

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**

**Texas Health and Human Services
November 2022**



TEXAS
Health and Human
Services

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 2022

Contact Information

For more information on this report, please contact:

Lisa Gore, M.S. CCC-SLP, Chair

Family Representative

Tulia

Email: lisa.gore@ttuhsc.edu

Table of Contents

1. Letter from the Chair	1
Message from the family members of the Policy Council for Children and Families	3
2. About the Policy Council for Children and Families	5
Policy Council for Children and Families Membership.....	6
3. Executive Summary	8
4. Long Term Services and Supports Workgroup Recommendations	9
Policy Issue: Improve access to Medicaid and cost-effective services for children with disabilities	9
Policy Issue: Strengthen and expand the community attendant and in-home nursing workforce.....	15
Policy Issue: Ensure children with disabilities grow up in families and continue to live in families and in the community as they age.	19
Policy Issue: Promotion of children’s mental health well-being and crisis prevention and intervention.....	27
5. Holistic Approach to Transition Workgroup Recommendations	35
Policy Issue: Physician education to provide training about health care transition (pediatric to adult, hospital to home, handoffs).	35
Policy Issue: Addressing health care is not currently part of school transition planning requirements.....	39
6. Autism Spectrum Disorder Workgroup Recommendations	43
Policy Issue: Requiring an ASD diagnosis or reconfirmation within three years of treatment is unnecessary, costly, and reduces access to care.....	43
Policy Issue: People with ASD have difficulty accessing ABA services.....	46
Policy Issue: Current use of the Autism Supplement in the IEP is not being used effectively to address gaps in education.	47
7. Child Care Workgroup Recommendations.....	52
Policy Issue: Ensure children with disabilities have access to high quality, inclusive child care settings.	52
8. Education and Employment Workgroup Recommendations	58
Policy Issue: Increase the funding allocation for ECI services for eligible infants and toddlers.	58
Policy Issue: Youth and young adults with disabilities need additional educational support to enter the workforce upon graduation from high school.....	61
Policy Issue: Minimal training is in place for special education inclusion in undergraduate educator training programs.	62
Policy Issue: Family support is critical to student success.....	66
Policy Issue: Current HHSC policy for newborn hearing screening may delay care for children who are Deaf or hard of hearing.	67
9. Conclusion.....	72
List of Acronyms	73

1. 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:

- Strengthen and expand the community attendant workforce.
- Address waiver interest list access, eligibility, and funding to increase the number of children growing up in families instead of institutions.
- Increase the threshold allowance for Medicaid Buy-in for Children and Adults to 300 percent of federal poverty level (FPL).
- Provide physician education for transition of care planning.
- Improve access to applied behavior analysis (ABA) services for children with autism spectrum disorder (ASD) by increasing funding levels for ABA services and addressing challenges with access to care.
- Support children with disabilities and their families with child care needs by providing training for licensed child care facilities to increase awareness of the requirements of the Americans with Disabilities Act.
- Increase funding for Early Childhood Intervention (ECI) programs to improve the amount of provider support available to care for children with disabilities.

- Data facilitation between providers to allow for timely referral and continuity of care.

The life-trajectory of child with a disability depends on the choices made by lawmakers and policymakers. These choices have far ranging impacts that will either support or limit our children's well-being and quality of life.

Over the past two years, we have seen how the novel coronavirus (COVID-19) federal public health emergency (PHE) has exposed cracks and amplified deficiencies in medical delivery systems and educational systems intended to provide care and resources to Texas children with disabilities and their families. Delays in authorizations for care and shortages of medicine and medical equipment have contributed to negative health outcomes and poorer quality of life as compared to children without disabilities.

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

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.
- First responders need additional resources to learn about types of disabilities and how to provide accessible communication in response to families and individuals in crisis.
- Plan and prepare for emergency situations such as natural disasters.
- Be committed to educating key decision-makers about the impact their decisions can have on the lives of Texans with disabilities and their families.

¹ Tally, Moses. (2017). Suicide attempts among adolescents with self-reported disabilities. Child psychiatry and human development. Retrieved October 25, 2022, from <https://pubmed.ncbi.nlm.nih.gov/29030735/>

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!

2. 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 is costly and negatively impacts all areas of the child's development. We must provide the services and supports families need to prevent the institutionalization of children with disabilities.
- Medicaid home and community-based services (HCS) 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

Voting Members

Lisa Gore, MS, CCC-SLP, Chair

Family Representative
Tulia

**Lisa Brodie, MA, CCC-SLP, Vice
Chair**

Family Representative
Deer Park

Bianca Ramirez, LCSW

Family Representative
San Antonio

Mary Helen Briones, LVN

Family Representative
San Angelo

Nicolas Morales

Youth Representative
San Antonio

Elizabeth Tucker

Advocacy Organization Representative,
EveryChild, Inc.
Austin

Martha Aguilar

Texas Parent to Parent
Austin

Sara Daugherty, MSN

Business Development Senior Director
Dell Children's Health Plan/Ascension
Insurance, Austin

Lori Urbina-Patlan

Family Representative, MEd, Special
Education Teacher, Edinburg

Mary Klentzman

Faith-based Representative, Powered
to Move, Plano

Dr. Matthew Okoro

Family Representative, Advance
Diagnostic Hospital Systems
Friendswood

Dr. Christine Murphy

Director of Pediatric Special Services
Division and Complex Care Clinic,
University of Texas Medical Branch at
Galveston, Dickinson

Dr. Michael Lindsey

Southern Methodist University/Nestor
Consultants, Inc., Dallas

Laura Kender

Mental Health Service Provider, My
Health My Resources of Tarrant County
Arlington

Brandy Jones

Advocate for Children and Families with
Autism Spectrum Disorder, Healing 4
Autism Outreach Ministry, Dallas

Ex Officio Members

Ivy Goldstein, Texas Department of State Health Services

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.

- Greg Mazick, RN, BSN
- Rona Statham, EveryChild, Inc.
- Patrick Randall, Health and Human Services Commission, Health, Developmental & Independence Services
- Linda Logan, Texas Council for Developmental Disabilities
- Heather Kuhlman, Health and Human Services Commission Policy and Program Development
- Jennifer Gonzales, Texas Department of Family and Protective Services

3. 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 supports that empower children with disabilities to achieve a good life and to give families the tools to help them along their path to success.

In 2001, the Executive Commissioner of the Health and Human Services (HHS) system established the 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 (HB) 1478, 77th Legislature, Regular Session, 2001.

PCCF has released several reports since its establishment in 2001. The last biennial report, written in 2020, included recommendations on funding of current and expansion of 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, continuity of member care emergency response during the federal PHE, ensure proactive communication and involvement for families utilizing Medicaid during the federal PHE, 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 2021.

Building on its 2020 report, the PCCF's second 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).

4. Long Term Services and Supports Workgroup Recommendations

Policy Issue: Improve access to Medicaid and cost-effective services for children with disabilities

Medicaid is vital for families of children with disabilities. Not only does it provide critically necessary health coverage to children with complex health care needs, but it is also the payor of long-term services and supports that allow children with disabilities to grow up in their homes and communities. The receipt of supports in the home prevents costlier institutional admissions. Since 2002, the number of children living in large institutional settings has decreased by approximately 69 percent.² If Texas is to sustain this trend, the state needs to ensure families have access to lower cost preventative services and long-term services and supports that allow children to remain healthy and allow families to remain intact as well as comprehensive waiver services for children who need support to move from an institution to a family. Currently children and families are waiting years for the support they need not only threatening the health of the child, but the well-being of the entire family.

Texas has one of the highest rates of uninsured children in the country. According to 2019 data from the US Census Bureau, the national average of uninsured children is 5.7 percent. Texas leads the country in the number of uninsured children under the age of 19 at 12.7 percent or 995,000 children. According to Georgetown University's Center for Children and Families in Washington, D.C., "No other state is even in double digits".³

In addition, according to the US Department of Health and Human Services 2019-2020 data from the National Survey of Children's Health, families

**31% OF TEXAS
FAMILIES RAISING
CHILDREN WITH
SPECIAL HEALTH
CARE NEEDS WHO
HAVE HEALTH
INSURANCE REPORT
THEIR INSURANCE IS
INADEQUATE.**

**Figure 1: Quote about
insurance needs for families
of children with disabilities**

² <https://www.hhs.texas.gov/sites/default/files/documents/permanency-planning-and-family-based-alternatives-report-july-2022.pdf>

³ <https://kidshealthcarereport.ccf.georgetown.edu/>

who do have insurance report their insurance is inadequate.⁴ That number is slightly higher in only six other states. It does not pay for all the services their children need, does not provide access to the providers their children need, and the out-of-pocket expenses are not reasonable and is not continuous throughout the year. Medicaid offers children better benefits with much lower cost-sharing, but access to Medicaid is limited because of family income restrictions.

Texas has several options to offer both uninsured and privately insured families to get the extra help they need in paying for their child's care through Medicaid. Improving access to Medicaid for children with disabilities and allowing more families to contribute to the cost of Medicaid premiums and improving access to lower cost waivers for children who meet an institutional level of care thereby reducing the need for a more comprehensive community-based waiver and reducing HCS waiver interest lists.

TEXANS HAVE LONG BEEN PROUD OF LEADING THE U.S. IN A VARIETY OF WAYS — OUR STATE IS RANKED FIRST IN EXPORTS AND ENERGY PRODUCTION, TO NAME JUST TWO. ONE DISTINCTION, HOWEVER, ISN'T SOMETHING TO BRAG ABOUT: TEXAS HAS BOTH THE HIGHEST NUMBER AND THE HIGHEST PERCENTAGE OF UNINSURED RESIDENTS IN THE NATION.

Figure 1: Excerpt from March 2020 Texas Comptroller's Report.

Source: <https://comptroller.texas.gov/economy/fiscal-notes/2020/oct/uninsured.php>

Recommendations

1. Apply the Family Opportunity Act's family income limit of 300 percent of the FPL 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 care.
2. Institute a Tax Equity Fiscal Responsibility Act (TEFRA) option for children who meet an institutional level of care to prevent placement in a facility.
3. Align the TxHML waiver's financial eligibility requirements with the other Texas HCS waivers so children can access the lower cost tiered waiver in lieu

⁴ <https://www.childhealthdata.org/browse/survey/results?q=8596&r=45>

of a more costly comprehensive waiver and remove the requirement that children with related conditions have an IQ below 75.

4. 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.

Discussion

Family Opportunity Act and Medicaid Buy-In for Children

In 2005, the federal government passed The Family Opportunity Act as part of the Deficit Reduction Act. The Act 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 FPL.⁵ This option allows families of children with a disability determination to pay a premium to access Medicaid. Texas is one of only a few states that used this Act to create a Medicaid Buy-In option for children. Texas' program was passed by the Texas Legislature in 2009 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.⁶ 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 September 2022, there were 758

THE COLORADO MEDICAID BUY-IN FOR CHILDREN WITH DISABILITIES HELPED REDUCE THE WAIT LISTS FOR WAIVER SERVICES BECAUSE FAMILIES WITH INCOME BELOW 300% FPL CAN NOW BUY-IN TO MEDICAID FOR THEIR CHILDREN WITH DISABILITIES.

Figure 2: Quote from The Catalyst Center

Source: <https://ciswh.org/project/the-catalyst-center/financing-strategy/medicaid-buy-ins/>

children in the Medicaid Buy-In program, far less than the 6,207 families the program was estimated to serve in 2014.⁷ While the federal legislation allows states to set the financial eligibility at up to 300 percent of the FPL, Texas has chosen a

⁵ <https://ciswh.org/project/the-catalyst-center/financing-strategy/medicaid-buy-ins/>

⁶ <https://capitol.texas.gov/tlodocs/81R/fiscalnotes/pdf/SB00187I.pdf#navpanes=0>

⁷ <https://www.hhs.texas.gov/sites/default/files/documents/medically-dependent-children-program-monitoring-sept-2022.pdf>

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. Given the high percentage of uninsured children in Texas, improved outreach is warranted.

TEFRA

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.

Currently 18 states and the District of Columbia have a TEFRA state plan option. In addition, two other states, New Hampshire and Arkansas have TEFRA look alike programs bringing the total number who participate to 21. 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.

- HELP ENSURE CHILDREN WITH COMPLEX HEALTH NEEDS RECEIVE MEDICALLY NECESSARY SERVICES
- PREVENT FAMILY FINANCIAL HARDSHIP, MEDICAL DEBT, AND BANKRUPTCY BY REDUCING FAMILIES' OUT-OF-POCKET EXPENSES
- BRIDGE GAPS IN THE SCOPE, AMOUNT, AND DURATION OF HEALTH SERVICES COVERED BY PRIVATE INSURANCE
- REMOVE INCENTIVE FOR FAMILIES TO LEAVE THE WORKFORCE OR DECLINE RAISES TO KEEP HOUSEHOLD INCOME LOW ENOUGH FOR A CHILD WITH COMPLEX HEALTH NEEDS TO QUALIFY FOR MEDICAID, WHICH IN TURN MEANS ALL CHILDREN IN THE HOUSEHOLD
- MAJORITY OF CHILDREN WILL CONTINUE TO HAVE PRIVATE INSURANCE AS PRIMARY SOURCE OF COVERAGE, WHILE MEDICAID IS PAYER OF LAST RESORT.

Figure 3: Quote from The Catalyst Center

Source: <https://ciswh.org/project/the-catalyst-center/financing-strategy/medicaid-buy-ins/>

MDCP and SSI Children

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

AS OF JULY 31, 2022, 6,677 CHILDREN WERE ON THE INTEREST LIST FOR THE MDCP WAIVER. THE WAIT FOR SERVICES IS APPROXIMATELY 2 – 3 YEARS

Figure 4: Number of Children on MDCP Interest List

Unlike the STAR+PLUS HCS waiver 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 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. The average percentage of children who are determined eligible for and accept MDCP when they reach the top of the interest list is 18 percent. HHSC refers to this as uptake rate. This means that only 1,202 of the 6,677 children currently on the list will likely be determined eligible and/or enroll in services.⁸ Approximately 37 percent of them have SSI. 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.

NUMBER OF CHILDREN ON MDCP INTEREST LIST BASED ON 18% UPTAKE RATE

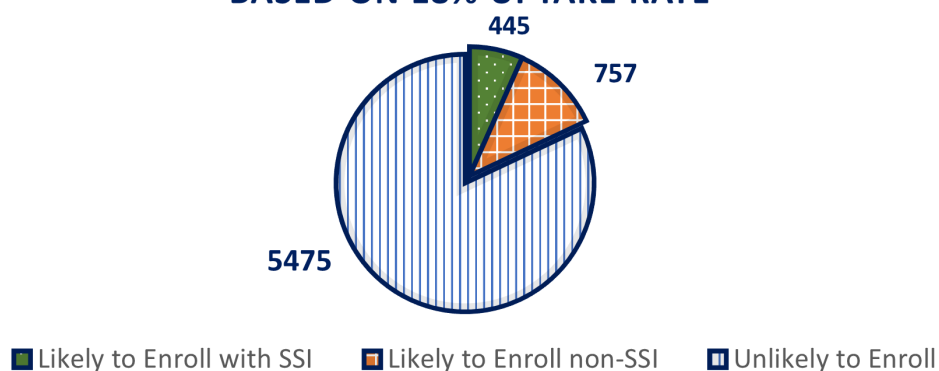


Figure 5: Chart Showing Number of Children on MDCP Interest List

Source: <https://www.hhs.texas.gov/sites/default/files/documents/house-hhs-committee-1115-waiver-may-5-2022.pdf>, Slide 42

TxHML Waiver

The TxHML waiver is Texas' lowest individual cost-cap waiver. It was first authorized in March 2004 to provide essential community-based services and supports to individuals with intellectual and developmental disabilities (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 premise was strong, but because Texas limited

⁸ <https://www.hhs.texas.gov/sites/default/files/documents/house-hhs-committee-1115-waiver-may-5-2022.pdf>, Slide 42

eligibility to only those who have Medicaid, many children and some adults who were engaging in supported employment were deemed ineligible and lost some of the state general revenue funded services they had been receiving. The yearly individual cost cap for the waiver is \$17,000.⁹

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

Policy Issue: Strengthen and expand the community attendant and in-home nursing workforce.

Every state in the country is experiencing an extreme home health care workforce crisis. Texas is no exception except that Texas is in the bottom five states in average pay for home health and personal care aides. The shortage has been exacerbated with the federal PHE and is not getting any better now that the federal PHE is easing. It has become a crisis. The number of families who report difficulty in getting the care they need for their children is high, children's hospitals are unable to discharge children home due to no in-home workforce, and families are resorting to out-of-home placement in facilities. The situation is becoming untenable and there is no relief in sight.

Recommendations

1. Increase wages for community attendants to a minimum of \$15.00 per hour.
2. Amend 1915(c) HCS waivers, 1915(k) Community First Choice, 1115 waivers, and all other HHS programs including ECI to allow parents of minor children, family relatives, and those living in the household, to be providers of home health services such as personal attendant services, habilitation, and respite.
3. Amend Texas Medicaid to include Licensed Health Aides (LHA) including parents as LHAs for children with medical complexities like programs in Arizona and Colorado.

⁹ <https://www.hhs.texas.gov/sites/default/files/documents/doing-business-with-hhs/providers/resources/ltss-waivers.pdf>

Discussion

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 \$8.11 per hour. The U.S. Bureau of Labor Statistics Occupational Employment and Wages May 2021 report lists Texas in the bottom five states nationally for attendant care pay along with Louisiana, Mississippi, Alabama, and West Virginia.¹⁰ The U.S. median wage was more than \$14 per hour with half of all states in the country paying 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."¹¹ 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.

According to a 2021 American Association of Retired Persons (AARP) report, 77

IN THE LOWEST PAYING STATES, HOME HEALTH CARE WORKERS TYPICALLY MAKE LESS THAN \$12 PER HOUR AS COMPARED TO THE NATIONAL MEDIAN WAGE OF \$22 PER HOUR

percent of people over the age of 50 say they want to age in place particularly after the federal PHE where people living in congregate care facilities were at increased risk of the infectious disease.¹²

Figure 6: Economic Policy Institute and New America, June 2, 2022

Investing in the home health workforce will lead to better

care and potential cost savings to the state. According to a report by Zandi and Yaros in 2021 every dollar spent boosts the economy by more than a dollar.¹³ Additionally, better care leads to fewer hospitalizations and out-of-home placements.

10 <https://www.bls.gov/oes/current/oessrcst.htm>

11 <https://www.epi.org/publication/state-home-health-care-wages/>

12 <https://www.aarp.org/home-family/your-home/info-2021/home-and-community-preferences-survey.html>

13 <https://www.moodyanalytics.com/-/media/article/2021/macroeconomic-consequences-of-the-infrastructure-investment-and-jobs-act-and-build-back-better-framework.pdf>

Inclusion of Relatives and Household Members as Part of Workforce

Texas has an untapped attendant care pool in parents and household 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 Community First Choice is already determined using a standardized tool administered by a third party serving as an administrative safeguard over hours. The parent’s 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

1 IN 6 HOME HEALTH CARE WORKERS LIVE BELOW THE POVERTY LINE AND DEPEND ON GOVERNMENT SAFETY NET BENEFITS TO MAKE ENDS MEET.

Figure 7: Economic Policy Institute and New America, June 2, 2022

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 has written a paper outlining the opportunities for states to increase their workforce by taking advantage of these Medicaid flexibilities.¹⁴

All Texas HCS 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 Texas Home Living (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.

¹⁴ <https://www.nashp.org/state-approaches-to-reimbursing-family-caregivers-of-children-and-youth-with-special-health-care-needs-through-medicaid/>

Parents as LHAs and Mid-Tier Workforce

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 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 parents who are trained as LHAs to care for children would not only assist in solving the nursing shortage crisis but would also save the state money by using a middle tier person instead of a nurse.

According to a recent 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 outpace the supply of nurses by 2025.¹⁵ It is likely that the supply for home health nurses will be lower than those in other settings.



BEING A MOTHER DOING MY BEST TO PROVIDE FOR MY CHILDREN TO MAKE SURE THEY'RE WELL TAKEN CARE OF IS A DUTY THAT I KNOW ALL TOO WELL. I LOVE EVERY MOMENT BUT THERE ARE HARD TIMES, FOR EXAMPLE, WHEN I'M UNABLE TO GO TO WORK DUE TO NOT HAVING NURSING CARE FOR DARWIN (PICTURED, RIGHT). IT LEAVES ME UNABLE TO WORK AT TIMES, AND WE STRUGGLE. IT WOULD BE A BLESSING TO BE ABLE TO WORK AT HOME WITH HIM AND BE ABLE TO PROVIDE FOR HIS MEDICAL CARE.

¹⁵ <https://www.dshs.texas.gov/legislative/2022-Reports/Healthcare-Workforce-9.pdf>

Texas has an opportunity to carefully create a program under which a family member of a child in Medicaid or another individual designated and approved by the child's parent or guardian may be licensed as a LHA and could provide care under the direction of a Registered Nurse. LHAs under this program 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.^{16,17}

Policy Issue: Ensure children with disabilities grow up in families and continue to live in families and in the community as they age.

It is the policy of the state to strive to ensure that the basic needs for safety, security, and stability are met for each child in Texas. A successful family is the most efficient and effective way to meet those needs. Local communities and the state must work together to provide encouragement and support for well-functioning families and ensure that each child receives the benefits of being a part of a successful permanent family as soon as possible.

Well-established factors that contribute to healthy development that are embedded in most families are missing in even the best congregate care. Institutionalization can negatively impact a child's physical, cognitive, neurodevelopmental, and social-psychological health.

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 General Residential Operations (GRO) licensed by the Department of Family and Protective Services (DFPS) is necessary.

16 <https://hcpf.colorado.gov/programs-parents-and-caretakers>

17 <https://raisingspecialkids.org/2022/04/29/new-licensed-health-aide-program-now-available-to-arizona-parents/>

"BRINGING HER HOME IS THE ABSOLUTE BEST THING WE COULD HAVE DONE. SHE IS AN ABSOLUTE PRECIOUS BUNDLE OF SUNSHINE. HER SMILE NO LONGER LIGHTS UP MY EVERY-OTHER WEEKEND, BUT EVERY GLORIOUS DAY. I THANK GOD FOR HER!"

Figure 9: Quote from mother of child who moved home from Texas nursing facility after seven years

In addition, 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 left behind young adults with medical complexities. 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 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.

Recommendations

1. Ensure Texas' commitment to Olmstead and Texans with disabilities by providing waiver funding to support children and young adults to move from or be diverted from facilities.
2. Fund the waiver interest lists to ensure children and young adults can live with families and in their communities.
3. Provide legislative direction and funding through an appropriation's rider for HHSC to amend the MDCP waiver to create reserved capacity for crisis diversion slots for a targeted group of children who are determined to be medically fragile and at imminent risk of nursing facility admission as an alternative to having to go into a nursing home.
4. Provide legislative direction and funding through an appropriations rider for HHSC to amend the HCS waiver to add Private Duty Nursing to the array of adult services and to allow adults with intense medical fragility to receive Level of Need 9 services instead of institutionalization.

5. Provide legislative direction and funding through an appropriations rider for HHSC to amend the TxHML waiver services to create a set aside number of slots for a targeted group of children graduating high school.
6. Provide legislative direction and funding through an appropriations rider for HHSC to amend the Individualized Skills and Socialization benefit in all waivers to better support individuals with high medical complexity who need supports during the day including individuals who are dependent on ventilators.

Discussion

Since 2002, Texas has experienced a 69 percent decrease in the number of children living in congregate facilities with six or more people resulting in a savings to the state and an improved quality of life for the child and family. Texas through its Family Based Alternatives and Permanency Planning efforts has led the nation in assisting individuals to move from restrictive institutional settings, including nursing facilities and intermediate care facilities, to the community. This includes assistance to families of children with disabilities so that children can grow up in families instead of institutions.

Table 1: Trends in the Number of Children by Institution

Institution Type	Baseline Number as of August 31, 2002	Number as of February 28, 2022	Percent Change Since August 2002
Nursing Facilities	234	55	-76 %
Small ICFs/IID	418	154	-63 %
Medium ICFs/IID	39	14	-64 %
Large ICFs/IID	264	9	-97 %
SSLC	241	116	-52 %
DFPS Licensed IID Facilities	73	47	-36 %
Total	1,269	395	-69 %

Source: Texas HHS Permanency Planning and Family-Based Alternatives Report, July 2022

Promoting Independence

The Texas Legislature has historically funded Medicaid waiver services for children to move from facilities to families and for those at imminent risk of admission to get the supports they need so the family unit remains intact. It is imperative that the work that has been started by the state continue. HCS waivers are needed to help children live in families.

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, 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.

**THE MEDICALLY DEPENDENT
CHILDREN PROGRAM WAIVER IS
CAPPED AT 50% OF THE COST OF
SUPPORTING A CHILD IN A
NURSING FACILITY**

Figure 10: Quote about the MDCP waiver

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.

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 were hard to find prior to the current federal PHE and is even harder now. Families and physicians of children who require ventilation to breathe and whose immune system and health are medically compromised are worried that admission to a congregate facility for even a short stay puts children at greater risk of contracting COVID-19 and requiring further hospitalization.

THE NURSING HOME STAY REQUIREMENT FOR MEDICALLY FRAGILE CHILDREN CAN IMPACT THEIR HEALTH AND COMFORT. FOR PARENTS OF MEDICALLY FRAGILE CHILDREN, TRAVELING TO NURSING FACILITIES IS STRESSFUL. IT COSTS FAMILIES HUNDREDS OF DOLLARS IN TRAVEL, MEALS, AND SUPPLIES NEEDED TO LEAVE THE HOUSE. ALSO, FAMILIES MISS WORK DUE TO TRAVELING TO FACILITIES WHICH AREN'T ALWAYS CLOSE TO HOME.

IT IS A NIGHTMARE THAT I DON'T WANT TO RELIVE, AND LIKE OTHER TRAUMA, I TRY TO FORGET IT. BUT I AM THANKFUL BECAUSE OF THE SERVICES IT LED TO. THERE HAS TO BE A BETTER WAY FOR FAMILIES TO PROVE THE NEEDS OF THEIR MEDICALLY FRAGILE CHILDREN.

Figure 11: Parent of a child who did a nursing stay for her son to qualify for MDCP

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 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 (SB) 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 only Texas Medicaid HCS 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

AT THE SAME TIME THAT OUR SON AGED OUT OF MDCP AND HIS PRIVATE DUTY NURSING BENEFITS WERE SLASHED, MY HUSBAND AND I ENTERED OUR 60'S. WHILE WE BECOME LESS PHYSICALLY ABLE TO DO THE DAILY HANDS-ON CARE, WE MUST DO MUCH MORE OF IT. IT BREAKS OUR HEARTS TO CONSIDER NURSING HOME PLACEMENT FOR OUR VIBRANT 21-YEAR-OLD, BUT FOR AGING PARENTS OF A CHILD WHO REQUIRES NURSING CARE, THERE ARE NO OTHER LONG-TERM SOLUTIONS.



Figure 12: The Benschoter Family

private duty nursing.¹⁸ 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 the young adults.

TxHML Waiver Set Aside for Children Graduating High School

One of the biggest issues facing Texas families of young adults graduating high school is graduating with no access to meaningful things to do during the day. According to the Department of Labor, the employment rate of people with disabilities continues to be very low. As of 2021, only 31.4 percent of adults with disabilities between the ages of 16 to 64 were employed. This is in comparison to 72.5 percent of people without disabilities.¹⁹

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

Texas could create reserved capacity in the 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.

19 <https://www.bls.gov/news.release/pdf/disabl.pdf>

TYKAIER (TY TY, PICTURED, RIGHT) IS A BEAUTIFUL, VIBRANT 26-YEAR-OLD WHO LOVES FAMILY MORE THAN ANYTHING. SHE HAS AN INTELLECTUAL DISABILITY AS WELL AS UNIQUE MEDICAL NEEDS. SHE WAS PLACED WITH A FOSTER CARE FAMILY WHEN SHE WAS 2. EVEN THOUGH FINANCIAL SUPPORT FROM THE STATE STOPPED WHEN SHE WAS 8, THE FAMILY HAS CONTINUED TO LOVE AND CARE FOR HER. THEY PLACED HER ON WAIVER INTEREST LISTS 11 YEARS AGO SO THEY COULD GET SOME HELP, BUT SO FAR, THEY HAVEN'T RECEIVED ANYTHING. TY TY'S PARENTS ARE NEARING RETIREMENT AND THEY WORRY THAT THE SUPPORT SHE NEEDS WILL NEVER COME. TY TY DESPERATELY WANTS TO STAY CLOSE TO DAD, MOM, AND HER BROTHERS AND SISTERS, BUT WITHOUT ADDITIONAL SUPPORT FROM A MEDICAID WAIVER STAYING IN HER SMALL TEXAS COMMUNITY MAY NOT BE POSSIBLE.



Figure 13: Quote from Ty Ty's family

Policy Issue: Promotion of children's mental health well-being and crisis prevention and intervention.

Children with disabilities who have complex needs often require a range of intensive services that “wrap around” their families to help them remain in their homes while they receive care. This requires different service providers to work together and in partnership with families to create a service plan that meets the needs of the youth and the adults who care for them. These more intensive services can include:

- Intensive case management that brings together a team of service providers to partner with the family in developing a care plan.
- Respite care services to help families cope with the stresses of daily care giving.
- Wrap-around supports and specialized therapies.
- Small, short-term crisis centers to allow stabilization and the development of comprehensive supports so the child can return home.
- Specialized out-of-home care for children in trained families in lieu of placement in a residential treatment center.

Recommendations

1. Develop funding mechanisms that support naturalistic, trauma-informed, collaborative treatment methodologies promoting preventative practices aimed to strengthen children's protective factors through building resiliency and developing social connections.
2. Amend Texas Medicaid waivers to allow more in-home respite to families and host families and create a flexible funding stream for respite for those who do not have a Medicaid waiver.
3. Improve access to critical mental health services for children in the Youth Empowerment Services (YES) waiver.
 - a. Provide funding to eliminate the waiting list.
 - b. Increase funding to Local Mental Health Authorities for expedited eligibility assessments, lower caseloads that better serve children with complex mental and behavioral support needs through a wraparound model and reduce administrative burdens.
 - c. Increase rates to providers to address mental health workforce shortages.

4. Include treatment foster care as a Medicaid benefit in lieu of residential treatment center placement for children with serious emotional disturbances even if not in conservatorship of the state.
5. Develop child focused, small, community-based, short-term, therapeutic, emergency out of home living options for children under the age of 22 who are in crisis until reaching stabilization, and a mechanism to fund them using waivers, Medicaid, and flexible funding streams.

Discussion

Funding to Strengthen Children's Mental Health and Well Being

National, state, and local experts including the American Academy of Pediatrics, American Academy of Child and Adolescent Psychiatry, and Children's Hospital Association issued a joint Declaration of a National Emergency in Child and Adolescent Mental Health.²⁰

In any given year, about 1 in 5 children has some type of mental health disorder and about 1 in 10 children have a disorder that substantially interferes with their daily life.²¹ An estimated 350,000 Texas children and adolescents experience severe mental health needs each year. Some of those identified at greater risk are children with disabilities and those with a prior history of trauma like children in foster care. Children with a history of multiple hardships and adversity are at increased risk for negative health, mental health, and social outcomes now and in the future.

The increase in children's mental health concerns effects schools, communities, and the state. The data shows that:

- Nearly 45 percent of children in special education (SpEd) with emotional disturbances drop out of school.²²

20 American Academy of Pediatrics. (10/19/2021) AAP-AACAP-CHA Declaration of a National Emergency in Child and Adolescent Mental Health.

21 Kessler, R.C., Berglund, P., Demler, O., Jin, R., Merikangas, K.R., & Walters, E.E. (2005). Lifetime prevalence and age of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. *Archives of General Psychiatry*, 62(6), 593-602.

22 National Association of State Mental Health Program Directors. (2012). *Too Significant To Fail: The Importance of State Behavioral Health Agencies in the Daily Lives of Americans with Mental Illness, for Their Families, and for Their Communities.*

- In 2021, nearly 40 percent of the youth referred to Texas juvenile probation departments had identified mental health needs.²³
- In 2020, 60 percent of youth entering state juvenile justice facilities had moderate to severe mental health issues.²⁴
- A high number of children in CPS without placement entered foster care because of their mental health needs, not because of abuse or neglect.²⁵

Providing targeted prevention and individualized mental health intervention strategies will support the mental wellness of all children and reduce pressures on schools, public mental health, child welfare, and juvenile justice systems. Mental health prevention and intervention services have multiple benefits: improving access to care; improving participation in treatment; identifying problems early and curbing the effects of mental health concerns among children; and improving children's ability to be successful in school, in the community and at home. A range of prevention and early intervention practices and procedures can help boost key protective factors in children's lives and reduce their risk of developing mental health-related concerns.²⁶

23 <https://www.tjtd.texas.gov/index.php/doc-library/send/338-reports-to-the-governor-and-legislative-budgetboard/3043-annual-report-2021>

24 Texas Juvenile Justice Department 2022-2023 Legislative Appropriations Request.

25 Understanding the Texas Foster Care Capacity Crisis released by the Texas Department of Family Protective Services, the Texas Alliance of Child and Family Services/the Texas Center for Child and Family Studies, and the Casey Family Programs

26 <https://static1.squarespace.com/static/5728d34462cd94b84dc567ed/t/62b39015de529c420ab8f46b/1655934997320/Children%27s+Mental+Health+Policy+Brief+June+2022.pdf>

HAVING TO WORK IS CRITICAL TO SUPPORT YOUR FAMILY AND THIS CAN BE DIFFICULT WHEN ONE DOESN'T HAVE THE MEANS TO PAY FOR HOME SERVICES. WE ASK THAT HHS PROGRAMS ARE AMENDED TO ALLOW FAMILIES TO BE PROVIDERS OF HOME HEALTH SERVICES SUCH AS PERSONAL ATTENDANT SERVICES, HABILITATION, AND RESPITE. YOUR SUPPORT WOULD GREATLY IMPACT FAMILIES LIKE MINE.



Figure 14: The Patlan Family (Pictured above)

Respite

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 30 days of respite per year. This is not always enough to provide families the relief they need. Families dealing with the day-to-day challenges of raising a child with disabilities including, a child with significant behavioral challenges or a child with complex medical care, must have access to adequate respite opportunities that allow the time needed to recover and rejuvenate as well as time needed to participate in the activities of other children. The limit on the respite benefit could be increased without increasing individual cost caps in waivers.

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

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.

YES Waiver

The Texas YES waiver is a 1915(c) Medicaid program that helps children and youth under the age of 19 with serious mental, emotional and behavioral difficulties live in their homes and communities. The YES waiver provides intensive services delivered within a strengths-based team planning process called “wraparound”. Wraparound builds on family and community support and utilizes YES services to help build your family’s natural support network and connection with your community. YES services are family-centered, coordinated, and effective at preventing out-of-home placement, promoting lifelong independence, and self-defined success.

According to Texans Care for Children’s June 2022 Policy Brief, *“Texas Leaders Must Help Parents Seeking Mental Health Support for Their Children,”*

*The YES Waiver Program provides effective mental health services to children, but it is not reaching as many families as it should, largely due to workforce challenges. The current waiver agreement between HHSC and the Centers for Medicare and Medicaid Services (CMS) authorizes Texas to provide up to 3,267 children with YES Waiver services statewide. However, less than 1,500 children have been enrolled in the program in any given quarter over the past five years. Local Mental Health Authorities (LMHAs) must maintain "inquiry lists" when they are unable to provide YES Waiver services to additional families. Not all children on inquiry lists will be eligible for the program, but their families typically must wait until the LMHA has the staff capacity to enroll a new child before their child receives an assessment. From April 2021 to March 2022, **2,656 children statewide were on YES Waiver Program inquiry lists, nearly double the number of children who were enrolled in the program in any given quarter during those twelve months.***

Once again, workforce challenges are reported to be the main barrier to LMHAs being able to enroll more families whose children are eligible for YES Waiver services into the program. The reimbursement rates set by HHSC for YES Waiver services often do not cover all of the costs associated with administering the program, such as assessing children for eligibility or having multiple mental health providers participate in wraparound team meetings, limiting LMHAs capacity to serve more children in the program even when authorized to do so.

The state must also take meaningful steps to ensure mental health providers are paid rates that cover the costs of delivering the services. Children and families can be eligible for intensive mental health services like wraparound service planning, family peer support services, extended observation services, or MST, but if providers are not willing or able to provide these services because the rates paid to deliver them are not sufficient to cover their costs, barriers to mental health care for children will continue.²⁷

Treatment Foster Care as an In Lieu of Benefit

In accordance with SB 1177, 86th Texas Legislature, Regular Session, 2019, HHSC must implement contract provisions to permit Medicaid managed care organizations

²⁷ <https://static1.squarespace.com/static/5728d34462cd94b84dc567ed/t/62b39015de529c420ab8f46b/1655934997320/Children%27s+Mental+Health+Policy+Brief+June+2022.pdf>

(MCOs) to offer medically appropriate, cost-effective, evidence-based behavioral health services in lieu of specified Medicaid state plan services.

HHSC has been working with the stakeholders including the State Medicaid Managed Care Advisory Committee (SMMCAC) to develop and analyze services for inclusion in the list of in lieu of benefits. HHSC has divided the recommended services into a phased implementation. Phase one services include services in lieu of inpatient hospitalization. Phase two services include services in lieu of outpatient services. A third group of services proposed by SMMCAC requires further consideration.

The third group of services includes Treatment Foster Care (TFC). TFC is a community-based treatment alternative to congregate care for children with challenging needs. There is growing evidence of TFC as a promising alternative used in child welfare, in children's mental health, and in the juvenile justice system. Compared to residential treatment services, TFC has been found to be less expensive and to produce at least as great behavioral improvements while enabling children to live in less restrictive family living environments. The benefit should be broadened beyond just those in the conservatorship of the state and included as an SB 1177 benefit.

Child Focused, Short Term, Out-of-Home Crisis Stabilization

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

START which stands for Systemic, Therapeutic, Assessment, Resources, and Treatment, is a community-based crisis prevention and intervention service model for individuals ages six and older with IDD and mental health needs.²⁸ START was

²⁸ <https://centerforstartservices.org/>

first developed in 1988 by Dr. Joan B. Beasley and was cited as a national model in the 2002 US Surgeon General's report on mental health disparities for people with IDD. The Center for START Services is located at the University of New Hampshire's Institute on Disability.

Based on a review of fiscal year 2019 START data, the program resulted in:

- High rates of stabilization following crisis. Most (73 percent) of the 3,000 crisis contacts in fiscal year 2019 resulted in individuals remaining in their current community-based setting, avoiding potential ED visits and/or psychiatric inpatient admissions.²⁹
- Reduced psychiatric hospitalization and ED usage. Children and adults enrolled in START programs visited the ED less and had fewer psychiatric hospitalizations than they did in the 12 months prior to receiving START services.³⁰

There are two START programs in Texas, Tarrant County and El Paso, that have been in operation since 2014.³¹ The goal of each program is to help people gain a higher quality of life by improving the delivery system for people with IDD and behavioral health needs. One of the critical services offered to children and families in START is the in-home therapeutic coaching of children and families as well as the coordination of services from a START Coordinator. Some START programs also offer short term crisis stabilization and respite centers and would be a good model to pursue in Texas. START is one of the services HHSC is analyzing as a potential in lieu of benefit to include in Phase 3.

29 [https://centerforstartservices.org/sites/www.centerforstartservices.org/files/Annual Reports/css_annual_report_fy19_final.pdf](https://centerforstartservices.org/sites/www.centerforstartservices.org/files/Annual%20Reports/css_annual_report_fy19_final.pdf)

30 Ibid.

31 <https://centerforstartservices.org/locations/texas>

5. Holistic Approach to Transition Workgroup Recommendations

Policy Issue: Physician education to provide training about health care transition (pediatric to adult, hospital to home, handoffs).

Dedicated transition training programs for physicians-in-training is underfunded currently, as documented by this council's last legislative report in the overall small number of internal medicine and pediatrics combined residency training programs across the state. Furthermore, few residents in family medicine, pediatrics, or internal medicine residency programs receive on-the-job training due to the paucity of transition medicine clinics in Texas, and lack of these opportunities result in few other clinicians-in-training (such as nurse practitioners, physician assistants, etc.) receiving appropriate education in transitions of care. As a result, young adults with disabilities and childhood onset conditions struggle to find appropriate adult primary and specialty care clinicians.

I DIDN'T HAVE HEALTHCARE TRANSITION REALLY AT ALL. I GOT TO MY LAST ORTHOPEDIST APPOINTMENT, AND IN THE LAST 5 MINUTES THEY DIDN'T SAY GOODBYE, NOR PREPARE ME SOCIALLY IN ANY WAY FOR THE END OF A 10+ YEAR RELATIONSHIP. IT WOULDN'T HAVE BEEN SO BAD IF THEY HAD GIVEN ME A LIST SHOWING ME WHERE TO GO NEXT... NOWHERE! INSTEAD, I GOT AN INCREDIBLY JARRING CLOSING, THAT COULD BE SUMMARIZED AS: 'SEE YA AROUND, GOOD LUCK... I GUESS'.

Figure 15: Quote from Amy L.

Young adults with special health care needs (YASHCN) and their families deserve to receive care in an appropriate setting from a knowledgeable clinician as a basic health care right, a right that has been recognized nationally by the American Medical Association, the American Dental Association, and the American Academy for Developmental Medicine and Dentistry. It has been long recognized that health

care professionals receive little to no formal training on caring patients with disabilities, and “research shows doctors overwhelmingly harbor negative views of [persons] with disabilities”.³² Leaders from these groups have partnered together to begin discussions on a timeline to make disability training a mandatory part of medical and dental student education. While this training in professional schools is an integral part of addressing the knowledge gap, it provides no support for the roughly 60,000 active practicing physicians in Texas.³³

While it is imperative to fortify the physicians-in-practice knowledge base for persons with these conditions, a more immediate need is to shore up education for transitions of care, activities that occur so many times every day. Doing so will protect the health and safety Texans with disability.

Many physicians in practice have limited understanding of their own deficiencies in education when providing care to YASHCN, and transitions of care expertise is required in so many more settings than just those related to YASHCN.

Recommendation

Adopt 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.

Discussion

The State of Texas must choose to support our physicians and their patients with disabilities through the adoption of educational expectations for transition of care services. Like HB 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 must 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

32 <https://www.disabilityscoop.com/2022/07/29/new-push-underway-to-train-doctors-dentists-on-developmental-disabilities/29931/>

33 <https://store.aamc.org/2021-state-physician-workforce-data-report.html>

savings across the state through reduced medical errors, and an overall healthier population.

Transitions in health care are risky, which this committee documented through extensive peer-reviewed literature summarization in our last legislative report, especially for YASHCN. However, this population isn't the only one with transition needs. The more medical complexities exist for an individual, the more transitions they experience, each ever increasing the risks for medical errors and iatrogenic conditions related to that transition. Risks with medical care transition may be seen as a problem unique only to YASHCN. However, with an aging population, similar needs exist for patients with dementia and adults aging with multiple comorbid conditions. According to the CDC, 51.8 percent of American adults have one chronic condition, and 27.2 percent of American adults have multiple chronic conditions.³⁴

Transitions occur in many formats:

- Pediatric to adult physicians between the ages of 18-21 years.
- Hospital to other outpatient facility or home at discharge.
- Within the hospital from one service or location to another, for example ICU to general inpatient ward, or from ED to ICU.
- Outpatient primary care to specialist and back again.

Gaps in medical services during the transition from pediatric to adult providers significantly raises emergency department use resulting in exacerbations of existing medical conditions and increased health care costs. Each time a patient is transitioned in setting or provider, the risks of information being lost or documented in error increases, thereby increasing risk for the individual. Even families experienced with transitions don't always know what to look for, especially since not all medical care occurs with absolute transparency and each situation holds unique nuances. Ultimately, we cannot demand patients and families be the most knowledgeable individuals on the medical team, especially during these periods of heightened stress.

34 https://www.cdc.gov/pcd/issues/2020/20_0130.htm

Amid competing interests for both professional and personal settings, how do we ensure our health care providers place priority on these topics? 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 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.³⁵

TRANSITION OF CARE FROM THE PEDIATRICS TO ADULT MEDICINE IS A KEY FACTOR THAT NOT ONLY HELPS REDUCE MISSED APPOINMENTS AND FOLLOW UPS, BUT ULTIMATELY REDUCES HOSPITALIZATION AND DETERIORATION OF PATIENTS WITH CHRONIC OR COMPLEX HEALTH CARE NEEDS. IT ALSO ESTABLISHES THE FOUNDATION OF ADEQUATE PREVENTIVE MEDICINE AND HEALTHY LIFESTYLE INTO THE ADULT YEARS. GETTING HEALTHCARE PROVIDERS TO LEARN AND UNDERSTAND THE FOUNDATIONS AND NEW UPDATES IN TRANSITION OF CARE OF ADOLESCENCE WILL BENEFIT GREATLY THIS PROCESS.

Figure 16: Quote from Marcela Navarro Holguin, MD, University of Texas Medical Branch at Galveston

Clearly, this policy recommendation is based on historical precedence for educational requirements, utilizes educational resources currently available and without cost, and would be quick and easy to implement with great benefit. This policy council implores the Texas Legislature to pass this policy recommendation, thereby providing much needed protection to our most vulnerable Texans.

³⁵ <https://reader.mediawiremobile.com/epmagazine/issues/208032/viewer?page=31>

Policy Issue: Addressing health care is not currently part of school transition planning requirements.

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 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.

This is easily preventable by ensuring that transition services are included in the ARD process. Texas law requires that part of the ARD process include 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.

Recommendations

1. Add a requirement in the Texas Administrative Code for the ARD committee to include health care transition in the independent living skills domain of the Individual Education Plan beginning at age 14 and continuing until the student graduates from the school system.
2. Add a requirement in the Texas Administrative Code for the Transition and Employment Designee (TED), a position required to be designated in all school districts, to add health care transition training to the information they are already required to provide teachers and parents of students enrolled in SpEd.

Discussion

The 2019-2020 National Survey of Children's Health revealed that 22.5 percent of youth in the U.S. with special health care needs received transition planning guidance from their health care providers.³⁶ In Texas, the percentage was only 14.9 percent. Since the health care providers are not assisting families in making this

36 <https://mchb.hrsa.gov/sites/default/files/mchb/programs-impact/nsch-data-brief-children-youth-special-health-care-needs.pdf>

critically important transition, it is totally logical to add the much-needed health care transition training to already existing transition planning required in public schools.

Rarely is there a solution to such a significant problem so easy and without a monetary cost attached. Even the transition specialists in schools find this to be a no-brainer – something that makes sense on many levels. Health is a functional life skill that needs to be developed to successfully function as an adult. This instruction can be accomplished through a collaborative effort between the school district and the parents. Making a few additions to the Texas Administrative Code will make an enormous, long-term difference for good in the lives of a multitude of Texans with disabilities and their families.

Legal Changes in Privacy Laws at Age 18

Legally, a young person will be responsible for managing all their medical care when they turn 18 unless protections are put in place for parents to share decisions or make decisions for them through legal power of attorney or guardianship. In 2015, Texas became the first state to have supported decision-making as a legal option.³⁷ The law states that an adult with a disability can make their own choice to sign a supported decision-making agreement without anyone asking or telling them to. This agreement allows the young person to get help managing their life without the restrictions of guardianship.

There are considerable differences between the benefits provided through pediatric and adult Medicaid managed care. Changes include the fact that Medicaid no longer pays for nursing care after a young person turns 21. The nursing care that one can qualify for as an adult is through a Medicaid waiver program, the hours are usually drastically reduced, and nurses are paid much less than STAR Kids Medicaid for children.³⁸ Also, dental services are provided in STAR Kids, but not in STAR+PLUS for adults.

Families and youth understandably expected their health care clinicians to provide them with the needed information to help young people prepare for this transition from pediatric to adult services. The reality is, however, that over 85 percent of the time, health care transition planning is not being addressed in pediatric medical practices.

37 https://www.thearcoftexas.org/wp-content/uploads/2016/06/Supported_Decision_Making_For_Families_2016-06.pdf

38 <https://www.navigatelifetexas.org/en/insurance-financial-help/texas-medicaid-waiver-programs-for-children-with-disabilities>

A simple and effective solution to assisting families navigate through the transition from pediatric to adult health care services would be to add health care to an already robust transition planning process already required by state law to be taking place in all public schools, which includes charter schools.

For a student receiving SpEd services, the Admission, Review, and Dismissal (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 Individualized Education Plan (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.

Students Should Be Taught How to Manage Their Own Health and Health Care

Significant changes occur when transitioning from pediatric to adult health care. By far, most youth with chronic health care needs and disabilities and their families, are unaware of the major changes that occur beginning at age 18 during the transition from pediatric to adult-based health care. Parents find themselves blindsided and horribly dismayed when they call to make an appointment for their 18-year-old child with their pediatric physicians – with whom they have developed a long-term, trusting relationship – and are told they are no longer eligible to see these physicians due to the patient's age.

Many pediatric doctors would like to continue serving these older patients; however, their hands are tied because they lack privileges to treat patients at adult hospitals. These physicians understand if the now-adult patient were to have a medical need after hours or on a weekend, the other pediatric physicians in their practice would not see them. Sadly, it is a long and frustrating effort to find primary care and specialist physicians who take specific insurance plans - Medicaid in particular - and who have the knowledge, desire, and ability to serve patients with chronic health conditions. These providers also need to be willing to spend time to fill out the frequent, extensive documentation required for medical supplies, durable medical equipment, nursing care, and numerous other essential aspects of their health care needs.

Transition planning in public schools addresses each student's strengths, needs, preferences, and interests and uses them to prepare their post-secondary goals. This is the plan for their future employment, post-secondary educational training, and independent living. Students in SpEd, most of whom have chronic or disabling conditions, also need to know how to manage their own health and health care to

the best of their abilities. This includes knowing their 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 accommodations they will need to be able to be successful in their occupation.

6. Autism Spectrum Disorder Workgroup Recommendations

Policy Issue: Requiring an ASD diagnosis or reconfirmation within three years of treatment is unnecessary, costly, and reduces access to care.

ASD diagnosis is based on the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) ASD criteria and assessments performed by pediatric neurologists, child psychiatrists, child psychologists, and developmental pediatricians.^{39,40}

ASD is a lifelong neurological difference that impacts individuals in social communication, social interaction, and restricted patterns of behavior. Symptoms cause clinically significant impairments in social, occupational, or other important areas of current functioning.⁴¹ Deficits perceived by others may reduce post intervention or by the individual masking difficulties. The disorder is still present in the individual even if skills improve and/or perceived deficits are reduced.⁴²

Access to qualified assessment providers is limited, specifically in rural Texas. Client waiting lists for assessment can be more than 18 months thus impacting access to needed services. Early and consistent intervention is key in progress for ASD individuals⁴³ and diagnosis and/or reconfirmation every three years is unnecessary, costly, and significantly reduces access to care.

39 American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Arlington, VA: American Psychiatric Association; 2013.

40 <https://publications.aap.org/pediatrics/article/145/1/e20193447/36917/Identification-Evaluation-and-Management-of?autologincheck=redirected?nfToken=00000000-0000-0000-0000-000000000000>

41 Ibid.

42 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6483965/>

43 <https://www.nichd.nih.gov/health/topics/autism/conditioninfo/treatments/early-intervention>

Recommendations

1. TMHP/MCOs should accept a scheduled appointment for evaluation and/or reconfirmation to initiate/continue ABA services or assist the client/family in scheduling an appointment for evaluation.
2. TMHP/HHSC should clarify/define necessary criteria and language for a diagnosis of ASD.

Discussion

Most diagnosing providers have a 6-12 month waiting list for an ASD evaluation.^{44,45} Client waiting lists can be significantly longer for providers in rural Texas. Waiting long periods of time puts individuals at a significant disadvantage as they are not yet eligible for crucial, clinical services to improve behaviors and it also puts them at risk for regression.⁴⁶ A scheduled ASD evaluation appointment should be accepted as a term to initiate necessary ABA services, to ensure and effect meaningful change in behaviors and potentially limit the disability. Likewise, if there is a current diagnosis of ASD, obtaining an appointment to reconfirm that diagnosis can be a challenge to complete the assessment before the diagnosis expires. ASD is a developmental disability, and it is unlikely that a child's medical diagnosis of ASD will change or be removed. Therefore, a three-year re-determination is unnecessary. MCOs should also assist families in obtaining evaluation appointments to ensure placement on an evaluation schedule and to assist in coordination of care.

Discrepancies in the current Medicaid Autism Services Benefit (ASB) as it pertains to diagnosis, also reduce access to care. A comprehensive diagnostic evaluation, with each element conducted by appropriately trained, specialized, or certified providers, is required to diagnose ASD. One of the required diagnostic criteria includes symptom severity level according to the most current edition of the DSM-V. To be eligible for ABA services, the diagnostic criteria and symptom severity level must be documented in levels⁴⁷. There is a lack of congruence between validated diagnostic assessments and the ASB, as clinicians are using severity categorizations, such as "mild, moderate, severe," in diagnostic reports, which

44 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6987484/#:~:text=Although%20the%20recommended%20maximum%20wait,between%202%20and%204%20years>

45 <https://news4sanantonio.com/news/san-antoniios-voice/wait-times-for-autism-diagnosis-in-sa-can-be-two-years>

46 <https://www.nichd.nih.gov/health/topics/autism/conditioninfo/treatments/early-intervention>

47 https://www.tmhp.com/sites/default/files/file-library/resources/provider-manuals/tmppm/pdf-chapters/2022/2022-02-february/2_Childrens_Services.pdf

correlate to common criteria and references in standardized assessments. These descriptors no longer support the DSM-V criteria and therefore, diagnostic reports are not acceptable and ABA services are denied or delayed. This is a considerable concern amongst families trying to access ABA services.

AS LANDON GREW AND MISSED ALMOST EVERY MILESTONE, A WIC REPRESENTATIVE REFERRED HIM TO ECI FOR ASSISTANCE. HOME HEALTH SERVICES WERE AVAILABLE, BUT LANDON NEEDED THE ECI MODEL. ECI IS ONE OF THE BEST ORGANIZATIONS OUR COMMUNITY HAS EVER WORKED WITH, THEY HELP CREATE SOLID FOUNDATIONS FOR EACH CHILD. LANDON RECEIVED SPEECH SERVICES AND WAS DIAGNOSED WITH AUTISM THROUGH EVALUATIONS. ECI HELPED LANDON ENROLL IN SCHOOL AT AGE THREE AND PROVIDED SUPPORT COACHING SERVICES ALONG WITH THE AUTISM PATHWAYS PROGRAM.



Figure 17: The Pemberton Family (Pictured above)

Policy Issue: People with ASD have difficulty accessing ABA services.

Under EPSDT, otherwise known as Texas Health Steps, benefit of Medicaid, members under the age of 21 are entitled to all health care services that are found to be medically necessary to treat conditions discovered in a child.⁴⁸ While this program has been around for decades, the federal government only recently clarified to state Medicaid agencies that all medically necessary services for ASD must be included, including ABA services.⁴⁹ Since 2014, state Medicaid agencies have been working to amend their state plans to clarify ABA as a covered benefit, when medically necessary. As of February 2022, Texas was one of the last states to implement the ASD services benefit.⁵⁰ And while Texas has implemented the benefit, there are systemic barriers to ABA services that still exist.

Recommendations

1. ABA authorizations should be individually based upon needs and medical necessity, not based upon age.
2. Initial authorization of ABA services should be six months rather than three months and reauthorizations should be six months.
3. The rates for ABA services must be set at a level that is sufficient to allow for network adequacy and corresponding access to care.

Discussion

There should not be age-related limits on authorized ABA hours. Services should be based upon medical necessity and be individually based, just as they are for other Medicaid therapy services, such as physical therapy, occupational therapy, and speech therapy.⁵¹ The authorization process should be streamlined for providers and the policy language clarified to ensure consistency amongst providers and MCOs. Additionally, initial ABA services should be authorized for six months, not three months, and reauthorization should be for six months. This also to be in alignment with other clinical services reimbursed by Medicaid.

48 <https://www.hhs.texas.gov/providers/health-services-providers/texas-health-steps>

49 <https://www.medicaid.gov/medicaid/benefits/autism-services/index.html>

50 <https://www.hhs.texas.gov/services/disability/autism/applied-behavior-analysis>

51 https://www.tmhp.com/sites/default/files/file-library/resources/provider-manuals/tmpppm/pdf-chapters/2022/2022-10-october/2_PT_OT_ST_Srvs.pdf

The reimbursement rates for ABA treatment must be set at a level sufficient to allow for network adequacy and access to care. There is a current shortage of licensed assistant behavior analysts and registered behavior technicians in Texas and there has been an increase in early diagnosis of ASD since the federal PHE. The Texas Association for Behavior Analysis – Public Policy Group surveyed providers after initial reimbursement rates were published in November 2021. When surveyed, 91 percent of Texas ABA providers said they want to serve individuals who receive Medicaid, but when presented with HHSC proposed rates, that number dropped to 17 percent.⁵² This will create challenges for MCOs in building an adequate network of providers. Without an adequate provider base, children who desperately need services will go unserved. When proposed rates were updated, the number of providers who stated that they were willing to serve the Medicaid population increased to 33 percent. This number is still inadequate to meet the needs of our children.

Policy Issue: Current use of the Autism Supplement in the IEP is not being used effectively to address gaps in education.

The Autism Supplement is part of the IEP where the ARD and IEP committee documents specific strategies to be considered and addressed.⁵³ This can help parents in the development of adequate and appropriate strategies for their child with ASD. While schools must consider the 11 strategies in the Autism Supplement, many parents are uninformed and do not understand all the resources and strategies available to their child. Considering these recommendations would better support students and their families and encourage specific practices that are incorporated into a child's natural routine at home, in the community and at school.

Parents of students on with ASD and with other disabilities would benefit from a structured process to identify and initiate SpEd services through their public schools. This process would ensure that the Autism Supplement recommendations follow their student with each grade level promotion.

⁵² Internal survey completed by the TxABA Public Policy Group, polling licensed behavior analysts in Texas.

⁵³ <https://tea.texas.gov/academics/special-student-populations/special-education/programs-and-services/autism>

Recommendations

1. Implement a step or screening tool during the school registration/enrollment process to identify students receiving SpEd services and ensure enrollment in appropriate programs and follow up by SpEd staff.
2. Provide electronic resources on information and services available to students, including links to sites, such as the Texas Transition and Employment Guide, SPEDTex, Texas HHS benefits, and local resources.
3. Provide training on ABA services for teachers and school personnel.
4. Continue funding for the “Innovative Services for Students with Autism” grant program.
5. ABA services in the schools should be billable as part of the School Health and Related Services (SHARS) program.
6. Schools should collaborate and provide coordination and continuity of care between settings and allow for outside ABA services and observation in the school setting, when appropriate, for optimum student success.
7. Consider a Tracking Teacher (TT) position specializing in SpEd, for each campus, to serve as the point of contact and coordination for students and families.

Discussion

A screening tool during the annual school registration process would allow students receiving SpEd services to be identified, ensuring enrollment in appropriate programs. During this process and when using an online enrollment and registration process, if parents or guardians answer in the affirmative, the student’s data will be entered into a queue for SpEd personnel to follow up and ensure that student is receiving all appropriate services. Likewise, students would be identified and provided with an online resource where parents or guardians may request additional information. This information would be available in various formats such as guides, brochures, fact sheets, online resource, videos, and training modules. Available services for their students would also be listed, such as state Medicaid waiver programs. Barriers that families often encounter are the lack of information on what state or federal programs are available for their student. Waiting lists for waiver programs in Texas vary with some being years long. The longer that an individual waits to get on the waiver interest list, the longer those services are not being utilized by individuals who need them the most.

Establishing a system at the onset when a qualifying diagnosis is made would establish a clear understanding of what parents and students should expect and when the determination will occur. An example of a checklist that could be modeled would be The Texas Transition and Employment Guide.⁵⁴

The TT would be a SpEd teacher on each campus who will serve as the point of contact for parents and school staff. The TT would be housed at the home campus and solely be responsible to coordinate SpEd services and support families. This would ensure that parents have knowledge of who they can contact if concerns or questions arise regarding their students 504 plan or IEP. The TT will provide information in plain language that is easy for parents to understand. The dedicated SpEd TT would attend ARD meetings at the student's home campus as a member of the ARD committee. Having familiarity with the student and campus personnel, this will serve a dual purpose. The TT would be able to make in-person assessments or evaluations prior to ARD meetings and provide "boots on the ground" based data. When the ARD meeting is held, the TT would provide observation-based data, educational goals, rating discussions and evaluation-based data which would be used for measuring progress on the student's written and agreed upon goals.

The Innovative Services to Students with Autism Grant Award⁵⁵ is available to all Texas local education agencies (LEAs), with priority given to collaborations across LEAs. The purpose of this grant opportunity is to increase capacity across Texas schools to implement innovative programs that effectively serve students with ASD ages 3 to 21. Continued funding of this grant would allow LEAs across the state to meet the needs of students and prepare them for their future more effectively.

General education teachers entering the profession have little training on SpEd and children with disabilities. Additional training is needed to help with early identification and treatment and should be considered for required continuing education. Sustained funding of the Innovative Services to Students with Autism Grant and funding of additional, specialized grants would provide for specialized training on evidence-based practices with ongoing coaching and education.

The SHARS program allows Texas LEAs and shared service arrangements to request reimbursement for Medicaid health-related services.^{56,57} As ABA services are now

54 <https://www.texastransition.org/apps/pages/texas-transition-and-employment-guide>

55 Also known as "Autism and Dyslexia Grant Award Programs", authorized by House Bill 1525, Section 10, 87th Texas Legislature, Senate Bill 1, Rider 69.

56 <https://tea.texas.gov/academics/special-student-populations/special-education/programs-and-services/school-health-and-related-services>

57 https://www.tmhp.com/sites/default/files/microsites/provider-manuals/tmppm/html/TMPPM/2_SHARS/2_SHARS.htm

reimbursed as part of the state Medicaid program, it is recommended that LEAs be reimbursed for ABA services provided in the school setting. These medically necessary and reasonable services will ensure that children with disabilities are able to participate in the educational program. Current Medicaid services covered by SHARS include occupational therapy, personal care services, physical therapy, psychological services (including assessments), and speech therapy. ABA services should be aligned with these other clinically necessary services to ensure that students are able to participate in the educational setting.

Lastly, schools should allow for collaboration and provide coordination of care between settings and allow for outside services, such as ABA, and observation in the school setting, when appropriate, for optimum student success.

MATTHEW IS A 15-YEAR-OLD FRESHMAN WHO ENJOYS READING ABOUT HISTORIC WAR BATTLES, GAMING, AND IS A CONNOISSEUR OF CHEESE PIZZA. HE PLANS ON HAVING HIS OWN YOUTUBE CHANNEL AND SHARING AN APARTMENT WITH HIS BEST FRIEND AFTER HIGH SCHOOL.

AT AGE THREE, HE WAS DIAGNOSED WITH AUTISM. BY KINDERGARTEN HE WAS DIAGNOSED WITH ADHD, OCD, AND AN ANXIETY DISORDER. TRACKING TEACHERS CAN HAVE A POSITIVE IMPACT FOR STUDENTS AND THEIR FAMILIES. MR. C AND MS. L HAVE BEEN PIVOTAL IN MATT'S SUCCESS OVER THE LAST 2 1/2 YEARS. HAVING SOMEONE AT THE HOME CAMPUS ALLOWS FOR REAL TIME INTERVENTIONS TO BE IMPLEMENTED IF NEEDED.



Figure 18: The Briones Family (Pictured above)

7. Child Care Workgroup Recommendations

Policy Issue: Ensure children with disabilities have access to high quality, inclusive child care settings.

Child care settings in early childhood are an integral part of learning for many children to develop the language, motor and social skills needed to be successful and ready for school. For children with disabilities, these early learning opportunities alongside their peers are even more critical. However, parents of children with disabilities continue to struggle to find and keep high-quality, consistent, inclusive child care.⁵⁸

Child care providers lack the training and support needed for them to feel confident to provide care for children with disabilities. They may be resistant to include children with disabilities due to lack of training on understanding the individual needs and how to care for children with disabilities. Child care providers may suspend or expel children that they deem to be too difficult to provide care for.⁵⁹

Parents that are not able to find and keep consistent high-quality child care for their child with disabilities have very few options for quality child care and are often at risk of losing or being forced to quit their job.⁶⁰ This causes a lot of economic and other stressors on the family unit.

ECI providers who are specially trained to provide services to young children with disabilities should be supported to provide services to children with disabilities in their natural environment, but often child care providers do not allow them to work with children in their classroom while a child is attending their child care facility or home.

Child care providers would be more likely to accept and provide quality child care for children with disabilities if they had additional training on how to care for children with disabilities and if they worked closely with parents and guardians to understand the individual needs of the child and to receive additional support from

⁵⁸ http://www.md-council.org/wp-content/uploads/2017/09/BarrierstoQuality_ChildCare_2012FINAL.pdf

⁵⁹ <https://journals.sagepub.com/doi/10.1177/1053815119886110>

⁶⁰ <https://www.americanprogress.org/article/child-care-crisis-disproportionately-affects-children-disabilities/>

ECI and Early Childhood Special Education (ECSE, formerly known as PPCD) providers.⁶¹

Recommendations

1. Texas HHSC should develop and adopt minimum standards for licensed child care facilities and registered family homes that prohibit discrimination based on disability and support inclusion of children with disabilities.
 - a. Ensure the facility or home promotes inclusive practices and integrates children with disabilities into the general activities of the facility or home.
 - b. Ensure activities are tailored to the strengths and needs of each child.
 - c. Ensure adequate supervision of children including an assessment of the wandering history of children attending the facility or home.
 - d. Ensure that ECI providers have access to children with disabilities attending the facility or home and provide services in the child's natural environment, the child's classroom.
2. Texas HHSC should develop and adopt rules requiring licensed child care facilities and registered family homes to provide written disclosures to a parent or guardian of a child with a disability attending the facility or home including:
 - a. An application to initiate a referral for ECI services and contact information for ECI providers.
 - b. Information on ECSE.
 - c. The policies of the facility or home on providing care to children with disabilities.
3. Texas HHSC should develop and adopt minimum training standards for employees, directors, and operators of licensed child care facilities and registered family homes on serving children with disabilities.
 - a. Ensure training on awareness of children with disabilities or developmental delays.
 - b. Ensure training on social emotional learning, positive behavior interventions and supports and trauma-informed care.

⁶¹ <https://tea.texas.gov/academics/special-student-populations/special-education/programs-and-services/early-childhood-special-education-ecse>

- c. Ensure training on providing care to children with disabilities including identification of potential developmental delays, referring children for specialized services and information on ECI services and ECSE.
- 4. Texas HHSC should develop rules for licensed child care facilities and registered family homes to report each suspension or expulsion of children attending the facility or home and include the disability status of the child.
- 5. Support children with disabilities and their families with child care needs by providing funding for child specific Non-Educational Community Based Support Services to support students with disabilities to attend inclusive after school, school break and summer child care programs.
- 6. Prohibiting discrimination based on disability in a child care facility or child care home and requiring that all child care applicants are given a copy of the American with Disabilities Act Title III & Child Care Operations to inform parents, families, and guardians of their rights regarding accommodations and discrimination prohibition.

Discussion

Minimum Standards for Licensed Child Care Facilities and Registered Family Homes

It is important for child care facilities and homes to have written policies and procedures in place that support inclusive services to children with disabilities. It should be made clear that the federal ADA law prohibits child care centers from discriminating against children because of a disability.⁶² This will help ensure that licensed child care facilities and registered family homes know and understand that the law applies to their facility or home and that they will be more likely to follow the law.

Children with disabilities may require reasonable accommodations to participate in the general activities of the facility or home.⁶³ The child care facility or home must work together with the child's parents and ECI providers, if available, to understand the child's individual needs and how best to provide care, including any special supervision needs, modifications of activities or the environment and integrate the child into the activities of the facility or home.

62 <https://www.ada.gov/childqanda.htm#:~:text=A%3A%20The%20ADA%20requires%20that,care%20center%27s%20programs%20and%20services.>

63 <https://www.navigatelifetexas.org/en/family-support/day-care-for-children-with-disabilities>

ECI services are most effective when they are provided in a child's natural environment, including the child care classroom. However, some ECI providers continue to not have access to provide services in the child care classroom even when the parents provide consent. Therefore, it is necessary to ensure child care providers are aware of the requirement and benefit to allowing ECI providers to work with a child in the child care classroom.

Information Provided to Parents and Guardians

It is important for child care facilities and homes to partner with local ECI providers and ECSE to ensure parents and guardians are aware of services that will benefit their child with disabilities. The sooner a child starts ECI services and ECSE the more effective they are.

ECI and ECSE services are effective at helping children reach developmental milestones, get ready for school, and potentially minimize the need for SpEd services.⁶⁴ Many children do not receive services until they start public school because the child's developmental delays and disabilities were not identified, or families do not know about ECI and ECSE services that they may qualify for. Child care providers are in a unique position to help make sure families know about and are referred to all available resources to help their child with disabilities.

The child care facility or home's policies and procedures about how they will provide inclusive services to children with disabilities should be accessible and provided to parents and guardians. It benefits parents and guardians to know what the center is doing to integrate their child including how they will modify activities or environments for their child.

Training for Child Care Providers

Child care providers might turn away children with disabilities from their child care facility or home because they lack the training to appropriately care for and teach children with disabilities. These providers need training to identify, understand, accommodate, and support the development of all children, including those with disabilities. It is equally important for child care providers to understand the benefit for all children when children with disabilities learn alongside their peers without disabilities. It must be a priority for child care providers to receive specific training on how to serve, care for, and teach children with disabilities in inclusive child care classrooms. Child care providers also need training to work together with parents

64 <https://www.parentcenterhub.org/ei-overview/>

and ECI and ECSE providers to ensure parents are aware of and receive all available resources and early interventions that will benefit the child.

Reporting of Suspensions and Expulsions

Children with disabilities may be disproportionately suspended or expelled from child care facilities or homes due to lack of knowledge about how to care for and teach children with disabilities and due to challenges or behaviors related to their disability.⁶⁵ Currently this information is not collected. It would be very helpful to have this information which would help to identify the issues and how best to address them including looking at training, technical assistance and support, staff to child ratios, and providing grants and other incentives.

Funding for Non-Educational Community Based Support Services

The lack of childcare options causes a severe strain on the family unit and can sometimes lead to a family seeking crisis intervention services and even out-of-home placement for their children with disabilities.⁶⁶ ⁶⁷ The legislature has seen the need to provide funding for additional support for children with ASD, children that have complex, high-cost needs and children that need non-educational support services to prevent these extreme circumstances. These programs have been effective in preventing children with disabilities from being placed in more restrictive settings. The legislature can use similar funding programs to provide support for high quality inclusive early education and childcare for children with disabilities ages 0-21.

Providing non-educational community-based support services to help pay for inclusive after school, school break, and summer programs for eligible students with disabilities will support the child to receive a free appropriate public education (FAPE) in the least restrictive environment. The after school, school break, and summer programs will help prevent a child from remaining in or needing to be placed in a residential facility primarily for educational purposes or to prevent a child from remaining in or needing to be placed in a more restrictive educational placement including disciplinary educational placements. Children and their families

65 <https://news.illinois.edu/view/6367/668258>

66 <https://www.americanprogress.org/article/child-care-crisis-disproportionately-affects-children-disabilities/>

67 <https://parents-together.org/this-is-how-the-child-care-crisis-hits-kids-with-special-needs-extra-hard/>

need support to receive after school, school break, and summer programs in inclusive public or private childcare settings.

8. Education and Employment Workgroup Recommendations

Policy Issue: Increase the funding allocation for ECI services for eligible infants and toddlers.

ECI services are an integral component of support for families as they learn how to help their infants and toddlers with disabilities and developmental delays grow and learn. Current funding is not adequate to support the number of children eligible for ECI services or to meet the specific needs of Texas infants and toddlers with disabilities and developmental delays.

Texas has consistently under-enrolled children with disabilities and developmental delays and serves a much lower percentage of children under age three compared to other states, ranking 45th in the country. The US Department of Education determined that Texas failed to adequately fund and deliver ECI services and required Texas to take corrective action including implementing new Child Find activities. ECI enrollment has already begun to increase, because of new Child Find activities and increased demand for services due to the federal PHE. Many programs are reporting serving above their contracted numbers. There is clearly a need to ensure funding for ECI reflects the increased need for ECI services across the state of Texas.

ECI programs across Texas report that the current per-child funding is not sufficient to provide the required services for enrolled children. Current funding per child is approximately the same as fiscal year 2016 - 2017 levels. Texas ECI has narrowed eligibility into the program to include only children with the most significant delays resulting in the average enrollee having more severe needs for services and therapies. ECI funding per-child has decreased alongside eligibility changes, requiring ECI contractors to do more with less funds. A recent survey of Texas ECI programs revealed that many of the responding programs are understaffed, with staffing shortages largely including speech therapists, early intervention therapists, occupational therapists, and other direct-service personnel. Increased per child funding is required to ensure appropriate staffing and needed services are available for children eligible and enrolled in ECI services.

Children’s early experiences have a profound impact on their later development.⁶⁸ Families of infants and toddlers with disabilities and developmental delays may face a variety of challenges including depression, substance misuse, a history of trauma, and other significant stressors. Families and early childhood caregivers need support to understand the impact of adult mental health on the developing child and how to promote better social and emotional outcomes for these children.

Recommendations

1. Base ECI funding on accurate projected numbers of Texas children eligible for services in the next biennium. HHSC should conduct a comprehensive analysis of projected caseloads considering new Child Find activities and increased enrollment.
2. Increase the per-child ECI funding to meet the needs of Texas infants and toddlers. HHSC should conduct a comprehensive assessment of per-child ECI funding needed to provide required services to enrolled infants and toddlers.
3. Increase capacity of ECI providers to support infant early childhood mental health consultation through the funding of tiered levels of services including:
 - a. Provide funding for programmatic consultation and coaching for inclusion of strong social emotional practices at the root of all ECI services to infants and toddlers and their families.
 - b. Enhance current funding to allow for family strengthening groups.
 - c. Provide funding for mental health providers to team with ECI providers to access and support implementing developmentally rich social emotional practices in all interactions with infants and toddlers and their families across multiple sectors.
 - d. Increase funding to ECI providers to allow for more intensive supports to be provided related to high intensity mental health needs: aggressive behaviors in child care centers; ASD; self-harm; etc.

⁶⁸ <https://nap.nationalacademies.org/catalog/19401/transforming-the-workforce-for-children-birth-through-age-8-a>

Discussion

Base ECI Funding on Accurate Projected Numbers of Eligible Children

Accurate Child Find projections are needed to ensure sufficient funding is available for all eligible and enrolled children. If outdated projections are used ECI providers will not have the funds needed to meet the increased community demand for services. Based on Texas federally mandated corrective action requiring new Child Find activities and increased demand due to the federal PHE, enrollment has already begun to increase and is projected to continue to increase in the coming biennium. It is important to ensure that all eligible children learn about and enroll in ECI services. Texas cannot afford to continue to under-enroll children in ECI services. The sooner a child with disabilities or developmental delays begins to receive ECI services the more likely they will meet developmental milestones and be prepared for school success.

Increase Per Child ECI Funding

ECI per-child funding continues to be well below what it needs to be to ensure infants and toddlers with disabilities and delays receive needed services. Increasing per child funding to reflect the true costs of services would result in restoring needed ECI staff across Texas, increasing the capability of ECI contractors to meet community demands for services, increasing the ability of contractors to reach per child monthly service hour targets, more stable and sustainable ECI contractors, and more services and service hours for infants and toddlers with the most significant needs to help them meet developmental milestones and prepare them for school success.

Support Infant Early Childhood Mental Health

Providing funding to increase the capacity of ECI providers to support early childhood mental health for infants and toddlers with disabilities and developmental delays and their families is needed to help adults understand and support children's early emotional development, promote strong relationships and supportive early childhood environments.

ECI professionals need support to positively impact the lives of infants and toddlers by helping families and early childhood caregivers: create positive learning environments, promote strong social and emotional practices, support children who exhibit challenging behaviors, understand how trauma and other stressors affect

behavior, implement trauma-informed strategies to prevent and minimize the impact of mental health disorders and increase access to mental health and other needed services for young children and their families.

Policy Issue: Youth and young adults with disabilities need additional educational support to enter the workforce upon graduation from high school.

The goal of becoming a productive contributing member of society requires supports for students with disabilities to achieve their post-high school employment goals. Texas has an extreme deficit in the number of vocational rehabilitation services (VRS) counselors to support the needs of students with disabilities planning their transition and graduation from school. Two ways to promote productivity of individuals in the community are to provide more support personnel and to provide more access to training for all students with disabilities at the high school level.

Recommendation

Fund Texas Workforce Commission to hire 50 counselors to meet the growing need of VRS for graduating high school students with a disability.

Discussion

There are not enough VRS counselors in Texas to support the growing need for graduating students with disabilities. VRS counselors help people with disabilities prepare for, find, keep, and advance in a competitive integrated employment.⁶⁹ VRS counselors work with individuals to ensure that they can make informed choices when selecting an employment goal, and connect people with services and service providers that will help them reach that goal.

Some examples of services provided are training, counseling, medical services, artificial limbs, hearing aids, transportation, sign language interpreters, Braille instructions, orientation and mobility instruction for individuals who have visual

69 [https://www.twc.texas.gov/jobseekers/vocational-rehabilitation-services#:~:text=Our%20Vocational%20Rehabilitation%20\(%20VR%20\)%20counselors,that%20lead%20to%20successful%20employment.](https://www.twc.texas.gov/jobseekers/vocational-rehabilitation-services#:~:text=Our%20Vocational%20Rehabilitation%20(%20VR%20)%20counselors,that%20lead%20to%20successful%20employment.)

impairments, on-the-job supports, and help finding a job.⁷⁰ Providing more VRS counselors to work directly with students with disabilities in high school will provide the student with needed information about employment options and access to vocation services and supports to help them achieve their post high school employment goals.

Policy Issue: Minimal training is in place for special education inclusion in undergraduate educator training programs.

Many factors go into the design of a truly inclusive education system. Some determine the way in which education systems are put in place, such as laws and policies, or governance and funding mechanisms. Others operate within the walls of the school. Teachers play a central role in welcoming and teaching all students, regardless of their background, ability, and identity. They need specific skills to adapt teaching to learners' diverse needs – a skill that is acutely needed during school shutdowns – but they need support and training to know how.

Recommendations

1. Train general education teachers to foster a welcoming inclusive environment. Work with Texas Education Agency (TEA) to develop a module for general education teacher's continuing education requirements on how to include students with disabilities in the general education classroom and include information on ABA services.
2. Ensure students with disabilities with communication needs receive appropriate assessment, instruction, therapy, accommodations, and assistive technology to allow them to successfully participate in and benefit from their education including providing appropriate alternative assessments and accommodations on statewide required assessments.
3. Promote collaboration between the school and private sector to align speech, occupational, and physical therapy, as well as ABA goals.

⁷⁰ <https://www.twc.texas.gov/vr-services-manual/vrsm-toc>

Discussion

Inclusive Classrooms and Instructional Design

Most students with disabilities spend all or a portion of their instructional day in general education classrooms. The federal Individuals with Disabilities Education Act (IDEA) requires that students with disabilities are educated in the least restrictive environment and that they should not be removed from the general education classroom without the provision of supplemental aids and services.⁷¹ The role of a general education teacher is to create a community conducive to ensuring all students meet their educational goals. To achieve this, general education teachers need ongoing training and support. The general education teacher along with the child's education team including SpEd teachers and aids, diagnosticians, therapists, and behavior specialists should work together to ensure the student receives appropriate instruction, accommodations, modifications, SpEd and related services, and materials to best support the student's diverse learning needs. Support for the general education teacher should include ongoing communication, co-planning time, co-teaching, technical assistance, assessments, and training to meet the child's unique needs.

Training general education teachers to be effective instructors in the inclusion classroom and how to teach students with special needs must continue to be a priority in developing teacher education programs and establishing continuing education requirements for teachers. It is very important that teacher education programs focus on providing appropriate instruction to those who will be instructing students with special needs because even if these teachers will be in a general education classroom, it is incredibly likely that general education teachers will be working with students with disabilities in their classrooms.

Minimal training is in place for SpEd inclusion in undergraduate educator training programs. Currently most undergraduate teacher education programs only require a one, three-hour survey course on Individual Differences, Exceptional Populations, or Introduction to Special Education.⁷² Therefore, it is imperative to work with the TEA to create and require continuing education for general education teachers to support them to provide instruction to students with disabilities in the general education classroom. Recommended coursework includes:

⁷¹ <https://sites.ed.gov/idea/regs/b/b/300.114>

⁷² <https://tea.texas.gov/texas-educators/preparation-and-continuing-education/educator-preparation-home>

- Introducing teachers to SpEd federal and state laws and rules (such as the federal IDEA and Section 504 of the 1973 Vocational Rehabilitation Act).
- Informing teachers about the characteristics of students with various disabilities and life-span needs of students with disabilities.
- Discussing the importance of collaboration with families of children with disabilities.
- Informing teachers about the Universal Design of Learning.
- Teaching teachers how to include positive behavior supports, differentiated instruction and various adaptations or modifications that they can make to accommodate students with disabilities in their classrooms.

Communication is a Human Right

The place of communication in human rights is usually seen in light of Article 19 of the Universal Declaration of Human Rights, which states that everyone has a “right to freedom of opinion and expression”, including the right “to seek, receive and impart information and ideas through any media and regardless of frontiers”.⁷³

Communication is paramount in imparting information so recommendations for formal assessment to determine communication needs should be required for those students that do not present with the ability to independently communicate. Students should be provided instruction, accommodations, modifications, therapy, and equipment to meet their individual communication needs. Assistive technology considerations should be addressed through assessment and implementation of appropriate devices to support the student. It is important to ensure that the student’s communication needs are addressed regarding statewide assessments and/or receive appropriate accommodations that meet their individual needs.

Collaboration Between a Student’s Educational Team and Providers

The mutual interest of children and families who receive services by the public school and private sector providers in collaboration is essential to create positive change in the lives of the individuals served and their families.

There are three main pathways for referral for SpEd or 504 services:

⁷³ <http://www.standup4humanrights.org/en/index.html>

1. **A school identifies that a child needs educational support.** This prompts an evaluation and establishes services that are school specific. The school's evaluation is how the IEP or 504 plan is developed that describes what services and supports a child will receive.⁷⁴ Each school system is federally mandated by section 504 of the Vocational Rehabilitation Act⁷⁵ or IDEA to provide a FAPE to students with disabilities. They are also bound by the Elementary and Secondary Education Act (formerly known as No Child Left Behind) that establishes criteria for educating all students.⁷⁶ These federal mandates may be interpreted differently by each school district and may result in different criteria for a child to receive services based on the school district.
2. **A health care provider identifies and diagnoses a condition where a child may need services and supports.** A provider documents medical necessity and completes a referral to the child's insurance or MCO. Even though a child starts receiving services and supports outside of the school setting, the school must complete an evaluation to determine the educational impact of this diagnosis. This may result in a child receiving the same types of supports by the same provider specialty (e.g., occupational or speech therapy), but services may be delivered by two different providers.
3. **Parent request.** Parents may also initiate a request for SpEd or 504 service evaluation in writing to their child's school. This request can be based on their own observations and concerns.

The school-based team cannot communicate with external health care providers unless the parent completes a Health Insurance Portability & Accountability Act (HIPAA) release of information form.⁷⁷ Health care providers also encounter Family Educational Rights and Privacy Act (FERPA), which is federal protection for a student's educational records that includes accommodations received by a child at school.⁷⁸

This is where collaboration becomes important for a child's success; parents are in the unique situation of being able to look at the whole picture. Parents are not restricted by HIPAA, so they are the conduit for information flow between education and health care providers. It is recommended that the various school and private

74 These services and supports are for the educational environment only and parents must follow assessment and referral processes as required by their medical insurance or Medicaid plan to receive services and supports outside of the school setting.

75 <https://www.eeoc.gov/statutes/rehabilitation-act-1973>

76 <https://www2.ed.gov/nclb/landing.jhtml>

77 <https://www.hhs.gov/hipaa/for-individuals/guidance-materials-for-consumers/index.html>

78 Family Educational Rights and Privacy Act (FERPA)

therapy providers explore ways to collaborate for the benefit of the student by sharing goals and strategies.

Policy Issue: Family support is critical to student success.

Self-care for parents is important because one's mental and physical condition affects the whole family. Many people, especially parents, dismiss self-care as something selfish or frivolous in the wake of caring for their child. It's far from either of those things. According to the National Institute of Mental Health (NIMH), self-care habits fall under six categories⁷⁹:

- Physical
- Psychological
- Emotional
- Spiritual
- Social
- Professional

Recommendation

Provide self-care training to parents through school districts.

Discussion

Parents need training on why self-care is critical to the family's well-being and how to participate in their own self-care for the benefit of their children. Burn out for parents of children with disabilities impact the lives of all members of the family and can lead to negative outcomes for children.

Require TEA to create a training for the importance of self-care and how to support the family through parental self-care to be provided as part of parent training in the schools.

⁷⁹ <https://www.nimh.nih.gov/>

Policy Issue: Current HHSC policy for newborn hearing screening may delay care for children who are Deaf or hard of hearing.

Hearing loss can affect a child's ability to develop speech, language, and social skills. The earlier a child who is Deaf or hard-of-hearing (DHH) receives services, the more likely they will reach their full potential.⁸⁰ ECI programs help young children with hearing loss learn language skills and can greatly improve a child's development.⁸¹ Babies that are diagnosed with hearing loss should start receiving ECI services no later than six months of age.

The Early Hearing Detection and Intervention (EHDI) program, also known as Texas EDHI (TEHDI) supports hearing screening for all infants by one month, identification of hearing loss by three months, and enrollment in early intervention by six months. These benchmarks, also referred to as 1-3-6 benchmarks, represent the very latest a child should receive follow-up to ensure infants with hearing loss receive intervention.⁸² The purpose of the 1-3-6 benchmarks is to ensure DHH infants are identified early and facilitate referral to early intervention services.

In addition to educational impacts of hearing loss, there are also economic costs. The lifetime costs of medical, educational, and occupational services for DHH children born in 2000 with hearing loss is estimated at \$2.1 billion.⁸³

Recommendation

Request HHSC, with the input of key stakeholder groups, conduct a thorough review of Medicaid and fee-for-service and managed care newborn hearing screening policies and practices to identify and implement recommendations, reduce barriers to care, and improve Texas' 1-3-6 EHDI outcomes.

80 <https://www.cdc.gov/ncbddd/hearingloss/features/ready-for-kindergarten.html>

81 <https://www.cdc.gov/ncbddd/hearingloss/treatment.html>

82 <https://www.cdc.gov/ncbddd/hearingloss/documents/hearing-factsheet-508.pdf>

83 <https://pubmed.ncbi.nlm.nih.gov/14749614/>

Discussion

Challenges with Information Systems and Reporting

All babies born in Texas must receive hearing screening, proper intervention, and referrals to services if suspected or diagnosed as DHH.⁸⁴ In 2020, 365,315 births were reported to TEHDI in 2020.⁸⁵ While 98% of infants passed hearing screenings, 5,834 did not and required follow-up assessment to confirm whether these infants required intervention. Over half of infants who did not pass a hearing screening in 2020 (52.6 percent) were either lost to follow-up (LTF) or lost to documentation (LTD) and are considered at-risk for hearing loss. This translates to 3,069 children in Texas who might not have received recommended services, a delay that can have significant developmental consequences.

Concerns about gaps in reporting

Many hospital birthing centers use contracted hearing screening programs to perform this service. There are approximately 250 certified newborn hearing screening programs across the state that provide services in hospital birthing centers. These contractors are responsible to ensure newborns who do not pass hearing screenings receive follow up care.⁸⁶ This includes referrals for any services like follow up once the infant leaves the hospital or referrals to an audiologist.

Often, hearing screening programs do not perform the outpatient screening and the baby is referred to their pediatrician for the screening or referral. Unfortunately, pediatric offices are encouraged, but typically do not report the results of follow-up screenings as they may be unaware of their reporting responsibilities.

The data reported to CDC EHDI supports the concern about gaps in identifying DHH infants. According to 2019 reports, the national average for early intervention enrollment by families with DHH children was 61.7 percent.⁸⁷ In 2019, Texas identified 387 babies as DHH and less than one third (32.5 percent) were enrolled in ECI programs. In 2020, the rate of ECI enrollment for DHH infants dropped to 26.7 percent.⁸⁸ Only 43 (10.6 percent) of infants diagnosed as DHH in 2020 met the 1-3-6 benchmark and were enrolled in ECI services enrolled by six months of age. It is suspected that the number of DHH infants are underreported to TEHDI. Further supporting this concern about underreported DHH infants, when comparing

84 <https://statutes.capitol.texas.gov/Docs/HS/htm/HS.47.htm>

85 <https://www.cdc.gov/ncbddd/hearingloss/ehdi-data2020.html>

86 <https://statutes.capitol.texas.gov/Docs/HS/htm/HS.47.htm>

87 <https://www.cdc.gov/ncbddd/hearingloss/ehdi-data2019.html>

88 <https://www.cdc.gov/ncbddd/hearingloss/ehdi-data2020.html>

2019 data reported by California, there were 440,428 births and 915 DHH, far fewer than Texas for the same reporting period.⁸⁹

Consent for newborn hearing screening program is unique to Texas

According to the EHDI National Technical Resource Center's State Informed Consent mandate provision page⁹⁰, Texas is the only state that requires parental consent to release hearing screening results and contact information to a state agency.

Texas Administrative Code requires consent for the DSHS TEHDI program to obtain personally identifiable information for babies receiving newborn hearing screenings.⁹¹ DSHS is required to follow up on screened infants to "...ensure that intervention is available to families for a newborn or infant identified as having hearing loss...".⁹² However, since the requirement of parental consent, there have been challenges receiving newborn hearing screening data. In 2020, one third of the TEHDI program's management information system records did not receive parental consent and were marked as confidential to DSHS. This means DSHS did not have access to contact records and could not coordinate follow-up for these babies. Incomplete data is less beneficial when using for public health surveillance.

There are inconsistencies between the two programs at DSHS that collect newborn screening data regarding consent (TEHDI and Clinical Care Coordination). Both programs reside within the Newborn Screening Unit at DSHS, however only the TEHDI newborn hearing screening program requires this type of consent. As a result, the same unit at DSHS must use two separate databases to capture data with no ability to interface and share data.

Medicaid Reimbursement and Access to Providers

Medicaid funding remains the biggest barrier to care and follow up. On June 12, 2018, an Epidemiologic Assistance (Epi-Aid) team from CDC arrived in Texas to investigate, in collaboration with TEHDI, to address several objectives including identifying potential next steps to reduce LFU or LTD.⁹³

89 <https://www.cdc.gov/ncbddd/hearingloss/ehdi-data2019.html>

90 <https://www.infanthearing.org/legislative/provisions/informedconsent.html>

91 [https://texreg.sos.state.tx.us/public/readtac\\$ext.TacPage?sl=R&app=9&p_dir=&p_rloc=&p_tloc=&p_ploc=&pg=1&p_tac=&ti=25&pt=1&ch=37&rl=503](https://texreg.sos.state.tx.us/public/readtac$ext.TacPage?sl=R&app=9&p_dir=&p_rloc=&p_tloc=&p_ploc=&pg=1&p_tac=&ti=25&pt=1&ch=37&rl=503)

92 <https://statutes.capitol.texas.gov/Docs/HS/htm/HS.47.htm>

93 <https://www.thieme-connect.com/products/ejournals/abstract/10.1055/a-1932-9985>

Problems with insurance coverage, reimbursement, and referrals were identified in the CDC Epi-Aid report as both a provider-related and family-related barrier to children receiving timely hearing-related services. A key report recommendation for Texas action was for HHSC to “review Medicaid reimbursement language, practices, and policies”.⁹⁴

If reimbursement rates are as problematic as Epi-Aid interviewees suggested, work to rectify this issue could have significant long-term impacts in Texas. For example, patients in rural areas face barriers in finding local providers with the capacity to diagnose infants with hearing loss because there are no or few providers contracted with Medicaid.

Shortages in ENT physicians, pediatric audiologists, and educational audiologists also contribute to lost follow up for care. Providers report that patients experience denials for services that require multiple revisions and phone calls to rectify which results in delayed testing and hearing aid fitting appointments. Providers also cite low reimbursement from Medicaid for office visits, fitting fees, and hearing aids and results in fewer providers who contract with Medicaid.

94 <https://www.thieme-connect.com/products/ejournals/abstract/10.1055/a-1932-9985>

WHEN OUR KIDS (PICTURED AT RIGHT) WERE BORN DEAF, MY HUSBAND AND I HAD NO IDEA WHAT NEXT STEPS TO TAKE. THROUGH ECI, WE WERE GIVEN RESOURCES, STRATEGIES, AND ENCOURAGEMENT TO GUIDE OUR CHILDREN AS THEY DEVELOPED AND LEARNED TO COMMUNICATE. THE PEOPLE WE CONNECTED WITH THROUGH ECI ARE STILL, TO THIS DAY, SOME OF OUR MOST DEAR FRIENDS. ECI QUITE LITERALLY CHANGED THE TRAJECTORY OF OUR FAMILY'S JOURNEY AND WE ARE FOREVER GRATEFUL.



Figure 19: The Stonescu Children (Pictured above)

9. Conclusion

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

These children and families face repeated and significant obstacles to receiving timely and quality-based care, especially in times of crisis whether it be a medical or family crisis or state or federal crisis. Parent and guardians of disabled and special needs children spend great amounts of time coordinating care across multiple providers and venues. The PCCF is asking you to carefully consider the recommendations discussed in this report, which are focused on improved delivery of medical & crisis care, improved access to medical and support systems to meet the varied complex needs of 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
ARD	Admission, Review, and Dismissal
ASB	Autism Services Benefit
ASD	Autism Spectrum Disorder
CDC	Centers for Disease Control and
CHIP	Children's Health Insurance Program
CMS	Centers for Medicare and Medicaid Services
DFPS	Texas Department of Family and Protective Services
DHH	Deaf or Hard of Hearing
DSHS	Texas Department of State Health Services
DSM-V	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
CHIP	Children's Health Insurance Program
CMS	Centers for Medicare and Medicaid Services
DFPS	Texas Department of Family and Protective Services
DHH	Deaf or Hard of Hearing
DSHS	Texas Department of State Health Services
DSM-V	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
ECI	Early Childhood Intervention
ECSE	Early Childhood Special Education
ED	Emergency Department
EHDI	Early Hearing Detection and Intervention
Epi-Aid	Epidemiologic Assistance Team from CDC
EPSDT	Early and Periodic Screening, Diagnostic, and Testing
FAPE	Free Appropriate Public Education
FERPA	Family Educational Rights and Privacy Act
FPL	Federal Poverty Level
GRO	General Residential Operations
HB	House Bill
HCS	Home and Community-Based Services
HHS	Health and Human Services
HHSC	Health and Human Services Commission
HIPAA	Health Insurance Portability & Accountability Act
ICF/IID	ICF for Individuals with Intellectual Disabilities
IDD	Intellectual and Developmental Disability
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Plan
LEA	Local Education Agencies
LHA	Licensed Health Aide
LMHA	Local Mental Health Authority

Acronym	Full Name
LTD	Lost to Documentation
LTF	Lost to Follow Up
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
SB	Senate Bill
SHARS	School Health and Related Services
SMMCAC	State Medicaid Managed Care Advisory Committee
SpEd	Special Education
SSI	Supplemental Security Income (Social Security)
SSLC	State Supported Living Center
START	Systemic, Therapeutic, Assessment, Resources, and Treatment
TEA	Texas Education Agency
TEFRA	Tax Equity Fiscal Responsibility Act
TEHDI	Texas Early Hearing Detection and Intervention
TFC	Treatment Foster Care
TT	Tracking Teacher
TxHML	Texas Home Living
VRS	Vocational Rehabilitation Services
YASHCN	Young Adults with Special Health Care Needs
YES	Youth Empowerment Services