

**Anffas 60 anni di futuro**  
Le nuove frontiere delle disabilità intellettive e  
disturbi del neurosviluppo

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# Self-Determination, Dignity, and Participation: The New Frontiers of Intellectual and Neurodevelopmental Disabilities

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# United Nations Convention on the Rights of People with Disabilities

## Article 3-General Principles

1. Respect for inherent **dignity**, individual **autonomy** including the freedom to make one's own **choices**, and independence of persons;

## **inherent [in-heer-uh-nt]**

*adjective*

1. existing in someone or something as a permanent and inseparable element, quality, or attribute.

*Synonyms*

innate, native, inbred, ingrained

dignity [dig-ni-tee]

1. The state of being worthy or honorable, elevation of mind or character, true worth;
2. Elevation, grandeur;
3. Elevated rank; honorable station; high office;
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From *dignus* [Latin] meaning worthy

# Dignity

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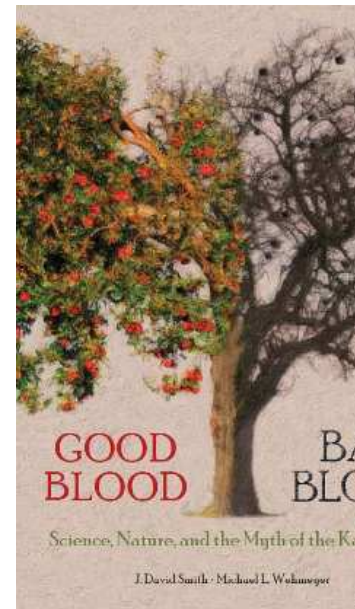
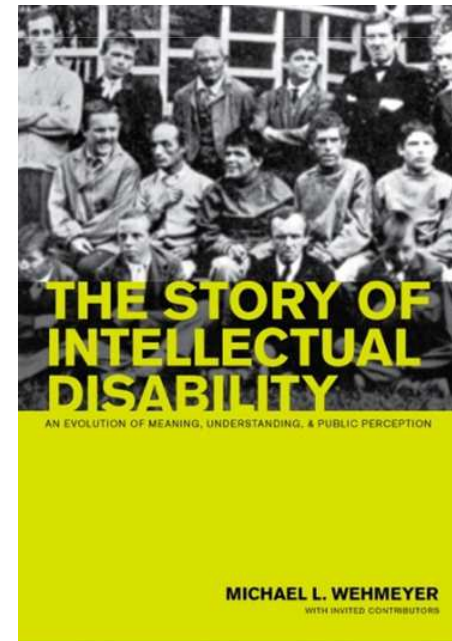
# Historic Understandings of Disability

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 model, disability was understood as a characteristic of the person; as residing with the person.

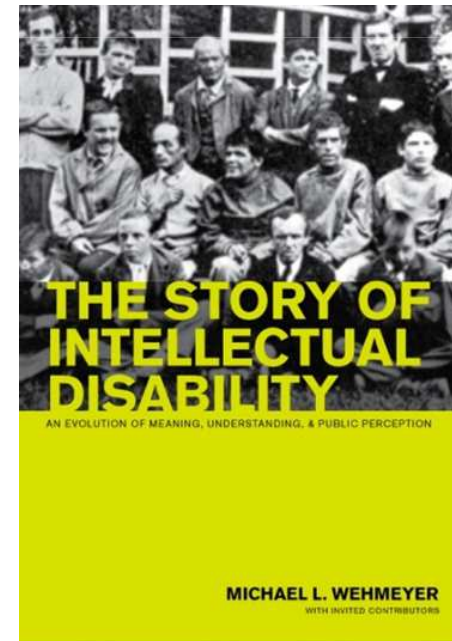
The person was seen as **broken, diseased, pathological, atypical, or aberrant**; as outside the norm.

Perhaps unavoidably, people with disabilities were, consequently, associated with numerous negative stereotypes.



# Historic Understandings of Disability

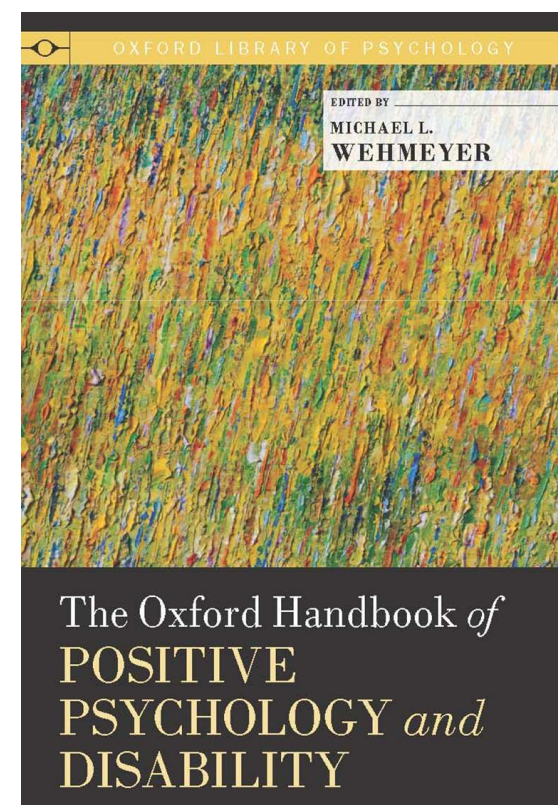
1. Understanding people as different soon becomes construed as inferior, leading to discrimination and maltreatment.
2. Separate is never equal.
3. We are constrained by our own lack of imagination.
4. We have always been wrong about what we believe people with disability can achieve.
5. The injustice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



# Emergence of Strengths-Based Models of Disability

1980- International Classification of Impairments, Disabilities, and Handicaps (ICIDH)

2001- International Classification of Functioning, Disability and Health (ICF)



# International Classification of Impairments, Disabilities, and Handicaps (ICIDH)(1980)

Prior WHO classification systems were intended to provide taxonomies of **impairments/diseases/disorders** for diagnosis (the International Classification of Diseases, or ICD, still principle tool used in the world).

ICIDH forwarded as a manual of classification of the consequences of disease, injuries, and other disorders and of their implications for the lives of the person experiencing these.

Examined impact of health condition on human functioning.

# International Classification of Functioning, Disability, and Health (ICF)(2001)

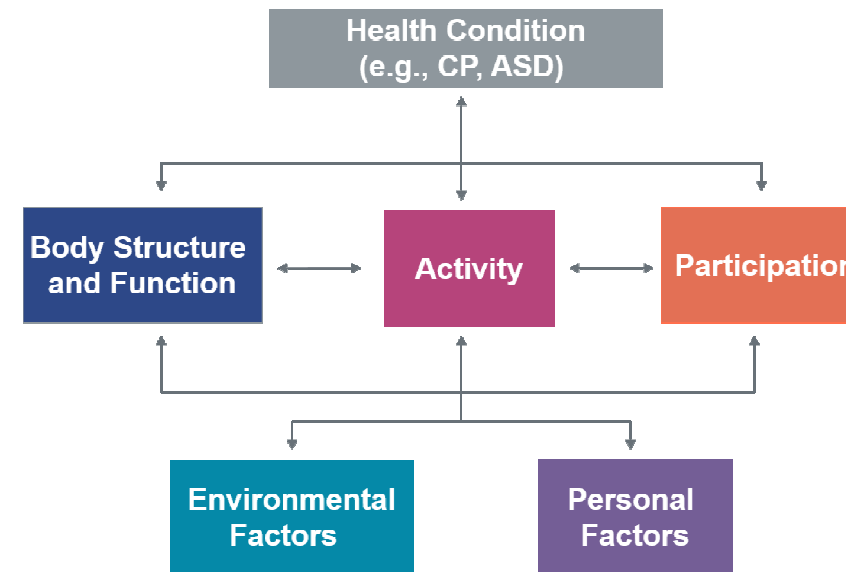


In response to criticisms of the ICIDH WHO introduced the ICF in 2001.

A universal classification of disability and health for use in health and health related sectors.

“ICF is named as it is because of its stress is on health and **functioning**, rather than on disability. Previously, disability began where health ended; once you were disabled, you were in a separate category. We want to get away from this kind of thinking. We want to make ICF a tool for measuring functioning in society, no matter what the reason for one's impairments. So it becomes a much more versatile tool with a much broader area of use than a traditional classification of health and disability.”

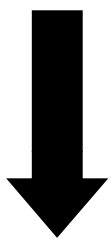
“This is a radical shift. From emphasizing people's disabilities, we now focus on their level of health.”



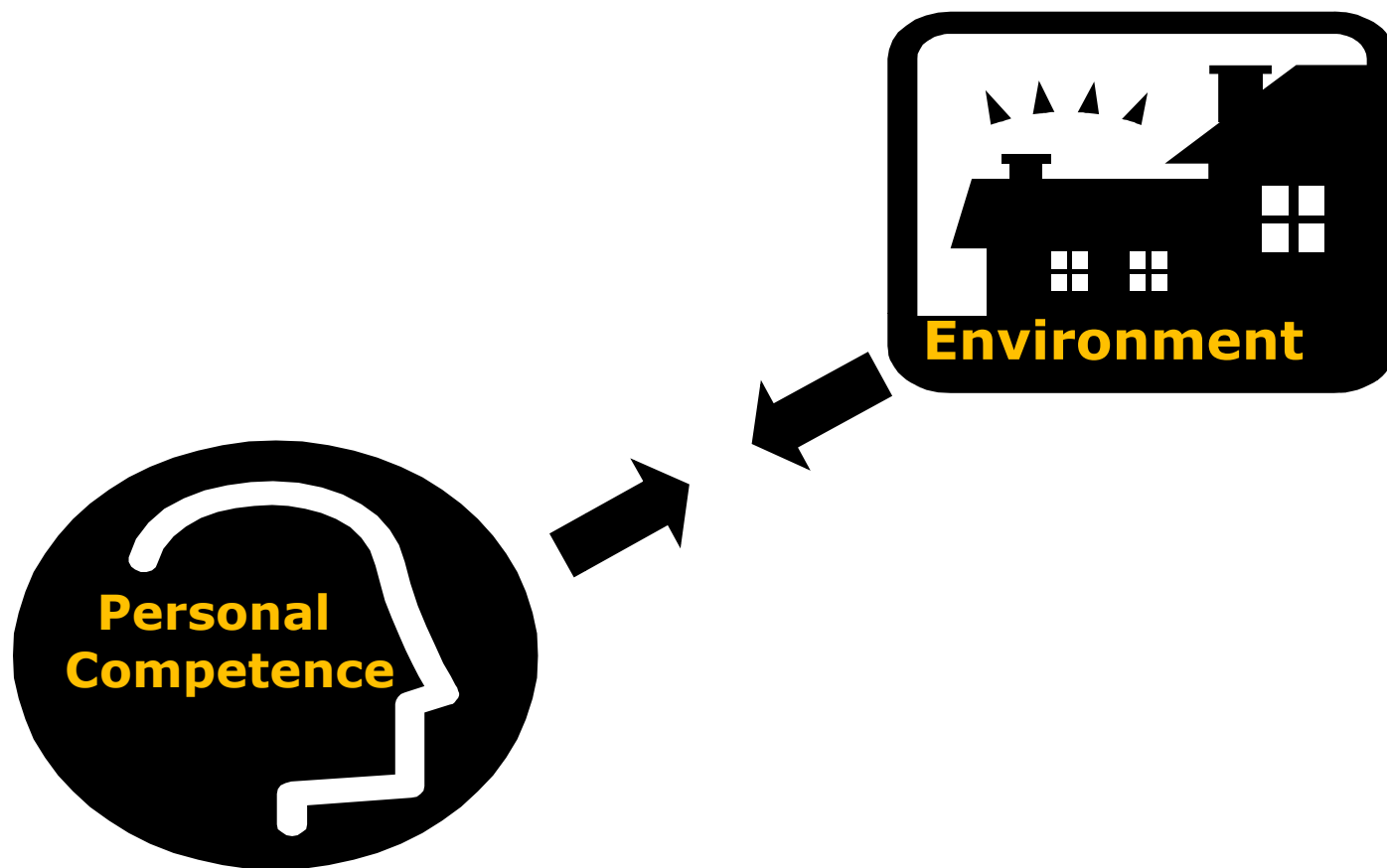


# Changing Expectations: Changing Understanding

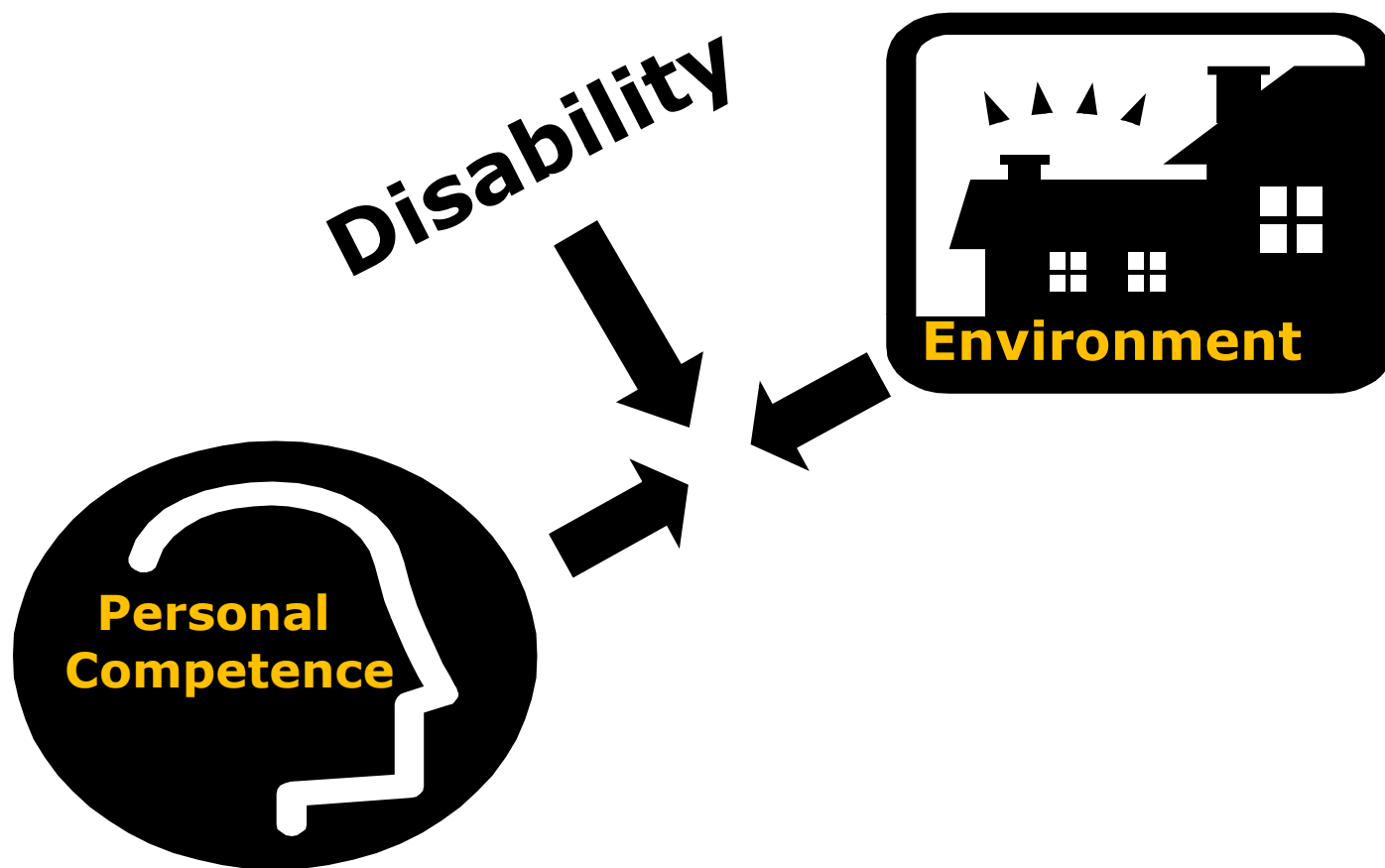
**Disability**



# Changing Expectations: Changing Understanding

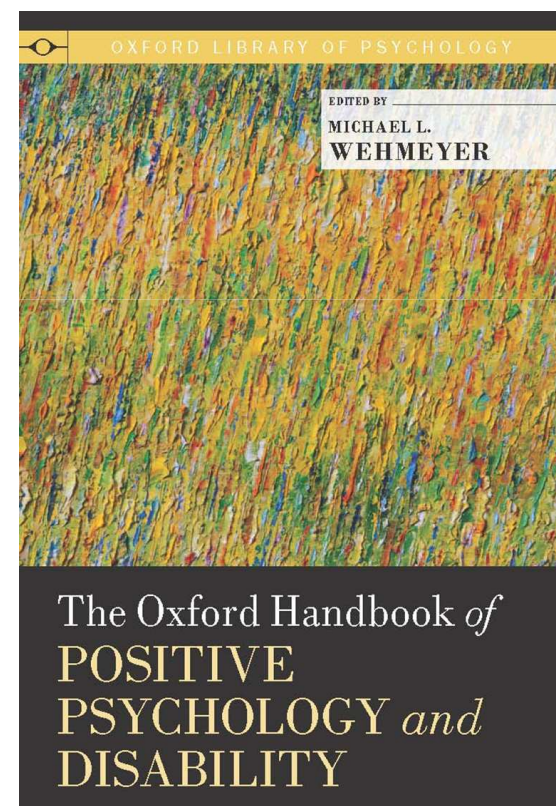


# Changing Expectations: Changing Understanding



# Implications of Changing Understandings of Disability

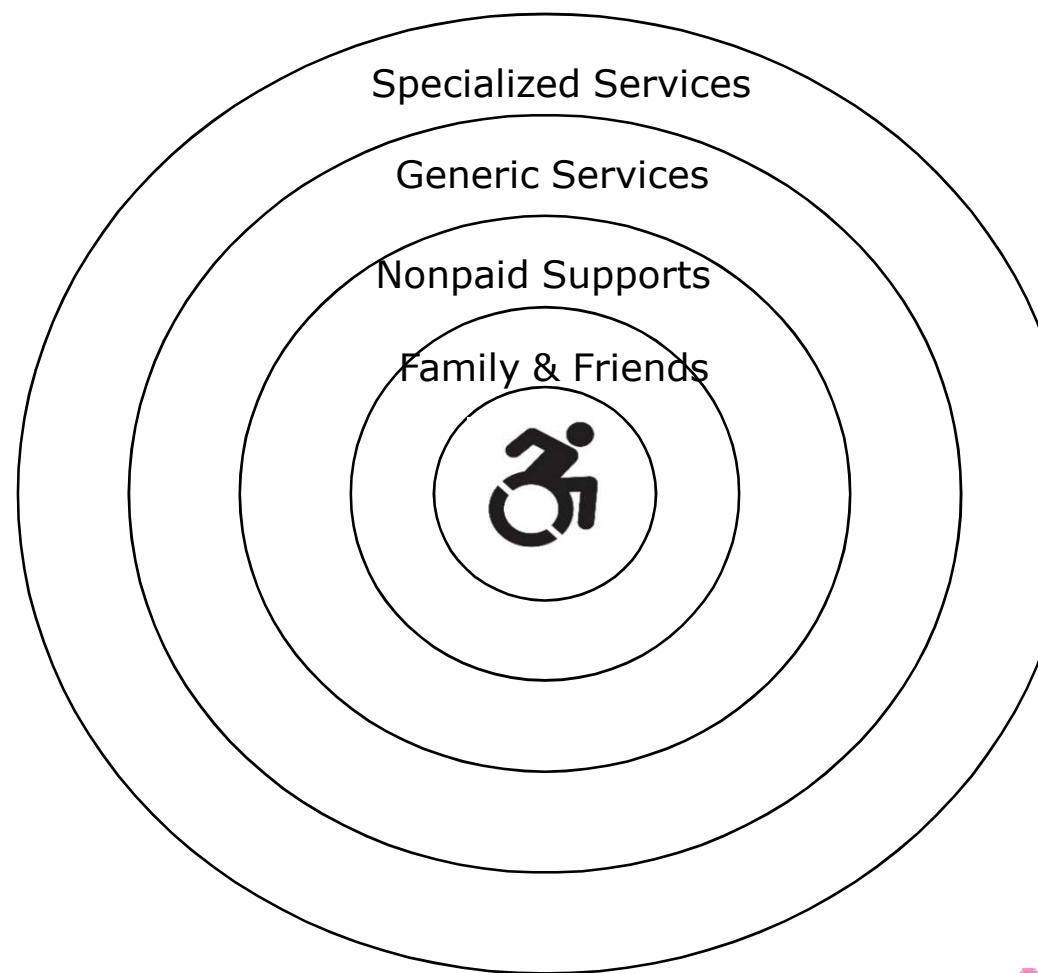
- Strengths-based
- Part of, not apart from, typical human functioning
- Focus on environment/context, not fixing individual
- Focus on participation
- Emphasizes supports, not programs



# Supports are 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**.

In other words, anything that enables a person to live a self-determined life.



# Implications of Changing Understandings of Disability



- Focus on:
  - Community **Inclusion**
  - **Empowerment**
  - Full Citizenship and **Participation**
  - **Self-Determination**

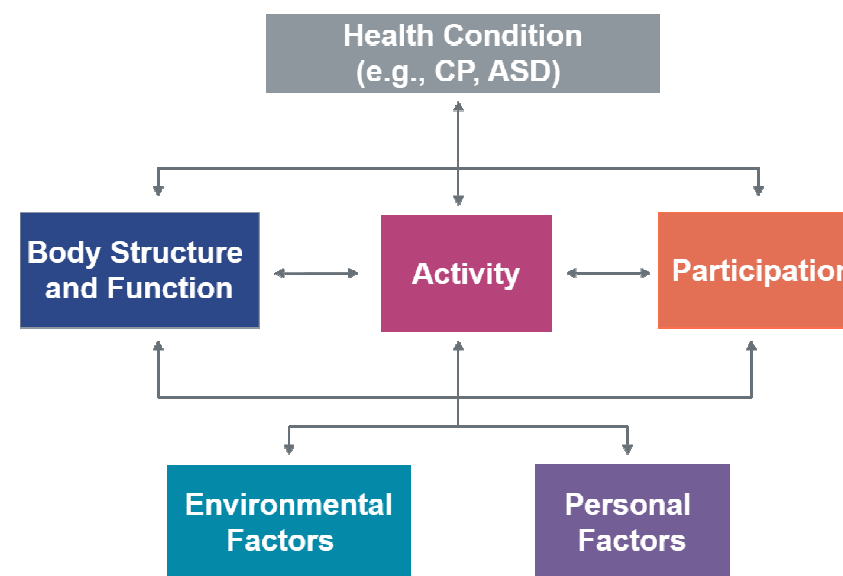
# Participation

## ICF

- Activity: Execution of a task or action by an individual.
- Participation: Involvement in a life situation.

Participation is a person's self-determined involvement in a pattern of life (i.e., roles, life situations, and activities).

- Self-determined involvement, as such, refers to a person's active, intentional, volitional, goal-directed, sustained, and connected engagement in a pattern of life.
- Pattern of life represents the roles, life situations, and activities that comprise daily life. In general, patterns of life represent socially defined sets of behavior that support participation.



# Dignity, Respect, Equality...

"People with autism should be treated with the same dignity, respect, and equality as people without autism." Jean-Paul Bovee



"We 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."  
Robert Williams



# The Right to Self-Determination

**Bengt Nirje (1972)**

One major facet of the normalization principle is to create conditions through which a [disabled] person experiences the normal respect to which any human being is entitled. Thus, the choices, wishes, desired, and aspirations of a [disabled] person have to be taken into consideration as much as possible in actions affecting him. To assert oneself with one's family, friends, neighbors, co-workers, other people, or vis-à-vis an agency is difficult for many persons. It is especially difficult for someone who has a disability or is otherwise perceived as devalued. But, in the end, even the impaired person has to manage as a distinct individual, and thus has his identity defined to himself, and to others, through the circumstances and conditions of his existence. **Thus, the road to self-determination is indeed both difficult and all-important for a person who is impaired.**



# The Right to Self-Determination

**Bengt Nirje (1972)**

Clearly articulates the importance of this personal self-determination to all people, not excluding people with intellectual and developmental 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.

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.



# The Dignity of Risk

**Robert Perske (1972)**

The world in which we live is not always safe, secure and predictable.... We must work to develop every human resource within us in order to prepare for these days. To deny any person their fair share of risk experiences is to further limit them for healthy living. (p. 199)



# **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.

# Self-Determination and Disability

Within the context of the disability rights and advocacy movement, the construct as a personal characteristic has been imbued with an **empowerment** and **rights** orientation. Empowerment is a term usually associated with social movements and is used in reference to actions that enhance the possibilities for people to exert control their lives.



# Self-Determination and Determinism

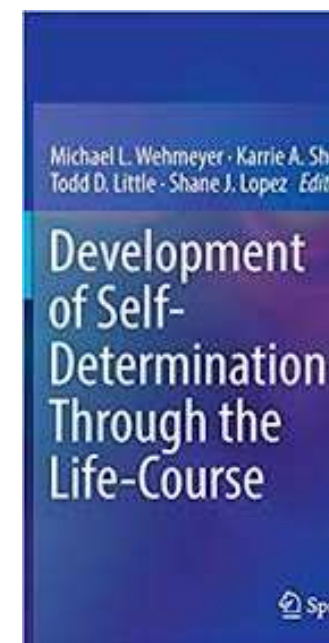
The philosophical doctrine of determinism posits that actions are *caused* by events or natural laws that precede or are antecedent to the occurrence of the action. Behavior, then, is governed by these other events or natural laws.

Self-determinism, or self-determination, implies that individuals **cause** themselves to act in certain ways, as opposed to someone or something else 'causing' them to act in other ways.



# Causal Agency Theory

- Causal Agency Theory explains how people become self-determined.
- 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 in his or her life” (Shogren et al., 2015).
- One purpose of Causal Agency Theory was to align our work with research in motivation to construct a theory of the development of self-determination.



# Misperceptions of Self-Determination

Self-determination is control.

Self-determination is independent performance.

Self-determination is just making a choice.

Self-determination is just involving students in planning.





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