are deprived of individualized caregiving during sensitive early developmental periods.

Early interventions that place children into families have resulted in substantial recovery to the child.

Institutions are consistently costlier than family-based or community-based care.\textsuperscript{32}

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.

\textbf{Recommendations:}

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

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.

\textbf{Background}

Since 2002, Texas has experienced a 62% decrease in the number of children living in congregate facilities with six or more people resulting in a savings to the state and an improved quality of life for the child and family. Texas through its Family Based Alternatives and Permanency Planning efforts has led the nation in assisting individuals to move from restrictive institutional settings, including nursing facilities and intermediate care facilities, to the community. This includes assistance to

\textsuperscript{32} https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(14)61131-4/fulltext
families of children with disabilities so that children can grow up in families instead of institutions.

Table 3: Trends in the Number of Children by Institution

<table>
<thead>
<tr>
<th>Institution Type</th>
<th>Baseline Number as of August 31, 2002</th>
<th>Number as of August 31, 2019</th>
<th>Percentage Change Since August 2002</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing Facilities</td>
<td>234</td>
<td>71</td>
<td>-70%</td>
</tr>
<tr>
<td>Small ICF/IID</td>
<td>418</td>
<td>171</td>
<td>-59%</td>
</tr>
<tr>
<td>Medium ICF/IID</td>
<td>39</td>
<td>18</td>
<td>-54%</td>
</tr>
<tr>
<td>Large ICF/IID</td>
<td>264</td>
<td>13</td>
<td>-95%</td>
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<tr>
<td>SSLC</td>
<td>241</td>
<td>163</td>
<td>-32%</td>
</tr>
<tr>
<td>DFPS GRO</td>
<td>73</td>
<td>43</td>
<td>-41%</td>
</tr>
<tr>
<td>Total</td>
<td>1,269</td>
<td>479</td>
<td>-62%</td>
</tr>
</tbody>
</table>


Promoting Independence Waivers

The Texas Legislature has historically funded Medicaid waiver services for children to move from facilities to families and for those at imminent risk of admission to get the supports they need so the family unit remains intact. It is imperative that the work that has been started by the state continue. Home and Community-Based Services (HCS) waivers are needed to assist the following number of children.

**HCS Waiver Slots to Support Transition from Institutions to Families**

- 20 children to move from nursing homes
- 50 children to move from small Intermediate Care Facilities (ICF)
- 35 children to move from General Residential Operations licensed by the Department of Family and Protective Services
HCS Waiver Slots to Support Diversion from Institutions to Families

- 100 children at risk of nursing home admission
- 100 children in crisis and at imminent risk of placement in an institution
- 300 children aging out of CPS foster care

MDCP Nursing Facility Stay Requirement

The Medically Dependent Children Program (MDCP) waiver allows children to leave nursing facilities and receive services and supports in their homes through a money follows the person process. The set aside was created in 2001 by the Texas legislature, formally Rider 37 of the General Appropriations Act, in response to the Texas Promoting Independence Plan. Since 2001, medically fragile children have been supported to grow up at home surrounded by family and friends in a cost-effective waiver that is capped at 50% of the cost of supporting the child in a nursing facility.

In order to qualify for the Money Follows the Person process, the waiver requires a child to complete a 30-day stay in a nursing facility, unless the child is extremely medically fragile and is approved by a strictly defined medical fragility determination by HHSC to complete a limited stay. The limited stay requires a child to enter a nursing facility for part of two days. Children who qualify for the medical fragility limited stay criteria have been determined by medical professionals as too medically fragile to complete the entire 30-day stay. Children who qualify often require a ventilator to breathe, have tracheostomies, require oxygen or have severely compromised immune systems.

While the limited stay has been a welcome relief to families struggling with the thought of placing their extremely medically fragile child in a nursing facility often far from home, or to divorce or declare bankruptcy in order to qualify for Medicaid, the process is fraught with problems including high costs to the system and families, administrative burdens to providers and the state, medical risks to medically fragile children, and an extremely high emotional toll on families. Some children need to be transported via an ambulance to the facility and home the next day. The cost of medical transportation alone to Medicaid is astronomical.

The need for access to a crisis diversion process for children with extreme medical fragility that does not require a child to be admitted to a nursing facility for part of two days was highlighted by the recent COVID-19 pandemic. Facilities that accept children for a limited stay were hard to find prior to the current public health emergency and is even harder now. Families and physicians of children who require ventilation to breathe and whose immune system and health are medically compromised are worried that admission to a congregate facility for even a short
A period of time puts children at greater risk of contracting COVID-19 and requiring further hospitalization.

Texas Medicaid has successfully created a crisis diversion process and reserved capacity in the Home and Community-Based Services (HCS) waiver for children and adults at risk of facility admission. Some years ago, the Department of Aging and Disability Services received approval to set aside funding for 100 adults at risk of nursing facility admission to receive Community Based Alternatives (CBA) waiver funding. HHSC needs legislative direction and funding from the legislature to create a similar diversion process in the MDCP waiver that does not require a medically fragile child to enter a nursing facility. Senate Bill 1207 from the 89th Texas Legislature set the stage but did not give HHSC sufficient direction or funding. (Sample stories for this section are below. Will work on these, pictures and releases. Also need data on the number of children who have qualified for a limited stay for the past several fiscal years).

Children’s stories related to the NF Stay:

1. A teenager with quadriplegia who uses a power wheelchair and a ventilator to breathe, was approved by HHSC for the MDCP limited stay in a nursing facility. The child’s mother did not have an adapted vehicle at the time of their stay. The Managed Care Organization had to reserve a VAS transportation service to get the child to the nursing facility and back. The child ended up at the nursing home for 13 hours while transportation was managed. There was significant stress on the family. The teen’s mother is a single parent with other children to care for and the coordination to make this all happen took a lot of work and resources.

2. The baby is a twin, so an immediate issue was trying to plan for someone to assist with taking care of the baby’s twin sister while the family was admitting their medically fragile child to a nursing facility for the overnight stay. The baby has a trach, uses a ventilator, and requires suctioning hourly. The baby is also fed through a g-tube. Even though the baby was 1 at the time of his nursing facility stay, he required the support of two people including his mother and a nurse. The mother attempted to schedule the nursing home stay for one date but the nurse that was going to go with them to assist in the care of the baby got sick and the stay was cancelled. It was impossible for the father to go with the mother because they could not find someone to watch the other twin. The mother could not drive to the nursing home by herself because she needed someone to care for her child during the drive. When everything was finally in place, the family was incredibly frustrated with the time and travel it took to get the child to the facility,
admit for a few hours only to turn around and drive home. The administrative cost to the child’s MCO was also high.

**Texas Home Living Waiver Set Aside for Children Graduating High School**

One of the biggest issues facing Texas families of young adults graduating high school is graduating with no access to meaningful things to do during the day. According to the Department of Labor, the employment rate of people with disabilities continues to be very low. Only 34% of adults with between the ages of 16 to 64 are employed. This is in comparison to 76% of people without disabilities.\(^33\)

If severity of disability is factored in, the number of employed adults with disabilities is even lower. Adults with significant disabilities often need long-term supports and services such as on-going job coaching and personal assistance services to engage in meaningful employment.

Texas could create reserved capacity in the Texas Home Living waiver which is the lowest cost waiver with a cap of $17,000 per person annually, targeted to young people graduating high school. Offering waiver services early to assist the young person to find and maintain employment could lead to a lower reliance on more comprehensive waivers in the future.

**Medicaid Waiver Interest List**

The wait for services from a Texas Medicaid Home and Community-Based Services waiver is long.

Some children spend 13 years waiting for services on waiver interest lists. Families of these children often have little alternative other than to seek admission of their children to a costly institution. Funding for waivers was not appropriated in the amount requested for the 2020-2021 biennium, leaving some children without access to the supports and services they need to live in a family. By implementing some of the recommendations made in this report, the Texas Legislature can make a significant step toward reducing the Medicaid waiver interest lists. These recommendations include:

1. Allowing children who have SSI and meet MDCP level of care access to the waiver with no wait.

\(^33\) https://www.dol.gov/odep/topics/DisabilityEmploymentStatistics.htm
2. Allowing families with income of up to 300% after disregards the opportunity to buy into Medicaid and increasing program outreach.
3. Allowing children who meet an institutional level of care to access Medicaid through a TEFRA option.
4. Aligning the eligibility of the Texas Home Living waiver (low cost waiver) with the eligibility requirement of other Texas waivers and also eliminating the IQ requirement.
5. Creating a target group in the Texas Home Living waiver for children graduating high school.

If these recommendations are accepted and acted upon, the need for funding to reduce the interest list by 10% might already be met and the opportunity for families and young people to actively engage in employment and assist in stimulating the Texas economy will be increased.

Figure 6: Angela, a young girl with down syndrome who has been on multiple waiver waiting lists since 2008.
Policy Issue: Improve access to mental health, trauma informed care and crisis services for children with disabilities to ensure children are supported to live in families in lieu of costly long-term institutions.

Children with IDD who have 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 individuals 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 respite.

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:
- Adequate time to assess the child
- Development of a plan for appropriate supports for the child to return home or move to another family-based alternative including additional respite and direct support.
- Supports in the respite setting to care for children with complex behavioral support needs including additional staff if needed.

2. Continue funding of the Texas START programs in Tarrant County and El Paso and increase the amount of funds to each site to for allow expansion to additional counties. Current START coordinators should be funded to serve as mentors to coordinators in the newly added counties. Critical services for this population of children include in-home therapeutic coaching of families, coordination of START services, and clinical services.

3. Create a funding mechanism for the services above including 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.

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

The Texas Task Force for Children with Special Needs in their 2011 – 2016 strategic plan developed recommendations aimed at ensuring children had the supports necessary to live in families. One of the key recommendations was to provide respite for families as well as host families so that families could get the relief needed from intensive caregiving, and the relief and time needed to allow families to regroup after a behavioral health crisis.

Access to respite for Texas families raising children with significant needs is limited for many, and non-existent for others. The following recommendations strengthen existing respite programs and create mechanisms for families who have no access to Medicaid funded respite to get the support needed to raise their children at home while ensuring the health and stability of the family.
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 Local Education Agencies, and an increase in the amount of funds designated for schools to allow schools to fund respite for families in need.
3. Amend the home and community-based waivers to allow an additional 30 to 60 days of respite per year. This includes 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.

Background

According to the American Academy of Pediatrics Council on Children with Disabilities, children with IDD are at higher risk of out-of-home placement than other children, particularly at higher risk of placement in residential facilities.34

Respite and Family Support

The following data is directly from a 2012 report by the National Respite Coalition regarding the need for and benefits of respite for children and young adults

Children with Special Health Care Needs or Disabilities and their Family Caregivers

- An estimated 16.8 million unpaid caregivers provide care to a child with special needs under the age of 18 in the U.S. The caregiving is defined as being due to a medical, behavioral, or other condition or disability—whether the condition is ongoing or a serious short-term medical condition, an emotional or behavior problem, or a developmental problem. Caregivers of children are less likely than caregivers of adults to be caring for just one person (51% vs. 68% respectively). Half of caregivers of children are providing care to their own son or daughter (55%). Child care recipients are

34 http://pediatrics.aappublications.org/content/138/6/e20163216
also commonly a grandchild (18%), another relative such as a niece or nephew (13%), a friend (8%), or some other non-relative (5%).

**Respite Use/Access Limited**

- Eighty-one percent of family caregivers of children with special health care needs do not use respite. In spite of their interest in finding time and life balance for themselves, 86% of caregivers caring for young adults ages 18-49 have not used a respite or companion service to free up their time.
- While the NAC/AARP survey did not ask why family caregivers did not use respite, such barriers have been well documented. They include cost, restrictive eligibility criteria, waiting lists, limited or no respite options, accessibility, inadequate supply of trained providers or appropriate programs, lack of information, or feelings related to lack of trust of outside providers, guilt, or non-identification as a family caregiver.

**Family Caregivers of CSHCN Experience Stress, Poor Health, and Social Limitations**

- A majority (64%) of family caregivers of children with special needs ages 0-17 experience physical strain; 17% experience high levels of physical strain.
- Among children who live with their mothers, 52.2% of children with special health care needs (CSHCN) compared to 42% of non-CSHCN have mothers who are not in excellent or very good physical and mental health, regardless of the mother's marital status. This discrepancy between children with and without special health care needs was evident in fathers' health status as well.
- CSHCN are more than twice as likely to have a parent who reported “usually or always” feeling stressed.

**Health and Economic Benefits of Respite for CSHCN and Their Families**

- Researchers at the University of Pennsylvania studied the records of over 28,000 children with autism ages 5 to 21 who were enrolled in Medicaid in 2004. They concluded that for every $1,000 states spent on respite services...
in the previous 60 days, there was an 8 percent drop in the odds of hospitalization.\textsuperscript{38}

In addition, The Texas Task Force for Children with Special Needs in their 2011 – 2016 strategic plan developed recommendations aimed at ensuring children with behavioral crises had the supports necessary to live in families. One of the key recommendations was to provide additional respite for families as well as host families so that families could get the relief needed to regroup after a behavioral health crisis.

**Out of Home Crisis Respite Options**

In 2008 the Texas Promoting Independence Advisory Committee established an ad-hoc committee to investigate the placement of children in State Supported Living Centers and to develop improvement recommendations. One of the recommendations was the development of emergency short-term living arrangements for children of families who are in crisis. The committee recommended funding of child focused out of home respite options that could support the child during crisis stabilization, assessment, training of the family and provider, and the development of a plan to return home or to family. Children with disabilities and behavioral support needs are spending lengthy periods of time in emergency rooms (some up to weeks), months in State Hospitals, placement in State Supported Living Centers and some families are relinquishing custody of their children to the Texas Department of Family and Protective Services to get the care they need.

**START**

START is a community-based crisis prevention and intervention service model for individuals age 6 and older with intellectual and developmental disabilities (IDD) and mental health (MH) needs. START was first developed in 1988 by Dr. Joan B. Beasley and was cited as a national model in the 2002 US Surgeon General’s report on mental health disparities for people with IDD. The Center for START Services is located at the University of New Hampshire’s Institute on Disability.

Based on a review of Fiscal Year 2019 START data, the program resulted in:

- High rates of stabilization following crisis
  73\% of the 3,000 crisis contacts in FY19 resulted in individuals remaining in their current community-based setting, avoiding potential ED visits and/or psychiatric inpatient admissions.

\textsuperscript{38} (Mandell, David S., et al, 2012).
Reduced psychiatric hospitalization and ED usage
Children and adults enrolled in START programs visit the emergency department less and have fewer psychiatric hospitalizations than they did in the 12 months prior to receiving START services.

There are two START programs in Texas, Tarrant County and El Paso, that have been in operation since 2014. The goal of each program is to help people gain a higher quality of life by improving the delivery system for people with IDD and behavioral health needs. The programs have supported more than 1,000 children and adults. 301 individuals were served in 2019 and 45% of the individuals were children under the age of 18. One of the critical services offered to children and families in START is the in-home therapeutic coaching of children and families as well as the coordination of services from a START Coordinator. A 2019 evaluation of both programs can be found at the following link.39
https://www.centerforstartservices.org/locations/texas

Increased Support Following Transition from an Institutions
The Texas Health and Human Services Commission recognized the need to ensure the safe transition of individuals from State Supported Living Centers to the community by using the Home and Community-based Services waiver (HCS) and assigning individuals an appropriate Level of Need for one-year post transition. The state made a conscious decision to fund waiver services during the transition at a Level of Need 6 to ensure that the medical, physical, and behavioral needs of the individuals were met, to ensure the success of the individual, and to prevent readmission. The practice has been well received and should be extended to individuals transitioning from other institution types such as large Intermediate Care Facilities and General Residential Operations licensed by the Texas Department of Family and Protective Services.

In-Home and Family Support
In the 1980s Texas implemented and funded a program called In-Home and Family Support that provided a small stipend to individuals to pay for things that were critical to their ability to safely live in their homes and communities. The program was funded with state general revenue dollars and while the amount of money allocated to an individual served was small at no more than $3,600 per year, the impact was significant. The program was not funded by the Legislature in 2017 and was therefore the money used to pay for respite and other critical supports to children and families without access to Medicaid or waiver no longer existed.

39 https://www.centerforstartservices.org/locations/texas
Non-Educational Funds (need to rewrite or cite where this information came from)

Non-Educational Community-Based Support Services funding was created by the 74th Texas Legislature as a recognition of the need to provide supports to children and families who are at risk of residential placement for education purposes. The funds are made available to school districts annually for the provision of non-educational community-based support services to certain students with disabilities and their families so that those students may receive a free appropriate public education in the least restrictive environment according to the Texas Education Code § 29.013.

Only school districts may apply for these funds and application is a local district decision and strictly voluntary. The purpose of these funds is to provide periodic, short-term non-educational services for students receiving special education services, who are at risk of residential placement for educational purposes.

The support services include in-home family support and respite services.40

Rider 16 of Article III, Education in the Texas Education Agency Section states “Non-educational Community-based Support Services. Out of General Revenue funds appropriated for Strategy A.2.3, Students with Disabilities, $987,300 in each fiscal year is allocated to non-educational community-based support services for certain students with disabilities as authorized under §29.013 of the Texas Education Code. Any unexpended balances as of August 31, 2020, are hereby appropriated for fiscal year 2021 for the same purposes.”

The funding for the program is relatively small given the size of the Texas and has not increased since the funds were first designated by the Texas Legislature twenty-five years ago in 1995. However, even with such a great need for support to families, 29% of the appropriated funds for 2018 were returned to the state. Some regions did not request any funds while others spent all of the funds they requested.

Table 4: Non-Education Community Based Supports, 2018

<table>
<thead>
<tr>
<th>Region</th>
<th>Budgeted</th>
<th>Spent</th>
<th>Lapsed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Region 1 ESC- Edinburg</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
</tr>
<tr>
<td>Region 2 ESC- Corpus Christ</td>
<td>$1500</td>
<td>$0</td>
<td>$1500</td>
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</table>

40 https://www.esc15.net/domain/51
<table>
<thead>
<tr>
<th>Region</th>
<th>Budgeted</th>
<th>Spent</th>
<th>Lapsed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Region 3 ESC- Victoria</td>
<td>$7500</td>
<td>$5687</td>
<td>$1813</td>
</tr>
<tr>
<td>Region 4 ESC - Houston</td>
<td>$136,500</td>
<td>$96,340</td>
<td>$40,160</td>
</tr>
<tr>
<td>Region 5 ESC - Beaumont</td>
<td>$5500</td>
<td>$4235</td>
<td>$1265</td>
</tr>
<tr>
<td>Region 6 ESC - Huntsville</td>
<td>$25,000</td>
<td>$25,000</td>
<td>$0</td>
</tr>
<tr>
<td>Region 7 ESC- Kilgore</td>
<td>$20,000</td>
<td>$13,250</td>
<td>$6750</td>
</tr>
<tr>
<td>Region 8 ESC- Mt. Pleasant</td>
<td>$1000</td>
<td>$1000</td>
<td>$0</td>
</tr>
<tr>
<td>Region 9 ESC- Wichita Falls</td>
<td>$7000</td>
<td>$7000</td>
<td>$0</td>
</tr>
<tr>
<td>Region 10 ESC- Richardson</td>
<td>$136,500</td>
<td>$101,356</td>
<td>$35,144</td>
</tr>
<tr>
<td>Region 11 ESC- Ft. Worth</td>
<td>$13,950</td>
<td>$4812</td>
<td>$9139</td>
</tr>
<tr>
<td>Region 12 ESC- Waco</td>
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<tr>
<td>Region 13 ESC-Austin</td>
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<tr>
<td>Region 14 ESC- Abilene</td>
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<td>Region 15 ESC-San Angelo</td>
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<tr>
<td>Region 16 ESC - Amarillo</td>
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<td>$0</td>
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<tr>
<td>Region 17 ESC-Lubbock</td>
<td>$9250</td>
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<td>$0</td>
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<td>Region 18 ESC- Midland</td>
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<td>Region 19 ESC- El Paso</td>
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<td>$3</td>
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<tr>
<td>Region 20 ESC-San Antonio</td>
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<td>$0</td>
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<tr>
<td>Unallocated</td>
<td>$169,300</td>
<td>$0</td>
<td>$169,300</td>
</tr>
<tr>
<td>Totals</td>
<td>$987,300</td>
<td>$701,274</td>
<td>$286,026</td>
</tr>
</tbody>
</table>
This is money that could have been used to support respite care and in-home supports for children with behavioral health conditions at risk of residential placement for educational purposes. There is a need for increased outreach and education to districts, teachers, families and others about the availability of the support a simplified process to access the needed support.

The Texas Education Agency in conjunction with Regional Education Service Centers and local ISDs should develop and implement a plan to provide specific outreach about Non-Educational Community Based Support Services to families of children receiving special education services who are already placed in or at high risk of being placed in an out of home placement or a more restrictive, segregated educational setting. This includes families of children placed in a Separate School, Residential Facility, Correctional Facility, Parentally Placed in Private Schools, or children in Homebound/Hospital Placements. In addition, families of children receiving special education services who have been expelled or are placed in Disciplinary Alternative Educational placements (DAEPs) or Juvenile Justice Alternative Educational Placements (JJAEPs) should be targeted for outreach.

Table 5: Texas Placement Data- Students with Disabilities, ages 6-21

<table>
<thead>
<tr>
<th></th>
<th>2017-2018</th>
<th>2018-2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Separate School</td>
<td>2,763</td>
<td>1,989</td>
</tr>
<tr>
<td>Residential Facility</td>
<td>82</td>
<td>87</td>
</tr>
<tr>
<td>Correctional Facility</td>
<td>522</td>
<td>515</td>
</tr>
<tr>
<td>Parentally Placed in Private Schools</td>
<td>654</td>
<td>642</td>
</tr>
<tr>
<td>Homebound/Hospital Placement</td>
<td>2,150</td>
<td>2,292</td>
</tr>
</tbody>
</table>


Table 6: State Level Annual Discipline Data for 2018-2019

| Spec. ED. Students Expelled to JJAEP | 494 |
| Spec. ED. Students Expelled         | 763 |
| Spec. ED. Students in DAEP Placement | 13,768 |
| Spec. ED. Students out of School Sus. | 42,547 |

Note: Retrieved from https://rptsvr1.tea.texas.gov/cgi/sas/broker?_service=marykay&_program=adhoc.download_static_summary.sas&district=&agg_level=STATE&referrer=Download_State_Summaries.html&test_flag=&_debug=0&school_yr=19&report_type=html&Download_State_Summary=Next
Quarterly benchmarks should be required to assist Education Service Centers to track the use of funds and to inform outreach and technical assistance efforts so that special education students have access to the needed resources to be educated in the least restrictive environment. The Service Centers should provide technical assistance to districts that have not requested funds or utilized funds fully. Benchmarks should also be used to evaluate whether funds need to be redistributed to districts with greater needs prior to the end of the year.

**Respite in 1915 (c) Waivers**

Texas Medicaid waiver programs including the Community Living Assistance and Support Services waiver, the Home and Community-Based Services waiver, the Texas Home Living waiver, and the Deaf Blind with Multiple Disabilities waiver offer families 30 days of respite per year. This is not always enough to provide families the relief they need. Families dealing with the day to day challenges of raising a child with disabilities including a child with significant behavioral challenges must have access to adequate respite opportunities that allow the time needed to recover and rejuvenate as well as time needed to participate in the activities of other children. The limit on the respite benefit could be increased without increasing individual cost caps in waivers.

**Respite in the Youth Empowerment Services Waiver**

According to data from a 2012 report by the National Respite Coalition,

- An estimated 4.5 to 6.3 million children and youth in US suffer from a serious mental health condition (about 10%); about 65% to 80% of these children and youth do not receive the specialty mental health services and supports they need.\(^4\)

The Texas YES waiver supports children under 19 with serious mental health conditions to live in their homes and families. One of the key services requested by families of children with mental health conditions is respite. Families report difficulty in getting respite services needed through the YES waiver unless the family recruits and hires the respite provider. This is often difficult for families who are often stressed and distanced from family and friends due to the support needs of their child.

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\(^4\) (Substance Abuse and Mental Health Administration (SAMHSA), 2011).
Respite for Host Families in the Home and Community-Based Services Waiver (HCS)

The Host Home benefit in the HCS waiver allows for children who cannot live at home with their families to live with another family who is paid a daily rate to care for them and ensure all of their needs including their permanency needs are met. Currently host families caring for children do not have access to respite outside of the daily rate. When the model rates for the HCS host home benefit were designed years ago, the model anticipated a family needing 30 days of respite. Initially 30 days of respite was built into the rate but has not been updated to reflect the current market. Many HCS host families do not obtain respite because the rate is insufficient to pay someone to assist in the home. Additionally, 30 days is insufficient for families caring for a child who has significant behavioral support needs and might not sleep or might exhibit extreme aggression. An additional 30 to 60 days of respite provided outside of the host home rate would help to ensure that host families have access to respite needed and to ensure children do not bounce from family to family. The HCS host family placement is likely to breakdown if the families caring for children with significant behavioral support needs do not get additional supports.

Policy Issue: Continuity of Member Care Emergency Response during COVID-19

PCCF members recommend a process that ensures members and families are informed of the specific emergency impacting members and communities. Committee members also recommend an emergency response plan that adequately addresses pandemic or other public health crisis, environmental and/or natural disaster response issues. The Continuity of Member Care Emergency Response Plan (COMCER) recommendations were developed to incorporate committee recommendations into HHSC’s disaster response plan.

Recommendation

Ensure that the COMCER Plan includes standardization amongst MCOs/HHSC for member and provider involvement and access.

1. Recommend that the COMCER Plan include a process for pandemic or identified public health emergency, and environmental/natural disasters for MCOs that provides commonality amongst MCO requirements.
2. COMCER plan should address issue(s) of HHSC extension and flexibility (even eligibility component) not on monthly basis but for extended period based on the longevity of the emergency response needed.

Key components include:
Exercises with providers serving medically fragile populations, such as Nursing Facilities.
Exercises should be designed to engage family, MCO staff, and other relevant stakeholders to work together to manage the response to a hypothetical incident.
MCOs must make adjustment to plans upon identifying needs through exercises, upon experiencing a disaster, or learning new information about outside resources.
Membership including key stakeholders to work together to manage the response to a hypothetical incident.
Disaster specific assessment developed by HHSC for MCOs to complete during disaster/pandemic (i.e. COVID assessments, SDOH, environmental assessments etc.).

3. HHSC should provide important elements on a defined template which MCO will report members impacted and services delivered during disaster and publish the report indicators.
4. MCO’s develop a team dedicated for response to include (suggestions):

- **Pandemic Response Coordinator**: Point of Contact for the Health Plan-a person who can answer all questions or refer to the point of contact within each dept. -- regarding MCO employee or system issues, member issues, providers impacted, and process changes during the pandemic.
- **MCO Education and Training**: (Member engagement) Person who will provide member education on the pandemic. Can produce short videos on different topics (YouTube): proper hand-washing, how to properly apply a face mask/covering, what to use in the event you don’t have a surgical mask, how to properly use hand sanitizer, infection control in their home, how to prepare
- **Network Resources** – MCOs to identify a key network representative who can serve in and out of network providers during the emergency response period.

**Background**

The COMCER plan must be based on a risk assessment for each service area in which the MCO operates. Dental Contractors must complete a statewide risk assessment because their Service Area is the entire state). The COMCER plan must address, at a minimum, the following:

1. The method used to ensure that Members are able to see Out-of-Network provides if Members are unable to access Covered Services from in Network Providers
2. The method used to ensure that prior authorizations are extended and transferred without burden to providers not previously serving the Member, when Members or Providers are displaced
3. The method used to ensure that claims will be accepted from providers within an extended deadline
4. The method used to allow providers who complete a simplified provider enrollment application to temporarily enroll in Medicaid, to submit claims, and for the MCO to process claims
5. The method used to allow pharmacies who complete an HHSC Vendor Drug Program Temporary Pharmacy Agreement form to submit claims, and for the MCO to process claims
6. The method used to track and monitor Members who reside in Nursing Facilities that have been evacuated, and to provide support to evacuating and accepting facilities proactively and as needed
7. The method by which the MCO will pay the evacuating Nursing Facility the full, contracted rate for services rendered by the accepting facility, even if the accepting facility is out-of-network or a non-Medicaid provider
8. The method by which the MCO/Pharmacy Benefit Manager claims system will waive edits or allow override of edits by at least Zip code for specific date ranges
9. The method used to ensure that CHIP co-pays including pharmacy, are not collected for a specific duration
10. The method by which the MCO will communicate with its contracted LTSS providers, including home and community support services agencies, assisted living facilities, adult foster care settings, nursing facilities, and MDCP and STAR+PLUS Waiver providers
11. The method by which the MCO will track and monitor the status of the delivery of LTSS for Members impacted by the disaster including those with the Consumer Directed Services (CDS) option.
12. The method by which MCOs will track impacted members and providers and report status of access to services and impacted areas to HHSC. Development and implementation of a standardized reporting template to ensure all MCOs are consistent in reporting emergency impact and response actions.
13. A method by which HHSC will ensure access to impacted areas and programs to the Medicaid community

The COMCER plan must include the actions the MCO will take and the objective the action(s) are trying to achieve. Objectives should include requirements listed in this section and any additional objectives required by the state or decided upon by the MCO.
MCOs will continue to make their COMCER plan available to members and implement a process to ensure members and providers are notified when a COMCER plan is activated. In addition, MCO’s should have the Service Back up Plan (Form 1740).

During any disaster, HHSC may work with state and federal partners to invoke any flexibilities listed above, or other flexibilities as needed. Flexibilities will be invoked for a specific geographic area and a specific timeframe, as identified by HHSC and in accordance with state and federal declarations, if applicable. MCOs must operationalize any flexibilities invoked by HHSC and in accordance with HHSC guidance to include coordinated response with Employers and FMLA’s of CDS.

MCOs must coordinate with local emergency management when creating COMCER plans immediately prior to, if the event is expected, and during an event to the extent possible. MCOs must identify plans to escalate needs through local emergency management, and mechanisms for assistance at the local level. Mechanisms for assistance at the local level may include resources for Members or Providers who reach MCO staff, such as:

1. Search and rescue contacts;
2. Emergency shelter contacts;
3. Information on applications to local, state, and federal resources for housing and food assistance;
4. Information on mental health resources including and beyond the MCOs provider network;
5. Any other resources deemed relevant to MCO contact with Members and Providers by the MCO and local emergency management.

**COMCER plans should address** procedures for assisting in the evacuation of bedridden and medically fragile Medicaid members via ambulance if necessary. COMCER plans should have a primary and secondary response plan in the event that the disaster does not allow for certain actions to be carried out. For example, MCOs should have a plan and backup plan if call center operations need to be temporarily moved if MCO staff are unable to report to work for a significant amount of time, and for other scenarios the MCO foresees as potentially disrupting day to day operations that impact Members and Providers.

**COMCER plans must also include key contacts within the MCO and organizations** with which the MCO will interact during a disaster, such as local emergency management and long-term care facility personnel. Contact information should include contact numbers that will be reachable in the event of an emergency, and email addresses.
16.1.13.3 Exercising of Plans and Updates:

MCOs must conduct disaster recovery, business continuity, and COMCER plan exercises at least annually, and should include in the exercises LTSS and other providers serving medically fragile populations, such as Nursing Facilities. Exercises should be designed to engage MCO staff and other relevant stakeholders to work together to manage the response to a hypothetical incident. MCOs must make adjustment to plans upon identifying needs through exercises, upon experiencing a disaster, or learning new information about outside resources.

16.1.13.4 MCO Communication with HHSC

MCOs must be able to communicate with HHSC on a daily basis or other interval, as set by HHSC, for a set period of time during a disaster and upon recovery from the disaster. MCOs must work with HHSC to gather and report on key information, such as Member location for Nursing Facility residents, provider network capabilities post-disaster, and other needs as identified by HHSC. At a minimum, MCOs should be able to communicate with HHSC:

- What the disaster is
- The date(s) of the event
- If any of their Members were affected, and if so, how many were affected
- If Members needed to be moved, and if so where they were moved
- If Members needed to be moved, and if so, where they were moved
- After action reviews to evaluate strengths and areas for improvement may be requested by HHSC after disasters. An after-action review is a candid, professional discussion and review of disaster response and recovery activities reviewing what happened, why it happened, and how to sustain strengths and improve on weaknesses.

Policy Issue: Ensure Proactive Communication and Involvement for Families utilizing Medicaid during COVID-19

During a state of natural, environmental, of health-related pandemic, communication can be overwhelming. For families eligible for Medicaid/Chip Services, it is essential that families receive clear, concise, and deliberate communication that is quick and accessible. Some of the challenges that affect communication with consumers include:

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Studies indicate many of the challenges are based on timeliness of information received, literacy to process information, access to information, and confusion between the role of providers, managed care organization, and HHSC.

**Recommendation**

To develop a multi-prong approach for consumers that is flexible. This ensures clients are provided clear direction on where to receive information and the channels to receive it during a pandemic, environmental or natural disaster are updated.

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

1. MCO communication to members through the following
   a. Website (English/Spanish)
   b. Member Advisory Committees
   c. Service Coordination/Service Management
   d. Texting (English/Spanish)
   e. Recorded Message (English/Spanish)
2. 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; and
   - Emergency contact information.
3. MCO communication to members through website, through advisory committees within MCO, and service coordinator available to educate families.

**Background**

Both HHSC and MCOs choose websites as the most proactive way to update information for a consumer. However, there is no evidence that states, in times of
need, clients go to the website to review service needs, authorizations, eligibility, etc. Multiple channels of communication will eliminate the following challenges:

- Literacy level of website.
- Website access may be limited because of cellular phone tower damage in a disaster that leads to a loss of overall service (phone, internet).
- Families may lack internet access because they have landlines or very simple mobile phones.
- Websites have a lot of information and bring “information overload to the consumer.”

The best practices will include identifying ways to communicate and educate families, providers, and MCOs.

1. HHSC driving scheduled (prearranged content) based on level of disaster/pandemic. This communication should be proactive with families, MCOs, and Providers. This can be accomplished through our workgroup.
2. Recommendations standardization of language (prior to events): All parties above should send out the same communication through different modalities (texting, email, letters, websites, recorded messages, etc.).
3. Add a tab on COMCER plan to have members review online.
4. Virtual/Face to Face Town hall meeting for members/families bi-weekly from HHSC.

Policy Issue: Changes to MDCP Waiver during COVID-19

The Medically Dependent Children Program waiver allows children who qualify for a nursing facility level of care to receive supports and services in their homes and communities. The MDCP waiver is one of the oldest waivers in Texas and has provided support to thousands of Texas children and families. Children in the waiver have complex health care needs. Some require mechanical ventilation to breathe, others require life sustaining nourishment through a gastrostomy tube, and others need intensive medical interventions on a regular basis.

At the beginning of the COVID-19 pandemic, several key issues arose for children in the MDCP waiver that need a long-term fix. This includes extending annual authorizations and plans of care for children currently enrolled in the MDCP waiver program by 12 months or longer depending on the length of the pandemic as well as ensuring children whose names rise to the top of the waiver interest list or children at imminent risk of nursing facility admission, have access to waiver services.
Recommendation

1. Extend MDCP plans of care that expired during the COVID19 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.

Background

Extensions of MDCP plans of care

Texas successfully secured approval from the Centers for Medicare and Medicaid Services through an Appendix K waiver application to extend MDCP plans of care that expired during the COVID 19 pandemic by 12 months. The provision allowed HHSC to authorize extensions for those children without requiring the Managed Care Organizations to perform face-to-face annual reassessments which could have unnecessarily led to COVID 19 exposure. HHSC authorized plan extensions on a 90-day basis through September 2020 and then made the key decision to authorize plans expiring March through November 2020 for 12 months. The 12-month extension should be applied to all plans expiring during the term of the pandemic.

Amending the MDCP waiver to allow for diversion from nursing facility admission

The MDCP waiver does not currently have a mechanism to allow children with extensive medical complexity to be diverted from a nursing facility. In order for children with medical fragility to get critical medical supports needed to remain at home, children either have to wait on a waiting list for years or be placed in a nursing home. For more background on this recommendation, please see page 38 of the report, MDCP Nursing Facility Stay Requirement.

MDCP Reassessments and Initial Assessments via Telehealth

The use of telehealth has expanded significantly during the COVID 19 pandemic and has become a recognized valuable mechanism to get care and supports safely to children and families. The STAR Kids Screening and Assessment Instrument is a tool that is administered annually to children receiving services through the MDCP waiver and to children entering the waiver from the interest list or from a nursing facility stay. Due to the pandemic, the release of waivers was stopped and children whose names reached the top of the interest list waited longer for services. In the
summer, HHSC started allowing Managed Care Organizations to conduct initial assessments via telehealth. While a face-to-face assessment may be optimal, telehealth assessments offer a safe alternative and should continue to be allowed throughout the course of the pandemic and perhaps even after the pandemic is over.

Policy Issue: Expansion of Telemedicine during COVID-19

Telehealth has been invaluable to families of children with disabilities during COVID and the flexibilities should be made permanent as well as better pay parities. We agree with the recommendations made by the E-Health Advisory Committee on telehealth extensions. Telehealth also provides immediate access for medically fragile children who may have access issues due to being in rural areas, but also to allow for visual and audio observation, diagnostics, therapeutic interventions, and family and provider consultation and education without waiting for an in-person visit. Benefits of telehealth include live audio-visual patient-provider conferencing, patient-provider education, remote patient monitoring, reduced exposure for medically fragile children, and immediate access which can often defer emergency room and urgent care visits and further complications. As a result of the Coronavirus pandemic, telehealth has evolved from being a side feature to an expectation, standard and necessity for health care delivery systems.

Recommendation

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 a telehealth benefit for children with home health intermittent nursing services (in addition to therapy) and behavioral health (Example: assessing patient status through parent questioning, patient observation, troubleshooting, and parent/family caregiver teaching).
4. Recommend that telehealth become a standard alternative for Medicaid and other state programs during times of pandemic/disaster for all “non-essential” home visits where ‘hands-on’ interventions are not absolutely needed.
5. Ensure families have access to technology and equipment and add diagnostic equipment funding for telemedicine at home. The quality of broadband varies, especially in rural areas and funding to allow for better equipment or
services is recommended, especially for families with medically fragile children who difficulty with accessing telemedicine.

6. Consider language barriers with access to telemedicine, such as software for translation or translation services.

7. Allow funding for telehealth technology remote patient monitoring and diagnostics for community partnerships with the school nurse and other health care professionals that will utilize diagnostic tools, such as checking temperatures and other diagnostic readings, to be transmitted.

**Background**

Prior to the Coronavirus pandemic, telehealth pilots were primarily focused on adult populations who had primary diagnoses of diabetes and hypertension. Telehealth has not historically been authorized as a primary care or home health benefit for children with Medicaid or other state programs. The benefits of telehealth for children include long-distance contact with parents and family caregivers, care, advice, reminders, education, intervention, monitoring, and remote admissions. Telemedicine as a benefit of telehealth can facilitate remote clinical services, such as diagnosis and monitoring through audio and visual technology. Barriers to accessing telehealth for medically fragile children include living in rural settings and lacking mobility or reliable transportation and limited funding for equipment to support telehealth. As a result, access to care is often restricted. Telehealth may bridge the gap and improve access through provider distance-learning, visual demonstration, supervision, and coordination of care between practitioners, online information and health data management, and healthcare system integration. Live audio-visual links through telehealth allow health professionals to connect and distribute information quickly and accurately in response to natural disasters, acts of terror and pandemics providing the ideal platform to for rapid dissemination of clinical guidelines for providers on the front lines of pediatric care.43

Telemedicine in general can facilitate less urgent medical consultations with many of the same advantages of emergency and urgent care consultations for children because it is ‘immediate’ and ‘timely’ for when consultation is needed. In other words, no waiting for an appointment and the observation is ‘in the moment’ when symptoms are present.44


Exposure to others is eliminated through telehealth and this is especially beneficial to the medically fragile pediatric population, who are often immunocompromised and have difficulty leaving home without medically assisted transports.

Medical devices that are FDA approved have the capability to auscultate heart, abdomen and lung sounds and transmitting diagnostic readings such as an oxygen saturation, blood pressure, heart rate, measuring body temperature and visual imaging for observation of the ear canal for ear symptoms and the throat.45

Addressing behavioral health disorders through telehealth has been shown to be beneficial and the SUPPORT for Patient and Communities Act requires guidance to states regarding reimbursement under Medicaid for substance abuse, mental health disorders, and behavioral health disorders.46

46 H.R. 6 – SUPPORT for Patient and Communities Act. CONGRESS.GOV., Internet: https://www.congress.gov/bill/115th-congress/house-bill/6/text?q=%7B%22search%22%3A%22SUPPORT+opioid%22%5B%22SUPPORT+Act+opioid%22%5D%7D&r=3&s=6
5. Conclusion

The Policy Council for Children and Families would like to thank you for your time and attention. We know that you have many demands on your time and attention, and we appreciate the work that you do to give all Texas children and their families a fulfilling and meaningful life.

These children and families face repeated and significant obstacles to receiving timely and quality-based care, especially in times of crisis whether it be a medical or family crisis or state or federal crisis. Parent and guardians of disabled and special needs children spend great amounts of time coordinating care across multiple providers and venues. The PCCF is asking you to carefully consider the recommendations discussed in this report, which are focused on improved delivery of medical & crisis care, improved access to medical and support systems to meet the varied complex needs of this vulnerable population and most importantly, promote independence and home based care where these children can live and grow up in family-centric environments. The best place for these children is at home with medical and social services that allow for the highest quality of life.

Figure 8: Olivia enjoying the outdoors.
### 6. List of Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Full Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
</tr>
<tr>
<td>CHIP</td>
<td>Children’s Health Insurance Program</td>
</tr>
<tr>
<td>CLASS</td>
<td>Community Living Assistance and Support Services</td>
</tr>
<tr>
<td>CMS</td>
<td>Centers for Medicare and Medicaid Services</td>
</tr>
<tr>
<td>CPC</td>
<td>Children’s Policy Council</td>
</tr>
<tr>
<td>CSHCN</td>
<td>Children with Special Healthcare Needs</td>
</tr>
<tr>
<td>DARS</td>
<td>Texas Department of Assistive and Rehabilitative Services</td>
</tr>
<tr>
<td>DFPS</td>
<td>Texas Department of Family and Protective Services</td>
</tr>
<tr>
<td>ECI</td>
<td>Early Childhood Intervention</td>
</tr>
<tr>
<td>GAA</td>
<td>General Appropriations Act</td>
</tr>
<tr>
<td>GRO</td>
<td>General Residential Operations</td>
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<tr>
<td>HCS</td>
<td>Home and Community-based Services</td>
</tr>
<tr>
<td>HHSC</td>
<td>Health and Human Services Commission</td>
</tr>
<tr>
<td>HIPP</td>
<td>Health Insurance Premium Payment</td>
</tr>
<tr>
<td>ICF</td>
<td>Intermediate Care Facilities</td>
</tr>
<tr>
<td>ICF/IID</td>
<td>ICF for Individuals with Intellectual Disabilities</td>
</tr>
<tr>
<td>IDD</td>
<td>Intellectual and Developmental Disability</td>
</tr>
<tr>
<td>Acronym</td>
<td>Full Name</td>
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<tr>
<td>-----------</td>
<td>---------------------------------------------------------------</td>
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<tr>
<td>IDD SRAC</td>
<td>Intellectual and Developmental Disability System Redesign</td>
</tr>
<tr>
<td></td>
<td>Advisory Committee</td>
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<tr>
<td>IDEA</td>
<td>Individuals with Disabilities Education Act</td>
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<tr>
<td>IID</td>
<td>Individuals with Intellectual Disabilities</td>
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<tr>
<td>LEA</td>
<td>Local Education Agencies</td>
</tr>
<tr>
<td>LTSS</td>
<td>Long-Term Services and Supports</td>
</tr>
<tr>
<td>MCO</td>
<td>Managed Care Organization</td>
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<tr>
<td>MDCP</td>
<td>Medically Dependent Children Program</td>
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<tr>
<td>PCCF</td>
<td>Policy Council for Children and Families</td>
</tr>
<tr>
<td>SB</td>
<td>Senate Bill</td>
</tr>
<tr>
<td>SPED</td>
<td>Special Education</td>
</tr>
<tr>
<td>SSI</td>
<td>Supplemental Security Income (Social Security)</td>
</tr>
<tr>
<td>SSLC</td>
<td>State Supported Living Center</td>
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<tr>
<td>TEA</td>
<td>Texas Education Agency</td>
</tr>
<tr>
<td>YES</td>
<td>Youth Empowerment Services</td>
</tr>
<tr>
<td>COMCER</td>
<td>Continuity of Member Care Emergency Response</td>
</tr>
</tbody>
</table>
## 7. Appendix: Overview of Recommendations

### Policy Issue: Continued funding of The Transition Clinic at Baylor College of Medicine / Texas Children Hospital and funding mechanism for the development of additional transition clinics across Texas

<table>
<thead>
<tr>
<th>Recommendations</th>
<th>Action Required</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Continue use of DSRIP funding until it is no longer available. This includes continued DSRIP funding to the current Transition Clinic which provides enhanced patient care, continuity of care and better outcomes for this complex population.</td>
<td>Legislative, Budgetary, CMS Approval TEA/HHSC collaboration</td>
</tr>
<tr>
<td>2. Develop a start-up funding source for Transition Clinics in all the major metropolitan areas of the state and include enhanced patient care and proven outcomes for this complex population. Look to develop Transition Clinics in conjunction to or in addition to existing pediatric complex care clinics.</td>
<td>Legislative, Budgetary</td>
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<tr>
<td>Recommendations</td>
<td>Action Required</td>
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<tr>
<td>3. Funding options for continued operations of the Transition Clinic in Houston and development of new transitions clinics could include:</td>
<td>Legislative, Budgetary</td>
</tr>
<tr>
<td>a. Transition DSRIP funding to managed care with goals aligned through a direct payment model. The directed payment model should be based on the Missouri Medicaid Access to Physician Services (MAPS) program, which includes quality reporting and monitoring activities. The size of the funding pool will be determined before each capitation rate year and will be based on factors such as anticipated utilization and the expected rate increase for certified Transition Clinics. MCO will pay providers contracted rates, and then quarterly incentive payments from the pool (calculated by the state based on actual utilization). Actuaries calculate the final capitation rates based on actual utilization data following the fourth quarter of the rate year.</td>
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<tr>
<td>b. Create a “capacity building pool” similar to the North Carolina 1115 Waiver pool, which will fund infrastructure and system start-up costs for new Transition Clinics for the first two years of the pilot program.</td>
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<tr>
<td>c. In addition to the capacity building and directed payment pools, the pilot program can include alternative payment model strategies tied to quality outcomes, such as shared savings for reductions in inpatient admissions.</td>
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<td>4. Develop in-house shared service coordination models with health plans to provide better health outcomes. This can include:</td>
<td>Legislative, HHSC Policy, CMS Approval</td>
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<tr>
<td>• Includes face to face visits with health plan service coordinator to provide better coordinated care.</td>
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<td>• Include weekly case conferences to identify any barriers.</td>
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<td>• Includes coordination with other health plans on coordination of benefits; coordination with other case managers; and alignment with networks.</td>
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<td>• Follow-up with specialty physicians and other providers to get pre-authorizations completed.</td>
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<td>• Serves as resource for clinic including any training needed such as covered benefits, transitioning for members aging out, etc.</td>
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<tr>
<td>• Monitor member outcomes.</td>
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</table>
## Policy Issue: Building Provider Capacity and Training for Adult Transition Clinics

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Action Required</th>
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<tbody>
<tr>
<td>1. Ensure continued funding for the only transition clinic as a means to</td>
<td>Legislative, Budgetary</td>
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<tr>
<td>continue one-on-one education of future medical professionals.</td>
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<td>2. Allow telemedicine consultative services to continue beyond the COVID-19</td>
<td>Legislative, Budgetary</td>
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<tr>
<td>pandemic as a way to improve access to health care providers specializing in</td>
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<td>treating children and adults with disabilities, possibly reducing wait times</td>
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<td>for new patients from referral time to time of first visit.</td>
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<tr>
<td>3. Increase capacity to train providers already in practice.</td>
<td>Legislative, Budgetary</td>
</tr>
<tr>
<td>a. Provide funding to create programs similar to those found in child</td>
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<tr>
<td>psychiatry to assist local medical providers currently in practice with</td>
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<td>access to resources and education in real-time.</td>
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<tr>
<td>i. Establish Project ECHO (Extension for Community Healthcare Outcomes) for</td>
<td></td>
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<tr>
<td>Pediatric to Adult Care Transitions</td>
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<tr>
<td>1. Project ECHO originated in 2003 at the University of New Mexico Health</td>
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<td>Science Center and was formed to allow dissemination of knowledge from</td>
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<td>academic centers to rural area providers.</td>
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<td>2. Incorporate CME of interest to both adult and pediatric care providers</td>
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<td>for this patient population in a virtual context.</td>
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<td>3. Establish a mentoring forum for providers interested in providing/receiving</td>
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<td>such training.</td>
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<td>4. Establish a CPAN-like network for complex care access centers.</td>
<td>Legislative, Budgetary, HHSC Policy</td>
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<tr>
<td>i. Assist with assessment and treatment of medical illnesses related to or</td>
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<td>complicated by underlying chronic conditions.</td>
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<tr>
<td>ii. Assist with identifying community resources for those impacted by complex</td>
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<tr>
<td>medical needs.</td>
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<td>iii. Provide didactic information to providers with regards to details</td>
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<td>related to congenital or childhood-onset chronic illness.</td>
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<tr>
<td>iv. Provide these services within a real-time setting, affording local</td>
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<tr>
<td>medical care providers the ability to</td>
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</tr>
<tr>
<td>Recommendation</td>
<td>Action Required</td>
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</tbody>
</table>
| request consultative services with a complex care specialist at the time of need. 1. Services are requested by phone call made to main network hotline during regular clinic hours. 2. Trained staff are available for information and/or consultation within minutes to answer the incoming request(s).  
  a. Staff include:  
    i. Network coordinator to answer basic questions and triage calls.  
    ii. Social work specialists to provide information on access to programs and other social networks/benefits for individuals with special needs.  
    iii. Clinician (physician, nurse practitioner, etc.) to provide guidance on clinical management inquiries. | Budgetary       |
| 5. Increase provider capacity by providing training through:  
  a. Allocate funding to teaching hospitals to provide more training positions (or develop new programs) for Internal Medicine-Pediatrics Residency Programs.  
  b. Special funding to Family Medicine Residency Programs who include added competencies regarding congenital and childhood-onset chronic conditions in their training programs. |                 |
## Policy Issue: Improve Access to Medicaid Insurance for Children with Disabilities

<table>
<thead>
<tr>
<th>Recommendations</th>
<th>Action Required</th>
</tr>
</thead>
</table>
| 1. Reduce the MDCP interest list by  
  a. allowing children who have SSI and meet nursing facility level of care to receive Medically Dependent Children Program waiver services with no wait; and  
  b. funding of MDCP waiver services for the approximately 575 children who do not have SSI or Medicaid and are waiting for critical medical and long-term supports for their children. | Legislative, Budgetary, HHSC policy/contract changes |
| 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. | Legislative, Budgetary |
| 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. | Legislative, Budgetary |
| 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. | Legislative, Budgetary |
### Policy Issue: Ensure Children with Disabilities Grown Up in the Families

<table>
<thead>
<tr>
<th>Recommendations</th>
<th>Action Required</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
<td>Legislative, Budgetary</td>
</tr>
<tr>
<td>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.</td>
<td>Legislative, Budgetary</td>
</tr>
<tr>
<td>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.</td>
<td>Legislative, Budgetary</td>
</tr>
<tr>
<td>4. Increase funding to support a 10% reduction of Medicaid waiver interest lists.</td>
<td>Legislative, Budgetary</td>
</tr>
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</table>

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

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Action Required</th>
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</table>
| 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:  
  a. Adequate time to assess the child | Legislative, Budgetary  |
Recommendation | Action Required
---|---
b. Development of a plan for appropriate supports for the child to return home or move to another family-based alternative including additional respite and direct support. | 
c. Supports in the respite setting to care for children with complex behavioral support needs including additional staff if needed. | 

2. Continue funding of the Texas START programs in Tarrant County and El Paso and increase the amount of funds to each site to for allow expansion to additional counties. Current START coordinators should be funded to serve as mentors to coordinators in the newly added counties. Critical services for this population of children include in-home therapeutic coaching of families, coordination of START services and clinical services. | Legislative, HHSC

3. Create a funding mechanism for the services above including 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. | Legislative, Budgetary

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. | HHSC Policy

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

Recommendation | Action Required
---|---
1. Reinstate the In-Home and Family Support program as a mechanism to fund respite services for families whose children do not have Medicaid. | Legislative, Budgetary

2. Ensure access to non-educational funds for children at risk of residential placement through improved outreach, service benchmarks for Local Education Agencies, and an increase in the amount of funds designated for schools to allow schools to fund respite for families in need. | Legislative, Budgetary
<table>
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<tr>
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<tbody>
<tr>
<td>3. Amend the home and community-based waivers to allow an additional 30 to 60 days of respite per year. This includes the HCS, CLASS, YES, Texas Home Living and DBMD waivers.</td>
<td>Legislative</td>
</tr>
<tr>
<td>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.</td>
<td>HHSC Policy</td>
</tr>
<tr>
<td>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.</td>
<td>HHSC Policy</td>
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**Policy Issue: Continuity of Member Care Emergency Response during COVID-19**

<table>
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<tr>
<th>Recommendation</th>
<th>Action Required</th>
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<tbody>
<tr>
<td>1. Recommend that the COMCER Plan include a process for pandemic or identified public health emergency, and environmental/natural disasters for MCOs that provides commonality amongst MCO requirements.</td>
<td>Legislative, Budgetary</td>
</tr>
<tr>
<td>2. COMCER plan should address issue(s) of HHSC extension and flexibility (even eligibility component) not on monthly basis but for extended period based on the longevity of the emergency response needed. Key components include: • Exercises with providers serving medically fragile populations, such as Nursing Facilities. • Exercises should be designed to engage family, MCO staff, and other relevant stakeholders to work together to manage the response to a hypothetical incident. • MCOs must make adjustment to plans upon identifying needs through exercises, upon experiencing a disaster, or learning new information about outside resources. • Membership including key stakeholders to work together to manage the response to a hypothetical incident. • Disaster specific assessment developed by HHSC for MCO’s to complete during disaster/pandemic (i.e. COVID assessments, SDOH, environmental assessments etc.).</td>
<td>Legislative, Budgetary</td>
</tr>
</tbody>
</table>
**Recommendation**

3. HHSC should provide important elements on a defined template which MCO will report members impacted and services delivered during disaster and publish the report indicators.

**Action Required**

Legislative

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**Recommendation**

1. MCO’s develop a team dedicated for response to include:

   - **Pandemic Response Coordinator:** Point of Contact for the Health Plan—a person who can answer all questions or refer to the point of contact within each dept. - regarding MCO employee or system issues, member issues, providers impacted, and process changes during the pandemic.

   - **MCO Education and Training: (Member engagement)** Person who will provide member education on the pandemic. They can produce short videos on different topics (You Tube): proper hand-washing, how to properly apply a face mask/covering, what to use in the event you don’t have a surgical mask, how to properly use hand sanitizer, infection control in their home, how to prepare

   - **Network Resources** – MCOs to identify a key network representative who can serve in and out of network providers during the emergency response period.

   **Action Required**

HHSC Policy, HHSC/DSHS Communications

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**Policy Issue: Ensure Proactive Communication and Involvement for Families utilizing Medicaid during COVID-19**

**Recommendation**

1. MCO communication to members through the following
   a. Website (English/Spanish)
   b. Member Advisory Committees
   c. Service Coordination/Service Management
   d. Texting (English/Spanish)
   e. Recorded Message (English/Spanish)

**Action Required**

Legislative, Budgetary
Recommendation | Action Required
--- | ---
2. 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; and
   • Emergency contact information. | Legislative, Budgetary

3. MCO communication to members through website, through advisory committees within MCO, and service coordinator available to educate families. | HHSC Communications

**Policy Issue: Changes to MDCP Waiver during COVID-19**

<table>
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<tr>
<th>Recommendations</th>
<th>Action Required</th>
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</table>
| 1. Extend MDCP plans of care that expired during the COVID19 pandemic by 12 months as allowed in Texas’ CMS approved Appendix K. | Legislative, Budgetary, HHSC policy/
| 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. | Legislative, Budgetary |
| 3. Allow for the MDCP initial assessments and annual reassessments to be conducted via telehealth. | Legislative, Budgetary |
# Policy Issue: Expansion of Telemedicine during COVID-19

<table>
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<tr>
<th>Recommendations</th>
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<tbody>
<tr>
<td>1. Identify technology that is user friendly across Texas.</td>
<td>Legislative, Budgetary</td>
</tr>
<tr>
<td>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.</td>
<td>Legislative, Budgetary</td>
</tr>
<tr>
<td>3. Authorize a telehealth benefit for children with home health intermittent nursing services (in addition to therapy) and behavioral health (Example: assessing patient status through parent questioning, patient observation, troubleshooting, and parent/family caregiver teaching).</td>
<td>Legislative, Budgetary</td>
</tr>
<tr>
<td>4. Recommend that telehealth become a standard alternative for Medicaid and other state programs during times of pandemic/disaster for all ‘non-essential’ home visits where ‘hands-on’ interventions are not absolutely needed.</td>
<td>HHSC Policy</td>
</tr>
<tr>
<td>5. Ensure families have access to technology and equipment and add diagnostic equipment funding for telemedicine at home. The quality of broadband varies, especially in rural areas and funding to allow for better equipment or services is recommended, especially for families with medically fragile children who difficulty with accessing telemedicine.</td>
<td>Legislative, Budgetary</td>
</tr>
<tr>
<td>6. Remove language barriers to accessing telemedicine; for example, providing translation software and/or translation services.</td>
<td>Budgetary, HHSC Policy</td>
</tr>
<tr>
<td>7. Fund telehealth technology, remote patient monitoring, and home-based diagnostics through community partnerships with the school nurse and other health care professionals.</td>
<td>Budgetary, HHSC Policy</td>
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