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

Source: RISP 2019, National Core Indicators. 2019, Braddock 2015
The System is Difficult to Navigate

- **DOE**
  Dept. of Education

- **DDS**
  Dept. of Disability Services

- **DOR**
  Dept. of Vocational Rehabilitation

- **HUD**
  Dept. of Housing & Urban Development

- **SSA**
  Social Security Administration

- **You**

- **1-on-1 Aide**
  Tutors

- **Affordable housing**

- **Speech Therapy**

- **Job Training**

- **Indep. Living Support**

- **Social Security Income**
2 YEARS OF RESEARCH

9 STATES

4 NEURODIVERSE HOMES

300+ INTERVIEWS

19 PROTOTYPES
Disability Rights are Human Rights
WHAT

WE’LL COVER

✓ History of the service “Cliff”
✓ Top 2 Service Policy Changes
✓ Top 6 Resources for Adulting
✓ Q&A
Before age 22

You

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After age 22

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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
- Transportation
- Music therapy
- Community Supports
- Supportive Living
2 SERVICE POLICY CHANGES

1. Person-centered Thinking
2. Self-Determination
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.
SELF-DETERMINATION
Institutionalization → Self-determination

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

**SELF-DETERMINATION PILOT PROJECT**
200 individuals started a Pilot Program in 5 regional centers 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.

**1900’s**

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

**1969**

**SELF DETERMINATION STATUTE PASSES**
Provides self-determination at all regional centers. It was supported by self-advocate and family organizations throughout California.

**1998**

**2013**

**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.

Sources: National Council on Disabilities, The Council on Quality and Leadership
States enabling self-directed services

% DD Population Using 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

Participant
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
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/](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
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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