

Support of Public Testimony on the Sunset Commission staff report on HHSC

Candace Aylor, RN, CFP

To: Texas Sunset Commission and staff

RE: Public Testimony provided on the Sunset Commission HHSC report

Date: 11/18/2014

To Whom It May Concern:

My name is Candace Aylor. I came to testify in the Sunset Commission hearing of public testimony on the Sunset staff report for HHSC, on November 13th, 2014. I provided testimony that I opposed Issue 13. Since my testimony was late in the day, and I honored Sen Nelson's request in not reading testimony, I humbly request that each member of the Sunset Commission read this written testimony in its entirety, and thoroughly consider the implications this has, even with recent modifications on sustaining youth and family voices as stakeholders in the decision-making process.

I am a parent advocate for the mental wellness of Texas children and youth. I am a Texan, born & raised... and I LOVE my state! I have also been a nurse in Texas for 13 years. I became an advocate, because I have children that struggle every day to feel mentally well. I have struggled with them, because, historically, we have done a terrible job in Texas of addressing and supporting the mental health needs of our young people.

As a clinical professional, I was able to clearly discern where we were failing. I sought those people and venues where conversations happen on the policies that impact children's mental health services. I am now a stakeholder at the state level, as well as locally and nationally. I currently serve as the Parent Representative and Vice-Chair of the Texas System of Care Consortium, the Policy Lead for the Texas Family Voice Network, and the Parent Representative on the Texas Children Recovering from Trauma initiative with DSHS, endeavoring to transform LMHAs statewide to become fully trauma-informed. As part of that project I have become a member of the National Child Traumatic Stress Network, and am very active within the network, serving on several collaborative groups. I am also the Mental Health listserv moderator for Texas Parent to Parent and Board Member with the Texas Federation of Families for Children's Mental Health and the Trauma Informed Care Consortium in Travis County. I understand the value of my input on improving the system.

Mental health is obviously a priority to the Sunset Commission staff, and I want to thank Sarah Kinkle and the staff at Sunset for the hard work they have done. I noted that "Behavioral" + "Mental Health" are found 172 times in the report when I did keyword searches. That's more than any other health conditions combined. Anecdotal, but tells me mental health is identified clearly as an area of much needed reform.

Mental health is also evidently a priority to the Commission. I want to thank Senator Nelson for her pledge, stated both days of invited and public testimony, to make mental health a priority that will be supported by the budget.

With all the best laid plans and good intentions, I still oppose Issue 13. Although I recognize a modification was recently made, it still does not address the most pressing problems with the recommendations. And, although I recognize reducing of duplication and improving on how advisory boards impact government, these recommendations are not the way to do it. Removing the statutory requirement and reporting function gives us as family member no guarantee our voices will continue to be heard. History tells us we need those requirements. Combining the family and youth stakeholders with agency stakeholder boards will:

- Dilute the topic of mental health among other disabilities, and
- Dilute youth and family voices more than they already are.

Removing staff and agency support of these advisory boards to save money will effectively eliminate stakeholder input from across the state, including poor and/or far away families and youth. ***This will result in the loss of the invaluable capital of in-kind time donated by passionate, invested and engaged stakeholders.***

Dissolving the Texas System of Care Consortium, just put into place last legislative session with SB421, and the Children's Policy Council, which is made up of primarily families and youth, without first developing a plan to, as Ms. Kirkle said in invited testimony on Nov. 12th, improve and elevate stakeholder input, doesn't give youth and families across the state the confidence that we need. Senator Nelson asked Ms. Kirkle on Nov 12th during her invited testimony what would exist in the interim if this plan is accepted. Mr. Kirkle did not answer that part of Senator Nelson's question, and that answer is crucial.

The more involved I have become, the more I have learned and grown as an advocate. I know that a truly sustainable, trauma-informed system of care transformation for all communities across the state is the essential work required for the improvements to the mental health system we are all seeking. Mr. Luce mentioned during invited testimony on Nov 12th, that communities should be able to develop systems that meet their needs, but those systems should also be built on a foundation of widely accepted standards. In mental health, those proven, evidence-based standards can be found within Systems of Care. I heard many statements during the day of invited testimony on Nov 12th, that stakeholder input is a priority. The national model for System of Care transformation requires an advisory board of representatives from every system that impacts children's mental health, AND 50% youth and families. The current structure of the Texas System of Care Consortium includes subcommittees: the Texas Family Voice Network, made up of all family leaders across the state, and ACCEPT, made up of youth and young adults. Both of these groups inform the work of the Texas System of Care Consortium. It is also important to point out that, in the work of reducing silos, the Texas System of Care Consortium has done that, bringing stakeholders from across the systems together to inform HHSC and the legislature on best practices in mental health as applied to the needs of the communities of Texas.

For these reasons, I strongly oppose Issue 13, and recent modifications. I strongly urge the Commission, the Sunset staff and Ms. Kirkle to consider making a plan for sustaining the important work of the advisory boards that includes current and even increased family and youth stakeholder input, while allowing the boards to continue working. I further recommend that no board should be dissolved until a majority has agreed to proposed changes to their structure. I would also urge the Commission to consider adding youth and family stakeholders to their workgroup in considering alternatives to the current recommendations in Issue 13.

Thank you for your time and attention. References follow.

Sincerely,

Candace Aylor, RN, CFP

System of Care

From the [Return on Investment in Systems of Care for Children with Behavioral Health Challenges](#) document published in April 2014 by the National Technical Assistance Center for Children’s Mental Health at Georgetown University’s Center for Child and Human Development:

“An estimated 20% of children in the United States have a diagnosable mental health condition, and mental health disorders are the most expensive conditions in childhood. Children and youth who receive mental health and substance use services in Medicaid, while less than 10% of the overall Medicaid child population, account for an estimated 38% of all Medicaid child expenditures (Pires, et al., 2013). Therefore, states have both quality and cost incentives to implement effective approaches for this population.

*For nearly 25 years, the federal Substance Abuse and Mental Health Services Administration (SAMHSA) has invested resources in the development of systems of care for children with behavioral health challenges and their families. Such resources are intended to improve quality and outcomes and control costs. **A system of care is an approach to the organization and financing of services for children with behavioral health challenges that is informed by well-tested values and principles.** System of care values and principles include a broad array of home- and community-based services and supports, individualized care provided in the least restrictive setting, family and youth involvement, cultural and linguistic competence, cross-system collaboration, customized care management, and accountability.” (Stroul, Pires, Boyce, Krivelyova, & Walrath, 2014)*

A tri-agency letter published in July, 2013, in partnership with the US Department of Health and Human Services (HHS) Administration for Children and Families (ACF), CMS and SAMHSA. The letter, intended as guidance to state Medicaid directors, explains complex trauma and how screening, functional assessment and effective treatments are essential to improve child outcomes. The federal policy guidance letter goes further to detail the link between behavioral and physical health:

“The landmark Adverse Childhood Experiences (ACE) Study demonstrated long-term consequences in adulthood of multiple adverse experiences that occur in childhood, including increased likelihood of stroke, diabetes, cardiovascular disease, cancer, and early death, as well as lower job performance and employment. ACEs are quite common. In this study, half of the over 17,000 participants had been exposed to at least one adverse childhood experience. However, when multiple ACEs were experienced, the results are compounded. Adults who experienced six or more ACEs were likely to die 20 years sooner than those with no ACEs. These consequences represent unfulfilled human potential and significant costs to public systems” (Sheldon, Tavenner, & Hyde, 2013).

[Federal Policy Guidance - Tri-Agency Letter on Trauma-Informed Treatment](#)

That federal policy guidance letter referenced a joint CMS and SAMHSA Informational Bulletin published earlier in 2013, titled *Coverage of Behavioral Health Services for Children, Youth, and Young Adults with Significant Mental Health Conditions* (Mann & Hyde, 2013). According to Dr. Gary Blau, Director of the Division of Service and Systems Improvement and the Center for Mental Health Services, SAMHSA, this is one of the most important publications for any entity endeavoring to improve behavioral health services utilizing systems of care. The programs detailed in this federal policy guidance focus on supplementing the traditional behavioral health benefits package with demonstrated effective home and community-based services, including:

- Intensive Care Coordination: Wraparound Approach
- Peer Services: Parent and Youth Support Services
- Intensive In-Home Services
- Respite Services
- Mobile Crisis Response and Stabilization Services
- Flex Funds (Customized Goods and Services)
- Trauma-Informed Systems and Evidence-Based Treatments Addressing Trauma
- Other Home and Community-Based Services

[Joint CMCS and SAMHSA Informational Bulletin: Coverage of Behavioral Health Services for Children, Youth, and Young Adults with Significant Mental Health Conditions](#)

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Through my clinical experience as a nurse, and my lived experience providing care coordination for family members with severe emotional disturbance, I became involved in children's mental health advocacy at the local, state and federal levels. I have a unique set of skills, knowledge and abilities that have made me a subject matter expert on emerging best practices for mental and behavioral health care. These best practices are not always implemented with fidelity to standard models, often resulting from efforts to afford communities the autonomy to implement new programs and practices in ways that meet their needs and strengths. Unfortunately, this can potentially lead to a loss of quality service delivery. I can assist TMF in identifying care models that will both improve quality and realize cost savings for the consumer, the direct care provider and the health coverage provider.

TMF Health Quality Institute stands poised to address the identified needs through existing and new partnerships with the state and other organizations and as a demonstrated leader in the region, TMF Health Quality Institute has potential to be the leader in the development of quality improvement initiatives for the quality improvement of Texas mental and behavioral health care systems.

With a comprehensive knowledge of best practices in mental and behavioral health services, combined with the extensive experience and knowledge TMF has in quality improvement, and building partnerships with key stakeholders in existing mental and behavioral health initiatives, TMF Health Quality Institute has potential to be the leader in the quality improvement of Texas mental and behavioral health care systems.

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From: [Sunset Advisory Commission](#)
To: [Cecelia Hartley](#)
Subject: FW: Form submission from: Public Input Form for Agencies Under Review (Public/After Publication)
Date: Saturday, October 18, 2014 11:06:52 AM

-----Original Message-----

From: sundrupal@capitol.local [<mailto:sundrupal@capitol.local>]
Sent: Friday, October 17, 2014 5:26 PM
To: Sunset Advisory Commission
Subject: Form submission from: Public Input Form for Agencies Under Review (Public/After Publication)

Submitted on Friday, October 17, 2014 - 17:26

Agency: HEALTH AND HUMAN SERVICES COMMISSION HHSC

First Name: Candace

Last Name: Aylor

Title:

Organization you are affiliated with: N/A

Email:

City: Austin

State: Texas

Your Comments About the Staff Report, Including Recommendations Supported or Opposed:

I oppose issue #1, in part. I do not agree that members of a resulting advisory board of the functional areas should not have voting authority.

Giving so much power to one individual, the Executive Commissioner of HHSC, who is appointed by the governor, circumvents the legislature, and thus the voices of the citizens of Texas.

I oppose in whole Issue 13. This issue and discussion of it in the staff report is ill informed, and minimizes the potential for the voices of youth and families to be entirely eliminated by agreeing to the recommendations of Issue 13. Many stakeholders on these boards are able to attend directly as a result of statutory requirements. Members of these boards are often fully invested in improving the service area on which they are focused. And they are all focused in unique ways. For instance, this recommendation ignores the importance of the significant needs of Texas children struggling with mental illness, thus diluting the voices of invested stakeholders championing best practices. The Texas System of Care Consortium provides a unique opportunity for state, community, youth and family collaboration around children's mental health which may not be able to continue in a different structure. History has shown that the focus on behavioral health services for children, youth and their families can become less of a priority focus among a broad spectrum of child and youth needs. Family and youth voices for children and youth with serious mental health challenges may not be present or less apparent if representation of special populations is consolidated.

Mental and behavioral health is mentioned collectively 172 times in this staff report. It is obvious that it is considered a priority to the writers, and youth and families are grateful. However, there are federal standards that must be met for Texas to be able to deliver the game changing services System of Care can offer our citizens, and that includes having an stand alone advisory board.

It is no surprise that, upon seeing behavioral health in one area, one might assume it is siloed by this structure. The opposite is actually true. It is by having been able to exist to address this critical need amongst stakeholders from EVERY child serving system, that real work has begun.

The System of Care Consortium has only been able to operate for a short time.

Allow it to remain, in addition to any advisory board that includes youth and/or family voice. Require that any resulting boards that are redesigned to have both youth and family voice, including adding a youth position in statute to the System of Care Consortium.

Show Texas that the voices of her children and families will not be left in the hands of administrators to tell us when then think they need to hear from us. This is the only way to ensure that HHSC processes and the legislature, through board reporting, will truly be informed by those they serve.

Any Alternative or New Recommendations on This Agency: The Texas System of Care Consortium could remain as an advisory board to specifically address children's mental health policy under the Medical and Social Services functional area of the newly redesigned HHSC. Under legislation, many stakeholders have been statutorily required to participate, and this has improved communication on children's mental health issues across all child serving systems. This should not only continue, but it should be further recommended to the legislature to include and increase youth and family voice on the Texas System of Care Consortium. I would ask that the Sunset Commission elect to continue the wonderful work that has been done thus far for children's mental health by championing the voices of families and youth, through continuing the legislatively mandated work of the Texas System of Care Consortium to be housed under the Medical and Social Services functional area.

My Comment Will Be Made Public: I agree