

Rights (in) Passage

Transition Age Youth Achieving Independence

Gerianne Prom
Danielle Skenadore, MSW
Milwaukee Center for Independence

Objectives

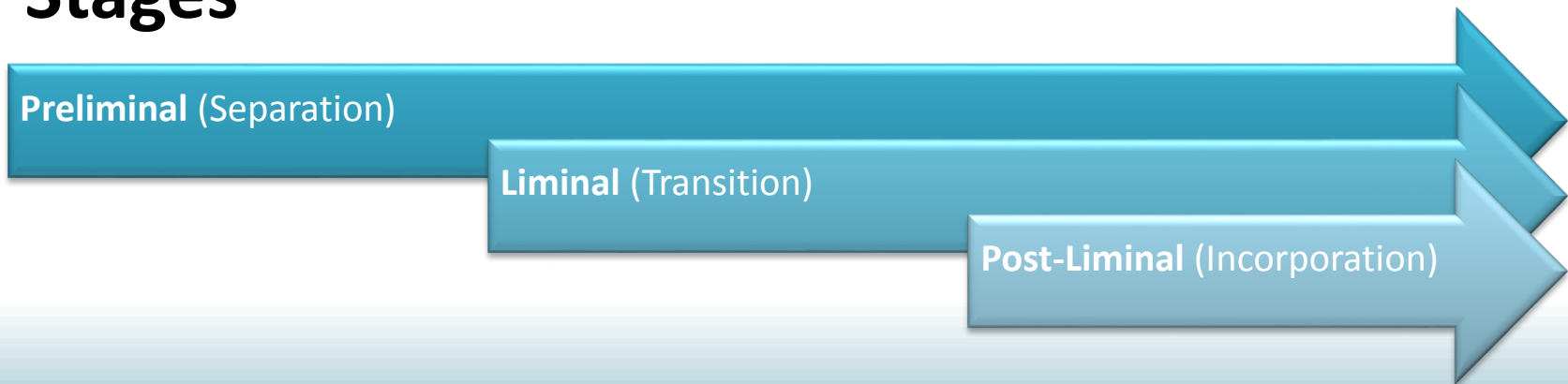
- Rites of Passage
- Rights in Passage
- Self-Directed Waiver History & Overview
- Models of Participant-Directed Services
- Challenges
- Solutions

Rights/Rites

RITE OF PASSAGE

: a ritual associated with a crisis or a change of status (as marriage, illness, or death) for an individual.

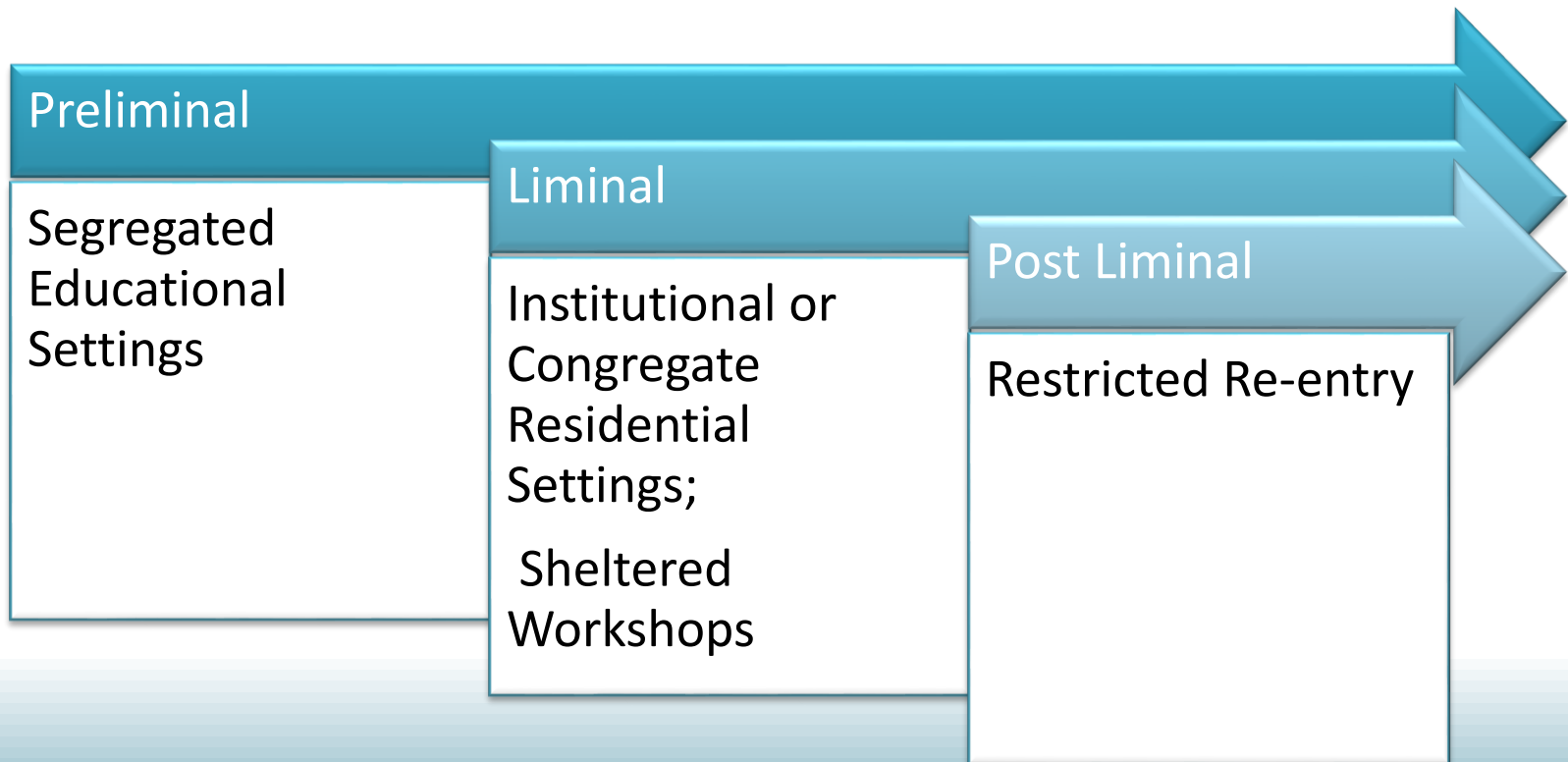
Stages



Passage into Adulthood

- Child to adult
- Legal adult (legal autonomy)
- High school graduation
- Exploration
- Post-secondary education
- Full-time employment
- Move from family home
- Right to vote
- Enlist in Armed Forces

Passage into Adulthood for Individuals with Disabilities in the Past



Factors Contributing to Perpetual Liminality

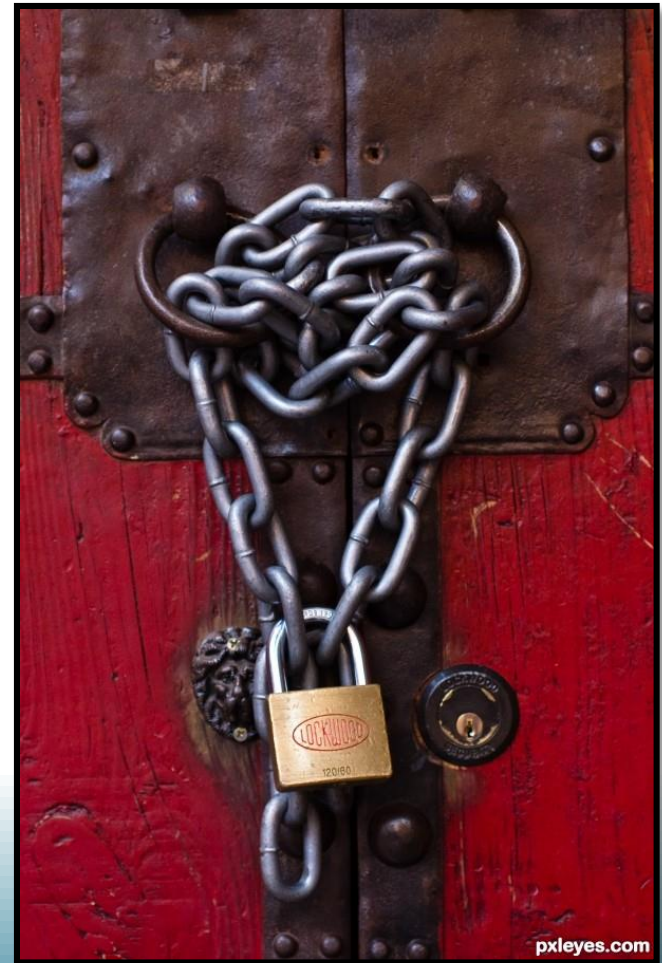
What happens when re-entry does not occur?

- Institutionalization
- Limited access to community living, employment, post-secondary education
- Restricted social mobility
- Prohibited opportunities for exploration
- Increased vulnerability
- Foster dependence

Liminality (Transition) and Disability

“The liminal personae resides in the margins of society while they prepare to adopt a new social status and re-enter society.”

“Ambiguity and paradox characterize the social situation of liminal persons. They are neither this nor that, child nor adult, woman nor mother. As a result, **the liminal individual is often invisible both structurally and physically.**”



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?

Cultural Shift: Legal Rights of Transition Age Youth with Disabilities

Legal Rights

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

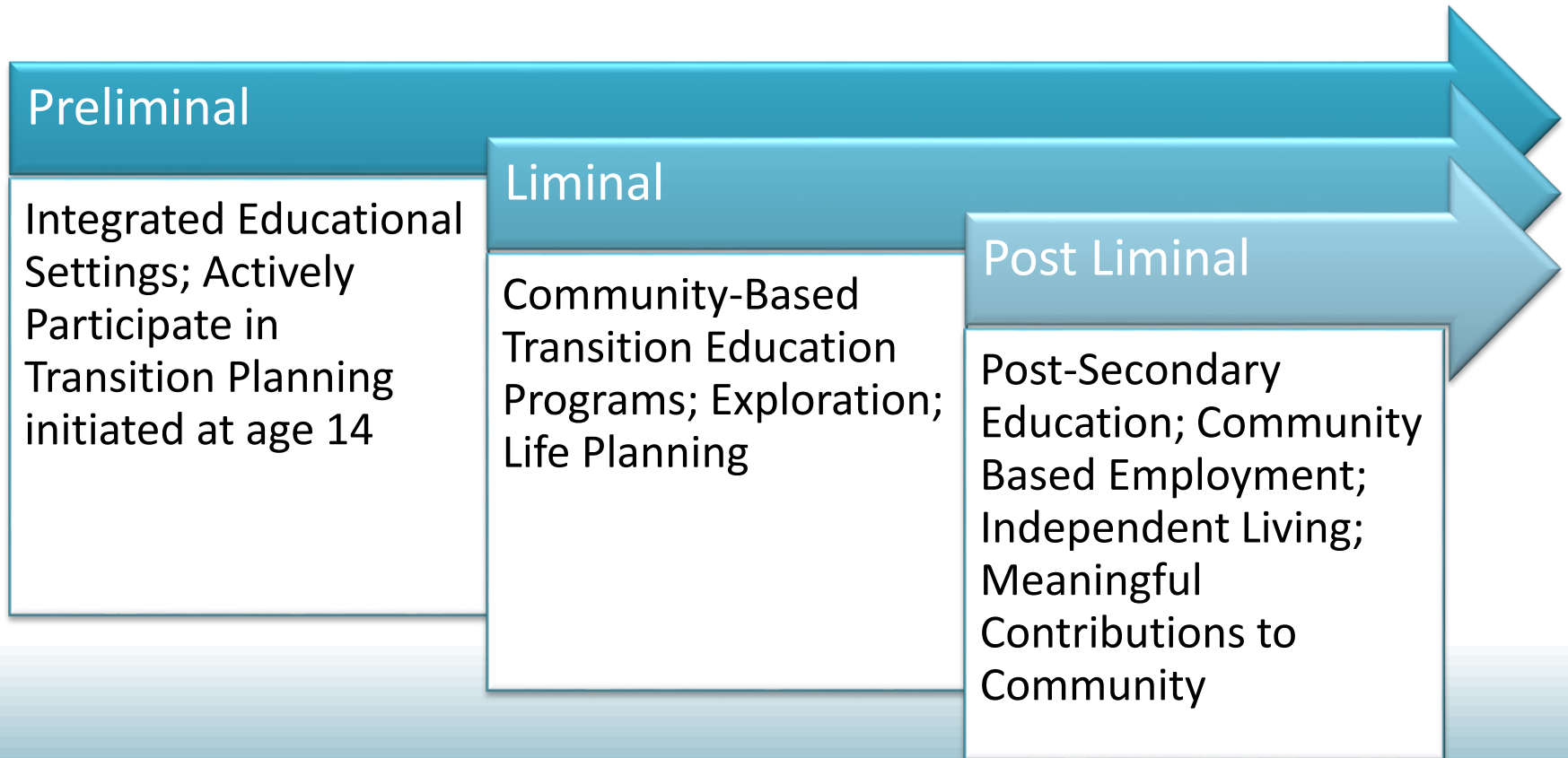
Social Justice Movements

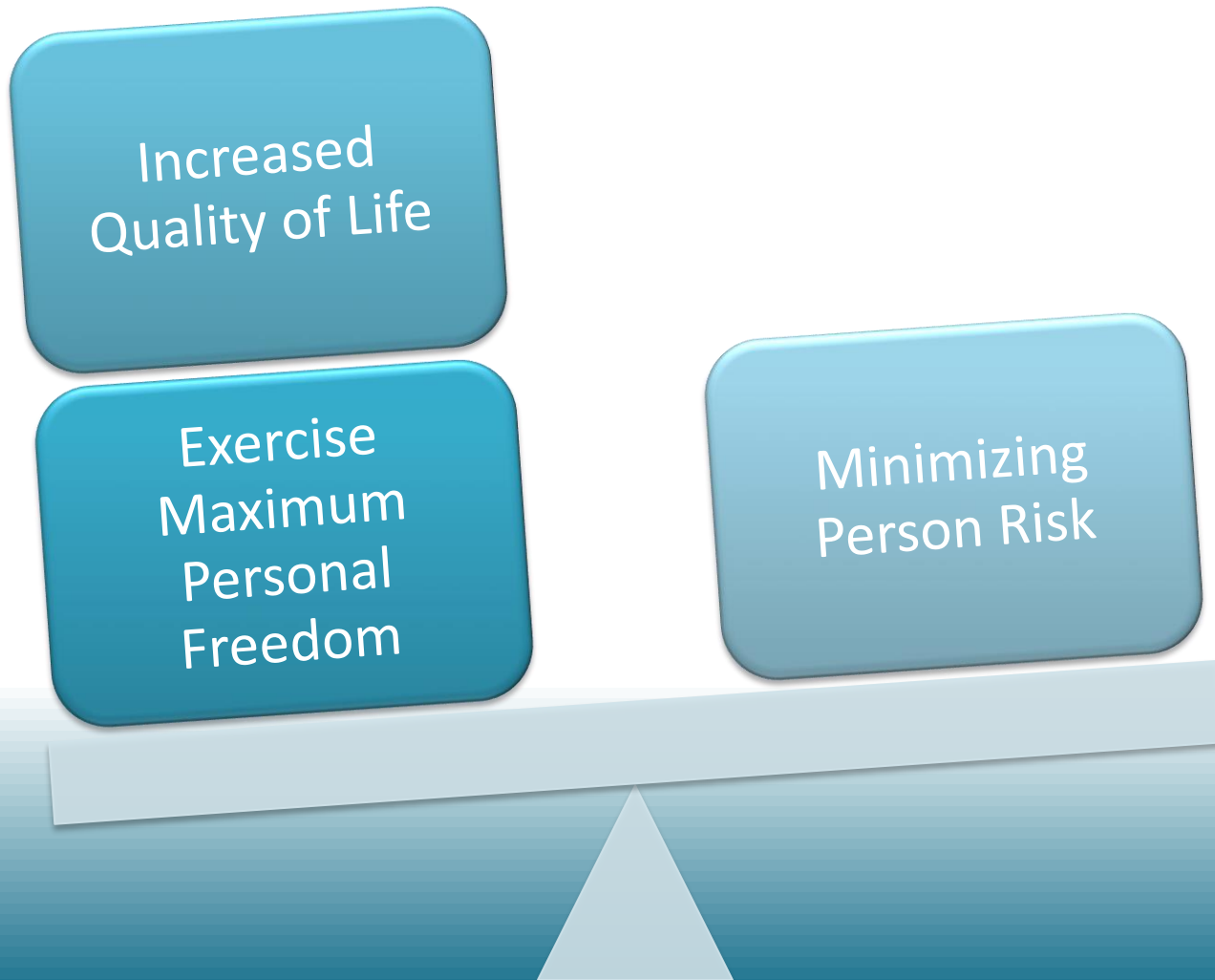
- Community Living Movement
- Employment Programs
- Rise of Self-Directed Service Models

“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.”

High School	Adult Services
Individuals with Disabilities Education Act (IDEA); free and appropriate public education (FAPE)	Section 504 of the Rehabilitation Act and the Americans with Disabilities Act (ADA)
School services are an entitlement (from ages 3-21 or until regular high school diploma requirements are met).	Adult services are based on eligibility which may be different for each agency.
School attendance is mandatory.	Consumers decide to use an adult service agency to support them in their employment goals.
School districts are required to identify students with disabilities through free evaluations and the individualized education program (IEP) process.	Consumers are responsible for disclosing and providing documentation of a disability. They must be self-advocates (see Opening Doors to Self-Determination Skills).
Students receive special education and related services to address needs based on identified disability.	Consumers apply for services needed through various adult service agencies.
Services include individually designed instruction, modifications, and accommodations based on IEP.	Services are individually designed through Individual Plans for Employment or a similar individualized plan developed with the consumer.
Progress toward IEP goals is monitored and communicated to the parent(s) and/or student.	Progress toward employment goals is monitored by the consumer and adult service provider. Self-advocacy is a must.
Schools assist in connecting the student with the community support agencies if so identified as a transition need according to the IEP.	Consumers must request services needed and identify what agencies would best meet their needs.

Passage into Adulthood for Individuals with Disabilities in the Present





SELF-DIRECTED SERVICES

Self-Determination Theory

Autonomy

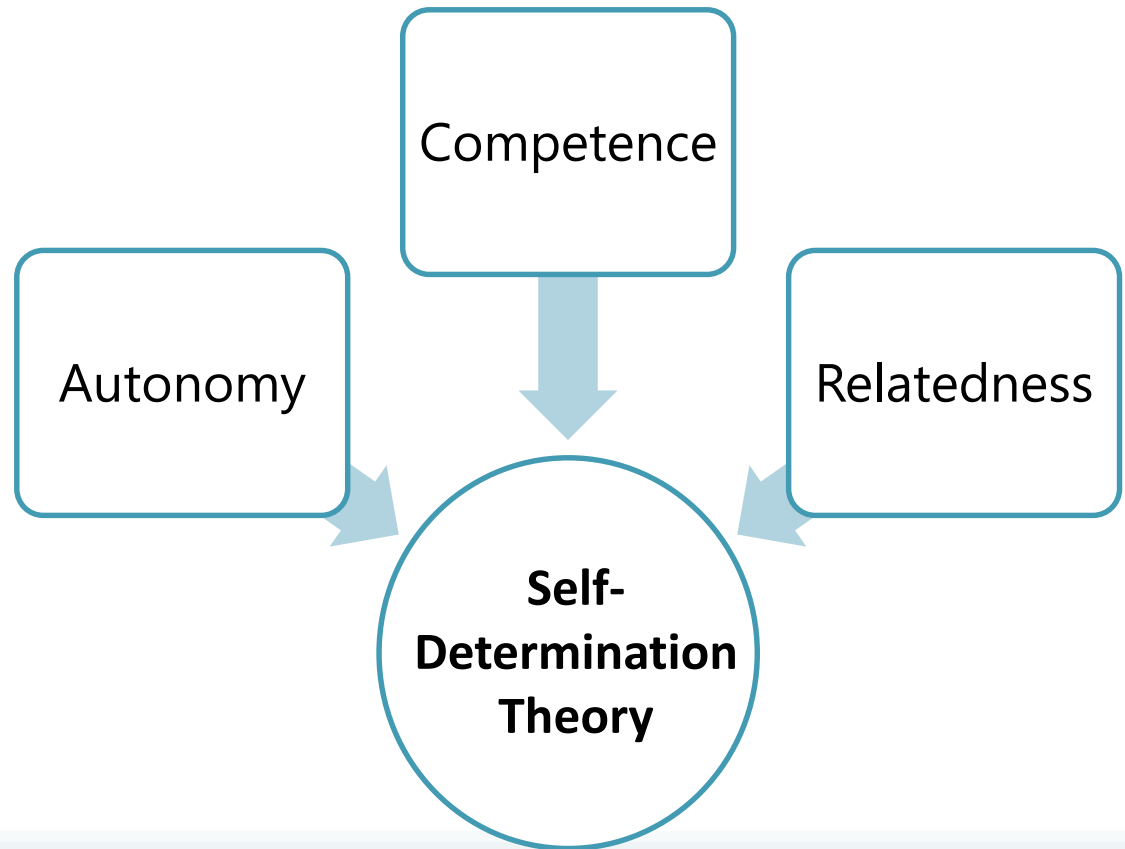
- Being Responsible
- Independent
- Able to Speak for Oneself

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.**

Paradigm Shift

Traditional Approach

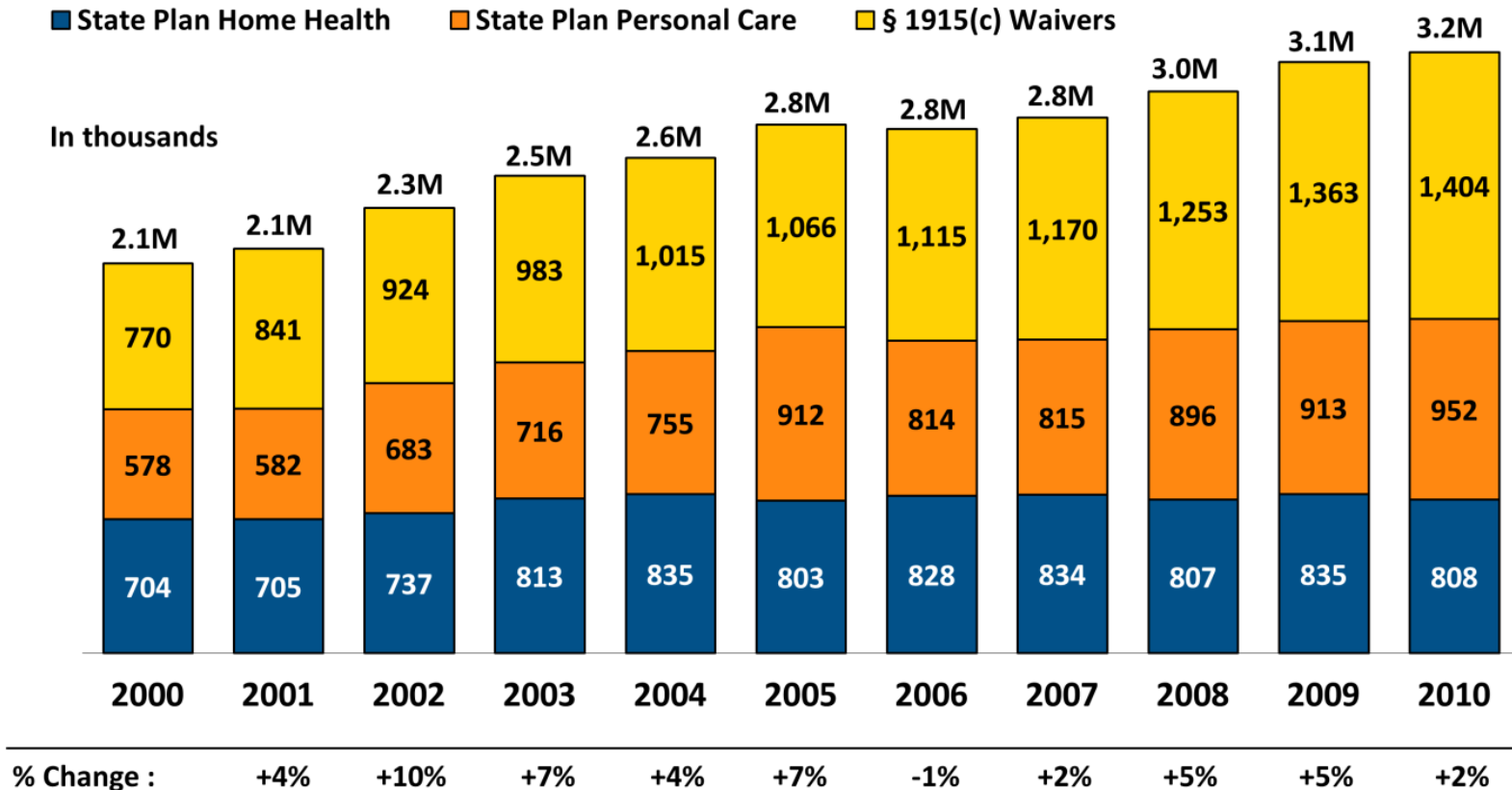
- The consumer is dependent upon the service provider to direct and deliver necessary supports
- Provider identifies and mitigates risk
- Provider monitors quality of supports
- Provider initiates and terminates service accordingly

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

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.

CMS and Self-Direction

Financial Management Services (FMS)

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

Quality Assurance and Improvement

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)

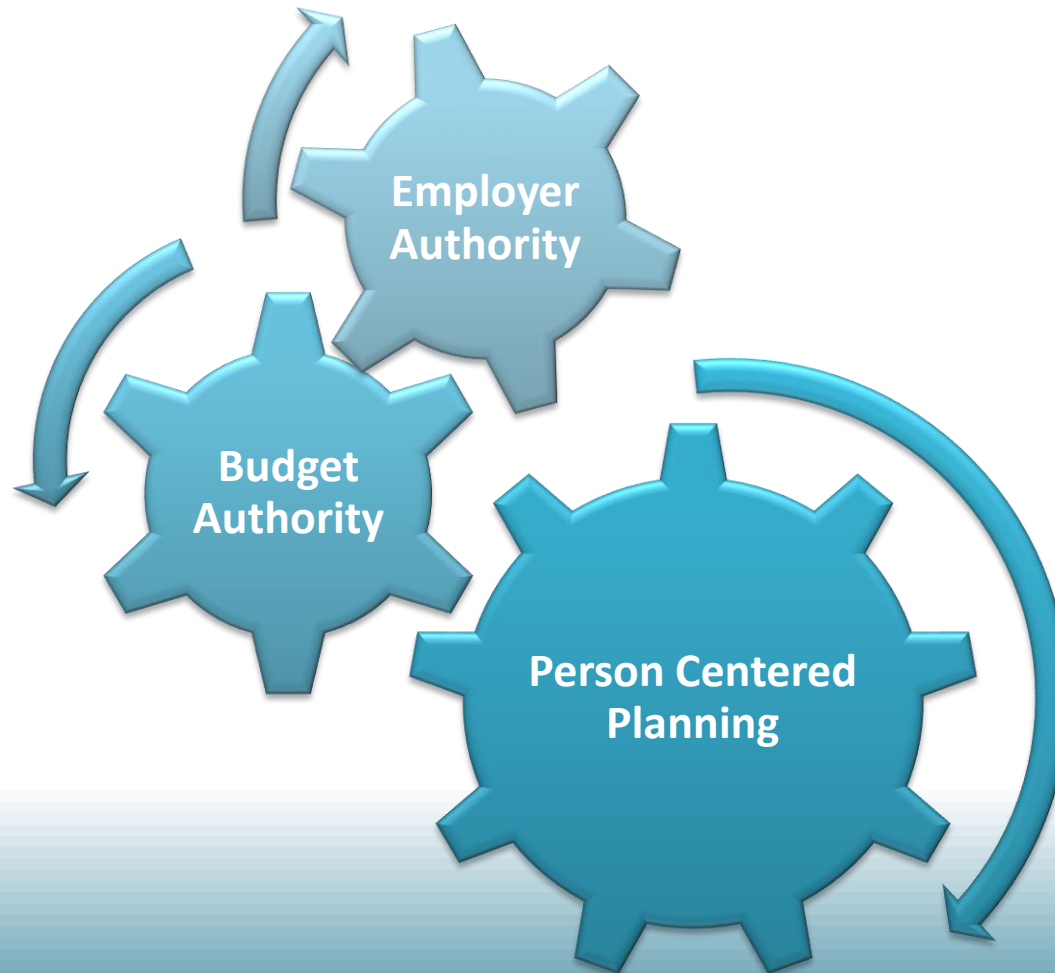
1915(k)
SPA

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

Best Practices

**SOLUTIONS TO SUPPORT SUCCESS
IN SELF-DIRECTED PROGRAMS**

Expectation

Engagement

Exploration

Expectation



Hi, I'm Noah.

I'm showing the world that
Down syndrome is ok!

<http://noahsdad.com/>

Expectation

Clayton Marr was the second, and youngest, person with Down syndrome in New Zealand to receive his Driver's license at 19 years old in 2009.

“It's important young people with Down syndrome keep in touch with mainstream kids. One reason they achieve so much this way is because they set goals against their peers.”

<http://noahsdad.com/down-syndrome-drivers-license/>



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

- 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

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.”

Systems Advocacy: Creating Change



Wisconsin's Self-Directed Support Options



A Better Bottom Line

- Governor Walker proclaimed 2014 as the Year of *A Better Bottom Line* to encourage and promote employment opportunities for people with disabilities.
- *A Better Bottom Line* is tailored after Delaware Governor Jack Markell's initiative with the National Governor's Association, which details the vast benefits for employers, employees, and communities.
- Expand DVR Services to 6,000 more individuals
- Expand **Project Search**





- Funded by the Administration on Intellectual and Developmental Disabilities
- Five-year, national systems change grant that focuses on improving, developing and implementing policies and practices that raise community expectations and overall employment outcomes for youth with intellectual/developmental disabilities (I/DD).
- Partners with Wisconsin Board for People with Developmental Disabilities, leadership at the Division of Vocational Rehabilitation, Department of Health Services, the Department of Public Instruction, AIDD partners, Disability Rights Wisconsin and Waisman Center-University Center for Excellence on Developmental Disabilities.
- <http://www.letsgettoworkwi.org/>

The Wisconsin Self-Determination Conference works to empower people with disabilities in Wisconsin to have more control over their lives.

Self-determination is strong in Wisconsin and Self-Directed Supports (SDS) is one of the most creative tools available for individuals with disabilities to get the support they need to get the life they want.



Disability Advocacy Day





MKE AREA TIME EXCHANGE

Cutting Edge Program Edgewood College



References

- Deegan, M.J., Willett, J., (2001) Liminality and Disability: Rites of Passage and Community in a Hypermodern Society. Disability Studies Quarterly, Volume 21, No.3. Retrieved from <http://dsq-sds.org/article/view/300/349> .
- Heller, T. et al. (2011). Self-Determination Across the Life Span: Issues and Gaps. A National Gateway to Self-Determination. Retrieved from: http://ngsd.org/sites/default/files/scaling_up_paper_3.pdf
- Jodock-King, S. (2010). Dignity of Risk. Disability Rights Washington. Retrieved from: <http://www.disabilityrightswa.org/advocacy-news/what-dignity-risk-means-me>
- Murphy, M. (2012) Participant Direction 101: A Primer for FMS Providers. National Resource Center for Participant Directed Services.
- National Council on Disability. (2013). The Case for Medicaid Self-Direction: A White Paper on Research, Practice, and Policy Opportunities. Retrieved from <http://www.ncd.gov/NCD/publications/2013/05222013A/>
- Ng, C et al. (2014). Medicaid Home and Community-Based Services Programs: 2010 Data Update. The Henry J. Kaiser Family Foundation.
- Robert Wood Johnson Foundation. (2004). Self-Determination for Persons with Developmental Disabilities. An RWJF National Program. Retrieved from: http://www.rwjf.org/content/dam/farm/reports/program_results_reports/2007/rwjf70028
- Robinson, M., Pfeffer, C., & Buccigrossi. (2003). Business Case for Inclusion and Engagement. wetWare, Inc. Rochester, NY. Retrieved from http://workforcediversitynetwork.com/docs/business_case_3.pdf
- Ryan, R., and Deci, E., (2000). "Self-Determination Theory and the Facilitation of Intrinsic Motivation, Social Development, and Well-Being." American Psychologist, 55.1: 68-78
- Schloss, P., Alper, S., Jayne, D., (1993) Self-Determination for Persons with Disabilities: Choice, Risk, and Dignity. Exceptional Children, Vol. 60, No. 3, p. 215-225. The Council for Exceptional Children.
- Wisconsin Department of Public Instruction. (2013). Opening Doors to Self-Determination Skills,. Retrieved from: <http://sped.dpi.wi.gov/files/sped/pdf/tranopndrs-self-determination.pdf>