



## Navigating the IDD Service System:

What services is a person with an IDD eligible for and why are they so hard to access? PART 2

Presented by Cindi Paschall, The Self-Determination Group

Tuesday, August 25, 2020



IDDCouncil





#### **PURPOSE**

To transform the region into an inclusive community where individuals with intellectual and developmental disabilities (IDD) thrive.

#### **MISSION**

To bring stakeholders together to create an environment for the development of an efficient and accessible system of support for people with intellectual and developmental disabilities.



#### and many individual and family memberships. Join us!



# Welcome August Members!

- Tamesha Sowell
- Cook Children's Medical Center
- Your Name Belongs Here!
  <u>Membership Form</u>

### **FACILITATOR**

CINDI IS A PARENT PASSIONATELY INVOLVED IN ADVANCING THE RIGHTS OF PEOPLE LIVING WITH DISABILITY LABELS. CINDI HAS DEDICATED THE PAST 24 YEARS TO ADVOCACY, APPLYING HER PERSONAL EXPERIENCE AND KNOWLEDGE IN HELPING OTHERS. OVER THE YEARS SHE HAS WORKED AND VOLUNTEERED FOR VARIOUS ORGANIZATIONS SET UP TO ASSIST AND EMPOWER INDIVIDUALS WHO HAVE A DISABILITY AND THEIR FAMILY TO LIVE A SELF-DETERMINED LIFE – ONE THEY DEFINE, NOT THE SYSTEM. CURRENTLY CINDI SERVES AS AN ASSISTANT OF THE SELF-DETERMINATION GROUP AND IS A FREQUENT SPEAKER AT LOCAL AND STATEWIDE EVENTS. CINDI'S PASSION IS FUELED BY HER DAUGHTER'S DETERMINATION TO LIVE A SELF-DETERMINED LIFE AND GIVE OTHERS A VOICE.





## Navigating the IDD Service System: What services is a person with an IDD eligible for and why are they so hard to access?

Part 2: Barriers to Access & What YOU Can Do To Help

Cindi Paschall - Assistant, The Self-Determination Group an affiliate of The Arc of DFW Area



- WHEN: Established in 2014 by Carissa Paschall & Jamie Butler
- **WHY:** Amplify the voices of people with disabilities to live a self-determined life life as each person defines it

Advance the disability rights movement

**AFFILIATIONS:** 

Texas Advocates







#### **STAY CONNECTED:**

Email: <u>TheSDG@thearcofdfw.org</u>

Facebook: @TheSelfDeterminationGroup

Session Goal: Answer the question: Why does it take so long to access LTSS programs & where we go from here.

- Quick review of IDD Services Programs
- Why the wait is so long for some services
- What you can do to help reduce the wait



## Long-Term Services and Supports (LTSS) Defined

Long Term Services and Supports (LTSS) are generally defined as **home and community-based services (HCBS)** or **institutional services** designed to help a person with a disability or chronic illness accomplish daily activities, optimize their health and retain their independence.



## **Texas LTSS Medicaid Entitlement Programs**

- State Supported Living Center (<u>SSLCs</u>)
- Private Community-Based <u>ICF/IID</u>
- Nursing Facility (NF)
- Community First Choice (<u>CFC</u>)
  - launched in 2015
  - institution level of care, to prevent institutionalization
  - part of many Waiver programs
  - can receive services while waiting for a Waiver

*Eligibility* creates an entitlement.

Can't establish a interest list for services.

Services are largely provided in an institution-based setting.

> Also called <u>State Plan Benefits</u>.



## **Texas LTSS Medicaid Waiver Programs**

- Community Living and Support Services (<u>CLASS</u>)
- Deaf Blind Multiple Disability (<u>DBMD</u>)
- Home and Community-based Services (<u>HCS</u>)
- Medically Dependent Children's Program (<u>MDCP</u>)
- STAR+PLUS Waiver
- Texas Home Living (<u>TxHmL</u>)
- Youth Empowerment Services (<u>YES</u>)
  \* for children and youth (3-18) with serious mental, behavioral and emotional support needs



Click <u>here</u> for *detailed* information about each waiver program.

## **Texas LTSS Medicaid Waiver Programs**

#### **Two Funding Paths**

#### 1) INTEREST LIST / "WAIT LIST"

first come, first served

#### 2) PROMOTING INDEPENDENCE

**HCS Diversion Slot** 

Transition from an institution to the community

Texas Promoting Independence (PI)

# Each program has different eligibility requirements...

#### AGE:

MDCP, STAR+Plus & Yes are the only Waiver programs that consider a person's age.

#### FINANCIAL:

Does NOT always consider parental income.

#### **FUNCTIONAL:**

Must be met for each specific waiver program.

Eligibility is **NOT** determined until a person reaches the top of the interest list.



## The "Interest" Lists

## Average wait time as of June 2020

## **Number Waiting**

CLASS	14-15 years	77,280
DBMD	4-5 years	859
HCS	15-16 years	107,430
MDCP	5-6 years	6,525
STAR+PLUS	4-5 years	15,431
TxHmL	4-5 years	89,799



View the Interest List Reduction Summary <u>here</u>. The unduplicated count across all six Interest Lists is: **162,538**.

## **Texas Medicaid Waiver Programs**

## **GET ON THE "INTEREST" LISTS NOW!**



- **HCS & TxHmL:** Contact your Local Intellectual and Developmental Disability Authority (LIDDA)
  - Tarrant County Residence: 1-800-866-2645, <u>www.mhmrtc.org</u>
  - Other Counties, find your LIDDA: <u>https://apps.hhs.texas.gov/contact/search.cfm</u>



**CLASS, DBMD & MDCP:** Call **1-877-438-5658** 



STAR+PLUS: Call 1-877-782-6440



**YES Waiver:** Click <u>here</u> for the phone number to your local mental or behavioral health authority YES waiver inquiry line.



# still waiting...

# **Institutional Bias**

## What we know...

- Texas ranks 49<sup>th</sup> among all 50 states and the District of Columbia on how well they serve individuals with IDD served by Medicaid
- Texas operates 13 SSLCs for a declining population
- ₃Texas has not closed an SSLC since 1996
- Texas entered into a <u>settlement agreement</u> with the DOJ in June 2009
  - ANE, sub-standard levels of care, and Olmstead violations (complaint)
  - Facilities have and continue to be evaluated by independent monitors 11 years later
- 2The Sunset Advisory Commission recommended the closure of the Austin SSLC in their 2015 report.



Source 1UCP: A Case for Inclusion 2019 <u>Report</u> 2Sunset Advisory Commission 2015 <u>Report</u> 3Down Sizing the State Supported Living Center System: Texas LBB Issue <u>Brief</u>

#### SSLCs are far more costly than community alternatives

#### Cost Analysis Report - 2019

Monthly Average Cost per Individual Served by Setting

State Operated ICF-IID/RC (State Supported Living Center [SSLC])*				
Long-Term Care Costs – Average	19,125.24			
Administrative/Overhead Costs	6,278.26			
Total State Operated ICF-IID/RC Costs	25,403.50			
Non-State Operated ICF-IID/RC (Community ICF/IID)				
Long-Term Care Costs – Average	4,347.95			
Acute Care Cost – Average	364.58			
Total non-State Operated ICF-IID/RC Costs	4,712.53			
HCS Waiver: Residential				
Long-Term Care Costs – Average	5,294.41			
Acute Care Cost – Average	839.09			
Total HCS: Residential Costs	6,133.50			
HCS Waiver: Non-Residential				
Long-Term Care Costs – Average	2,848.28			
Acute Care Cost – Average	655.16			
Total HCS: Non-Residential Costs	3,503.44			
HCS Waiver: All Settings				
Long-Term Care Costs – Average	3,670.75			
Acute Care Cost – Average	716.97			
Total HCS: All Settings Costs	4,387.72			
Texas Home Living Waiver (TxHmL)				
Long-Term Care Costs – Average	1,914.73			
Acute Care Cost – Average	729.92			
Total TxHmL Costs	2,644.65			

\*Data are based on fiscal year 2018 cost report as fiscal year 2019 cost report has not been audited.



Texas HHSC Cost Comparison Report

Table 9: Cost Projections for Maintenance of Residential and Day Program/Direct Support Services Buildings for SSLCs, Fiscal Years 2017-2025

	Day Program & Direct Support Buildings	Residential Buildings	Sub-Total	% of Total Maintenance Cost	Total Maintenance Cost
2017	32,086,185	32,742,072	64,828,257	64.4%	100,638,435
2018	10,708,445	10,464,549	21,172,994	46.0%	70,372,475
2019	43,946,694	47,973,245	91,919,939	68.5%	134,130,007
2020	14,705,004	13,145,247	27,850,251	52.6%	80,957,703
2021	13,502,162	15,637,591	29,139,753	53.0%	54,966,743
2022	13,502,162	15,637,591	29,139,753	53.0%	54,966,743
2023	11,126,166	10,390,548	21,516,713	46.8%	46,022,332
2024	11,126,166	10,390,548	21,516,713	46.8%	46,022,332
2025	11,126,166	10,390,548	21,516,713	46.8%	46,022,332
Total	\$161,829,150	\$166,771,939	\$328,601,086	53.1%	\$634,099,102



Legislative Appropriations <u>Request</u> For Fiscal Years 2020-2021

# **How Can YOU Help?**

## ADVOCATE - IT IS NOT ENOUGH TO BE RIGHT!

"Freedom is never voluntarily given by the oppressor; it must be demanded by the oppressed." -- MLK, Jr.

- Educate yourself, family, friends and decision makers
- <u>Sign-up</u> for and respond to Action Alerts from The Arc of Texas
- Know the candidates running for office where do they stand
- VOTE like your life depends on it, because it does!
- Provide public testimony
- Write a Letter to the Editor
- Share information through social media



# **Why Your Help is Needed**

## To help amplify the voice of people with disabilities

Medicaid Waiver programs are NOT entitlement programs

State Legislature decides the number of slots to fund, or NOT fund every biennium

Everyone should have the right to self-determination

Because we can no longer ask people with disabilities to be patient while they

## WAIT WAIT WAIT WAIT

for access to community-based services so they can live the life others take for granted!



# THANK YOU!

We're not just advocating for access and equality. We're advocating for our basic human rights! The quality of our lives, our entire existence! Cindi Paschall Assistant, The Self-Determination Group

Email: <u>TheSDG@thearcofdfw.org</u>

Facebook: @TheSelfDeterminationGroup





# Thank you!

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