October 17, 2014

The Honorable Jane Nelson, Chair

State Senator

The Honorable Brian Birdwell

State Senator

The Honorable Charles Schwertner

State Senator

The Honorable Donna Campbell

State Senator

The Honorable Juan "Chuy" Hinojosa

State Senator

Ms. Dawn Buckingham, M.D.

Public Member

The Honorable Four Price, Vice Chair

State Representative

The Honorable Cindy Burkett

State Representative

The Honorable Harold V. Dutton, Jr.

State Representative

The Honorable Larry Gonzales

State Representative

The Honorable Richard Pena Raymond

State Representative

Mr. Tom Luce

Public Member

Honorable Texas Sunset Advisory Commission Members:

I am submitting these comments on behalf of the Texas Council on Autism & Pervasive Developmental Disorders (Council) on the October 2014 Sunset Report titled *Health and Human Services Commission and System Issues* (HHSC Report).

I commend the Sunset staff on a thorough and comprehensive job on such a large and complicated enterprise. The HHSC Report captures many of the significant issues that need to be addressed across the enterprise that the Council itself has been working diligently to address:

- The immense difficulty for parents and family members in navigating a fragmented system
- The lack of data needed to properly assess and manage services
- The inefficiency of working within the bureaucracy across HHSC and its five service agencies
- The concerns about the transition to managed care for the IDD population

 Overall concerns regarding quality of care in terms of evidence-based practices, addressing supports and services across the life span, and finding and implementing innovative contemporary practices that either provide better outcomes or improve cost structures

These issues, as well several related issues are clearly articulated and addressed in the HHSC Report. The Council supports and endorses the issues and recommendations in the HHSC Report with one fundamental caveat.

As parents of children with significant intellectual, developmental, and physical disabilities, and as professionals with extensive experience working with this population, the Council finds it difficult to give carte blanche trust to a state bureaucracy, specifically a single state agency official, to be sensitive to the needs and concerns expressed by parents, families, professionals, and the public. Yet this is exactly what the HHSC Report recommends by cutting out all legislatively mandated oversight and input by clients and the public. This leaves all input to the sole discretion of the executive commissioner. While the Council supports the goal to make the enterprise more efficient, this is a fundamental tenant that should not be discarded. We urge the Commission to explore options to retain an updated model for this type of legislatively mandated oversight and input from clients and the public to ensure that those most vulnerable in the HHSC system are not inadvertently overlooked or neglected.

The Sunset staff was wise to retain the basic functions of the Council. The prevalence of autism has climbed significantly with a 10-17% increase annually in recent years (Centers for Disease Control and Prevention, 2013). Numbers in such staggering proportions leave significant challenges to any state health and human services agency charged with serving individuals with ASD across the lifespan, from early screening, diagnosis, and intervention to insure an optimal outcome for Texas with disabilities, which translates into saving life span costs for Texas, to the difficulty of providing proper adult services. We trust that new HHSC enterprise that emerges in 2016 will embrace the statutory charges in Chapter 114 of the Texas Human Resources Code.

Thank you for your good work and service to the state of Texas.

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Sincerely,

Frank McCamant

Chair

cc:

Members, Texas Council on Autism & PDD