Texas Children's Policy Council Recommendations for Improving Services for Texas Children with Disabilities

As Required by

H.B. 1478, 77th Legislature,

Regular Session, 2001

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1. Letter from Chair

To the Texas Legislature and Health and Human Services Commission (HHSC) Executive Commissioner Charles Smith:

The number of families raising children with disabilities in Texas is high and is growing. Childhood disability is on the rise in every demographic, with the highest growth rates in mental, behavioral health, and emotional conditions. The Centers for Disease Control and Prevention estimates that one in every 88 U.S. children and one in 54 American boys have autism, a 78 percent increase since 2002. An estimated 13.9 percent of children under 18 have some type of special health care need.

As the population of Texas continues to grow, so will the need to provide supports that empower children with disabilities to achieve a good life and to give families the tools to help them along their path to success. The Children's Policy Council (CPC) continues to serve as a strong voice for the families of children with disabilities in Texas and respectfully submits this legislative report, *Recommendations for Improving Services for Children with Disabilities in Texas, 2016*, as required by House Bill (H.B.) 1478, 77th Legislature, Regular Session, 2001.

Legislation passed in recent years will significantly affect how services are delivered to children with disabilities in Texas. Senate Bill (S.B.) 7, 83rd Legislature, Regular Session, 2013, moved the provision of services for children with disabilities to managed care through the STAR Kids program. HHSC consulted with the CPC in the development and implementation of STAR Kids. The Council appreciates efforts of the Texas Legislature, HHSC, and the Health and Human Services agencies to improve the lives of children with disabilities and their families. We especially appreciate the opportunity to collaborate with HHSC these past several years on issues surrounding long-term services and supports, acute care, service coordination, durable medical equipment, and implementation of STAR Kids. HHSC has begun implementing STAR Kids and included recommendations from the CPC in its program design.

This report continues the CPC's focus on improving access to critical services within STAR Kids. Our first recommendation calls on the state to ensure that all children with Supplemental Security Income (SSI) eligibility be allowed

access to waiver services, just as adults with SSI now are, while at least maintaining the same funding levels for other families on an interest list.

Overall, the report addresses seven key topics:

- Children belong in families: nursing facility diversion, promoting independence, medical necessity, and skilled versus non-skilled caregivers
- Great places to learn: school programs and resources for better mental health and success in school
- Access to appropriate treatment: autism state plan amendment and behavior analyst certification
- Families today, bright futures tomorrow: children and youth in foster care
- Improve access to meaningful integrated employment to create a meaningful day
- Reform sheltered workshops and day habilitation while transitioning to a meaningful integrated day
- Support the recommendation made by the sunset advisory commission staff to close six state supported living centers

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

Respectfully,

Leah Rummel, Chairperson
Texas Children’s Policy Council

2. Message from the Family Members of the Children's Policy Council

Families who care for children and youth with disabilities face challenges that other families do not face. Caring for children and youth with cognitive, mental health, and/or physical disabilities often requires more one-on-one time with a caregiver, early childhood and special education, multiple doctor visits, more hospital stays, prescriptions for medications, medical durable equipment, nursing care, and behavioral intervention, among many other supports. Families, friends, and others often try to help out, but most of the care is up to the parents. Families struggle every day to maintain some sense of normalcy and emotional family health.

Policy decisions are made by individuals who, more often than not, know little about our children and families. Here are a few things we would like legislators to know about what it's like to raise a child with a disability.

- We view our children as valuable members of Texas society. We ask that you recognize their right to live lives of dignity and be treated with respect. We ask that you provide the help we need to keep our children/youth at home and our families safe.
- Disability is non-partisan and non-discriminatory. Our children live in families of every political affiliation. Our children come from every race, culture, socio-economic level, and religion.
- Millions of dollars in informal care are provided to individuals with disabilities each year by family members. Parents are not trying to avoid their parental responsibilities.
- Like all children, our children want to grow up, emancipate, and make a contribution to their world. Preparing our children with disabilities to become productive and independent is good for our children and good for Texas.
- Raising children with a disability can be all-encompassing. Families give their hearts, time, health, bank accounts and whatever else is needed to care for their child, but many times it's not enough and more services are required. We simply need more help than we can provide to keep our families emotionally healthy and intact.
- Families – more often than not – cannot be at agency or legislative hearings. The legislative process is not family friendly. Most families cannot take off from work or from taking care of their children to spend 16 hours a day waiting in a committee room for a particular bill to be

heard in committee. We care! We just may not be able to actively participate in the process.
- Families of children with significant behavior challenges or children who have significant medical needs often cannot go on family outings, cannot take family vacations, or even find it difficult to go to the grocery store. Asking for respite isn't a luxury, it's a necessity.
- We enjoy our children. We don't want you to feel sorry for us!

We thank the policy makers of the State of Texas!

Children's Policy Council Members

Council Members

Leah Rummel, Chair, Family Member
Emily Rogers, Secretary, Family Member
David Evans, Funding Expert Member
Mary Klentzman, Faith-Based Member
Greg Mazick, Private Service Member
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Special thanks to our Agency Resource Participants and Ex-Officio members for helping us to understand and navigate the maze of the human service agencies of the State of Texas. In particular, we want to recognize Carl Tapia, M.D., not only for his service to the Children's Policy Council, but also for his commitment in his medical practice to Texas children who have complex care needs. We would also like to thank Cassandra Marx and members of the HHSC Facilitation Team for all their hard work with the CPC. Special thanks to Emily Rogers, who led the drafting of this report and to Megan Coulter for helping support the CPC and assisting with the completion of this report.

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3. About the Council

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

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

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

4. Overview of Recommendations

Children Belong in Families:

Nursing Facility Diversion, Promoting Independence, Medical Necessity, and Skilled vs. Non-Skilled Caregivers

Topic	Recommendation	Action Required
Nursing facility diversion	1. **Divert children from nursing facilities** by allowing all children and young adults who have Supplemental Security Income (Social Security) (SSI) and meet the Medically Dependent Children Program (MDCP) eligibility criteria entry into waiver services in STAR Kids or STAR Health with no wait. For those individuals who are on the interest list and do not have SSI, maintain at least the current level of effort to offer those individuals waiver services at the existing rate.	**Legislative, Budgetary, CMS Approval**
	2. **Fund Promoting Independence initiatives** for children, including waivers to support children to move from facilities and to divert children from admission.	**Legislative, Budgetary**
Access to skilled nursing level of care and skilled delegation	3. Health and Human Services Commission (HHSC)/ Department of Aging and Disability Services (DADS) should modify criteria used in Medicaid and in the Medicaid Home and Community Based Services (HCBS) waivers to allow access to nursing services **based on the needs and acuity of the child, the stability and predictability of the child's condition, and the determination that without nursing the child will be at risk for further medical complications, including death**. Denials of nursing should not be based solely on a lack of identifiable skilled interventions, often mechanical in nature.	**HHSC Medicaid Policy Change**

Topic	Recommendation	Action Required
	4. HHSC/DADS should allow the provision **of skilled nursing services via "delegated service to non-licensed persons"** in Medicaid and in the HCBS waivers. However, in the absence of a qualified non-licensed person to whom the nurse could safely delegate, the state should require nursing to be approved.	**HHSC Medicaid Policy Change**
	5. HHSC/DADS should create a **certification/training process**, whereby personal care attendants may acquire additional skills, such as pulmonary massage, feeding techniques, etc., and provide these skills under the supervision of a skilled nurse.	**HHSC Medicaid Policy Change**
	6. HHSC/DADS should **enhance reimbursement for delegated nursing services by Unlicensed Assistive Personnel (UAPs)** to attract and maintain an adequate provider base.	**Legislative, Budgetary, CMS Approval**
	7. HHSC/DADS should **broaden the Medicaid appeals and fair hearings process** to include opportunities for less formal, higher level review of the unique needs of certain children. This could also include an alternative dispute resolution such as mediation or mediation offered by the State Office of Administrative Hearings.	**Legislative, Budgetary, Policy Change**

Great Places to Learn:

School Programs and Resources for Better Mental Health and Success in School

Topic	Recommendation	Action Required
TEA Office of Student Mental Health	1. The Legislature should establish/designate an Office of Student Mental Health within the Texas Education Agency (TEA) that is charged with: (1) developing and overseeing a plan to identify, leverage, and align existing TEA resources to promote success in students in both general and special education with or at-risk of mental illness and (2) coordinating with other state agencies, such as HHSC, Texas Workforce Commission (TWC), Department of State Health Services (DSHS), Texas Juvenile Justice Department (TJJD), and Department of Family and Protective Services (DFPS) to promote strong school-community partnerships at the state and local levels.	**Legislative, Budgetary**
Mental health integration	2. The Legislature should expand the role of and appropriation to the Region 4 Education Service Center's Texas Behavior Support Network to build capacity within the other 20 Education Service Centers (ESCs) throughout the state to train and support school districts on best practices for integrating evidence-based/informed mental health interventions into a positive behavior interventions and support (PBIS) framework to improve student outcomes.	**Legislative, Budgetary**
	3. The Legislature should fund a demonstration project through TEA and the Region 4 ESC to assist school districts in integrating mental health interventions into a PBIS framework.	**Legislative, Budgetary**
Building mental health curriculum, best practices, and provider access	4. The Legislature should build in-state capacity to promote safe and supportive schools by designating an ESC or an institute of higher education as a state lead to offer schools guidance and training on trauma-informed practices in school settings.	**TEA Policy, Legislative, Budgetary**

Topic	Recommendation	Action Required
	5. TEA and HHSC should provide school districts with guidance on collaborating with community mental health providers to identify and disseminate innovating and promising practices that are already happening in schools/communities in the state.	**TEA/HHSC Policy**
	6. TEA and HHSC should host an annual statewide conference on strategies to advance best practices in mental health in school, including trauma informed practices, social and emotional learning, and partnering with community service providers.	**TEA/HHSC Collaboration**

Access to Appropriate Treatment:

Autism State Plan Amendment and Behavior Analyst Certification

Topic	Recommendation	Action Required
Access to autism treatment in Medicaid	1. HHSC should seek approval for a Medicaid State Plan amendment that would make a package of services available to all Medicaid eligible persons with autism to ensure they receive all necessary services.	**HHSC Policy, Legislative, Budgetary, CMS Approval**
	2. The Legislature should create a state license for Board Certified Behavior Analysts (BCBAs) that requires education, experience, and training and supervision of ancillary staff at levels consistent with licensure of other licensed professionals working with children.	**Legislative, Budgetary**

Families Today, Bright Futures Tomorrow: Children and Youth in Foster Care

Children with IDD in RTCs

Topic	Recommendation	Action Required
Tracking/ data of children with IDD	1. **Require tracking** of all children and youth with intellectual and developmental disabilities (IDD) who are in the custody of the state and living in a residential treatment center (RTC) for more than 12 months.	**DFPS Administrative, Legislative**
	2. **Include this data** in the DFPS quarterly report to HHSC's Promoting Independence Advisory Committee.	**DFPS Administrative, Legislative**
Access to services	3. Include children and youth with IDD who are in the custody of the state and who have resided in a DFPS licensed RTC for more than one year as a **priority population in the Promoting Independence Plan.**	**Legislative**
	4. Provide these children and youth with IDD living in an RTC the same **expedited access to community waiver services** as children residing in other long term care facilities, such as state supported living centers (SSLCs) and intermediate care facilities for individuals with an intellectual disability or related condition (ICFs/IID).	**Legislative, CMS Approval**
	5. Request and appropriate funding for **20 to 25 Home and Community-based Services (HCS) waiver slots per biennium for children and youth** with IDD who are in the custody the state and living in an RTC for more than 12 months.	**Legislative, Budgetary**

Family Opportunities for Children in GRO

Topic	Recommendation	Action Required
Access to services	6. The Legislature should **increase the number of HCS waiver slots** appropriated for children with IDD living in General Residential Operations (GRO) from 25 to 35 for the 2018-2019 biennium.	**Legislative, Budgetary**

Transition Services for Youth Aging out of CPS

Topic	Recommendation	Action Required
Access to services	7. DFPS should **establish children's eligibility for Preparation for Adult Living (PAL) benefits prior to youth with developmental disabilities transitioning from Child Protective Services** (**CPS) care.** Require the DFPS Commissioner to sign off on all cases in which the youth does not have established eligibility and provide documented rationale for the decision.	**DFPS Policy or Legislative**
	8. Require all DFPS caseworkers and PAL staff to **support youth with disabilities to qualify for PAL benefits** using all allowable forms of eligibility including the youth's special education status.	**DFPS Policy or Legislative**
Person Centered Plan	9. Require DFPS to ensure that all youth with an intellectual and developmental disability have **a person centered plan, a transition plan for aging out of CPS, and a positive behavior support plan where needed.** Ensure the plans include connection to local services, supports, and resources including Community First Choice (CFC) and Medicaid managed care. Ensure receiving service providers are well informed and trained in positive behavior supports and techniques needed to support the individual if applicable.	**DFPS/HHSC Policy or Legislative**

Topic	Recommendation	Action Required
	10. Require the youth's team to **collaborate with the designated local intellectual and developmental disability authority (LIDDA)** and include the LIDDA in the development of the transition plan, the Circle of Support meeting, and the Family Group conferences.	**Legislative**
	11. Develop and implement a system **to identify and track children and youth with IDD in the conservatorship of the State**. Require tracking to include: • Length of time the children are in care • Number of the children eligible, accessing, or exiting the system without benefits associated with aging out of care (PAL, Tuition Fee Waiver, etc.) • Number of children who are being referred for HHSC/DADS guardianship, the number accepted, the number denied, and the number being informed of and accessing Supported Decision Making • Number of youth transitioning with Community First Choice	**Legislative, Budgetary**
	12. **Require training of DFPS caseworkers and PAL workers on transition supports** for children and youth with IDD including resources that will be available to them after they age out of care.	**Legislative, Budgetary**

Improve Access to Meaningful Integrated Employment to Create a Meaningful Day

Topic	Recommendation	Action Required
CFC expansion	1. **Support community integration through adequate funding and by permitting the flexible use of funds at adequate rates within the cost cap.** • **Individuals should have the flexibility to use CFC in the implementation of their person-centered plan to ensure a meaningful day**, including successful community participation, volunteering and/or supported employment and employment assistance as part of the benefit. CPC recommends adding these services as part of CFC. CFC is not available to individuals who receive HCS residential services, so adequate funding and flexibility in the program is needed to ensure sufficient, high quality staff to support the individual.	**Legislative, Budgetary, CMS Approval**
Funding flexibility	• Community inclusion requires waiver structure flexibility. CPC recommends HHSC **develop and promote self-direction and pooling of day services dollars** to participate in shared interests in the community for up to three or four individuals to provide staff and transportation. Provide access to transportation services in all waivers to support community participation, including individuals receiving residential services during times residential services typically are not provided. Waiver participants should be permitted to: i. Self-direct the funds currently used to pay for day habilitation programming and redirect those funds to purchase supports for individualized activities, and ii. Pool funding for services on their plans of care, like day habilitation funds and attendant/CFC, with that of other waiver participants.	**Legislative, Budgetary, CMS Approval**

Topic	Recommendation	Action Required
Creative models	• **Provide incentives for reallocation of resources and creative models** that improve access to the greater community during weekdays, evenings, and weekends. Staffing and a transportation plan will likely be needed.	**Legislative, Budgetary, CMS Approval**
Socialization	• **Developing new or maintaining relationships and friendships** should be supported within a model to promote community integration.	**HHSC Policy**
Work incentives	2. Support competitive integrated employment through education on work incentives. • **Support competitive, integrated employment** by developing and/or expanding existing educational campaigns and other initiatives to not only increase awareness of work incentives and provide accurate information, but to also assist with applying for and implementing work incentives that allow individuals who receive SSI to exclude money, resources, and certain expenses from total earned income.	**Legislative, Budgetary**
	• **Focus on training and providing resources** for LIDDAs, managed care organizations (MCOs), and IDD providers, including how to collaborate with local businesses and training about vocational rehabilitative (VR) services, such as Ticket to Work and other support services that can be accessed through any participating employment network or state VR services so that the LIDDAs and providers can better assist individuals and their families and supporters to pursue person centered, competitive, integrated employment goals.	**HHSC Policy**

Topic	Recommendation	Action Required
Increase in finding meaningful employment	3. Increase supported employment and employment assistance utilization. • **Increase availability, accountability, and utilization of Medicaid waiver supported employment and employment assistant services.** Better define expectations and implement systemic reporting so that statewide progress toward successful employment outcomes based on the employment goals can be recognized. Continued increase in competitive supported employment utilization for persons with IDD should be the goal. Create a centralized location people can go to for employment related resources. Continue to expand and enhance local employer recruitment training efforts.	**HHSC and TWC Policy**
Employment and volunteer opportunities flexibility	4. Increase the flexibility of employment services. • **Provide choice regarding competitively paid, integrated community employment** (full or part time) that promotes self-sufficiency and non-paid volunteer work that will lead to employment that allows meaningful contribution to the needs of one's community based on an individual's interests and preferences. • **Allow for flexible, individualized scheduling** of preferred employment, employment exploration, and volunteer activities with supports, including staff, tailored to the person's individual needs. These services should be available during the weekday, evening, and weekends and also for individuals receiving residential services.	**HHSC Policy or Legislative, Budgetary**

Topic	Recommendation	Action Required
Supported employment rates and incentives	5. Ensure sufficient supported employment rates and incentives to promote meaningful opportunities for work. • **Establish consistent rates**, contracting structures, and performance measures with a clear intent of obtaining and maintaining competitive, integrated employment. • Establish a rate structure that would **provide a higher reimbursement rate for those with a greater level of need and/or supports**. • Incentivize day habilitation providers, community rehabilitation providers, and other interested programs/parties providing services in segregated work settings to **reallocate resources to competitive, integrated employment**.	**Legislative, Budgetary**

Reform Sheltered Workshops and Day Habilitation while Transitioning to a Meaningful Integrated Day

Topic	Recommendation	Action Required
Oversight, reporting and monitoring	1. **Improve reporting, contract oversight, and monitoring of day habilitation, pre-vocational services, and sheltered workshops to assure safety.** • Require DFPS and HHSC/DADS to **track data on abuse, neglect, and exploitation** in facilities providing day habilitation or prevocational services and sheltered workshops. • Require HHSC to **compile and make public basic information and data** on locations providing day habilitation or prevocational services to persons in ICF/IID or HCS, Texas Home Living (TxHmL), Community Living Assistance and Support Services (CLASS), and Deaf Blind with Multiple Disabilities (DBMD) waivers, including data on violations and deficiencies found during a survey. Data recommended to be collected incudes staff participant ratio, weekly schedule of activities, information on community outings including frequency that participants attend them, and frequency and content of staff development provided.	**Legislative, Budgetary**
Day habilitation is a choice	2. **Disclose to waiver participants that day habilitation and prevocational services are a choice and are not mandatory.** Require that service planning team to inform waiver participants that they **may choose or decline to include day habilitation or prevocational services on their individual plans of care.** The service planning team must inform the waiver participants of other opportunities such as **supported employment** and **employment assistance.**	**HHSC Policy**

Topic	Recommendation	Action Required
Transition from subminimum wage	3. **Transition from subminimum wage work in sheltered workshops and other settings for Medicaid waiver participants.** • Require service planning teams to identify program participants working in 14(c) settings. Create a transition plan to **move away from individuals participating in facility based segregated work environments that pay subminimum wage**. • Create initiatives for employment assistance providers/counselors/specialists to be present in segregated work settings to establish ongoing relationships with the employees and assist them in an appropriate discovery and planning process to **transition to competitive, integrated employment**. • **Require case managers and service coordinators to address employment goals** at least annually for all individuals receiving services from a Medicaid waiver program.	**Legislative, Budgetary, CMS Approval**

Support the Recommendation Made by the Sunset Advisory Commission Staff to Close Six State Supported Living Centers

Topic	Recommendation	Action Required
State Supported Living Centers	1. Texas should close the Austin SSLC by August 31, 2019, and close five other centers by August 31, 2024. Each person in these large state-run institutions should be eligible to transition to the least restrictive environment.	**Legislative**
State Supported Living Centers	2. Texas should declare a moratorium on the new placement of children into any SSLC.	**Legislative**

5. Policy Issues and Recommendations

Children Belong in Families: Nursing Facility Diversion, Promoting Independence, Medical Necessity, and Skilled versus Non-Skilled Caregivers

When children have needs that go beyond what their families can meet, sometimes families must place their children into nursing facilities or other institutions. However, in many cases, placement outside the home can be avoided and families can remain together if families have access to critical supports such as waiver services, personal care services (PCS), and private duty nursing (PDN). If out of home placement is ever needed, children should be supported in families instead of facilities.

Policy Issue: Medically Dependent Children Program (MDCP) Interest List Reduction

As of January 31, 2016, a total of 18,615 children and young adults were on the interest list for the Medically Dependent Children's Program (MDCP) waiver.[1] A wait of approximately four to five years to receive services can have serious consequences for children with complex medical needs and their families. With the implementation of STAR Kids in November 2016, Texas has an opportunity to significantly reduce the MDCP interest list by allowing all children and young adults up to age 21 who receive supplemental security income (SSI) and meet MDCP waiver eligibility to automatically receive services with no wait. Texas implemented a similar initiative for adults when the STAR+PLUS waiver rolled out and, as a result, has virtually eliminated the interest list for adults. Children who qualify for a Medicaid waiver, in lieu of receiving services in a nursing facility, should have similar access to services as those guaranteed to an adult.

Recommendation

1. **Divert children from nursing facilities** by allowing all children and young adults who have SSI and meet the MDCP eligibility criteria entry into waiver services in STAR Kids or STAR Health with no wait. For those individuals who are on the interest list and do not have SSI, maintain at

[1] "Report to the Promoting Independence Advisory Committee." Health and Human Services Commission, 2016.

least the current level of effort to offer those individuals waiver services at the existing rate.

Background

Children who qualify for a Medicaid waiver in lieu of receiving services in a nursing facility should have similar access to services as those guaranteed to an adult. When the STAR+PLUS waiver rolled out in Texas, adults who had SSI and qualified for the STAR+PLUS waiver received services with no wait. This practice has virtually eliminated the interest list for adults who qualify for the nursing facility waiver and has assisted individuals to stay in their homes and communities. STAR Kids began in November 2016. Children and young adults with SSI or who are served by 1915(c) waivers will enroll in the STAR Kids Medicaid managed care plan to receive their acute care services and some long-term services and supports (LTSS), PCS, and PDN. Children enrolled in the MDCP waiver will also receive their waiver services through STAR Kids. With the change in service delivery model for MDCP, Texas has not changed the number of appropriated "slots" for the waiver. As such, entry to the waiver still will be managed by an interest list. Unlike adults in the STAR+PLUS waiver, under STAR Kids, children and young adults who have SSI and meet MDCP eligibility criteria may not access waiver services until they come to the top of the interest list. 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 historical take-up rate in the MDCP waiver is 10.4 percent.[2] Therefore, of the 18,615 individuals on the interest list as of April 2016, only 1,936 people are expected to be deemed eligible and accept services when offered. Of the 1,936 individuals, a little more than 1,000 will have SSI. Implementing this recommendation will make a significant difference in quality of life for families and will drastically reduce the MDCP interest list.

[2] "House Committee on Appropriates Subcommittee on Article II Charge #10." Texas Department of Aging and Disability Services, 2016.

How much would it cost to meet the needs of children who need a nursing facility level of care in their homes?[3]

Table 1: Scenario 1 Providing MDCP services to individuals on interest list who meet nursing facility level of care and have SSI

	Eligible per Month	Total Annual Cost All Funds	Total Annual Cost General Revenue
FY2018	1,121	$20,000,000	$8,764,000
FY2019	1,164	$21,000,000	$9,202,200
Biennial		$41,000,000	$17,966,200

Table 2: Scenario 2 Providing MDCP services to individuals on interest list who meet nursing facility level of care, regardless of SSI

	Eligible per Month	*Total Annual Cost All Funds	*Total Annual Cost General Revenue
FY2018	2,107	$113,000,000	$49,516,600
FY2019	2,188	$117,000,000	$51,269,400
Biennial		$230,000,000	$100,786,000

Source for Tables 1 and 2: HHSC System Forecasting, April 2016.

Policy Issue: Getting and Keeping Children Out of Institutions

Access to community-based waivers has allowed children to grow up in loving and well supported families, has saved the state money, and has contributed to rebalancing the Texas long term services and supports system. This work should continue and be expanded to those who have not yet been included.

Recommendation

2. Fund Promoting Independence initiatives for children including waivers to support children to move from facilities and to divert children from admission.

Background

It is the policy of the state of Texas that children belong in families. For many years now, the Texas Legislature has funded waiver services to support children to move from facilities and to divert them from facility admission as

[3] Notes for Tables 1 and 2: Analysis assumes a start date of September 2017. The term "General Revenue" refers to state dollars. In scenario 2, non-SSI clients would become eligible for both regular Medicaid and MDCP services.

part of its commitment to Olmstead[4] and the Texas Promoting Independence Plan. Between August of 2002 and 2015, the number of children and young adults growing up in nursing facilities has decreased by approximately 72 percent, large intermediate care facilities for individuals with an intellectual disability or related condition (ICF/IID) by 92 percent, small ICF/IID by 63 percent, and Department of Family and Protective Services (DFPS) General Residential Operations (GRO) by 56 percent.[5]

The Texas Legislature has historically funded Home and Community-based Services (HCS) waiver services for the following populations:

- Individuals living in large or medium ICFs/IID;
- Children and youth aging out of DFPS foster care;
- Individuals at risk of admission to an SSLC;
- Children living in DFPS GRO;
- Individuals with IDD in state hospitals; and most recently
- Children at risk of admission to nursing facilities.

Policy Issue: Access to Skilled Nursing

Parents and family caregivers of children and young adults with medically complex conditions often find it difficult to access the appropriate level of care their family member requires. Children and young adults are being denied Medicaid-funded nursing when the need exists for the skilled intervention, judgment, and oversight of a nurse, but the child does not require mechanical interventions (or easily identifiable or observed "hands-on" skills, such as suctioning a tracheostomy, connecting a patient to a ventilator, or inserting a urinary catheter). The child or young adult is often denied access to skilled nursing based on a decision by Medicaid noting that the child does not have sufficient identifiable skilled needs to qualify for private duty nursing. Skilled needs are often identified by mechanical 'hands-on' type interventions rather than by the actual complexity of the child or young adult's medical needs. Families are then told to access unlicensed personal assistance services through the PCS program or through their Medicaid waiver. However, the child or young adult's care is often too complex for unlicensed personal care attendants who have very little training in medical interventions and who are paid a rate which does not promote employment stability. While the program might allow delegation by a

[4] The U.S. Supreme Court held in 1999 (Olmstead v. LC) that people with disabilities have a qualified right to receive state funded supports and services in the community rather than institutions.

[5] "Permanency Planning and Family-Based Alternatives Report." Texas Department of Aging and Disability Services, March 2016.

licensed nurse, nurses refuse to delegate when they do not believe the task can be safely performed by an insufficiently trained provider.

When delegation is permitted, but not appropriate or available, nursing should be approved. According to the Board of Nurse Examiners, professional nursing can be practiced by unlicensed personnel under the supervision of a licensed nurse, but only under stable and predictable situations. Therefore, medical necessity for PDN versus personal assistance services must first and foremost be based on what is needed for the child to be safely supported. The decision about which discipline should provide the service, a nurse or an unlicensed personal care attendant, should not be based solely on mechanical interventions or the amount and frequency of the skilled interventions.

Recommendations

3. HHSC/DADS should modify criteria used in Medicaid and in the Medicaid Home and Community Based Services (HCBS)[6] waivers to allow access to nursing services **based on the needs and acuity of the child, the stability and predictability of the child's condition, and the determination that without nursing the child will be at risk for further medical complications including death.** Denials of nursing should not be based solely on a lack of identifiable skilled interventions, often mechanical in nature.
4. HHSC/DADS should allow the provision of skilled nursing services via "delegated service to non-licensed persons" in Medicaid and in the HCBS waivers. However, in the absence of a qualified non-licensed person to whom the nurse could safely delegate, the state should require nursing to be approved.
5. HHSC/DADS should create a **certification/training process** whereby personal care attendants may acquire additional skills, such as pulmonary massage, feeding techniques, etc. and provide these skills under the supervision of a skilled nurse.
6. HHSC/DADS should enhance reimbursement for delegated nursing services by unlicensed assistive personnel (UAPs) to attract and maintain an adequate provider base.
7. HHSC/DADS should broaden the Medicaid appeals and fair hearings process to include opportunities for less formal, higher level review of the unique needs of certain children. This could also include an alternative

[6] HCBS is a term used to describe all home and community-based services. HCS is a 1915(c) waiver program to help individuals in Texas live in the community who would otherwise be eligible to live in an ICF/IID.

dispute resolution such as mediation or mediation offered by the State Office of Administrative Hearings.

Background

In addition to the supports provided by waivers, skilled nursing services help families meet the needs of their children at home. Certain medical criteria normally result in the approval for nursing care under Medicaid. The Texas Medicaid Policy and Procedures Manual (TMPPM), under the Children's Services Handbook, Section 2.13.2.2.2, addresses what must be considered when submitting a request for private duty nursing. Some examples of medical criteria that would qualify a child for skilled nursing services are clearly identified by mechanical intervention, such as a child having tracheostomy, but others are not so clear. Examples of skilled needs not clearly identified with mechanical intervention include:

- Elimination difficulties but who are not catheterized
- Swallowing issues who do not necessarily have a feeding tube (G-tube) administering oral feedings with high risk for aspiration
- Uncontrolled seizures and seizure precautions for safety and Diastat administration
- Frequent hospitalizations and use of emergency department
- Noninvasive breathing support, such as Continuous Positive Airway Pressure (CPAP)
- Administering CPAP or Bi-level Positive Airway Pressure (BiPAP) via face mask

Private Duty Nursing (PDN)

PDN is considered medically necessary when a client has a disability, physical or mental illness, or chronic condition and requires continuous, skillful observations, judgments, and interventions to correct or ameliorate his or her health status. The TMPPM, under the Children's Services Handbook, Sec. 2.13.2.2.2, notes that Medical necessity for PDN under the Texas Health Steps Comprehensive Care Program (CCP) must address the following considerations when submitting a request for PDN:

- Is the client dependent on technology to sustain life
- Does the client require ongoing and frequent skilled interventions to maintain or improve health status
- Will delaying skilled intervention impact the health status of the client, if so, how will the health status be affected
- Deterioration of a chronic condition
- Risk of death
- Loss of function
- Imminent risk to health status due to medical fragility

Inconsistent Availability of Care Compromises the Ability to Live at Home

Luke, now 23 years old, experienced a brain injury at birth. He has diagnoses of functional quadriplegia, severe cognitive disability, and blindness. Since Luke's birth, his parents have cared for him with little mechanical intervention. He can swallow, but cannot feed himself, so he's orally fed a diet of pureed foods and liquids five times a day. He cannot urinate on his own, so they massage his bladder every three hours. His parents administer aggressive pulmonary hygiene twice a day. With this care, Luke has never required suctioning or had aspiration pneumonia, a urinary tract infection, or skin breakdown.

When Luke reached puberty and his body grew, his care became more challenging. His parents have always been his primary caregivers, but they have also hired college students to provide Luke with "attendant" care, a service via the CLASS waiver program. As Luke got older, it became more difficult to find attendants who care for him. His parents applied for skilled nursing care for Luke but were denied the service, as Luke's care does not involve mechanical intervention. State programs, such as CLASS, would pay for a nurse for Luke to administer tube feedings, catheterize, or suction him, yet will not pay for the non-mechanical strategies used to successfully treat and care for Luke over the last 23 years.

Definitions

Personal Care Services (PCS)

PCS are support services provided to clients who meet the definition of medical necessity and require assistance with the performance of activities of daily living (ADLs), instrumental activities of daily living (IADLs), and health maintenance activities (HMAs) due to a physical, cognitive, or behavioral limitation related to a client's disability or chronic health condition. PCS are provided by someone other than the responsible adult of the client who is a minor child or the spouse of the client. The scope of ADLs, IADLs, and HMAs includes a range of activities that healthy, nondisabled adults can perform for themselves. Typically, developing children gradually and sequentially acquire the ability to perform these ADLs, IADLs, and HMAs for themselves. If a typically developing child of the same chronological age could not safely and independently perform an ADL, IADL, or HMA without adult supervision, then the client's responsible adult ensures that the client's needs for the ADLs,

IADLs, and HMAs are met. PCS include direct intervention (assisting the client in performing a task) or indirect intervention (cueing or redirecting the client to perform a task) including, but not limited to, the following:

- ADLs—bathing, dressing, eating, locomotion or mobility, personal hygiene, positioning, toileting, and transferring
- IADLs—escort or assistance with transportation services, grocery or household shopping, laundry, light housework, meal preparation, medication assistance, money management, and telephone use or other communication (TMPPM, Children Services Handbook, Sec. 2.11.2)

Great Places to Learn: School Programs and Resources for Better Mental Health and Success in School

Children spend a substantial amount of their time in school, and having a safe and supportive school environment provides children, especially those with mental health needs, an opportunity to reach their full capacity. With sufficient training and resources, schools can meet the educational needs of all children.

Policy Issue: Helping Schools Meet the Educational Needs of Students with Mental Health Concerns

While the Legislature has taken significant steps to build the capacity of educators to recognize red flags signaling a student may be experiencing a mental health crisis and know what to do to connect them to appropriate services, it has remained largely silent when it comes to helping schools meet the educational needs of students struggling with mental health concerns.

The Legislature and state agencies should offer school districts leadership, guidance, and support to help them address barriers to learning associated with mental health concerns in students.

Recommendations

1. The Legislature should establish/designate an Office of Student Mental Health within the Texas Education Agency (TEA) that is charged with: (1) developing and overseeing a plan to identify, leverage, and align existing TEA resources to promote success in students in both general and special education with or at-risk of mental illness; (2) coordinating with other state agencies (HHSC, DSHS, TJJD, DFPS) to promote strong school-community partnerships at the state and local levels.
2. The Legislature should expand the role of and appropriation to the Region 4 Education Service Center's Texas Behavior Support Network to

build capacity within the other 20 Education Service Centers (ESCs) throughout the state to train and support school districts on best practices for integrating evidence-based/informed mental health interventions into a positive behavior interventions and support (PBIS) framework to improve student outcomes.

3. The Legislature should fund a demonstration project through TEA and the Region 4 ESC to assist school districts in integrating mental health interventions into a PBIS framework.
4. The Legislature should build in-state capacity to promote safe and supportive schools by designating an ESC or an institute of higher education as a state lead to offer schools guidance and training on trauma-informed practices in school settings.
5. TEA and HHSC should provide school districts with guidance on collaborating with community mental health providers to identify and disseminate innovative and promising practices that are already happening in schools/communities in the state.
6. TEA and HHSC should host an annual statewide conference on strategies to advance best and promising practices in mental health in schools, including trauma informed practices, social and emotional learning, and partnering with community service providers.

Background

Students with mental health concerns are at higher risk of missing school, struggling academically, and being disciplined for behaviors that may stem from their disorder.[7] Between 1999 and 2009, public schools in Texas suspended or expelled for discretionary reasons nine out of 10 students classified as having an emotional disturbance.[8] Students with serious mental illness are twice as likely as peers without serious mental health concerns to drop out of school.[9]

Research has identified effective practices that schools can use to improve the academic outcomes of students with mental health concerns, including providing tiered levels of interventions and supports like those used within a school-wide positive behavior interventions and support (PBIS) approach to

[7] Studies cited in Stagmann S, and J. Cooper. "Children's Mental Health: What Every Policymaker Should Know." National Center for Children in Poverty, 2010, http://www.nccp.org/publications/pub_929.html

[8] "Breaking School Rules Report." Council of State Governments Justice Center, 2011, http://justicecenter.csg.org/resources/juveniles

[9] Wagner, M. "Outcomes for Youths with Serious Emotional Disturbance in Secondary School and Early Adulthood." Critical Issues for Children and Youths, 1995.

behavior management using trauma informed practices, embedding social emotional learning into existing curriculums, and providing school-based mental health services.

School districts in Texas are required to have plans in place to prevent suicide, truancy, and dropout – all of which link closely to mental health concerns – but the state provides no guidance to schools on how to address these serious issues in an effective, coordinated approach that leverage school resources to have the most impact on a broad range of interconnected outcomes. Texas helps train educators to recognize potential mental health concerns in students and how to prevent crises, but the state provides very limited guidance or support to help students whose mental health concerns interfere with their performance in school.

Establishing a dedicated office within TEA to better leverage and coordinate resources would help schools bring what we know works into practice. Encouraging and assisting schools to partner with community-based providers and offer school-based mental health services would increase access to services while keeping students learning in a classroom environment. Building capacity through the state's ESC network or universities can help bring innovative school-based strategies into practice providing schools with training, technical assistance, and evaluation.

Integrating Mental Health Interventions in School Helps Students to be Successful in Life

Tenth grade student Lindsay was placed in her district's Discipline Alternative Education Program (DAEP) due to fighting. Luckily for her, Lindsay attended a school district that had trained its staff to approach students not asking "what's wrong with you?" but instead "what happened to you?" Lindsay's school district also has school counselors and social workers who are able to attend to students' social and emotional issues as well.

Because of this, Lindsay began attending a counseling group in school designed to give girls the opportunity to feel empowered and gain self-awareness. In this safe and supportive group environment, Lindsay disclosed how she witnessed unhealthy relationships in her past and how she learned to cope with conflict in an aggressive manner. A school counselor began to meet weekly with Lindsay, in addition to Lindsay's continued participation in the group.

These school-based, trauma-informed strategies worked. Lindsay displayed significant improvement in her attendance, behavior, and

grades. She returned to her home campus and successfully completed her sophomore year. The following year she was accepted into a self-paced, credit recovery program that allowed her to make up for having been held back a grade level when she was younger. Lindsay went on to graduate early and is now enrolled at a local community college. Her goal is to become a nurse. She seeks help when she needs it and continues to have a close relationship with her school counselor.

Access to Appropriate Treatment: Autism State Plan Amendment and Behavior Analyst Certification

Evidence-based interventions delivered by qualified therapists and medical providers have the power to improve outcomes and quality of life for individuals with autism. Whether a child receives interventions through Medicaid or a parent's insurance, families should be made aware of all the evidence-based treatment options, and families should have the ability to choose from a pool of well-trained, credentialed therapists.

Accessing Treatment for Autism Spectrum Disorders Should Not Depend on Wealth or the Ability to Identify Qualified Professionals

Lena received a diagnosis of autism just before her third birthday. After several months of meeting with teachers, an educational diagnostician, and then a medical team, her parents had anticipated the diagnosis. They asked about applied behavioral analysis (ABA) at the specialty clinic where they found themselves. The response they got took them aback. "Get as much ABA as you can afford," they were told. Soon her parents discovered that their self-funded insurance plan did not cover ABA at all, though they were fortunate to be able to pay for a limited number of therapy hours out of pocket.

Lena began ABA right away, and her parents learned strategies to manage difficult behaviors and help Lena gain independence and stay safe. Through ABA, Lena gained vocabulary and could ask for what she wanted, which reduced the frustration she experienced. Her parents learned to manage dangerous behaviors by anticipating them and recognizing the events and warning signs that preceded them. Lena's parents were grateful to have found qualified therapists. When they first began looking for help, it felt as though the services they needed were on a secret menu. The difficulty in finding services or even knowing what

to ask for was daunting. It's easy to imagine that many parents of children with autism either don't know how to seek out qualified professional help or can't afford the necessary services anyway.

The skills Lena has learned in ABA have expanded her ability to communicate, helped her make meaningful friendships, and increased her enjoyment of life. It is hard to imagine going without these things because Medicaid doesn't offer treatment or because a family can't identify a qualified professional.

Policy Issue: Autism State Plan Amendment

The State of Texas needs a State Plan amendment to address the treatment needs of children who receive Medicaid and are diagnosed with autism spectrum disorder (ASD or autism). Amending the plan will leverage state dollars to serve many more Texans who have autism. The Centers for Medicare and Medicaid Services (CMS) has issued clear guidance to states that they must make available all medically necessary treatment to children with autism.[10]

Recommendation

1. HHSC should seek approval for a Medicaid State Plan amendment that would make a package of services available to all Medicaid eligible persons with autism to **ensure they receive all necessary services.**

[10] Mann, C. "Clarification of Medicaid Coverage of Service to Children with Autism." Maryland Department of Health and Human Services, 2014. Retrieved from https://www.medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-07-07-14.pdf

Background

The Centers for Disease Control and Prevention (CDC) has estimated that 1 in 45 children have been identified with autism.[11] Autism is a complex disorder that manifests in individuals very differently. People on the autism spectrum are not all alike. Their needs vary and can often go above and beyond behavioral issues, with many experiencing serious comorbidities such as epilepsy, sleep disturbances, and gastrointestinal disorders. In treatment, one size does not fit all. Focusing all available autism resources on behavioral interventions does not address the needs of the whole person nor does it meet the needs of persons across the spectrum. The call for a full range of services is likely to continue and increase. It is important that services available to children continue in the transition to adulthood and beyond.

Autism services should be made available to everyone who needs them. CMS encourages states to articulate which services are available for the treatment of autism in their state plan amendments.[12] On July 6, 2015, the U.S. Department of Education (DOE), Office of Special Education Programs, reiterated CMS' message that applied behavior analysis (ABA) is not the only evidence-based intervention for children with autism, e.g., speech and language needs were being reported as not met. The DOE letter cited the CMS bulletin mentioned above as a well as the CMS document "Medicaid and CHIP FAQ: Services to Address Autism," September 2014.[13]

Texans with autism may not be receiving services for which they are eligible under Medicaid. Currently, only a subset of those diagnosed receive services through the Children's Autism Program at HHSC. Although funding for the autism program was increased to $22 million by the 84th Legislature, services are limited to providing ABA to children on the autism spectrum through Board Certified Behavior Analysts (BCBAs) for brief periods of time to target specific behavioral needs. For those needing a more intensive ABA program and those seeking treatments other than ABA, only limited publicly funded options exist, and families struggle to find services available to treat autism.

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[11] Zablotsky et al. "Estimated Prevalence of Autism and Other Developmental Disabilities Following Questionnaire Changes in the 2014 National Health Interview Survey. National Health Statistics Reports, 2014, http://www.cdc.gov/nchs/data/nhsr/nhsr087.pdf

[12] "Medicaid and CHIP FAQs: Services to Address Autism." Maryland Department of Health and Human Services, 2014, https://www.medicaid.gov/federal-policy-guidance/downloads/faq-09-24-2014.pdf

[13] Ibid.

Policy Issue: Behavior Analyst Certification

Texas lacks a board to regulate behavior analysts. Board licensure would ensure that those holding themselves out as behavior analysts have a similar level of education, experience, and supervision of ancillary staff as required by other providers licensed by the state. BCBAs require significantly fewer hours of supervised training than other master's level professionals who work directly with children and are licensed in Texas.

Current standards regulating BCBAs are inadequate and are not enforceable by the state. Thus, Texas currently does not receive federal Medicaid matching funds for these services. However, state licensure would be a significant step to clear the way for behavior analysts to bill Medicaid, allowing Texas to draw down the matching funds.

Recommendation

1. The Legislature should **create a state license for BCBAs** that requires education, experience, and training and supervision of ancillary staff at levels consistent with licensure of other licensed professionals working with children.

Background

One way to expand access to treatment would be to regulate behavior analysts in Texas similar to other health and mental health professionals. BCBA licensure would help increase access to qualified behavior analysts and regulate services to ensure quality delivery. During the 84th Legislature, a bill proposing to license BCBAs was filed but did not pass. Many noted that the reliance on third party certification would not provide adequate licensure standards and would not allow for necessary state oversight of services that in some cases may involve aversive procedures. Today, individuals can call themselves "behavior analysts" and provide questionable services to children with autism. Licensure would establish a professional standard of care by the state.

Families Today, Bright Futures Tomorrow: Children and Youth in Foster Care

Children and youth with IDD who are part of the DFPS system need supports to move from institutions to families and to transition from childhood to adulthood. Children with IDD tend to be placed in DFPS institutions instead of families due to inadequate supports for their complex needs, while youth with IDD who transition to adulthood from DFPS often transition without the supports they need to be successful. Increasing data collection to better

understand the number of children with IDD living in DFPS facilities, providing access to appropriate waiver services to enable the children to live in families, and promoting better transitions for youth exiting the foster care system to help them further their education and secure employment will improve their lives and lead to better outcomes for the state's health and human services system.

Policy Issue: Children with Intellectual and Developmental Disabilities who are in Conservatorship of Child Protective Services Remain in Residential Treatment Centers for too Long

The state does not adequately track children and youth with IDD residing in DFPS licensed residential treatment centers (RTCs). Preliminary information revealed by the closing of two RTCs in February 2016 indicated that some residents were children and youth with IDD. Children and youth with IDD should not live in an RTC for an extended period of time.

Recommendations

1. **Require tracking** of all children and youth with IDD who are in the custody of the state and living in an RTC for more than 12 months.
2. **Include this data** in the DFPS quarterly report to HHSC's Promoting Independence Advisory Committee.
3. Include children and youth with IDD who are in the custody of the state and who have resided in a DFPS licensed RTC for more than one year as a **priority population in the Promoting Independence Plan**.
4. Provide children and youth with IDD living in an RTC the same **expedited access to community waiver services** as children residing in other long-term care facilities, such as SSLCs and ICFs/IID.
5. Request and appropriate funding for **20 to 25 HCS waiver slots per biennium for children and youth** with IDD who are in the custody the state and living in an RTC for more than 12 months.

Background

In 2012, children and youth with IDD residing in DFPS licensed long-term care facilities known as GRO were added to the Texas Promoting Independence Plan as a priority population. At the time, it was not well known that children with IDD were also living in RTCs for extended periods of time. The facilities are designed to be short term psychiatric treatment facilities, not long term living arrangements. In order for children with IDD to have the supports necessary to successfully live with a family, they must have access to a long term services and supports waiver. In addition, DFPS

must identify and track children with IDD residing in an RTC to better understand and plan for the children's long term needs.

Policy Issue: Children and Youth with IDD Continue to be Placed in GRO When no Other Alternatives are Available. In Order to Meet the Time Frame Specified in the Promoting Independence Plan, Waiver Funding for this Population of Children Needs to be Increased.

Recommendation

6. The Legislature should **increase the number of HCS waiver slots** appropriated for children with IDD living in GRO from 25 to 35 for the 2018-2019 biennium.

Background

The 83rd and 84th Legislatures each approved funding for 25 children per biennium to move out of GRO with the support of the HCS waiver. Twenty-five children successfully moved to families in fiscal year 2014 and fiscal year 2015, and all of the appropriated waiver slots are on track to be fully utilized during the current (2016-2017) biennium.

Children, who historically spent many years in non-family settings, have successfully moved to families as a result of the initiative. Children with IDD, however, continue to be placed in GRO when no other alternatives are available. In order to meet the time frame specified in the Promoting Independence Plan, the number of HCS waiver slots appropriated for this population of children needs to be increased.

Policy Issue: Ensure Youth Aging out of CPS Receive the Transition Services They Need to be Successful

Youth with IDD who are in the conservatorship of the state are aging out of Child Protective Services (CPS) without comprehensive transition planning. Services meant to support youth to transition to adulthood, such as the Preparation for Adult Living (PAL) benefits including the Transitional Living Allowance and the College Tuition and Fee Waiver Exemption, are at risk if the individual does not access the services by a certain time frame. In addition, many of these youth will need long term services and supports from Medicaid home and community based waivers or the Medicaid state plan. It is imperative for the success of youth with IDD to have person centered planning and a comprehensive plan of services. They should not age out of care without having knowledge of and access to the benefits to which they are entitled.

Recommendations

7. DFPS should **establish children's eligibility for PAL benefits prior to youth with developmental disabilities transitioning from CPS care**. Require the DFPS Commissioner to sign off on all cases in which the youth does not have established eligibility and provide documented rationale for the **decision.**
8. Require all DFPS caseworkers and PAL staff **to support youth with disabilities to qualify for PAL benefits** using all allowable forms of eligibility, including the youth's special education status.
9. Require DFPS to ensure that all youth with IDD have a **person centered plan, a transition plan for aging out of CPS, and a positive behavior support plan where needed**. Ensure the plans include connection to local services, supports, and resources including CFC and Medicaid managed care. Ensure receiving service providers are well informed and trained in positive behavior supports and techniques needed to support the individual if applicable.
10. Require the youth's team to **collaborate with the designated local intellectual and developmental disability authority (LIDDA)** and include the LIDDA in the development of the transition plan, the Circle of Support meeting, and the Family Group conferences.
11. Develop and implement a system **to identify and track children and youth with IDD in the conservatorship of the State**. Require tracking to include:
    - Length of time children are in care
    - Number of children eligible, accessing, or exiting the system without benefits associated with aging out of care (PAL, Tuition fee Waiver, etc.)
    - Number of children who are being referred for HHSC/DADS guardianship, the number accepted, the number denied, and the number being informed of and accessing Supported Decision Making
    - Number of youth transitioning with CFC
12. Require training of DFPS caseworkers and PAL workers on transition supports for children and youth with IDD, including resources that will be available to them after they age out of care.

Background

Youth aging out of CPS care have benefits they are entitled to which are often not accessed. Improving both the best practices of CPS caseworkers and collaborative efforts with community resources will assist the individual with utilizing these financial benefits. This can and will improve a young adult's ability to further his or her education and employment opportunities.

Anecdotal evidence suggests that children and youth with disabilities in foster care do not have the same knowledge of and access to their entitlement benefits as their non-disabled peers.

Improve Access to Meaningful Integrated Employment to Create a Meaningful Day

People need varying levels of support to be successful at jobs. Employment in the general workforce is the first and preferred outcome for publicly funded services for all working age people with disabilities, regardless of level of disability.

Policy Issue: Access to Real Jobs with Real Wages

Senate Bill (S.B.) 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.[14] The recommendations below continue to strengthen transition to a more meaningful integrated day for persons with disabilities, including youth transitioning to adult services.

Recommendations

Innovations for Meaningful Day Activities:

1. **Support community integration through adequate funding and by permitting the flexible use of funds at adequate rates within the cost cap.**
   - Individuals should have the flexibility to use CFC in the implementation of their person-centered plan to ensure a meaningful day, including successful community participation, volunteering and/or supported employment, and employment assistance as part of the benefit. CPC recommends adding these services as part of CFC. CFC is not available to individuals who receive HCS residential services, so adequate funding and flexibility in the program is needed to ensure sufficient, high quality staff to support the individual.
   - Community inclusion requires waiver structure flexibility. CPC recommends HHSC **develop and promote self-direction and pooling of day services dollars and attendant service dollars** to participate in shared interests in the community for up to three or four individuals to provide staff and transportation. Provide access to

[14] APSE Statement on Employment First. Association of People Supporting Employment First. http://www.apse.org/wp-content/uploads/2014/04/APSE-Employment-First-Statement.pdf

transportation services in all waivers to support community participation, including individuals receiving residential services during times residential services are not provided. Waiver participants should be permitted to:

i. Self-direct the funds currently used to pay for day habilitation programming and redirect those funds to purchase supports for individualized activities, and
ii. Pool funding for services on their plans of care, like day habilitation funds and attendant/CFC, with that of other waiver participants.

- **Provide incentives for reallocation of resources and creative models** that improve access to the greater community during weekdays, evenings, and weekends. Staffing and a transportation plan will likely be needed.
- Developing new or maintaining relationships and friendships should be supported within a model to promote community integration.

Promote Employment Services

2. **Support competitive integrated employment through education on work incentives.**
   - **Support competitive, integrated employment** by developing and/or expanding existing educational campaigns and other initiatives to not only increase awareness of work incentives and provide accurate information, but to also assist with applying for and implementing work incentives that allow individuals who receive SSI to exclude money, resources, and certain expenses from total earned income.
   - **Focus on training and providing resources** for LIDDAs, MCOs, and IDD providers, including how to collaborate with local businesses and training about vocational rehabilitative (VR) services, such as Ticket to Work and other support services that can be accessed through any participating employment network or state VR services so that the LIDDAs and providers can better assist individuals and their families and supporters to pursue person centered, competitive, integrated employment goals.
3. **Increase supported employment and employment assistance utilization.**
   - **Increase availability, accountability, and utilization of Medicaid waiver supported employment and employment assistant services.** Better define expectations and implement systemic reporting so that statewide progress toward successful employment benchmarks based on the employment goals can be recognized.

Continued increase in competitive supported employment utilization for persons with IDD should be the goal. Create a centralized location people can go to for employment related resources. Continue to expand and enhance local employer recruitment training efforts.

4. **Increase the flexibility of employment services.**
   - **Provide choice regarding competitively paid, integrated community employment** (full or part time) that promotes self-sufficiency and non-paid volunteer work that will lead to employment that allows meaningful contribution to the needs of one's community based on an individual's interests and preferences.
   - **Allow for flexible, individualized scheduling** of preferred employment, employment exploration, and volunteer activities with supports, including staff, tailored to the person's individual needs. These services should be available during the weekday, evening, and weekends and also for individuals receiving residential services.
5. **Ensure sufficient supported employment rates and incentives to promote meaningful opportunities for work**.
   - **Establish consistent rates**, contracting structures, and performance measures with a clear intent of obtaining and maintaining competitive, integrated employment.
   - Establish a rate structure that would provide a higher reimbursement rate for those with a greater level of need and/or supports.
   - Incentivize day habilitation providers, community rehabilitation providers, and other interested programs/parties providing services in segregated work settings to **reallocate resources to competitive, integrated employment.**

Brandon at KOOP Radio

Brandon delivering mail at UT

Meaningful Work for a Meaningful Life

Brandon is a young adult who is working towards his goals for a meaningful life. Brandon works at The University of Texas at Austin and at a durable medical equipment company every afternoon. He sorts the mail, categorizes, places the mail in his mail carrier, and delivers the mail to nine floors. Brandon loves the interaction with each person as he delivers the mail. He is learning how to engage with his peers and learning the value of work. He is so happy when he receives his check for a job well done. Brandon also volunteers at the KOOP Radio show "Off the Beatles Path" where he selects Beatles songs for the weekly show. Brandon loves the Beatles. Part of his person centered plan includes being involved in music activities focused on the Beatles. Brandon rarely misses a week on this show.

Background

While the overall unemployment rate continues to decrease to its lowest level in many years, the rate for people with disabilities remains unacceptably high at both the state and national levels. As of 2015, the unemployment rate, a statistic that includes only individuals who are working or actively seeking work, stood at 10.7 percent for people with a disability, compared to 5.1 percent for other people in the workforce or seeking work.[15] In 2015, only 17.5 percent of persons with a disability were employed as reported by

[15] "People with Disabilities: A Texas Profile." Texas Workforce Investment Council, June 2016.

the U.S. Bureau of Labor Statistics.[16] In contrast, the employment-population ratio for those without a disability was 65 percent.[17]

Reform Sheltered Workshops and Day Habilitation while Transitioning to a Meaningful Integrated Day

As children with disabilities grow up and transition to adulthood, many struggle to find activities during the day that fulfill their need to contribute and be connected with the community. A shift is needed to transition the current LTSS system from one predicated on segregated group day habilitation and sheltered workshops to one that includes meaningful day activities that are individualized, inclusive, and community based.

Policy Issue: People Need to Have Choices about How to Spend Their Day

Many families depend on day habilitation or sheltered workshops for their young adults to provide supervised activities during work hours. Moreover, many people think they are required to attend day habilitation during the day because the current planning process does not support people with disabilities to access community services, volunteer, or acquire meaningful employment and job exploration. A system that includes day habilitation, pre-vocational services, employment assistance and supported employment, and CFC should both provide for health and safety and accommodate individualized choices regarding how people with IDD spend their day.

[16] "Persons with a Disability: Labor Force Characteristics Summary." Bureau of Labor Statistics, 2016, http://www.bls.gov/news.release/disabl.nr0.htm
[17] Ibid.

Creating a Meaningful Day Pt. I

Lathom, at the age of 20, was accepted into a work-study program during his last two years of high school to help prepare him for employment related services after he graduated. He successfully worked at The Hampton (folding towels, baking cookies, and vacuuming), Goodwill (putting clothes on hangers and hanging in correct order), Austin Food Bank (putting food items into bags), and a church (setting out chairs and then folding them up and putting away) with some support. However, he did not receive the necessary assistance to seek any kind of employment or supported employment after leaving high school even though a DARS representative had visited his program throughout the school year and had assisted one or two other students in securing employment. When the program was notified that Lathom would be moving to Houston, no information or contact person was provided to assist Lathom with employment opportunities. Once he was moved to the Houston area, the parent asked for employment assistance through the group home provider but was told they did not think he was employable and placed him in a day (habilitation) program instead.

Recommendations to the HHS System:

Minimum Standards – these minimum standards are recommended to be implemented for a more individualized, integrated, and meaningful day activity system. Effective September 28, 2016, HHSC adopted new rules for locations that provide day habilitation services (in HCS, TxHmL, and DBMD) and prevocational services (in CLASS), that do not address the following CPC recommendations. CPC believes that strong oversight and reporting is needed to assure persons with IDD are receiving those services in locations that are safe.

1. **Improve reporting, contract oversight, and monitoring of day habilitation, pre-vocational services, and sheltered workshops to assure safety.**
   - Require DFPS and HHSC/DADS to **track data on abuse, neglect, and exploitation** in facilities providing day habilitation or prevocational services and sheltered workshops.
   - Require HHSC to **compile and make public basic information and data** on locations providing day habilitation or prevocational services to persons in ICF/IID or HCS, TxHmL, CLASS, and DBMD, including data on violations and deficiencies found during a survey. Data

recommended to be collected includes staff participant ratio, weekly schedule of activities, information on community outings including frequency that participants attend them, and frequency and content of staff development provided.

2. **Disclose to waiver participants that day habilitation and prevocational services are a choice and are not mandatory**. Require the service planning team to inform waiver participants that they **may choose or decline to include day habilitation or prevocational services on their individual plans of care**. The service planning team must inform the waiver participants of other opportunities such as **supported employment** and **employment assistance**.
3. **Transition from subminimum wage work in sheltered workshops and other settings for Medicaid waiver participants.**
   - Require service planning teams to identify program participants working in 14(c) settings. Create a transition plan to **move away from individuals participating in facility based segregated work environments that pay subminimum wage**.
   - Create initiatives for employment assistance providers/counselors/specialists to be present in segregated work settings to establish ongoing relationships with the employees and assist them in an appropriate discovery and planning process to **transition to competitive, integrated employment**.
   - Require case managers and service coordinators to address employment goals at least annually for all individuals receiving services from a Medicaid waiver program.

Background

Currently, individuals with IDD receiving day habilitation or prevocational services do not have full access to the greater community through their waiver program. Individuals, regardless of where they live, who receive day habilitation services get the services primarily in facility settings with no or limited access to the community during day habilitation hours. CFC provides some flexibility to meet individualized goals for individuals living in their own or their family's home. CFC is not available to individuals receiving HCS residential services. The current planning process does not support people with disabilities to access community services, volunteer, or acquire meaningful employment and job exploration. The CPC feels strongly that young adults with disabilities need the flexibility to use CFC to allow for success in the community.

Families are concerned that day habilitation programs charge different providers and individuals different rates in an effort to "cream" or "cherry pick" the easiest to serve individuals. It might make services less individualized for those with low service needs. It might make it more difficult to find services for those with a high level of need (LON). However, without a direct relationship between the state and the day habilitation providers, HHSC could not dictate a private company's fee structure. HHSC/DADS could prohibit providers from supplementing the state rate, but it would not limit a day habilitation's right not to do business with all providers in the service area.

Day habilitation is a service. The comprehensive service provider is required to implement the plan by securing waiver services included in the individual plan of care. Although a comprehensive provider is only required to contract with other providers willing to take the state rate, and there may be a shortage of day habilitation providers in a given area, the comprehensive provider is required to make an effort. Providers who fail to make an effort should be held accountable.

Despite the availability of Social Security Administration (SSA) initiatives, work incentives, and the Ticket to Work program, these employment services remain underutilized nationally and in Texas, particularly for individuals with IDD. Texas Medicaid waiver services of employment assistance and supported employment are grossly underutilized, 0.43 percent and 1.24 percent respectively.[18]

Service plan implementation lacks flexibility to support individual choices related to competitive, integrated employment and volunteer and community exploration related to community jobs, in part due to the lack of providers of employment assistance and supported employment and transportation limitations.

The Texas Employment First policy established by S.B. 1226 addresses this need for competitive, integrated employment for all Texans with disabilities. It is yet to be implemented.

Individuals with IDD, compared to individuals with other disabilities and individuals without disabilities, experience a higher rate of unemployment. Many people with IDD who do work often do so in segregated settings and are paid subminimum wages. These individuals with IDD would benefit from

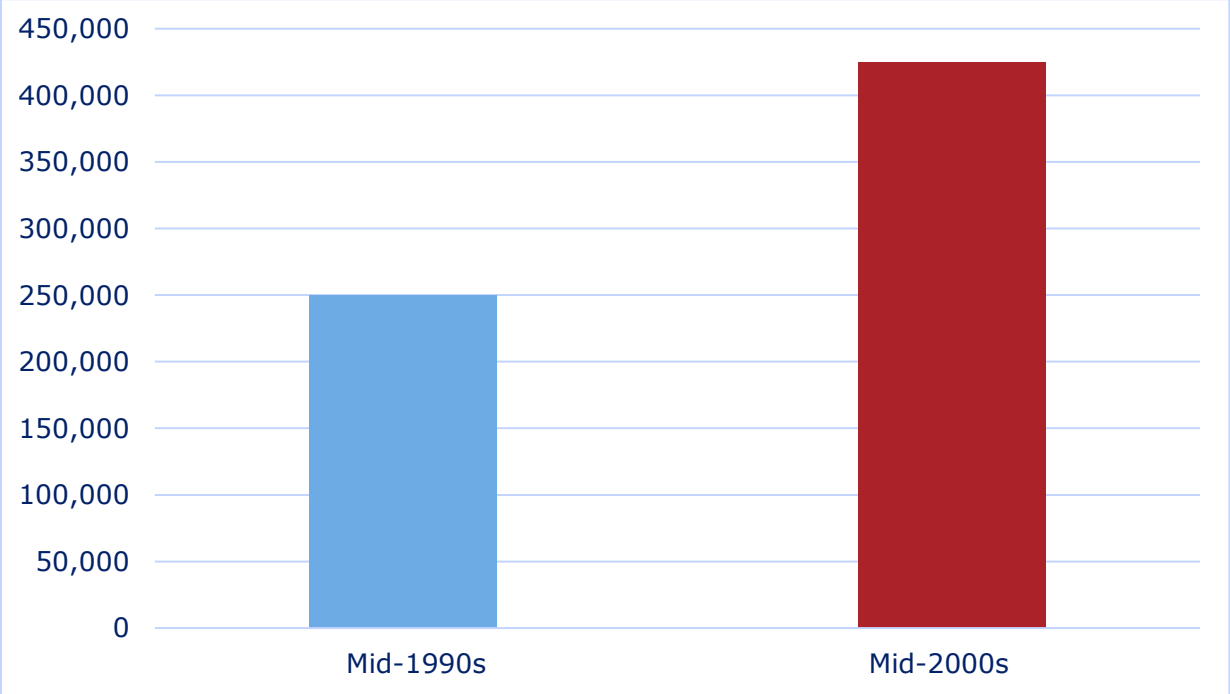
[18] "Transition and WIOA." Texas Council for Developmental Disabilities, http://www.tcdd.texas.gov/wp-content/uploads/2016/04/Cncl_Meeting_Binder_May16_tab13.pdf

increased access to employment assistance and supported employment services. Although these services are offered, there currently is a serious lack of providers.

Subminimum Wage

Based on April 2015 data from the U.S. Department of Labor's (DOL) Wage and Hour Division (WHD), there are approximately 109 subminimum wage certificate holders in Texas.[19] Ninety percent of these entities are Community Rehabilitation Programs (CRPs), which are work centers (also referred to as sheltered workshops) that specialize in the employment of workers with disabilities and may also provide rehabilitation.

Figure 1: Growth of Number of People in Sheltered Workshops after the Passage of the ADA in 1990



Source: "Living on a Dime and Left Behind." Disability Rights Texas, July 12, 2016, p. 8.

Nearly 10,000 individuals in Texas sheltered workshops are paid subminimum wages according to the latest DOL figures.[20] Two-thirds of these 14(c) organizations in Texas do not pay minimum wage or above to a single one of their employees. Moreover, 44 of the 76 organizations reporting wage information pay 50 cents or less per hour. Even more troubling, according to

[19] Section 14(c) of the Fair Labor Standards Act authorizes certified employers to pay wages less than the Federal minimum wage to workers who have disabilities.
[20] "Wage and Hour Division." *U.S. Department of Labor*, https://www.dol.gov/whd/specialemployment/

14(c) application documents, 18 of the 72 reporting organizations admit that they also serve as the representative payee agency for their workers (a representative payee is an organization or individual appointed to receive Social Security benefits for an individual).

Creating a Meaningful Day Pt. II

Sam is a talkative young man who has been working at a sheltered workshop for 11 years. He wants "to get out of here" and "move on" to something better. He says he has tried to "escape" the workshop but has been unsuccessful. His workshop is in a rural area, miles from accessible transportation options or community services. He says that the job skills he has learned at the workshop are "hanging out with friends and chilling." He had no trouble recounting that he gets paid $179 for 30 hours of work, but is only "allowed" to receive $25 and doesn't know why. He would love to work at a gift shop, but can't get out.

Texas law supports 14(c) organizations by requiring state agencies to purchase the products and services produced by workers being paid subminimum wage. Under Texas law, state agencies are exempt from competitive bidding requirements when purchasing products and services from persons with disabilities and must report all exceptions.[21] The Texas Workforce Commission manages these "state use" contracts that implement this Texas law.[22]

Unfortunately, the state of Texas gives some of these "state use" contracts to entities paying subminimum wages. Twelve entities in Texas with state use contracts hold 14(c) certificates to pay subminimum wages. A review of the data reveals that some of these entities pay as little as three cents per hour, while the employing organizations' leadership is making six-figure annual salaries. State agencies and local governments are using Texas taxpayer money to pay these contracting organizations for the services provided by individuals with disabilities. The State Use contracts paying subminimum wages totaled over $5 million.

[21] Tex. Gov't Code §2155.138.

[22] Oversight of "state use" contracts was transferred to TWC under S.B. 212, 84th Legislature, Regular Session, 2015. Previously, that function was performed by the Texas Council on Purchasing from People with Disabilities (now abolished). TWC established the Purchasing from People with Disabilities Advisory Committee to assist in establishing performance goals for the Purchasing from People with Disabilities program.

Creating a Meaningful Day Pt. III

Julie is an articulate young woman who has been working at her current sheltered workshop for two years. She graduated from high school and went to work in the fast food industry. She says that she used to earn about $300 every two weeks at the fast food restaurant. But since her guardian moved her to the sheltered workshop, she receives $30 every two weeks. She wants to earn more but feels like she is trapped. At one point she had a DARS counselor, but he told her that he couldn't help her. She dreams of leaving the workshop and working with animals in the community.

Support the Recommendation Made by the Sunset Advisory Commission Staff to Close Six State Supported Living Centers

The CPC strongly recommends an immediate moratorium on the placement of children into any SSLC and agrees with the recommendation made by Sunset Advisory Commission staff to close six SSLCs.[23]

Although the service delivery system for people with IDD has largely shifted to community settings, Texas maintains a system of large state-run institutions for people with IDD, including children. Since the 1960s, service delivery for people with IDD has evolved from an institutional model to a community model. In 1999, the U.S. Supreme Court issued the Olmstead decision which required, through the Americans with Disabilities Act, people with IDD to be served in the most integrated setting appropriate and required states to provide community-based options. While Texas closed two institutions in 1995, since the Olmstead decision in 1999, Texas has downsized but not closed any of its remaining institutions. Texas has been under increased scrutiny due to continual violations and harm to residents of the large state-run institutions. As a result, the CPC continues to strongly recommend that Texas close the Austin SSLC by August 31, 2019, and close five other centers by August 31, 2024. Each person in these large state-run institutions should be eligible to transition to the least restrictive environment.

[23] "Sunset Advisory Commission Staff Report with Final Results." Department of Aging and Disability Services, 2015.

6. Conclusion

One thing that unites all families is a desire to witness their children grow, gain independence, and be integrated into the life of the community. Children with disabilities and their families work hard every day to achieve these goals, and there are many stories of success that encourage others to keep going. The reality though is that for many children with disabilities, individual effort is not enough. They need the support of their communities and that of the institutions governed by the state. Texas can do more for children with disabilities by:

- Keeping children out of nursing homes when medically necessary treatments can be provided in their own homes;
- Ensuring schools provide safe learning environments and support for children with mental health needs;
- Giving children with autism spectrum disorders access to treatment;
- Helping children with disabilities in foster care live with families and making sure they are supported as they transition into adulthood;
- Creating and expanding opportunities for children with disabilities to have meaningful experiences through employment, volunteering, and skill development as they mature into adulthood; and
- Transitioning residents of six SSLCs to the community.

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

List of Acronyms

Acronym	Full Name
ABA	Applied Behavior Analysis
ADA	Americans with Disabilities Act
ADL	Activities of Daily Living
ASD	Autism Spectrum Disorder
BCBA	Bi-level Positive Airway Pressure
BiPAP	Board Certified Behavior Analyst
CCP	Texas Health Steps Comprehensive Care Program
CDC	Centers for Disease Control and Prevention
CFC	Community First Choice
CHIP	Children's Health Insurance Program
CLASS	Community Living Assistance and Support Services
CMCS	Center for Medicaid and CHIP Services
CMS	Centers for Medicare and Medicaid Services
CPAP	Continuous Positive Airway Pressure
CPC	Children's Policy Council
CPS	Child Protective Services
CRP	Community Rehabilitation Program
DADS	Texas Department of Aging and Disability Services
DARS	Texas Department of Assistive and Rehabilitative Services
DBMD	Deaf Blind with Multiple Disabilities
DFPS	Texas Department of Family and Protective Services
DOE	United States Department of Education
DOL	United States Department of Labor
DSHS	Texas Department of State Health Services
GRO	General Residential Operations
ESC	Education Service Centers
HCBS	Home and Community Based Services (a general term)
HCS	Home and Community-based Services (a specific program)

Acronym	Full Name
HHSC	Health and Human Services Commission
HMA	Health Maintenance Activities
IADLs	Instrumental Activities of Daily Living
ICF	Intermediate Care Facilities
IDD	Intellectual and Developmental Disability
IID	Individuals with Intellectual Disabilities
LIDDA	Local Intellectual and Developmental Disability Authority
LON	Level of Need
LTSS	Long-Term Services and Supports
MCO	Managed Care Organization
MDCP	Medically Dependent Children Program
OSEP	Office of Special Education Programs
PAL	Preparation for Adult Living
PBIS	Positive Behavior Interventions and Support
PCS	Personal Care Services
PDN	Private Duty Nursing
RTC	Residential Treatment Center
SEL	Social and Emotional Learning
SSA	Social Security Administration
SSI	Supplemental Security Income (Social Security)
SSLC	State Supported Living Center
TEA	Texas Education Agency
TJJD	Texas Juvenile Justice Department
TMPPM	Texas Medicaid Policy and Procedures Manual
TWC	Texas Workforce Commission
TxHmL	Texas Home Living
UAP	Unlicensed Assistive Personnel
VR	Vocational Rehabilitation

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