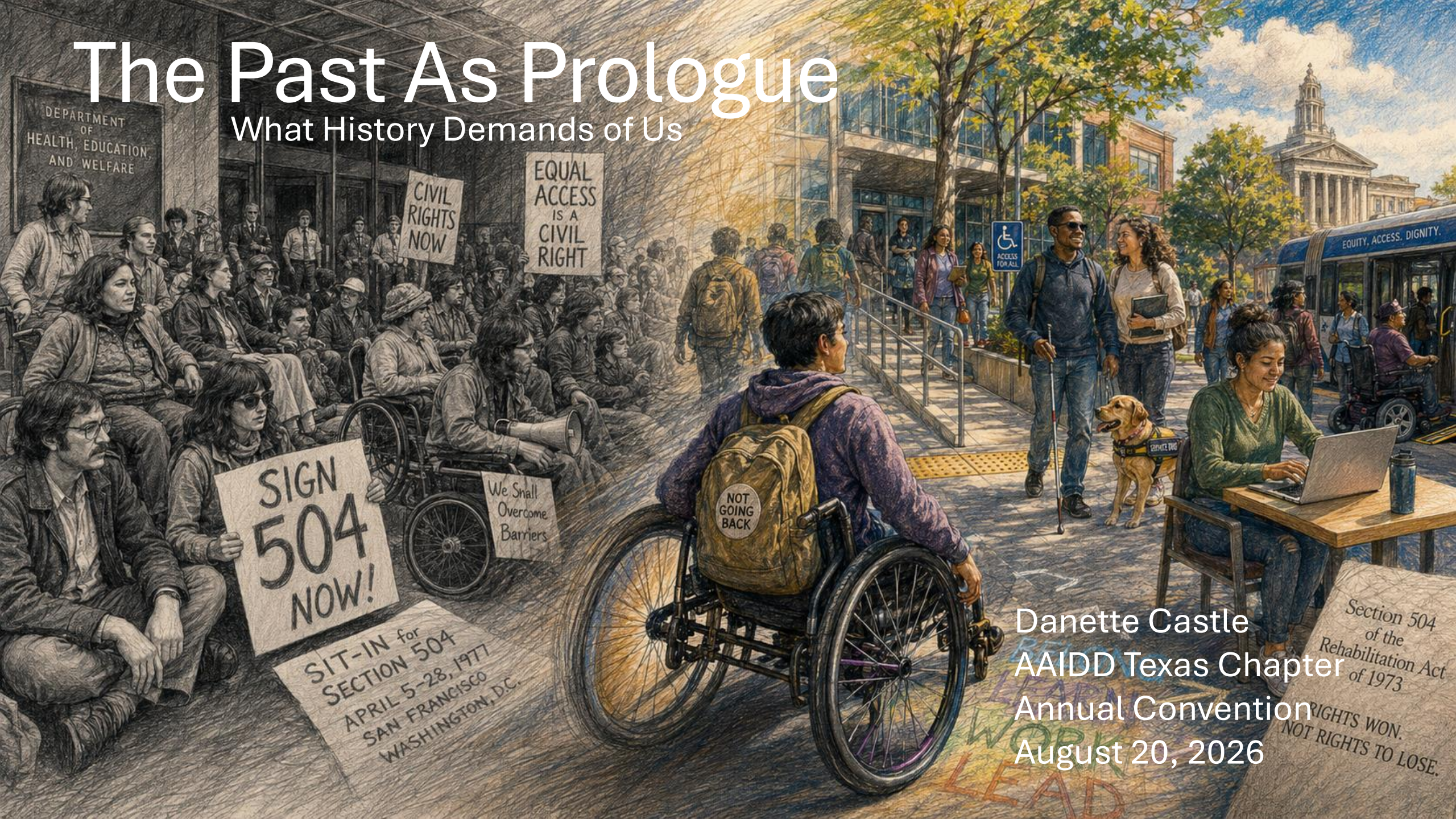
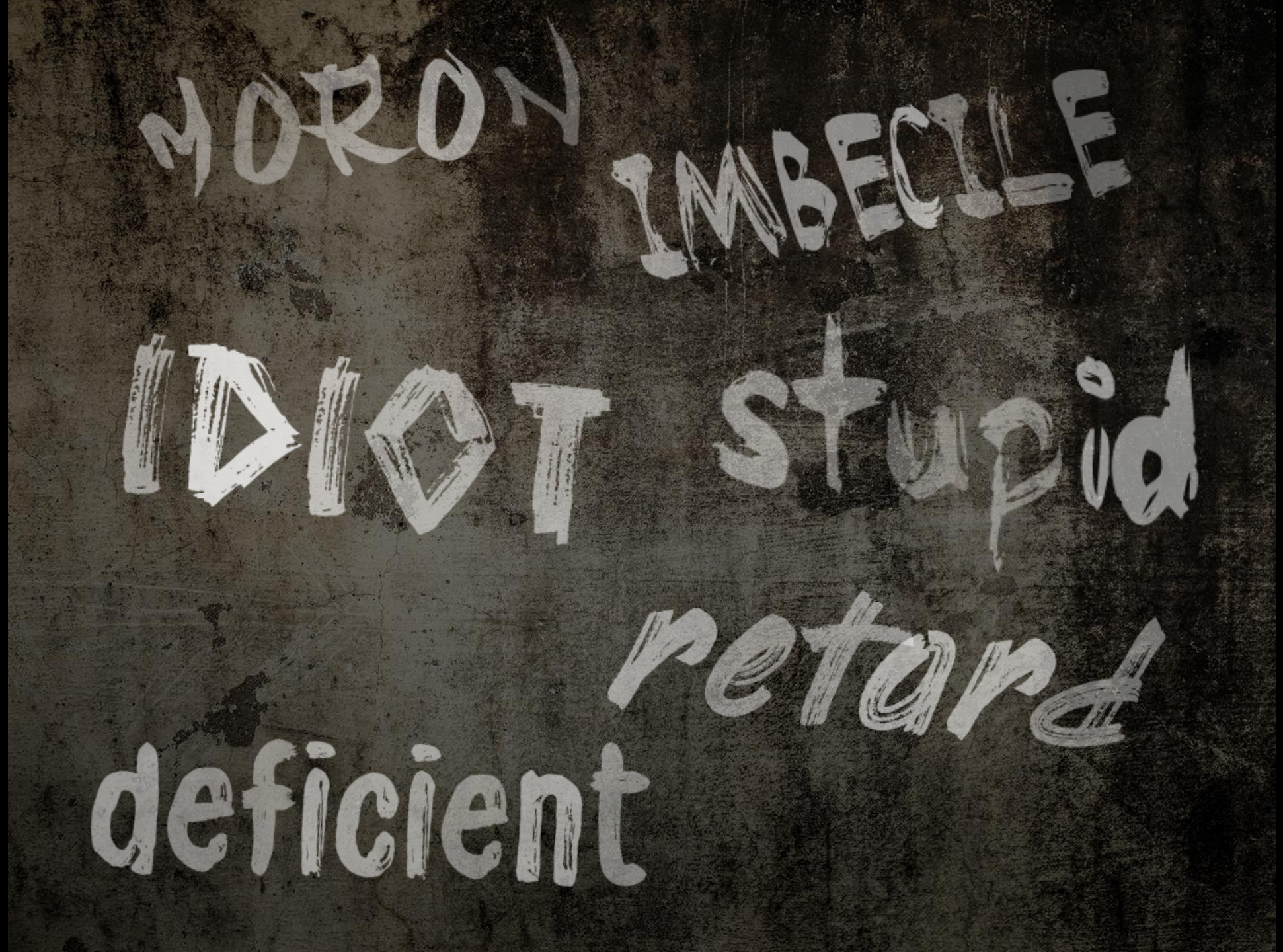
The Past As Prologue

What History Demands of Us



Danette Castle
AAIDD Texas Chapter
Annual Convention
August 20, 2026


MORON
IMBECILE
IDIOT
stupid
retard
deficient

1870

Present

aaidd American Association on Intellectual and Developmental Disabilities

1876–1906 Association of Medical Officers of American Institutions for Idiotic and Feebleminded Persons

1906–1933 American Association for the Study of the Feebleminded

1933–1987 American Association on Mental Deficiency

1987–2007 American Association on Mental Retardation

2007– American Association on Intellectual and Developmental Disabilities

The Arc

1950–1952 National Association of Parents and Friends of Mentally Retarded Children

1952–1973 National Association for Retarded Children (NARC)

1973–1981 National Association for Retarded Citizens (NARC)

1981–1992 Association for Retarded Citizens of the United States (ARC)

1992– The Arc of the United States (or simply The Arc)

The Past as Prologue:

What History Demands of Us

Catalysts for Change

U.S. Supreme Court Olmstead v. L.C. (1999)

HB 2377 Local Authority pilot (1995)

Federal Americans with Disabilities Act (ADA) of 1990

Texas Mentally Retarded Persons Act (MRPA) of 1977

Federal P.L. 94-142 Education of the Handicapped Act (1975)

Lelsz v. Kavanagh class action lawsuit (1974)

Section 504 of the Rehabilitation Act of 1973

Presidents Committee on Mental Retardation established (1966)

***Christmas in Purgatory* by Burton Blatt published (1966)**

Federal Social Security Act amendments Medicare/Medicaid (1965)

Texas MHMR Act of 1965

Federal Community Mental Health Act of 1963

Association for Retarded Children of the U.S. formed (1951)

Federal Social Security Act (1935)

Catalysts for Change

Sunset Review Process Initiated (2026)

SB 26 LMHA/LIDDA reporting, services, and programs (2023)

SB 944 Commitments to State Supported Living Centers (2023)

General Appropriations Act Funding for Specialized MH for IDD Pilots (2017)

Boys in the Bunkhouse by Dan Barry published (2017)

General Appropriations Act Crisis Funding (2015)

Sunset Reorganization of Texas HHS agencies (2015)

SB 7 IDD transition to managed care (2013)

HB 1481 Respectful Language (2011)

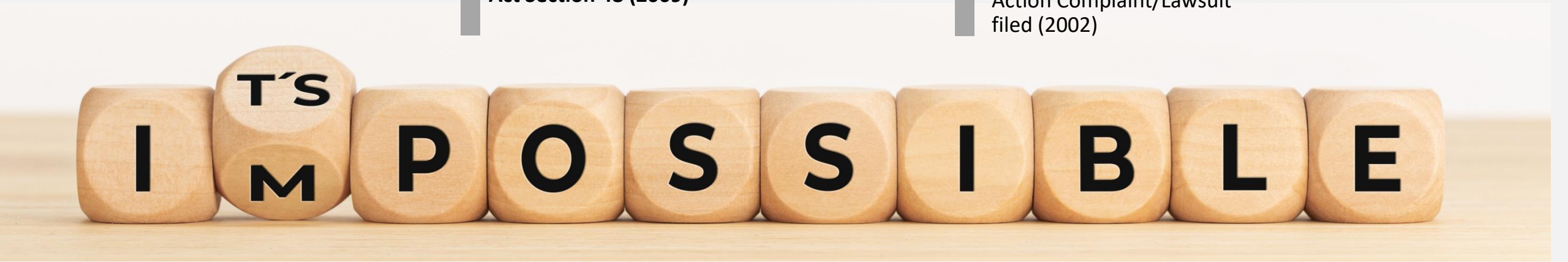
Federal Rosa's Law (2010)

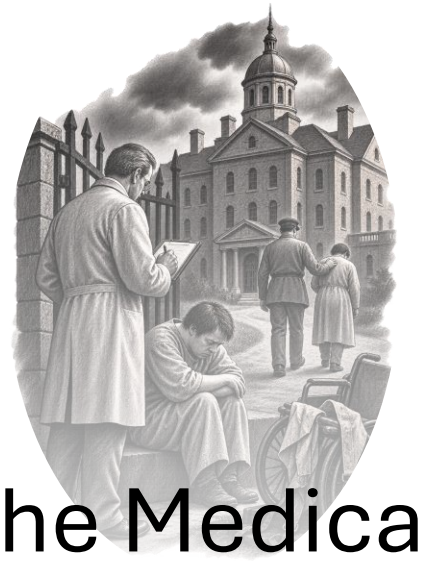
General Appropriations Act Section 48 (2009)

Interim Select Committee on Texas ICF programs (2008)

HB 2292 Reorganization of Texas HHS agencies (2003)

Travis v. Gilbert Class Action Complaint/Lawsuit filed (2002)





The Medical & Institutional Model

19th Century

The Charity Model

Early to Mid–20th Century

Shift Toward Civil Rights

1960s–1970s

Rights & Self-Advocacy Model

1990 to Present

The Past as Prologue:

What History Demands of Us

H-E-B

Hogg Foundation *for* Mental Health

Community Mental Health and Mental Retardation Act of 1963

- Federal funding for Community MH and MR
- Community-based service philosophy
- Emphasized natural support systems, new medications, regionalized relationship with state facilities
- Catalyst for state legislation and funding

Texas MHMR Act of 1965
[Texas Health & Safety Code 534.001]

- Authorized local taxing authorities (counties, cities, hospital districts, school districts) to
  - create local governmental entity
  - appoint local governing board
  - develop community alternatives to treatment in large residential facilities
- Established local, state and federal partnership to create a community-based system for people with mental illness and intellectual disabilities
- Created the Texas Department of MHMR


CHRISTMAS IN PURGATORY
A Photographic Essay on Mental Retardation
BURTON BLATT
FRED KAPLAN

From Access → to Inclusion → to Integration

Section 504

"You cannot discriminate against me because I have a disability

P.L. 94-142

"A child with a disability has a right to an education alongside children without disabilities to the maximum extent appropriate

The ADA

"Disability discrimination is a civil-rights issue throughout public life, including state and local government services

Olmstead

"Unnecessary segregation in an institution can itself be discrimination, and people should have access to community services when the legal criteria are met

Together these reflect a major evolution in American disability policy:

From Access → to Inclusion → to Integration

November 29, 1975

President Gerald Ford

Public Law 94-142

Education for All Handicapped Children Act

Guaranteed a free, appropriate public education to each child with a disability in every state and locality across the country

THE WORST HANDICAP OF ALL?

Being deprived of the right to education

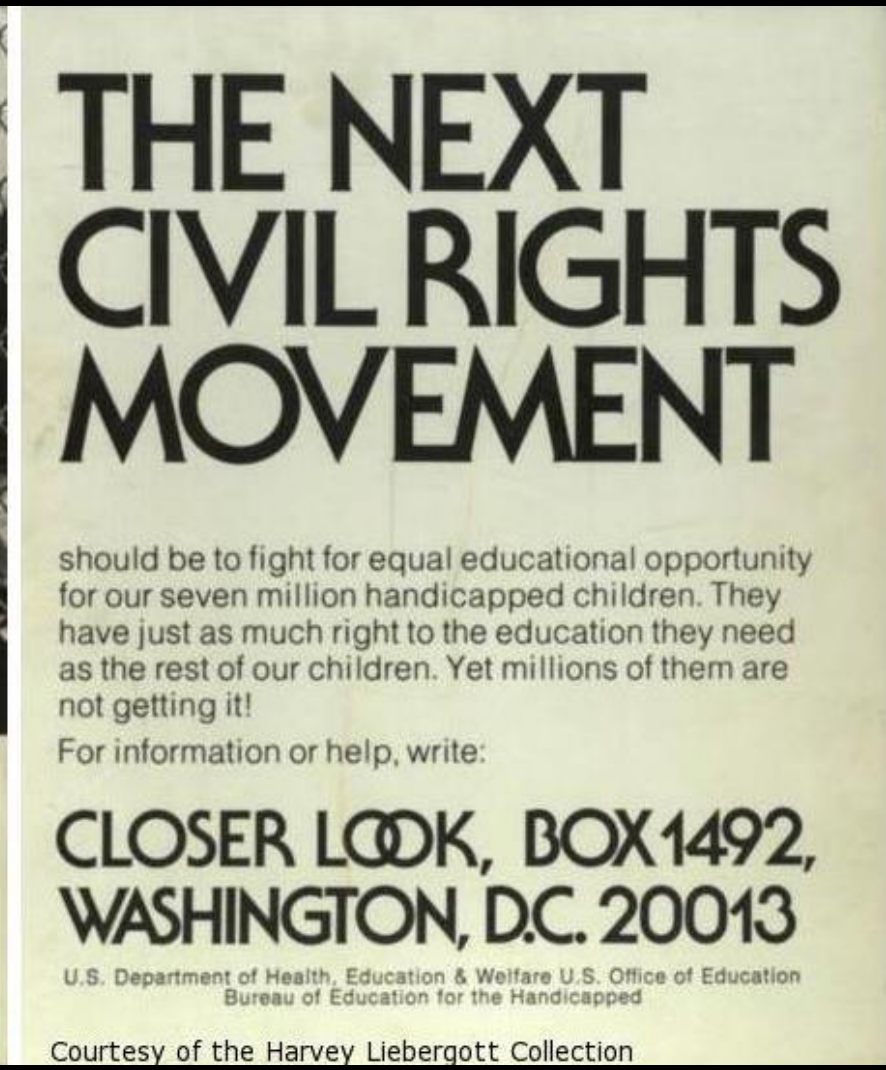
There are seven million handicapped children in America. They need special education to develop their full potential as people. And they have a right to that education. Yet less than half the children who need special education are getting it.

For information about special education for handicapped children – or for help – write:

CLOSER LOOK, BOX 1492, WASHINGTON, D.C. 20013

U.S. Department of Health, Education & Welfare U.S. Office of Education Bureau of Education for the Handicapped

Courtesy of the Harvey Liebergott Collection



THE NEXT CIVIL RIGHTS MOVEMENT

should be to fight for equal educational opportunity for our seven million handicapped children. They have just as much right to the education they need as the rest of our children. Yet millions of them are not getting it!

For information or help, write:

CLOSER LOOK, BOX 1492, WASHINGTON, D.C. 20013

U.S. Department of Health, Education & Welfare U.S. Office of Education Bureau of Education for the Handicapped

Courtesy of the Harvey Liebergott Collection

Courtesy of the Harvey Liebergott Collection

ADMINISTRATION BUILDING - STATE HOSPITAL - WOODWARD - IA - 5164.


HEMLOCK
Joe

Medicaid Role in IDD Service Development

1974 ICF/MR for State School Beds

1976 Community ICF/MR

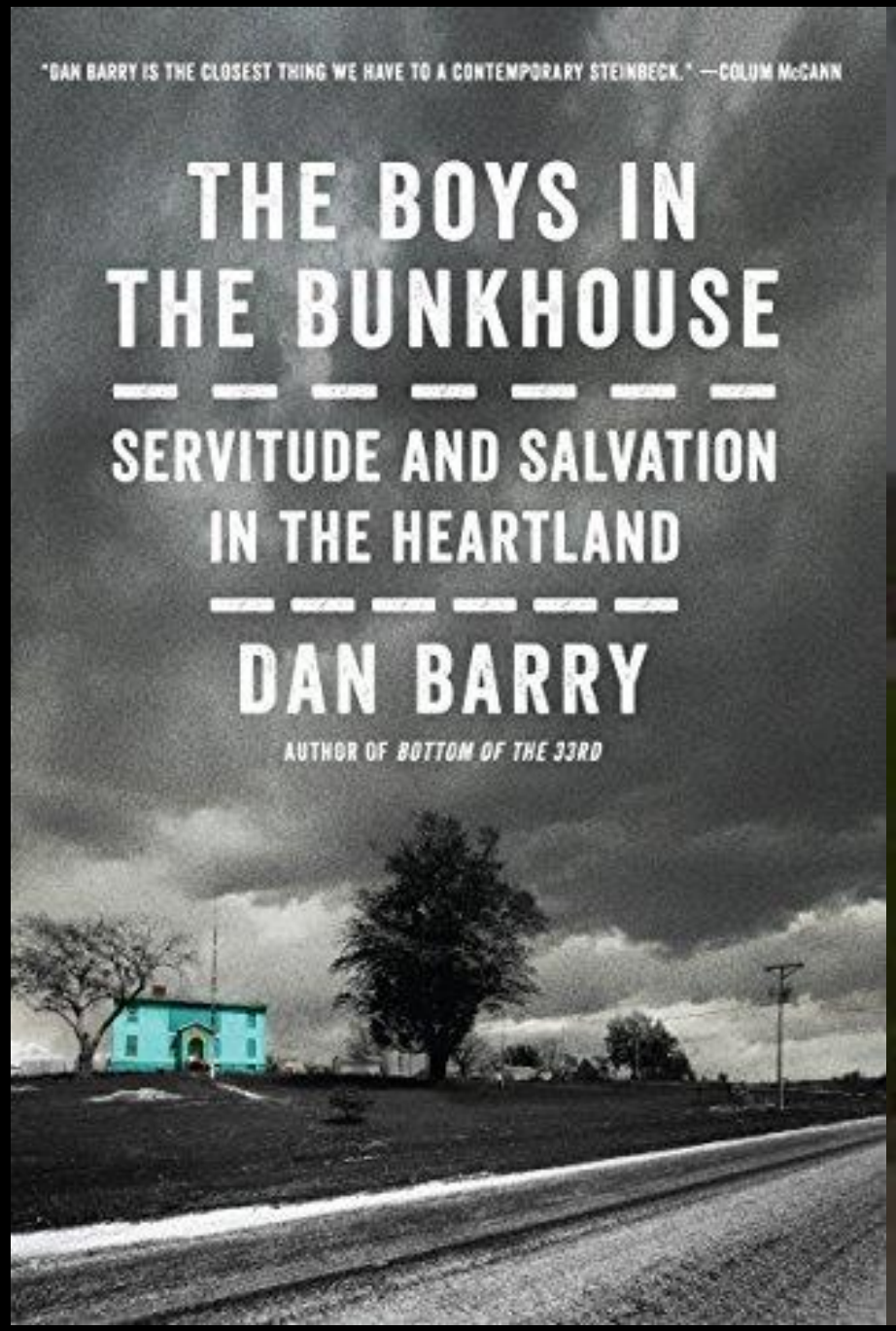
1985 HCS Waiver

1993 Expanded HCS Waiver for State School to Community Movement

1996–1997 Expanded HCS Through Refinancing Strategies and Community Slots

1997 ICF & HCS Rate Reimbursement Methodologies Changed

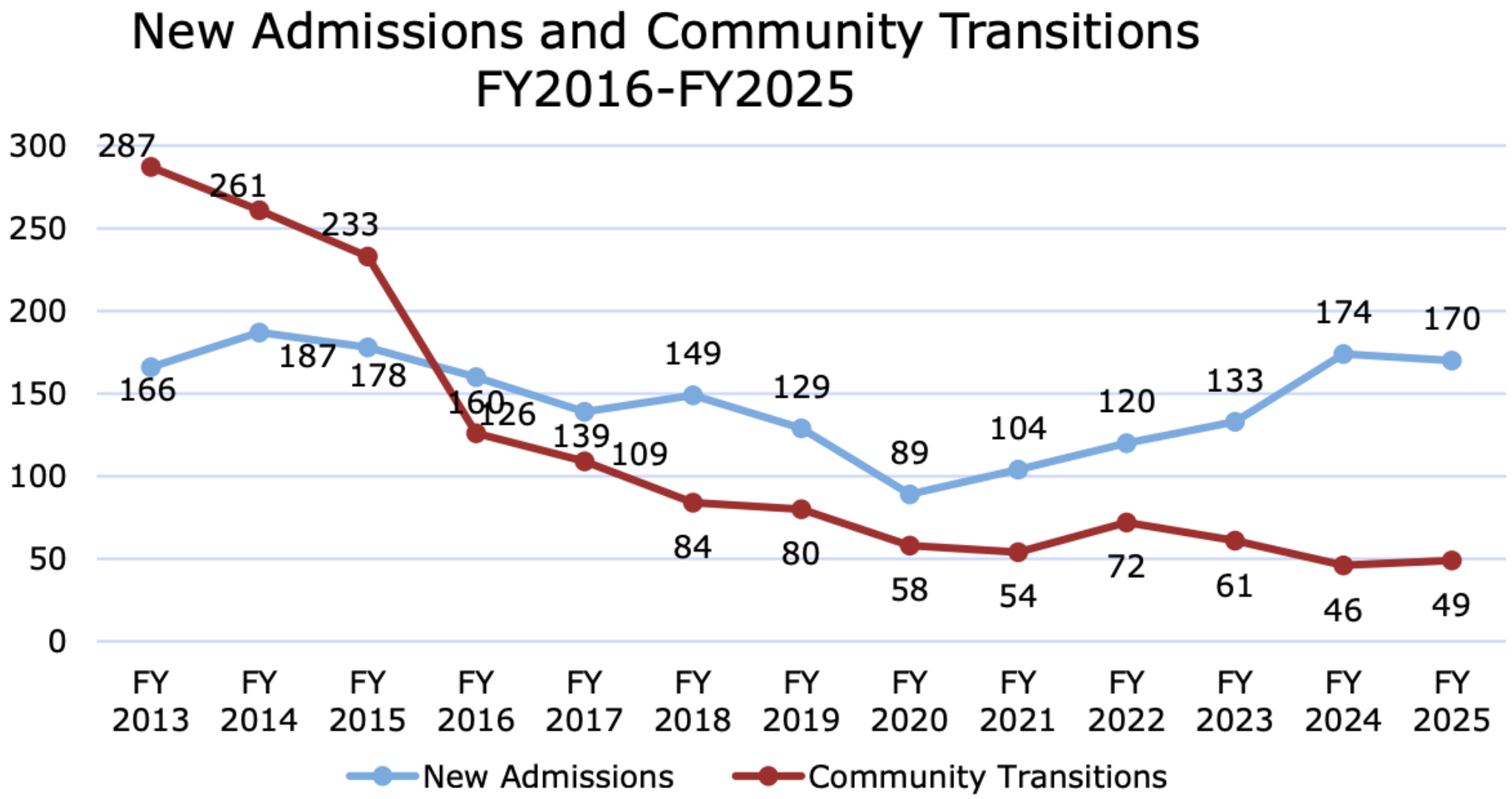
2004 Texas Home Living Waiver


"DAN BARRY IS THE CLOSEST THING WE HAVE TO A CONTEMPORARY STEINBECK." —COLUM McCANN
THE BOYS IN THE BUNKHOUSE
SERVITUDE AND SALVATION IN THE HEARTLAND
DAN BARRY
AUTHOR OF BOTTOM OF THE 33RD

2014–2015 Sunset Review of Texas HHSC and the Department of Aging and Disability Services (DADS)

SSLC Closures	Require DADS to close the Austin State Supported Living Center
Establish Closure Commission	Form SSLC Closure Commission to evaluate remaining 12 SSLCs and select 5 additional facilities for closure
Resource Reallocation	Shift Funds saved from closures to build up community-based capacity
Crisis Management	Create and scale mobile crisis management teams statewide to support individuals with complex behavioral and developmental needs in community settings
Medical Staffing	Increase staffing ratios and reimbursement levels for individuals requiring specialized medical care

State Supported Living Centers

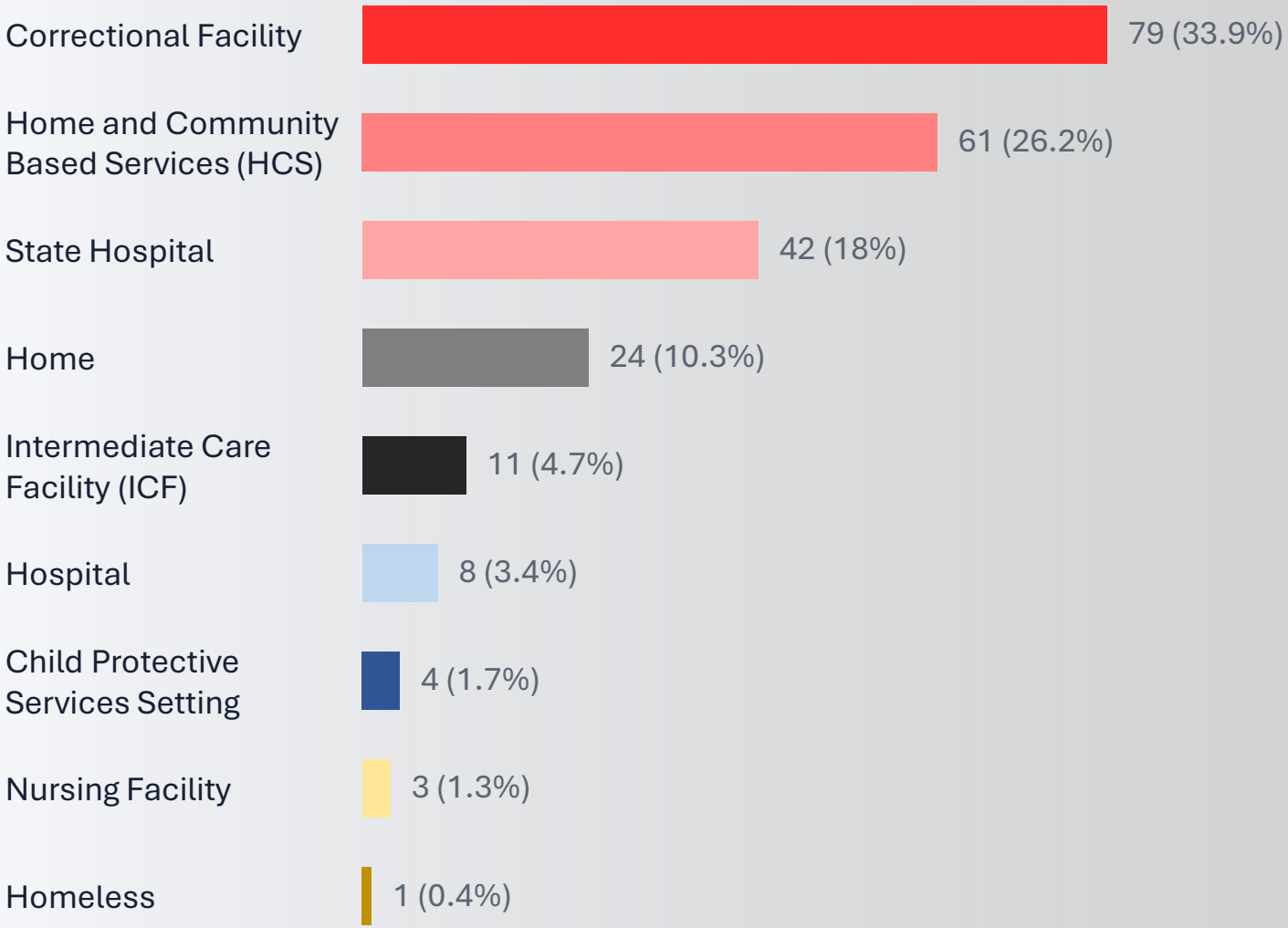


IDD SERVICES: COST COMPARISON

IDD PROGRAM OR SERVICE	AVERAGE ANNUAL COST PER PERSON SERVED	NUMBER THAT COULD BE SERVED USING FUNDS EQUIVALENT TO SUPPORTING 1 PERSON IN AN SSLC
Texas Home Living (TxHmL)	$33,218.00	11.4 people 
HCS Nonresidential	$38,186.36	9.9 people 
Community ICF	$65,310.24	5.8 people 
HCS Residential	$80,031.72	4.7 people 
State Supported Living Center	$377,616.00	1.0 person 

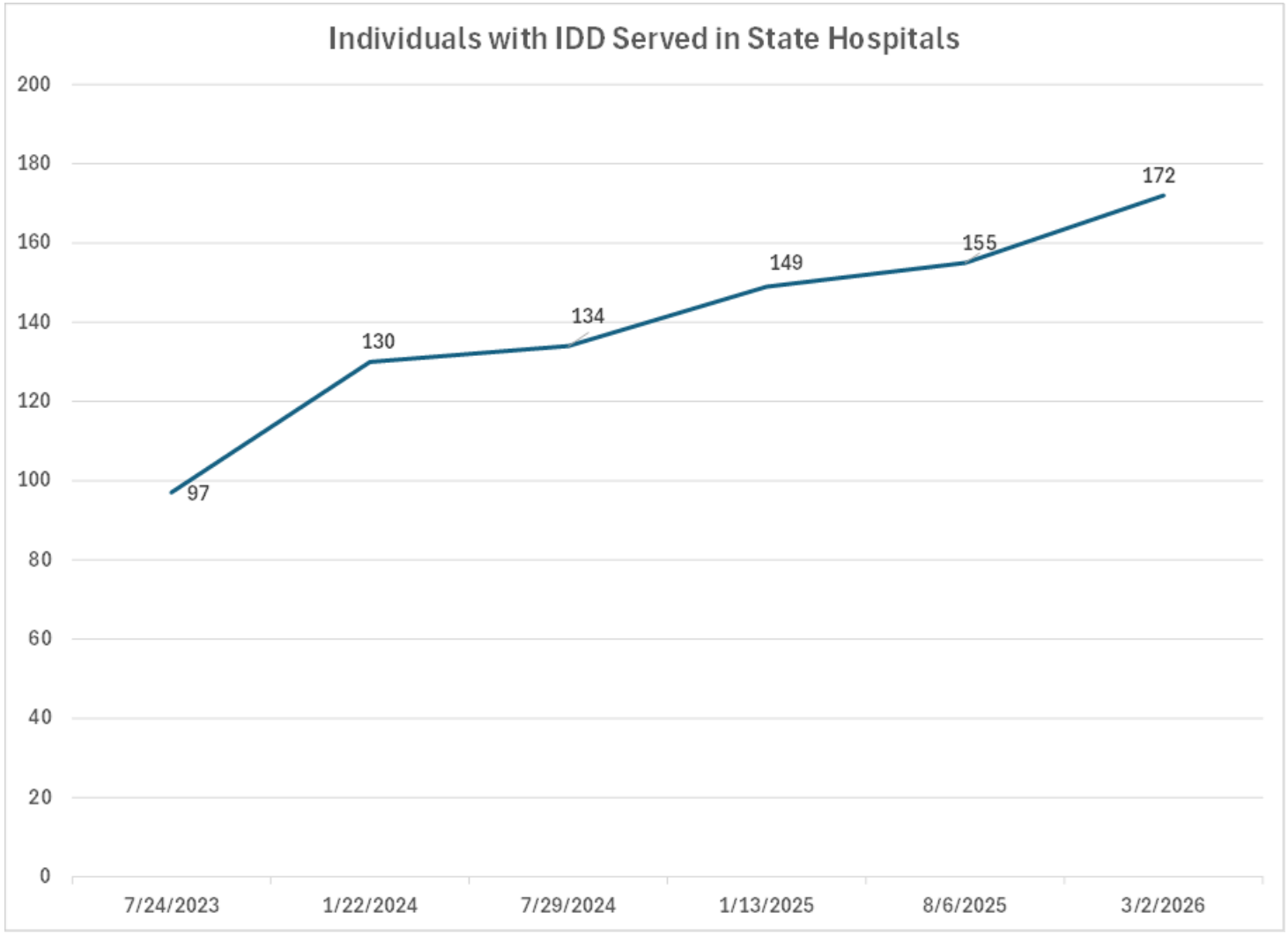
Data based on HHSC FY27 Appropriation Measures

The admissions cross-section



State Hospitals

"Since 2024, the hospitals have experienced **a steady increase** in the number of patients with co-occurring intellectual or developmental disabilities requiring inpatient psychiatric care." *--FY 2026 State Hospital Long-range Plan Report (draft)*



SB 944 (2023) – Civil Commitment for State Supported Living Center Admissions

Allows court to make a commitment order without Interdisciplinary Team recommendation in limited cases.

Court must still find the individual meets eligibility criteria beyond a reasonable doubt

Intent to create ready access to SSLCs by shortening/streamlining the admission process

Misconceptions about what contributes to delays

Factors Affecting SSLC Admissions

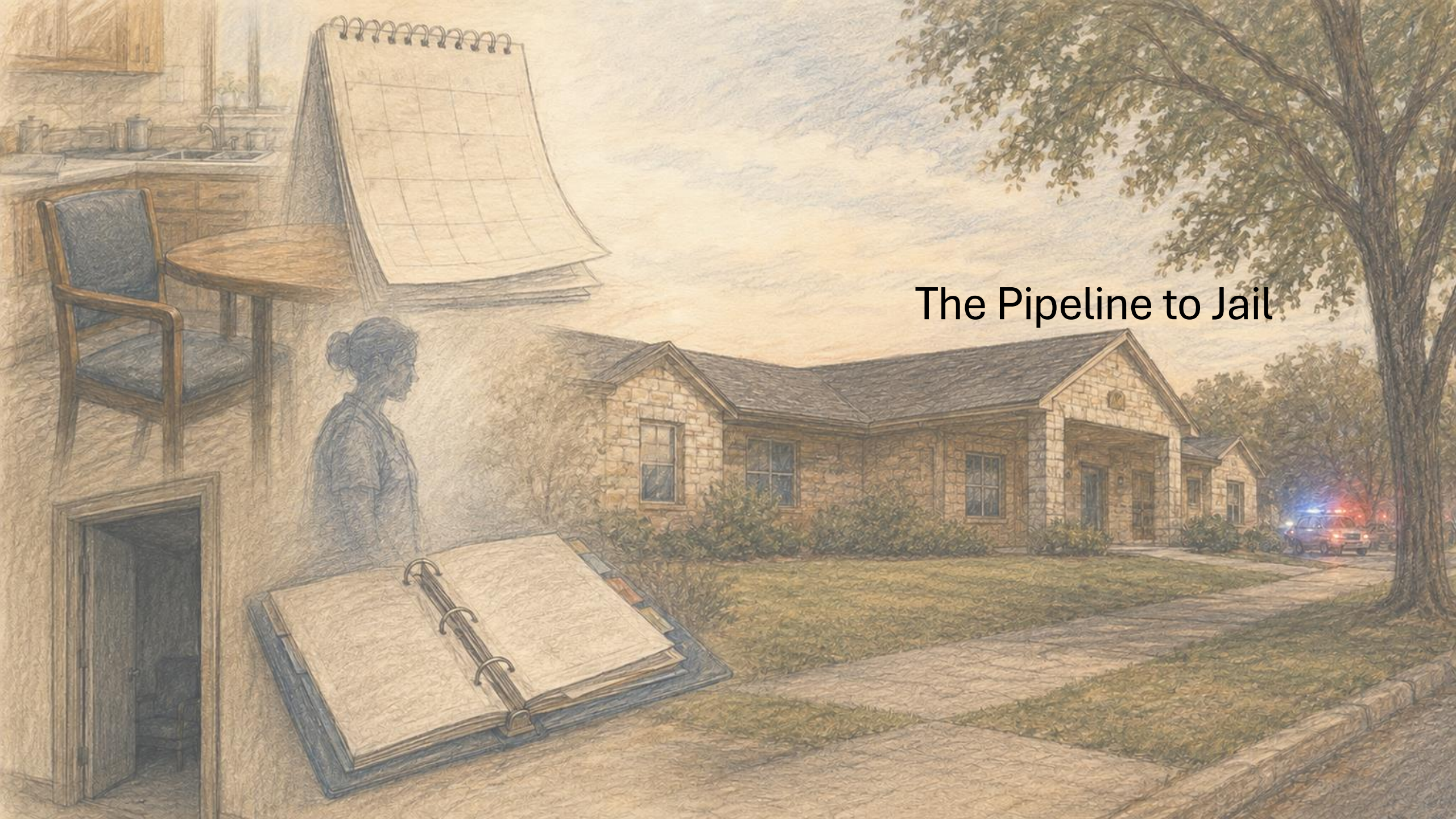
Increased volume at the front door pushing SSLCs past operational capacity due to:

- diminished quality of care in community services
- increased interactions between individuals with IDD and criminal justice system, state psychiatric hospitals
- DFPS seeks SSLC admission for high-needs youth under state conservatorship

As Community Capacity Shrinks…

Families have fewer choices

Scarcity has a cost, too


The Pipeline to Jail

Why are we seeing more people who cannot be sustained in community ?

- Provider closures
- Workforce shortages
- Loss of expertise
- Insufficient reimbursement
- Delayed access to crisis supports
- Behavioral consultation shortages

Community is not simply a location—it's a support system.

People succeed in community when the system around them understands their needs and has access to the resources necessary to make life work

Is this a job you would take for ~~$10.60~~/hour?

$13.00/hr.

Staffing	**1 community IDD direct care worker in a group home supports 3 – 6 individuals at the same time**
Basic Needs/ Health and Safety	▪ Preparing special diets, mealtime assistance ▪ Showering/brushing teeth/dressing ▪ Toileting/handwashing/changing diapers ▪ Cleaning, disinfecting common areas ▪ Conducting fire drills during the day and night
Individualized Support	▪ Exercising hypervigilance for medical vulnerabilities and behavior triggers ▪ Implementing multiple individualized plans of care ▪ Intervening in medical and behavioral emergencies ▪ Interacting with individuals who are not verbal ▪ Transporting to and from appointments, church, jobs, social activities, shopping, etc.
Medication Management	▪ Preparing, administering, and monitoring medications ▪ Documenting and maintaining medication records

IDD direct care workers also teach daily living skills to help individuals gain as much independence as possible.

Residential Options

for Individuals with an Intellectual Disability or Related Condition

TEXAS Health and Human Services

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.

Search for a vacancy at an SSLC at https://apps.hhs.texas.gov/icfsearch

~~$17.50 - $21/hr.~~

$17.71 — $24.57/hr.

Community-based Intermediate Care Facility for Individuals with an Intellectual Disability or Related Conditions

Community-based ICFs/IID provide 24-hour residential services for people with intellectual disabilities or related conditions. Residents have access to comprehensive and individualized services and supports in their local communities including:

- Primary and specialty medical care
- Behavioral treatment
- Clinical therapies
- Nursing
- Dental treatment
- Vocational and employment services, skills training and habilitation services
- Adaptive aids
- Specialized diets
- Planned activities such as shopping, dining out, going to movies and other recreational and leisure activities in their local communities

Most community-based ICFs/IID across Texas serve people in homes that accommodate up to six people; however a few are larger.

Search for a vacancy at a community-based ICF/IID at https://apps.hhs.texas.gov/icfsearch

~~$10.60/hr.~~

$13.00/hr.

Home and Community-based Services Program: Group Home or Host Home and Companion Care

The HCS program can provide 24-hour residential assistance for people with intellectual disabilities or related conditions who live in:

- A group home where no more than four people receiving services live.
- A host home and companion care setting.

The HCS program provides services across Texas for people to successfully integrate into their local community and have opportunities to participate as citizens to the maximum extent possible, whether they are receiving 24-hour residential services or services in their own home or family's home.

A person receiving HCS residential assistance has access to:

- Comprehensive and individualized primary and specialty medical care
- Behavioral support
- Day habilitation
- Clinical therapies
- Dental treatment
- Nursing
- Employment assistance and supported employment
- Adaptive aids
- Minor home modifications
- Activities designed to provide recreational integration into their local community, including shopping, dining out, going to movies and other leisure activities

Service coordination is provided by the local intellectual and developmental disability authority.

~~$10.60/hr.~~

There is an interest list for the HCS program.

Search for a vacancy at a HCS group home at https://apps.hhs.texas.gov/hcssearch

$13.00/hr.

For more information about services and supports for individuals with intellectual and developmental disabilities contact your local IDD authority at:

To find the local IDD authority that serves your area go to https://apps.hhs.texas.gov/contact/search.cfm

17DD40


Real Choice Requires
A viable provider network
Supportive service coordination
Timely information
Open
Specialized expertise
Available residential capacity
Qualified Staff

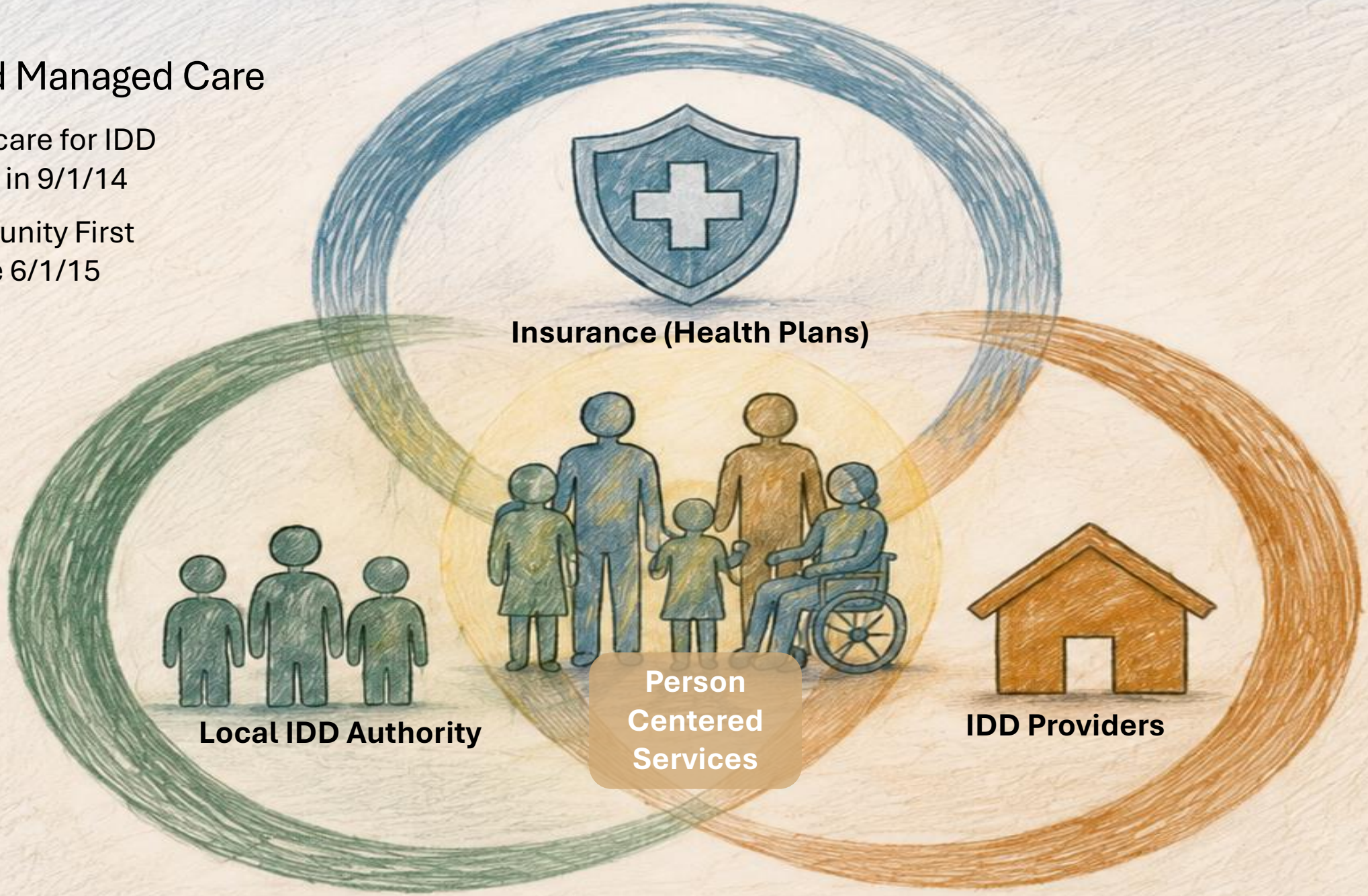
504

Rehabilitation Act of 1973

Medicaid Managed Care

Acute care for IDD carved in 9/1/14

Community First Choice 6/1/15



What Can YOU Do to be a Catalyst for Change?

Educate & Engage

Share Success Stories and Challenges

Build Relationships and Find Champions

Monitor Legal Action

Three Points *That Every Decision Maker Must Hear*

1 We must preserve real choice

People with extensive needs can and do live successfully in community and some may require institutional care.

2 Community living doesn't happen by itself

It requires providers, workforce, expertise, service coordination, crisis capacity and local system knowledge

3 Those capabilities have already weakened significantly

Bottom Line

If Texas changes the current structure, it needs a credible answer for **where each essential function & the expertise behind it will reside.**

What History Demands of Us