Texas Children's Policy Council

Recommendations for Improving Services for Texas Children with Disabilities

Statutorily Required by H.B. 1478, 77th Legislature of the State of Texas

Submitted to the Texas Legislature

&

Executive Commissioner of the Texas Health and Human Services Commission

September 2014

http://www.hhsc.state.tx.us/si/cpc/index.shtml

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September 1, 2014

To the Texas Legislature and Executive Commissioner Kyle Janek, M.D., HHSC

The Children's Policy Council respectfully submits its legislative report, *Recommendations for Improving Services for Children with Disabilities in Texas, 2014*, as required by House Bill (H.B.) 1478, 77th Texas Legislature, 2001.

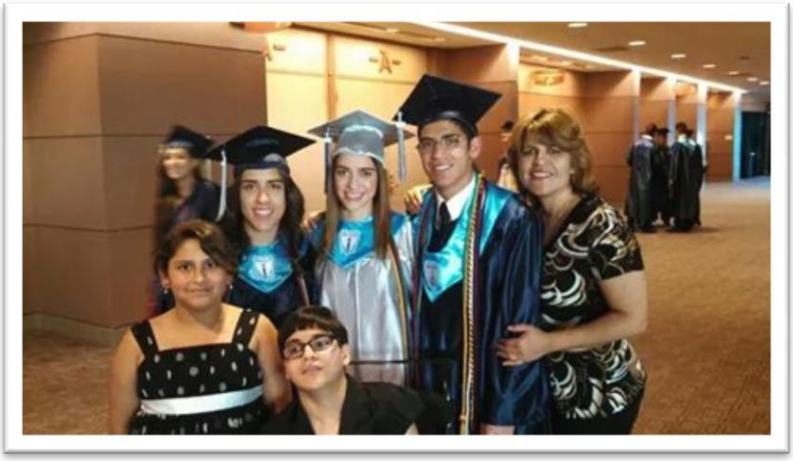
Legislation passed this last session will significantly affect how services are delivered to children with disabilities in Texas, and how the Children's Policy Council (CPC) operates. Senate Bill 7 moves the provision of services for children to managed care. HHSC is consulting with the CPC in the development and implementation of STAR Kids. Senate Bill 50 added mental health to the CPC's charge, which will change the make-up of the committee and add to the thoroughness of our charge to provide for Texas children.

The Council appreciates efforts of the Texas Legislature and the Health and Human Services Commission and HHS agencies to improve the lives of children with disabilities and their families. We especially appreciate the opportunities to collaborate with HSSC these past two years on issues surrounding long term services and support, acute care, durable medical equipment, and implementation of STAR Kids.

The recommendations found in this report focus on the areas of transition, mental health and STAR Kids, as well as emerging issues that the CPC thinks will significantly impact the lives of children with disabilities, their families and communities in the state of Texas. The Council respectfully requests your serious consideration of and support for the recommendations included in this report.

Respectfully,

Denise Sonleitner
Chair, Children's Policy Council



A 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 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
Denise Sonleitner, Chair, Family Member
Karen Yeaman, Vice Chair, Family Member
Brianna Stiglets, Secretary, Business Community Member
Michelle Bartlett, Family Member
David Evans, Funding Expert Member
Kristen Fleming, Family Member
Michelle Jenkins, Family Member
Mary Klentzman, Faith-based Member
Greg Mazick, Private Service Member
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Leah Rummel, Family Member
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Ivy Goldstein, Department of State Health Services
Jessica Ramos, Texas Council for Developmental Disabilities

Ex-Officio Members
Carl Tapia, M.D., Texas Pediatric Society, Physician Member, Texas Children's Hospital
Angelo Giardino, M.D., Texas Pediatric Society, Physician Member, Texas Children's Hospital

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.

Background

Since its creation in 2001, the Children's Policy Council 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 area 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

Goals

The Children's Policy Council (CPC) meets regularly to identify barriers, gather data, analyze available information, discuss options, and develop recommendations. In addition to the CPC's biennial legislative report, we meet gather information through several means:

1. Communication with family members and family support organizations around the state.
2. Individual member service on local and state task forces and councils. CPC members presently serve on the following groups:
    - STAR Kids Managed Care Advisory Committee
    - Managed Care Advisory Council
    - STAR+PLUS Quality Council
    - IDD Advisory Council
    - Promoting Independence Advisory Council
    - Texas Respite Coalition
    - Early Childhood Intervention Advisory Committee
    - Family Voice/Texas System of Care
    - Hogg Foundation Work Group on Seclusions and Restraints
3. Regular attendance of stakeholder meetings:
    - ADRC Council

- Task Force for Children with Special Needs

4. Presentations and collaborations with HHSC enterprise leaders and staff:
   - Presentation to HHSC staff on Long-term services and supports (May 2012)
   - Presentation to HHSC staff on Acute care (August 2012)
   - White Paper on statewide Dental
   - White Paper on Pharmacy Benefits
   - DME Discussion Group (October 2012 to present)
   - CPC STAR Kids WG (October 2013 to present)
5. Individual member testimony at public hearings.
6. Legislative briefings and information presentations on issues related to raising a child who has a disability:

- Legislative Educational session-Legislative Conference Center (October 2012)
- Raising a Children with a Disability 101-Capitol Cafeteria (January 2013)

7. Addressing emerging issues facing children with disabilities and their families.

Acknowledgements

CPC is focusing on making sure that family voices throughout the state are heard and represented in CPC activities and in our legislative report. We support and applaud the work of the Task Force on Children with Special Needs in the development of the website.

Children's Policy Council members would also like to express our thanks and gratitude to Terry Beattie and Cassandra Marx, HHSC Office of Program Coordination for Children and Youth for their years of support and service to the Children's Policy Council.

Finally, to our friend Larry Swift, who served for years as the HHSC agency representative on the Council. We valued and miss his wealth of knowledge.

Legislative Accomplishments in 2013

Since the submission of 2012 Children's Policy Council Recommendations, many items of legislation have been reviewed and passed that will impact the lives of Texas children with disabilities and special health care needs. A few notable accomplishments include:

Positive Behavior Support

- SB 831 *requiring DSHS and TEA to expand and post on their websites a list of best practices programs for early mental health promotion, intervention, substance abuse, and positive youth development*
- SB 460 *requiring training in mental health and positive behavior supports for educator training; training for school personnel in early warning signs of mental health concerns, suicide and bullying; and adds mental health concerns to school health advisory councils*
- SB 58 Behavioral health services, shall be integrated into the Medicaid managed care program

Mental Health Services

- The waiting lists for community mental health services was fully funded to provide mental health services for 286 children waiting and 6,242 adults on waiting lists
- HB 3793 *LMHAs will offer mental health "first aid" training to community members & educators at no cost*
- SB 50 *added mental health to the Children's Policy Council's charge*
- SB 44 requiring DFPS to being tracking the number of children whose parents voluntarily relinquish custody solely to obtain mental health services for their child; requires DFPS to offer joint conservatorship; and prevent parents from being identified as RAPRS (refusal to accept parental responsibility) and whose names are added to the abuse and neglect registry by DFPS
- SB 126 Local mental health authorities, managed care mental health and contractors for substance abuse services to establish and maintain a public reporting system of performance and outcome measures relating to mental health and substance abuse services

Education

- HB 642 *requiring teachers and principals to receive continuing education in specific areas including training on diverse populations including students with disabilities*
- HB 617 (Ricky's Bill) *requiring improved transition services for students with disabilities by requiring school districts to assign at least one employee to serve as the special education transition and employment services designee*

Medicaid/Healthcare

- SB 7 *requiring a comprehensive and sustainable program devised for Medicaid Acute Care and Long Term Support Services. The HHSC Executive Commissioner is charged with consulting with the CPC in the development of STAR Kids.*

Recommendation Summary of the Children's Policy Council

Children with disabilities need many supports to grow up to be successful citizens of the State of Texas. We have come a long way, yet there are still areas that need attention. Having recognized this, the Children's Policy Council (CPC) also recognizes the importance of identifying priorities for the 2015-2016 biennium. In 2014, the CPC has targeted the following priorities:

Mental health

In 2013, the legislature added mental health (MH) to the CPC's charge (S.B. 50, 2013). Since that time, the CPC has been focusing on learning about the issues facing families raising a child with a mental illness or serious emotional disturbance, reaching out to mental health groups around the state, and recruiting MH representatives to the council. In particular, the CPC acknowledges and supports the work of The System of Care Consortium on Family Voice Leadership network development and Family Partners network development.

STAR Kids

HHSC Executive Commissioner is charged with consulting with the CPC in the development of STAR Kids through Senate Bill 7 (SB 7, 2013). In October 2013, a CPC STAR Kids workgroup was formed and has met regularly, providing input and recommendations to HHSC and the STAR Kids Advisory Council.

A copy of the CPC's STAR Kids Work Group recommendations, submitted to HHSC in March, 2014 can be found at http://www.hhsc.state.tx.us/medicaid/managed-care/mmc/Council-Recommendations.pdf. The work group was invited to present its recommendations to the STAR Kids Advisory Committee at its meeting on June 2, 2014.

The development and implementation of STAR Kids must be done with ongoing input from families and must allow children to receive the services they need to thrive in their communities

Transition:

A consequence of a council comprised largely of parents who have children aging out of the school system is a keen awareness and insight by the CPC of the barriers to a seamless

transition to adulthood. We present recommendations in the areas of health care transition, employment, housing, and guardianship.

In conjunction with CPC's focus on Transition in its legislative recommendations, the Council is very excited about the addition of two youth members on the CPC. These members have a very personal perspective on what transition means to a young person approaching adulthood.

Critical Issues

The CPC identified two issues that threaten the health and safety of some children with complex medical support needs and require immediate action by the Health and Human Services Commission (HHSC) and/or the Texas Legislature:

- The dramatic increase in Medically Dependent Children's Program (MDCP) waiver eligibility denials for children who have been on the program for many years
- Baclofen Pumps

Emerging Issues

While the CPC did identify and focus on the preceding priorities for its work this biennium, it also worked on issues that arose that it felt required consideration that might rise to that level for a priority if not addressed. Over the last couple of years, the CPC has been following and providing input on emerging issues that affect children with disabilities in Texas, such as:

- Prescribed Pediatric Extended Care Centers (PPECC)
- Durable Medical Equipment (DME) denials
- Aging and Disability Resource Centers (ADRC)
- Cannabidiol for children with severe seizures and autism

CPC is focusing on making sure that family voices throughout the state are heard and represented in CPC activities and in our legislative report.

Mental Health

Mental health refers to how people think, feel, and act as they cope with life's situations. It affects how people handle stress, relate to one another, and make decisions and whether they are able to do so successfully. Like adults, children and youth (birth to age 22) can have mental health disorders that affect their behavior and interfere with the way they think and act.

On May 17, 2013, in its Morbidity and Mortality Weekly Report (MMWR), the Centers for Disease Control and Prevention (CDC), issued Mental Health Surveillance Among Children – United States, 2005-2011, in which it concludes: "mental disorders among children are an important public health issue because of their prevalence, early onset, and impact on the child, family, and community."

Mental health is important to overall health. Mental disorders are chronic health conditions that can continue through the lifespan. Without early diagnosis and treatment, children with mental disorders can have problems at home, in school, and in forming friendships. This can also interfere with their healthy development, and these problems can continue into adulthood.

Based on the National Research Council and Institute of Medicine report (Preventing mental, emotional, and behavioral disorders among young people: progress and possibilities, 2009) that gathered findings from previous studies, it is estimated that 13 to 20 percent of children living in the United States (up to 1 out of 5 children) experience a mental disorder in a given year and an estimated $247 billion is spent each year on childhood mental disorders.

In Texas, two out of three child care providers surveyed report caring for children with a behavioral or emotional difficulty. Among Texas children with diagnosed mental illness, severe emotional disturbance, or at risk of being removed from their homes or classrooms for mental health reasons, only 18% receive the mental health treatment for which they qualify. In 2007, there were an estimated 685,569 children with a mental illness in Texas.[1]

Mental Health

Policy Issue: Access and Barriers to Mental Health Services

Many children receive mental health services through the Medicaid program, but families must meet the income requirements or the child must be on a home and community-based waiver. However, low reimbursement for Medicaid services remain a substantial barrier to receiving services. If a child is not on Medicaid, non-traditional supports such as respite and family support programs are not available. For children with serious emotional disturbances, the Youth Empowerment Waiver (YES) has demonstrated significant improvements in emotional and behavioral health, as well as better functioning and less danger to self and others. The YES Waiver provides wrap around services, living and family supports, and useful therapies such as music, art, and recreational therapy.[2] However, the YES wavier is only available in 3 counties.

Access to behavioral supports is a critical failing of our system. We need to help families and providers to understand that optimal development depends on a stimulating environment with predictable and caring caregivers. Serious, emotionally charged early life experiences will certainly lead to developmental and behavior problems. There is almost no place that offers appropriate therapies (parent child interactive therapy, child parent psychotherapy, cognitive behavioral therapy, and attachment and self-regulation therapy). [3] Novel programs, like the Dallas School-based Youth and Family Services, provide culturally competent mental health treatment to children and their families, resulting in better attendance, fewer discipline problems, and more success in schools.[4]

Lack of transportation compounds the difficulty for children with behavioral and mental health disorders to receive services. One psychiatrist in Beaumont shared that his Medicaid patients had a 50% no show rate, which he attributed to difficulty with transportation. A recent analysis of the YES Waiver demonstrated that few families are able to take advantage of transportation options, even when a covered benefit. [2]

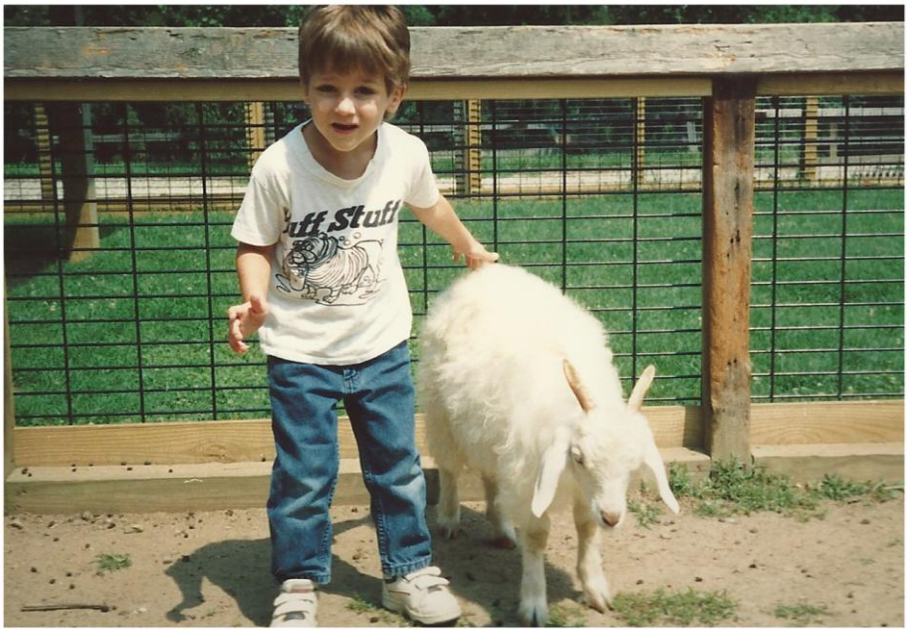
Recommendations

1. Provide a transparent evaluation process, so that families and stakeholders can easily understand the priority issues and statewide and regional progress

2. Support expansion of the YES Waiver. The success of the Waiver will hinge on streamlined eligibility and support to communities to develop collaborative mental health networks
3. Support access to therapies that focus on parent-child interaction
4. Analyze the existing transportation system for opportunities to improve ease and access for families

Background

46% of children have a lifetime prevalence of any mental health disorder, and 21% of children have a lifetime prevalence of a severe disorder.[5] Only half of children with mental health disorders receive any treatment.[6] In Texas, only 1 in 3 children who qualify for services receive them.[7] Despite the large need for services, over half of Texas counties are designated as a Health Professional Shortage Area for mental health. A recent analysis suggested that Texas has less than half of the required number of child and adolescent psychiatrists to meet the mental health needs of children.[8]



Mental Health

Policy Issue: Integrating Mental Health with Primary Care

There have been no widespread efforts to integrate primary care and mental health care in Texas.[9] Access to mental health services typically depends on a diagnosis. However, there is great overlap in childhood mental health disorders; the rate of developmental progress in childhood makes it complex to characterize symptoms and children often have more than one co-occurring disorder. Many experts feel that "symptoms" are more relevant in treating mental health disorders than diagnostic labels.[10] Given the high prevalence of mental health disorders in children, necessity of pediatric expertise to evaluate symptoms that contribute to functional impairment, with a system already built around the "primary care provider," projects have focused on integrating mental health with primary care services.[11 & 12] Such integration has been associated with improved outcomes, such as reduced readmission rates, better preventive care, and lower costs.[13]

Medications, such as psychotropic medications, are the last choice many families want to make. However, for many children with serious emotional disturbances, psychotropic medication use is a critical part of therapy.[11] Recent changes to the state formulary for psychotropic medications places unequal burden on children and restricts access to beneficial, necessary treatments. The American Academy of Child & Adolescent Psychiatry discusses that use of medications in children is often "off label" due to Food and Drug Administration requirements, but that professional societies provide strong support and quality standards to allow families and their providers to make the best choice according to the individual needs and circumstances of the family. Adding barriers such as "hard edits" and requirement for prior authorizations restricts access to necessary medications often promote cost over safety and quality.[14]

Recommendations

1. Encourage flexibility in accessing mental health services based on symptoms and functioning, rather than a diagnosis
2. Support funding for programs and learning collaboratives that integrate mental health into primary care
3. Reduce barriers to necessary psychotropic medications for children and adolescents

Mental Health

Policy Issue: Fragmentation

The 83rd Legislature made a large investment in the behavioral health system. However, given the fragmentation and complexity of the behavioral health system in Texas, much more work is needed.[15] In contrast to other health services (where public and private funding is roughly equal), the majority of behavioral health funding is through the Medicaid program. In general, the capacity to deliver mental health services is shrinking, such that emergency rooms and hospitals account for a growing share of behavioral health treatment.[13] In fact, 70% of emergency rooms report boarding patients with psychiatric conditions for days, sometimes weeks.[15] For children, this is often due to a lack of inpatient facilities, particularly "med psych" units that can serve both medical and behavioral needs. It should be noted that children with serious emotional disturbance are only 2-5% of Texas youth with behavioral health needs, but account for 60% of utilization.[16]

A recent report documented that Texas children receive mental health services from multiple, uncoordinated agencies. The majority of funding is spent on medications and hospital services.[16] Local solutions, with options for flexible spending to meet service needs, have proven effective in Texas, but widespread expansion has been limited by lack of state funding and fragmentation of local mental health authorities from other health systems.[16]

Recommendations

1. Support programs for screening and coordination services for mental health and substance abuse in emergency rooms and hospitals
2. Evaluate the issue of "boarding" children in emergency rooms and assess the capacity of inpatient programs for children
3. Develop a statewide, cross-agency infrastructure to identify and address barriers to mental health care and provide technical assistance to local programs to expand evidence-based and collaborative practices
4. Increase state support to local agencies that serve children with comprehensive, flexible services. In regions where these agencies don't exist, support funding for demonstration projects to develop local capacity and leadership

Access

1 Final Report: Children's Mental Health Services, Children's Task Force, Austin Travis County Integral Care, 2013. Accessed at http://www.cdc.gov/mentalhealth/basics.htm

2 University of Texas, Texas Institute for Excellence in Mental Health. Youth Empowerment Services Program Evaluation. January 2013. Accessed at http://www.dshs.state.tx.us/mhsa/yes/

3 American Academy of Pediatrics. Helping foster and adoptive families cope with trauma. 2013. Accessed at http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/healthy-foster-care-america/Documents/Guide.pdf

4 National Alliance on Mental Illness. Model program: A culturally competent school-based mental health program. Accessed at http://www.nami.org/Content/NavigationMenu/Inform_Yourself/About_Public_Policy/New_Freedom_Commission/Dallas_School-based_Youth_and_Family_Centers.htm

5 National Institute of Mental Health. Any disorder among children. Accessed at http://www.nimh.nih.gov/Statistics/1ANYDIS_CHILD.shtml

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7 Texans Care for Children. Make meeting children's unique needs a priority in planning. Accessed at http://texanscareforchildren.org/Images/Interior/reports/20-mh5-uniqueneeds.pdf

8 Hogg Foundation for Mental Health. Crisis point: Mental health workforce shortages in Texas. March 2011. Accessed at http://www.hogg.utexas.edu/uploads/documents/Mental_Health_Crisis_final_032111.pdf

Integrating mental health with primary care

9 Public Consulting Group. Analysis of the Texas Public Behavioral Health System: Recommendations for System Redesign. Accessed at http://www.publicconsultinggroup.com/client/txdshs/documents/Analysis%20of%20the%20Texas%20Public%20Behavioral%20Health%20System_Recommendations%20for%20System%20Redesign.pdf

10 Saginaw County Community Mental Health Authority. A guide to evidence-based mental health practices for children, adolescents, and their families. Sept 2006. Accessed at https://www.sccmha.org/quality/A%20Guide%20to%20Evidence-Based%20Mental%20Health%20Practices%20for%20Children%20Adolescents%20and%20their%20Families.pdf

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12 Hogg Foundation for Mental Health. An evaluation of the collaborative care model of integrated health care in Texas. Accessed at http://www.hogg.utexas.edu/uploads/documents/CollaborativeCareModel_EvaluationReport1.pdf

13 American Hospital Association. Bringing behavioral health into the care continuum: Opportunities to improve quality, costs, and outcomes. Jan 2012. Accessed at http://www.aha.org/research/reports/tw/12jan-tw-behavhealth.pdf

14 American Academy of Child & Adolescent Psychiatry. Pharmaceutical benefit management and the use of psychotropic medication for children and adolescent. January 2009. Accessed at http://www.aacap.org/aacap/Policy_Statements/2009/Pharmaceutical_Benefit_Management_and_the_Use_of_Psychotropic_Medication_for_Children_and_Adolescent.aspx

Fragmentation

15 Texas Hospital Association. Facing behavioral health issues in Texas: Problems and solutions. Accessed at http://www.tha.org/HealthCareProviders/Issues/BehavioralMentalHea096F/FacingBehavioralHea094D/index.asp

16 Texas Mental Health Transformation Working Group. Children's Coordinated Funding Committee Final Report. March 2011. Accessed at http://www.mhtransformation.org/documents/reports/CCF_FinalReport-508_April2011.pdf

STAR Kids

The STAR Kids subcommittee of the CPC developed a comprehensive set of comments and recommendations that were submitted to the Texas Health and Human Services Commission as the agency worked to develop the STAR Kids program and the subsequent Request for Proposals. A full copy of the comments can be found on the Texas Health and Human Services website:
http://www.hhsc.state.tx.us/medicaid/managed-care/mmc/Council-recommendations.pdf with a high level summary provided below.

Comprehensive service coordination enables children with special health care needs and chronic conditions to navigate through complex Medicaid managed care systems. Service coordination includes brokering of social support and medical services, breaking down barriers between systems of care, and doing whatever it takes to assist families to keep children healthy and safe at home.

1. All children in STAR Kids should receive service coordination
2. Families should have the ability to request a change of service coordinator when desired
3. There should be options for service coordination independent of the Managed Care Organization

A **standardized comprehensive pediatric assessment** should be utilized to assess a child for skilled and non-skilled services and should lead to the development of a comprehensive plan of care.

1. Assessment should be conducted by the provider that has the best knowledge of the needs of the child
2. Assessment must be comprehensive and person centered

Coordination of Private Insurance coverage and Medicaid Managed Care coverage is critical since a number of children might have both.

Access to an adequate provider network is critical for children with special health care needs.

1. Networks should include a full range of primary, specialty and ancillary pediatric providers, including mental health providers

2. Children must be allowed access to out-of-network providers at no additional cost due to their complex medical needs
3. Allow for use of mobile clinics and behavioral health intervention teams especially in rural parts of the state

STAR Kids must ensure that the Managed Care Organizations follow a **standardized prior authorization process** that is streamlined, transparent, has reasonable timeframes, and is not burdensome and complex to the extent that access to needed services are not impeded, delayed or arbitrarily delayed.

1. Prior authorization process should not vary from MCO to MCO
2. Access to medically necessary benefits should not be approved or denied based on chronological age, place of service, or other discriminating criteria

Early and ongoing **outreach and education** to families of children eligible for STAR Kids is critical to the success of the program.

1. Must begin a minimum of 6 months prior to the roll out preferably earlier
2. Must be conducted in the native language of the child and family
3. Written material must be clearly written and easy to read

Oversight and accountability of the STAR Kids program is important to families.

1. Create a committee of families whose children are served by STAR Kids to meet on a regular basis to discuss issues and concerns with the program
2. HHSC should provide a biannual report to CPC on status of STAR Kids and quality monitoring

STAR Kids

Policy Issue: Medically Dependent Children's Program (MDCP) Eligibility

As of June 30, 2014 there were 27,428 waiting for services on the interest list for the Medically Dependent Children's Program. Children and young adults have to wait between 5 and 6 years to receive services. With the implementation of STAR Kids in September of 2016, Texas has an opportunity to significantly decrease the MDCP waiting list and serve children and young adults who are at risk of institutionalization by allowing all children and young adults who receive SSI and meet waiver eligibility to automatically receive services with no wait. This is the same strategy that HHSC has employed since the inception of STAR+PLUS to reduce the legacy Community Based Alternatives waiting list.

Recommendation

Allow all SSI children and young adults under the age of 21 who meet the eligibility for MDCP to automatically receive waiver level of services in STAR Kids with no wait.

Background

STAR+PLUS began as a pilot in Harris County in 1998. Individuals with SSI who were on the CBA interest list and who met the waiver eligibility criteria automatically came off the interest list and started receiving services. This policy has received overwhelming support and continues today. The Health and Human Services Commission reported to the Texas Senate Health and Human Services Committee on August 14, 2014 that with the complete roll out of STAR+PLUS on September 1, 2014, an additional 2,645 individuals on the interest list for the Community Based Alternatives waiver will be removed from the interest list and immediately be assessed for services through the STAR+PLUS waiver.

Senate Bill 7 of the 83rd Texas Legislature legislatively mandated the development of STAR Kids, a managed care program for Texas children and young adults under the age of 21 who are SSI eligible or who are receiving services under a Texas home and community-based waiver. The legislation requires that children receive their MDCP waiver services under STAR Kids. The MDCP waiver provides a cost effective alternative to the institutionalization of children. The individual cost of services is capped at less than 50% of what is paid to a nursing facility.

Texas has determined that it is in the best interest of the state to provide STAR+PLUS waiver services with no wait to individuals over 21 who meet eligibility for nursing facility level of care and should do the same for children under the age of 21 in STAR Kids.

STAR Kids

Policy Issue: Skilled Nursing Services

Access to skilled nursing in the Medicaid program is not transparent and sometimes does not make sense. Many families are at-risk for caregiver exhaustion or inappropriate hospitalizations because they can't get appropriate skilled nursing support in the home. Certain medical criteria normally results in the approval for nursing care under Medicaid, such as a child having tracheostomy, but others are not so clear. Some examples of children not automatically covered include:

- Children who are not catheterized but have elimination difficulties
- Children with swallowing issues who do not necessarily have a feeding tube (G-tube)
- Children with uncontrolled seizures
- Children with frequent hospitalizations
- Children with noninvasive breathing support, such as Continuous Positive Airway Passage (CPAP) or Bi-level Positive Airway Pressure (BiPAP)

The approval of Medicaid funding for nursing whether provided under the Texas Medicaid State Plan or under a Medicaid Home and Community-based Services waiver is often based on the child's need for invasive mechanical interventions. The approval does not take into consideration the need for nursing to ensure the health of the child who is medically complex, but perhaps not dependent on invasive supports. For example:

- CLASS will pay for a nurse to administer tube feedings, catheterize, or suction. It will not pay for oral feedings for a child with swallowing issues, bladder massage or pulmonary hygiene
- In a hospital, mechanical interventions may be the most efficient or possibly the only option; however in the home setting this is often not the case

Skilled nurses are trained to provide the most appropriate, compassionate care, whether with or without machines. Not all children need mechanical interventions to survive.

Recommendation

Modify criteria used in Medicaid and in the waivers to allow access to nursing services based on the needs of the child, the stability of the child and the determination that without nursing the child will be a risk for further medical complications including death.

Background

In the Medicaid programs, children do not qualify for skilled nursing services related to services such as feedings, toileting, breathing, digestion, etc. unless their care involves mechanical intervention, such as tracheotomy, tube feedings or catheterization. Children also will not qualify for skilled nursing unless it is a life threatening immediate condition such as frequent seizures or having been hospitalized on a frequent basis. Many children receive assistance through non-mechanical means, such as liquid and pureed feedings, aggressive pulmonary hygiene, and bladder massage. These do not quality for skilled nursing services but both avenues are within the purview of what constitutes “skilled nursing.”

Luke, now 22 years old, was brain injured at birth. He is blind, functionally quadriplegic and severely cognitively impaired. 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. They 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 caregivers to provide Luke with “attendant” care, a service via the CLASS waiver program. As Luke has gotten older, it has become more difficult to hire, train and retain attendants. 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 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 22 years.

STAR Kids

Policy Issue: Patient Centered Medical Home

Many parents realize at some point that their child's complex health conditions are more than they can manage on their own. At times there could be many specialists involved with no one to coordinate them or oversee the big picture. Their child is receiving fragmented uncoordinated care. This also results in costs for services that may not be needed or may be duplicated. "For children with chronic diseases or disabling conditions, the lack of a complete record and a 'medical home' is a major deterrent to adequate health supervision."[1]

Secondary Policy Issue

The concept of Patient Centered Medical Home needs to be clearly defined for Texas families. The terms "medical home" and "health home" are confusing to patients, their families, and providers. In this recommendation, we will use the more common term of Patient Centered Medical Home. Family's input is critical as Texas, advocacy groups, and Managed Care Organizations further define and implement the concept. After we create a definition for Patient Centered Medical Home, we need to make it available to families across Texas.

Recommendations

1. Make a provision within STAR Kids that Managed Care Organizations (MCO) provide all children with disabilities, chronic illness and other special health care needs with a Patient Centered Medical Home. The Medical Home components should be based on information from the National Center for Medical Homehttp://www.medicalhomeinfo.org/
2. Create a common definition for Patient Centered Medical Home. Use materials created by the National Center for Medical Home (http://www.medicalhomeinfo.org/) and to assist in the definition and implementation, call on the expertise of medical home demonstration projects such as the Statewide Association for Regional Medical Home Advancement (a HRSA sponsored partnership between Texas Pediatric Society, Texas Title V, and Texas Parent to Parent) and the Texas Medical Home Initiative
3. Have the Managed Care Organizations create standardized training materials for families, physicians, and public health agencies and disseminate

Background

"The state of the art in "health care home" is of course linked to its particular time in history and development. Although there has been a flurry of interest and work around "medical home" recently, the concept has been around for at least 40 years. Sia et al (2004), in a history of the medical home concept, report the first documented use of the term "medical home" in Standards of Child Health Care, a book published by the American Academy of Pediatrics (AAP) in 1967 that emphasized having a central location for a child's pediatric records, and contains this quote:

"For children with chronic diseases or disabling conditions, the lack of a complete record and a 'medical home' is a major deterrent to adequate health supervision. Wherever the child is cared for, the question should be asked, 'Where is the child's medical home?' and any pertinent information should be transmitted to that place."

Since the 1970's, increasingly organized clinical and policy work aimed at reducing the fragmentation of care among independent providers in disparate locations has taken place—starting in pediatrics and then blending in similar efforts in family medicine and internal medicine. By March 2007, the American Academy of Family Physicians (AAFP), the American Academy of Pediatrics (AAP), the American College of Physicians (ACP), and the American Osteopathic Association (AOA) issued a joint statement of principles of the "Patient-Centered Medical Home", thus bringing these disciplines together on goals and principles."

Prepared by C.J. Peek, PhD, Associate Professor, University of Minnesota Medical School under the guidance of the Institute for Clinical Systems Improvement for the Minnesota Department of Health and the Minnesota Department of Human Services http://www.health.state.mn.us/healthreform/homes/background/icsireport.pdf

Current efforts in Texas include:

Texas Title V, Texas Pediatric Society, Texas Parent to Parent, and Texas Children's Health Plan received funding from the HRSA administration to create Statewide Association for Regional Medical Home AdvanCement (STARMHAC). STARMHAC is a statewide learning collaborative to plan for medical home advancement for children and youth with special health care needs (CYSHCN). STARMHAC recruits regional coalitions of providers, community

organizations, and families to support local initiatives for change and supports regional coalitions in quality improvement initiatives to increase access to a medical home for children with disabilities and special health care needs.

- DSHS CSHCN Medical Home Workgroup's mission is to enhance the development of Medical Homes within the primary care setting. The workgroup includes family members of children with special health care needs, representatives from community organizations, state agencies and family advocacy organizations, community physicians and other health care providers, and other partners
- The workgroup has developed and implemented a strategic plan to achieve the goal that all children in Texas, including children and youth with special health care needs, will receive their health care in a medical home. A key part of the strategic plan is to increase the number of health care practitioners who provide a medical home
- The Texas Medical Home Initiative, a non-profit, multi-stakeholder organization, is dedicated to implementing the Patient-Centered Medical Home model of care in Texas, since its inception in 2008. They currently have 7 adult primary care practices in the North and East Texas areas that are committed to this pilot. They have engaged Health TeamWorks to provide initial practice assessments of the practices' readiness to become patient-centered medical homes. Six of the 7 practices achieve Level 3 NCQA recognition as medical homes; the 7th achieved Level 2

In April 2013, the TMHI and the Texas Health Institute co-sponsored the first statewide conference on medical/health homes. Almost 300 interested people attended from all regions of Texas. A second Health Home Summit in May, 2014 was also well attended.

STAR Kids

Policy Issue – Baclofen Pumps

Individuals who have Medicaid are experiencing incredible difficulty in getting their Baclofen pump refilled and maintained. The physicians are reporting that the Medicaid reimbursement rate is insufficient and does not cover the actual cost of the medication and maintenance. Families of children whose pain and spasticity are controlled by the Baclofen pump are now faced with a dangerous weaning process and are having to have the pump surgically removed. Without the medication delivered via the pump their children are now faced with incredible pain. This problem has been highlighted with the move to Medicaid managed care.

Recommendation

Require that the Medicaid payment rate paid to physicians for the maintenance and refill of the Baclofen pump be increased to one that actually pays for the cost of the medicine and the cost to the physician. This includes Medicaid payments made on behalf of beneficiaries through Managed Care Organizations.

Background

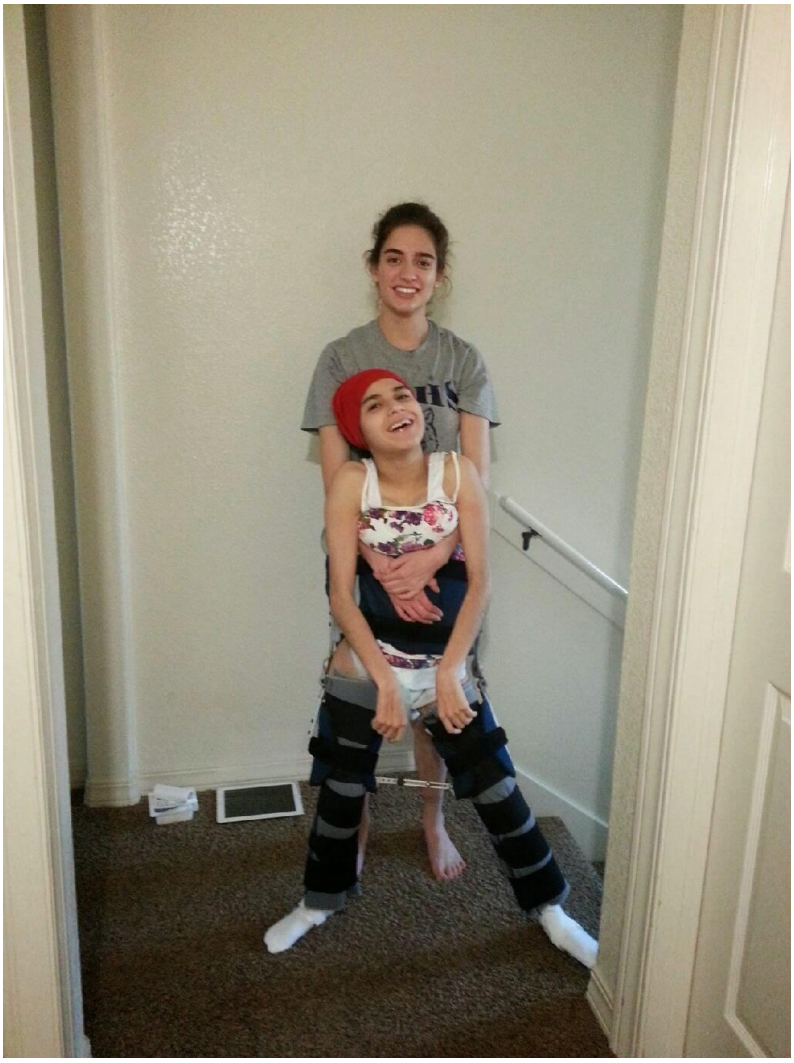
The SynchroMed Drug Infusion System includes a programmable pump and catheter that are surgically placed under the skin of the abdomen. The system delivers a liquid form of the drug baclofen (Lioresal® Intrathecal) directly to the fluid around the spinal cord. Because the drug is delivered directly to where it's needed in the spinal fluid, it relieves spasticity with smaller amounts of medication.

People who suffer from severe spasticity resulting from cerebral palsy, multiple sclerosis, stroke, brain injury, or spinal cord injury are some of the many individuals that benefit from the pump. Individuals that currently have the pump are individuals that suffer from severe spasticity or spasms that interfere with function or daily activities and severe spasticity or spasms interfere with daily care or positioning. It also helps individuals be more independent, allowing them to feed or dress themselves, sit more comfortably, or transfer more easily. It may provide long-term control of spasticity in people living with cerebral palsy or brain injury. It reduces spasticity

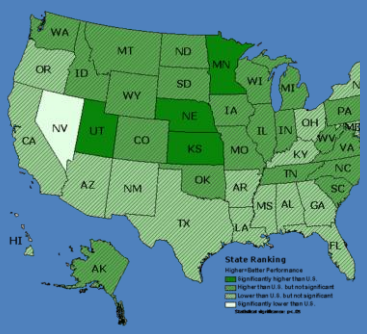
in both the upper and lower limbs of those living with cerebral palsy, brain injury, and stroke. These are some of the benefits the pump offers individuals with it.

Many families and doctors worried about the risks involved in the sudden stop of Intrathecal Baclofen therapy which can result in serious Baclofen withdrawal symptoms such as high fever, changed mental status, muscle stiffness, and in some cases may result in loss of function of many vital organs and death.

Families of individuals who benefit greatly from the pump and who rely on payment from Texas Medicaid are now faced with the removal of the pump and a life changing drug for their children.



According to the National Survey of Children with Special Health Care Needs 2009-2010, the outcome that youth with special health care needs receive the services necessary to make the transition to adult health care was achieved 40% of the time nationally and **in Texas** this standard was met for **35.4% of youth**



Texas is in the bottom 10 states. Rankings and rates are inclusive of all types of insurance and the uninsured.

The Data Resource Center for Child and Adolescent Health is a project of the Child and Adolescent Health Measurement Initiative (CAHMI) supported by Cooperative Agreement 1-U59-MC06980-01 from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). With funding and direction from MCHB, these surveys were conducted by the Centers for Disease Control and Prevention's National Center for Health Statistics. CAHMI is responsible for the analyses, interpretations, presentations and conclusions included on this site.

Transition: Preparing for Adulthood

Transition for individuals with disabilities is a lifelong process beginning at birth. Transition from youth to adult services impacts youth with disabilities in many aspects of life and care including the ability to:

- Access health care comparable to services received as a child
- Retain personal rights with the least restrictive assistance
- Work alongside peers in an integrated setting
- Reside in the least restrictive environment
- Develop friendships and engage in social opportunities
- Engage in independent decision making

CPC strongly supports Texas becoming an Employment First State this year. We, as parents and Texans, work to prepare our children for their transition from school to college or work. This process is exceedingly more difficult for a young person with disabilities. If we can assist our youth with disabilities to work and earn income, live in a less restricted setting, participate in decision making that affects their lives, and have the opportunity to develop friendships and participate in social opportunities, it is a win-win situation for all of us – the individual with disabilities, their parents or caregivers, legislators, and taxpayers.

Transition: Preparing for Adulthood

Person-Centered Planning and Transition Planning and Consultation

Policy Issue: Person-Centered Planning

Most youth leave home and start out on their own but the situation for youth with disabilities is very different. Families of youth with disabilities must have tools and services to assist them to plan for the future.

The CPC's recommendations concerning transition from child to adult services begin with two general and crucial transition models: Person Centered Planning and Transition Consultants.

After the introduction of Person Centered Planning, positive changes were found in six areas. Person Centered Planning resulted in a 52% increase in the size of social networks; a 2.4 increase in contact with a member of their family; 40% increase in the level of contact with friends; 30% increase in the number of community-based activities; 33% increase in hours per week of scheduled day activities; and 2.8 times more choice. Therefore, the research supports the current emphasis within health and social care policy on using Person Centered Planning to improve the life chances of people with learning disabilities (Robertson et al 2005).

Recommendation: Person-Centered Planning

The CPC recommends that a robust person-centered planning process be provided to all youth with disabilities as they transition to adult services, beginning at age 14. Person centered planning should include standards such as those defined by the Institute of Person Centered Practices, the collaborative effort of the Texas Center for Disability Studies at The University of Texas at Austin and the Center on Disability and Development at Texas A&M University. HHSC should require that all Home- and Community-Based Services (HCBS) waiver, STAR+PLUS, STAR Kids, and STAR Health participants have access to an independent person centered planning process to avoid any conflicts of interest. The planning process must be holistic, focused on all aspects of the individual's life, and provided both to individuals utilizing the Consumer Directed Services (CDS) option and those accessing services in the agency model. Person centered planning should address alternatives to guardianship starting at age 14 to prevent or delay the need for guardianship.

Background:

To assist a young person with disabilities in making important lifelong decisions, the young person with disabilities should have access to quality person centered planning. "Person- centered planning" means a process for planning and supporting the individual

receiving services that builds upon the individual's capacity to engage in activities that promote community life and that honors the individual's preferences, choices, and abilities. Parents and guardians of children and young adults with disabilities need the tools to better understand their child or young adult's plan for the future. As part of the development of a proper person-centered plan, parents will begin to recognize the benefits of a well-defined plan for the future, goals of the person with a disability and allowing the person with a disability to self-advocate and become independent. This is especially important during years of transition into adult services and adult responsibilities.

Youth with disabilities should have access to quality Person Centered Planning services in order to effectively make lifelong care and quality of life decisions. *Person Centered Planning* means a process for planning and supporting the individual receiving services that builds upon their strengths, abilities, and interests to help ensure meaningful participation in activities and community life. This process honors the youth's preferences, choices, and abilities while addressing their health and safety needs. The person-centered planning process will allow parents and youth to develop a comprehensive, well-defined plan together which focuses on the youth's self-identified goals. This process will also allow youth with disabilities to begin to advocate for themselves, which will serve as an important skill during the transition years.

Recommendation: Transition Planning and Consultation

HHSC should provide a "Transition Consultant or Community Supports Navigator" as a new Medicaid waiver benefit. This benefit is different than what is provided through school and through any HCBS waiver in that the transition consultant is only focused on transition into adult services. The "Transition Consultant" will guide the youth and family through the transition planning process.

Transition Planning and Consultation

Transition planning should be collaborative, informed by the person-centered plan and include development of a written transition plan based on the model plan developed by "Got Transition" (http://gottransition.org/resourceGet.cfm?id=226). This plan should be provided annually until age 14 and at least annually or more frequently, as appropriate, through age 22. A "Transition Consultant or Community Supports Navigator" should be provided to all children with disabilities. The consultant should be available to the young person with disabilities as needed

through age 22. The consultant shall also ensure that all young adults with disabilities have a health care professional who recognizes the unique challenges that come with transition and assumes responsibility for health care, care coordination and any future health care planning. This should be done in partnership with other providers, the youth and family, and intended to be uninterrupted comprehensive and accessible care within their community.

A successful model for comprehensive transition planning utilizing consultants is Rhode Islands, "Community Supports Navigator Program" (http://www.ric.edu/sherlockcenter/csn.html). The program provides transition support for youth ages 18 – 22, and their families by:

- Working closely with the youth, family and trusted allies to develop a plan for life after high school, based on the young person's strengths, interests and goals
- Working with the youth, families and their Independent Education Plan (IEP) teams to ensure quality transition programming while still in school
- Guiding individuals and their teams in identifying opportunities for community employment, recreation and meaningful participation in community life
- Guiding youth, families and teams in identifying natural, community and formals supports that will help them meet their goals
- Guiding youth and families through the application process for supports through the Texas Department of Assistive Rehabilitation (DARS), the Texas Department of Aging and Disability Services (DADS), the Texas Department of State Health Services (DSHS), the Texas Health and Human Services, SSI, Medicaid and other appropriate public supports
- Assisting youth and families in evaluating and choosing the supports that best match their goals and vision
- Assisting youth and families in designing and managing self-directed supports when this is their choice
- Providing information and resources on such topics as transportation options, alternatives to guardianship, housing options, healthcare, etc.

Transition: Preparing for Adulthood

Policy Issue: Healthcare Transition for Young Adults with Disabilities

In Texas, children with disabilities between 14 to 22 years transitioning from children's health care services to adult services may experience anyone of the difficulties below when attempting to continue services:

- Pediatricians often drop patients between the ages of 18 – 21, causing issues with continuation of care
- Young adults require access to adult-oriented healthcare services, including reproductive health and screenings for adult risk factors
- Loss of insurance through parent's plan at age 26 causes risks and gaps in services, which may risk the long-term health of the young adult
- Changes in the authorization process and requirements occur when transitioning from pediatric to general medicine often causing delays in treatment
- Level of provider training for adults with special needs is not as thorough as pediatric training, and it is not uncommon that the level of care significantly decreases for adults as they transition from childhood service providers
- There is a low prevalence of adult providers to serve young adults with disabilities as they transition to adult health care
- Youth and families may not be aware and are then not prepared when state Medicaid plan benefits change and are reduced at age 21

Recommendations: Understanding of existing health conditions

A person with disabilities transitioning into adult health services has the right to understand and consent to treatment for their own health conditions. To ensure this right, individualized education should be jointly developed by the youth, involved family members, long term services and supports providers and medical professionals involved in the care of the individual. Details important to understanding the youth's health status, conditions and history should be aggregated in a single, easy to understand, portable format belonging to the individual. Such a file would be provided through Medicaid and include important information concerning the young person with disabilities' health information and be recommended to be provided to each young person with disabilities beginning at age 14 and updated annually.

The information would be reviewed with the young person so they may better understand their diagnoses and treatments. The goal is for the young people to understand their health conditions and treatment options and be able to give consent (with support) for treatment and to develop personal responsibility for their own health. The goal for the physicians is to ensure that adult providers have all the information they need to provide care to a young adult with special health care needs/disabilities

1. The CPC supports the recommendations of the AAP Consensus Statement and the Got Transition's Six Core Elements

The CPP recommends the adoption and implementation of the AAP consensus statement (http://pediatrics.aappublications.org/content/110/Supplement_3/1304.short) and the Got Transition's Six Core Elements as best practices:
http://www.gottransition.org/providers/index.cfm
Some of the recommendations below are included in these additional recommendations.

2. Develop and implement core knowledge and skills required of health care professionals to provide developmentally appropriate health care transition services

Incorporate core competencies into training and certification requirements for primary care and specialty residents. Provide incentives and additional funding for physicians and providers to provide services to this unique population; and base incentive payments based on healthcare outcomes.

3. Increase the availability of medical homes for youth transitioning to adult services

Texas is fortunate to have a unique medical clinic for youth with disabilities as they transition into adult services in Houston, the Transition Medicine Clinic at Baylor College of Medicine. The CPC strongly recommends supporting the increase of these types of clinics as medical homes throughout Texas. Clinics like these provide medical care and social support services to the growing population of adolescents/young adults with a chronic childhood illness or disability as they move from pediatric to adult healthcare.

The goal of the clinic is to prevent urgent healthcare crisis and to minimize the impact of a shrinking social support network that these patients and families have come to rely on in the

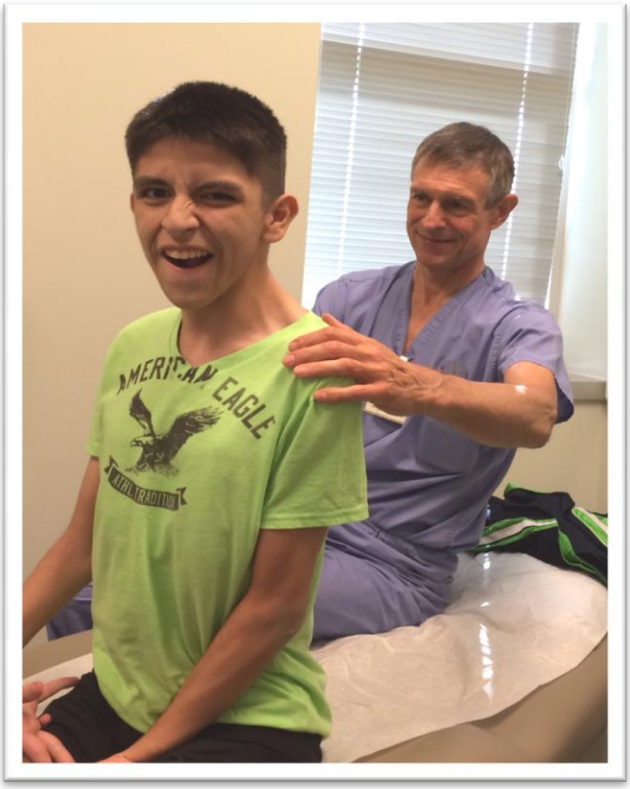
pediatric healthcare system. This includes helping them overcome obstacles encountered in both adult Medicaid and private health insurance systems.

4. Provide affordable, continuous health insurance coverage

Ensure the needs of children with disabilities are met from childhood through adolescence and into adulthood by providing continuous health insurance coverage. Insurance coverage should include health care transition planning and coordination for those with complex medical conditions.

5. Include access to telemedicine

Telemedicine and telehealth technology provides unique and complex medical services statewide. Telemedicine has the ability to eliminate barriers existing in rural communities by providing physician services without commute and are crucial to the health of young adults with disabilities.



6. Assist young adults with disabilities in selecting physicians and providers during transition through their transition consultant

The process of identifying a provider to manage healthcare with the youth with disabilities during transition should begin to occur between ages of 14 - 22. While it is preferable that individuals are able to successfully transition to an adult provider, it must be acknowledged that some individuals would be better served retaining their pediatric provider. In such cases an individual should be allowed to transition into adult services while maintaining their pediatric provider. The transition consultant can assist with this process while working closely with the managed care plan.

7. Provide young adults with disabilities written guide on how to access adult services

HHSC should provide to each youth with disabilities ages 14 and up a simple, clear guide on how to access adult services, including access to benefits through the HCBS waivers or STAR+PLUS. The guide should provide specific guidance on how to transition services for dental care, durable medical equipment and supplies, therapies and nursing from a state plan benefit to a waiver benefit. The differences between Medicaid state plan benefits for youth up to 21 and the changes in benefits for individuals over 21 needs to be clearly outlined and explained so that youth and families can prepare for the reduction in services.

Transition: Preparing for Adulthood

Policy Issue: Transition to Employment for Young Adults with Disabilities

Texas benefits when working-age adults with disabilities are as self-sufficient as possible and contribute to the economy as part of the general workforce. Most working-age adults and youth with disabilities can earn competitive wages within the general workforce and have the right to pursue the full range of available employment opportunities.

Anyone who wants to be employed should receive services and supports for as long as needed to obtain and maintain integrated, competitive employment, regardless of disability or level of disability. All state agencies, including schools that fund or provide employment, vocational, or transition services and supports for persons with disabilities have a shared responsibility to implement Texas' Employment First principles.

Nathan Levine stands in the Hilton Austin kitchen, loading pots, pans, dishes and trays into a noisy industrial dishwasher. Nathan has severe autism. He cannot communicate orally. He can't stand certain sounds, can have trouble focusing and doesn't always seem to understand what is being said to him. But at the Hilton, he has found success that his family says other people can achieve, too. "I think it's inspirational," said his mother, Linda. For years, disability rights advocates have been pushing employers to hire people with special needs. As of June 2012, according to the Bureau of Labor Statistics, 27.6 percent of working-age people with disabilities were employed. Advocates say that number would be much higher if more employers were open to the idea. "You just have to be creative, said Bea Jaramillo, the Hilton's director of human resources. "If you want to make it work, you can make it work." People with disabilities can thrive in the workplace, Linda said, but they need a chance to prove it.
http://www.statesman.com/news/news/man-shows-how-people-with-disabilities-can-thrive-/nWDkW/

Recommendations

1. Implement Employment First Principles

Earning a living wage through competitive employment in the general workforce is the priority and preferred outcome for working-age individuals with disabilities who receive public benefits. This practice is known as Employment First.

Employment First principles should be developed for each state program providing employment assistance and employment support and these principles should be defined and implemented consistently across agencies to ensure that a person receiving services is not adversely affected by discrepancies across programs.

State agencies should develop best practices to ensure success of the Employment First initiative. Research to identify best practices should include investigating successful employment programs in other states. In particular, Oklahoma, Kansas, Washington and New Hampshire have successful, innovative programs.

2. Agencies should update criteria, assessment and/or evaluations in compliance with employment first policies. Ensure eligibility criteria are applied consistently across DARS and local DARS office

People who receive Supplemental Security Income, Medicaid, and Home and Community-based Services through Medicaid waiver programs are currently at an increased risk for unemployment compared to the general population. They should have access to employment assistance and supported employment through existing state agency programs. Parents and young persons with disabilities have identified gaps in the ability to access services between responsible agencies, including those persons with disabilities in STAR+PLUS.

The Department of Assistive and Rehabilitative Services must strengthen eligibility determinations to ensure all persons with disabilities have the opportunity to work based on the state's Employment First policy. The legislature should direct DARS to:

- Update eligibility criteria, assessment and/or evaluations to be in compliance with Employment First policies

- Ensure that eligibility criteria are applied consistently across the agency and local DARS offices
- Ensure services to all young adults who receive Social Security

The guiding principles of employment programs should be based on individual preferences and informed choice. State agencies (DARS, DADS, TWC, TEA) should form partnerships to overcome perceived and real barriers to employment for individuals with disabilities.

3. State-funded Employment Services should be comprehensive

Develop technical support teams that specialize in comprehensive education and best practice training for DARS staff that focus on all types and levels of disabilities. This would include persons with significant disabilities, including those with autism, those who are non-verbal, those who use assistive technology, those with personal attendant supports and those with significant behavioral challenges. These units would develop appropriate testing based on the person's disability, develop job trials and discovery and develop a plan for employment unique to the skills of the person and focused on an integrated setting.

Agencies responsible for employment services for persons with disabilities should strengthen partnerships with employers, providing greater opportunities for employment.
Additional services may include:

- Job trials
- Supported employment
- Peer support
- Self-directed service models allowing individuals to hire private job coaches or support staff
- Individualized relationships between employee and employer
- Self-employment opportunities

4. Revamp sheltered workshops and day habilitation programs:

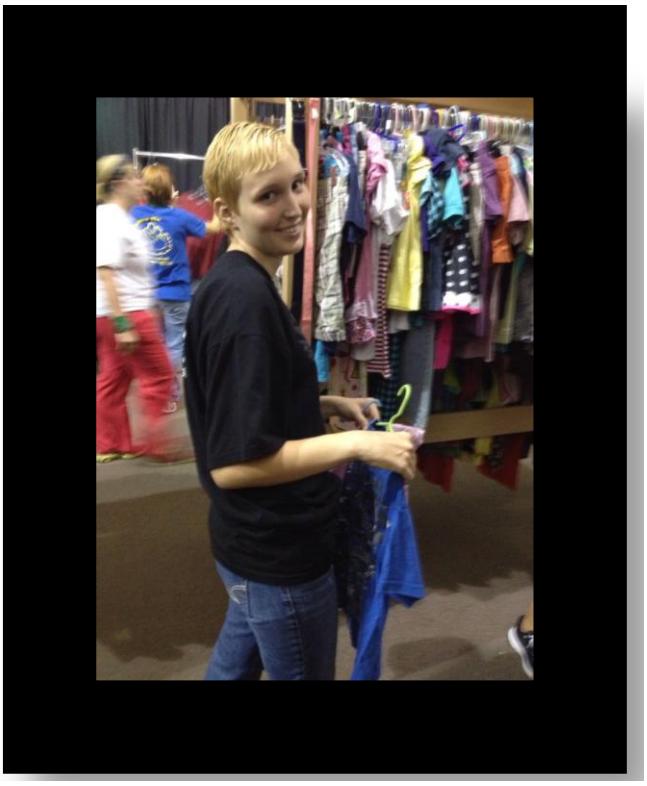
DADS should identify all sheltered workshops operating in Texas and develop a plan to transition those persons participating in the sheltered workshops to integrated competitive employment. The findings from DADS research on the identification of the sheltered workshops and a plan for transition should be provided for public comment.

DADS should develop standards for day habilitation programs that follow the state's Employment First policy. DADS should ensure that each day habilitation program becomes registered and provide age appropriate services, meets health and safety standards and program standards for day habilitation settings developed by DADS. DADS should ensure that the public and the Children's Policy Council are involved in the development of the standards.

Background

Meaningful, paid work is significant to quality of life for all working-age adults, including individuals with disabilities and includes the following benefits:

- Ability to earn and keep competitive wages which provide for disposable income and less reliance on public benefits
- Opportunity to develop and expand personal relationships and natural supports
- Establishing an identity and reputation as a competent and contributing member to one's community
- Increased health and safety through greater visibility in the community
- Increased self-esteem
- Empowerment and choice to pursue desired lifestyles, beyond what services can provide acquisition of skills that allow for the development of a career path



Transition: Preparing for Adulthood

Policy Issue: Guardianship & Alternatives to Guardianship

The purpose statement for guardianship in Texas Probate Code includes the charge to maintain the maximum level of self-reliance and independence of the "incapacitated person", but judges indicate they have no direction about how to achieve this goal. As a result, courts frequently grant full guardianship instead of alternatives to guardianship or limited guardianship because it seems to be the only clear course of action. Guardianship is a legal tool which allows a person or persons to make decisions for another individual.

Guardianship removes the civil rights and privileges of a person by assigning control of their life to someone else. Decision-making skills and alternatives to guardianship are important areas to be assessed and considered during transition. Even though individuals with disabilities may need services or assistance to help them make their own decisions, they should retain the right to make choices about aspects of their lives whenever possible.

Recommendations

1. Public Schools Rights and Responsibilities

Disability rights advocates have indicated that schools are inconsistent in their treatment of young adults with disabilities and their rights. It is a key component to the future of the young adult with disabilities that rights are presented during transition which begins at age 14 and until leaving school based services, including the right for the young adult with disabilities to select alternatives to guardianship. Some parents report pressure from schools to seek guardianship in order to access educational information and attend meetings. To address parents' fears, CPC recommends that schools provide parents and young adults with disabilities a listing of their rights and responsibilities. Included in this information should be an explanation of:

- Rights under Scooter's law
- Participation of parents and students in ARD IEPs after the 18th birthday
- Graduation options up to age 22
- Alternatives to guardianship

This information on rights and responsibilities must be provided annually to the young adult with disabilities and their parents or guardians beginning at age 14 until they no longer receive school-based services

2. Considerations from the Guardianship Reform and Supported Decision Making (GRSDM) Workgroup

The GRSDM is a cross-section of groups, including organizations representing people with physical, mental, intellectual and developmental disabilities, seniors, and the legal community. They collaborated to develop policy recommendations that address opportunities and challenges associated with the Texas guardianship system. The CPC agrees with the recommendations of the GRSDM concerning guardianship and alternatives to guardianship. These recommendations include:

1. Bill of Rights for Wards - would list the rights that individuals under guardianship get to keep, such as the right to live, work and play in the most integrated setting, visit with people of their choice, and appear before the court to express their preferences or concerns

2. Supported Decision-Making Agreement - would establish an informal alternative to guardianship where individuals could choose people they trust to help them understand the decisions they need to make and to communicate their decisions to others

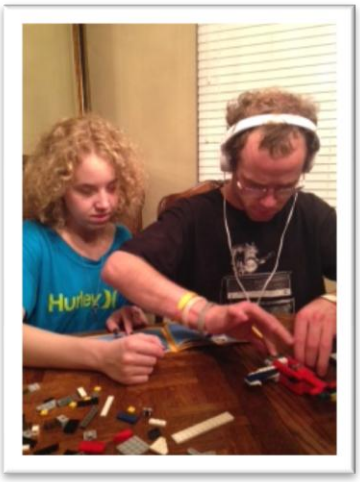
3. Alternatives to Guardianship - would list the alternatives to guardianship scattered throughout code immediately following the purpose statement with a directive to the court to determine whether alternatives could meet the needs of the person in lieu of guardianship. Specific for kids

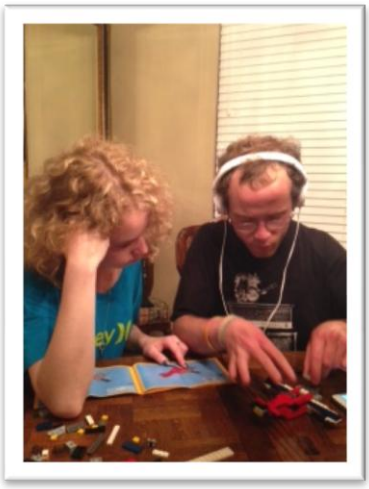
4. Change Term from “Ward” to “Person” - would change the impersonal term “ward” to “person under guardianship”

5. Limits of Guardianship with Services and Supports – would require the court to determine if formal and informal supports are in place or available to enable the person to meet their need for food, clothing, or shelter, care for their physical or mental health,

manage financial affairs and/or make decisions so that guardianship may be averted or limited.

6. Duties of Guardians - would improve protection for individuals committed to institutional settings. This proposal calls for guardians to visit a person under a guardianship and living in an institution every month, and provide timely response to calls, emails or letters about the person
7. Guardianship and Decisions about Residence – would require that people under guardianship should, if possible, be able to make decisions about where they reside





Transition: Preparing for Adulthood

Policy Issue: Housing

The Texas Medicaid waiver programs offer limited housing opportunities. The waiver with the most available housing options for persons with intellectual and developmental disabilities is the HCS wavier. The HCS program has a large interest list of 67,201 with a current wait time of 10-12 years. Most of the people on the HCS interest list are on the list because of the housing options available only in this waiver.

There is not a single county in Texas where even a modest efficiency apartment is priced according to Fair Market Rent or is affordable (affordable rent for sole SSI recipient is $210/month). 15.9% of working-age people with disabilities receive SSI payments in Texas**.** The vast majority of low-income individuals with complex needs make well below 30% of any county's average median income

Appropriate housing options for children and adults with disabilities should be permanent, safe, accessible, integrated, and affordable.

The Children's Policy Council has received many comments from parents concerning housing for their adult children. The CPC would support (Long Term Support Services) LTSS system reforms that reduce reliance on provider controlled housing and provide incentives that encourage consumer controlled housing. Such a system would empower persons with disabilities by ensuring that they have the support necessary to make informed choices about their housing options.

The CPC supports housing options that are fully integrated in the community, in close proximity to goods and services and do not take the system backwards by perpetuating congregate living environments no matter how well intentioned. CPC does not support including large residential options in systems redesign, and we note that providers indicate the cost of retrofitting existing homes to accommodate more residents is generally cost prohibitive.

Recommendations

1. Promote innovative living options

Assist in promoting innovative permanent living options for person's with intellectual and developmental disabilities (IDD) such as shared attendants, host homes, non-provider homes shared

by people using multiple waivers, private/public funding of homes, innovative shared living arrangements and small private group homes through the Transition Consultant or Community Supports Navigator. This process should include:

- Planning to identify and achieve the most independent living arrangement
- Access to all living options under the HCBS waiver program and STAR+PLUS
- Providing housing option materials in conjunction with transition planning
- Development of a roommate matching program
- Removing barriers of current waiver programs
- Providing incentives for attracting companion care providers

To be effective, the above recommendations should be considered a part of the person centered plan developed by the HCBS provider in transition planning. DADS may be best fit to draft written guidance on shared housing requirements for persons in different waiver

programs. For persons with intellectual or developmental disabilities (IDD) living in provider owned options (State Supporting Living Centers (SSLCs), Integral Care Facilities persons with intellectual or developmental disabilities (ICF-IID) facilities, group homes), require the service coordinator to perform the "Community Living Option Information Process (CLOIP)" for individuals with IDD to educate them on how to access the most independent living arrangement.

2. Expand the Promoting Independence Advisory Committee's focus

Include housing options that maximize independence and are affordable to people with disabilities, including persons with intellectual disabilities, with Section 8 Housing Choice Vouchers, the Project Access Program, and Section 811. State health and human service agencies are currently collaborating to ensure that people with physical disabilities have access to these important housing options via Money Follows the Person and persons with intellectual and developmental disabilities should have similar opportunities. The CPC supports reserving waiver services slots for persons who become eligible for public housing opportunities so they can take advantage of independent living opportunities when they become available.

3. Provide consistent HCBS benefit definition and criteria

Develop consistency in HCBS benefit definition/criteria and inclusion of adequate benefits for young adults with disabilities across Medicaid programs which should be encouraged to ensure equivalent benefit levels for individuals whose complexity is likely to not change, including housing options. Minimize the loss of services, including medical and educational services from youth to adult programs that put individuals at increased risk for institutionalization. Provide individualized meaningful day activity services including integrated employment opportunities.

Additionally, include assistive technology and home modifications as a cost effective support and alternative to more intensive human intervention, including the use of simple environmental control units such as cameras, keyless locks, ear bud coaching, and automatic door openers ensures safety while decreasing the need for more supervision. Improve coordination with Texas Technology Access Program, DARS and other state agencies to access these technologies.

Small group homes

Ensure community based homes:

- do not exceed three or four people
- provide a home environment that meet the needs of the individual and not an institution
- be accountable to ensure the ability to meet the individuality of each person in the home
- provide individualized meaningful day activities including integrated employment opportunities

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

The Children's Policy Council strongly recommends an immediate moratorium on the placement of children into any state supported living centers and supports the recommendation made by Sunset Advisory Commission staff to close six State Supporting Living Centers (SSLC).

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 this decision in 1999, Texas has downsized but not closed any of its remaining 13 institutions. In 2013, Texas operates more large public residential facilities than any other state, and houses more people in each institution than in most other states. 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 DADS to close the Austin SSLC by August 31, 2017 and close the remaining centers by no later than August 31, 2022. Each person in these large state-run institutions should be considered eligible for transition to the least restrictive environment.

CRITICAL ISSUES

Policy Issue: MDCP Denials

Children and young adults who receive services under the Medically Dependent Children's Program are losing eligibility for the waiver due to a change in the way the state is assessing medical necessity and interpreting the requirement of a family to provide care for their children. Children who have had no change in their health status and have been on the waiver for a number of years are now losing eligibility for the waiver and in many instances Medicaid as a result of the denial. This is a significant issue for children and families. The loss of respite and ensuing Medicaid coverage is placing children at risk of imminent institutionalization, including placement in a nursing facility for which the waiver was originally designed to prevent.

Recommendation

1. Require the Department of Aging and Disability Services to stop the denial of eligibility for individuals undergoing annual reassessments if nothing has changed in the child or young adults' medical condition

2. Require the Department of Aging and Disability Services to transition those individuals who are losing eligibility due to an improvement in their medical condition, but who still need significant supports because of their disability into another DADS waiver

3. Require the Department of Aging and Disability Services to review the denials of individuals who have lost services due to lack of medical necessity since April of 2013. Reinstate services to those who did not have an improvement in their medical condition and offer an alternative to those who are better served under one of the other home and community-based services waivers

Background

The Medically Dependent Children's Program is a Texas Medicaid Home and Community-based Services waiver for children and young adults under the age of 21 who qualify for nursing facility level of care. The waiver provides families caring for children with disabilities with much

needed respite, home modifications, flexible family support and adaptive aids so that they can care for their children in the home as opposed to seeking placement in a nursing facility. The waiver has been in operation in Texas for almost 30 years and has provided an invaluable service to families. Approximately 5,000 individuals are served in this waiver. This waiver in combination with other state efforts has led to a 70% reduction in the number of children residing in Texas nursing facilities. These children are now able to move from the nursing home to family with the support of the waiver.

In April of 2013 the state undertook an initiative to refine and change the way that children and young adults are assessed and evaluated for admission into the waiver and for continued eligibility for the waiver. As a result of this initiative there has been an increase in the number of denials. Some of these individuals have been on the waiver for years and are now being told they no longer qualify for medical necessity even though nothing has changed in their medical condition. These families are not only losing the respite that they accessed through the waiver, but many are also losing access to Medicaid which pays for their doctors, prescription medications, durable medical equipment and medically necessary supplies.

In FY 13, 431 individuals receiving MDCP lost eligibility, 37.1% were denied due to lack of medical necessity. This number increased to 478 denials during the first 8 months of FY 14, with a jump of 56.5% of those individuals denied due to lack of medical necessity.

Emerging Issues

A goal of the Children's Policy Council is to stay in tune with the changing needs of children with disabilities and special health care needs and their families. Many times we hear of emerging issues in our community involvement or they may be brought directly to the Council. Concerns we are currently facing include:

Alternative Therapies: Medical Marijuana and Cannabidiol (CBD Oil)

Families in Texas are moving out of state to obtain CBD oil for children with complex seizure disorders or autism

- Families risk arrest and fines for carrying a controlled substance if they return to Texas
- Families may potentially self-medicate children with marijuana obtained illegally and not tested for appropriate levels of THC and cannabis

The CPC endorses the recommendation to create a work group of advocates, Legislators, and families of children with disabilities to explore the issue of families not having access to certain therapies that may greatly benefit children.

CHILDREN'S POLICY COUNCIL RECOMMENDATIONS SUMMARY

MENTAL HEALTH RECOMMENDATIONS

Recommendations to Address Access and Barriers to Mental Health Services

1. Provide a transparent evaluation process, so that families and stakeholders can easily understand the priority issues and statewide and regional progress
2. Support expansion of the YES Waiver. The success of the Waiver will hinge on streamlined eligibility and support to communities to develop collaborative mental health networks
3. Support access to therapies that focus on parent-child interaction
4. Analyze the existing transportation system for opportunities to improve ease and access for families

Recommendations to Address Integrating Mental Health with Primary Care

1. Encourage flexibility in accessing mental health services based on symptoms and functioning, rather than a diagnosis
2. Support funding for programs and learning collaboratives that integrate mental health into primary care
3. Reduce barriers to necessary psychotropic medications for children and adolescents

Recommendations to Address Fragmentation

1. Support programs for screening and coordination services for mental health and substance abuse in emergency rooms and hospitals
2. Evaluate the issue of "boarding" children in emergency rooms and assess the capacity of inpatient programs for children
3. Develop a statewide, cross-agency infrastructure to identify and address barriers to mental health care and provide technical assistance to local programs to expand evidence-based and collaborative practices
4. Increase state support to local agencies that serve children with comprehensive, flexible services. In regions where these agencies don't exist, support funding for demonstration projects to develop local capacity and leadership

STAR KIDS RECOMMENDATIONS

Recommendations to Address MDCP Eligibility for Children on SSI

1. Allow all SSI children and young adults under the age of 21 who meet the eligibility for MDCP to automatically receive waiver level of services in STAR Kids with no wait

Recommendations to Address Skilled Nursing Services

1. Modify criteria used in Medicaid and in the waivers to allow access to nursing services based on the needs of the child, the stability of the child and the determination that without nursing the child will be a risk for further medical complications including death

Recommendations to Address Patient Centered Medical Home

1. Make a provision within STAR Kids that Managed Care Organizations (MCO) provide all children with disabilities, chronic illness and other special health care needs with a Patient Centered Medical Home. The Medical Home components should be based on information from the National Center for Medical Home (http://www.medicalhomeinfo.org/).
2. Create a common definition for Patient Centered Medical Home. Use materials created by the National Center for Medical Home (http://www.medicalhomeinfo.org/) and to assist in the definition and implementation, call on the expertise of medical home demonstration projects such as the Statewide Association for Regional Medical Home Advancement (a HRSA sponsored partnership between Texas Pediatric Society, Texas Title V, and Texas Parent to Parent) and the Texas Medical Home Initiative
3. Have the Managed Care Organizations create training materials for families, physicians, and public health agencies and disseminate

Recommendations to Address Issues with the Baclofen Pumps

1. Require that the Medicaid payment rate paid to physicians for the maintenance and refill of the Baclofen pump be increased to one that actually pays for the cost of the medicine and the cost to the physician. This includes Medicaid payments made on behalf of beneficiaries through Managed Care Organizations

TRANSITION RECOMMENDATIONS

Recommendations to Address Person-Centered Planning

1. Person centered planning should include standards such as those defined by the Institute of Person Centered Practices
2. HHSC should require that all HCBS waiver, STAR+PLUS, STAR Kids, and STAR Health participants have access to an independent person centered planning process to avoid conflicts of interest
3. The planning process must be holistic, focused on all aspects of the individual's life, and provided both to individuals using the Consumer Directed Services (CDS) option and those accessing services in the agency model
4. Person centered planning should address alternatives to guardianship starting at age 14 to prevent or delay the need for guardianship

Recommendations to Address Transition Planning and Consultation

1. HHSC should provide a "Transition Consultant or Community Supports Navigator" as a new Medicaid waiver benefit to guide the youth and family through the transition planning process

The CPC supports the recommendations of the AAP Consensus Statement and the Got Transition's Six Core Elements.

1. Develop and implement core knowledge and skills required of health care professionals to provide developmentally appropriate health care transition services
2. Increase the availability of medical homes for youth transitioning to adult services
3. Provide affordable, continuous health insurance coverage
4. Include access to telemedicine
5. Assist young adults with disabilities in selecting physicians and providers during transition through their transition consultant
6. Provide young adults with disabilities written guide on how to access adult services

<u>Recommendations to Address Employment</u>

1. Agencies should update criteria, assessment and/or evaluations in compliance with employment first policies
2. Ensure eligibility criteria are applied consistently across DARS and local DARS office

3. DADS should clearly identify all sheltered workshops still continuing to operate in Texas and develop a plan for transition for those persons participating in the sheltered workshops to integrated competitive employment

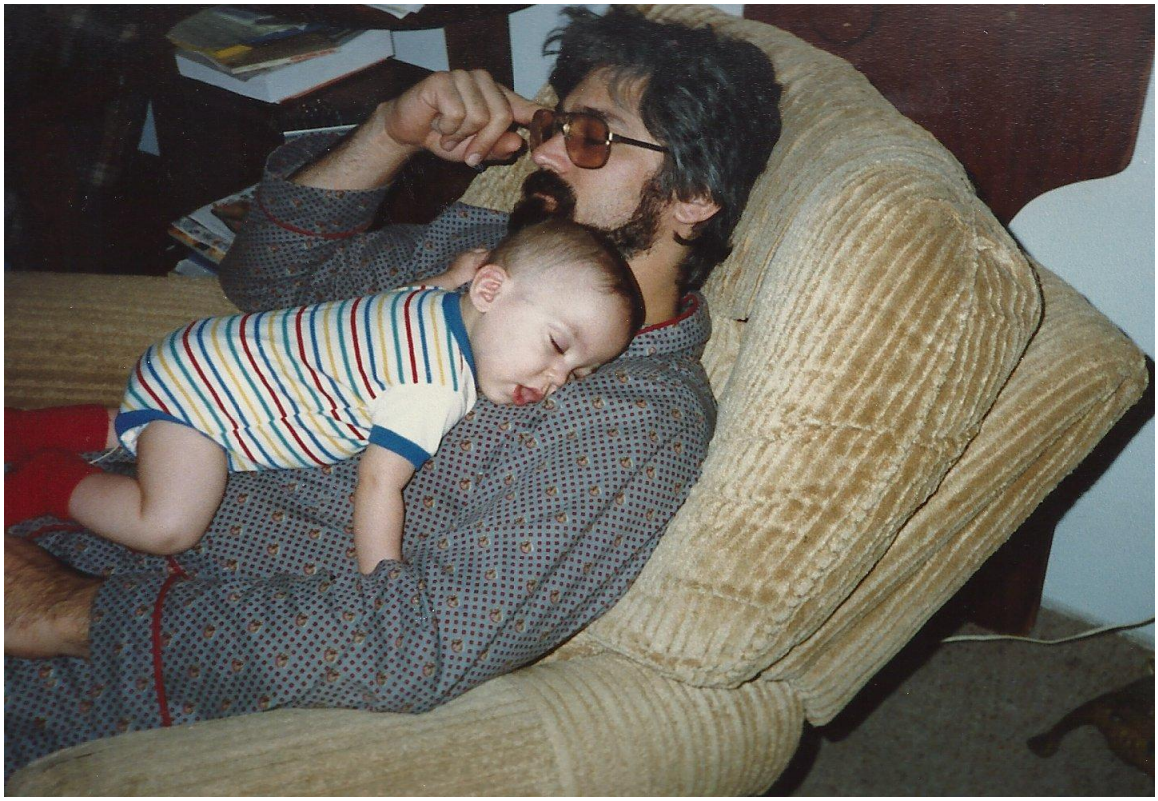
Recommendations to Address Guardianship

1. Schools should provide parents and young adults with disabilities a listing of their rights and responsibilities. Included in this information should be an explanation of:
    - Rights under Scooter's law
    - Participation of parents and students in ARD IEPs after the 18th birthday
    - Graduation options up to age 22
    - Alternatives to guardianship
2. Support the Guardianship Reform and Supported Decision Making (GRSDM) recommendations as follows:
    - Develop a Bill of Rights for people under guardianship
    - Develop supported decision-making agreements
    - Emphasize the use of alternatives to guardianship
    - Change the term "ward" to "person
    - Use limited guardianships when a person has access to services and supports
    - Increase the duties of guardians
    - Allow people under guardianship to make decisions about where they reside

Recommendations to Address Housing

1. Promote innovative living options
2. Ensure community based homes:
    a. do not exceed three or four people
    b. provide a home environment that meet the needs of the individual and not an institution
    c. be accountable to ensure the ability to meet the individuality of each person in the home
    d. provide individualized meaningful day activities including integrated employment opportunities
3. Support the Recommendation Made by the Sunset Advisory Commission Staff to Close Six State Supported Living Centers

CRITICAL ISSUE RECOMMENDATIONS

Recommendations to Address MDCP Denials

1. Require the DADS to stop the denial of eligibility for individuals at annual reassessment if nothing has changed in the child or young adult's medical condition
2. Require the DADS to transition those individuals who lose eligibility due to an improvement in their medical condition, but who still need significant supports because of their disability, into another DADS waiver
3. Require the DADS to review the denials of individuals who have lost services due to lack of medical necessity since April of 2013
    - Reinstate services to those who did not have an improvement in their medical condition and
    - offer an alternative to those who are better served under one of the other home and community-based services waivers.