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

As Required by
House Bill 1478, 77th Legislature,
Regular Session, 2001

Policy Council for Children and Families
November 2024

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1. 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://www.hhs.texas.gov/about/leadership/advisory-committees/policy-council-children-families.

Report Date

November 2024

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2. Letter from the Chair

To the Texas Legislature and Health and Human Services Commission (HHSC) Executive Commissioner Cecile Erwin 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 PCCF by the HHSC Executive Commissioner.

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

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

Some of the recommendations in this report include:

- Improved opportunities for early childhood development and childcare.
- Stronger educational support for children with disabilities.
- Increased opportunities for post-secondary education and support.
- Better in-home support for children, parents, and families.
- Improved access and better healthcare coordination.
- Improved access to community support for children involved in the juvenile justice system.

The life-trajectory of a 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. Implementing these recommendations will ensure Texas children with disabilities grow up to live fulfilling, meaningful lives and are actively engaged, contributing members in their communities. The PCCF respectfully requests your consideration of and support for the recommendations included in this report.

Respectfully,

Lisa Gore, M.S. CCC-SLP

Chairperson of the Policy Council for Children and Families

Message from the family members of the Policy Council for Children and Families

Every family member serves a role in improving the quality of life for an individual with a disability. As such, we know that:

- Increasing the capacity for self-determination ensures that one day people with disabilities may exercise control over their own lives.
- Children with disabilities can access information and deserve a voice in the policymaking process.
- Family members of Texans with disabilities and other representatives can influence the policymaking process by promoting opportunities for disability-related advocacy.
- Inclusive classrooms benefit all students, not only students with disabilities.
- Access to outpatient mental health services is important. The odds of attempted suicide among adolescents with disabilities are 3.5 times higher than adolescents without disability.[1]
- People with disabilities are twice as likely to experience violent crime and abuse than people without disabilities. Barriers to accessing services make it difficult for people with disabilities to report abuse and seek intervention.
- Respite care improves caregiver resilience. Community funding or other alternative modes of funding are necessary to support families with respite care.
- Being committed to educating key decision-makers about the impact their decisions can have on the lives of Texans with disabilities and their families is critical.

Moreover, our elected Texas representatives share this responsibility by:

- Understanding that disability knows no boundaries. It is non-partisan, non-discriminatory and cuts across lines of political party, income, race, religion, and culture.
- Ensuring policies in Texas have a positive impact on the lives of children and families with disabilities.
- Including Texans with disabilities and their families in policymaking. Thank you for your dedicated time serving as our elected officials!

[1] Tally, Moses. (2017). Suicide attempts among adolescents with self-reported disabilities. Child Psychiatry and Human Development. https://pubmed.ncbi.nlm.nih.gov/29030735/

3. About the Policy Council for Children and Families

Since its creation in 2001, the PCCF 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 negatively impacts children'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 (HCBS) 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 a world where all children can achieve their potential.

Policy Council for Children and Families Membership

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Jolene Sanders, Vice Chair
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Acknowledgements

We would like to thank the families and individuals who generously shared their stories and photos in this report. We would also like to thank the subject matter experts who shared their knowledge and expertise.

4. Executive Summary

The PCCF is a voice for families of children with disabilities in Texas. As the population of Texas continues to grow, so will the need to provide support that empowers 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 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.

PCCF has released several reports since its establishment in 2001. The last biennial report, written in 2022, included recommendations to fund current and expand additional transition clinics across Texas; build provider capacity and training for adult transition clinics; improve access to Medicaid for children with disabilities; ensure children with disabilities grow up in families instead of institutions; 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; increase access to respite services for families of children with disabilities to strengthen and support families to remain together; maintain continuity of member care emergency response during the federal Public Health Emergency (PHE), ensure proactive communication and involvement for families utilizing Medicaid during the federal PHE, including changes to Medically Dependent Children Program (MDCP) waiver during the federal PHE and expansion of telemedicine during the federal PHE. These recommendations informed discussion and legislation when the Texas Legislature met in 2023.

Building on its 2022 report, the PCCF's 2024 biennial report includes the following recommendations, 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).

5. PCCF Recommendations

Research shows that growth and development are more rapid in the early years of life. The earlier delays are identified and addressed, the greater the chance of eliminating them and/or reducing the need for future services. Early high-quality service to children with significant developmental delays and their families vastly improves the future outcomes for children and offers families the information and skills they need to help increase their child's potential.

Early Childhood Recommendations

Childcare

Promote access to inclusive, high-quality childcare for children with disabilities and developmental delays.

1. Revise childcare licensing minimum standards to require that childcare operational policies include:
    a. Notification to families about obligation of childcare provider to comply with considerations under the Americans with Disabilities Act (ADA).
    b. Information on Texas Early Childhood Intervention (ECI) and how parents can request a screening for their child though their local provider.
2. Enhance childcare subsidy reimbursement rates for providers whose employees attend training that addresses serving children with disabilities, early childhood mental health, or similar topics that support caregivers in facilitating healthy inclusion practices.

Early Childhood Intervention

Increase funding for ECI programs to account for the increased demand for and enrollment in ECI services, the rising costs of providing those services, and the staff recruitment and retention.

Pre-K Programs

Make full day Pre-Kindergarten (Pre-K) programs an option for children who are or may be eligible for Early Childhood Special Education (ECSE) services by adding an eligibility category to existing Pre-K rules.

Shared from a mother on how much progress her son has made in ECI because of the support of his early intervention specialist.

"Our early child intervention specialist is like family, I am getting teared up just sharing this with you… She has been with my son since he was 2 months old.

My son loves her, when she walks into class he gives her kisses on the cheek, I can see on the camera, he cries when she goes to wash her hands because he wants her to come to him!

She is always giving me tips to do and always willing to help me in any way. She is always busy and my son says things like give him a tight hug to relax him. She is so calming, and she just changes my day and puts me at ease. She is so knowledgeable and uses books to help me. She just has this calming way; she never raises her voice.

I cannot put into words what an impact she has made in our family. My son would have progressed as far with her. When he was 8 months she worked on crawling and shared her tidbits and next visit he was crawling! I totally trust her, whatever she tells us is for the best for my son."

Education Recommendations

School and Special Education Funding

Invest in formula and non-formula funding for special education by adopting a multi-tiered service intensity funding formula for special education to support students in their least restrictive environment.

School Health and Related Services

Support access to School Health and Related Services (SHARS) such as Speech Therapy, Nursing and Personal Care Services for children with disabilities by making a supplemental appropriation to offset the loss of $300 million in SHARS reimbursements to Texas.

Increase Families' Ability to Actively Engage with Classrooms

Revise current laws pertaining to installation and monitoring of cameras in classrooms to protect the health and safety of students with disabilities.

1. A school district or open-enrollment charter school shall retain video recorded from a camera placed under this section for at least six months after the date the video was recorded.
2. Improve data collection and reporting to the Texas Education Agency (TEA) on camera installations by district and campus including number of requests for installation, grades served in classrooms with cameras, requests to view footage, who viewed footage (administrator, parent, child protective services, etc.) and outcomes of investigative processes.

Family Information and Access to Non-Educational Funds

1. Require school districts to a) refer students receiving Special Education (SpED) or 504 services to their Local Intellectual and Developmental Disability Authority (LIDDA) or their Local Mental Health Authority (LMHA) for community support and b) provide current information about Texas Home and Community-Based Services (HCBS) waivers including what they provide

and interest list contact information to families during their child's annual Admission, Review and Dismissal (ARD) or 504 committee meeting.

2. Ensure access to non-educational funds for children at risk of residential placement through improved outreach, service benchmarks for Local Education Agencies (LEA), and an increase in the amount of funds designated for schools to allow schools to fund respite for families in need.

Shared from a PCCF Council Member:

"I am a retired special education director and teacher and worked with students with rare disabilities for 35 years. I've seen the stressed look on the faces of parents who have children with behavioral support needs. I knew the work taking place in the classroom was not being carried over at home and something had to change.

I began working with one student at a time and once a month I would include the student in planned activities for the weekend such as church, grocery shopping, and family reunions. The same rules that I required in the classroom, I required in the community. I incorporated the life skills portion of the student's education plan into what we were doing on the weekends.

It was so successful, the school decided to apply for non-educational grants to provide the benefit to students once a month. I did this for 12 years until I retired. The students' parents saw how much the non-educational service benefitted their children.

Years have passed and my students have graduated high school. I see them being productive citizens and smile knowing I was able to have influence in their lives."

Post Secondary Education and Transition Recommendations

Health Care Transition Training and Information in Schools

1. Require schools to include health care transition to the ARD for students beginning at age 14 and continuing until the student graduates.
2. Require school Transition and Employment Designees (TED) to add health care transition training to the information provided to teachers and parents of students enrolled in SpED.

Improve Postsecondary Opportunities

Improve access for students with disabilities to pursue the postsecondary opportunities of their choice.

1. Improve data sharing between the TEA and the Texas Higher Education Coordinating Board (THECB).
2. Promote awareness of postsecondary opportunities for students with disabilities through interagency coordination and stakeholder involvement.
3. Appropriate funds to increase the amount of money provided to districts for students with disabilities who graduate College, Career and Military Ready (CCMR).

Access to Meaningful Days Post School

1. Add off-site Individualized Skills and Socialization (ISS) to all waivers and ensure adequate funding to support individuals with high medical and behavioral support needs.
2. Provide legislative direction and funding through an appropriations rider for HHSC to amend the Texas Home Living (TxHmL) waiver to create a set aside number of slots for a targeted group of children graduating high school.

Child, Parent and Family Support Recommendations

A successful family is the most effective way to meet a child's basic needs for safety, security, and stability. 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.

Family caregivers are a scarce resource and should be protected and supported. If they walked off the job, we'd be $600 billion short.[2]

Support parents to care for their children with disabilities at home while continuing to meet the needs of their families.

1. Ensure families have access to medically necessary home care services and respite in a manner that supports families to keep their children at home.
2. Require all eligibility, assessments for services and all components of service delivery are fair and equitable for all families, including families with parents who work outside the home.
3. Expand and create respite care programs for Texas families of children with disabilities through the creation and funding of a flexible funding pool like the successful In-Home and Family Support Program (IH/FSP).
4. Direct HHSC to amend Texas Medicaid waivers to allow more in-home respite to families and HCS host families, and ensure rates are sufficient to ensure an adequate network of providers.

More than 53 million family caregivers of children and adults provide the vast majority of long-term services and supports to individuals of all ages living at home, yet 86% of those caring for adults, and a

[2] Horovitz, B. (2023, July 14). New AARP report finds family caregivers provide $600 billion in unpaid care across the U.S. AARP. https://www.aarp.org/caregiving/financial-legal/info-2023/unpaid-caregivers-provide-billions-in-care.html

similar percentage caring for children, have not received respite services.[3]

Prevent unnecessary out-of-home placement of children with disabilities by reducing the wait time for Home and Community-Based Services waivers.

Reduce the time children spend waiting for in-home services and reduce the likelihood of a family having to seek costly out-of-home services through the following strategies:

1. Align the TxHmL waiver's financial eligibility requirements with the other Texas HCBS waivers so children can access the lower cost tiered waiver in lieu of a more costly comprehensive waiver and remove the requirement that children with related conditions have an IQ below 75.
2. Reduce the MDCP interest list and divert children from nursing facilities by allowing children who have Supplemental Security Income (SSI) and meet the functional eligibility for the waiver, access to MDCP with no wait.
3. Provide funding to reduce the Medicaid Home and Community-Based Services (HCBS) interest lists.
4. Increase funding to Local Intellectual and Developmental Disability Authorities (LIDDA) and other entities responsible for completing waiver and Community First Choice (CFC) eligibility assessments and waiver enrollments; and allow for flexibility in the type of assessment used, assessor qualifications, and frequency of assessments.

Shared from a PCCF Council Member:

"The Medically dependent Children Program has been instrumental in offering in-home support services, which allows my son to thrive in a comfortable, familiar environment while receiving the necessary care. These services have alleviated a tremendous burden on our family, enabling us to focus more on his well-being and less on the

[3] National respite Coalition. (n.d.). National Strategy to Support Family Caregivers Calls for More Respite Urge Congress to Support More Funding for Lifespan Respite and other Caregiver Supports in FY 2025.https://archrespite.org/wp-content/uploads/2024/06/appropriations_alert_june_fy2025.pdf

financial strain that often comes with managing a child's complex medical needs."

Provide funding and legislative direction for children with disabilities to move and be diverted from institutions to live with families.

Ensure Texas' commitment to promoting independence and permanency for children with disabilities.

1. Provide waiver funding to support children and young adults to move from or be diverted from facilities and to live in families. Facilities include nursing facilities, intermediate care facilities, General Residential Operations and Residential Treatment Centers (GRO/RTC).
2. Provide legislative direction and funding through an appropriation's rider for HHSC to amend the MDCP waiver to create reserved capacity for nursing facility crisis diversion slots for a targeted group of children who are determined to be medically fragile and at imminent risk of nursing facility admission as an alternative to having to go into a nursing home.
3. Provide legislative direction and funding through an appropriations rider for HHSC to amend the Texas Home Living (TxHmL) waiver to create a set aside number of slots for a targeted group of children graduating high school.

Strengthen the In-Home Workforce

1. Increase wages for community attendants to a living wage, or no lower than $15.00 to $17.00 per hour.

2. Ensure HHSC rates for community attendants are set at an amount that is high enough to comply with Department of Labor requirements including time and a-half for non-exempt employees.

3. Amend 1915(c) HCBS waivers, 1915(k) CFC, and 1115 waivers to the extent allowed by federal law, to allow family relatives, and those living in the household, to be providers of home health services such as personal attendant services, habilitation, and respite.

4. Amend Texas Medicaid State Plan to add trained aides, such as Certified Nurse Aides, in the home for children with medical complexities; and amend

the Medicaid waiver programs to allow adults with disabilities to access the benefit through a Home and Community-Based Services waiver.

Figure 2: Shared from a mother whose child receives Medicaid nursing services.

"My children with special health care needs are truly a blessing. My son has a genetic disorder that results in medication resistant epilepsy and various medical and physical challenges. Although he qualifies for 72 Hours of nursing care hours, the current nursing shortage often leaves those hours unfilled. When the agency is unable to provide the required care, I step in, which causes me to miss work and lose income. Being able to care for him while also being compensated would significantly improve our lives and ensure financial stability."

Healthcare Recommendations

Children with complex needs including multiple diagnoses are reliant on an array of healthcare providers which require extensive coordination, often placing a tremendous responsibility on families to manage. Without collaborative, integrated, coordinated care, children are at risk of receiving inaccurate diagnoses and silos in care due to limits on centralized data and health record sharing, lack of integrated health homes with specialty in diagnosing and serving children with high medical complexities crossing both medical and behavioral healthcare, as well as gaps in the continuum of support and services.

Recommendations to address these needs of our children with extensive and complicated needs include:

- Access to Health Insurance
- Better Healthcare Data
- Integrated and Coordinated Healthcare
- Improved Network Adequacy in Medicaid
- Improved access to Applied Behavior Analysis
- Continuum of Supports and Services for Children with Mental Health Concerns

Shared from a PCCF Council Member.

"Having access to Medicaid services has been a transformative experience for our family.

These programs have significantly improved my son's quality of life by providing access to essential healthcare services and resources that we otherwise might not have been able to afford. We've secured specialized therapies, medical equipment, and regular check-ups to ensure he receives the best care tailored to his unique needs."

Increase Access to Health Insurance for children with disabilities.

1. Apply the Family Opportunity Act's family income limit of 300 percent of the Federal Poverty Level after income disregards to the Texas Medicaid Buy-In

for Children program and improve outreach so more families can contribute to the cost of their children's health insurance.

2. Institute a Tax Equity Fiscal Responsibility Act (TEFRA) option for children who meet an institutional level of care to access Medicaid.

   The Louisiana legislature passed a bill, Act 421 of the 2019 Regular Legislative Session creating a TEFRA option for children with disabilities living at home to receive Medicaid coverage if they meet an institutional level of care for Intermediate Care Facilities, nursing facility, or hospital. Louisiana Medicaid received approval from the Centers for Medicare & Medicaid (CMS) to implement the program as a State Plan Amendment effective January 1, 2022.[4]

Collect better healthcare data through the development of a statewide registry for children with disabilities.

Fund the development of a centralized statewide registry for children with medical complexity to inform future policy and system improvements through data-informed and data-driven best practice standards and quality outcome measures.

Develop and appropriately fund integrated health homes and collaborative care for children and adults with medical complexity, developmental disabilities, and serious mental health care needs.

1. Provide base funding for comprehensive care clinics and investigate tying the funding for the clinics to Texas medical schools.
2. Incentivize value-based payment arrangements designed to address the special effort required to meaningfully develop comprehensive person-centered care plans and adequately reimburse providers for non-encounter-based processes that lead to better outcomes.
3. Pay providers a higher rate for caring for children with medical complexities, children with intellectual and developmental disabilities and children with

[4] Act 421 children's Medicaid Option (421-CMO): LA Dept. of health. Act 421 Children's Medicaid Option (421-CMO) | La Dept. of Health. (n.d.). https://ldh.la.gov/page/act-421-childrens-medicaid-option-421cmo

serious and persistent mental illness and reduce some of the administrative barriers that impede access to collaborative care models. Implement the following strategies:

   a. Designate consult level billing or an extra payment category for preparing and producing a detailed care plan. Care plan preparation and discussion is largely a non-reimbursed service currently even though it takes more than two hours of time; a large part of it may not be a face-to-face encounter.

   b. Reimburse for collaborative care management services at 120% of Medicare rates to increase adoption and ensure the program is financially sustainable.

   c. Remove restrictions on the number of 99494 codes allowed per patient per month to facilitate and ensure appropriate care initiation.

   d. Allow paraprofessionals with formal education (bachelor's level or higher) or specialized training to serve as care managers.

4. Ensure federally qualified health centers (FQHCs) and rural health clinics (RHCs) can obtain reimbursement for collaborative care management services through Medicaid, as intended by SB 672 of the 87th Texas Legislature.

Improve Network Adequacy in Medicaid

1. Increase the number of primary and specialty care providers available to care for young adults with medical complexities who are aging out of pediatric care, including primary care specialists, dentists who use sedation, and oral surgeons, through the following strategies:

   a. Increase the availability of participating adult physicians in geographic areas of concern.

   b. Strengthen the coordination and communication between pediatric-sending and adult-receiving practices.

   c. Expand the level of Health Care Transition support, including care coordination, available to medically complex youth and young adults and their caregivers.

d. Improve appropriate use of health care by funding the design and evaluation of innovative value-based transition payment pilots based on payment and quality options in The National Alliance to Advance Adolescent Health's Recommendations for Value-Based Transition Payment for Pediatric and Adult Health Care Systems: A Leadership Roundtable Report.

e. Require physician education to provide training about health care transition through the adoption of educational requirements for physician license renewals through the Texas Medical Board for transition of care planning services, like HB 2059, which requires clinicians providing direct patient care to participate in human trafficking prevention education as a stipulation for license renewal.

2. Pilot a service fulfillment strategy as a network adequacy measure for long-term services and support delivered through Medicaid Managed Care.

Access to Services for Children with Autism

1. Improve access to Applied Behavior Analysis (ABA) and autism services for individuals with autism through the following strategies:

   a. Require HHSC to create an autism services advisory board to report on access to care, barriers with benefit, overall utilization, and network adequacy across the HHS service delivery system.

   b. Ensure Medicaid reimbursement rates for ABA services are set at a level that is sufficient to allow for network adequacy and corresponding access to care.

   c. Require HHSC to extend the diagnostic evaluation time frame beyond the current 3 years and increase authorization of ABA services from three months to six months to reduce administrative burdens on providers and managed care organizations (MCOs).

   d. Increase funding for the Children's Autism Program at HHSC.

Shared from a PCCF Council Member:

"My daughter was removed from her birth family as a baby, returned and removed again and placed in my foster/adoption home when she was 4. She experienced a great deal of trauma in her first

few years of life that has led her to have very complicated physical and mental health care needs.

She has had psychiatric hospitalizations. She requires ongoing care and multiple doctors' appointments. Although she has normal INTELLIGENCE, she struggles daily.

She is now a beautiful young adult, but continuing to manage the continuum of care is difficult."

Create and Strengthen a Continuum of Supports and Services for Children with Mental Health Concerns

1. Strengthen the operation of one system of care for all children and youth. Address behavioral health concerns at a young age to prevent more complex needs at an older age.
2. Embed navigators across partner organizations within communities and strengthen their knowledge of children with dual diagnoses and resources across the behavioral health and child welfare system.
3. Broaden eligibility for existing community services through diversifying funding streams, allowing for dual diagnosis service provisions, and allowing for greater clinical expertise in creating program plans with families which wrap around the family and youth to support the youth being successful in remaining in their home environment.
4. Provide respite to families.
    a. In Home: modeling after current respite procedures for families enrolled in Early Childhood Intervention, allow families to identify providers for up to 20 hours a month and receive reimbursement. A tiered payment system allows for basic level to intensive level of reimbursement.
    b. Day Respite: Create therapeutic home environment for children ages 7 through 12 for families seeking day respite on weekend and summer days.
    c. Short Term: Utilize adolescent crisis respite units for day and short-term respite for 13 through 17-year-olds.

d. Long Term: Create long term therapeutic respite for stabilization needs (6-9 months).

5. Create short term diagnostic centers that provide a 30 - 60 day enriched diagnostic period to better identify diagnoses, needs and provide recommendations for continued therapeutic needs and care.

   a. Develop and fund small, community-based, short term, therapeutic, emergency out of home living options for children in crisis until reaching stabilization.

Shared from a PCCF Council Member:

"A 14-year-old teen with autism and severe aggression was in a hospital emergency room tied to a bed for days without being able to go anywhere. This admission followed multiple admissions due to aggression to her recently widowed mother. The teen was offered an HCS waiver, but no provider was able to support her due to her aggression. Crisis respite providers would not take her because of her "medical condition." She was placed on a waiting list for admission to a state psychiatric hospital. She was finally able to secure services in Minnesota."

6. Improve Residential Treatment for Children.

   a. Amend the Texas Medicaid State Plan to allow for payment of Residential Treatment for all children who need it, not just those in the child welfare system.

   b. Include Treatment Foster Care (TFC) as a Medicaid benefit in lieu of Residential Treatment Center (RTC) for children even if not in conservatorship of the state.

   c. Fund long term respite for those transitioning from RTCs.

   d. Develop and fund Pediatric Intensive Psychiatric Rehab in Texas.

Shared from a PCCF Council Member following a conversation with a Child Assessment Center.

"A Child came to us after a failed adoption, entering care for the second time in her short life. When the child came in, it was with no permanent connections, no adults or family approved for or wanted contact and the child had just experienced another significant disruption in her life.

As we started to work with Child, we were able to identify some significant mental health needs that had never been addressed since

the child was first abused as a young child. Our team immediately began advocating for the specialized services needed to address that specific trauma, and we were able to get the child engaged in services within a couple of weeks.

While we were working on the assessment report, our clinical team walked through the mobility map with the child to walk back through their placement history and to tease out those meaningful connections from each placement, family, teachers, neighbors, maybe a coach, etc. As we were doing this, the Child focused on a certain placement where the child had close contact with an aunt. An aunt that was not on any of our paperwork.

Through the permanency team we were able to arrange the first visit with Aunt and a cousin, which was so meaningful to a child that had been feeling completely disconnected from all of the important relationships that had formed while young. The aunt has since expressed interest in becoming a permanent option for Child.

Child has since transitioned over to our RTC program with therapeutic supports, supportive supervision, and nurturing care."

Community Recommendations

Depression and anxiety are the most frequently identified mental health conditions among people with IDD, but the prevalence of schizophrenia is disproportionately high. Additionally, people with IDD frequently have behavioral health needs that are the result of post-traumatic stress. The behavioral health system in Texas has begun to focus more specifically on the mental health and wellness of those with IDD. People with IDD should have access to quality behavioral health services, trauma-informed care, and opportunities for recovery. Additionally, supports should be adequate in both approach and intensity to avoid unnecessary hospitalizations or incarcerations.

Research indicates that youth involved in the justice system experience disabilities at a rate approximately three times higher than that of youth without disabilities. As a state, it is imperative that the state continue to systematically evaluate strategies to mitigate juvenile justice involvement among youth, enhance the provision of services aimed at reducing recidivism, augment the deployment of peer support specialists for justice-involved youth and strengthen access to crisis services for persons dually diagnosed with IDD and mental and behavioral health needs. By strategically addressing these focus areas, the state can initiate a reduction in the level of involvement.

Recommendations to address community support for children with or at risk of juvenile justice system involvement:

- Bolster mental health and behavioral health services in schools and the community to divert youth and young adults with disabilities away from juvenile justice system involvement.
- Provide coordinated mental health or other potential services upon re-entry to reduce recidivism.
- Increase the utilization of peer support specialists for justice-involved youth and young adults.

Bolster mental health and behavioral health services in schools and the community to divert youth and young adults with disabilities away from juvenile justice system involvement.

1. Provide trauma informed or person-centered training for youth with mental health or mental health/intellectual disability dual diagnoses to include available community and state resources to assist with prevention of juvenile involvement.[5]
2. Partner youth with mentors to ensure understanding and guidance is available to help avoid initial juvenile involvement or to decrease odds of reentering the juvenile justice system.
3. Partner with Department of Family and Protective Services (DFPS) or other state agencies to identify youth at risk of re-offending or re-entering the juvenile justice system offer different options and strategies to lead to a different outcome.[6]
4. Provide funding for specialized training for law enforcement and correctional officers on interacting with youth or young adults who may have disabilities.

Provide coordinated mental health or other potential services upon re-entry to reduce recidivism through:

1. Individual plan for Integrating (IPI) back into their assigned settings.
2. Utilizing person-centered, age-appropriate practices.

Increase the utilization of peer support specialists for justice-involved youth and young adults.

1. Pilot an alternative credentialling for peer specialists to eliminate barriers such as cost and time requirements to complete training, service reimbursement rates, and criminal history.

[5] IDD Home Page - MHW-IDD. MHW. (2023, April 25). https://training.mhw-idd.uthscsa.edu/
[6] Detention of persons with IDD. (n.d.). https://www.tcjs.state.tx.us/wp-content/uploads/2020/12/Detention_of_Persons_with_IDD.pdf

2. Establish rules to permit peer support specialists to provide services in carceral settings.
3. Potentially review and amend current legislation to incorporate IDD and special populations. For example, the 85th Texas Legislature passed H.B. 1486 (85th, Price/Schwertner) which required HHSC to create a Medicaid reimbursable state plan benefit for peer support services.

To operationalize this directive, the legislation directed HHSC to develop rules that:

- Establish training requirements for peer specialists;
- Establish certification requirements for peer specialists;
- Define the scope of services peer specialists may provide;
- Distinguish peer services from other services that a person must hold a license to provide; and
- Develop other rules necessary to protect the health and safety of persons receiving peer services.[7]

[7] 85(R) HB 1486 - enrolled version - Bill Text. (2017). House Bill 1486 https://capitol.texas.gov/tlodocs/85R/billtext/html/HB01486F.HTM

6. Conclusion

The PCCF 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 children with disabilities 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.

List of Acronyms

Acronym	Full Name
ABA	Applied Behavior Analysis
ADT	Admit-Discharge-Transfer
ARD	Admission, Review, and Dismissal
CCMR	College, Career, and Military Ready
CFC	Community First Choice
CHIP	Children Health Insurance Program
CMC	Children with Medical Complexity
CMS	Centers for Medicare & Medicaid Services
CTP	Comprehensive Transition Programs
DAEP	Disciplinary Alternative Educational Placement
DFPS	Texas Department of Family and Protective Services
DSHS	Texas Department of State Health Services
ECI	Early Childhood Intervention
ECSE	Early Childhood Special Education
ED	Emergency Department
EPSDT	Early and Periodic Screening, Diagnostic, and Testing
ESC	Education Service Center
FAPE	Free Appropriate Public Education
FPL	Federal Poverty Level
FQHC	Federally Qualified Health Centers
FY	Fiscal Year
GRO	General Residential Operations
HB	House Bill
HCBS	Home and Community-Based Services
HCS	Home and Community-based Services waiver
HCT	Health Care Transition
HHS	Health and Human Services
HHSC	Health and Human Services Commission
HIPAA	Health Insurance Portability & Accountability Act
IBC	Industry-Based Certificate
ICF	Intermediate Care Facility
ICF/IID	ICF for Individuals with Intellectual Disabilities
IDD	Intellectual and Developmental Disability
IEP	Individualized Education Plan
IHE	Institution of Higher Education
IH/FSP	In-Home and family Support Program
IPI	Individual Plan for Integrating
ISD	Independent School District
ISS	Individualized Skills and Socialization
JJAEP	Juvenile Justice Alternative Educational Placements
LEA	Local Education Agencies

Acronym	Full Name
LHA	Licensed Health Aide
LIDDA	Local Intellectual and Developmental Disability Authority
LMHA	Local Mental Health Authority
LTSS	Long-Term Services and Supports
MCO	Managed Care Organization
MDCP	Medically Dependent Children Program
PCCF	Policy Council for Children and Families
PHE	Novel Coronavirus (COVID-19) Federal Public Health Emergency
Pre-K	Pre-Kindergarten
RHC	Rural Health Clinic
RTC	Residential Treatment Center
SB	Senate Bill
SHARS	School Health and Related Services
SpEd	Special Education
SSI	Supplemental Security Income
SSLC	State Supported Living Center
TCM	Targeted Case Management
TEA	Texas Education Agency
TED	Transition and Employment Designees
TEFRA	Tax Equity Fiscal Responsibility Act
TFC	Treatment Foster Care
THECB	Texas Higher Education Coordinating Board
TT	Tracking Teacher
TPEIR	Texas Public Education Information Resource
TSDS	Texas Student Data System
TSI	Texas Success Institute
TxHmL	Texas Home Living
YASHCN	Young Adults with Special Health Care Needs

Appendix A. Background Data for Recommendations

Early Childhood

Make full-day Pre-K programs an option for children who are or may be eligible for Early Childhood Special Education services by adding an eligibility category to existing Pre-K rules.

Many parents in Texas and across the country struggle to find a full-day childcare provider who will accept a child with a disability and educate them alongside their nondisabled peers. A recent Texas PDG Early Learning Needs Assessment survey received several responses from parents about the need for inclusive care for their child with a disability. This challenge can cause children with disabilities to either enroll in early learning programs later than their nondisabled peers or miss out on early learning opportunities altogether. Texas should create more inclusive early learning options for young children with disabilities. Texas can accomplish this through continued training and additional resources for early education providers to plan and create inclusive classrooms. Texas can also achieve this goal by adding children with an individual education plan (IEP) to the eligibility criteria for full-day, public pre-k. An example of similar public pre-k eligibility can be found in the state of Kentucky's Public Preschool Program.

In addition, when a child receiving ECI services turns three, they age out of the program and may be eligible to receive interventions and services at their local public school. This transition from ECI to Early Childhood Special Education (ECSE) can be challenging for parents to navigate, which can cause the child to have gaps in services or be dropped altogether. Texas should evaluate how the state and/or ECI programs share information with parents whose children are transitioning from ECI services to ECSE. All parents should be able to easily access information about the transition to ECSE and the services that ECSE provides. The state should implement a recommendation in the November Federal Policy Statement on Inclusion of Children with Disabilities in Early Childhood Programs, which urges states to build strong partnerships between the state's systems and programs that provide services to young children. Ensuring there is collaboration between HHSC,

ECI providers, and the local education agencies will help to make the transition from ECI to ECSE as seamless as possible.

Education

Improve Information and Access to Families to Non-Education Supports

School district referral of students with IDD to the Local Intellectual and Developmental Authority and Information to families about Medicaid waivers

Parents of a child diagnosed with a disability or special need have an intense need to find information that can help their child and family. For many families, the place to go to search for information is the Internet, which provides an overwhelming volume of complex information that is not easily accessed. The Texas system of state and private services for children with special needs is fragmented and difficult to navigate, even for those parents who know what they are looking for.

The Task Force for Children with Special Needs, which was legislatively mandated in 2009 identified "Informed and Empowered" Parents as its highest priority. In addition, the Texas IDD Strategic Plan identified as one of its core gaps, Ease of System Navigation. The plan states that "people in any stage of life need to be able to readily identify and link to IDD services and related benefits for which they may be eligible."[8]

Strategy 1.1.2 of the plan is to empower and strengthen people and their families, teach them about resources and services early and as eligibility and services change. Since children spend more time in school than any other location, schools are the logical location for referrals to the LIDDA and to information about Medicaid waivers.

[8] Texas statewide intellectual and developmental disabilities. (n.d.). https://www.hhs.texas.gov/sites/default/files/documents/statewide-idd-strategic-plan-jan-13-2022.pdf

Access to non-educational funds for children through improved outreach and amount of funds appropriated

Non-Educational Community-Based Support Services funding was created by the 74th Texas Legislature as a recognition of the need to provide support 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 (FAPE) in the least restrictive environment according to the Texas Education Code, Section 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.

Rider 16 of Article III, Education in the TEA 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 Texas Education Code, Section 29.013.

Any unexpended balances as of August 31, 2024, are hereby appropriated for fiscal year 2025 for the same purposes."[9]

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 almost thirty years ago in 1995. However, even with such a great need for support to families, of the appropriated funds FY 22, $438,616 were utilized and for FY 23, $555,318 were utilized. This is money that could have been used to support respite care and in-home support 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 support, and a simplified process to access the needed support.

[9] General appropriation Act - GAA 88th 2024-25. (n.d.). https://www.lbb.texas.gov/Documents/GAA/General_Appropriations_Act_2024_2025.pdf

The TEA in FY 2025 moved the operation of the funds to a single Education Service Center (ESC). Having one ESC will hopefully improve outreach and distribution of the funds. The TEA in conjunction with the appointed lead ESC and local independent school districts (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.

Quarterly benchmarks should be required to assist ESC 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.

Post Secondary Education and Transition

Health Care Transition Training and Information in Schools

Good health lays the foundation for all areas of transition planning – higher education, employment, vocational training, and independent living. Lack of essential information and intentional planning for a health care transition jeopardizes success in all these areas and puts young adults with disabilities and chronic health conditions at risk for serious and possibly life-threatening consequences. This is costly for the individual and their family, while adding significant, long-term higher costs for health care.

For a student receiving SpEd services, the ARD Committee made up of the child's teacher, therapists, and other school or district staff gather for a meeting at least once each year to develop the student's IEP. In these meetings information is

shared regarding the student's strengths and needs, and measurable goals are developed for the student that can be reasonably accomplished in one year.

Texas law requires that part of the ARD process includes planning for transition to adulthood which must begin no later than at age 14 for all youth who receive SpEd services. However, addressing health care, though essential for a successful transition to adulthood, currently is not part of school transition planning requirements.

It is essential that young adults know how to manage their own health and health care and that families know how to assist their young adult children. This includes knowing medical needs, medications, what to do in a medical emergency, how to make a doctor's appointment, how to refill medications, how privacy changes when they become a legal adult at 18, why it is important to have and carry health insurance, how to request accommodations, and how to ask questions. Youth with health care needs will be prevented from obtaining and keeping a job if they are unable to get to work consistently and on time because of their health. They need to be able to articulate their support needs and any accommodation they will need to be able to be successful in their occupation.

Improve Postsecondary Opportunities

Improve access for students with disabilities to pursue the postsecondary opportunities of their choice.

Improve data sharing between the TEA and the THECB through the use of the following strategies.

- Include post-secondary outcome data for students with disabilities, including students with IDD in the Texas Public Education Information Resource (TPEIR) and Texas Student Data System (TSDS) reports.
- Identify school districts that offer dual credit/concurrent enrollment opportunities for students with IDD.
- Provide time for the advisory council and the THECB to research how students with IDD and their families can learn about and be encouraged and/or supported in enrolling in for credit-earning courses in high school.
- Appoint a strategic planning committee to identify shared data and analyze outcome data to set a baseline for the participation of students with IDD in career and technical education. There is a correlation between participation in CTE and positive postschool outcomes in higher education and employment.

- The strategic planning committee should identify strengths and needs related to the transition services in K-12 that facilitate the preparation for and participation in college and/or employment for students with IDD.

Promote awareness of postsecondary opportunities for students with disabilities through interagency coordination and stakeholder involvement.

Comprehensive Transition Programs (CTPs) are designed to support students with intellectual disabilities who want to continue academic, career, and independent living instruction to prepare for gainful employment. CTPs were created by the Higher Education Opportunity Act of 2008. The act defined the key requirements that all CTP programs must provide to students, gave a definition of a student with an intellectual disability, and opened up access to federal student aid for students with intellectual disability attending an approved CTP program, even if those students do not have a standard high school diploma or are not matriculating towards a degree. To date, there are only 4 CTPs approved by the U.S. Department of Education in Texas.

The Texas Legislature should direct the THECB to establish a program to incentivize and support the creation and approval of additional CTPs within more institutions of higher education across Texas.

THECB, in consultation with existing CTPs and Think College, an institute for promoting inclusive higher education options for people with IDD, should create training materials instructing IHEs and providing technical assistance on how to apply to become an approved CTP so that students with IDD who have exited high school are eligible to receive federal financial aid.

Partnerships should be leveraged to provide grants to allow IHEs to develop postsecondary educational programs on their college campuses or training schools that develop support and services for students with IDD, especially in rural communities.

THECB should oversee collaborations between IHE and LEAs that will facilitate communication on postsecondary programs and services that support students with IDD, as well as interventions and strategies that have been successful.

Through dissemination at state conferences (Texas Transition Conference, Texas Association of Vocational Adjustment Coordinators, Texas Council of Administrators of SpEd, IHEs should share with LEAs the interventions and strategies that have been successful in supporting students with IDD in postsecondary education.

Interventions and strategies should be added as an activity to develop resource materials for LEAs by the Texas Transition Network to be posted on the Texas Education Agency network website for Texas Transition.

The TEA should also develop a recommendation using the TEA correspondence tool "To the Administrator Addressed," and the THECB should develop a recommendation communication to the IHE disability services staff, to train support personnel for students with disabilities regarding behavior as a barrier to accessing inclusive environments. In 2018, the THECB funded a grant to train educators and behavior specialists in functional behavior assessment and intervention plan procedures to overcome barriers to future participation in higher education and/or employment. The free THECB training materials are available at the Region 13 Education Service Center in Austin in the Texas State Leadership Autism Training network.

Appropriate funds to increase the amount of money provided to districts for students with disabilities who graduate College, Career and Military Ready (CCMR).

Districts receive the following amounts for qualifying graduates that exceed the threshold performance set for each group (the threshold performance matches performance within each group meeting the CCMR standard at the 25th percentile of 2017 performance statewide). Graduates who were enrolled in a special education program would count as either economically disadvantaged or non-economically disadvantaged in addition to the special education group.

District Funding

- Economically Disadvantaged $5,000
- Non-Economically Disadvantaged $3,000
- Special Education $2,000

College ready is defined as:

- Meets Texas Success Initiative (TSI) criteria, and
- Enrolls at a postsecondary institution immediately following high school; or earns an associate degree

Career ready is defined as:

- Meets TSI criteria, and

- Earns an industry-based certification (IBC); or earns a level I or level II certificate.

Military Ready is defined as enlisting in the U.S. Armed Forces.

The funding should be equivalent to Economically Disadvantaged with the following two levels.

- Special Education: $5000 (+ $3,000 increase) meeting already established criteria of CCMR
- $2000 (removing the requirement of TSI, but add in Career Ready component "Workforce Skills and/or Job Placement")

Access to Meaningful Days Post School

TxHmL Waiver Set-Asides

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 US Bureau of Labor Statistics, the employment rate of people with disabilities continues to be very low. As of 2024, only 40.0 percent of adults with disabilities between the ages of 16 to 64 were employed. This is in comparison to 78.2 percent of people without disabilities.[10]

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 support and services such as on-going job coaching and personal assistance services to engage in meaningful employment.

Texas could create reserved capacity in the TxHmL 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.

[10] Disability employment statistics. DOL. (n.d.). https://www.dol.gov/agencies/odep/research-evaluation/statistics

Child, Parent and Family Support

Support parents to care for their children with disabilities at home while continuing to meet the needs of their families.

Fair and Equitable Services

According to the 2020 - 2021 National Survey of Children's Health, Texas leads the nation in the percentage of parents of children with special health care needs who have left a job, taken a leave of absence, or cut down on the hours worked because of their child's health condition at 21.8 percent compared to 17.1 percent nationally.[11] The impact of forgone family employment was more acutely experienced by families of children with special health care needs. A study published in the American Association of Pediatrics (AAP) September 2021 Pediatrics journal found that 14.5 percent of families of children with special healthcare needs experienced a reduction of loss in employment resulting in $18,000 in lost annual income. Hispanic families were disproportionately impacted.[12] The authors recommend the development of policies that support pediatric home health care services.

> *"The connection between child health and family employment is quantifiable and substantial. We suggest more policies and programs that address the impact of CSHCN including pediatric home health care services."*[13]

In January 2024 Texas proposed a rule that would prohibit a family member from leaving the home at any time during the provision of medically necessary Medicaid private duty nursing for their child. The change would have a chilling effect on the ability of families to care for their medically fragile children at home and would lead to families placing their children in facilities in order to work and care for their family. House Bill 2873 pertaining to waiver programs for children with disabilities or special health care needs overwhelmingly passed the Texas House and Texas Senate and was signed into law in 1999. The legislation requires HHSC ensure

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[11] The Catalyst Center. Chartbook State Data. (n.d.). https://chartbook.ciswh.org/statedata
[12] AAP. (n.d.). https://publications.aap.org/pediatrics/article/148/3/e2020035378/181089/Children-With-Special-Health-Care-Needs-and?autologincheck=redirected
[13] Foster, C. C., Chorniy, A., Kwon, S., Kan, K., Heard-Garris, N., & Davis, M. M. (2021, September). Children with special health care needs and Forgone family employment. Pediatrics. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9219960/

"eligibility requirements, assessments for service needs, and other components of service delivery are designed to be fair and equitable for all families, including families with parents who work outside the home."[OBJ] The Council recommends a similar provision for medically necessary services under Texas Medicaid. The Council recommends a similar provision for medically necessary services under Texas Medicaid.

"Family caregivers are a scarce resource and should be protected and supported. If they walked off the job, we'd be $600 billion short."[14]

Creation of Flexible Funding Pool for Respite

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 like respite 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 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.

More than 53 million family caregivers of children and adults provide the vast majority of long-term services and supports to individuals of all ages living at home, yet 86% of those caring for adults, and a similar percentage caring for children, have not received respite services.[15]

Respite in Texas Medicaid waivers

Texas Medicaid waiver programs, including the Community Living Assistance and Support Services waiver, the HCS waiver, the TxHmL waiver, and the Deaf Blind with Multiple Disabilities waiver, offer families a limited amount of respite per year. This is not always enough to provide families with 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 or a child with complex medical care, must have access to adequate respite opportunities that allow the time needed to

[14] Horovitz, B. (2023, July 14). New AARP report finds family caregivers provide $600 billion in unpaid care across the U.S. AARP. https://www.aarp.org/caregiving/financial-legal/info-2023/unpaid-caregivers-provide-billions-in-care.html

[15]National respite Coalition. (n.d.). National Strategy to Support Family Caregivers Calls for More Respite Urge Congress to Support More Funding for Lifespan Respite and other Caregiver Supports in FY 2025.https://archrespite.org/wp-content/uploads/2024/06/appropriations_alert_june_fy2025.pdf

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.

The host home benefit in the HCS waiver allows 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 their needs, including their permanency needs, are met.

> *Respite, the most requested service by family caregivers, has been shown to reduce stress and social isolation, help improve caregiver health and wellbeing, bolster family stability, keep marriages intact, and help avoid or delay costlier out-of-home Placements.*[16]

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. According to a 2022 report by the National Academy for State Health Policy, although most state Medicaid waivers cover respite care, the majority of states allocate a small fraction of their total 1915(c) waiver budget toward these services. The median percentage of 1915(c) waiver funding allocated for respite care is 0.49%.[17] 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 support.

[16]National respite Coalition. (n.d.). National Strategy to Support Family Caregivers Calls for More Respite Urge Congress to Support More Funding for Lifespan Respite and other Caregiver Supports in FY 2025.https://archrespite.org/wp-content/uploads/2024/06/appropriations_alert_june_fy2025.pdf

[17] Hodges, K. (2024, May 10). State respite care spending is low in most home and community-based 1915(c) waivers. NASHP. https://nashp.org/state-tracker/state-respite-care-spending-is-low-in-most-home-and-community-based-1915c-waivers/

Prevent unnecessary out-of-home placement of children with disabilities by reducing the wait time for Home and Community-Based Services waivers.

TxHmL Waiver

The TxHmL waiver is Texas' lowest individual cost-cap waiver. It provides essential community-based services and support to individuals with intellectual and developmental disabilities (IDD) living in their own homes or with their families. Texas financed the waiver by taking state general revenue typically used to pay for respite and other safety net services to draw down federal match. The yearly individual cap for the waiver is $17,000.

Aligning TxHmL waiver's financial eligibility to be the same as other Texas Medicaid waivers while also removing the IQ cap of 75 for children with related conditions will 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.

MDCP and SSI Children

The MDCP waiver provides services to children with significant medical complexities and who often rely on life sustaining technology as a cost-effective alternative to the institutionalization of children in nursing facilities. MDCP services include respite, minor home modifications, adaptive aids, and flexible family support.

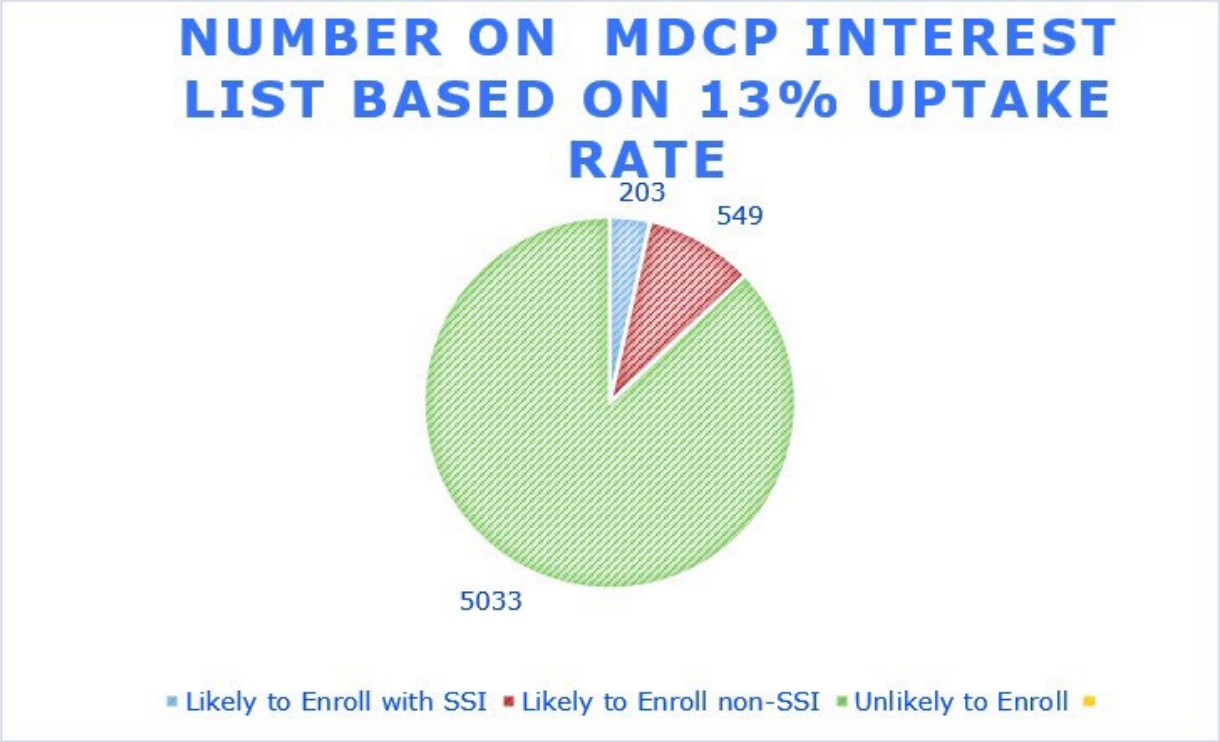
Unlike the STAR+PLUS home and community-based services waiver (STAR+PLUS HCBS) that allows adults who have SSI and meet waiver eligibility access to the waiver with no wait, children who have SSI and meet MDCP eligibility criteria cannot access waiver services until their names come to the top of the interest list. The policy implemented for the STAR+PLUS HCBS waiver is what led to a significant reduction in the number of individuals waiting for services.

Eligibility for MDCP is determined when the child's name reaches the top of the list and receives an offer. According to an HHSC presentation to the House Human Services Committee on August 27, 2024, the average percentage of children who are determined eligible for and accept MDCP when they reach the top of the interest list is 13 percent.[18] HHSC refers to this as an uptake rate. This means that

[18] Texas House of Representatives. (n.d.). Texas house. https://house.texas.gov/videos/20655

approximately 752 of the 5,785 children on the list as of July 31, 2024, will likely be determined eligible and/or enroll in services.[19] Approximately 27 percent of the children on the MDCP interest list as of July 31, 2024, have SSI.[20] If they were given access to the waiver with no wait, the remaining number of children on the interest list would drop dramatically, making it economically feasible to eliminate the waiting list. The children on the MDCP waiver are children with medical complexities who meet nursing facility level of care and need access to services to prevent admission to a nursing facility.

Figure 6: Chart Showing Number of Children on MDCP Interest List



Funding for Medicaid Home and Community-Based waiver Interest Lists

According to the November 2023 Kaiser Family Foundation report, Texas has the largest number of individuals on Medicaid Home and Community-Based waiver interest lists. Most of the individuals waiting are individuals with intellectual and/or

[19] Texas Health and Human Service Commission. (2024). https://www.hhs.texas.gov/sites/default/files/documents/interest-list-data-july-2024.xlsx
[20] Texas Health and Human Service Commission. (2024). https://www.hhs.texas.gov/sites/default/files/documents/csil-individuals-receiving-sass-ssi-services-overview-rider-july-2024.xlsx

developmental disabilities.[21] Texas is one of six states that does not screen for eligibility prior to an individual's name being placed on a waiver interest list. Based on discussion during the August 27, 2024, Texas House Human Services Committee meeting, there is interest in looking at ways to reduce the Texas waivers list.[22] While the state investigates alternatives, it is important that funds be dedicated to enrolling individuals into services. The report also contains strategies to reduce the interest lists. For example:

1. Allow children with SSI who meet MDCP waiver eligibility to enroll in waiver with no wait.
2. Align the TxHmL waiver's financial eligibility requirements with the other Texas HCBS waivers so children can access the lower cost tiered waiver in lieu of a more costly comprehensive waiver. Also, remove the requirement that children with related conditions have an IQ below 75.
3. Implement a TEFRA option for families of children with disabilities to access Medicaid. The Louisiana legislature passed a bill, Act 421 of the 2019 Regular Legislative Session creating a TEFRA option for children with disabilities living at home to receive Medicaid coverage if they meet an institutional level of care for Intermediated Care Facilities for, nursing facility or hospital.[23] Louisiana Medicaid received approval from CMS to implement the program as a State Plan Amendment effective January 1, 2022.

Funding for Timely Eligibility Assessments

Additional funding is needed for the LIDDA to complete waiver eligibility assessments and to ensure timely enrollment into the waivers. Not only are LIDDAs responsible for determining eligibility for the HCS and TxHmL waivers, but the LIDDAs are also responsible for completing eligibility for individuals with IDD seeking CFC. An analysis conducted by the Texas Council of the cost of providing IDD Targeted Case Management (TCM) compared to the Medicaid reimbursement

[21]Medicaid HCBS waiver waiting list enrollment, by Target Population and whether states screen for eligibility. KFF. (2024, October 31). https://www.kff.org/medicaid/state-indicator/medicaid-hcbs-waiver-waiting-list-enrollment-by-target-population-and-whether-states-screen-for-eligibility/?currentTimeframe=0&sortModel=%7B%22colId%22%3A%22Location%22%2C%22sort%22%3A%22asc%22%7D

[22]Medicaid HCBS waiver waiting list enrollment, by Target Population and whether states screen for eligibility. KFF. (2024, October 31). https://www.kff.org/medicaid/state-indicator/medicaid-hcbs-waiver-waiting-list-enrollment-by-target-population-and-whether-states-screen-for-eligibility/?currentTimeframe=0&sortModel=%7B%22colId%22%3A%22Location%22%2C%22sort%22%3A%22asc%22%7D

[23]Act 421 children's Medicaid Option (421-CMO): LA Dept. of health. Act 421 Children's Medicaid Option (421-CMO) | La Dept. of Health. (n.d.). https://ldh.la.gov/page/act-421-childrens-medicaid-option-421cmo

rate revealed a loss of over $40 million each year for fiscal years 20 through 22. The data is based on information provided in the Mental Health Early Childhood Intervention and Intellectual and Developmental Disability (MEI) Cost Report that is filed annually and reviewed by HHSC. The information utilized is after HHSC review and adjustments.

Provide funding and legislative direction for children with disabilities to move and be diverted from institutions to live with families.

Promoting Independence and Waiver Funding for Children to Move from or Be Diverted from Institutions to Families

Since 2002, Texas has experienced a 67 percent decrease in the number of children living in congregate facilities with six or more people resulting in savings to the state and an improved quality of life for children and families.[24] Of those remaining in larger facilities, 34 percent are minors, and 66 percent are young adults under 22 years of age.[24] 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 families of children with disabilities so that children can grow up in families instead of institutions. 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 support they need so the family unit remains intact.

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 or be diverted from nursing homes, group homes, large institutions, and GRO licensed by the Department of Family and Protective Services (DFPS) is necessary. It is imperative that the work that has been started by the state continues including funding of HCS waivers which is the only HCBS waiver in Texas that has a family-based alternative option for children who cannot live at home.

[24] Permanency Planning and family-based alternatives. (n.d.). https://www.hhs.texas.gov/sites/default/files/documents/permanency-planning-family-based-alternatives-july-2024.pdf

Figure 2. Trends in the Number of Children by Institution, HHSC, and DFPS

Institution Type	Baseline Number as of August 31, 2002	Number as of February 29, 2024	Percent Change Since August 2002
Nursing Facilities	234	83	-65%
Small ICFs/IID	418	126	-70%
Medium ICFs/IID	39	20	-49%
Large ICFs/IID	264	4	-98%
SSLC	241	148	-39%
HCS Group Homes	312	535	71%
General Residential Operations	73	38	-48%
Total	1,581	945	-40%
Total with HCS Excluded	**1,269**	**419**	**-67%**

Figure 3. Number of Children in Institution, HHSC, and DFPS by type of Facility and Age of Child[25]

Institution Type	Minors 0-17	Ages 18-21	Total
Nursing Facilities	48	35	83
Small ICFs/IID	12	114	126
Medium ICFs/IID	1	19	20
Large ICFs/IID	2	2	4
SSLC	49	99	148
HCS Group Homes	127	408	535
General Residential Operations	32	6	38
Total	271	683	945
Total with HCS Excluded	**144**	**275**	**419**

[25] Permanency Planning and family-based alternatives. (n.d.). https://www.hhs.texas.gov/sites/default/files/documents/permanency-planning-family-based-alternatives-july-2024.pdf

MDCP Nursing Facility Stay Requirement

The 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 (GAA), 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.

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 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. In addition, nursing facilities charge families upwards of $300 for the limited stay, making it not a viable option for all families.

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 federal PHE. Facilities that accept children for a limited stay are hard to find. 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 stay puts children at greater risk of contracting an illness and requiring further hospitalization.

Texas Medicaid has successfully created a crisis diversion process and reserved capacity in the HCS waiver for children and adults at risk of facility admission.

Some years ago, the Department of Aging and Disability Services (DADS) received approval to set aside funding for 100 adults at risk of nursing facility admission to receive Community Based Alternatives 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 (S.B.) 1207 from the 89th Texas Legislature set the stage but did not give HHSC sufficient direction or funding.

HCS for Adults with Intense Medical Complexities

The evolution and success of community programs designed to keep people with disabilities at home with their families or in their community close to their families has been incredible, however young adults with medical complexities are often left behind. When families of young adults with medical complexities reach the point of needing an out of home placement – they receive the same answer that is decades old – admission to a state supported living center (SSLC) or a nursing home. This placement most likely results in the adult with medical complexity being placed miles away from his/her family which greatly restricts the family's ability to be involved in their adult child's life and care. Funding and changes to the HCS waiver are needed to ensure adults can live with families and in communities.

The only Texas Medicaid HCBS waiver that pays for the type of alternative family that the children and young adults who cannot live at home need is the HCS waiver through the host home benefit. There is no equivalent benefit in the other waivers. Children who have been assisted to move from nursing facilities to family-based alternatives depend on the HCS waiver's host home benefit for payment for the daily care provided to the child as well as Medicaid nursing in the home.

When young adults turn 21 years old, they lose access to the Medicaid Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) provision which requires Medicaid to provide all medically necessary services to those under 21 including private duty nursing. This proves extremely problematic for some young adults in the HCS waiver who are medically fragile. They cannot get the same level of nursing in the HCS waiver, and if they need out-of-home placement in a host family or in the community they are denied as being too medically fragile. To remedy the issue and to ensure young adults with medical complexities continue to live with families and in their communities, the state must add private duty nursing to the HCS waiver as well as ensure young adults receive HCS Level of Need 9 funding allocation. This affects only a small group of individuals, but the consequence of not making these changes is life threatening for these young adults.

Strengthen the In-Home Workforce

Community Attendant Wage Increase

Home health care workers are critical to the lives and well-being of children with disabilities. They help children and adults remain in their homes and communities and assist with tasks like eating, bathing, and dressing. Currently, the base wage for Medicaid community attendants in Texas is $10.60 per hour. The U.S. Bureau of Labor Statistics Occupational Employment and Wages May 2023 report[26] and the PHI National Direct Care Workforce Resource Center list[27] Texas in the bottom two states nationally for attendant care pay second only to Louisiana. The U.S. mean wage was more than $16.05[28] per hour while the median hourly wages adjusted for inflation was $16.13.[29] Half of all states in the country pay more.

According to the Economic Policy Institute and New America's report, all states must set higher wage benchmarks for home health care workers, "every state undervalues the home health care workforce which is overwhelmingly composed of women and people of color." They further estimate that more than 1 million additional home health care workers will be needed by 2029. This is problematic because people are opting to remain at home instead of moving to facilities.

> *In all 50 states and the District of Columbia, the direct care worker median wage is lower than the median wage for other occupations with similar entry level requirements, such as janitors, retail salespersons, and customer service representatives. In many states, direct care worker wages also do not compete with occupations with lower entry-level requirements.* [30]

Investing in the home health workforce will lead to better care and potential cost savings for the state. According to a report by Zandi and Yaros, in 2021 every

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[26] U.S. Bureau of Labor Statistics. (2024, April 3). Home Health and Personal Care Aides. U.S. Bureau of Labor Statistics. https://www.bls.gov/oes/current/oes311120.htm
[27] Phi's Workforce Data Center. PHI. (2024, October 25). https://www.phinational.org/policy-research/workforce-data-center/#var=Wage+Trends
[28] U.S. Bureau of Labor Statistics. (2024, April 3). Home Health and Personal Care Aides. U.S. Bureau of Labor Statistics. https://www.bls.gov/oes/current/oes311120.htm
[29] Phi's Workforce Data Center. PHI. (2024, October 25). https://www.phinational.org/policy-research/workforce-data-center/#var=Wage+Trends
[30] Phi's Workforce Data Center. PHI. (2024, October 25). https://www.phinational.org/policy-research/workforce-data-center/#var=Wage+Trends

dollar spent boosts the economy by more than a dollar and leads to fewer hospitalizations and out-of-home placements.[31]

Inclusion of Relatives and Household Members as Part of Workforce

Texas has an untapped attendant care pool in family members of children with disabilities. Allowing parents of minor children to be personal care attendants for their children will assist in solving part of the community attendant care crisis. Texas has access to tools to make this happen by considering the "extraordinary care" required by children with disabilities. The assessment of hours a child qualifies for under a waiver or CFC is already determined using a standardized tool administered by a third party serving as an administrative safeguard over hours. The parents' direct care work would be overseen by an independent entity as well. The care provided by the legally responsible person is in the child's best interest because not only does the parent know their child the best, but they are the most reliable people in the child's life. The expected benefit of this change is families will be able to care for their children at home instead of seeking out-of-home placement. In January 2021, the National Academy for State Health Policy wrote a paper outlining the opportunities for states to increase their workforce by taking advantage of these Medicaid flexibilities.

All Texas HCBS waivers should allow members of the individual's household to provide community attendant care and habilitation. Due to the high cost of living and cultural variations among families, many families have multiple generations living under one roof. Family members such as adult children, siblings, grandparents, and others should be allowed to provide the assessed number of attendant hours an individual needs. This is currently allowed in most 1915(c) waivers except for TxHML and the HCS waiver and needs to be extended to those waivers. There would be no increased cost to the state, but improved outcomes for the individual.

Certified Nurse Aides or Licensed Health Aides

Texas is experiencing an extreme nursing shortage which has unduly affected the ability for children with medical complexities to get nursing care in the home. Children are remaining in neonatal intensive care units and pediatric intensive care

[31]Macroeconomic-consequences-of-the-infrastructure. (n.d.). https://www.moodysanalytics.com/-/media/article/2021/macroeconomic-consequences-of-the-infrastructure-investment-and-jobs-act-and-build-back-better-framework.pdf

units for an extraordinary amount of time because home health nurses are unavailable to provide care in the home. Children's hospitals have no other recourse than to call Child Protective Services if the child only has one trained caregiver or needs to work outside of the home. Allowing certified nurse aides/ licensed health aides (LHAs) who are trained to care for children with medical complexities would not only assist in solving the nursing shortage crisis but would also save the state money by using a trained caregiver other than a nurse.

According to a report by the Center for Nursing Workforce Studies at the Texas Department of State Health Services (DSHS), the demand for Licensed Vocational Nurses and Registered Nurses is projected to increase by 39.5 percent in home health from 2022 to 2036, and Texas is projected to face a shortage of nurses by 2036 and even earlier for Licensed Vocational Nurses.[32]

Texas has an opportunity to carefully create a program under which a certified nurse aide/or LHA could provide care under the direction of a Registered Nurse. Individuals would be required to be trained, licensed, and included in a registry. There are similar programs in Colorado and Arizona which have been well received by the states, families, and provider organizations.

Healthcare

Increase Access to Health Insurance for Children with Disabilities

Family Opportunity Act and Medicaid Buy-In for Children

In 2006, the federal government passed The Family Opportunity Act as part of the Deficit Reduction Act. The Act allows 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 percent of the federal poverty level (FPL).[33] 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

[32] Texas center nursing workforce studies. (2024, March.). Nurse supply and demand projection executive summary. https://www.dshs.texas.gov/sites/default/files/chs/cnws/2023_SupplyDemandReport_ExecutiveSummary.pdf

[33] Medicaid buy-in: Catalyst center. The Health & Disability Working Group (HDWG) | Health & Disability Working Group. (n.d.). https://www.hdwg.org/catalyst/cover-more-kids/medicaid-buy-in

Texas Legislature in 2009 with 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.

The Texas legislature estimated the program would initially support 2,412 families to contribute to the cost of their children's care by paying a premium for Medicaid.[34] The fiscal note stated that the intent would be for the program to increase over time to 6,207 families by fiscal year 2014. As of February 2024, there were 484 children in the Medicaid Buy-In program, far less than the 6,207 families the program was estimated to serve in 2014.[35] While the federal legislation allows states to set the financial eligibility at up to 300 percent of the FPL, Texas has chosen a lower financial eligibility of 150 percent. Texas could increase eligibility to 300 percent of adjusted gross income as have other states like Colorado. Eligibility for Colorado's program is 300 percent after income disregards. Texas should also develop an outreach plan to ensure families of children with disabilities know about the option to participate in the program and have correct information about family income. Given the high percentage of uninsured children in Texas, improved outreach is warranted.

Tax Equity and Fiscal Responsibility Act

The 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" after a five-month-old girl in Iowa contracted encephalitis in the early 1980s 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.

As of 2022, 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

[34] 81(R) SB 18 - House Committee report version - fiscal note. (n.d.). https://capitol.texas.gov/tlodocs/81R/fiscalnotes/pdf/SB00187I.pdf#navpanes=0
[35] Medically dependent children program monitoring report. (n.d.). https://www.hhs.texas.gov/sites/default/files/documents/medically-dependent-children-program-monitoring-report-april-2024.pdf

programs bringing the total number who participate to 21.[36] New Hampshire's Home Care for Children with Severe Disabilities program uses a single pathway to Medicaid for children with disabilities under a state statute. It disregards parental income for children who need an institutional level of care, including the type of care associated with Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID). This includes children with disabilities, including those with serious emotional disturbances, developmental disabilities, or physical disabilities, and thus is much broader than most TEFRA programs.

The Louisiana legislature passed a bill, Act 421 of the 2019 Regular Legislative Session creating a TEFRA option for children with disabilities living at home to receive Medicaid coverage if they meet an institutional level of care for Intermediate Care Facilities for, nursing facility or hospital. Louisiana Medicaid received approval from CMS to implement the program as a State Plan Amendment effective January 1, 2022.[37]

Collect Better Healthcare Data

Centralized statewide registry for children with medical complexity to inform future policy and system improvements through data-informed and data-driven best practice standards and quality outcome measures

Texas has a tremendous opportunity to build on the success and momentum of the work of complex care pediatricians, families, providers, advocates, and others aimed at creating effective systems of care for children with medical complexity (CMC) and their families. CMC are a subset of children with special health care needs who are the most medically fragile. Recent adverse experiences with disenrollment of CMC from Medicaid during the Medicaid Unwinding, highlighted the importance of a centralized data registry for children with medical complexity. One of the benefits of centralized data registry for children with medical complexity is

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[36] Tefra. Center for Innovation in Social Work & Health. (2021, November 5). https://ciswh.org/project/the-catalyst-center/financing-strategy/tefra/#:~:text=Currently%2C%2018%20states%20and%20the,Katie%20Beckett%20State%20Plan%20Option

[37] Permanency Planning and family-based alternatives. (n.d.). https://www.hhs.texas.gov/sites/default/files/documents/permanency-planning-family-based-alternatives-july-2024.pdf

mitigating loss of coverage and ensuring access to care for this vulnerable population.

Children with complex medical needs make up less than 1 percent of the total Texas Medicaid population but nearly 40 percent of the costs to our state. CMC account for some of the highest utilizers of health care system resources and are a population with the greatest potential to implement positive, evidence-based, and cost-saving measures. Identification and access to comprehensive data about this population, which is currently unavailable and inaccessible, through a centralized, statewide registry would:

- Improve access to care and tracking of outcomes for children with complex medical needs;
- Ensure more effective, data-driven designation and utilization of resources and state funds;
- Allow tracking of evidence-based clinical care through relevant claims data and help identify opportunities for integration and standardization of best practice and minimum standards of care;
- Help identify redundancies and deficits; and
- Provide data to identify cost-effective efforts leading to decrease potentially preventable emergency department and other high-cost, resource utilization.

The opportunity of such a statewide registry for children with medical complexity to help inform future policy and system improvements through data-informed and data-driven best practice standards and quality outcome measures is great. The potential collaboration and work with a qualified health-related institution, the state's existing All Payor Claims Database, and an advisory board to inform the creation and long-term sustainability of a data registry for CMC are opportunities that are welcome and need to be explored.

HHSC has developed some requirements to support sharing and transparency for Admit-Discharge-Transfer (ADT) data. These same concepts can be leveraged to ensure HIPAA compliant, shareable data to support improving access to care and tracking of outcomes for children with complex medical needs.

Develop and Appropriately Funded Integrated and Coordinated Healthcare

Funding for Comprehensive Care Clinics

According to the 2020-2021 National Survey of Children's Health, 24.8 percent of Texas children with complex health care needs receive coordinated, ongoing, comprehensive care within a medical home, compared to 38 percent of children nationally. In communities where there are enhanced health homes – dedicated to medically fragile children, the opportunities for better integration of care coordination services have not been adequately explored, utilized, and incentivized. These clinics have a longitudinal relationship with families and provide care coordination, social services and are well networked with the local specialist panels and children's hospitals. However, there is no template on how to fold this existing resource into a viable center of excellence. These centers, including the few transition clinics in the states, could serve as bright spots for evidence generation on best practices. Absent any template for collaboration and no direction or incentivization from the state, leaders of most of these clinics spend a lot of time and energy trying to craft contracts with multiple health plans with reimbursement rates that cover only a small fraction of the center's budget. As most are supported by a combination of grants and subsidies, their financial viability is tenuous and will likely jeopardize the care of hundreds of children with medical complexities.

Improve Network Adequacy in Medicaid

Increase the number of primary and specialty care providers available to care for children and young adults with medical complexities who are aging out of pediatric care

The geographic size and rural composition of much of Texas has created barriers for some children transitioning from pediatric to adult physicians. Rural areas often lack physician availability to accept complex medical cases while those who do often have lengthy new patient wait times. These barriers have negatively impacted the member's ability to receive care timely, make adult provider selections, and have a seamless transition to adult services. As a result, many young adults are remaining with pediatric providers when they should be seeing adult care providers. In addition, many adverse and preventable complications for medically complex individuals result when the handoff to adult care is not carefully coordinated and planned for.

Expand and improve health care transition for children moving from pediatric to adult care

According to the American Academy of Pediatrics, American Academy of Family Physicians, and the American College of Physicians 2018 Clinical Report on supporting health care transition (HCT) from adolescence to adulthood, evaluation studies document beneficial outcomes of a structured transition process in terms of quality of care, appropriate service use, and improved patient and family experience. Unfortunately, the majority of Texas families of youth with special health care needs between the ages of 12 – 17 reports not receiving the services needed to make the necessary transitions to adult health care, work and independence. Only 16.9 percent of families surveyed in the 2020-2021 National Survey of Children's Health, report positive transitions to adult health care, work, and independence.[38] The national average is 20.5 percent. Texas can improve the transition outcomes of the youth through innovative transition pilots that include value-based payments and payment and quality options.[39]

Physician Education and Training about Health Care Transition

The State of Texas can support physicians and their patients with disabilities through the adoption of educational expectations for transition of care services. Like H.B. 2059, through which the state legislature required clinicians providing direct patient care to participate in human trafficking prevention education for license renewal requirements for the Texas Medical Board, so too can the legislature endorse a continuing medical education requirement for transition planning education.

Investment in this recommendation will result in timely widespread adoption of the latest best practices for transitions of care, keep clinicians updated at least biannually on any important changes or developments, result in potential medical savings across the state through reduced medical errors, and an overall healthier population.

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[38] U.S. National Library of Medicine. (n.d.-a). White Ph, Cooley WC; Transitions Clinical Report Authoring Group; American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians. supporting the health care transition from adolescence to adulthood in the medical home. pediatrics. 2018;142(5): E20182587. Pediatrics. https://pubmed.ncbi.nlm.nih.gov/30705144/

[39] McManus, M., White, P., Schmidt, A. (2024, February 9). *Recommendations for value-based transition payment for pediatric and Adult Health Care Systems*: A Leadership Roundtable Report. Washington, DC: The National Alliance to Advance Adolescent Health, 2018. Lucile Packard Foundation for Children's Health. https://www.lpfch.org/publication/recommendations-value-based-transition-payment-pediatric-and-adult-health-care-systems

Addition of the requirement for completion of dedicated continuing education for professional licensure would result in all physicians receiving regular, updated refresher training with each license renewal. Education that is relevant, online, and easily accessible across multiple devices (and potentially free) is the best way to deliver content, allowing professionals to access content at their own pace and in their preferred setting. Multiple training modules have been developed specifically addressing the unique requirements of Young Adults with Special Health Care Needs (YASHCN) and for persons with IDD, with the curriculum in IDD health care having been proved effective in improving confidence in delivering care to the IDD population among professional school trainees as well as clinicians in practice.[40]

Pilot a Service Fulfillment Network Adequacy Measure for Long-Term Services and Supports in Medicaid

Families report difficulty getting the long-term services and support they are authorized to receive including Personal Assistance Services, CFC, Private Duty Nursing, and therapy. According to a 2018 report by the Community Living Policy Center, 31 percent of states are utilizing some kind of service fulfillment standard for in-home services. These standards typically measure the gap between hours authorized and hours received.[41] There is an opportunity for Texas to pilot this kind of measure using the current Electronic Visit Verification system.

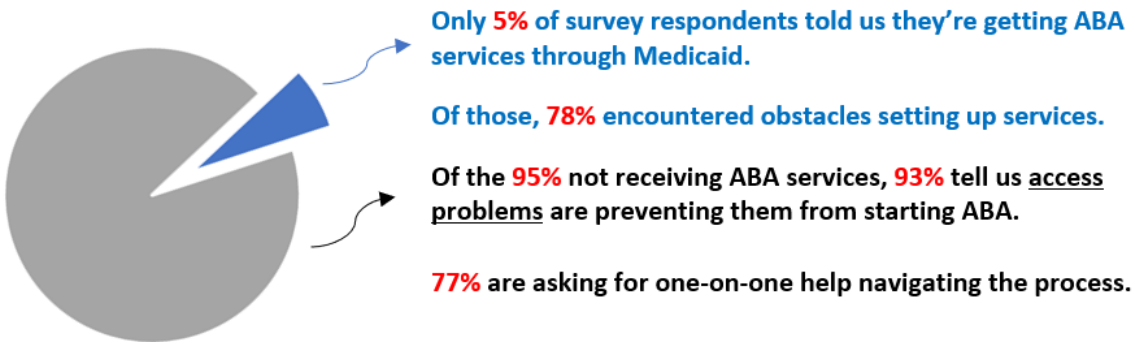
Improve Access to Autism Services

Improve Access to Applied Behavioral Analysis

According to Autism Speaks, in the fall of 2022 they conducted a survey asking for feedback on Texas Medicaid's new Applied Behavior Analysis benefit and hundreds of people responded.[42] Below is a summary of some of the responses.

[40] Mediawire. (2013, September 16). 2022-08. MÃ©lange Magazine Publications. https://reader.mediawiremobile.com/epmagazine/issues/208032/viewer?page=31
[41] Ne'eman, A. (2018, December). Managed long-term services and supports. https://heller.brandeis.edu/community-living-policy/images/pdfpublications/2018decembermltss-assessing-provider-network-adequacy.pdf
[42] Benestante, J., & Benestante, J. (2023, November 6). *ABA/Medicaid benefit- rate hearing 11/14/23*. Autism Society of Texas. https://www.texasautismsociety.org/aba-medicaid-benefit-rate-hearing-11-14-23/

Figure 7: Survey results on Texas Medicaid's new Applied Behavior Analysis benefit.



Parents are struggling to find ABA providers for children with Medicaid. The reimbursement rates for ABA under the Medicaid benefit have not been high enough for many providers to be able to take children on Medicaid. In addition, the process to become a Medicaid/ABA provider has been long and challenging. These factors have led to a slower rollout of the ABA benefit and a lack of therapy providers, which in turn has impacted families across the state who are struggling to find a provider that takes Medicaid, or they if they find a provider, their children are on long waitlists to begin receiving needed services.[43]

Increase Funding for Autism Services Program

According to HHSC's Autism Services Program, autism spectrum disorder is the fastest growing serious, developmental disability, affecting an estimated one out of 36 children in the United States. With this number growing at a significant rate, there continues to be an unmet need for services.[44]

The Health and Human Services Children's Autism Program provided services to 791 children with autism in FY 2024. The program provides invaluable support and help to improve the quality of life for children on the autism spectrum and their families.

[43] Benestante, J., & Benestante, J. (2023, November 6). *ABA/Medicaid benefit- rate hearing 11/14/23*. Autism Society of Texas. https://www.texasautismsociety.org/aba-medicaid-benefit-rate-hearing-11-14-23/
[44] Children's autism program. Texas Health and Human Services. (n.d.). https://www.hhs.texas.gov/services/disability/childrens-autism-program

Create and Strengthen Continuum of Support for Children with Mental Health Concerns

Strengthen the operation of one system of care for all children and youth.

Effective evidence-based system of care models such as Help Me Grow, which is currently operational in 12 Texas communities under the affiliation between the Department of State Health Services and Help Me Grow National recognize that key components are necessary to function with fidelity, and program opportunities must be aligned based on resulting evaluation and outcome data. Key core components must include Centralized Access and Navigation, Family Engagement, Provider Support and Training, and Evaluation and Outcome Data and Research. One key organization must assume the organizing responsibility as well as continuous quality improvement and scale and spread strategies.

The system of care must be cross sector (healthcare, childcare, education) and be equipped with knowledge and resources covering prenatal to 18 years of age. Supports, resource, and programs address children with dual diagnoses and span across promotion, prevention, intervention, and crisis services and supports. Navigation occurs across a spectrum of universal to intensive with some elements of targeted universalism.

Embed navigators across partner organizations within communities and strengthen their knowledge of children with dual diagnoses and resources across the behavioral health and child welfare system.

Strengthen the centralized access and navigation component of the system of care through training existing staff in partner organizations to operate within the framework of the system of care model and within the same information and referral system. Building upon an existing pilot in Texas, utilize identified case managers, navigators, community health workers, and home visitors to ensure that families only have to enter the system at a single-entry point and via standard screenings have needs identified and referrals made to match their needs across partner organizations.

Broaden eligibility for existing community services through diversifying funding streams, allowing for dual diagnosis service provisions, and allowing for greater clinical expertise in creating program plans with families which wrap around the family and youth to support the youth being successful in remaining in their home environment.

Program eligibility restrictions related to single funding sources result in families and children being required to go through multiple evaluation and eligibility evaluations rather than having integrated comprehensive evaluations from a team equipped and knowledgeable across diagnoses and conditions. Single funding sources pose barriers for families to receive appropriate services due to programs and services frequently being tied to a single diagnosis. Families benefit from service providers having a wrap around, team approach in which the team has blended funding streams and vast knowledge and expertise which allows for collaborative care and provision of services.

Provide respite to families.

Families' need for respite are quite varied and require a continuum of respite opportunities to address those unique needs. Current respite models such as the procedures utilized within the ECI program for families whose needs can be addressed within their home environment by providers familiar to the family and child are good examples of low intensive respite needs and appropriate service models while current adolescent crisis respite units funded for youth with therapeutic needs that require more intensive levels of support for both the family and youth are available in limited communities across the state. Missing from the current continuum of respite options in prevention respite strategies such as day respite out of home and highly intensive strategies such as longer term therapeutic out of home residential services.

Create short term diagnostic centers that provide a 30 - 60 day enriched diagnostic period to better identify diagnoses, needs and provide recommendations for continued therapeutic needs and care.

Improve Residential Treatment for Children.

The current therapeutic opportunities available for children within the child welfare system are not available for those who are at risk of placement in the system. Additionally, opportunities for residential treatment, therapeutic foster care, and

intensive psychiatric rehabilitative services for children at risk would provide not only therapeutic benefit, but also potentially have a positive impact on children remaining within their homes. Intensive psychiatric rehabilitative services are also needed within the state of Texas to allow for keeping children closer to their loved ones and homes.

Community

Depression and anxiety are the most frequently identified mental health conditions among people with IDD, but the prevalence of schizophrenia is disproportionately high. Additionally, people with IDD frequently have behavioral health needs that are the result of post-traumatic stress. The behavioral health system in Texas has begun to focus more specifically on the mental health and wellness of those with IDD. People with IDD should have access to quality behavioral health services, trauma-informed care, and opportunities for recovery. Additionally, supports should be adequate in both approach and intensity to avoid unnecessary hospitalizations or incarcerations.

Research indicates that youth involved in the justice system experience disabilities at a rate approximately three times higher than that of youth without disabilities. As a state, it is imperative that the state continue to systematically evaluate strategies to mitigate juvenile justice involvement among youth, enhance the provision of services aimed at reducing recidivism, augment the deployment of peer support specialists for justice-involved youth and strengthen access to crisis services for persons dual diagnosed with IDD and mental and behavioral health needs. By strategically addressing these focus areas, the state can initiate a reduction in the level of involvement.

Bolster mental health and behavioral health services available in schools and the community to divert youth and young adults with disabilities away from juvenile justice system involvement.

- Provide trauma informed or person-centered training for youth with mental health or mental health/intellectual disability dual diagnoses to include available community and state resources to assist with prevention of juvenile involvement.

- Partner youth with mentors to ensure understanding and guidance is available to help avoid initial juvenile involvement or to decrease odds of reentering the juvenile justice system.
- Partner with DFPS or other state agencies to identify youth at risk of re-offending or re-entering the juvenile justice system to offer different options and strategies to lead to a different outcome.[45]
- Provide funding for specialized training for law enforcement and correctional officers on interacting with youth or young adults who may have disabilities.

A web-based series of training courses has been developed and is offered free of charge online. The series, Mental Health Wellness for Individuals with Intellectual and Developmental Disabilities (MHW-IDD), is available at http:// training.mhw-idd.uthscsa.edu/. The course consists of the following six modules:

- Co-occurring Disorders: Intellectual and Developmental Disabilities and Mental Illness
- Trauma Informed Care for Individuals with IDD
- Functional Behavioral Assessment and Behavior Support
- Overview of Genetic Syndromes Associated with IDD
- Overview of other Medical Diagnoses Associated with IDD
- Putting it all Together: Supports and Strategies for Direct Service Workers

Expand Crisis Systems of Care and Pre-Arrest Diversion Strategies including coordinated mental health

Behavioral health and justice systems face challenges from the growing number of people experiencing behavioral health crises. In many communities across Texas, there are few options available for a person in crisis. Law enforcement agencies, emergency departments, jails, and prisons have become the safety nets, yet are often underequipped to provide the care people need. Incorporated into the Texas Statewide Behavioral Health Strategic Plan, "Strategic Planning and Listening Session Themes", a proposed strategies section was developed that integrated a significant portion of this subcommittee's discussions. Throughout the strategic planning and listening sessions, multiple stakeholders emphasized the importance

[45]Detention of persons with IDD. (n.d.-b). https://www.tcjs.state.tx.us/wp-content/uploads/2020/12/Detention_of_Persons_with_IDD.pdf

of State and local partners working together to better address the behavioral health needs of people and the community and to enhance diversion opportunities.

Below are strategies that focus on from the strategic plan and the committee:

- Developing a resource hub on diversion programs;
- Communicating information about diversion programs to stakeholders (public, communities, schools, faith-based communities, etc.);
- Increasing the use of diversionary paths, specialty courts, and relevant reentry efforts for special populations;
- Establishing mental health defender programs that cover every county in the state;
- Ensuring that every community has a place where people can voluntarily receive de-escalation, respite, and connection to services, particularly places that offer peer support;
- Utilizing trained mental health law enforcement to respond to crisis calls;
- Diverting mental health calls, when safe and feasible, away from law enforcement;
- Training 911 operators to dispatch mental health calls to mental health providers;
- Developing diversion programs in rural counties;
- Ensuring all crisis services are safe, accessible, accountable, and well-funded; and
- Leveraging technology to support crisis response and diversion.

The Opportunity to Strengthen Local Collaborations

Cross-system collaboration is key to ensuring better outcomes for people with diagnosable MI, SUD, and/or IDD. Collaboration can be difficult and funding "silos" make cross-systems efforts more challenging. Limited resources create a competitive and/or protective environment. Systems represent different cultures with their own histories, languages, values, concerns, and operations. Positively, collaboration fosters comprehensive thinking, brings diverse people, organizations, and sectors together, and can change the way communities solve problems. Throughout the strategic planning and listening sessions, participants emphasized the importance of bringing behavioral health, justice, housing, and other key stakeholders together to address issues facing their community. Specifically, participants suggested the plan include strategies that focus on:

- Refining and enhancing a full continuum of care for people who are justice involved through local collaboration and coordination;
- Establishing forensic services coordinators that cover every county in the state;
- Strengthening relationships between housing, justice, and behavioral health services to improve reentry, reintegration;
- Strengthening local behavioral health and law enforcement collaborations;
- Offering opportunities for team building between state hospitals and community partners;
- Supporting increased collaboration between state hospitals, jails and LMHAs/LBHAs to improve the initial handoff when people are released from jail and returning to the community;
- Individual plan for Integrating (IPI) back into their assigned settings; and
- Utilizing person centered, age-appropriate practices.

The Need for Cross-System Training and Education

Robust community-based care and supports can help minimize justice contact for people with diagnosable MI, SUD, and/or IDD. Such programs also provide opportunities for diversion once a person is involved in the justice system. Collaboration, education, and cross-training (involving both justice and behavioral health stakeholders) is critical in driving practice and policy changes. Throughout the strategic planning and listening sessions, participants identified multiple strategies to build on and enhance cross-system training and education for law enforcement, behavioral health providers, courts and the judiciary, sheriffs, state hospitals, and other key stakeholders. Specifically, participants suggested this plan include strategies that focus on:

- Developing a coordinated resource and technical support strategy;
- Educating judges and defense and prosecuting attorneys on the components of quality competency evaluations;
- Promoting general education for the public on how to access treatment and avoid justice-involvement;
- Improving mental health training for attorneys;
- Providing trauma-informed training for law enforcement;
- Promoting Mental Health First Aid for all professionals working with people who have diagnosable MI, SUD, and/or IDD;

- Promoting awareness across the SIM of MH, SUD, and IDD resources that exist in local communities;
- Promoting general training and awareness on the importance of diversion to all stakeholders across the SIM;
- Developing community education and awareness campaigns regarding local community resources and SUD treatment; and
- Expanding academic partnerships with local partners, including city and county governments.

Increase the utilization of peer support specialists for justice-involved youth and young adults

One of the recommendations is to expand the current certification process for mental health peer specialist to focus on persons with IDD and MH to eliminate barriers such as cost and time requirements. The certification can be expanded based on the Texas Health and Human Services Commission peer support certification for the state Medicaid Program Peer Specialist certification effective January 1, 2019.

The rules established to permit peer support specialists to provide services in carceral settings to persons dually diagnosed with mental health and IDD conditions should include:

- Establish training requirements for IDD/MH peer specialists;
- Establish certification requirements for IDD/MH peer specialists;
- Define the scope of services IDD/MH peer specialists may provide;
- Distinguish IDD/MH peer services from other services that a person must hold a license to provide; and
- Develop any other rules necessary to protect the health and safety of persons receiving IDD/MH peer services.[46,47]

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[46] 85(R) HB 1486 - enrolled version - Bill Text. (2017). House Bill 1486 https://capitol.texas.gov/tlodocs/85R/billtext/html/HB01486F.HTM

[47] Texas Statewide Behavioral Health Strategic Plan - 2022-2026. Texas Health and Human Services. (n.d.). https://www.hhs.texas.gov/reports/2022/11/texas-statewide-behavioral-health-strategic-plan-2022-2026