



**Parents and Allies for Remarkable Texans  
Living at Texas State Supported Living Centers.**

**September 9, 2022**

**Parents and Allies of Remarkable Texans (PART) is made up of individual members who are parents, relatives or guardians of the individuals who live in Texas State Supported Living Centers operated by the Texas HHS Health & Specialty Care System.**

**It is governed by a Board of Directors made up of parents, relatives or guardians representing the various thirteen State Supported Living Centers located in Texas.**

**We believe that State Supported Living Centers should continue to be an important part of the continuum of care provided for the Intellectually and Developmentally Disabled of Texas.**

**PART supports the TEA in providing parents with an array of options in the event their child requires specialized care.**



# Rebecca Japko LVN

**PART President since 2020**

**Member Human Rights Committee since 2019**

**Graduate Texas Partners & Policymaking 2019**

**Resume Highlights:**

- **School Nurse for 7 years in three districts**
- **LVN Brenham State Supported Living Center**
- **Nurse Manager & Executive Director Memory Care Assisted Living**
- **Psychiatric Nurse at Austin State Hospital**

**Sister and guardian to a woman with profound disabilities living at Brenham State Supported Living Center**

3/27/22, 12:32 AM

Children with disabilities face criminal charges from school | Fort Worth Star-Telegram

Subscribe for just \$3 for 3 months



'Broken system' sends North Texas students with disabilities from classroom to courtroom

MARCH 24, 2022 5:00 AM



North Texas parents decry 'excessive' restraints used on kids with disabilities in schools

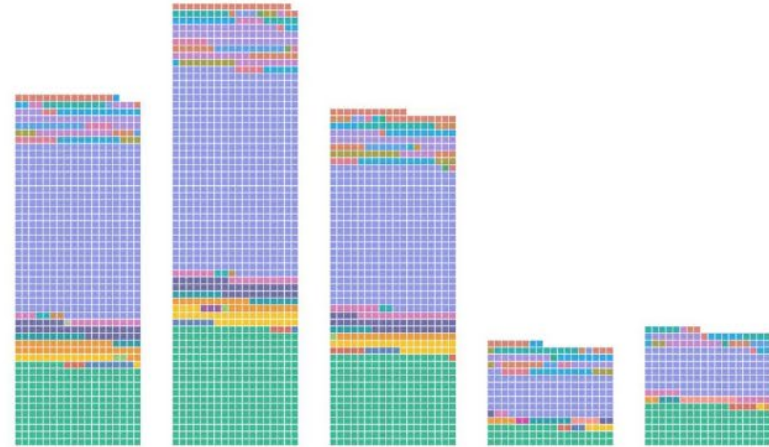
MARCH 24, 2022 5:00 AM

'Broken system' sends North Texas students with disabilities from classroom to courtroom  
North Texas parents decry "excessive" restraints used on kids with disabilities in schools



Students with disabilities face disproportionate discipline at North Texas schools

MARCH 24, 2022 5:00 AM



How many children are referred by schools to Tarrant County Juvenile Detention Center?

MARCH 24, 2022 5:00 AM

Students with disabilities face disproportionate discipline at North Texas schools  
How many children are referred by schools to Tarrant County Juvenile Detention Center

## 2020-2021 districts that disciplined higher than the state average

Districts in Region 11 that disciplined special education students at higher than the state average rate in at least one category.

District	In school suspension percent special education	Out of school suspension percent special education	Disciplinary alternative school placement percent special education
Texas average	5.78%	2.59%	0.94

Source: Texas Education Agency

 A Flourish data visualization

STEVE WILSON [SWILSON@STAR-TELEGRAM.COM](mailto:SWILSON@STAR-TELEGRAM.COM)



**A MELTDOWN** is a medical emergency for those with severe autism and it is not a disciplinary issue.

- **As children with Autism, get older and bigger, meltdowns are harder to handle.**
- **They are disruptive, scary and many times terrify the whole family.**
- **Families experience holes punched in walls, self harming, dishes broken, windows and light fixtures broken, assaults on parents and siblings.**
- **Elopement is always a possibility no matter the age.**

[Act now for severe autism](#)

 **PART**

# National Council Severe Autism



[ncsautism.org](https://ncsautism.org)

Pursuing recognition, policy and solutions for the surging population of individuals, families and caregivers affected by severe forms of autism and related disorders.

## Profound Autism

A proposed term that captures the following:

1. Need for 24 hour access to an adult when problems arise
2. Inability to be alone in a residence
3. Inability to manage basic ADLs

As proposed by Lord et al. in the Lancet Commission on the future of care and clinical research in autism, 2022





## How many 8-year-old children were identified with ASD in 2018?

About **1 in 44** (2.3%) 8-year-old children were identified with ASD by the ADDM Network.

## How did the percentage of children identified with ASD vary across geographic areas?

The percentage of children identified with ASD **varied widely** across geographic areas.

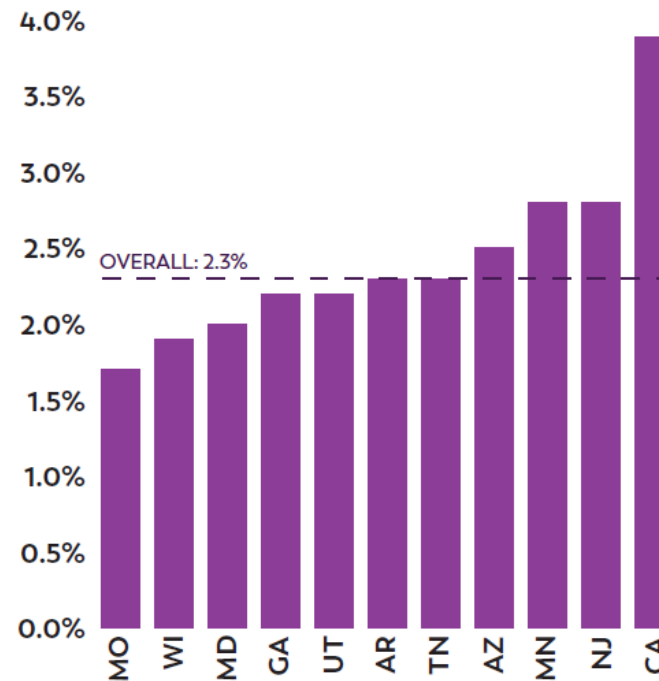
Across the ADDM Network, the percentage of 8-year-old children who were identified with ASD ranged from a low of **1.7% or 1 in 60 children in Missouri** to a high of **3.9% or 1 in 26 children in California**. Sites with limited or no direct access to special education records had lower percentages of children identified with ASD.

**1 in 44**

**8-year-old** children were identified with ASD in 2018 by the ADDM Network

### Percentage of 8-year-old children

identified with ASD by ADDM Network Site



**Approximately 2.3% of children in the U.S. are identified with having autism. This rate has more than doubled over the past two decades.**

**Between 27–50% percent of those children have severe autism & approximately 50% have IDD.**

# Severe challenging behaviors in children, teens and adults with severe autism

## Forms of Problem Behavior

Self injurious behavior	<b>SIB</b>	<ul style="list-style-type: none"> <li>• head banging, head hitting</li> <li>• self biting</li> <li>• pulling out own hair</li> <li>• skin picking</li> <li>• face slapping</li> </ul>	<ul style="list-style-type: none"> <li>• eye poking</li> <li>• self scratching</li> <li>• lip/tongue/gum biting</li> <li>• knee to face, chin</li> <li>• tooth self-extraction</li> </ul>
	<b>Aggression</b>	<ul style="list-style-type: none"> <li>• hitting</li> <li>• kicking</li> <li>• scratching</li> </ul>	<ul style="list-style-type: none"> <li>• biting</li> <li>• pinching</li> <li>• choking</li> </ul>
	<b>Disruption</b>	<ul style="list-style-type: none"> <li>• throwing objects</li> <li>• breaking/ripping items</li> <li>• knocking over furniture</li> </ul>	<ul style="list-style-type: none"> <li>• screaming</li> <li>• spitting</li> <li>• breaking windows, doors</li> </ul>
Swallows non-food items	<b>Pica</b>	<ul style="list-style-type: none"> <li>• ingestion of: rocks</li> <li>• dirt, miracle grow</li> <li>• feces, painted wood</li> </ul>	<ul style="list-style-type: none"> <li>• glass, clothes</li> <li>• oil, pens, toothbrush</li> <li>• metal, metal spiral from notebook</li> </ul>
	<b>Other PB</b>	<ul style="list-style-type: none"> <li>• elopement</li> <li>• fecal smearing</li> <li>• disrobing</li> </ul>	<ul style="list-style-type: none"> <li>• inserting objects into electrical outlets</li> <li>• jumping out of a window</li> <li>• excessive stereotypic behavior</li> </ul>

Lee E. Wachtel, M.D. Medical Director, Neurobehavioral Unit Kennedy Krieger Institute  
 Imtiaz Mubbashar, M.D. - Wah Medical College in Pakistan & Duke University Hospital

**INSAR 2022**  
**Hybrid Annual Meeting**  
**Special Interest Groups**



**May 13, 2022**



Autism home away from home

Can anyone recommend a place they like that is like a campus for the more severe on the spectrum? A place that has everything on site including recreation, nurses and doctors, and work opportunities?

4

27 Comments

Like

Comment

View 3 more comments

All Comments



There is one in NJ and Chicago and that is about it. There definitely needs to be more of these.

Like · Reply · 2h



1



What is the one in Chicago?

Like · Reply · 1h



1



where in Chicago??

Like · Reply · 57m



What is the one in NJ?



If I ever win the lottery, this is what I would do with the money. Needs to be a places like this all over the country

Like · Reply · 1h



2

# Parents are looking and waiting for help

The Neurobehavioral Unit (NBU) at Kennedy Krieger Institute  
Baltimore, MD 21205

16-bed inpatient unit dedicated to the assessment and treatment of children and young adults with developmental disabilities and intellectual disabilities who have severe behavioral problems.

KKI Neurobehavioral Unit Waitlist  
Waiting time for admission  
6-24+ months

# Common Problems in ASD

- Survey of 487 school children identified as ASD in their IEP-parent report
  - **Easy frustration (60%)**
  - **Inattention (50%)**
  - **Hyperactivity (40%)**
  - **Temper tantrums (30%)**
  - **Irritable (20%)**
  - **Fearful/anxious (13%)**
  - **Harming self (SIB) (11%)**
  - **Destroying property (11%)**
  - **Physical aggression (5%)**

Luc Lecavalier 2006

**These were children with autism who are out in the community (in school) who were not assessed in a clinical setting.**

**11% of 487 =  
53 school children  
5% of 487 = 24**



# Prevalence of Serious Challenging Behavior

**Aggression:** *Physical aggression toward other people not verbal aggression*

• Kanne & Mazurek, 2011

1380 youth using the ADI-R

The Autism Diagnostic Interview-Revised (ADI-R) is a standardized interview used to diagnose autism and distinguish it from other developmental disorders.

**Aggression towards:**  
68 % parents  
49% non-caregiver

• Mazurek et al., 2013

**ATN: Autism Treatment Network**

1584 youth ATN Parent Survey  
Is child currently demonstrating physical aggression?  
53% yes

PART

**Psychiatric Hospitalization for Serious Emotional and Behavioral Challenges in Autism—Matthew Siegel, M.D.**

<https://www.youtube.com/watch?v=WhsVznIRY-w>

# Multi-disciplinary Treatment Team

- **Child/Adolescent Psychiatry**
- **Behavior Psychologist**
- **Behavior Analyst (BCBA)**
- **Special Education**
- **Speech Language Pathologist**
- **Occupational Therapist**
- **Nursing**
- **Social Work**
- **Dietician**

# Consensus Best Practices Recommendations for ASD

- **Create therapeutic spaces and appropriate activities**
- **Provide STRUCTURED educational services**
- **Provide direct care staff specific training**
- **A longer length of stay to change behavior**
- **Assess co-morbidities and address them along with the primary problem**



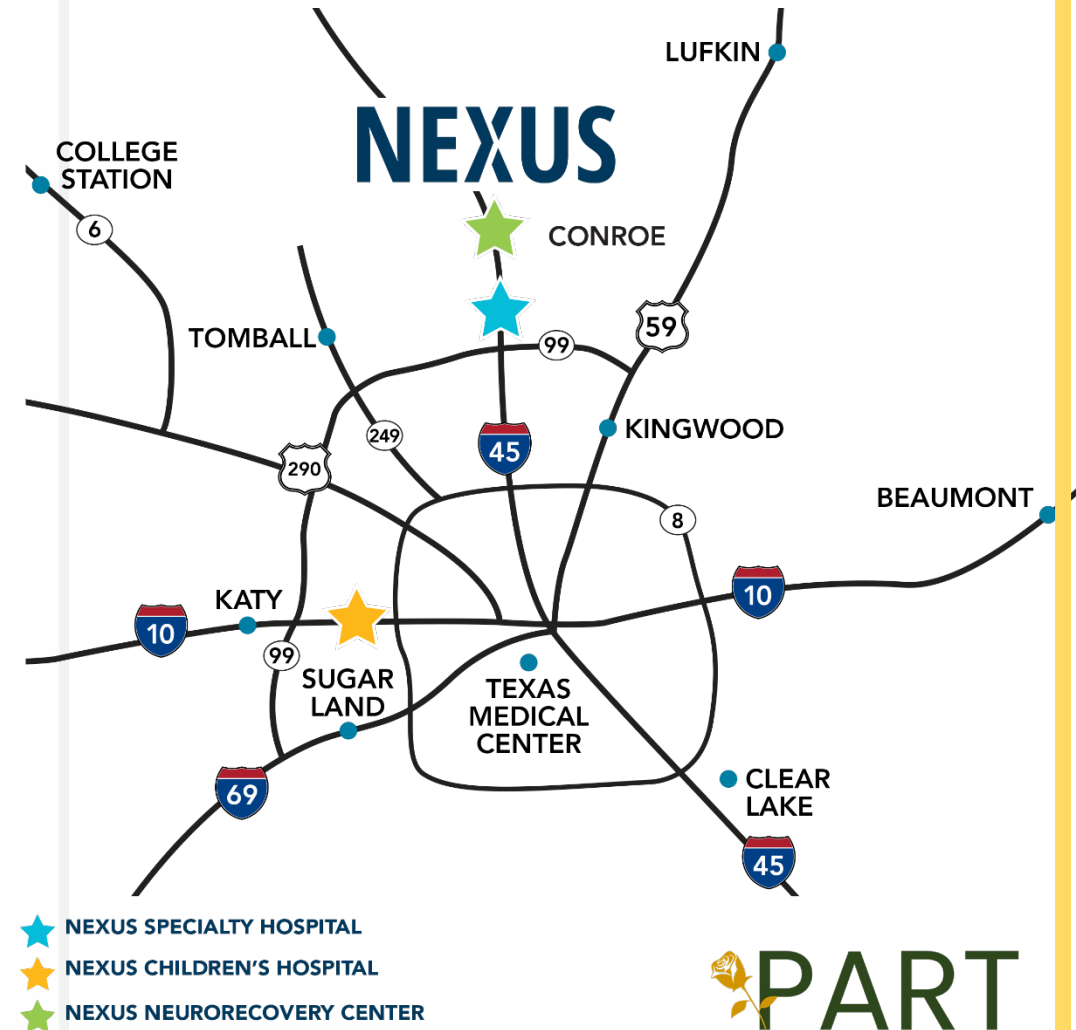
## NEUROBEHAVIORAL SERVICES AT LEADING HOUSTON CHILDREN'S HOSPITAL

Nexus Children's Hospital, a specialty pediatric hospital in Houston, Texas, manages complex patients that have behavioral issues making them a challenge to be treated in the acute care setting, but also have medical issues that are preventing admission to a behavioral health facility. Working with patients who may have been unsuccessful in traditional rehabilitation environments, Nexus' patients benefit from our individualized treatment plans and home-like environment.

Providing treatment to a traditionally underserved population, Nexus Children's Hospital neurorehabilitation services focus on minimizing handicapping conditions that stem from a whole host of injuries including falls, asphyxiation, shaken baby syndrome, near drowning, and motor vehicle accidents. Depending on the severity of the trauma, our patients have a range of physical, emotional, and mental issues from concussions to severe brain injury.

Our interdisciplinary team, consisting of psychiatrists, neurologists, and psychologists, care for our young patients on-site at our family-centric hospitals, eliminating the need to fractionalize care. Working together, our team prescribes behavioral interventions, rehabilitation, and pharmacological therapy in the form of individualized care plans.

Because this patient population has experienced an injury to their vital frontal lobe when it was still developing, executive functions have been disrupted. Since brain cells were damaged before our patients had learned valuable skills that help them control emotions and behavior, our team delivers habilitation strategies so the brain can begin to mimic developmentally appropriate actions. Through these tactics, our patients begin learning skills they would have developed naturally during maturation. Helping our patients develop these skills leads them towards a more productive and meaningful life is the main goal of our program.





## State Supported Living Centers

SSLCs provide 24-hour residential services in a structured environment for people with intellectual disabilities. Residents live in a safe, campus-based setting where they receive individualized onsite behavioral treatment and health care, including primary and specialty medical care, psychiatry, nursing and dental. Additional on-campus services include:

- Clinical therapies provided by full-time professional staff
- 24/7 one-to-one supervision as needed
- 24/7 video surveillance of living, dining and day program areas
- Vocational and employment services, skills training and habilitation services
- Customized adaptive aids, including seating and positioning devices
- Specialized, quality-controlled meals to fit a wide variety of diets
- Religious services for different faiths

SSLCs also provide services such as transportation and staff, so residents may maintain connections with their families and natural support systems. Planned activities, such as shopping, dining out, going to movies and other leisure activities provide recreation in residents' local communities.

There are 13 SSLCs across Texas (Abilene, Austin, Brenham, Corpus Christi, Denton, El Paso, Harlingen, Lubbock, Lufkin, Mexia, Richmond, San Angelo and San Antonio). Each SSLC serves between 60 and 460 residents.

# Texas State Supported Living Centers



Brenham SSLC

# 5 Criteria must be met to have a Civil Commitment to a SSLC

HSC Sec. 593.052. ORDER FOR (CIVIL) COMMITMENT. (a) A proposed resident may not be committed to a residential care facility (SSLC) unless:

- (1) the proposed resident is a person with an intellectual disability;
- (2) evidence is presented showing that because of the proposed resident's intellectual disability, the proposed resident:
  - (A) represents a substantial risk of physical impairment or injury to the proposed resident or others; or
  - (B) is unable to provide for and is not providing for the proposed resident's most basic personal physical needs;
- (3) the proposed resident cannot be adequately and appropriately habilitated in an available, less restrictive setting; and
- (4) the residential care facility provides habilitative services, care, training, and treatment appropriate to the proposed resident's needs.

At least 2 Texas courts of appeals have found that in order to commit a person for long-term placement in a State Supported Living Center, each of the elements in subsection 593.052(a) of the Texas HSC must be proven BEYOND a reasonable doubt (highest burden of proof).

- See *Pratt v. State*, 907 S.W.2d 38, 44 (Tex. App.—Dallas 1995, writ denied);
- In re *A.W.*, 443 S.W.3d 405, 414 (Tex. App.—Eastland 2014, no pet.).

# Oversight-Ensuring the rights and safety of residents



## State Operations Manual: Appendix J

- Guidance to Surveyors: Intermediate Care Facilities for Individuals with Intellectual Disabilities



## Dept of Justice Settlement Agreement-June 2009

- Agreement to make meaningful changes in the operations of each SSLC to achieve targeted improvements in services and supports for individuals.



## Independent Ombudsman: SB 643-81(R)

- Their responsibility is to protect the rights of people who live at SSLCs and make biannual reports to the Governor and other elected officials.



## Human Rights Officer (HRO)

- Ensures the legal and basic human rights of residents of the SSLC are promoted and protected.

# CMS State Operations Manual Appendix J

## Conditions of participation

1. § 483.410 Governing body and management.
2. § 483.420 Client protections.
3. § 483.430 Facility staffing.
4. § 483.440 Active treatment services.
5. § 483.450 Client behavior and facility practices.
6. § 483.460 Health care services.
7. § 483.470 Physical environment.
8. § 483.475 Emergency preparedness.
9. § 483.480 Dietetic services.



**ICF/IID must meet the standards specified in subpart I of part 483 of Title 42**

**Current Compliance with the Settlement Agreement (as of 6/23/2022)**

Section C: Restraints	Section D: Incident Management	Section J: Psychiatric Care and Services	Section K: Psychology	Section L: Medical Care	Section N: Pharmacy	Section Q: Dental
10 SSLCs in Substantial Compliance	12 SSLCs in Substantial Compliance	5 SSLCs in Substantial Compliance	6 SSLCs in Substantial Compliance	1 SSLC in Substantial Compliance	7 SSLCs in Substantial Compliance	5 SSLCs in Substantial Compliance
Abilene	Abilene	Abilene	Abilene	Austin	Abilene	Abilene
Austin	Austin	Austin	Austin		Austin	Austin
Brenham	Brenham	Corpus Christi	Lufkin		Brenham	Brenham
Denton	Corpus Christi	Denton	San Antonio		Corpus Christi	Corpus Christi
Lubbock	Denton	Lubbock	Richmond		Denton	Denton
Lufkin	El Paso		San Angelo		El Paso	
Mexia	Lubbock				Lubbock	
Richmond	Lufkin					
San Angelo	Mexia					
San Antonio	Richmond					
	Rio Grande					
	San Antonio					

# Dept of Justice Settlement Agreement

- The centers are evaluated by independent monitors every nine months under five domains of care through Quality Service Reviews that focus on outcomes for individuals.
- One goal of implementing the QSR system is to establish clear metrics that state staff may use to evaluate performance of centers.
- Following each review the monitors submit a report detailing their on-site visits.
- HHSC, DOJ, and the independent settlement agreement monitors worked together at the conclusion of the eighth round of settlement agreement monitoring reviews to restructure and refine the criteria and tools utilized in determining compliance with the provisions of the settlement agreement.

## State Supported Living Center Long Range Planning Report



# SSLC Independent Ombudsman



*The Office of the Independent Ombudsman for State Supported Living Centers. Front row left to right: Adam Parks, Talya Hines, Seth Bowman, Jessica Rosa, Candace Jennings. Second row left to right: Edward Leal, Deatrice Potlow, Isabel Ponce, Carrie Martin, Brian Morton, Susan Aguilar, James Clark, Kellen Davis, Horacio Flores, Brianna Teague, Brenda Frausto, Gevona Hicks. Not pictured: Jill Antilley.*

- **The SSLC Independent Ombudsman is an appointee of the Governor.**
- **An Assistant Independent Ombudsman (AIO) oversees and audits their specific SSLC and is a confidential intermediary for residents, clients, family members, or guardians.**
- **The biannual report contain the recommendations of each AIO regarding their review of resident rights, staff to client ratios, and DSP training.**
- **The report also provides an account from each ombudsman’s cases to add perspective to the data and show the unique opportunity their role allows.**
- **The majority of investigations are initiated by the ombudsmen which demonstrates their inherent independence.**

# YOUR RIGHTS.....

In a State Center

Published by  
Texas Department  
of Aging and  
Disability Services

## Human Rights Officer

- The Human Rights Officer (HRO) reviews all rights restrictions recommended by the Interdisciplinary Team.
- The HRO conducts the meetings of the Human Rights Committee (HRC).
- The HRO ensures that the Legally Authorized Representative (LAR/guardian) has agreed to the restrictions.
- The individual or the LAR has the right to attend the HRC meeting to inform the HRC about their feelings or any concerns regarding the rights restriction(s).
- The HRC reviews any Interdisciplinary Team recommendations that would limit one or more rights of a resident.
- The HRC is made up of the HRO, a LAR, a community member and two SSLC professionals.
- This review is a due process to ensure that any resident's rights restrictions are necessary and appropriate.

# SB 643-81(R)

- **Video camera surveillance in common areas of each SSLC**
- **Mandatory FBI and DPS fingerprint background checks for SSLC employees & volunteers and ensure that it receives real-time arrest information**
- **Random drug tests of SSLC employees in our SSLCs**
- **Toll-free hotline to report any abuse, neglect and misconduct at our SSLCs & the number must be posted prominently at every facility**
- **Authorizes the Texas Office of Inspector General to assist local prosecutors in cases of any abuse, neglect, or exploitation**
- **Requires HHSC to contract with an independent party to conduct mortality reviews of any deaths in a state school**
- **Extensive Center employee training – 3 weeks orientation & 2 weeks orientation on the home**
- **Center directors additional duties added :**
  - ❑ **Ensuring that the civil rights of center residents are protected**
  - ❑ **Ensuring the health, safety, and general welfare of center residents**
  - ❑ **Monitoring the arrival and departure of individuals to and from the Center as appropriate to ensure the safety of residents**





**PARENTS AND ALLIES FOR REMARKABLE TEXANS  
LIVING IN TEXAS STATE SUPPORTED LIVING CENTERS**

## **CHOICES FOR A LIFETIME OPTIONS FOR ALL**

**PART supports the TEA in providing parents with the information on all options in the event their child requires specialized care.**

**The parent or guardian is an active part of the Interdisciplinary Team at the SSLCs and they may request a meeting of the Team at any time to discuss concerns.**

**The utilization of the SSLCs will build capacity to serve these children with most severe behaviors.**

**Ultimately structured care for these children will prevent the cycle of trauma and provides life sustaining support.**

# Thank you

**“And I think what it really comes down to is really trying to match distinct services to distinct needs.”**

**Joaquin Sapien, Reporter and one of the Producers for the PBS Frontline documentary “Right to Fail”**