
Navigating the Cliff

Reimagining Neurodivergent Adulthood

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MEET STEPHEN

PAINTER • PHILOSOPHER • MENTAL HEALTH
ADVOCATE • AWESOME LITTLE BROTHER

Current supports fall short



75%

lack college degrees



81%

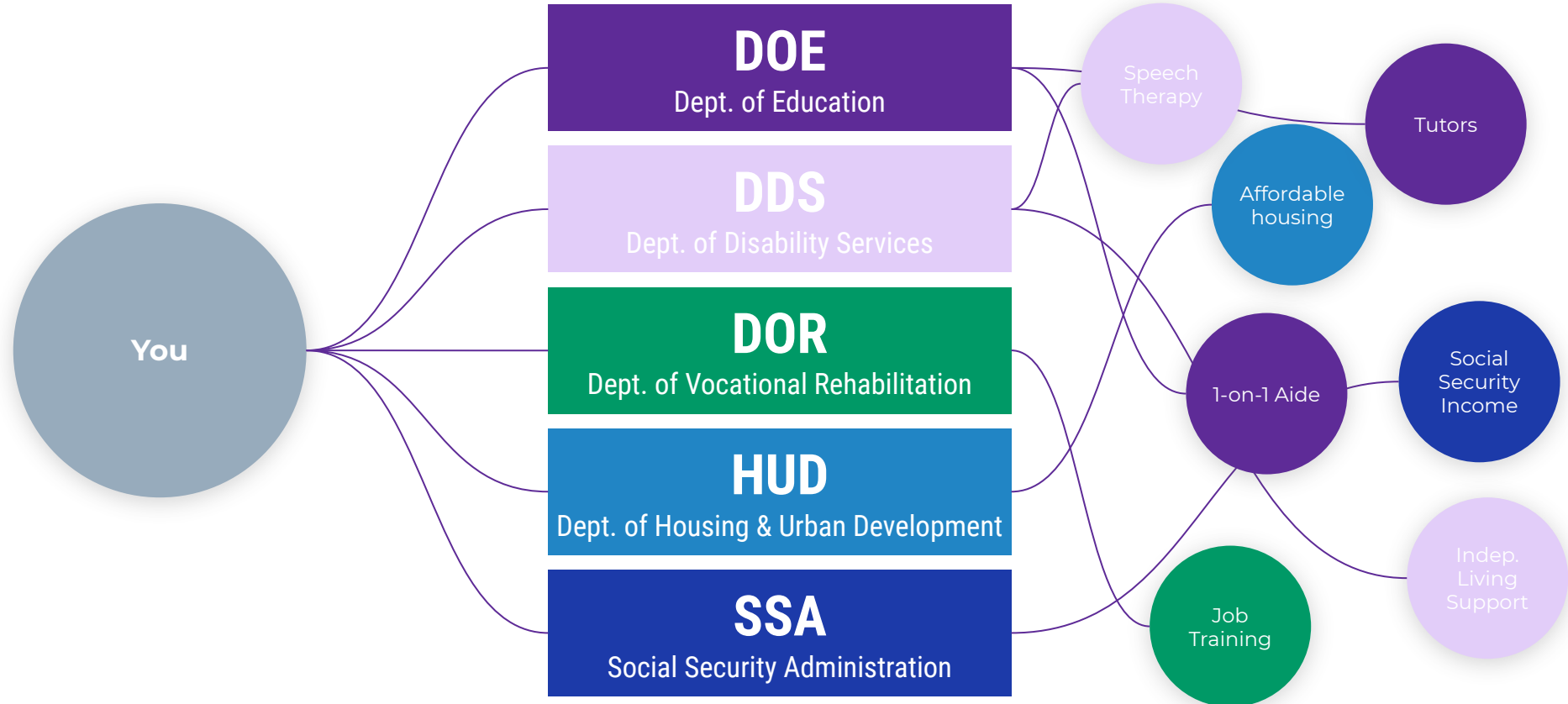
are unemployed



71%

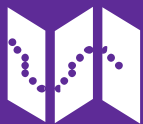
live with parents

The System is Difficult to Navigate





2 YEARS OF RESEARCH



9
STATES



4
NEURODIVERSE
HOMES



300+
INTERVIEWS



19
PROTOTYPES



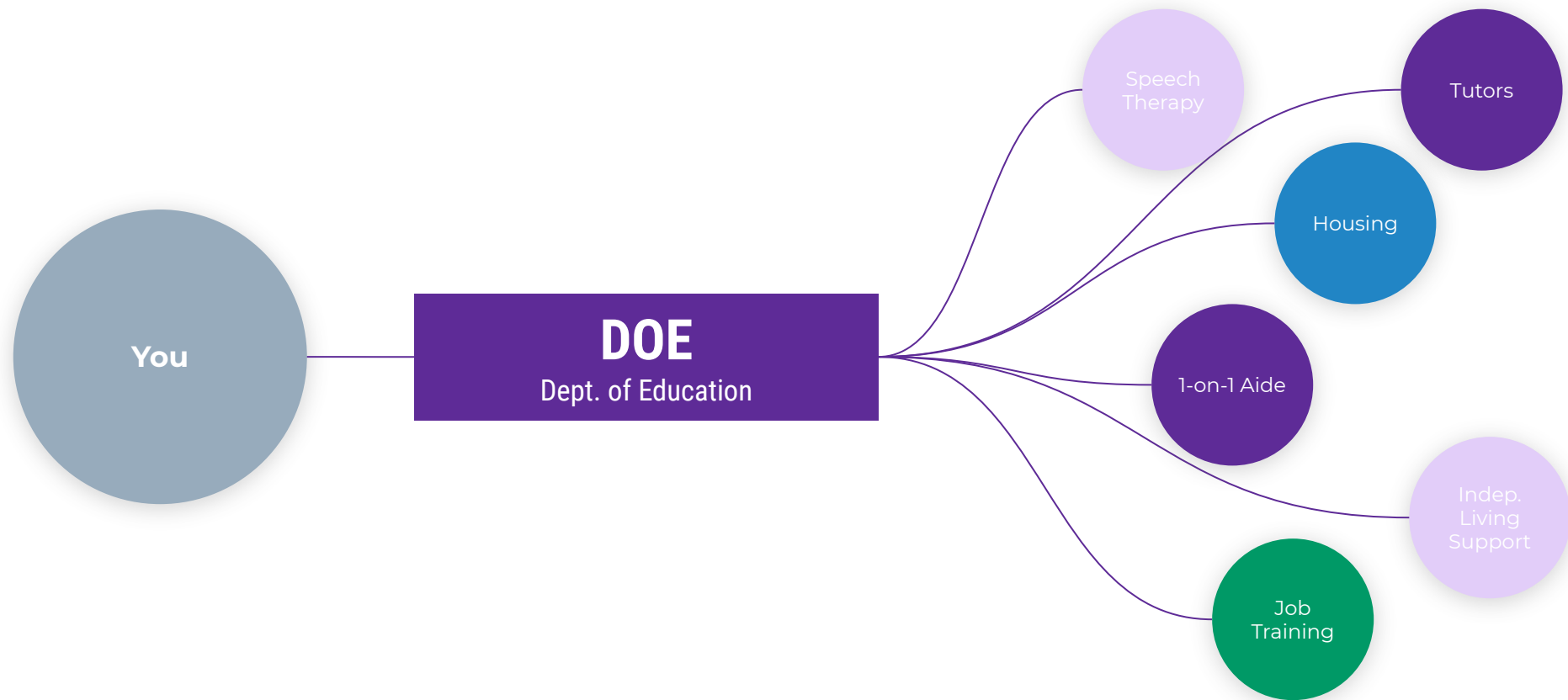
WHAT

WE'LL COVER

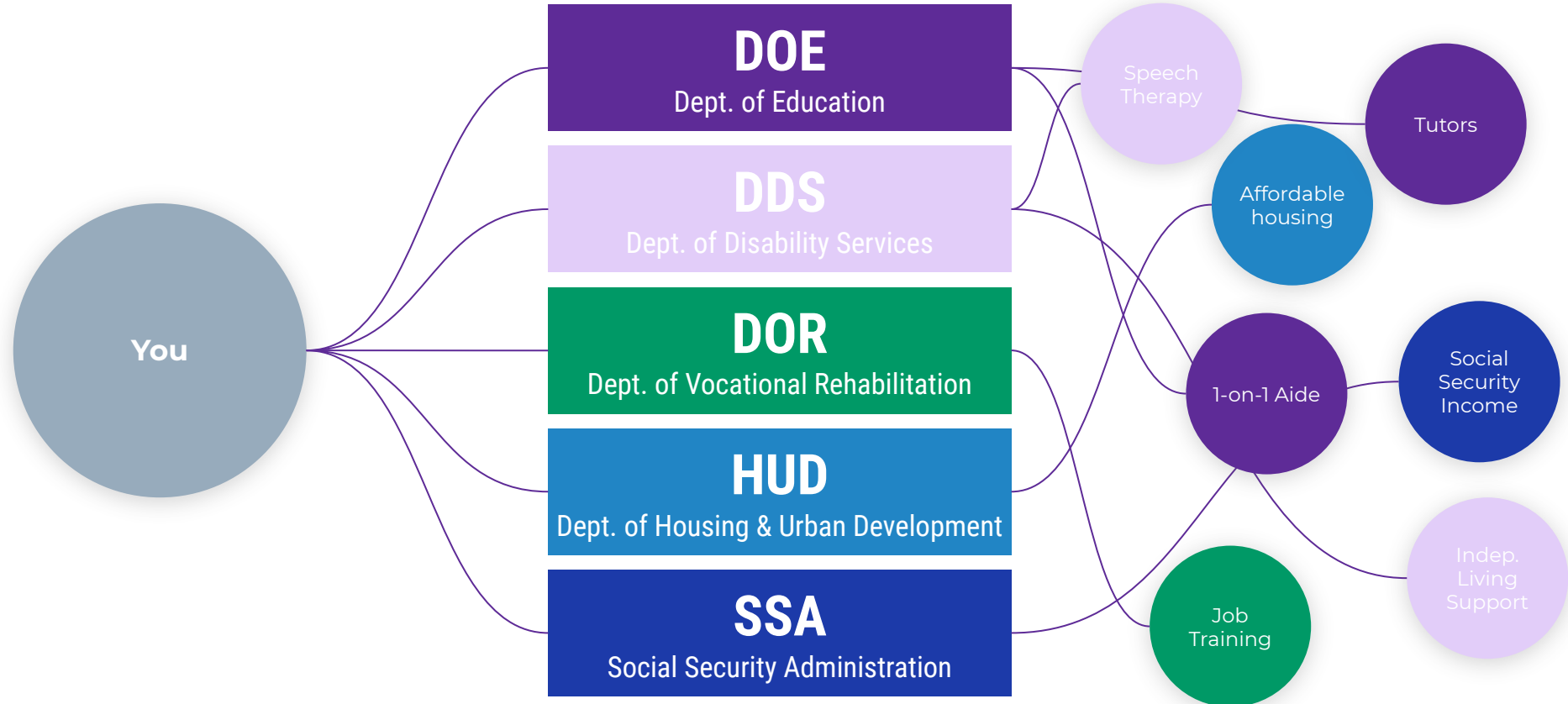


- ✓ History of the service “Cliff”
- ✓ Top 2 Service Policy Changes
- ✓ Top 6 Resources for Adulting
- ✓ Q&A

Before age 22



After age 22



Role of Medicaid



FEDERAL

CMS

Centers for Medicare & Medicaid Services

STATE

DDS

Dept. of Disability Services

HCBS

Home & Community-Based Waiver

~\$50K

Per Year

1-1 Aides

Residential
housing

Transport-
ation

Music
therapy

Community
Supports

Supportive
Living

2 SERVICE POLICY CHANGES



1. Person-centered Thinking
2. Self-Determination

#1

PERSON-CENTERED THINKING



Person-Centered Practices



Approach used to develop plans where:

- ▶ The person guides the process toward a vision he or she envisions
- ▶ The person decides what is **important to** him or her to have a fulfilling, satisfying life and what's **important for** him or her to be healthy and safe



Pillars of Person-Centered Thinking and Doing



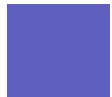
Presume Competence

Every person can direct his or her planning process.



Focus on strengths

Focus on what a person does well, not on their deficits or what they can't do



Behavior is communication

Even if a person can't communicate by speaking, they have a right to make choices, whether it's by smiling, gesturing, typing, using pictures, or even getting angry.



Every person can have a meaningful life in the community

Every person has a right to live and participate in their community and not only be in programs just for people with disabilities



Respect cultural diversity

A person's family, religious, ethnic, and racial cultures should be taken into account

#2

SELF-DETERMINATION



Institutionalization → Self-determination



HISTORICAL

Most people with Developmental Disabilities are housed in large institutions, separated from their families and society

1900's

1969

LANTERMAN ACT

Historic shift moving people toward community integration. Service decisions made collaboratively with regional center.

SELF-DETERMINATION PILOT PROJECT

200 individuals started a Pilot Program in 5 regional centers throughout California.

1998

2013

SELF DETERMINATION STATUTE PASSES

Provides self-determination at all regional centers. It was supported by self-advocate and family organizations throughout California.

SELF-DETERMINATION FOR ALL

The phase-in program ends, and self-determination becomes available as an option for all CA Regional Center Clients

2021

5 Principles Of Self Determination



1

FREEDOM - The right to plan your own life and make your own decisions

2

AUTHORITY - The right to control how your Spending Plan is used

3

SUPPORT - The right to choose who supports you to live, work and play in your community

4

RESPONSIBILITY - The right to make decisions to control your life, to be accountable for using public money and to live an engaged life in your community.

5

CONFIRMATION - You are the most important person when making decision about your life.

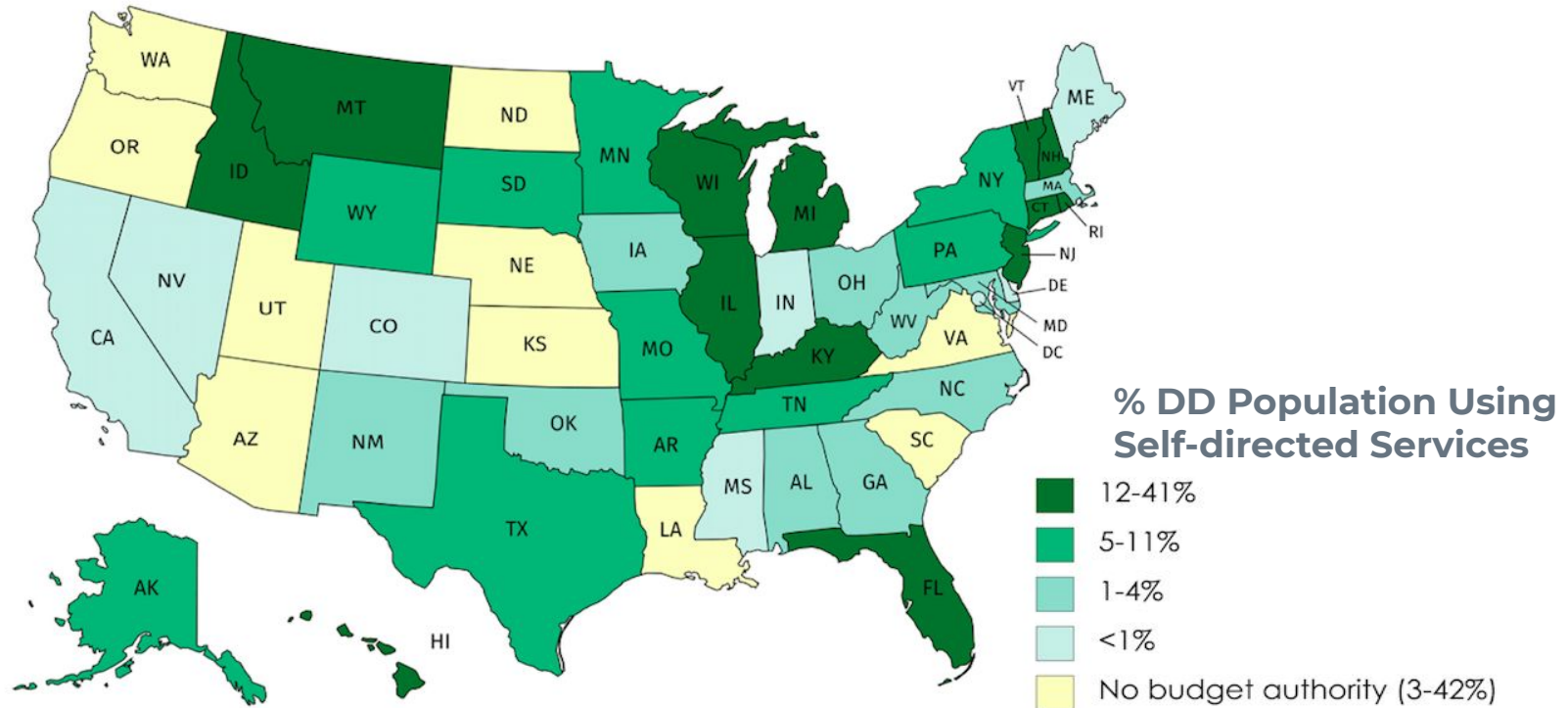
Rise of Self-Determination



- ▶ **Self-direction means flexible budgets and consumer choice**
 - Self-determination or self-directed care means that instead of the traditional system of state case managers allocating funding for pre-approved services, individuals are allowed to purchase a vary array of goods and services within their budget and hire support brokers to assist in budget allocation
 - This creates a huge opportunity for flexibility and choice but also a challenge - participants have little help or support to guide them on how to spend their money and how to find and select good service providers
 - NeuroNav helps clients navigate self-direction - achieving positive outcomes and reducing complexity

- ▶ **Self-determination (or self-directed services) is widespread and positioned to grow**
 - CA is not alone - all 50 states offer at least one program that allows DD consumers to self-direct care

States enabling self-directed services



Source: National Core Indicators,
Research and Training Center on Community Living at the University of Minnesota

Key Players & Roles



(Optional) Independent Facilitator

- Facilitates Person Centered Plan
- Helps navigate the program
- Assists with identifying community resources, services and supports
- Helps voice the wants and needs of the participant

Regional Center

- Develops written service plan
- Certifies spending plan
- Responds to change in circumstances

Circle of Support

- Consists of Family, Friends, and favored Teachers & Support staff
- Assist in the Person Centered Plan, IPP, and managing the program



(Required) FMS

- Manages individual budget
- Makes payments
- Facilitates criminal background checks

NeuroNav Services in California



Person-Centered Plans

- ❑ Person-centered planning activities to design service plan
- ❑ 1-page profile
- ❑ Action plan

Independent Facilitation

- ❑ Advise clients on service matches in their community
- ❑ Database of 10,000+ community services across CA

Custom Services

- ❑ Free Consultations
- ❑ Custom Plans

2 **SERVICE POLICY CHANGES**



1. Person-centered Thinking
2. Self-Determination



6

RESOURCES FOR ADULT SERVICES

1. Community
2. Education
3. Employment
4. Health
5. Finances
6. Housing

Community

#1 RESOURCE

Local
Department of
Developmental
Services



HOW IT HELPS

Provides annual funding (~\$50k per client nationwide) for services in the community through the Medicaid Home & Community-Based services.

Contact your state's department to learn more about the assessment process.

ADDITIONAL RESOURCES

- Variety of local departments that offer inclusive activities like local parks and recreation centers

Education

#1 RESOURCE

Think College



HOW IT HELPS

Helps people with disabilities find and enroll in inclusive higher ed and put in place supports to succeed.

Visit there website: <https://thinkcollege.net/>

ADDITIONAL RESOURCES

- Stanford Neurodiversity Project
- Local Community Colleges

Employment

#1 RESOURCE

Local
Department of
Vocational
Rehabilitation

HOW IT HELPS

Provides job and vocational services including training, counseling, job placement and supported employment

Contact your state's department to learn more about the assessment process.

ADDITIONAL RESOURCES

- Stanford Neurodiversity Project
- Identifor



Health

#1 RESOURCE

Medicaid



HOW IT HELPS

Medicaid offers long-term supports and services under the HCBS waiver. It also offers affordable or free health insurance.

Enroll in Medicaid at
<https://www.healthcare.gov/>

ADDITIONAL RESOURCES

- Parents coverage until age 26
- Private insurance options

Finances

#1 RESOURCE

Achieving a Better Life Experience (ABLE) Account



HOW IT HELPS

Savings account for disability-related expenses, similar to the current 529 education savings plans that help families save for college.

Contact your state's department to learn more about the assessment process.

ADDITIONAL RESOURCES

- Special Needs Trust - enables supplemental income without impacting benefit eligibility

Housing

#1 RESOURCE

Social Security Income (SSI)



HOW IT HELPS

SSI can be used for living expenses including rent. This is a monthly cash amount that varies from state to state of approximately \$794/month.

Apply via the Social Security Administration (SSA)

ADDITIONAL RESOURCES

- Housing Vouchers from Department of Housing and Urban Development



6

RESOURCES FOR ADULT SERVICES

1. Housing
2. Education
3. Employment
4. Health
5. Community
6. Finances



Live the life you want





Thanks!

Any final questions?

You can find me at:

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