

# Changing Tides

The Role of Professionals in Self-Directed Support Programs

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# cfi

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INDEPENDENCE



# Objectives

- Improve understanding of self-determination theory.
- Self-Directed Waiver history & overview.
- Evaluate the role of case managers in self-directed programs.
- Examine research and apply best practices.
- Adapt person-centered planning methods.
- Learn how to identify boundary and ethical dilemmas and develop skills to assess, manage, and mitigate risk.

# Cultural Shift: Legal Rights of Individuals with Disabilities

## Legal Rights

- Americans with Disabilities Act (ADA)
- Olmstead decision (1999)

## Social Justice Movements

- Community Living Movement
- Employment Programs
- Rise of Self-Directed Service Models

“Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society.”

The Developmental Disabilities Assistance and Bill of Rights Act of 2000

# Self-Determination Theory

## **Autonomy**

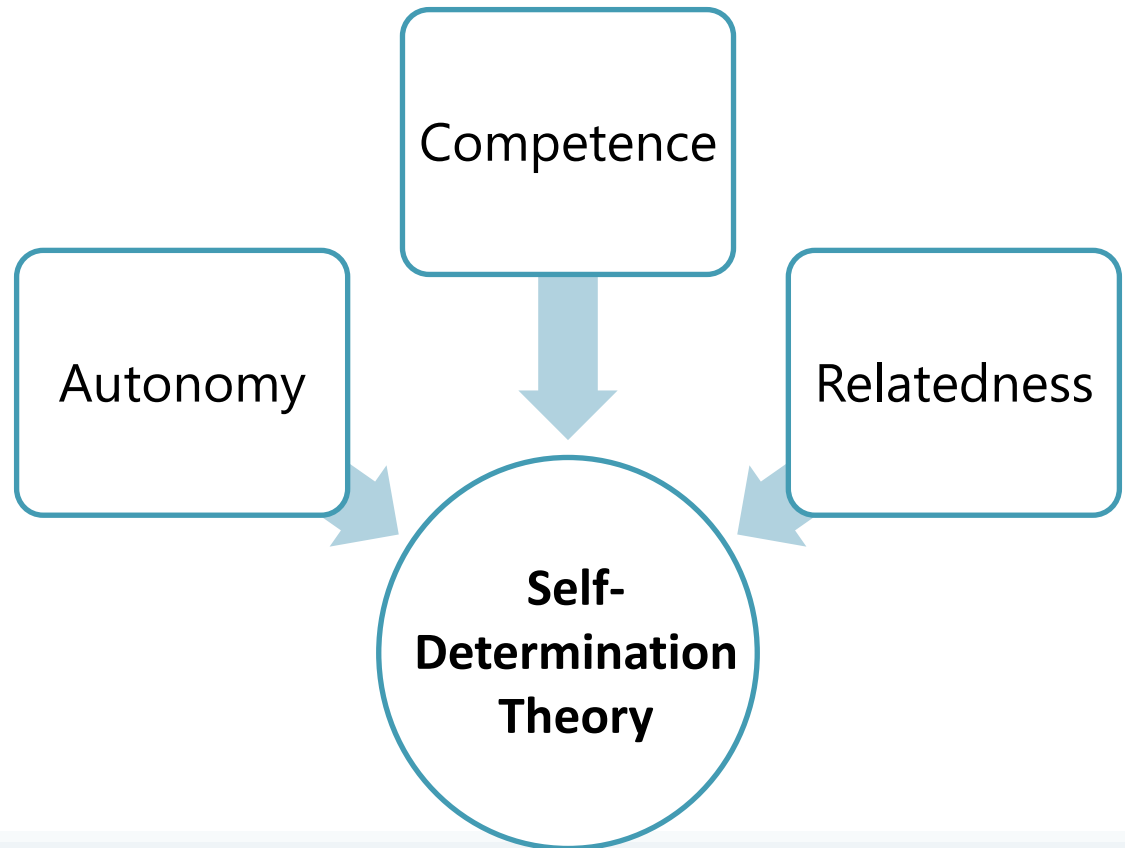
- Being Responsible
- Independent
- Able to Speak for Oneself

## **Competence**

- The ability to do something successfully or efficiently
- A specific range of skill, knowledge, or ability

## **Relatedness**

- The state of being connected or associated
- The state of having developed from the same origin
- The state of being part of the same family, community, or program



# History of Self-Directed Supports

- **WWII:** VA-backed cash-benefit program allows vets with disabilities to hire caregivers.
- **1953:** L.A. county-based program discovers cost saving alternatives to inpatient care. Over next 20 years, this program evolves into state-wide In-Home Supportive Services.
- **1960s-1980s:** Independent Living Movement – shift to home and community-based care.



# History of Self-Directed Supports

- **1993:** Robert Wood Johnson Foundation works with Monadnock Developmental Services to test a new approach to the delivery of services to persons with developmental disabilities in Keene, New Hampshire.
  - Individuals controlled planning
  - Individuals allowed Budget Authority
  - Expand Program from 42 to 500
- **1995:** RWJF awards grant to New Hampshire to duplicate the Monadnock Self-Determination Project statewide.

# History of Self-Directed Supports

- **1996:** Partnership between U.S. Department of Health and Human Services and RWJF launches demonstration programs.
  - Self-Determination program
    - ID/DD (18 states received seed money to develop programs)
    - \$5 Million
  - Independent Choices program
    - Seniors and non-elderly with physical disabilities
  - Cash and Counseling Demonstration
    - Arkansas, Florida, New Jersey (later replicated in 12 states)

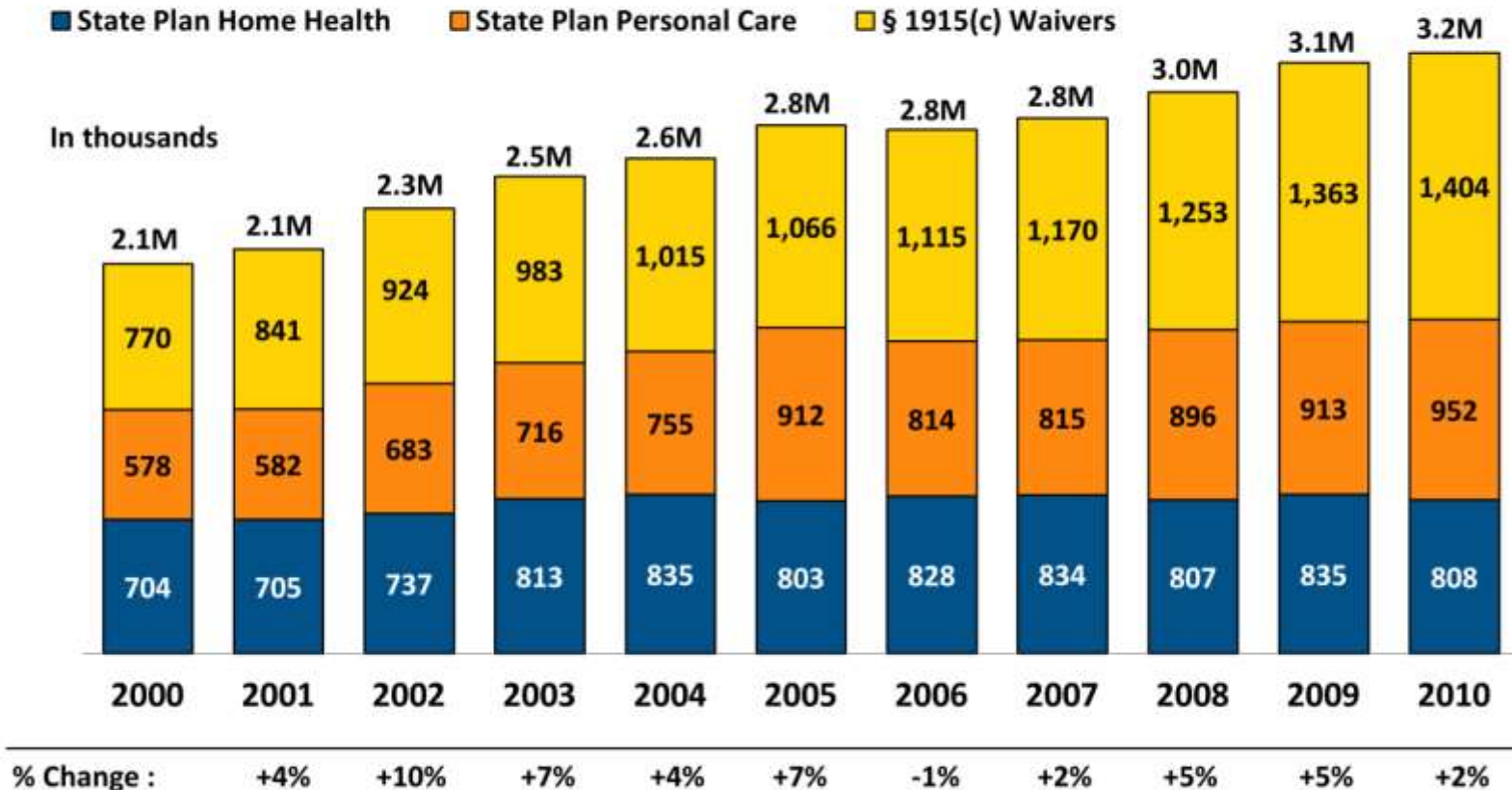


# History of Self-Directed Supports

- **Outcomes**
  - Shift in decision making
  - Perceived changes in quality of life
  - Increased cost savings
  - Decreased waitlists
  - Spurred growth of organized self-advocacy
- Success of these programs influenced Congress to evolve home and community based service options as part of 1915(c) waiver programs for states.
- **By 2012, 88% of 1915 (c) waiver states either allowed or required some form of self-direction.**

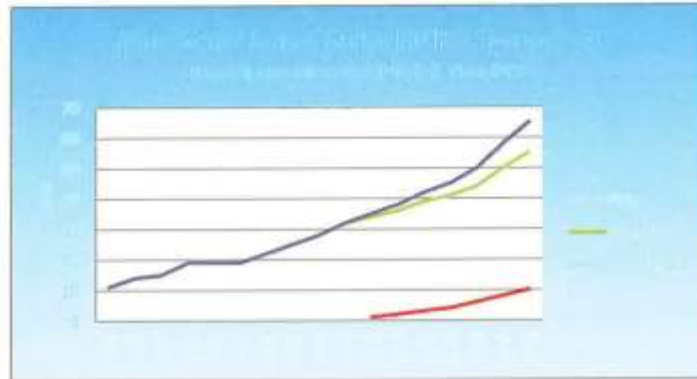
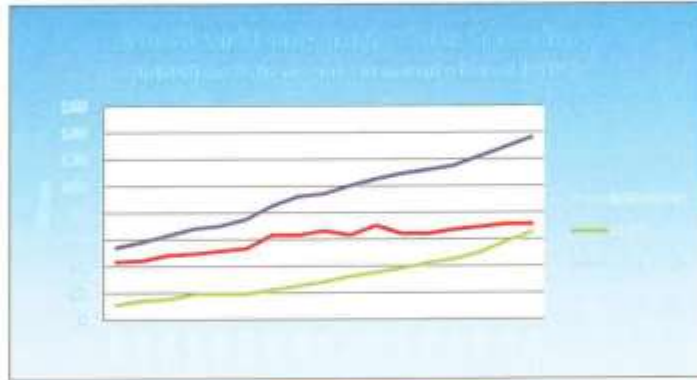
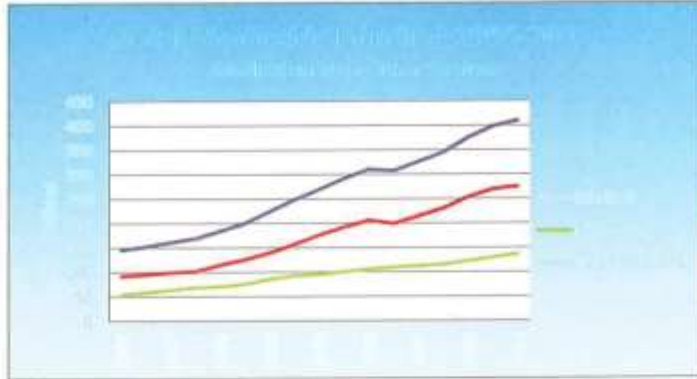
Figure 1

# Growth in Medicaid HCBS Participants, by Program, 2000-2010



NOTE: Figures are updated annually and may not correspond with previous reports.

SOURCES: Kaiser Commission on Medicaid and the Uninsured (KCMU) and University of California, San Francisco (UCSF) analysis of CMS Form 372 data and program surveys.



# CMS and Self-Direction

## Self-Direction Guidelines

1. Person-centered planning process
2. Service plan
3. Individualized budget
4. Information and assistance in support of self-determination

## Support Guidelines

A supports broker/consultant/counselor must be available to each individual who elects the self-direction option.

<http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Self-Directed-Services.html>



# CMS and Self-Direction

- Financial Management Services (FMS) must be available to assist individuals in exercising budget authority.
  1. Understand billing and documentation responsibilities;
  2. Perform payroll and employer-related duties (e.g., withholding and filing federal, state, local and unemployment taxes; purchasing workers' compensation or other forms of insurance; collecting and processing worker timesheets; calculating and processing employee benefits; and issuing payroll checks);
  3. Purchase approved goods and services;
  4. Track and monitor individual budget expenditures; and
  5. Identify expenditures that are over or under the budget
- Each State Medicaid Agency (SMA) is tasked with having in place a system of continuous quality assurance and improvement.

# Medicaid Home and Community Based Waivers

1915(c)

Home and Community-Based Services Waiver

1915(i)  
SPA

State Plan Home and Community-Based Services

1915(j)  
SPA

Self-Directed Personal Assistance Services (PAS)

1915(k)  
SPA

Community First Choice Option

1115

Research and Demonstration Project Waiver

# Core Tenets of Self-Directed Services



# Person-Centered Planning

- Integral part of self-directed programs
- Methodologies vary
- Identifying major life goals and make related decisions
  - Housing
  - Caregivers
  - Agency Services
  - Employment
  - Transportation
  - Healthcare
  - Community Engagement
  - Advocacy
  - Post-Secondary Education

Person Centering Thinking → Person Centered Doing



# Budget Authority

- Budget Authority means that a participant has choice and control over what goods and services to purchase within their spending plan.

## Examples:

- Supportive Home Care Services (Agency)
- Day Services
- Continuing Education
- Therapies
- Vocational Services
- Support Broker Services
- Exceptional Expenses
- Durable Medical Equipment
- Home Modifications

# Employer Authority

Participants utilizing employer authority are responsible for:

- Recognizing personal needs and long term care goals
- Creating job descriptions and employee schedules
- Finding eligible employees and providing the Employee Start-up packet
- Operating employer authority within authorized service plan
- Monitoring services received
- Choosing time report submission modality
- Authorizing time reports
- Communicating openly and honestly with employees, F/EA, counseling services, and all other entities
- Training, supervising, and directing all employees
- Terminating employees as needed
- Avoiding fraudulent behavior

# Challenges

- Access
- Self-Actualization
- Boundary Setting

“Most family members and youth with disabilities do not recognize the contradiction between self-determination and substitute decision-making and possessed only a limited understanding of guardianship and its alternatives.”

“Research suggests that the daily interaction between [Direct Support Professionals] DSPs and the people they serve often inhibits self-determination...conflict often ensues when persons with disabilities express a desire to control their supports while service staff persons prefer to determine how and when their work tasks are carried out.”

Self-Determination Across the Life Span: Issues and Gaps, A National Gateway to Self-Determination

# Video

Role of Case Managers in Self-Directed Programs

# CHANGING TIDES



# Paradigm Shift

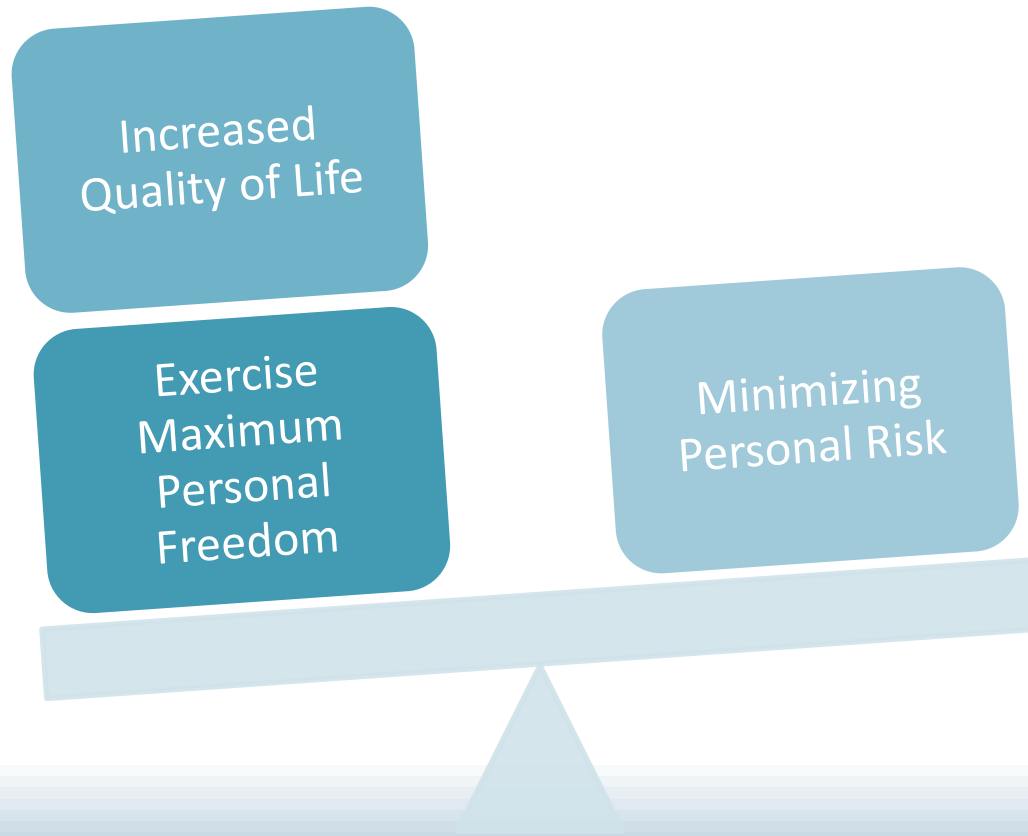
## Traditional Approach

- The consumer is dependent upon the service provider to direct and deliver necessary supports
- Provider identifies and mitigates risk
- Provider monitors quality of supports
- Provider initiates and terminates service accordingly

## Self-Directed Approach

- Individual defines his or her needs
- Individual designates “circle of support”
- Individual controls resources and staffing
- Individual determines the role the service provider will play in their life
- Individual determines quality of supports
- Individual initiates and terminates service accordingly

# Video



Increased  
Quality of Life

Exercise  
Maximum  
Personal  
Freedom

Minimizing  
Personal Risk



# Mitigate Risk



# Case Study: Boundary Crossing

- Agency with Choice model
- Parent informed agency that client was stabbed during a altercation with hired caregiver.
- Upon investigation, client and caregiver were in a relationship. Caregiver was trying to break up with client.
- Occurred outside of scheduled shift.
- Police report indicated that client injured self. Caregiver did not attack client, not charged.

Gain insight into the relationship of a client and an in-home caregiver; in effort to understand the struggles that exists with boundaries.



# Mitigate Risk

- What are our risks?
  - The dynamics of a business relationship being added to a personal relationship.
  - The personal relationship has impact on service delivery.
  - The tendency for a business relationship to evolve into a personal relationship.



# Case Study

- Organizational Response Necessary
  - Understand Occurrences
  - Document Dual Relationships
  - Assess Potential Risks
  - Provide Intervention
  - Understand Impact

How?

# Boundaries Guru Group

Do you have healthy  
**BOUNDARIES?**



The confidence to politely let the people  
around you know that they need to respect  
the rules

fb/Sye of Relief

# Workgroup Goal Statement

The Boundaries Guru Workgroup will meet bi-weekly through August 31, 2014 in effort to gain insight into the spectrum of caregiver/care-receiver boundary issues that exist within the business units of the Center for Independence.

In addition, the group will begin to develop and implement strategies that will positively impact identified areas of concerns.



# Accomplishments

1. Surveyed direct-line employees and leaders for areas of concern. (Post-it exercise)
2. Researched the literature for relevant data, trends, tools, and best practices (very limited information found)
3. Gathered current internal policies, procedures, work rules, work instructions, standards, educational materials, and other relevant tools and documents.
4. Identified internal data collection systems, and completed an analysis to gain additional insight into areas of concern.





# Accomplishments

4. Developed recommendations and strategies to address areas of concern. Sample documents/products created:

- Professional boundary standards
  - Boundary categories, definitions, examples of both caregiver and client boundary crossings (beta)
  - Customizable to an area
  - Acknowledgment document for new hires, annual training, disciplinary actions, and a caregiver change in category



- A caregiver training power point
- A brochure for clients
- Monthly and annual trackers for boundary crossings
- Employee handbook updates

# Preliminary Take-Away

- Both clients and caregivers lack insight into the complex role of the paid caregiver, and the into responsibilities that each have in order maintain a healthy service delivery relationship.
- Boundary crossings in the preferred relationship are more prevalent than initially thought, and harder to detect and intervene.
- Boundary crossings that go undetected in the preferred relationship, tend show up when the caregiver moves into a pool relationship .

# Preliminary Take-Away

- The business relationship has a tendency to drift into a personal one. It is not unusual for a client to pay a compliment on a survey regarding their caregiver... “they have become my friend.”
- Clients will “protect” preferred caregivers, or caregivers they have become close to; not wanting to get them in trouble. Case managers often get involved in this dynamic.
- The paid caregiver is not viewed as a legitimate employment/career; and is not taken serious by the caregiver or society.
- Culture and socio-economics have an impact and cannot be overlooked.

# Strategies

- Education is greatly needed for all: clients, caregivers, case managers, family members....
- Clients need to be empowered not to accept poor service delivery, and to speak up.
- Ways to “decrease the risk” for clients to “blow the whistle” on caregivers should be explored.

# Dignity of Risk?

What happens when we accept the  
**Dignity of Risk?**

# Dignity of Risk

## by Sharon Jodock-King

What if you never got to make a mistake?

What if your money was always kept in an envelope where you couldn't get it?

What if you were never given the chance to do well at something?

What if your only chance to be with people different from you was with your own family?

What if the job you did was not useful?

What if you never got to make a decision?

What if the only risky thing you could do was to act out?

What if you couldn't go outside because the last time you did it rained?

What if you took the wrong bus once and now you can't take another one?

# Dignity of Risk

by Sharon Jodock-King

What if you got into trouble and you were sent away and you could never come back because they always remember you are trouble?

What if you worked and got paid 46 cents an hour?

What if you had to wear your winter coat when it rained because it was all you had?

What if you had no privacy?

What if you could do part of your grocery shopping but were not allowed to because you couldn't do all of your shopping alone?

What if you spent three hours each day just waiting?

What if you grew old and never knew adulthood?

What if you never got a chance?

**Expectation**

**Engagement**

**Exploration**



# Expectation



<http://noahsdad.com/>

# Expectation

## 12 Things I wish I knew the day our son received a Down syndrome diagnosis

1. Noah being born with Down syndrome doesn't mean he's sick or unhealthy.
2. Noah's not going to be a *vegetable*. In fact, far from it.
3. Noah's going to laugh and play just like every other kid.
4. Noah shares more things in common with a child without Down syndrome than differences.
5. In a few weeks your son having Down syndrome won't be a big deal.
6. You're going to have the ability to make a huge impact in the world.
7. Your going to have so much fun with your son. In fact, you're going to have even more fun than you ever imagined!
8. You aren't alone.
9. Your didn't just exchange a happy story for a sad one.
10. Other people's stories aren't your stories.
11. Stay off internet.
12. You and your family are going to be just fine

<http://noahsdad.com/>



# Cutting Edge Program Edgewood College



# Video

- <https://www.youtube.com/watch?v=NlbGl4G8ebk>
- Chris/Nancy Video

# Engagement

## Dimension 1: Source of Input

- The individual has complete responsibility to make choice
- Professionals or parents have input into decisions, but the final and binding choice is made by the individual
- Decision making is viewed as mutual, reciprocal process in which the individual is an equal partner
- Decisions are made by parents and professionals, with some input from the individual
- The individual has no input into decisions

## Dimension 2: Degree of Risk

- The choice involves some potential for immediate risk, but little possibility of long-term harm to individual or others
- The decision involves mild risk with minimal possibility for long-lasting harm to the individual or others
- The choice results in a moderate probability for long-lasting harm to the individual or others
- The decision involves an almost certain outcome that includes person injury

## Dimension 3: Degree to Which Input is Binding

- Outside Input is nonbinding
- Outside Input is binding but only for a portion of the decision
- Outside Input is binding once the individual's input has been given equal weight in the development of a range of choice options
- Outside Input is binding, with the individual's input considered only if deemed advisable by others
- External individuals exert total control over the outcome

# Engagement

## Dimension 1: Source of Input

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# Exploration

Early childhood through adolescence :

- Capacity building
  - Self-regulation skill development (goal setting, self-monitoring, self-reinforcement)
  - Exercising choice and decision making
  - Supported problem solving

“Adolescents will have a difficultly becoming self-determined young adults unless their early family and education experiences have laid a solid foundation upon which to build more sophisticated skills and capacities.”

Self-Determination Across the Life Span: Issues and Gaps, A  
National Gateway to Self-Determination

# Questions?



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