What is Self-Determination?

Michael L. Wehmeyer
Karrie A. Shogren
Department of Special Education
Beach Center on Disability
Kansas University Center on Developmental Disabilities
University of Kansas
Setting Expectations
At least one goal of education is to “produce responsible, self-sufficient citizens who possess the self-esteem, initiative, skills and wisdom to continue individual growth and pursue knowledge” (p. 163).

“In every school in this country a few children succeed regardless of the instruction they receive. Teachers identify these students early because they have purpose in their lives. They know what they like, what they can do, what they want, and how to get it. These young people…. are self-determined” (p. ix).

“Self-determination is education’s ultimate goal. Reform aimed at self-determination would distribute the responsibility for learning and performance as shared among teachers, parents, and the student, with primary control remaining with the student” (p. 214).

Agenda

Day 1
- What is Self-Determination?
- Why is Promoting Self-Determination Important?
- Self-Determined Learning Model of Instruction
- Self-Determined Career Development Model

Day 2
- Whose Future is it Anyway?
- Assessment
- Age (middle, high, 18-21) Planning
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.
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?
Ruth’s Plan For Her Future

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

Tear five small pieces of paper (about the size of a postage stamp). Hold one hand out, palm up, and place all five pieces on your palm.
Who Are We? What Are They?

- We like things
- We attempt to make friends
- We love people
- We take a break
- We have hobbies
- We insist
- We have talents
- We stand up for ourselves
- We decide to change our minds

- They fixate on objects
- They are attention seeking
- They are dependent
- They go off task
- They self-stim
- They tantrum
- They have splinter skills
- They are non-compliant
- They have short attention spans
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?
"Many states have already passed sterilization laws for eugenic purposes, and I hope Rhode Island won’t stay behind much longer. Unless something is done to stop the propagation of the mentally deficient, we cannot expect the coming generations to be predominantly virile and sound in mind and body. In that case, a general deterioration of intelligence and the preponderance of inferior stock is inevitable, especially since the trend all along has been for smaller families in the higher grades of the population. Modern society circumvents nature’s law of the survival of the fittest, but we mustn’t go too far in allowing not only the survival but also the multiplication of the unfit."

Dr. Joseph Henry Ladd
Circa 1944-45
Historic Understandings of Disability

- Historically, disability was understood within a model that was an extension of the medical model, which conceived health as an *interiorized state* and health problems as an *individual pathology*; a problem within the person.

- Within such a context, disability was understood as a characteristic of the person; as residing with the person.
  - The person was seen as broken, diseased, pathological, atypical, or aberrant; as outside the norm.
  - Perhaps unavoidably, people with disabilities were, consequently, associated with numerous negative stereotypes.
  - Particularly with introduction of Mental Age estimates, led to “infantilization” of people with disabilities.
History the Disability Movement

Parent Movement
1950 to 1990

- Earlier stereotypes of disability were replaced with more humane, though still in many ways debilitating, stereotypes.
- People with disabilities were seen as objects to be fixed, cured, rehabilitated and, at the same time pitied; as “victims” of their disabling condition, worthy of charity.
  - Holy innocents; eternal children
- Increased emphasis on “mental age.”
- Emergence of “hidden disabilities” as worthy of focus.
- Fundamentally, though, how disability was understood (e.g., as a problem residing within the person) did not change.
HI KIDS!

Won't you join the Roy Rogers-Dale Evans "Helping Hand Riders" by making your contribution in this envelope and returning it to your teacher. Remember, "Retarded Children Can Be Helped!"
Historic Understandings of Disability...

1. Understanding people as different soon becomes construed as inferior, leading to discrimination and maltreatment.
2. Separate is never equal.
3. We are constrained by our own lack of imagination.
4. We have always been wrong about what we believe people with intellectual disability can achieve.
5. The injustice committed against people with intellectual disability throughout time has been to deny them the dignity afforded to persons simply by their status as human beings.
The Normalization Principle

1. Normal rhythm of day.
2. Normal routine of life.
3. Normal rhythm of the year.
5. The person’s choices, wishes and desires have to be taken into consideration as nearly as possible, and respected.
8. Standards of the physical facility should be the same as those regularly applied in society to the same kind of facilities for ordinary citizens.

Bengt Nirje
Independent Living and Disability Rights Movements

- Hand in hand with civil rights and disability rights movement.
- Emphasized access and equality of opportunity, with a focus on independent living.

Ed Roberts
Emergence of Supported Employment
History the Disability Movement

Self-Advocacy/ Self-Determination Movement
1990 to Today

- Community Inclusion
- Empowerment
- Self-Determination
ICF and Human Functioning 2001

- International Classification of Functioning, Disability, and Health (ICF)
  - “The WHO's ICF reflects the modern day thinking about disability and embodies a paradigm shift in the way health and disability are understood and measured.”

A Model of Human Functioning

- “Functioning is an umbrella term encompassing all body functions, activities, and participation.”
- Body functions are the physiological functions of body systems (including psychological functions).
- Body structures are anatomical parts of the body such as organs, limbs and their components.
- Activity is the execution of a task or action by an individual.
- Participation is involvement in life situations.
ICF and Disability

Disability

- Disability serves as an umbrella term for limitations in human functioning involving impairments, activity limitations, or participation restrictions.
- Impairments are problems in body function or structure such as a significant deviation or loss.
- Activity limitations are difficulties an individual may have in executing activities.
- Participation restrictions are problems an individual may experience in involvement in life situations.
- Contextual Factors are (a) environmental factors and (b) personal factors.
Changing Expectations: Changing Understanding
Changing Expectations: Changing Understanding

Personal (In)Competence

Environment
Implications of Changing Understandings of Disability

- Focus on environment/context, not fixing individual;
- Strengths-based
- Emphasizes supports, not programs
An Array of Supports

- Specialized Services
- Generic Services
- Nonpaid Supports
- Family & Friends
Implications for the Education of Students with Disabilities

- Access to the general education curriculum and Third Generation Inclusive Practices
- Universal Design for Learning.
- Supported employment, supported living.
- Multi-Tiered Systems of Support
- A focus on self-determination and student-directed learning
What is Self-Determination?
**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.**

Self-Governing

classifying (sèlf´gùv´er-nîng) adjective
1. Exercising control or rule over oneself or itself.
2. Having the right or power of self-government; autonomous.

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.”
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.
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.
Self-Determination, Volition, and Intentionality

- 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.
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).
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.
Nirje (1972)

- clearly articulates the importance of this personal self-determination to all people, not excluding people with mental retardation 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.
What is Self-Determination?

- **Self-Determination** is a dispositional characteristic manifested as acting as the causal agent in one’s life. Self-determined people (i.e., causal agents) act in service to freely chosen goals. Self-determined actions function to enable a person to be the causal agent is his or her life.

- People who are ‘causal agents’ in their lives make, or cause, things to happen in their lives.

- **Essential Characteristics**
  - Volitional Action
  - Agentic Action
  - Action Control Beliefs

Shogren et al. (2014)
Component Elements of Self-Determined Behavior

- Choice-making
- Decision-making
- Problem-solving
- Goal setting and attainment
- Self-advocacy
- Self-observation, evaluation and reinforcement
- Internal locus of control
- Positive attributions of efficacy and outcome expectancy
- Self-awareness
- Self-knowledge
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.
Misperceptions of Self-Determination

- Self-determination is control
- Self-determination is independent performance.
The Arc’s Bill Sackter Award
Misperceptions of Self-Determination

- Self-determination is control.
- Self-determination is independent performance.
- Self-determination is just making a choice.
- Self-determination is something you do to someone else or a service delivery model (a way of doing planning, funding services).
Why Focus on Self-Determination?

- Importance to people with disabilities;
- Current adult outcomes for people with disabilities;
- Educational best practices (transition, student involvement).
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."
Importance to People with Disabilities

- In People First, I learned I could make my own choices. That was the best day of my life. Barbara Easlon, Enid, Oklahoma.
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
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.”
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.”
Current Student Outcomes

If students floated in life jackets for 12 years, would they be expected to swim if the jackets were suddenly jerked away?

Probably not.

The situation is similar for students receiving special education services. All too often these students are not taught how to self-manage their own lives before they are thrust into the cold water of post-school reality (Martin, et al., 1995).