



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## What is Self-Determination & Why is it Important to People with Developmental Disabilities?

**Michael L. Wehmeyer, Ph.D.**

Professor, Special Education, University of Kansas

Director, Kansas University Center on Developmental Disabilities

Co-Principal Investigator, National Gateway to Self-Determination Project



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Setting Expectations



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Ruth's History

- Ruth was born with cerebral palsy. She has severe muscle spasms that affect her arms and legs. She has seizures that are only partially controlled by medication. Ruth has trouble breathing, eating, and swallowing. She has to either sit in a wheelchair or lie in bed. She has never spoken, but she makes sounds. She cannot feed herself, bathe, or get dressed on her own. No one knows how smart she is because she cannot take the tests people use to measure intelligence.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Planning for Ruth's Future

- Where will Ruth live when she leaves school?
- With whom should Ruth live?
- In what day activities could Ruth take part?
- What types of services will Ruth need?





# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Ruth's Plan For Her Future



- Ruth Sienkiewicz-Mercer & Steven Kaplan
- *I Raise My Eyes to Say Yes*



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Where will Ruth live?

Ruth lives independently in her own home in Northampton, Massachusetts. She moved from Belchertown State School in 1978 after living there for 16 years. Since she moved from the school, she has lived in two different apartments. In 1989 she was the keynote speaker at the closure of Belchertown.





# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## With whom should Ruth live?

Her husband, Norman. After securing her freedom, Ruth married a longtime friend. They live together and enjoy occasional, though not too frequent, visits from their in-laws.





# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## In what day activities could Ruth take part?

Ruth travels extensively as a speaker and lecturer and continues to write. She is a frequent keynote speaker. On Saturdays she likes to grocery shop and do her laundry. Sundays are her day of rest.





# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## What types of services will Ruth need?

Most of all Ruth needs people to support her and listen to her. **These people are called her friends.** She needs the assistance provided by a personal care attendant employed by Ruth and Norman. She needs a little luck to win the lottery. **She needs more money than SSI provides.** She needs phone and utility services. She needs the State of Massachusetts to repair the potholes from the winter storms.





# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Expectations and Stereotypes

- Expectations, stereotypes, and biases (ours included) impact everything we do as professionals.
- Historically, our expectations have been too low for people with disabilities. Why should that be any different now?



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## What is Self-Determination?

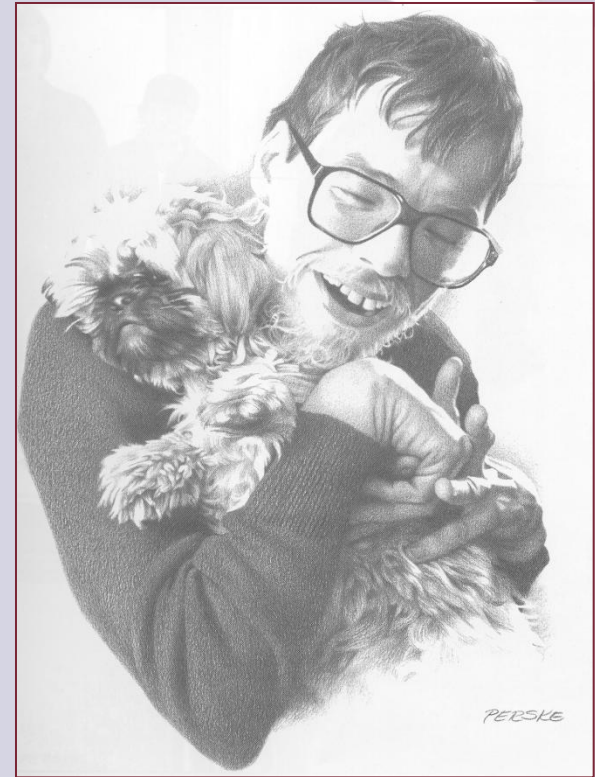


# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Robert Williams

“we (people with disabilities) don’t have to be told what self-determination means. We know it is just another word for a life filled with rising expectations, dignity, respect and opportunities.”





# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Do We Have to be Told What Self-Determination Means?

'When I use a word,' Humpty Dumpty said, in a rather scornful tone, 'it means just what I choose it to mean, neither more nor less.'

'The question is,' said Alice, 'whether you *can* make words mean so many different things.'





# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Requirements of Scientific Terms

- Philosophers of science require scientific terms to strive for two principle criteria: clarity and utility.
  - Clarity requires that when a party uses a certain term, it defines the term clearly and uses it consistently as defined. If another party uses the same term in a different sense, then this other party needs to make clear how it defines and uses that term (Wolfensberger, 1994, p. 285).
- When a term acquires too much “baggage” (surplus meaning; emotion; acrimony; multiple, inconsistent or confusing meanings), then rather than trying to constantly reiterate one’s own definition of it in one’s own discourse, it may be better to abandon it and craft a new term, or even a new construct (p. 286).
- In essence, a term that means anything to anybody eventually means nothing to anyone.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Too Much Baggage?

### Google Search for “What Is Self-Determination?”

- Making a choice.
- Being resolute and determined.
- Ability of people to control their own lives.
- Managing your own financial resources.
- Making a decision.
- Speaking up for yourself.
- Participating in the democratic process.
- Free will.
- Personal control.
- A new way of distributing public funds.
- Exercising one’s right to life, liberty, and the pursuit of happiness.
- Owning one’s own home.
- A natural or basic human right.
- Being independent or autonomous
- The right of people to make a choice.
- A way to reduce the cost of social services.
- Developing plans and acting on them.
- Having access to the social, cultural, economic, and political opportunities of one’s community.
- Running one’s IEP meeting.
- Being assertive.
- Freedom. Authority. Support. Responsibility.
- Power ideology or empowerment.
- Attitudes, abilities, and skills that allow individuals to define personal goals, take initiative to reach those goals, and make choices.
- Believing you can control your destiny.
- Causal agency.
- A philosophy of service delivery.

[End of Page 30 of 833 web pages]



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## self-determination: *noun* (sèlf' dî-tûr'me-nâ'shen)

1. Determination of one's own fate or course of action without compulsion;
2. Freedom of the people of a given area to determine their own political status; independence.

*self-determined, adj.-- self-determining, adj.*

The American Heritage Dictionary of the English Language,  
Third Edition (1992). Houghton Mifflin Company.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## What is Self-Determination?

- National, political, or collective self-determination;
  - Emerged from twin 18<sup>th</sup> Century notion that the people, not monarchs are sovereign, and that the people are to be thought of as “the nation.”
  - Through 19<sup>th</sup> Century the belief that a people should have the right and opportunity to determine their own government spread and gained wide acceptance.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## What is Self-Determination?

- Personal or individual self-determination:
  - 1920s emerged as core concept in field of social work. “Client self-determination is the focal point of the value system in social work. Without self-determination, human dignity and worth are meaningless” (Biestek & Gehrig, 1978).
  - Client participation, client responsibility for plan-making, self-help, self-direction, self-expression.
  - Ongoing tension between social work’s value for client self-determination and issues (mental illness and medication).



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## What is Self-Determination?

- Personal or individual self-determination:
  - Emerged as a construct as the science of personality psychology developed during the 1930s and 1940s.
  - The earliest conceptualizations of self-determination within the personality literature (e.g., Angyal, 1941) used the term as it related to questions of determinism.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Self-Determination in Personality Psychology

- Personal or individual self-determination:
  - Self-determination as a personality construct proposes that one's life course is “determined” (e.g., caused) by either autonomous and heteronomous functions, where autonomous means self-governing or governed from inside, and heteronomous means governed from outside.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Misperceptions of Self-Determination

- Self-determination is control



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Self-Determination as Control

- At the heart of the understanding of the self-determination construct by most in disability advocacy and supports is the notion that self-determination is the same as control.
- Within the context of the disability rights and advocacy movement, the construct has been imbued with the empowerment and “rights” orientation typically associated with the sense of the term as a national or political construct.
- When self-determination is equated with control at the personal meaning of the construct, what people understand that to mean involves making complex decisions, solving difficult problems, and engaging in a number cognitively complex behaviors and, whether fair or accurate or not, dismiss the possibility that people with severe cognitive impairments can become self-determined since they cannot perform these complex cognitive tasks.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Self-Determination as Control

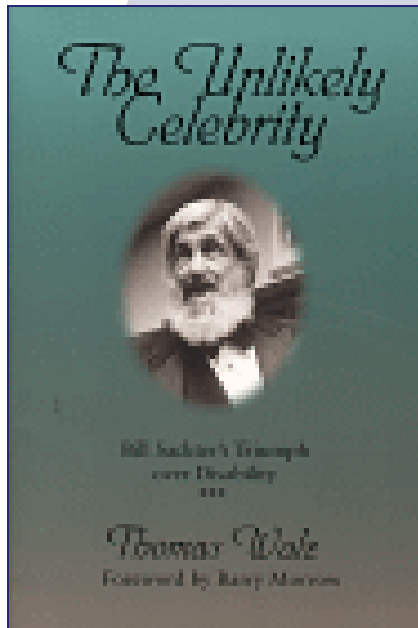
- The concept of personal control refers to having control over outcomes. Thus, people with disabilities would have personal control if a contingency in the environment allows them to attain an outcome by doing an instrumental behavior. In contrast, self-determination is about the self-initiation and self-regulation of one's own behavior. Of course, one needs to have control over outcomes in order to be self-determining, but personal control does not ensure self-determination.
- A person could be instructed "You will get a candy bar if you wash your face, comb your hair, and brush your teeth now," and could control the outcome (getting a candy bar) by doing the required behaviors, yet still not be acting in a self-determined manner, that is acting volitionally. (Deci, 2003, p. 23)



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Self-Determination as Control



The Arc's Bill Sackter Award



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Misperceptions of Self-Determination

- Self-determination is control.
- Self-determination is independent performance.
- Self-determination is just making a choice.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## If Not Control... What?

- Self-Determination: Determination of one's mind or will by itself toward an object." (Oxford English Dictionary, 1683)
- The noun 'determination' has a number of meanings that influence how one understands this definition.
  - To make a *determination* means to come to a decision or render a judgment.
  - To act with *determination* means to be firm in one's resolve and resolute.
- One, thus, might conclude that self-*determination* means to make one's own decisions or to act resolutely.
- The source of the word 'determination' in self-*determination* is, however, the philosophical doctrine of *determinism*.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Self-Determination and Determinism

- The philosophical doctrine of determinism posits that actions are *caused* by events or natural laws that precede or are antecedent to the occurrence of the action. Behavior, then, is governed by these other events or natural laws.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Forms of Determinism

- Psychological determinism: natural laws are strictly determinative of future consequences.
- Psychological determinism: human beliefs and actions follow ineluctably from the combination of experience and anterior psychological conditions.
- Theological determinism: an omnipotent being (God) decrees or has foreknowledge of the future of the world, and is 'in control' of humankind's destiny.
- Economic Determinism
- Environmental Determinism
- Cultural Determinism
- Relative (or Familial) Determinism,
- Neurophysiological Determinism
- Biological Determinism
- Genetic Determinism



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Self-Determination and Determinism

- Self-determinism, or self-determination, implies that individuals *cause* themselves to act in certain ways, as opposed to someone or something else ‘causing’ us to act in certain ways
- People who are self-determined embody the characteristic or quality of ‘self-determination,’ a noun referring to the degree to which that person acts or behaves in ways that are self- (instead of other-) caused.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Self-Determination and Volition

- This self vs. other dichotomy is not just equivalent to saying that self-determination refers to actions caused by forces literally internal to the person versus forces outside the person, because genes, neurotransmitters, and other determinants are, clearly, internal to the person.
- Instead, the meaning of self-determinism is linked to the capacity of humans to, in a sense, override other determinants of their behavior so as to act based on their own will.
- That is why the term *volition* is central to understanding self-determination.
  - *Volition* refers to making conscious *choices* or the actual power to make conscious choices, or will.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Self-Determination and Intention

- Self-determination refers to self- (vs. other-) caused actions, to people acting volitionally, based on their own will.
- Volition is defined as the capability of conscious choice and decision and *intention*.
- Volitional behavior, then, implies intent.
  - Intentional action refers to actions done deliberately and purposefully.
- Self-determined behavior is volitional and intentional. People who are self-determined act with intent. That intent, we have proposed, is to act as *causal agents* in their lives.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Self-Determination and Disability

- Within the context of the disability rights and advocacy movement, the construct as a personal characteristic has been imbued with the empowerment and “rights” orientation typically associated with the sense of the term as a national or political construct. Empowerment is a term usually associated with social movements, and typically is used, as Rappaport (1981) stated, in reference to actions that “enhance the possibilities for people to control their lives” (p. 15).



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Self-Determination and Disability



- Nirje (1972):
  - Chapter in Normalization by Wolfensberger titled The Right to Self-Determination.
  - use of the term self-determination, while still pertaining to the rights of a particular group of people (e.g., people with intellectual disability), moved its application from issues of national or corporate self-governance, freedom, and independence, to a use of the term in reference to individuals. It is a call for individual or personal self-determination.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Self-Determination and Disability

### Nirje (1972) continued



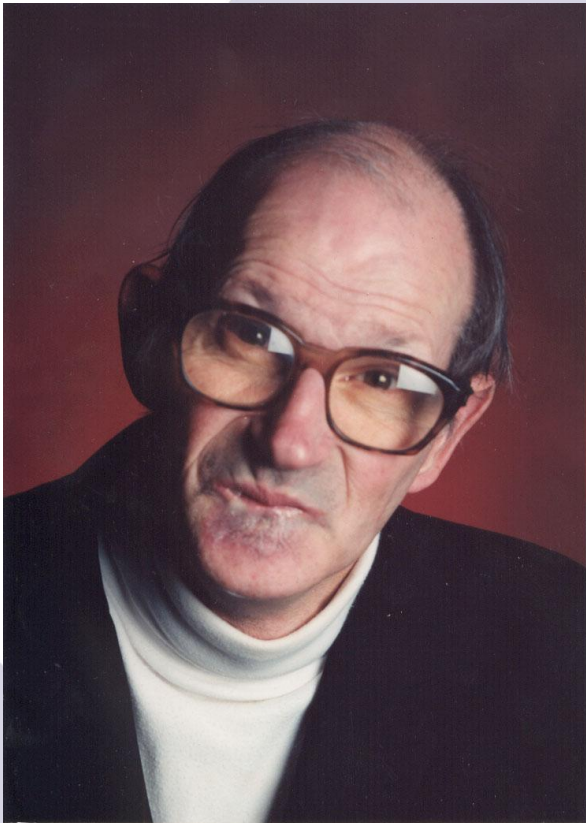
- clearly articulates the importance of this personal self-determination to all people, not excluding people with intellectual disability or other significant disabilities;
- equates self-determination with the respect and dignity to which all people are entitled;
- recognized that people define themselves, and others define them, by the circumstances and conditions of their lives. Salmon Rushdie, the noted novelist, once said in a newspaper interview that "our lives teach us who we are."
- This recognition that self-determination is fundamental to attaining respect and dignity and to perceiving oneself as worthy and valued is a major reason people with disabilities have been unequivocal and consistent in their demand for control in their lives.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## What is Self-Determination?



“When I moved to New Bedford, I wanted to open a checking account. I went over to the bank and gave the \$10 to open the account and asked them if there would be a problem. They said no. But, when I went back a couple of days later, they said they couldn’t understand my signature.”

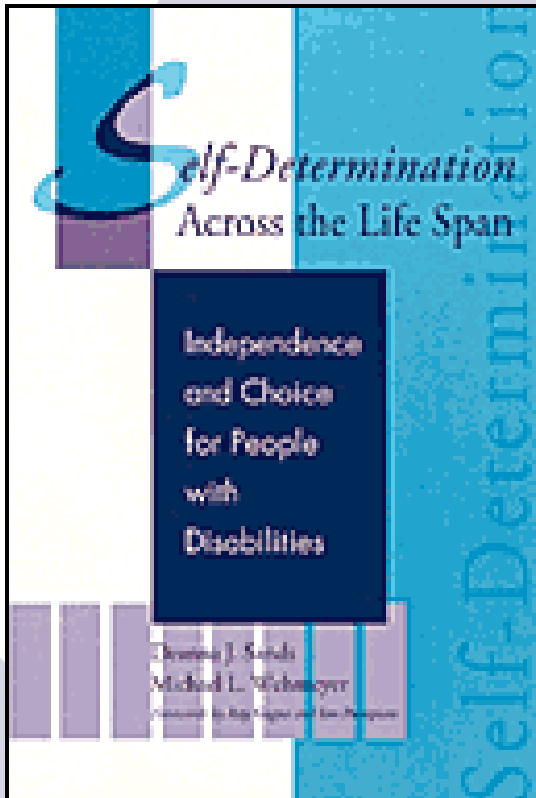
Raymond J. Gagne



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## What is Self-Determination?



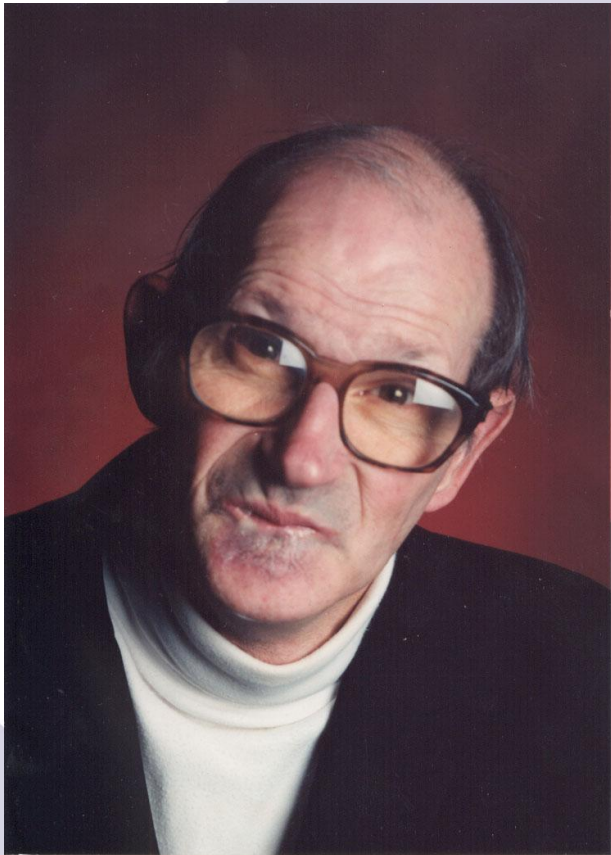
“I thought about this and realized that I had a checking account before I moved, and that had worked fine. The next morning, I put on a suit and tie and went down to the main branch. I asked to see the bank president. They told me he was in a meeting. I told them I would wait.”



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## What is Self-Determination?



“I waited for about 2 minutes and he came out. He brought me into a room and asked me what the problem was. I told him. I also brought my canceled checks and showed him that I had an account before. He apologized and I got my checking account.

That is why self-determination is important to me.”



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## What is Self-Determination?

- Self-determined behavior refers to volitional actions that enable one to act as the primary *causal agent* in one's life and to maintain or improve one's quality of life.
  - A causal agent is someone who makes or causes things to happen in his or her life.
  - Self-determination contributes to a persons overall quality of life (Schalock, 1996).





# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## The Emergence of Self-Determination

- Enhanced capacity as a result of:
  - attainment of developmental milestones;
  - acquisition of component elements.
- Opportunity to assume control as a result of:
  - environments that support control and choice;
  - frequent experiences of choice and control.
- Supports and accommodations.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Why Focus on Self-Determination?



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Why Focus on Self-Determination?

- Consistent with new paradigms of disability that view disability as a function of the fit between the person's capacities and the context in which the person needs to function.

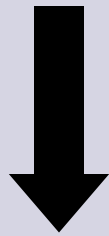


A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

# Historical Conceptualizations of Disability

Disability

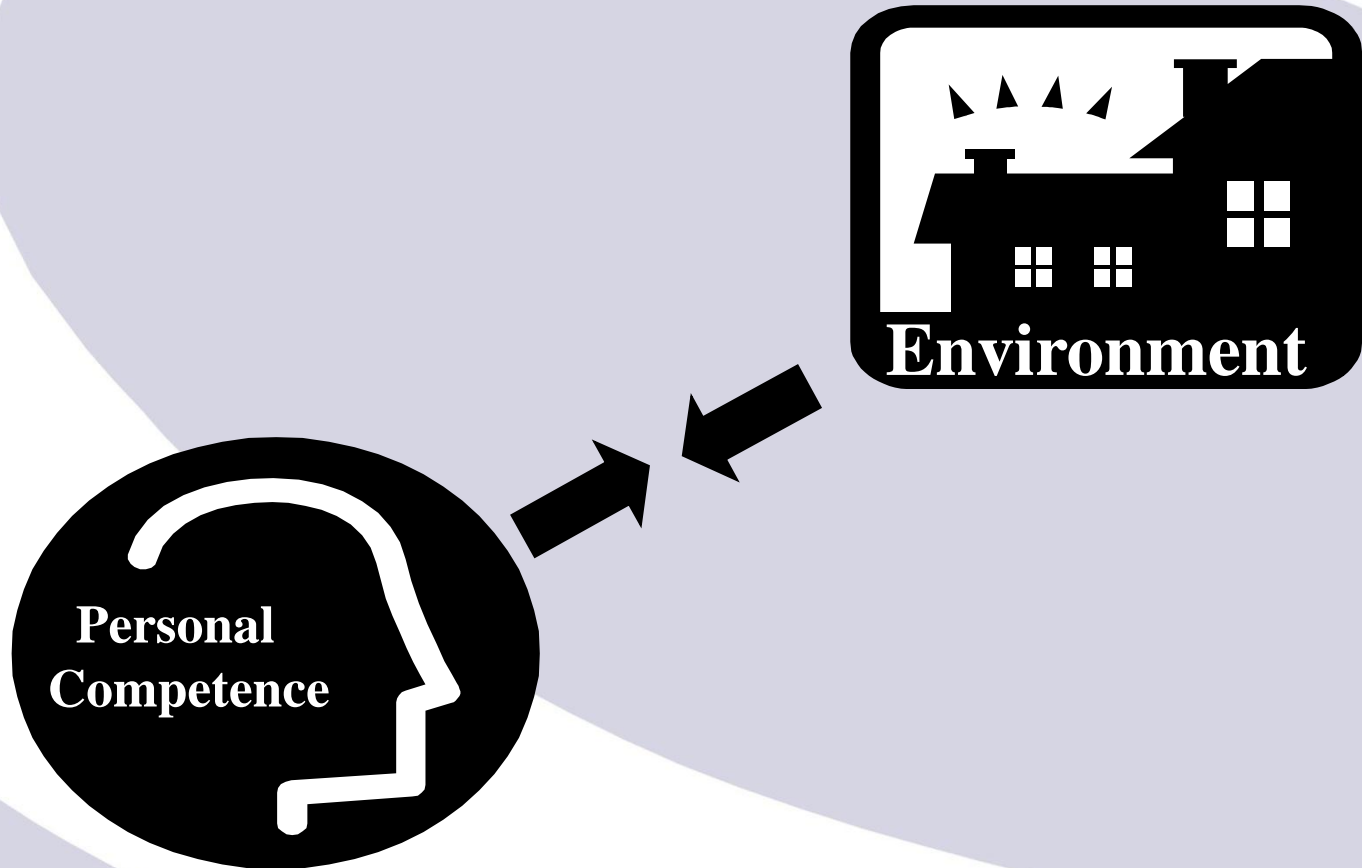




# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Changing Expectations: Changing Conceptualizations



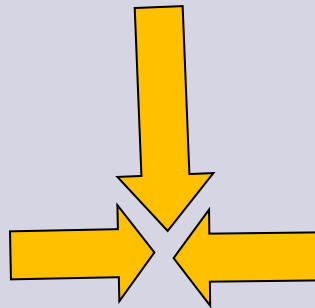


# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Changing Expectations: Changing Conceptualizations

Disability





# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Implications for Intervention

- Strengths-based with a focus on promoting self-determination
- Focus on environment/context, not fixing individual;
- Emphasizes supports, not programs



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Supports

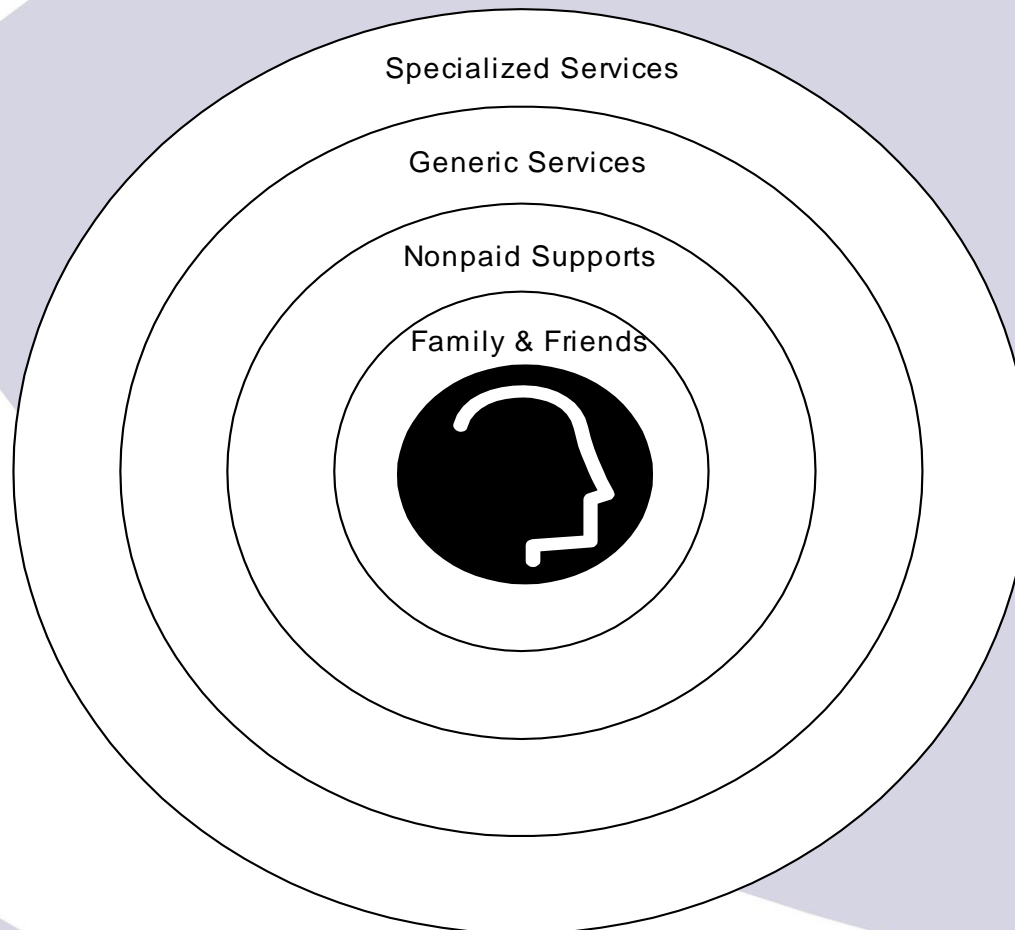
- Resources and strategies that:
  - promote the interests and causes of individuals with or without disabilities;
  - enable them to access opportunities, information, and relationships inherent within integrated work and living environments;
  - result in enhanced interdependence, productivity, community inclusion, life satisfaction, and human functioning.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## An Array of Supports





# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Why Focus on Self-Determination?

- **New paradigms of disability.**
- **Importance to people with disability**
- **Impact on adult outcomes and quality of life**



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Pearl S. Buck,

1932 Pulitzer Prize, 1938 Nobel Prize



"none who have always been free can understand the terrible fascinating power of the hope of freedom to those who are not free."



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Self-Determination and Adult Outcomes

- Multiple research studies find that a person's self-determination status predicts higher quality of life.
- Self-determination status is positively correlated with more positive post-secondary outcomes, including employment, independent living, and community inclusion for youth with disabilities.
- Young adults who are more engaged in personally-valued recreation activities are more self-determined, suggesting a reciprocal relationship between recreation activities and self-determination.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Self-Determination and Adult Outcomes

- Students with cognitive disabilities who leave school as self-determined young people:
  - Are more independent one year after graduation.
  - Are more likely to live somewhere other than where they lived in high school one year after graduation.
  - Are significantly more likely to be employed for pay at higher wages one year after graduation.
  - Are significantly more likely to be employed in a position that provides health care, sick leave, and vacation benefits three years after graduation.
  - Are significantly more likely to live independently three years after graduation.



A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

# Self-Determination and People with Developmental Disabilities: What Does The Research Tell Us?



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Self-Determination and People with Developmental Disabilities

- Research shows that youth/adults with disabilities are less self-determined than their non-disabled peers.
  - It is important, however, not to assume that this in any way reflects the capacity of people with disabilities to become self-determined. The research clearly shows that people with disabilities have many fewer opportunities to make choices and express preferences across their daily lives.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Factors Contributing to Self-Determination

- The environments in which youth/adults with disabilities live, learn, work, and play limit opportunities to learn skills and have experiences leading to enhanced self-determination and to act in a self-determined manner.
  - More restrictive environments (congregate settings, non-community-based settings) limit opportunities for choice-making and restrict personal autonomy.
- Although many people believe that people with intellectual disability cannot be self-determined because of their cognitive impairment, research consistently shows that while SD is positively correlated with IQ, that relationship is generally weak and IQ is not predictive of self-determination status.
  - IQ is predictive\* of where one lives/works, which in turn is predictive of self-determination status by virtue of the above-noted findings.

\*By predictive, we simply mean the research shows a statistical relationship between IQ and where one lives/works. This should not be interpreted to mean that IQ must, by any means, be predictive of where one lives or works; it is simply the case at the current time.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Perceptions of Self-Determination and People with Developmental Disabilities

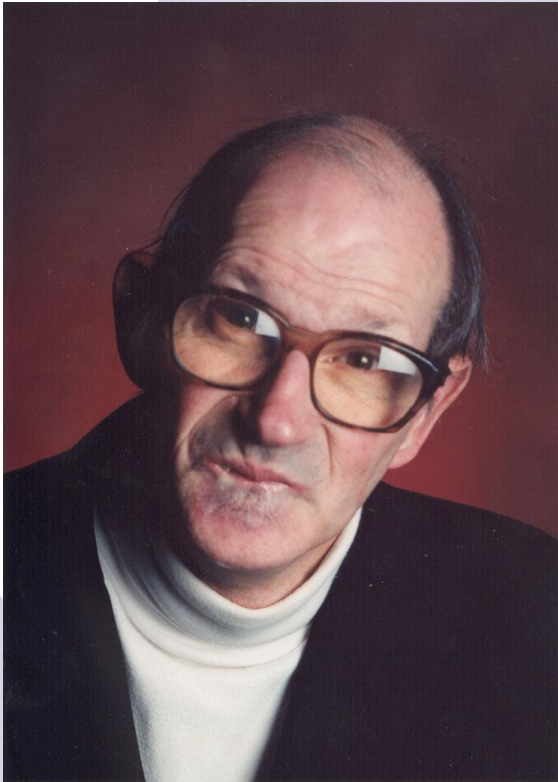
- Adults with disabilities themselves rank self-determination as more important than do professionals and parents/family members.
- Special education teachers report that:
  - they are familiar with self-determination;
  - believe self-determination is an important component of transition planning;
  - their level of training, students' type and level of disability, and type of teaching placement impact their ratings of the importance of promoting self-determination.
- Parents of school-age students with disabilities perceive promotion of self-determination as important.
  - Report that they do not believe that their sons/daughters receive enough instruction on component elements of self-determined behavior at school.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## A Self-Made Man by Raymond J. Gagne



“My name is Raymond J. Gagne. This is a true story. I was born on January 10, 1945 in Attleboro, Massachusetts. I am a person with cerebral palsy” (p. 327).



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Eight Years of Power

- My mother felt there was something wrong with me. She took me to many doctors and hospitals to see if they knew how to help me. They told my mother I would never walk.
- When I was home, I used to sit in a rocking chair next to a yellow window. My brothers and sisters went to school. At the time, there was no school for me.
- When I was 8, my mother told me I was going away.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## A Life of No Power: Eighteen Years in an Institution

- After arriving at the state school, I was put in Building 7.
- Every morning we would wake up at 6:00. An attendant would help me put on the clothes he had laid out the night before. I didn't have any say about what I wore.
- The staff never seemed to prepare me for living outside the institution. They didn't seem to think I would make it on my own. Up until the age of 14, I wasn't allowed to go to school.





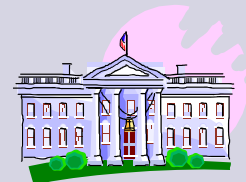
# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Twenty Years in the Real World: A Struggle for Power



- The day I moved out, some staff told me I would be back in a month. **They may be still waiting for me to come back.**
- That same year I went on a vacation to Washington, D.C. by myself. This was the first time I had ever done this.
- During the fall I moved into my own apartment after a counselor at a camp for people with cerebral palsy told me she thought I could.





# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Twenty Years in the Real World: A Struggle for Power

- I learned about Section 504 of the Rehabilitation Act and helped found a self-advocacy group. I learned the skills of leadership, advocacy, consumer organizing, and assertiveness by watching people, participating in group meetings, and asking questions. My ability to communicate my ideas and to facilitate work toward changing the status quo developed over time.



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Twenty Years in the Real World: A Struggle for Power

- Unlike the staff at the institution, the human services professionals I met at this job **treated me with respect**. They gave me a chance to contribute my input and feedback and believed in many of my ideas. My colleagues also adapted the working environment to help me communicate with them.





# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

## Twenty Years in the Real World: A Struggle for Power

- I wrote this story to let people know what it was like growing up in an institution from the 1950s through the 1970s. The total lack of power in making decisions about my life made me angry and I was treated as an outcast. I feel that what has happened to me should never happen again.