



**Texas Policy Council
for Children and
Families**

**Recommendations for
Improving Services for
Children with
Disabilities**

December 2018

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

About This Report

This report was prepared by members of the Policy Council for Children and Families (PCCF). 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 on at regularly scheduled PCCF meetings in accordance with the Texas Open Meetings Act. Information about these meetings is available at <https://hhs.texas.gov/about-hhs/leadership/advisory-committees/policy-council-children-families>

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1. Letter from the Chair

Honorable Members, Texas Senate
Honorable Members, Texas House of Representatives
Executive Commissioner, Texas Health and Human Services Commission

Dear Senators, Representatives, and Commissioner:

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 approximately two years of research, analysis, public input, and feedback on issues of importance to children and young adults with disabilities and their families. PCCF members leveraged and prioritized their own lived experiences and drew upon the expertise of professional members and subject matter experts to identify broad areas of concern.

Public input was requested and received continually during the writing of this report, resulting in a more robust, inclusive, and useful product. Public testimony from parents, advocates, and people with disabilities about their daily experiences added depth and dimension to the PCCF policy recommendations. Simply put, stakeholder input has been indispensable in crafting actionable recommendations that both minimize unintended consequences and provide thoughtful solutions to existing problems.

At the end of the day, the positive or negative life trajectory of a child with a disability depends on the choices made by lawmakers—choices that either support, or limit, our children. Implementing these recommendations would allow our children with disabilities in Texas to have better and more meaningful lives.

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

Sincerely,

Chris Masey, Chairperson

Message from the Family Members of the Policy Council for Children and Families



It takes a village to raise a child with special needs. Children with cognitive, mental health, and/or physical disabilities need additional assistance from their families as well as paid personnel such as therapists, physicians, medical specialists, caseworkers, teachers, and many others. Children and youth with disabilities spend more time in hospitals, require more doctor visits, have more appointments with both physical and mental health therapists, require more medications and durable medical equipment, and need more assistance at school than their peers. Families often struggle with the expenses and logistics associated with coordinating care for their disabled children, usually while caring for other children and maintaining a home, a marriage, and a career.

Texas state policies have a profound impact on the lives of children with special needs as well as the emotional and financial health of their families. Many of these policy decisions are made by elected representatives who may not have direct experience with children with disabilities. Therefore, we would like our legislators to know the following about raising a child who has a disability:

- Disability is non-partisan and non-discriminatory. Disability cuts across lines of political party, income, race, religion, and culture.

- Our children are Texans, and we ask that they are allowed to lead productive and dignified lives. Our children deserve to grow up with the same respect and opportunities that all Texas children are afforded.
- Like all children, our children dream of growing up and becoming independent adults with careers, families, and homes of their own. Helping our children become productive and independent members of society not only helps them, but it also saves Texas money.
- Texas families spend millions to care for their disabled children. We do this because we love our children and want them to be as independent and happy as they can possibly be. No family wants a handout. We simply need assistance providing some of the supports that our children need to help them achieve their goals and to help families stay emotionally and economically healthy.
- Families fight every day for appropriate medical care, insurance reimbursements, educational services, and community inclusion. Nothing comes easily, and the depth and intensity of the concern and the desire to provide what our children need is often exhausting.
- All children belong in families, not in institutions. Only the family can provide a child with the love and support that their children need to grow up to be emotionally healthy. Providing supports for families to care for their children within the home is much more cost effective than caring for a child in a state-supported living center.
- Children with disabilities are at greater risk for abuse and suicide. We want to be sure that our children are safe at school and in the community and that they receive the mental health services they need to be emotionally healthy.
- Many of our children are academically well suited for higher education.
 - ▶ However, their dropout rate is much higher than that of their non-disabled peers. They need additional supports to help them transition from high school to college.
- Our children deserve access to meaningful employment services, provided in community setting that leads to integrated and competitive employment.
- We don't want your sympathy. We love our children! We just ask for the assistance we need to help them grow up independent and happy.

Thank you for your time and for serving as our elected representatives!

2. About the Council

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

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

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

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Acknowledgements

The council would like to thank Greg Mazick for his many contributions as a subject matter expert.

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



3. Policy Issues and Recommendations

Policy Issue: Improving Individual and Family Support

Children with disabilities need supports and services to lead full and meaningful lives in their families, schools, and communities. Their families also need supports to help them as their children grow and develop. Supports include personal care and habilitation, respite for the family, and flexible supports during times of crisis. Families and individuals with disabilities need access to tools to navigate the complex healthcare and support system, increase the quality of care a parent can provide at home, and prepare their children for the future. The root of all planning starts with a robust person-centered plan. The Policy Council for Children and Families (PCCF) is asking for greater access to person-centered planning, continued funding for the invaluable resource website Navigate Life Texas, adequate respite, crisis supports, greater flexibility within waivers, and cost-effective Community First Choice (CFC).

Recommendations

1. Ensure robust and holistic person-centered planning (PCP) for all children with disabilities.
 - a. Require the use of standards defined by the Institute of Person-Centered Practices.¹
 - b. Ensure PCP is part of child to adult healthcare transition services beginning at age 12.
 - c. Require Texas school districts provide PCP for all transition age youth (ages 14 – 21) receiving special education services.
 - d. Require conflict-free independent PCP for all children receiving services through a Medicaid waiver, STAR Health, STAR Kids and STAR Plus, including those using consumer-directed services.
 - e. Provide PCP in a language appropriate to the child and family.
 - f. Require that all PCP for transition-age youth includes alternatives to guardianship and information on supported decision-making.

¹ <http://www.person-centered-practices.org/>

2. Continue funding for the Navigate Life Texas website, including funding for updates and expansion, and ensure all state agencies are linked to the website.
3. Ensure access to adequate and meaningful respite care for families of children with disabilities, allowing families to receive a break from exhaustive caregiving.
 - a. Provide general revenue funding (similar to In-Home and Family Support) for respite to families who do not have access to Medicaid or a Medicaid waiver.
 - b. Promote innovative respite cooperatives among families in the same communities using nonprofit organizations to organize and maintain services.
4. Provide time-limited flexible funding to families of children with disabilities during a crisis.
 - a. Support positive behavior supports, short-term care at home and out-of-home, home modifications, transportation, and training.
 - b. Identify and approve the funding through an individual support plan.
 - c. Manage the funds through a local entity with assigned coordinators who can prioritize and authorize support plans and funds, such as the Local Intellectual and Developmental Disability Authorities (LIDDAs) and the Local Mental Health Authorities (LMHAs).
 - d. Consider the use of general revenue to fund these supports.
 - e. Amend the Texas Home Living waiver eligibility to disregard parental income for those who have urgent needs.
5. Allow flexibility within the home and community-based (HCS) waivers as part of the restructure of waiver benefits for persons with intellectual and developmental disabilities (IDD) to meet the new Home and Community-Based Service (HCBS) settings requirements in Community First Choice (CFC).
 - a. Allow people on different waivers to share resources without exceeding preset limits (ration guidelines).
 - b. Explore a common set of benefits among waivers to meet the needs of an individual.
6. Improve access to CFC and habilitation for individuals as an alternative to institutional care.
 - a. HHSC should create a document that describes habilitation and how to obtain services.

- b. Require managed care organizations (MCOs) to provide all Medicaid recipients information on CFC and the ability to receive habilitation in addition to personal care services.
- c. Provide funding and set a rate for CFC that:
 - i. Attracts direct service providers with experience in habilitation,
 - ii. Attracts employees in rural parts of the state, and
 - iii. Promotes employment longevity.
- d. Ensure MCOs understand that people with high physical and medical needs benefit from habilitation including training in how to direct their care.
- e. Ensure CFC tools allow for assessment of the habilitative needs of individuals with high physical and medical support needs.

Background

Person-centered planning (PCP) is an important tool that can assist a young person with disabilities in making important lifelong care and quality of life decisions. The person-centered planning process allows parents and youth to develop a comprehensive, well-defined plan together that focuses on the youth's self-identified goals and allows the individual to self-advocate, an important skill during the transition into adult services and responsibilities to become independent.

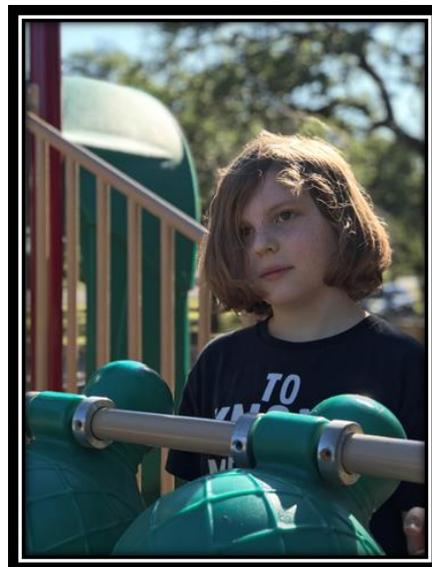
The Navigate Life Texas website has grown immensely since its inception by the Task Force for Children with Disabilities and has continued to serve as a vital resource for families to find access to support services. However, there are still many families, and even state workers, who are unaware of its existence. In order to inform more parents of the resources available to them, every state agency should provide a link to the website on their pages and encourage every parent of a child with a disability, chronic illness, or other special care need to visit the website for resources.

Respite care for parents and family members who serve as primary caregivers is crucial to maintaining quality care at home. However, without Medicaid waiver funding, parents receive little respite. Taking a break on a weekly basis to attend to pressing needs for their other children, spending time with their partner or spouse to maintain their relationship, or just taking time for themselves is very important.

Families of children with disabilities face the challenges that all families face. However, they also face additional challenges related to their child's disability. Urgent situations may include a child's challenging behavior, medical condition, or

mental health crisis. They may also include caregiver incapacity due to competing needs of other family members, caregiver illness, family emergency, or exhaustion due to lack of assistance. With no way to access family support, families are sometime forced to turn to an expensive publicly funded institution to provide services and supports. However, short-term, low-cost measures often would suffice to bring the situation under control. **Flexible urgent family support** is needed for families whose children do not have Medicaid and or a Medicaid waiver. The foundation of family support for children with developmental disabilities are Medicaid waiver services. This leaves families without cost effective options while they wait on waiver support lists for 5 to 13 years. Family crises will not wait.

Community First Choice (CFC) became part of the Texas State Medicaid Plan in June 2015. The goal of the state in including CFC as a state plan service was to offer individuals on Medicaid a benefit that would prevent the need for costly institutionalization and would support individuals stuck on waiver interest lists as they wait for a more comprehensive package of supports. HHSC projected that approximately 12,000 individuals without Medicaid waivers would be enrolled in CFC, which has a 6% higher match rate from the federal government. To date, the CFC benefit is underutilized. Children and families continue to report they have never heard of the benefit, while others who have been approved for services report they are unable to find someone to provide direct support in the home given the low rate of pay for direct service workers. An effectively working CFC benefit keeps people out of costlier institutional settings and leads to better quality of life and health outcomes for people with disabilities.



Policy Issue: Promoting Independence and Waiver Interest List Funding

Approximately 1,100 children and young adults with disabilities under 22 years of age are living in institutions. Children with disabilities belong in families. Since 2002, the number of children living in large facilities with six or more children has decreased by approximately 62%², but there is more work to be done. The PCCF recognizes the significant accomplishments of Texas to support children and adults to move from institutions to the community and recommends continued funding for waivers as not only a cost-effective alternative to institutions, but one that promotes healthy growth and development of children. For children to live in families, they need access to Medicaid waivers.

Recommendations

1. Fund Home and Community-based Services (HCS) waiver service spaces for the following children to move from institutions to families:
 - a. 35 children living in DFPS General Residential Operations;
 - b. 20 children to move from nursing facilities;
 - c. 500 individuals to move from large/medium ICFs/IIDs (Intermediate Care Facilities for Individuals with an Intellectual Disability);
 - d. 120 individuals to move from state psychiatric hospitals; and
 - e. 50 children to move from small ICFs/IIDs to families.
2. Fund waiver service spaces for the following children at imminent risk of institutionalization:
 - a. 216 children aging out of DFPS foster care (HCS waiver);
 - b. 400 individuals in crisis to prevent institutionalization (HCS waiver);
 - c. 600 individuals at risk of placement in nursing facilities (HCS waiver);
 - d. 100 children who are medically fragile at imminent risk of placement in nursing facilities (MDCP waiver); and
 - e. 100 children who are at imminent risk of institutionalization in a nursing facility or Intermediate Care Facility (ICF) (CLASS waiver).
3. Provide funding for increased capacity to reduce the Medicaid waiver interest list by 20,000 to ensure more children can grow up in families.

² Texas Government Code. *Permanency Planning*, Title 4, Section 531.152. Retrieved from <http://www.statutes.legis.state.tx.us/Docs/GV/htm/GV.531.htm>

Background

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.³

Since 2002, Texas has experienced a 62% decrease in the number of children living in congregate facilities with six or more people resulting in a savings to the state and an improved quality of life for the child and family.⁴ Texas 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.⁵



Funding for waivers for children to move from institutions to families and to reduce waiver interest lists is necessary. Some children spend from 5 to 13 years waiting for services on waiver interest lists. Families of these children often have little alternative other than to seek admission of their children to a costly institution. Funding for waivers was not appropriated in the amount requested for the 2018-2019 biennium, leaving some children without access to the supports and services they need to live in a family.

² *Ibid.*

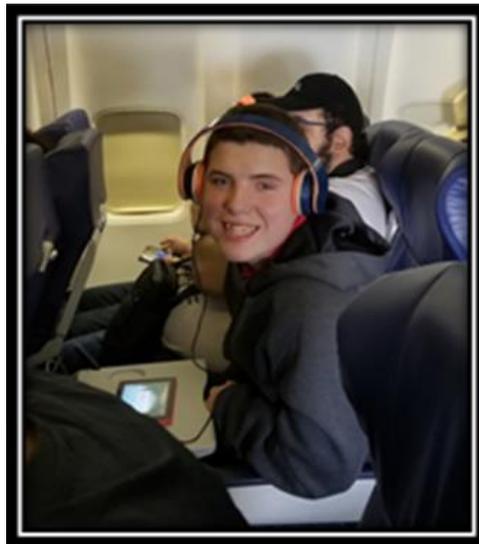
⁴ *Ibid.*

⁵ Coughlin, R., Ward, J., et al. (2017). Money Follows the Person Demonstration: Overview of State Grantee Progress, January to December 2016. *Mathematica Policy Research*. Retrieved from <https://www.medicare.gov/medicaid/ltss/downloads/money-follows-the-person/2016-cross-state-report.pdf>

Mason's Story

Mason loves to sing, dance, play basketball, go to church, and help others. However, due to family circumstances and his disability support needs, he has lived in multiple homes and large facilities. He struggled for years to find a place he could truly call home. In February 2017, with the support of the Texas Health and Human Service Commission's Family Based Alternatives contract and a Promoting Independence waiver for children living in DFPS facilities, Mason moved to a family. The family and Mason decided that they were a forever family and wanted to take the next step. In November 2017, Mason became an official member of the family and to celebrate his adoption and his 17th birthday, the family took a vacation to Mexico where he flew on a plane, walked on the beach for the first time, and relaxed in a hammock in the shade.

Mason is going to school, is exploring employment opportunities through his school's supported employment program, and is loving life. He receives behavioral support through a Home and Community-based Services (HCS) waiver and receives Community First Choice (CFC) services.



Policy Issue: STAR Kids

STAR Kids, the Texas Medicaid managed care delivery model for children and young adults under the age of 21 with disabilities, was implemented on November 1, 2016. Acute care services as well as the Medically Dependent Children Program (MDCP) waiver are now delivered under the new program, which serves approximately 160,000 children. Only 3% of the children in STAR Kids receive MDCP waiver services. The PCCF has actively worked with HHSC on improvements to STAR Kids to allow children who have medically complex conditions, children with intellectual and developmental disabilities, children with mental health care needs, and others get the medically necessary services they need.

Recommendations

1. Require a more standard and streamlined prior authorization process among the STAR Kids health plans for private duty nursing and other services.
 - a. Decrease administrative burdens, prevent gaps in services and delays in authorizations, and ensure individuals access to medically needed services without discrimination and inconsistencies across plans.
 - b. Decrease re-authorization frequency for children with chronic conditions that are not likely to change.
 - c. Ensure continuation of prior authorization of nursing services and other services when a child and family have a pending appeal (fair hearing request) and do not allow a managed care organization (MCO) to end any authorization before the case has been heard.
2. Encourage nurse delegation in personal care services through education initiatives, rate enhancements, and value-based arrangements.
 - a. Provide an increased rate of pay for unlicensed assistive personnel who are trained to perform delegated tasks.
 - b. Promote and educate providers, parents, and recipients on what is considered "safe and appropriate" delegated services.
 - c. Increase funding to home health agencies and nurses to train and supervise unlicensed assistive personnel who perform nurse delegated tasks.
3. Allow children who receive Supplemental Security Income (SSI) and meet the Medically Dependent Children Program (MDCP) waiver eligibility requirements immediate access to waiver level services with no wait.
 - a. Children enrolled in STAR Health.
 - b. Children enrolled in STAR Kids.

4. Maintain the current funding levels to offer children on the interest list (who do not have SSI) waiver services.
5. Offer children who have lost eligibility for Medicaid due to loss of Medically Dependent Children Program (MDCP) eligibility in STAR Kids, access to another 1915(c) waiver such as Community Living Assistance and Support Services (CLASS) or Home and Community-Based Services (HCS).
 - a. Create a set-aside in the HCS and CLASS waiver for 50 children each, per biennium in this category.
6. Provide families timely notice of their right to seek an appeal and a Medicaid fair hearing when Medicaid services including waiver services, nursing, personal care services, and therapy are reduced or denied.
 - a. Require managed care health plans to send notification for a denial or reduction in service within one day of the date on the notification.
 - b. Require the notice to be delivered via registered mail to ensure the time frame is followed.
 - c. Ensure notices sent by HHSC and the health plans are written in plain language for families with detail on why the denial occurred, what is needed to meet medical necessity requirements, deadlines for the appeal, and information on maintaining the same level of service during the appeal and fair hearing process until a final determination is made.

Background

Standardized and Streamlined Authorization Process

The PCCF is concerned about the lack of certainty and clarity in the prior authorization process in STAR Kids, as well as burdensome requests for information from managed care organizations (MCOs). Policies and prior authorization processes were established by the state prior to the roll out of STAR Kids. Today families are working with multiple MCOs, each with its own set of authorization requirements and review processes—some of which are onerous to providers and families and which cause delays in authorization for needed services. Physicians, therapists, home health agencies, durable medical equipment companies, and others all have reported an increase of up to 25% in their administrative costs due to paperwork requirements of the MCOs. Providers are leaving STAR Kids due to increased administrative burdens.

Families and physicians in STAR Kids have voiced concerns about medical necessity determinations by MCOs that are contrary to the determinations made by the child's physician. Children are experiencing a reduction in authorizations for private duty nursing, the Medically Dependent Children Program (MDCP) waiver, therapies, and other procedures. HHSC has a definition of medical necessity and when there is a dispute, the determination and standard of medical necessity should default to the child's physician.

Nurse delegation in Personal Care Services (PCS)

The current Medicaid system does not fully support nurse delegation. The rate paid to direct service providers through personal care services (PCS) is low, which results in high turnover and reluctance on the part of nurses to delegate. Families are reluctant to use nurse delegation because of their children's medical fragility and because PCS attendants are hard to find and do not remain on the job long. More training needs to be provided to families, providers, and members about nurse delegation and what is safe and appropriate. Also, home health agencies and nurses need a rate and payment mechanism that supports the training of unlicensed assistive personnel and supervision.

Transition from private duty nursing to delegated attendant services will result in cost savings to the state. The benefit to people served will be through increased access to long term services and supports, more stable service plans, and smoother transitions to adult services.

Immediate access to Medically Dependent Children Program (MDCP) waiver level services with no wait

Medically Dependent Children Program (MDCP) services, which can help prevent institutionalization, include: respite, minor home modifications, adaptive aids, flexible family supports, financial management, transition assistance services, supported employment, and employment assistance. The MDCP waiver provides a cost-effective alternative to the institutionalization of children. The individual cost of services is capped at less than 50% of what is paid to a nursing facility.

As of May 2018, 16,480 children and young adults were waiting for the MDCP waiver. The wait for services is approximately five years.⁶ With the change in service delivery model for MDCP to the STAR Kids Medicaid managed care model, Texas has not changed the number of appropriated “slots” for the waiver. As such, entry to the waiver and access to waiver services is still managed using an interest list. Unlike the STAR+PLUS waiver, children and young adults with STAR Kids who have Supplemental Security Income (SSI) and meet MDCP eligibility criteria cannot access waiver services until they come to the top of the interest list.

Eligibility for MDCP is determined when the child gets to the top of the interest list and not when their name is added. The average percentage of children who are determined eligible for MDCP when they reach the top of the interest list is approximately 10.4% of the previous biennium’s interest list. According to HHSC’s chief financial officer, the current uptake rate for MDCP is estimated at 15%, which means only 2,526 of the 16,840 children waiting for services will be deemed eligible when they get to the top of the list. Approximately 1,170 of the 2,526 who would be eligible for the waiver and take the waiver if offered have Supplemental Security Income (SSI).

The policy of providing adults who have Supplemental Security Income (SSI) (and meet medical necessity) with automatic access to waiver services in STAR Plus has received overwhelming support. Approximately 99.6% of individuals without SSI who are waiting for STAR Plus waiver services have been on the interest list for less than one year.⁷ If the state decided to implement the same policy that has been successfully implemented for the adult STAR Plus SSI waiver population, the Medically Dependent Children Program interest list would decrease by more than 46%, which is the percentage of children on the interest list who have SSI.

Loss of Medically Dependent Children Program (MDCP) eligibility and access to another 1915(c) Waiver

With the implementation of STAR Kids and a new assessment instrument, the percentage of children who have lost Medically Dependent Children Program (MDCP) eligibility at their annual reassessment has increased from 3.13% in fiscal

⁶ Texas Health and Human Services Commission. *Interest List Reduction*. Retrieved from <https://hhs.texas.gov/about-hhs/records-statistics/interest-list-reduction>

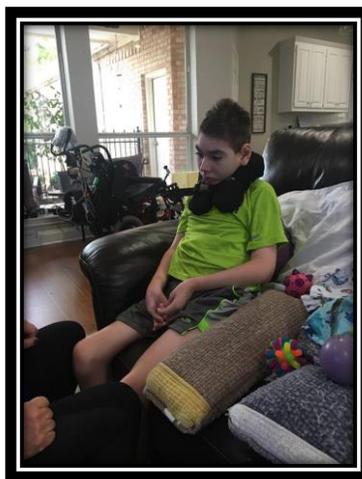
⁷ *Ibid.*

year 2016 to as high as 10% in July 2018, according to data presented to the STAR Kids Advisory Committee at its September 6, 2018, meeting. Children who waited for more than five years for services and have been receiving waiver services through MDCP are not only losing access to their long-term services and supports, but may also be losing their healthcare coverage or healthcare insurance.

Many of the children who have lost eligibility for Medicaid due to their loss of MDCP eligibility continue to need the long-term services and supports offered in other 1915(c) waivers, such as CLASS or HCS. Not only have children lost their waiver services, some have lost access to critical health care and long-term services and supports such as personal care services. Without these services children are at risk of unnecessary institutionalization in intermediate care facilities and nursing facilities at a high cost to the children, their families, and the state. Children should not simply be placed on another interest list and required to wait an additional 10 years or more for services.

Notices and appeals

The PCCF has received feedback from families about issues with filing Medicaid appeals. For services to continue during the appeal process, an individual must request the appeal within 10 days from the date on the notification letter. By the time families receive the letter, days have passed, leaving a very short period of time to file the appeal and ensure continued services. In addition, issues with the communication process between all parties are evident. The reasons cited in the appeal must be clear and written in plain language that is easily understood.



Policy Issue: Intellectual and Developmental Disabilities (IDD) Waivers and Managed Care

If Medicaid waiver services shift from a fee-for-service program managed by HHSC to a managed care model, the transition must be done thoughtfully and carefully. Children should not lose access to supports and services that keep them healthy and safe in families. The recent carve-in of the Medically Dependent Children's Program (MDCP) into STAR Kids resulted in a significant number of children losing access to critical waiver services and Medicaid. Families should not have to undergo another carve-in of critical services without sufficient planning and safeguards.

Recommendation

1. Delay inclusion of the intellectual and developmental disabilities (IDD) waivers in managed care. The PCCF supports the recommendation made by the System's Redesign Advisory Committee (SRAC) to delay the carve-in of the IDD waivers until assurances can be made regarding readiness.

Background

The Intellectual and Developmental Disability System Redesign Advisory Committee (IDD SRAC) created as part of Senate Bill 7 by the 83rd Legislature in 2015 is charged with advising HHSC on the implementation of acute care and long-term services and supports for individuals with intellectual and developmental disabilities (IDD). The committee strongly recommended that HHSC delay the transition of IDD Long-term Services and Supports (LTSS) to a managed care model until necessary systems changes are accomplished. The committee requested that HHSC evaluate the lessons learned from the STAR Kids IDD acute care carve-in and use those lessons to improve the system before any additional waivers are carved into Medicaid managed care. The PCCF concurs with the IDD SRAC recommendation.

Policy Issue: Medicaid-Funded Therapy

Access to physical, occupational, and speech therapy can vastly improve the life of a child with a disability. With appropriate therapy evaluations and services children can be mobile in their homes and communities, have less spasticity and fewer contractures, transfer independently, communicate with others through the support of an augmentative communication device, learn proper swallowing techniques that prevent devastating pneumonia, and more. Some families, however, are having difficulty securing prior authorization for therapy services that have been deemed medically necessary by their physicians to correct or ameliorate a condition, and providers are facing administrative burdens that delay and make securing prior authorization difficult.

Recommendations

1. Ensure children with disabilities get the therapy needed to maximize and maintain their abilities.
2. Restore Medicaid fee schedules to the amount prior to the 2016 cuts and ensure adequate funding for health plans and access to therapy services for children.
3. Provide utilization review reports on a quarterly basis to providers and the public regarding therapy waiting lists, delays in initiation of therapy services and managed care organization (MCO) network adequacy.
4. Provide utilization review reports on cost savings associated with the changes to the May 1, 2016, therapy policy, detailing quality outcome measures and utilization review measures using best practices. Use any savings from the policy changes to restore rate cuts.
5. Monitor and evaluate prior authorization processes and documentation requirements across MCOs to ensure access to care without inconsistencies across plans.
6. Implement an attestation form for physicians to confirm an ongoing chronic condition and extend prior authorization period for children with chronic condition to decrease administrative delays in authorization and save administrative costs.

Background

All children under age 21 with Medicaid are eligible for health care benefits under the federal Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program. According the Centers for Medicaid and Medicare Services, “EPSDT’s goal is to assure that individual children get the health care they need when they need it—the right care to the right child at the right time in the right setting.”⁸

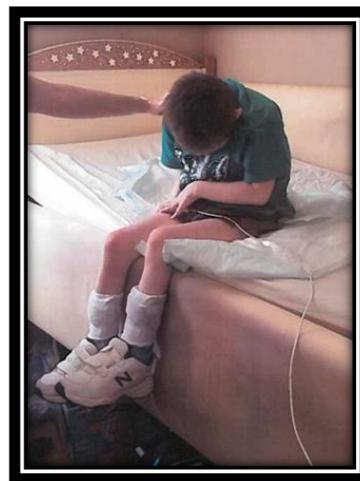
Services that maintain or improve the child’s current health condition are also covered in EPSDT because they “ameliorate” a condition. Maintenance services are defined as services that sustain or support rather than those that cure or improve health problems. Services are covered when they prevent a condition from worsening or prevent development of additional health problems. The common definition of “ameliorate” is to “make more tolerable.” Thus, services such as physical and occupational therapy are covered when they have an ameliorative, maintenance purpose. This is particularly important for children with disabilities, because such services can prevent conditions from worsening, reduce pain, and avert the development of more costly illnesses and conditions.⁹

Therapy Keeps Scotty Healthy, Home

By Catherine Carlton

For several years Scotty has received twice weekly speech, physical and occupational therapy thanks to fee-for-service Medicaid. Since Star Kids, his therapy has been drastically reduced.

I can assure you that Scotty has progressed with the assistance of frequent therapy. It is true that his progress has not come at the same pace as those with fewer global disabilities. But this progress is real, observable and measurable.



⁸ The Centers for Medicare and Medicaid Services (2014). *EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents*. Retrieved from https://www.medicare.gov/medicaid/benefits/downloads/epsdt_coverage_guide.pdf

⁹ *Ibid.*

In the last six months, Scotty:

- Sat upright with minimal assistance for 45 seconds and then 60 seconds.
- Held his head upright for 15 seconds without assistance.
- Reached for and engaged with toys for more than three minutes.

Perhaps this sounds like incremental progress to you. But to us, **these are major milestones.**

It means Scotty is able to engage more life skills by improving his head and neck control, which helps with swallowing and decreases chances of aspiration; increasing his trunk control, which aids digestion and the ability to breathe deeply, avoiding respiratory problems; and increasing stability and balance, which aids us and his caregivers in transfers from wheelchair to bed and back. These are critical skills for our son.

Scotty requires assistance with every task in his life. With the help of therapy, he has exceeded expectations for lifespan, quality of life and abilities. For example:

- Scotty has avoided hip surgery. His rigorous work in a stander has built strength and endurance while upright.
- Scotty was receiving bone density intravenous treatments. However, with direction from his endocrinologist, we have been able to stop this costly treatment thanks to the strides he's made in building bone strength during therapy sessions.
- Scotty has had ONE pressure sore in his life, and it took weeks of intense care to recover. Without frequent adjustments that therapists oversee for his wheelchair and sit-to-stand device, he would have more of these sores. It takes professional expertise to note the subtle changes and adjustments necessary for his wheelchair and stander as he grows.

It is no exaggeration to say that his therapists have helped keep him alive, out of the hospital and prevented the need for more expensive and invasive surgeries and treatments.



Policy Issue: Network Adequacy in Medicaid

Some children with disabilities are experiencing difficulty in finding providers within their Medicaid managed care organization (MCO) networks including primary care physicians and specialists. In addition, some members are struggling to keep their preferred vendor and are being directed to an MCO preferred provider arrangement that does not meet their needs. The Medicaid MCO network must be adequate to meet the needs of children and young adults and flexible to allow for non-preferred providers. The PCCF believes the following recommendations will lead to improved outcomes for children and the system.

Recommendations

1. Ensure network adequacy standards in Medicaid to meet the needs of children with developmental disabilities.
 - a. Create network adequacy standards that require managed care networks to have enough physicians to meet the needs of children with developmental disabilities. HHSC must ensure that each MCO is contracted with an adequate number of primary and specialist physicians, developmental pediatricians, therapists, home health agencies and hospitals that care for children with disabilities.
 - b. List criteria in MCO contracts for their call center staff to be able to identify providers within their network that care for children with disabilities, including behavioral and cognitive chronic disorders, so they can adequately assist families, members, and legally authorized representatives in identifying providers to meet their specialized needs.
 - c. HHSC should amend the Texas State Medicaid Plan to allow licensed board-certified behavior analysts (BCBAs) to be reimbursed for services under the plan to increase Applied Behavioral Analysis (ABA) provider availability.
2. HHSC should clearly define requirements on how preferred provider arrangements may be utilized ensuring:
 - a. Members are given a choice of two to three providers for specialty services and durable medical equipment including non-preferred provider-arranged services.
 - b. Members have the right to choose the best services or equipment that meets their medical necessity, regardless of provider arrangement with the Managed Care Organization (MCO).

- c. MCOs must submit all preferred provider contracts to HHSC for review and approval.
 - d. MCO call center staff must inform members of non-preferred providers along with preferred providers available in the network.
3. Stop the implementation of a value-based purchasing model in which an MCO designates a single provider for all therapy evaluations and/or designates a preferred provider for treatment services and then waives prior authorization requirements for families willing to use the preferred provider.
 - a. This model eliminates freedom-of-choice for Medicaid beneficiaries.
 - b. Designating a sole provider as the preferred provider for treatment services and eliminating prior authorization requirements for families that use this provider may have the effect of creating an exclusive provider network.
 - c. HHSC should require that any payment model implemented by a MCO be research based, consider stakeholder input, maintain consumer access to services, and improve quality.
 - d. HHSC should ensure accountability measures are in place.

Background

Some MCOs in STAR Kids utilize a preferred vendor for the durable medical equipment and medical supply needs of their members. While HHSC has provided clarification that children in STAR Kids must be able to opt out of a preferred provider arrangement if it does not meet their needs, durable medical equipment providers are having trouble operating under the new Medicaid managed care system due to:

- An increase of up to 25% in administrative costs and burdens for providers in submitting prior authorization and submitting claims;
- Significant rate decreases of between 12% to 14% for equipment and supplies including enteral formulas; and
- Prior authorization processes that are not consistent across MCOs; of the 10 MCOs in STAR Kids, each has with its own unique prior authorization process.

Policy Issue: Access to Healthcare for Children without Medicaid

According to the 2017 U.S. Census data, Texas has both the largest number and percentage of uninsured residents in the United States at 4.82 million (17.3%).¹⁰ Approximately 10.7% of Texas children under the age of 19 are uninsured. This is in comparison to 5.4% nationally. Texas children's uninsured rate still leaves it at the bottom of the rankings among the states with the worst uninsured rates for children and teens.¹¹ Children with disabilities need health insurance due to their special health care needs.

Recommendations

1. Provide sufficient funding for the Children with Special Healthcare Needs (CSHCN) Services Program to ensure children are not waiting to access healthcare.
2. HHSC should provide greater clarification on what is considered cost effectiveness for eligibility for payment from the Health Insurance Premium Payment (HIPP) program, as well as greater clarification on what evidence is needed to prove cost effectiveness.

Background

Established in 1933, the Children with Special Healthcare Needs (CSHCN) program provides assistance with healthcare and support services to residents of Texas. The program is a payor of last resort, meaning that families utilize the program benefits only when they have no other means to pay for access care. The program places individuals on a waiting list when there are not enough funds. This program is critical for preventing unnecessary utilization of the emergency room and preventing delays in care leading to a worsening health status. It also provides

¹⁰ Berchick, E.R., Hood, E., Barnett, J.C. (2018). Health Insurance Coverage in the United States: 2017. *United States Census Bureau*. Retrieved from <https://www.census.gov/content/dam/Census/library/publications/2018/demo/p60-264.pdf>

¹¹ Dunkelberg, A. (2018). Why 272,000 More Texans Were Uninsured in 2017 - and How We Can Fix This. *Center for Public Policy Priorities Blog*. Retrieved from <http://bettertexasblog.org/2018/09/why-272000-more-texans-were-uninsured-in-2017-and-how-we-can-fix-this/>

family-centered, community-based, culturally competent, and coordinated health care and family support services.

The Health Insurance Premium Payment (HIPP) program is a state Medicaid program that reimburses eligible individuals for their share of an employer-sponsored health insurance premium payment. The program reimburses insurance premiums if it is more cost-effective than paying Medicaid expenditures. This may include coverage for the full family premium or partial family premium. Currently families are being denied HIPP based on a determination that it is not cost effective. There are no clear guidelines on how HHSC determines cost effectiveness. Families are asked to submit large numbers of documents to the state and are experiencing high denial rates. In addition, families have experienced some technical difficulties with the system. For example, in August 2017 premiums were mailed instead of directly deposited with no system wide notification of recipients.



Policy Issue: Compassionate Use Program

The Texas Compassionate Use Act (SB 339, 84th Legislative Session) permits approved physicians to prescribe low-tetrahydrocannabinol (THC) cannabis to pediatric patients with severe seizure disorders. Given the limited number of physicians currently registered in the program, the PCCF is concerned about disparities in access to the program across Texas. In addition, access to medical marijuana across the United States is becoming more common and for a wider-range of conditions than seizure disorders. Families who move to Texas with a previous treatment regimen may lose the ability to obtain the prescribed medicine that they were legally prescribed in another state.

Recommendations

1. Evaluate access to the Texas Compassionate Use Program and determine what modifications would facilitate equal access across the state.
2. Given disparities between states, authorize HHSC to conduct an evaluation of the current use of medical marijuana in other states, as well as identify stakeholder consensus on other beneficial medical uses beyond treatment of severe seizure disorders.
3. Because of the discrepancies in access and in laws across states, provide protections for individuals and families of individuals who are authorized to use medical marijuana in other states.

Background

Twenty-nine states have approved medical marijuana for use of serious health conditions. Forty percent of children in the US, therefore, live in states that permit pediatric medical use of marijuana.¹² Families may move to Texas having been under the care of a physician prescribing medical marijuana, or they may seek care in other states. This leads to a dilemma for Texas physicians, who must decide how to proceed with the child's care and medical plan. A recent study found that over 30% of pediatric cancer providers reported families inquire about use of medical marijuana to control symptoms of cancer treatment or for end-of-life care, and

¹² Stubblefield, S. (2017). Survey of complementary and alternative medicine in pediatric inpatient settings. *Complementary Therapies in Medicine*. 35, 20-24. Retrieved from <https://www.sciencedirect.com/science/article/pii/S0965229917305721?via%3Dihub>

92% of providers were willing to help children get access to compassionate use of medical marijuana.¹³ This indicates that medical providers are likely to recommend medical marijuana or cannabidiol (CBD) for uses other than seizure disorders.

Currently, there are 48 providers in Texas approved in the Compassionate Use Registry to prescribe low-THC cannabis.¹⁴ While the registry has grown, providers are not evenly distributed throughout the state, causing a disparity in access for many Texas families and difficulties in transporting prescriptions.

Some states recognize prescriptions for residents from other states. Currently seven states with broader cannabis programs recognize patient's prescriptions across state boundaries.¹⁵ Families who have sought care and authorized prescriptions from another state need protection from criminal prosecution.

Callen's Story

Our son, Callen, has a rare genetic mutation known as KCNB1, and is one of about 75 documented cases in the world. Callen is almost eight years old. The middle of three brothers, Callen is energetic, and his smile will light up any room. He is non-verbal, but his eyes and charm help him communicate with anyone near him.

KCNB1 key symptoms include poly-seizure profiles (different types of seizures), seizures that are resistant to treatment, early onset of seizure types that may initially go unrecognized, abnormal electroencephalograms (EEG), developmental delays, hypotonia, and intellectual disabilities. Callen displays all of these and has an autism diagnosis.

After falling behind developmentally, Callen was diagnosed with myoclonic seizures just after his first birthday. He could barely hold up his head and was referred to as a "floppy baby" due to hypotonia. Callen had upwards of 75 clusters of quick "jerk" seizures throughout the day. With two pharmaceutical antiepileptic drugs (AED),

¹³ Ananth, P., Clement, M., et al. (2018). *Provider Perspectives on Use of Medical Marijuana in Children with Cancer*. 141(1). Retrieved from <http://pediatrics.aappublications.org/content/141/1/e20170559>

¹⁴ Texas Department of Public Safety. *Compassionate Use Registry of Texas*. Retrieved from <https://curt.dps.texas.gov/app/public/searchPhysician.xhtml>

¹⁵ The National Conference of State Legislatures (2018). *State Medical Marijuana Law*. Retrieved from <http://www.ncsl.org/research/health/state-medical-marijuana-laws.aspx>

the seizures were controlled, and he was seizure free for over three years. During this time however, Callen made little progress developmentally, and he still had abnormal EEGs. Looking back now, we believe that the lack of progress was likely partially due to the AEDs that were working to slow brain activity to stop the seizures. Then, after a surgery to place a gastrostomy tube (G-tube) in Callen's stomach for feeding, he had a full-on tonic-clonic seizure in recovery at the hospital. After that, Callen averaged two seizures a month, each normally lasting over four minutes. Each seizure is a new painful experience, and we never know when it will end or what will happen to him once it does.

Since starting CBD oil with Callen, we've been able to stop giving him one of the pharmaceutical AEDs he had been taking for over five years. The AED had long term effects such as liver failure and metabolic acidosis. The introduction of the CBD oil also seemed to almost wake him up from a fog that had been in his brain. Cognitively speaking, he is improving and beginning to better understand the world around him. Callen was recently prescribed the Lonestar tincture, which was obtained from Compassionate Cultivation in Austin, TX.

As of this writing, Callen is almost three months seizure-free!! This is the longest he has gone without a seizure in almost four years. Our family has noticed a much higher level of functioning in his communication, cognition, recognition, and his negative behaviors have begun to decrease in numbers.



Policy Issue: Early Childhood Intervention (ECI)

It is crucial that all children who need early intervention services receive adequate supports. The Early Childhood Intervention (ECI) program provides services for children from birth to the age of three. ECI provides critical and fundamental supports in order for children with developmental delays or disabilities to gain and use skills they will need to participate meaningfully in their everyday lives. Access to medically necessary services is a federal entitlement under both Title XIX of the Social Security Act (Medicaid) and Part C of the Individuals with Disabilities Education Act (IDEA). However, the services provided by for ECI in Texas are currently administered like a block grant with stringent enrollment requirements and a limited budget. ECI should be managed in a similar fashion to the state Medicaid expenses where eligible children receive the needed services, and then Texas requests supplemental funds for the Legislature in the next biennium to cover any shortfalls. The sooner children with developmental delays or disabilities receive assistance and support, the greater the personal and societal return. The ECI program must be funded in a manner that ensures critical services and supports for children and families are not reduced or limited in response to fluctuations in the state's budget.

Recommendations

1. Funding
 - a. Fully fund Early Childhood Intervention Services (ECI) and create a mechanism to fund case growth based on children's need for services; not based on available funding.
 - b. Increase state general revenue spending on ECI in order leverage additional federal matching funds to expand services.
 - c. Leverage Texas Education Agency (TEA) Child Find funds to pursue new contracts for ECI providers for evaluations, screening and assessments for Local Education Agencies (LEAs) to meet current 45-day evaluation requirements.
2. Eligibility standards to qualify for Early Childhood Intervention (ECI) have changed over the past decade which has limited the number of children who are participating in the ECI system. HHSC should:
 - a. Review current eligibility requirements to ensure that eligibility is determined by a child's need and not a capped budget amount.

3. To ensure a robust Early Childhood Intervention (ECI) provider network HHSC should:
 - a. Restore previous Medicaid therapy rate cuts that has affected ECI provider rates.
 - b. Increase per child allotment to contractors to cover actual costs of services.
 - c. Allow reimbursement for providers to serve all children who are eligible for services. In many instances providers are serving more people than they are getting reimbursed for because services for ECI are mandated and most providers are reluctant to turn away children in need.
 - d. Detach ECI provider rates from Medicaid rate setting, including:
 - i. Provide additional funds billable category for provider's staff dedicated specifically for "Child Find" and transition coordination for pre-kindergarten.
 - ii. Require health insurance plans to cover rehabilitative and habilitative services included in an individualized family service plan issued by an ECI provider.
4. Provide guidance to parents/caregivers regarding opportunities to request additional therapies through their primary care or other health care providers in addition to services provided by Early Childhood Intervention (ECI).
5. Increase state level coordination between Early Childhood Intervention (ECI) staff at the HHSC and Special Education staff at TEA:
 - a. Align HHSC's ECI eligibility and Child Find procedures and goals with TEA's Corrective Action Plan to address issues related to noncompliance with Individuals with Disabilities Education Act (IDEA).
 - b. Consider alternative models of agency coordination between HHSC staff and TEA staff in order to provide more program efficacy and to serve more children under the program.
 - c. Conduct research with regards to appropriately identifying and serving children transitioning between ECI, pre-kindergarten, and kindergarten to ensure continuity of services.
 - d. Increase community level coordination between ECI providers and school districts to inform districts of the students' needs, provide student evaluations, and align school preparatory goals with Preschool Program for Children with Disabilities (PPCD) and prekindergarten goals.

Background

Early Childhood Intervention (ECI) is a school preparation program that serves as the first and most vital part of the educational continuum for infants and toddlers who have physical, cognitive, behavioral disabilities, and developmental delays. The purpose of ECI is to provide young children with the basic skills necessary to enter, thrive, and succeed in kindergarten or the Preschool Program for Children with Disabilities (PPCD) and beyond.

The U.S. Department of Education administers IDEA, which requires ECI programs to serve all eligible infants and toddlers up to the age of three. In Texas, the Texas Education Agency (TEA) is responsible for identifying the eligible infants and toddlers for evaluation services through the program Child Find while the Texas Health and Human Services Commission (HHSC) serves as the designated state agency for ECI and provides a range of therapies for young children through local agencies and organizations.

The current ECI eligibility requirements are too restrictive and need to be re-evaluated to determine whether too many infants and toddlers with, or at risk for, disabilities or developmental delays are being excluded from the program. It is essential that eligibility is determined by each individual child's needs and not by a predetermined budget.

With two-thirds of children receiving ECI services being enrolled in Medicaid, the Texas Legislature's Medicaid reimbursement rate reduction for speech, physical, occupational, and other therapies for children in 2015 severely impacted provider rates. Provider rates were only modestly restored (25%) by the legislature in 2017, and in the past eight years 18 providers have left the program due to inadequate funding.

The ECI program provides children, their families, communities, and the state with a return on investment that goes beyond dollars and cents. It reduces the scope and duration of additional services and enhances educational, employment, and life outcomes for children. The sooner children with, or at risk for, developmental disabilities receive assistance and support, the greater the personal and societal economic return. A report from the Symposium on Early Childhood Science and Policy sponsored by the National Governor's Association and Harvard University found that effective ECI programs return \$4 to \$9 per dollar invested.

Policy Issue: Special Education

The Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act of 1973 (Section 504) address the rights of students with disabilities in school and other educational settings. As was widely reported, the U.S. Department of Education has recently found that Texas violated IDEA by failing to ensure students with disabilities were properly evaluated and provided with an adequate free and appropriate public education (FAPE).

English language learners were reportedly disproportionately impacted by this violation. Texas needs a uniform statewide policy for ensuring that students who need both special education services and English language education receive adequate and appropriate services and supports.

Recommendations

1. Appropriate funding must be provided for children with disabilities to be assessed, identified, and provided services and supports they need to receive an equal education. Any corrective action plan developed by TEA should receive the necessary funding to reach plan goals.
2. Ensure full stakeholder involvement in any corrective action plan, including students, parents, and advocates, is a priority.
3. Due to students with disabilities' susceptibility to experiencing mental health challenges, appropriate and thorough assessments should be conducted to identify these challenges early. Untreated mental health issues impede learning in the classroom and further delay development.
 - a. Direct TEA to establish a workgroup to develop guidance and criteria for selecting and using appropriate disability and age assessments, so that regardless of which school professional is conducting the assessment, the student is receiving the necessary mental health and classroom supports.
 - b. Conduct research to look at national recommended standards and best practices for other states.
4. Provide districts with targeted guidance, technical assistance, and resources to ensure students with emotional disturbances and English language learners (ELL) are identified and provided appropriate services.

- a. Require TEA to monitor implementation of ELL/special education assessments/evaluation and services in school districts statewide within two years following United States Department of Education (USDE) acceptance of the Texas corrective action plan. Monitoring should be informed by previously cited federal regulations on disproportionality and disparities.
 - b. Create incentives for bilingual teachers to obtain certification in special education services.
5. Special education (SPED) funding weights should be updated to adequately fund special education services for children with disabilities.

Background

In 2004, the Texas Education Agency (TEA) created a monitoring system to measure school district performance. Buried within that system was the Special Education (SPED) Representation Indicator (#10), which set a target SPED enrollment at only 8.5%. As a result, tens of thousands of Texas kids were denied the service that they were legally entitled. After an investigation from the Department of Education (DOE), the DOE required TEA to address and remediate the situation. If TEA effectively implements the corrective action plan required by the DOE, special education identification rates in Texas should increase to be comparable to the national average (12.5%).

Students who are English language learners (ELLs) and those who also have intellectual and developmental disabilities (IDD) were disproportionately affected by the 8.5% target enrollment. These students were not adequately identified by Child Find, evaluated for special education services in their native tongue, or provided a free appropriate public education (FAPE) under (IDEA). Instead, students who are ELL with IDD are often referred to English language classes only, and IDD educational needs are often neither evaluated nor addressed. Texas must ensure that it complies with federal law and school districts should be provided assistance in developing appropriate evaluations for all students.

A key to meeting the needs of ELLs with developmental disabilities is providing incentives for bilingual teachers who obtain special education services certification.

As two of the fastest growing subgroups of students served in Texas public schools, Texas must examine the current state of services needed by students.¹⁶

Policy Issue: Safe and Supportive School Environments

Like all students, students with disabilities learn best in schools where they feel safe and supported and when schools respond to student challenges in ways that keep students healthy, safe, and learning. Students with disabilities experience the same types of trauma and mental health concerns as their peers. They are also more likely to experience trauma through things like social isolation, bullying, or being secluded or restrained. Unfortunately, mental health concerns among students with disabilities often go unrecognized and unaddressed, as behaviors stemming from depression, anxiety, or trauma are overshadowed by, or even attributed to, the student's disability. This likely contributes to the disproportionate rates of students with disabilities receiving exclusionary discipline referrals.

Recommendations

1. Increase the use of school-wide practices known to increase student connection to school, support the social and emotional well-being of students, and promote learning.
 - a. Establish and fund a statewide center available to assist schools in selecting and implementing school-based intervention strategies.
 - b. Require teachers and other school personnel to receive training in trauma-informed instruction and school practices.
2. Increase the ability of school personnel, especially those providing special education services, to recognize and respond to potential mental health concerns among students with intellectual and developmental disabilities (IDD), including making appropriate referrals for mental health services when necessary.
 - a. Amend educator certification and professional development requirements to require training on identifying mental health, trauma, or suicide concerns.
 - b. Require education service centers (ESC) to provide training in trauma-informed practice specifically developed for use with children with IDD.

¹⁶ Special acknowledgement to Ashley Ford, Policy and Communications Specialist, Texas Council for Developmental Disabilities, for her contribution to this recommendation.

- c. Direct TEA to collaborate with HHSC to develop guidance to districts on identifying mental health concerns in students enrolled in special education, including the use of mental health screenings and assessments, and providing services and supports to address concerns as appropriate and needed.
3. Improve data collection on the use restraints in schools and clearly differentiate time-outs from seclusion.
 - a. As part of existing data collection on the use of restraints in schools, include information on the types of restraints used, the circumstances that led to their use, and the purpose for which they were used.
 - b. Amend the definition of "time-out" in the Texas Education Code to clearly differentiate it from seclusion and prevent time-outs from being used to inappropriately exclude students from classroom activities/environment.
 - c. Move statutes related to seclusion and restraint in the Texas Education Code from the chapter of law that addresses Student Discipline (Chapter 37) to the chapter of law that addresses Student Health and Safety (Chapter 38).

Background

Children with intellectual and developmental disabilities (IDD) are three times more likely to experience trauma and abuse than their peers. However, they are rarely assessed for trauma or other mental health challenges. One reason is that children with IDD often respond to traumatic experiences differently than their peers. Because of this, the mental health needs of children with IDD remain unaddressed until they begin to show behavioral problems in the classroom. These behaviors, which are often a response to trauma, are misinterpreted as "challenging," "difficult," or "disruptive." Instead of supporting students with disabilities to overcome trauma or work toward recovery, far too often schools focus solely on managing behaviors and making students compliant. This can lead to unnecessary disciplinary action, including suspension, which may delay a child's recovery and reduce their chance of success within the classroom. Training in trauma-informed practice for children with IDD will provide teachers with knowledge and skills that can help them create a classroom environment that fosters healing and promotes learning.

The National Child Traumatic Stress Network (NTSCN) and the Hogg Foundation for Mental Health partnered to develop *Road to Recovery: Supporting Children with*

Intellectual and Developmental Disabilities Who have Experienced Trauma, a two-day train-the-trainer toolkit. Educators have noted that this training has expanded their understanding of trauma and their ability to recognize that many students they work with have experienced trauma.

Policy Issue: Mental Health

Individuals with developmental disabilities are at increased risk for developing mental health problems across the lifespan, and in turn, are at increased risk for suicidal behavior;^{17 18} research indicates a child with a developmental disability is six times more likely to have a mental health problem than a person who does not have a developmental disability.^{19 20} Children with IDD and co-occurring mental health conditions need supports and services in order to live full and meaningful lives.

Recommendations

1. Improve mental health services for children including Youth Empowerment Services (YES) waiver services so that children in need of out of home services can live in a family and avoid institutionalization.
 - a. Allow children in the YES waiver to reside in host home settings for a period longer than 90 days.
 - b. HHSC should develop community capacity among YES waiver providers to create host home options for children who need emergency out of home placement.

¹⁷ Lunsy, Y. (2014). Periodic health examinations for adults with developmental disabilities. *Canadian Family Physician*. 60(2). 109-110. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3922550/>

¹⁸ Ludi, E, Ballard, E.D., et al. (2012). Suicide Risk in Youth with Intellectual Disability: The Challenges of Screening. *Journal of Development and Behavioral Pediatrics*. 33(5). 431-440 Retrieved from <https://insights.ovid.com/pubmed?pmid=22668827>

¹⁹ Merrick, J., Merrick, E. et al. (2006). A review of suicidality in persons with intellectual disability. *Israel Journal of Psychiatry and Related Sciences*. 43(4). 258-264. Retrieved from <https://www.ncbi.nlm.nih.gov/corehtml/query/egifs/http:--doctoronly.co.il-wp-content-uploads-2012-06-Israel-Journal-of-Psychiatry-Logo.jpg>

²⁰ Walters, A.S., Barrett, R.P., Knapp, L.G., Borden, M.C. (1995). Suicidal behavior in children and adolescents with mental retardation. *Research in Developmental Disabilities*. 16(2), 85-96. Retrieved from <https://www.sciencedirect.com/science/article/abs/pii/0891422294000298>

- c. HHSC should create educational information for families regarding the development of a recovery plan for children discharging from residential treatment as well as those in outpatient treatment.
 - d. HHSC should review current processes to ensure the recovery plan and YES waiver service plan are shared with the family and relevant providers to more optimally coordinate care and meet the member's needs. This is especially important for children with co-morbid conditions.
- 2. Expand, fund, and fully implement certified family partner services and peer supports for families.
 - a. Expand the Medicaid State Plan family partner certification process for children with disabilities similar to the current family partner certification program designed to serve families of children and adolescents receiving mental/behavioral health services. Also, provide funding to make this service available to families without Medicaid.
 - b. Direct HHSC to develop and disseminate guidance to providers/professionals serving children/youth with Intellectual or Developmental Disabilities (IDD) on best practices for supporting adolescents with developmental disabilities who are exhibiting suicidal behavior, including providing supplemental information for Mental Health First Aid trainings to addressing individuals with IDD.
 - c. Include goals and strategies related to individuals with IDD within the Texas State Plan for Suicide Prevention.

Background

The YES waiver was implemented in Texas in 2009 and provides children with serious and pervasive mental health conditions support to stay in their homes and communities. One of the services under the waiver is Support Family Services. Children can live with a trained host family for a period while the issues at home are stabilized. To date, very few children in the YES waiver utilize this service because there is no real mechanism to find and support the host families.

Family partners have been one of the cornerstone features in the child and adolescent mental/behavioral health system of care in Texas. A family partner is a person who has lived experience as the primary caregiver of a child or youth with an emotional, behavioral, or co-occurring disorder and who has successfully demonstrated through training and certification the qualifications necessary to navigate the Texas system. These individuals help support family engagement and

voice in the treatment and service decisions. The Family Partner may also be known as a peer support specialist, a parent navigator, a family navigator, or a family support specialist.

According to a 2008 report written by the National Federation of Families for Children’s Mental Health, family peer-to-peer support is the most fundamental element of the children’s mental health family movement. Families have always intuitively known that sharing information, support, and advocacy with one another is key to overcoming the challenges of raising and supporting a child with emotional, mental, or behavioral disorders.²¹

In 2011 Via Hope Texas, an initiative of Mental Health America of Texas and the National Alliance on Mental Illness of Texas supported by funding from the Texas Department of State Health Services and the Hogg Foundation, developed and implemented a Family Partner training and certification program.²² General revenue was used to fund certified family partners to serve as role models for consumer families. Texas has amended the Medicaid State Plan to add credentialed family partners to the list of qualified providers of rehabilitative services. The family partners are employees or contractors of a Medicaid enrolled provider who have life experience as a parent or primary caregiver for a child receiving mental health services. There is no equivalent Family Partner certification for families of children with disabilities.

Suicidal behavior by adolescents with developmental disabilities is an under-recognized, yet significant problem, particularly among adolescents with underlying psychiatric disorders.²³ Mental health concerns/trauma often go unrecognized in children with IDD. Not recognizing the risk factors of children and youth with IDD lessens the likelihood of identifying suicidality within this population. Children and

²¹ National Federation of Families for Children’s Mental Health (2008). *Family Peer-to-Peer Support Programs in Children’s Mental Health: A Critical Guide*. Retrieved from <http://www.ipfcc.org/bestpractices/Family-Peer-to-Peer-Critical-Issues.pdf>

²² Hogg Foundation for Mental Health (2014). *A Guide to Understanding Mental Health Systems and Services in Texas*. Retrieved from http://hogg.utexas.edu/wp-content/uploads/2015/10/mhguide_final-11.pdf

²³ Hannon, G., Taylor, E.P., (2013). Suicidal behavior in adolescents and young adults with ASD: findings from a systematic review. *Clinical Psychology Review*. 33(8). Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/24201088>

adolescents with IDD present some unique challenges for suicide risk assessment. Suicidal behavior in youth with developmental disabilities is likely underreported and frequently overlooked due to diagnostic overshadowing. Suicidal behavior in individuals with IDD is often confused with self-injurious behavior.²⁴ Children and adolescents may injure themselves for reasons other than suicide, such as to relieve stress or numbness, or due to difficulty communicating emotions or physical pain.²⁵

Children and youth with developmental disabilities, such as autism and intellectual disability, are more likely to engage in other forms of self-injury than children without these disabilities.²⁶ Youth with depression, anxiety disorder, and conduct disorder have a higher chance of self-violence, including suicide, than children without these disorders.

It is important to understand the reasons for self-directed violence and other forms of self-injury among children with disabilities in order to find the best treatment. It is also important to coordinate care given by family, school, and healthcare providers.



²⁴ Menolascino, F., Lazer, J., Stark, J.A. (1989). Diagnosis and management of depression and suicide behavior in persons with severe mental retardation. *Journal of the Multihandicapped Person*. 2(2). 89-103. Retrieved from <https://link.springer.com/article/10.1007/BF01098948>

²⁵ Kitchener, B.A., Jorm, A.F., Kelly, C.M., Pappas, R., Frize, M. (2010). Intellectual Disability Mental Health First Aid Manual. *Melbourne: Mental Health First Aid Australia*. Retrieved from <https://mhfa.com.au/file/1592/download>

²⁶ Centers for Disease Control and Prevention. *Self-Directed Violence and Other Forms of Self-Injury*. Retrieved from <https://www.cdc.gov/ncbddd/disabilityandsafety/self-injury.html>

Policy Issue: Healthcare Transition

Children with disabilities between 12 to 26 years who are transitioning from children's health care services to adult services may experience any one of the following difficulties when attempting to access adult healthcare:

- Loss of a pediatrician who stops caring for patients between the ages of 18 – 21, causing issues with continuity of care;
- Lack of access by young adults to adult-oriented healthcare services, including reproductive health and screenings for adult risk factors;
- Loss of insurance through parent's plan at age 26 causing risks and gaps in services, which may risk their long-term health;
- Changes in the authorization process and requirements when transitioning from pediatric to general medicine often causing delays in treatment, such as when transitioning from STAR Kids and STAR Health to STAR Plus;
- Lack of physician training to care for adults with special needs compared to the training of pediatric providers, resulting in a significant decrease in care for young adults with disabilities as they transition from childhood service providers;
- Limited availability of non-physician health care providers to serve young adults with disabilities as they transition to adult health care; and
- Lack of information for youth and families regarding Medicaid plan benefits changes at the age of 21.

Recommendations

1. Improve the healthcare transition of children from childhood to adulthood in Medicaid managed care by enhancing network adequacy. Create incentives for adult practitioners to receive young adults with special health care needs including payment incentives that allow for longer appointment times needed to meet the needs of children and young adults with medically complex conditions.
 - a. Require Managed Care Organizations (MCOs) to develop payment mechanisms to enable both pediatric and adult care providers to receive payment for medically necessary services concurrently during the transition process.
 - b. Create network adequacy standards that require plans to have enough primary care physicians, specialists, therapists, home health agencies,

- and hospitals to meet the needs of young adults with disabilities and complex and chronic conditions.
- c. HHSC should partner with physician organizations to provide education about transition and evaluate if contract amendments between MCOs and physicians are necessary to ensure continuity and prevent pediatric providers from discharging young adults from pediatric care before adult providers are secured.
 - d. Require MCOs to list in their provider directory primary care physicians and specialists who treat transition age youth and adults.
2. Increase the availability of medical homes and transition clinics for youth transitioning to adulthood.
 - a. Recruit new centers of excellence for transition across the state.
 - b. Define performance measures for MCOs for specialized medical home projects that incentivize providers to promote out-of-the-box thinking.
 - c. Create network structures where pediatric and adult provider groups work together like a consolidated clinic to provide improved services to transitioning youth with developmental disabilities, or behavioral and cognitive disabilities.
 3. Improve the healthcare transition of children from childhood to adulthood through adoption of transition standards and best practices.
 - a. Begin medical transition planning at age 12 instead of age 15.
 - b. Adopt and implement the American Academy of Pediatrics consensus statement on transition ²⁷ and Got Transition's Six Core Element²⁸ as best practices.
 - c. Develop and implement core knowledge and skills required of health care professionals to provide developmentally appropriate health care transition services.
 - i. Incorporate core competencies into training and certification requirements for primary care and specialty residents.
 - ii. Provide incentives and additional funding for physicians and to deliver services to this unique group of people.
 - iii. Base incentive payment on healthcare outcomes.

²⁷ American Academy of Pediatrics (2002). A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*. 110(3). Retrieved from http://pediatrics.aappublications.org/content/110/Supplement_3/1304.short

²⁸ National Alliance to Advance Adolescent Health. Health Care Providers. Got Transition. Retrieved from <https://www.gottransition.org/providers/index.cfm?>

4. Improve the healthcare transition of childhood to adulthood through the following managed care system improvements.
 - a. Add transition service coordinators for young adults between the ages of 21 to 26 to STAR Plus.
 - b. Add transition service processes to STAR Health and STAR Kids.
 - c. Require MCO transition coordinators to have training in the following:
 - i. Alternatives to guardianship;
 - ii. Supported decision making;
 - iii. Creative housing options including shared living arrangements and host homes;
 - iv. Supported employment; and
 - v. Eligibility requirements for services and supports and provide assistance to individuals with disabilities as they navigate through the process.

Background

Optimal health care is achieved when each person, at every age, receives medically and developmentally appropriate care. The goal of a planned health care transition is to maximize lifelong functioning and well-being for all youth, including those who have unique health care needs. This process includes ensuring that high-quality care services are available in an uninterrupted manner as the person moves from adolescence to adulthood.²⁹

Texas is fortunate to have a unique medical clinic for youth with disabilities as they transition into adult services in Houston, the Transition Medicine Clinic at Baylor College of Medicine. The PCCF strongly recommends supporting the increase of these types of clinics as medical homes throughout Texas. Clinics like these provide medical care and social support services to the growing population of adolescents/young adults with a chronic childhood illness or disability as they move from pediatric to adult healthcare. The goal of the clinic is to prevent an urgent healthcare crisis and to minimize the impact of a shrinking social support network that these patients and families have come to rely upon in the pediatric healthcare system. This includes helping them overcome obstacles encountered in both adult Medicaid and private health insurance systems.

²⁹ *Ibid.* (26)

Policy Issue: Transition to Adulthood: Employment, Housing, and Education

Most youth leave home and begin their own independent life as young adults, but the situation for youth with disabilities can be very different. Youth and young adults with disabilities require the services and supports to assist them as they move from childhood to adulthood. This includes training and preparation for transition to adulthood at an early age, postsecondary education opportunities, supported or integrated employment, creative integrated housing, meaningful community day services, and information on work incentives and ABLE accounts.

Recommendations

1. Ensure better accountability, availability, and continuity of vocational rehabilitation services.
 - a. Provide a comparative analysis of programs, including scope, quantity, and funding sources, provided by the Texas Department of Assistive and Rehabilitative Services (DARS) before the transformation and HHSC/Texas Workforce Commission (TWC) since the transformation.
 - b. Provide an analysis of impact of Workforce Innovation and Opportunity Act (WIOA) on service delivery model and funding sources provided by DARS and HHSC/TWC.
 - c. Ensure continuity of level of service provided by DARS prior to transformation by providing:
 - i. Guidance on changes to program service delivery model provided to clients, families, local education agencies, and local service providers.
 - ii. Access to funding sources utilized by programs prior to transformation.
 - iii. Instructions to local education agencies and local service providers on funding if programming not provided by HHSC/TWC.
2. Ensure information and training be provided to families regarding the Achieving a Better Life Experience (ABLE) Act of 2014.
 - a. Provide information and training to families regarding the ABLE Act through state agency programs, public schools, nonprofits, and other organizations who work with people with disabilities and their families.

- b. Provide a thorough analysis of investment and savings options available to families as they and their child design a meaningful life and plan long-term services and supports. Most families are unaware of the differences between third party special needs trusts, first party special needs trusts, and 529A (ABLE) savings accounts.
3. Ensure training for students and families on services and benefits beginning at age 12 through age 21 and notification of the Texas Transition and Employment Guide³⁰ for students before they leave the public-school system.
 - a. Provide training on services and benefits for student's age 18 through 21 before the student leaves school.
 - b. Provide a guide(s) of services to students and their families prior to age 18.
 - c. Include and document the guides and training in the Admission, Review, and Dismissal (ARD) and 504 processes.
4. Promote integrated employment with competitive wages.
 - a. Improve access to employment opportunities, including competitive wages, employment assistance, and integrated day habilitation for individuals with Intellectual and Developmental Disability (IDD).
 - b. Ensure employment services and enhanced day habilitation through Medicaid waivers meet community integration and home and community-based settings requirements and support people to work and participate in their communities.
 - c. Create a new designation for Historically Underutilized Businesses (HUB) vendors to include those run by people with disabilities.
 - d. HHSC and TWC should create a broad statewide task force of employers to expand employment opportunities for people with disabilities.
 - e. Increase access to benefit employment counselors.
5. Create, fund, and implement creative housing and supports for adults with disabilities to live independently.
 - a. Provide funding for housing navigators to assist adults with disabilities and their families set up affordable, collaborative, creative, and culturally appropriate housing for adults.
 - b. HHSC should develop a workgroup to promote housing options for persons with intellectual and developmental disabilities (IDD).

³⁰ <https://www.transitionintexas.org/guide>

6. Direct the Texas Higher Education Coordinating Board to assist colleges and universities in enhancing their transition services for students with disabilities by providing information and resources on effective practices in supporting students with disabilities.
7. Build upon House Bill 1807, 84th Legislature, which requires Texas Higher Education Coordinating Board to establish and maintain an inventory of all postsecondary educational programs and services provided for persons with intellectual and developmental disabilities on its website and submit the inventory to the TEA for inclusion in the Texas Transition and Employment Guide. See: Postsecondary programs and services for students with Intellectual and Developmental Disabilities.
8. Require institutes of higher education to provide on their websites information and resources directed to both parents and students with the aim of promoting the success of students with disabilities enrolled in higher education.
9. Establish a course in the University Studies or General Studies area, possibly dual credit, designed to allow an opportunity for high school students or beginning college students with disabilities to learn more about college life and the skills needed for success in higher education, such as time management and navigating life in college.

Background

Employment

People with disabilities need varying levels of support to have successful employment outcomes. Competitive integrated employment is the first and preferred outcome for publicly funded services for all working age people with disabilities, regardless of level of disability. Senate Bill 1226, 83rd Legislature, Regular Session, 2013, established the Employment First policy promoting competitive employment opportunities that provide a living wage for individuals with disabilities. Texas has slowly implemented Employment First principles.

While the unemployment rate continues to decrease to the lowest level in history, the rate for people with disabilities remains unacceptably high at both the state and national levels. As of 2017, the unemployment rate, a statistic that includes only individuals who are working or actively seeking work, stood at 9.2% for people with

a disability, compared to 4.2% for other people in the workforce or seeking work³¹. In 2017, only 18.67% of persons with a disability were employed as reported by the U.S. Bureau of Labor Statistics. In contrast, the employment-population ratio for those without a disability was 65.7%.³²

Meaningful Day

Some families depend on day habilitation or sheltered workshops to provide supervised activities during traditional work hours for their young adults. Unfortunately, some families think they are required to attend day habilitation during the day because the current transition planning process does not adequately support people with disabilities with many opportunities to access integrated community services, volunteer, job exploration or acquire meaningful employment. A system that more fully includes a larger variety of work options, including day habilitation, pre-vocational services, employment assistance, and supported employment, could provide for more satisfying options for individuals with disabilities.

Housing and Transition Support

Young adults with disabilities face challenges when moving out of the family home. These include the high cost of living in many cities and the cost of finding and maintaining a home that fits the individual's unique needs. One collaborative, creative approach to this housing issue is to assist families to work together to set up a home for two to three individuals to live together. A model for this arrangement has been pioneered in Iowa, a "Family Consortium," in which families are offered guidance for a year or longer to work out a living arrangement for their children. The advantages include reduced expenses by pooling resources, using technology for monitoring safety and well-being, more expansive family care workforce, increased individual choice of community settings, and increased social opportunities.

Housing is at the heart of a family's value and care system—and so must line up with the unique needs and culture beliefs of each family. Ideally, a variety of living

³¹ United States Bureau of Labor Statistics (2018). *Persons with a Disability: Labor Force Characteristics Summary*. Retrieved from <https://www.bls.gov/news.release/disabl.nr0.htm>

³² *Ibid.*

arrangements for adults with disabilities should exist. For example, an adult with a disability might live on their own in the community, live next door to their family or another supportive family, live with a sibling, in a family compound or in a separate area of the family home.

Personal networks provide another avenue to help an adult move into a separate residence and reassure a family that the individual will have ongoing, caring oversight and community. A network is a small circle of volunteers committed to the well-being of the person at the center, who meet on a regular basis to provide assistance with decisions, emotional support, problem-solving and brain-storming, and connections to the community, so that an individual and a family can enrich the present and plan for a future when the parents are no longer available.³³

Postsecondary Education

Although most students (with and without disabilities) must make adjustments when they get to college, these new challenges may affect students with disabilities because their unique learning needs. A supportive set of accommodations are critical to success in this new academic environment. About one-third of students with disabilities enrolled in a four-year program graduate within 8 years.³⁴ With the appropriate transition and support services, most students with disabilities can succeed and thrive.

Texas universities could help prepare students in a variety of ways (summer or general studies courses) for college by educating them about the college academic expectations, how to navigate in the university environment, and teaching them the time management and organizational skills that are essential for success at the college level.

³³ Texas Parent to Parent. *Texas Network Connections*. Retrieved from <http://www.txp2p.org/services/texas-network-connections>

³⁴ Mader, J., Butrymowicz, S. (2017). The Low Number of Students With Disabilities Graduating From College is a Crisis. *Huffington Post*. Retrieved from https://www.huffingtonpost.com/entry/students-with-disabilities-college_us_5a0602d7e4b05673aa592cb4

4. Conclusion

The Policy Council for Children and Families would like to thank you for considering these recommendations. 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.



List of Acronyms

Acronym	Full Name
ABLE	Achieving a Better life Experience Act of 20147
AED	Anti-Epileptic Drugs
ARD	Admission, Review, and Dismissal
ASD	Autism Spectrum Disorder
CBD	Cannabidiol
CDC	Centers for Disease Control and Prevention
CFC	Community First Choice
CLASS	Community Living Assistance and Support Services
CMS	Centers for Medicare and Medicaid Services
CPC	Children’s Policy Council
CSHCN	Children with Special Healthcare Needs
DARS	Texas Department of Assistive and Rehabilitative Services
DFPS	Texas Department of Family and Protective Services
ECI	Early Childhood Intervention
EEG	Electroencephalogram
ELL	English Language Learners
EPSDT	Early and Periodic Screening, Diagnostic, and Treatment
ESC	Education Service Centers
FAPE	Free Appropriate Public Education
FY	Fiscal Year
HCS	Home and Community-based Services
HHSC	Health and Human Services Commission
HIPP	Health Insurance Premium Payment
HUB	Historically Underutilized Businesses
ICF	Intermediate Care Facilities
IDD	Intellectual and Developmental Disability

Acronym	Full Name
IDD SRAC	Intellectual and Developmental Disability System Redesign Advisory Committee
IDEA	Individuals with Disabilities Education Act
IID	Individuals with Intellectual Disabilities
LEA	Local Education Agencies
LTSS	Long-Term Services and Supports
MCO	Managed Care Organization
MDCP	Medically Dependent Children Program
NTSCN	National Child Traumatic Stress Network
PCCF	Policy Council for Children and Families
PCP	Person-Centered Planning
PCS	Personal Care Services
PPCD	Preschool Program for Children with Disabilities
SB	Senate Bill
SPED	Special Education
SSI	Supplemental Security Income (Social Security)
TEA	Texas Education Agency
THC	Tetrahydrocannabinol
TWC	Texas Workforce Commission
USDE	United States Department of Education
WIOA	Workforce Innovations and Opportunity Act
YES	Youth Empowerment Services

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Appendix: Overview of Recommendations

A. Improving Individual and Family Support

Recommendation	Action Required
<ol style="list-style-type: none"> 1. Ensure robust and holistic person-centered planning (PCP) for all children with disabilities. <ol style="list-style-type: none"> a. Require the use of standards defined by the Institute of Person-Centered Practices (http://www.person-centered-practices.org/). b. Ensure PCP is part of child to adult healthcare transition services beginning at age 12. c. Require Texas school districts provide PCP for all transition age youth (ages 14 – 21) receiving special education services. d. Require conflict-free independent PCP for all children receiving services through a Medicaid waiver, STAR Health, STAR Kids and STAR Plus, including those using consumer-directed services. e. Provide PCP in a language appropriate to the child and family. f. Require that all PCP for transition-age youth includes alternatives to guardianship and information on supported decision-making. 	<p>Legislative, Budgetary, CMS Approval TEA/HHSC collaboration</p>
<ol style="list-style-type: none"> 2. Continue funding for the Navigate Life Texas website including funding for updates and expansion to ensure all state agencies are linked to the website. 	<p>Legislative, Budgetary</p>
<ol style="list-style-type: none"> 3. Ensure access to adequate and meaningful respite care for families of children with disabilities, allowing families to receive a break from exhaustive caregiving. <ol style="list-style-type: none"> a. Provide general revenue funding (similar to In-Home and Family Support) for respite to families who do not have access to Medicaid or a Medicaid waiver. b. Promote innovative respite cooperatives among families in the same communities using nonprofit organizations to organize and maintain services. 	<p>Legislative, Budgetary</p>
<ol style="list-style-type: none"> 4. Provide time-limited flexible funding to families of children with disabilities during a crisis. 	<p>Legislative, HHSC</p>

Recommendation	Action Required
<ul style="list-style-type: none"> a. Support positive behavior supports, short-term care at home and out-of-home, home modifications, transportation, and training. b. Identify and approve the funding through an individual support plan. c. Manage the funds through a local entity with assigned coordinators who can prioritize and authorize support plans and funds, such as the Local Intellectual and Developmental Disability Authorities (LIDDAs) and the Local Mental Health Authorities (LMHAs). d. Consider the use of general revenue to fund these supports. e. Amend the Texas Home Living waiver eligibility to disregard parental income for those who have urgent needs. 	<p>Policy, CMS Approval</p>
<ul style="list-style-type: none"> 5. Allow flexibility within the home and community-based waivers as part of the restructure of waiver benefits for persons with intellectual and developmental disabilities (IDD) to meet the new Home and Community-Based Service (HCBS) settings requirements in Community First Choice (CFC). <ul style="list-style-type: none"> a. Allow people on different waivers to share resources without exceeding preset limits (ration guidelines). b. Explore a common set of benefits among waivers to meet the needs of an individual. 	<p>Legislative, HHSC, Policy, CMS Approval</p>
<ul style="list-style-type: none"> 6. Improve access to Community First Choice (CFC) and habilitation for individuals as an alternative to institutional care. <ul style="list-style-type: none"> a. HHSC should create a document that describes habilitation and how to obtain services. b. Require managed care organizations (MCOs) to provide all Medicaid recipients information on CFC and the ability to receive habilitation in addition to personal care services. c. Provide funding and set a rate for CFC that: <ul style="list-style-type: none"> i. Attracts direct service providers with experience in habilitation, ii. Attracts employees in rural parts of the state, and iii. Promotes employment longevity. d. Ensure MCOs understand that people with high physical and medical needs benefit from habilitation including training in how to direct their care. e. Ensure CFC tools allow for assessment of the habilitative needs of individuals with high physical and medical support needs. 	<p>Legislative, Budgetary, HHSC</p>

B. Promoting Independence and Waiver List Funding

Recommendation	Action Required
<p>1. Fund Home and Community-based Services (HCS) waiver service spaces for the following children to move from institutions to families:</p> <ul style="list-style-type: none"> a. 35 children living in DFPS General Residential Operations; b. 20 children to move from nursing facilities; c. 500 individuals to move from large/medium ICFs/IIDs (Intermediate Care Facilities for Individuals with an Intellectual Disability); d. 120 individuals to move from state psychiatric hospitals; and e. 50 children to move from small ICFs/IIDs to families. 	Legislative, Budgetary
<p>2. Fund waiver service spaces for the following children at imminent risk of institutionalization:</p> <ul style="list-style-type: none"> a. 216 children aging out of DFPS foster care (HCS waiver); b. 400 individuals in crisis to prevent institutionalization (HCS waiver); c. 600 individuals at risk of placement in nursing facilities (HCS waiver); d. 100 children who are medically fragile at imminent risk of placement in nursing facilities (MDCP waiver); and e. 100 children who are at imminent risk of institutionalization in a nursing facility or Intermediate Care Facility (ICF) (CLASS waiver). 	Legislative, Budgetary
<p>3. Provide funding for increased capacity to reduce the Medicaid waiver interest list by 20,000 to ensure more children can grow up in families.</p>	Legislative, Budgetary, HHSC Exceptional Item #15

C. STAR Kids

Recommendation	Action Required
<p>1. Require a more standard and streamlined prior authorization process among the STAR Kids health plans for private duty nursing and other services.</p>	Legislative, Budgetary, HHSC policy/contract changes

Recommendation	Action Required
<ul style="list-style-type: none"> a. Decrease administrative burdens, prevent gaps in services and delays in authorizations, and ensure individuals access to medically needed services without discrimination and inconsistencies across plans. b. Decrease reauthorization frequency for children with chronic conditions that are not likely to change. c. Ensure continuation of prior authorization of nursing services and other services when a child and family have a pending appeal (fair hearing request) and do not allow a managed care organization (MCO) to end any authorization before the case has been heard. 	
<ul style="list-style-type: none"> 2. Encourage nurse delegation in personal care services through education initiatives, rate enhancements, and value-based arrangements. <ul style="list-style-type: none"> a. Provide an increased rate of pay for unlicensed assistive personnel who are trained to perform delegated tasks. b. Promote and educate providers, parents, and recipients on what is considered "safe and appropriate" delegated services. c. Increase funding to home health agencies and nurses to train and supervise unlicensed assistive personnel who perform nurse delegated tasks. 	Legislative, Budgetary
<ul style="list-style-type: none"> 3. Allow children who receive Supplemental Security Income (SSI) and meet the Medically Dependent Children Program (MDCP) waiver eligibility requirements immediate access to waiver level services with no wait. <ul style="list-style-type: none"> a. Children enrolled in STAR Health b. Children enrolled in STAR Kids 	Legislative, Budgetary
<ul style="list-style-type: none"> 4. Maintain the current funding levels to offer children on the interest list (who do not have SSI) waiver services. 	Legislative, Budgetary
<ul style="list-style-type: none"> 5. Offer children who have lost eligibility for Medicaid due to loss of Medically Dependent Children Program (MDCP) eligibility in STAR Kids, access to another 1915(c) waiver such as Community Living Assistance and Support Services (CLASS) or Home and Community-Based Services (HCS). <ul style="list-style-type: none"> a. Create a set-aside in the HCS and CLASS waiver for 50 children each, per biennium in this category. 	Legislative, Budgetary, CMS Approval

Recommendation	Action Required
<p>6. Provide families timely notice of their right to seek an appeal and a Medicaid fair hearing when Medicaid services including waiver services, nursing, personal care services, and therapy are reduced or denied.</p> <ul style="list-style-type: none"> a. Require managed care health plans to send notification for a denial or reduction in service within one day of the date on the notification. b. Require the notice to be delivered via registered mail to ensure the time frame is followed. c. Ensure notices sent by HHSC and the health plans are written in plain language for families with detail on why the denial occurred, what is needed to meet medical necessity requirements, deadlines for the appeal, and information on maintaining the same level of service during the appeal and fair hearing process until a final determination is made. 	<p>Legislative, Budgetary, CMS Approval</p>

D. IDD Waivers and Managed Care

Recommendation	Action Required
<p>1. Delay inclusion of the intellectual and developmental disabilities (IDD) waivers in managed care. The PCCF supports the recommendation made by the System’s Redesign Advisory Committee (SRAC) to delay the carve-in of the IDD waivers until assurances can be made regarding readiness.</p>	<p>Legislative</p>

E. Medicaid Funded Therapy

Recommendation	Action Required
<p>1. Ensure children with disabilities get the therapy needed to maximize and maintain their abilities.</p>	<p>Legislative, Budgetary</p>
<p>2. Restore Medicaid fee schedules to the amount prior to the 2016 cuts and ensure adequate funding for health plans and access to therapy services for children.</p>	<p>Legislative, Budgetary</p>

Recommendation	Action Required
3. Provide utilization review reports on a quarterly basis to providers and the public regarding therapy waiting lists, delays in initiation of therapy services and managed care organization (MCO) network adequacy.	Legislative, HHSC Policy
4. Provide utilization review reports on cost saving associated with the changes to the May 1, 2016, therapy policy, detailing quality outcome measures and utilization review measures using best practices. Use any savings from the policy changes to restore rate cuts	Legislative, HHSC Policy
5. Monitor and evaluate prior authorization processes and documentation requirements across MCOs to ensure access to care without inconsistencies across plans.	Legislative, HHSC
6. Implement an attestation form for physicians to confirm an ongoing chronic condition to decrease administrative delays in authorization and save administrative costs.	Legislative, HHSC Policy

F. Network Adequacy in Medicaid

Recommendations	Action Required
1. Ensure network adequacy standards in Medicaid to meet the needs of children with developmental disabilities. <ul style="list-style-type: none"> a. Create network adequacy standards that require managed care networks to have enough physicians to meet the needs of children with developmental disabilities. HHSC must ensure that each MCO is contracted with an adequate number of primary and specialist physicians, developmental pediatricians, therapists, home health agencies and hospitals that care for children with disabilities. b. List criteria in MCO contracts for their call center staff to be able to identify providers within their network that care for children with disabilities, including behavioral and cognitive chronic disorders, so they can adequately assist families, members, and legally authorized representatives in identifying providers to meet their specialized needs. 	Legislative, Budgetary

Recommendations	Action Required
<ul style="list-style-type: none"> c. HHSC should amend the Texas State Medicaid Plan to allow licensed board-certified behavior analysts (BCBAs) to be reimbursed for services under the plan to increase Applied Behavioral Analysis (ABA) provider ability. 	
<ul style="list-style-type: none"> 2. HHSC should clearly define requirements on how preferred provider arrangements may be utilized ensuring: <ul style="list-style-type: none"> a. Members are given a choice of two to three providers for specialty services and durable medical equipment including non-preferred provider-arranged services. b. Members have the right to choose the best services or equipment that meets their medical necessity, regardless of provider arrangement with the Managed Care Organization (MCO). c. MCOs must submit all preferred provider contracts to HHSC for review and approval. d. MCO call center staff must inform members of non-preferred providers along with preferred providers available in the network. 	Legislative
<ul style="list-style-type: none"> 3. Stop the implementation of a value-based purchasing model in which an MCO designates a single provider for all therapy evaluations and/or designates a preferred provider for treatment services and then waives prior authorization requirements for families willing to use the preferred provider. <ul style="list-style-type: none"> a. This model eliminates freedom-of-choice for Medicaid beneficiaries. b. Designating a sole provider as the preferred provider for treatment services and eliminating prior authorization requirements for families that use this provider may have the effect of creating an exclusive provider network. c. HHSC should require that any payment model implemented by a MCO be research based, consider stakeholder input, maintain consumer access to services, and improve quality. d. HHSC should ensure accountability measures are in place. 	Legislative

G. Access to Healthcare for Children without Medicaid

Recommendation	Action Required
1. Provide sufficient funding for the Children with Special Healthcare Needs (CSHCN) Services Program to ensure children are not waiting to access healthcare.	Legislative, Budgetary
2. HHSC should provide greater clarification on what is considered cost effectiveness for eligibility for payment from the Health Insurance Premium Payment (HIPP) program, as well as greater clarification on what evidence is needed to prove cost effectiveness.	Legislative, HHSC

H. Compassionate Use Program

Recommendation	Action Required
1. Evaluate access to the Texas Compassionate Use Program and determine what modifications would facilitate equal access across the state.	Legislative, Budgetary
2. Given disparities between states, authorize HHSC to conduct an evaluation of the current use of medical marijuana in other states, as well as identify stakeholder consensus on other beneficial medical uses beyond treatment of severe seizure disorders.	Legislative, Budgetary
3. Because of the discrepancies in access and in laws across states, provide protections for individuals and families of individuals who are authorized to use medical marijuana in other states.	Legislative

I. Early Childhood Intervention Services (ECI)

Recommendation	Action Required
<p>1. Funding</p> <ul style="list-style-type: none"> a. Fully fund Early Childhood Intervention Services (ECI) and create a mechanism to fund case growth based on children's need for services; not based on available funding. b. Increase state general revenue spending on ECI in order leverage additional federal matching funds to expand services. c. Leverage Texas Education Agency (TEA) Child Find funds to pursue new contracts for ECI providers for evaluations, screening and assessments for Local Education Agencies (LEAs) to meet current 45-day evaluation requirements. 	<p>Legislative, Budgetary</p>
<p>2. Eligibility standards to qualify for Early Childhood Intervention (ECI) have changed over the past decade which has limited the number of children who are participating in the ECI system. HHSC should:</p> <ul style="list-style-type: none"> a. Review current eligibility requirements to ensure that eligibility is determined by a child's need and not a capped budget amount. 	<p>HHSC</p>
<p>3. To ensure a robust Early Childhood Intervention (ECI) provider network HHSC should:</p> <ul style="list-style-type: none"> a. Restore previous Medicaid therapy rate cuts that has affected ECI provider rates. b. Increase per child allotment to contractors to cover actual costs of services. c. Allow reimbursement for providers to serve all children who are eligible for services. In many instances providers are serving more people than they are getting reimbursed for because services for ECI are mandated and most providers are reluctant to turn away children in need. d. Detach ECI provider rates from Medicaid rate setting, including: <ul style="list-style-type: none"> i. Provide additional funds billable category for provider's staff dedicated specifically for "Child Find" and transition coordination for pre-kindergarten. ii. Require health insurance plans to cover rehabilitative and habilitative services included in an individualized family service plan issued by an ECI provider. 	<p>HHSC</p>

Recommendation	Action Required
<p>4. Provide guidance to parents/caregivers regarding opportunities to request additional therapies through their primary care or other health care providers in addition to services provided by Early Childhood Intervention (ECI).</p>	<p>Legislative, Budgetary</p>
<p>5. Increase state level coordination between Early Childhood Intervention (ECI) staff at the HHSC and Special Education staff at TEA:</p> <ul style="list-style-type: none"> a. Align HHSC’s ECI eligibility and Child Find procedures and goals with TEA’s Corrective Action Plan to address issues related to noncompliance with Individuals with Disabilities Education Act (IDEA). b. Consider alternative models of agency coordination between HHSC staff and TEA staff in order to provide more program efficacy and to serve more children under the program. c. Conduct research with regards to appropriately identifying and serving children transitioning between ECI, pre-kindergarten, and kindergarten to ensure continuity of services. d. Increase community level coordination between ECI providers and school districts to inform districts of the students’ needs, provide student evaluations, and align school preparatory goals with Preschool Program for Children with Disabilities (PPCD) and prekindergarten goals. 	<p>HHSC TEA</p>

J. Special Education

Recommendation	Action Required
<p>1. Appropriate funding must be provided for children with disabilities to be assessed, identified and provided services and supports they need to receive an equal education. Any corrective action plan developed by TEA should receive the necessary funding to reach plan goals.</p>	<p>Budgetary, TEA</p>
<p>2. Ensure full stakeholder involvement in any corrective action plan, including students, parents, and advocates, is a priority.</p>	<p>TEA</p>

Recommendation	Action Required
<p>3. Due to students with disabilities’ susceptibility to experiencing mental health challenges, appropriate and thorough assessments should be conducted to identify these challenges early. Untreated mental health issues impede learning in the classroom and further delay development.</p> <ul style="list-style-type: none"> a. Direct TEA to establish a workgroup to develop guidance and criteria for selecting and using appropriate disability and age assessments, so that regardless of which school professional is conducting the assessment, the student is receiving the necessary mental health and classroom supports. b. Conduct research to look at national recommended standards and best practices in other states 	TEA
<p>4. Provide districts with targeted guidance, technical assistance and resources to ensure students with emotional disturbance and English language learner are identified and provided appropriate services.</p> <ul style="list-style-type: none"> a. Require TEA to monitor implementation of ELL/special education assessments/evaluation and services in school districts statewide within two years following United States Department of Education (USDE) acceptance of the Texas corrective action plan. Monitoring should be informed by previously cited federal regulations on disproportionality and disparities. b. Create incentives for bilingual teachers to obtain certification in special education services. 	TEA
<p>5. Special Education (SPED) funding weights should be updated to adequately fund special education services for children with disabilities.</p>	Budgetary, TEA

K. Safe and Supportive School Environments

Recommendation	Action Required
<p>1. Increase the use of school-wide practices known to increase student connection to school, support the social and emotional well-being of students, and promote learning.</p>	Budgetary, TEA

Recommendation	Action Required
<ul style="list-style-type: none"> a. Establish and fund a statewide center available to assist schools in selecting and implementing school-based intervention strategies. b. Require teachers and other school personnel to receive training in trauma-informed instruction and school practices. 	
<ul style="list-style-type: none"> 2. Increase the ability of school personnel, especially those providing special education services, to recognize and respond to potential mental health concerns among students with intellectual and developmental disabilities (IDD), including making appropriate referrals for mental health services when necessary. <ul style="list-style-type: none"> a. Amend educator certification and professional development requirements to require training on identifying mental health, trauma, or suicide concerns. b. Require education service centers (ESC) to provide training in trauma-informed practice specifically developed for use with children with IDD. c. Direct TEA to collaborate with HHSC to develop guidance to districts on identifying mental health concerns in students enrolled in special education, including the use of mental health screenings and assessments, and providing services and supports to address concerns as appropriate and needed. 	TEA, HHSC
<ul style="list-style-type: none"> 3. Improve data collection on the use restraints in schools and clearly differentiate time-outs from seclusion. <ul style="list-style-type: none"> a. As part of existing data collection on the use of restraints in schools, include information on the types of restraints used, the circumstances that led to their use, and the purpose for which they were used. b. Amend the definition of "time-out" in the Texas Education Code to clearly differentiate it from seclusion and prevent time-outs from being used to inappropriately exclude students from classroom activities/environment. c. Move statutes related to seclusion and restraint in the Texas Education Code from the chapter of law that addresses Student Discipline (Chapter 37) to the chapter of law that addresses Student Health and Safety (Chapter 38). 	TEA

L. Mental Health

Recommendation	Action Required
<ol style="list-style-type: none"> 1. Improve mental health services for children including Youth Empowerment Services (YES) waiver services so that children in need of out of home services can live in a family and avoid institutionalization. <ol style="list-style-type: none"> a. Allow children in the YES waiver to reside in host home settings for a period longer than 90 days. b. HHSC should develop community capacity among YES waiver providers to create host home options for children who need emergency out of home placement. c. HHSC should create educational information for families regarding the development of a recovery plan for children discharging from residential treatment as well as those in outpatient treatment. d. HHSC should review current processes to ensure the recovery plan and YES waiver service plan are shared with the family and relevant providers to more optimally coordinate care and meet the member's needs. This is especially important for children with co-morbid conditions. 	<p>Legislative, Budgetary, CMS Approval</p>
<ol style="list-style-type: none"> 2. Expand, fund, and fully implement certified family partner services and peer supports for families. <ol style="list-style-type: none"> a. Expand the Medicaid State Plan family partner certification process for children with disabilities similar to the current family partner certification program designed to serve families of children and adolescents receiving mental/behavioral health services. Also, provide funding to make this service available to families without Medicaid. b. Direct HHSC to develop and disseminate guidance to providers/professionals serving children/youth with Intellectual or Developmental Disabilities (IDD) on best practices for supporting adolescents with developmental disabilities who are exhibiting suicidal behavior, including providing supplemental information for Mental Health First Aid trainings to addressing individuals with IDD. c. Include goals and strategies related to individuals with IDD within the Texas State Plan for Suicide Prevention. 	<p>Legislative, Budgetary</p>

M. Healthcare Transition

Recommendation	Action Required
<p>1. Improve the healthcare transition of children from childhood to adulthood in Medicaid Managed Care by enhancing network adequacy. Create incentives for adult practitioners to receive young adults with special health care needs including payment incentives that allow for longer appointment times needed to meet the needs of children and young adults with medically complex conditions</p> <ul style="list-style-type: none"> a. Require MCOs to develop payment mechanisms to enable both pediatric and adult care providers to receive payment for medically necessary services concurrently during the transition process. b. Create network adequacy standards that require plans to have enough primary care physicians, specialists, therapists, home health agencies and hospitals, to meet the needs of young adults with disabilities and complex and chronic conditions. c. HHSC should partner with physician organizations to provide education about transition and evaluate if contract amendments between MCOs and physicians are necessary to ensure continuity and prevent pediatric providers from aging-out young adults before adult providers are secured. d. Require MCOs to list in their provider directory, primary care physicians and specialists who see transition age youth and adults. 	HHSC
<p>2. Increase the availability of medical homes and transition clinics for youth transitioning to adulthood.</p> <ul style="list-style-type: none"> a. Recruit new centers of excellence for transition across the state. b. Define the performance measures for MCOs for specialized medical home projects that incentivize providers to promote out-of-the-box thinking. c. Create network structures where pediatric and adult provider groups work together, link a consolidated clinic to provide improved services to transitioning youth with developmental disabilities, or behavioral and cognitive disabilities. 	HHSC
<p>3. Improve the healthcare transition of children from childhood to adulthood through adoption of transition standards and best practices.</p>	Budgetary, HHSC

Recommendation	Action Required
<ul style="list-style-type: none"> a. Begin medical transition planning at age 12 instead of age 15. b. Adopt and implement the American Academy of Pediatrics consensus statement on transition and Got Transition’s Six Core Elements as best practices. c. Develop and implement programs and incentives to improve core knowledge and skills for health care professionals to deliver developmentally appropriate health care transition services. <ul style="list-style-type: none"> i. Incorporate core competencies into training and certification requirements for primary care and specialty residents. ii. Provide incentive and additional funding for physicians and deliver services to this unique group of people. iii. Base incentive payments on healthcare outcomes. 	
<ul style="list-style-type: none"> 4. Improve the healthcare transition of children to adulthood through the following managed care system improvements. <ul style="list-style-type: none"> a. Add transition service coordinators for young adults between the ages of 21 to 26 to STAR Plus. b. Add a transition service process to STAR Health and STAR Kids. c. Require MCO transition coordinators to have training in the following: <ul style="list-style-type: none"> i. Alternative to guardianship; ii. Supported decision making; iii. Creative housing options including shared living arrangements and host homes; iv. Supported employment; and v. Eligibility requirements for services and supports and provide help to navigate people with disabilities through that process. 	<p>Budgetary, HHSC</p>

N. Transition to Adulthood: Employment, Housing, and Education

Recommendation	Action Required
<ol style="list-style-type: none"> 1. Ensure better accountability, availability, and continuity of vocational rehabilitation services. <ol style="list-style-type: none"> a. Provide a comparative analysis of programs, including scope, quantity, and funding sources, provided by the Texas Department of Assistive and Rehabilitative Services (DARS) before the transformation and HHSC/Texas Workforce Commission (TWC) since the transformation. b. Provide an analysis of impact of Workforce Innovation and Opportunity Act (WIOA) on service delivery model and funding sources provided by DARS and HHSC/TWC. c. Ensure continuity of level of service provided by DARS prior to transformation by providing: <ol style="list-style-type: none"> i. Guidance on changes to program service delivery model provided to clients, families, local education agencies, and local service providers. ii. Access to funding sources utilized by programs prior to transformation. iii. Instructions to local education agencies and local service providers on funding if programming not provided by HHSC/TWC. 	<p>HHSC, TWC</p>
<ol style="list-style-type: none"> 2. Ensure information and training be provided to families regarding the Achieving a Better Life Experience (ABLE) Act of 2014. <ol style="list-style-type: none"> a. Provide information and training to families regarding the ABLE Act through state agency programs, public schools, nonprofits, and other organizations who work with people with disabilities and their families. b. Provide a thorough analysis of investment and savings options available to families as they and their child design a meaningful life and plan long-term services and supports. Most families are unaware of the differences between third party special needs trusts, first party special needs trusts, and 529A (ABLE) savings accounts. 	<p>HHSC, TEA</p>
<ol style="list-style-type: none"> 3. Ensure training for students and families on services and benefits beginning at age 12 through age 21 and notification of the Texas Transition and Employment Guide (https://www.transitionintexas.org/guide) for students before they leave the public-school system. 	<p>HHSC, TEA, TWC</p>

Recommendation	Action Required
<ul style="list-style-type: none"> a. Provide training on services and benefits for student’s age 18 through 21 before the student leaves school. b. Provide a guide(s) of services to students and their families prior to age 18. c. Include and document the guides and training in the Admission, Review, and Dismissal (ARD) and 504 processes. 	
<ul style="list-style-type: none"> 4. Promote integrated employment with competitive wages. <ul style="list-style-type: none"> a. Improve access to employment opportunities, including competitive wages, employment assistance, and integrated day habilitation for individuals with Intellectual and Developmental Disability (IDD). b. Ensure employment services and enhanced day habilitation through Medicaid waivers meet community integration and home and community-based settings requirements and support people to work and participate in their communities. c. Create a new designation for Historically Underutilized Businesses (HUB) vendors to include those run by people with disabilities. d. HHSC and TWC should create a broad statewide task force of employers to expand employment opportunities for people with disabilities. e. Increase access to benefit employment counselors. 	<p>Legislative, Budgetary, HHSC, TxCPA, TWC</p>
<ul style="list-style-type: none"> 5. Create, fund, and implement creative housing and supports for adults with disabilities to live independently. <ul style="list-style-type: none"> a. Provide funding for housing navigators to assist adults with disabilities and their families set up affordable, collaborative, creative, and culturally appropriate housing for adults. b. HHSC should develop a workgroup to promote housing options for persons with intellectual and developmental disabilities (IDD). 	<p>Legislative, Budgetary, HHSC, TDHCA</p>
<ul style="list-style-type: none"> 6. Direct the Texas Higher Education Coordinating Board to assist colleges and universities in enhancing their transition services for students with disabilities by providing information and resources on effective practices in supporting students with disabilities. 	<p>THECB</p>

Recommendation	Action Required
<p>7. Build upon House Bill 1807, 84th Legislature, which requires Texas Higher Education Coordinating Board to establish and maintain an inventory of all postsecondary educational programs and services provided for persons with intellectual and developmental disabilities on its website and submit the inventory to the TEA for inclusion in the Texas Transition and Employment Guide. See: <u>Postsecondary programs and services for students with Intellectual and Developmental Disabilities.</u></p>	THECB
<p>8. Require institutes of higher education to provide on their websites information and resources directed to both parents and students with the aim of promoting the success of students with disabilities enrolled in higher education.</p>	THECB
<p>9. Establish a course in the University Studies or General Studies area, possibly dual credit, designed to allow an opportunity for high school students or beginning college students with disabilities to learn more about college life and the skills needed for success in higher education, such as time management and navigating life in college.</p>	THECB