

Self-Determination as a Guiding Principle for the Delivery of Services to Persons with Disabilities

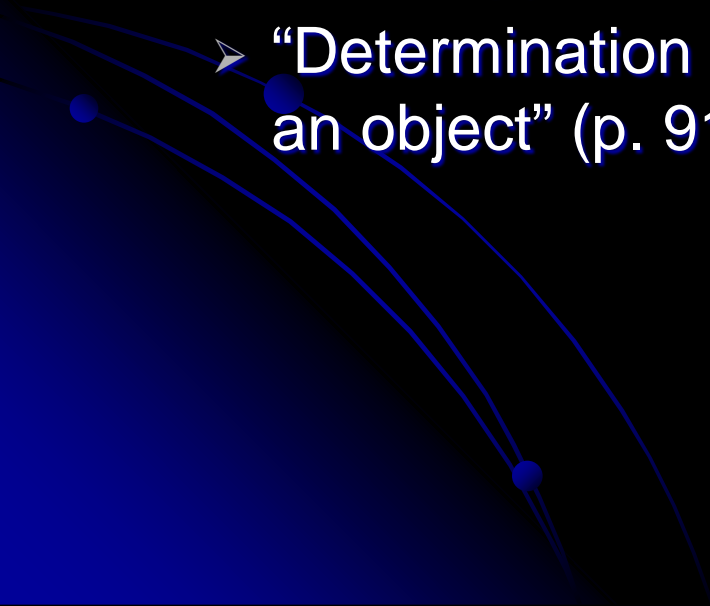
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How Does it Feel to be Self-Determined?

- Think of at least one experience that you have encountered in which you were NOT in control but want to be and others exerted control over outcomes that were important to you.
 - How did it feel to NOT be in control?
- Think of at least one experience that you have encountered in which you had the degree of control you desired over outcomes that were important to you.
 - How did it feel to be in control?

What is Self-Determination?

- Initially emerged from centuries old debates about free will and determinism
 - Earliest formal use 1683 (Oxford English Dictionary)
 - “Determination of one’s mind or will by itself toward an object” (p. 919)
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What is Self-Determination?

- The basic rights of all human beings include their freedom, equality, and power to execute their will...
- *These rights are distinguishable from people themselves and can be given up to others, but only under conditions in which the individual gives their consent...*
- *Situations in which basic rights are never granted or when a person is subjected to the arbitrary and/or absolute will of another are a form of slavery*

Locke, John (1690) *Two Treatises of Government*

Recent Conceptualizations

- “Volitional actions that allow one to act as the primary causal agent in one’s life and maintain or improve one’s quality of life.”

Wehmeyer, 2005 , p. 117

- Self-determination is believing in yourself, making your own decisions, and being responsible for them

High School Student, North Dakota

- Power, choice, and most important, the right to chase our dreams...The chance to direct our lives the way we want to, not the way others expect us to.

Irving Martin, Self-Advocate, Minnesota

Definition of Self-Determination

Self-determination refers to individuals exercising the degree of control over their lives that they desire within those areas of life that are important to them.

Abery & Stancliffe (2003)



Self-Determination vs. Personal Control

How are they are different?

- **Shared Control**

- Most individuals do not desire to have complete control but wish to share it in some areas of life with trusted others.

- **Ceding Control to Others**

- In some areas of life a person may not particularly value having control and voluntarily cede it to others.

- **Individual Differences/Change Across Time**

- Areas of life over which personal control is valued are different for each person and typically change over time.

What is Self-Determination?

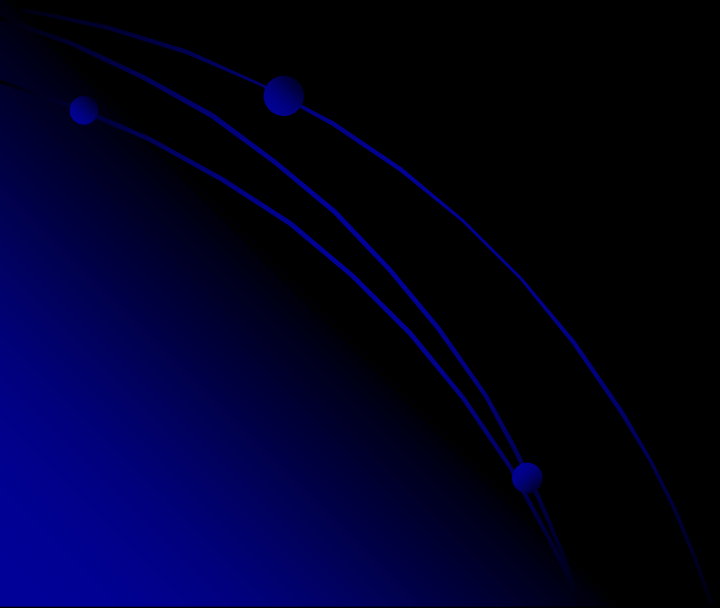
- Having the degree of control you desire over day-to-day decisions
 - what to wear
 - what to eat
 - what time to go to bed
- Having the degree of control you desire over long-term decisions
 - where and with whom to live
 - where to work
 - what type of work to do

Misconceptions about the Construct

- Self-determination implies the independent performance of behaviors (either/or argument)
- Self-determination is primarily about making choices
- There are a specific set of skills, knowledge, and attitudes/beliefs *NECESSARY for self-determination*
- Self-determination is a program you can implement
 - e.g., student led IEPs, person-centered support planning, independent budgets

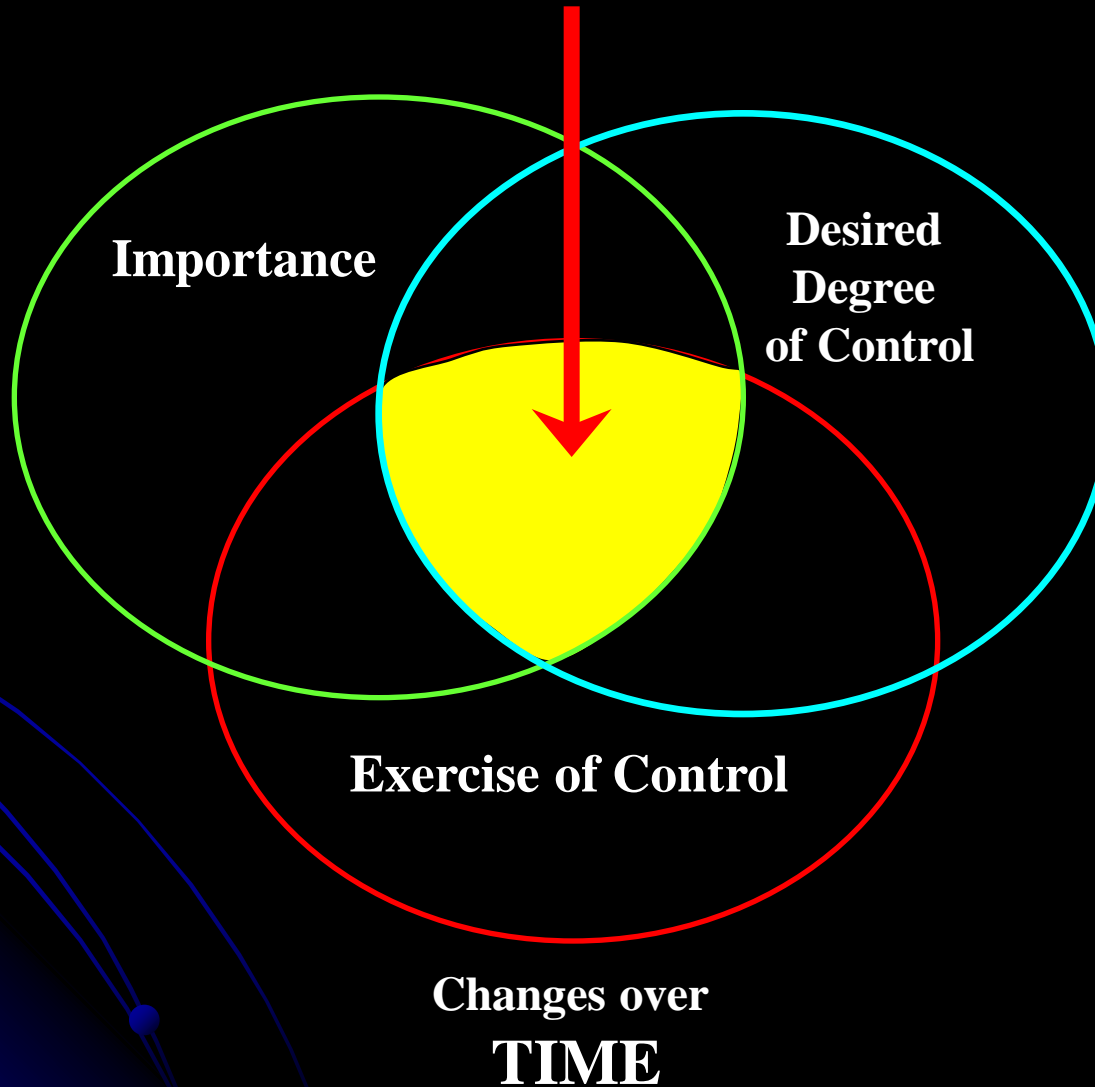
What is Self-Determination?

- Self-determination is about supporting people to make the things that they want to happen...actually happen in their lives.



Tripartite Model of Self-Determination

Self-Determination



Self-Determination Competencies

Skills

Goal Setting
Choice/Decision-Making
Problem-Solving
Self-Regulation
Communication
Social
Independent Living

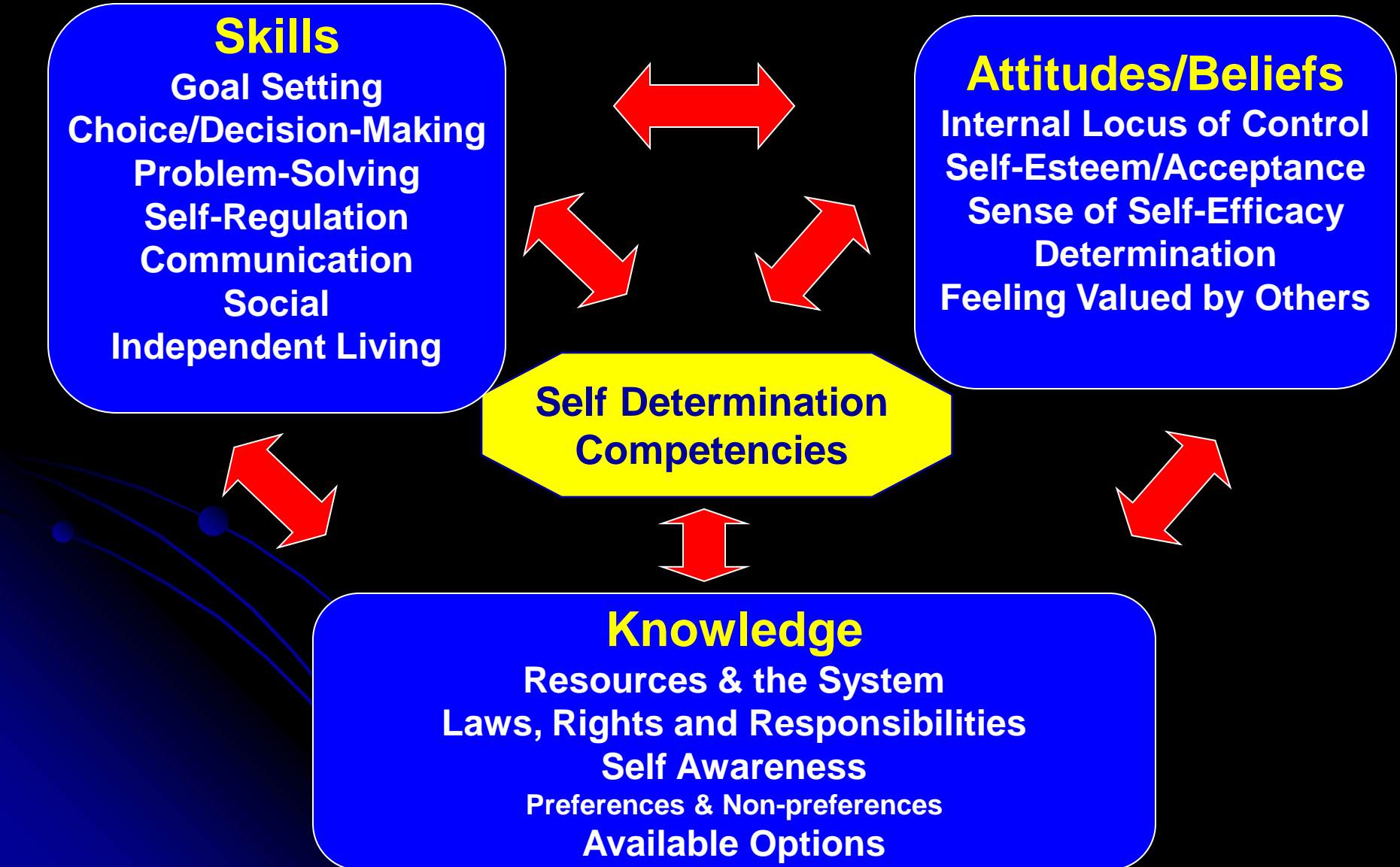
Attitudes/Beliefs

Internal Locus of Control
Self-Esteem/Acceptance
Sense of Self-Efficacy
Determination
Feeling Valued by Others

Self Determination Competencies

Knowledge

Resources & the System
Laws, Rights and Responsibilities
Self Awareness
Preferences & Non-preferences
Available Options

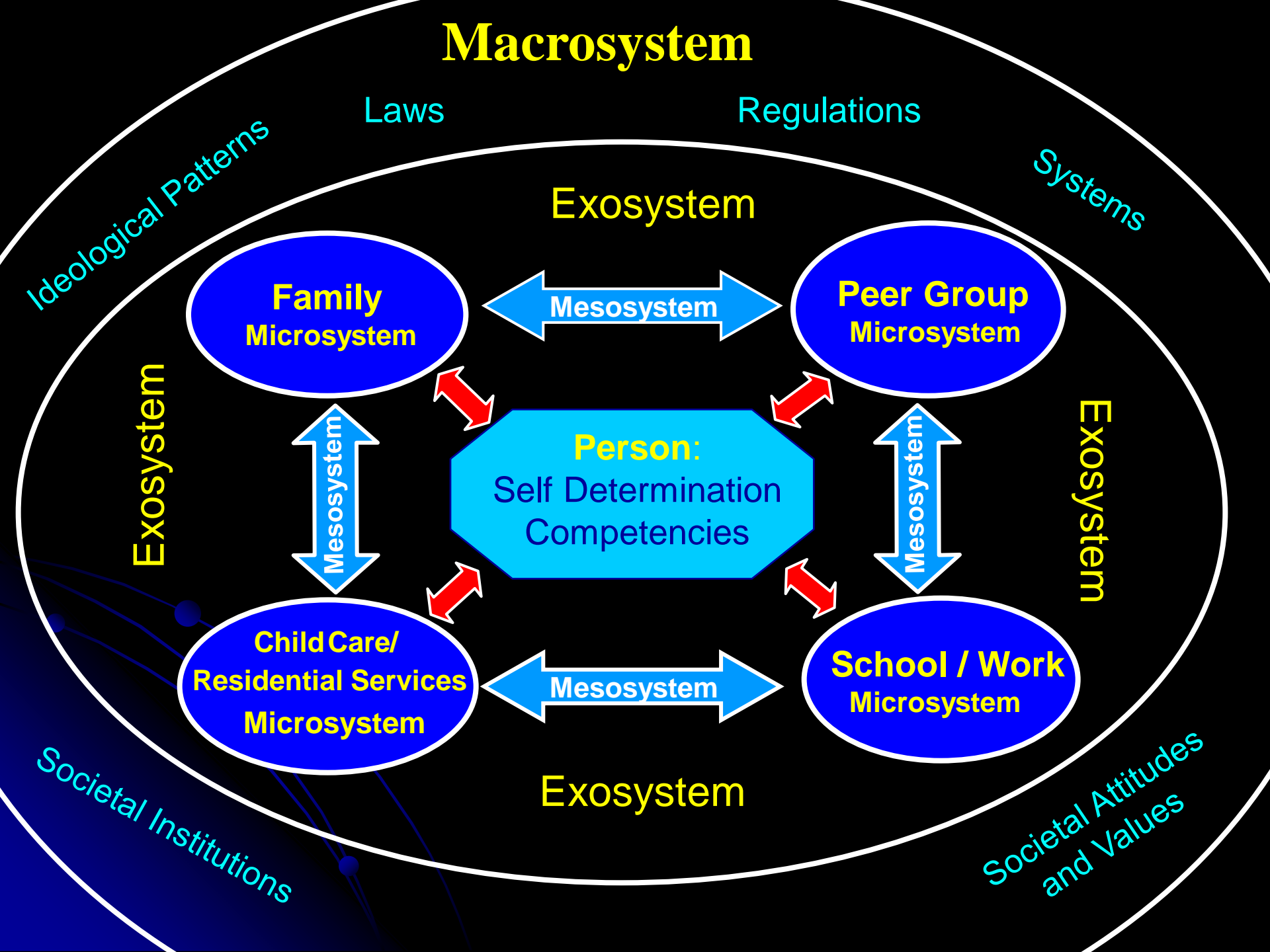


Environmental Influences

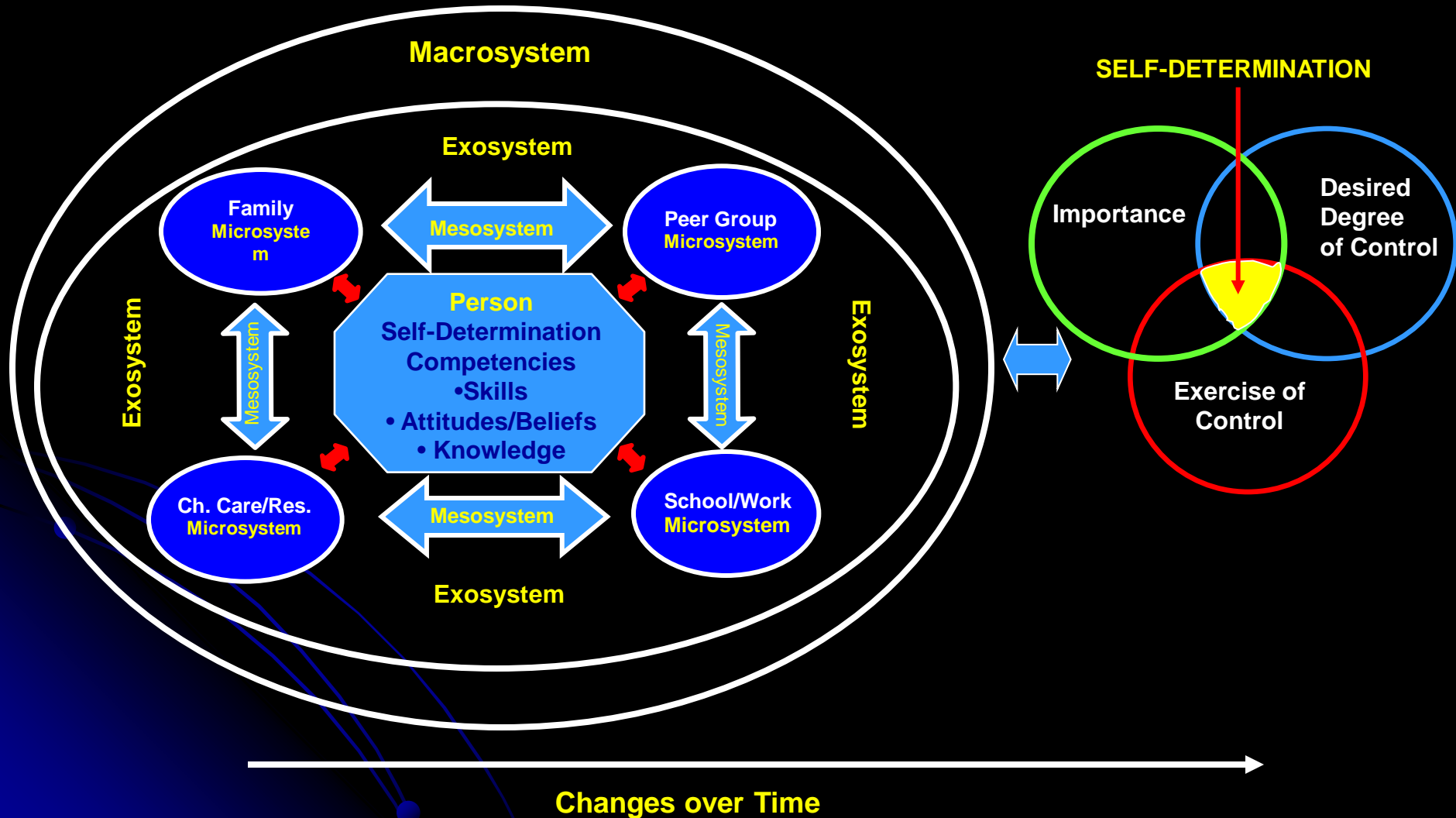
- **Missing Factor: *The Environment***

- Without opportunities for self-determination an individual loses their motivation to exert personal control.
- Many of the skills, knowledge, and attitudes that support self-determination can only be acquired and refined through real-life experiences.
- If existing self-determination capacities are not practiced they wither away.

Macrosystem



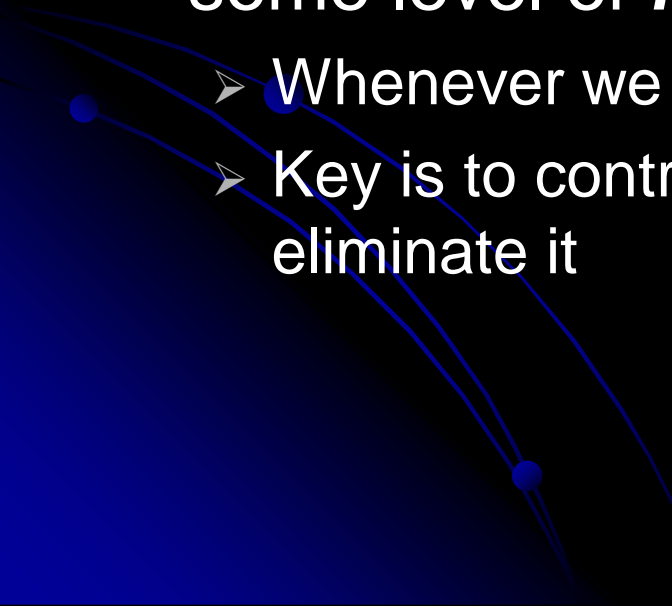
Self-Determination: An Ecological Process



What We Have Learned

- ***All persons*** desire and are capable of some degree of self-determination:
 - Some persons need few supports
 - Other persons need more supports
- Self-determination exists along a continuum.
- Self-determination is a ***life-span*** issue:
 - Infancy until
 - Death

What We Have Learned

- Self-determination is naturally reinforcing.
 - When individuals experience self-determination expect them to ask for more
 - Self-determination requires the assumption of some level of *risk*.
 - Whenever we exercise control...we take some risk
 - Key is to control or minimize risk not attempt to eliminate it
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What We Have Learned

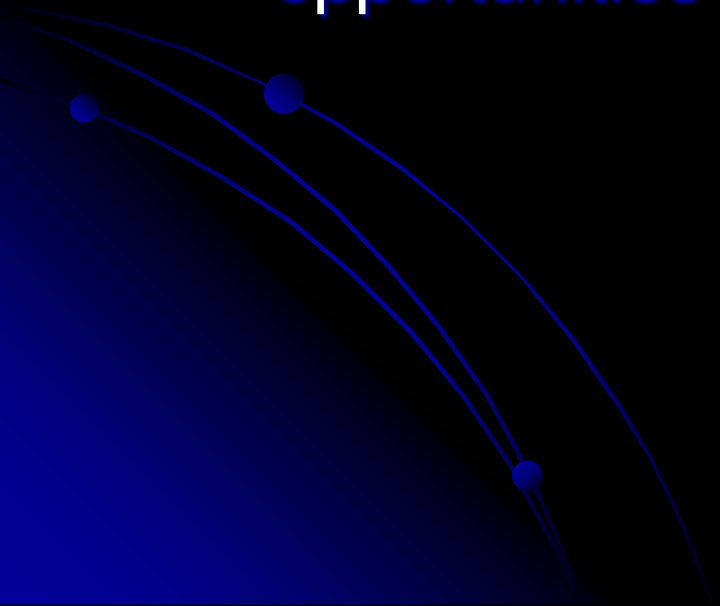
- Self-determination results from an interaction between the individual and the environment.
 - SD always occurs within a social context
- The manner in which people view and express self-determination is affected by their:
 - ***Family,***
 - ***Age***
 - ***Sex, and***
 - ***Culture.***

Mediating Factors

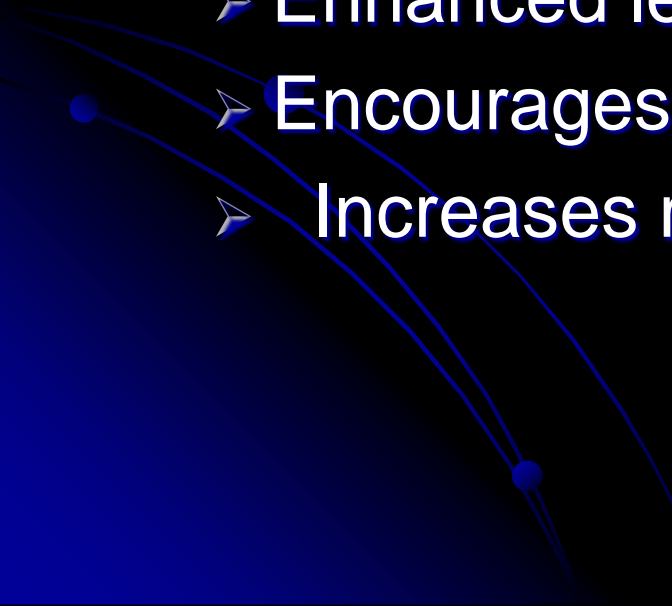
- ***Social Effectiveness***: One's ability to use social skills, behaviors and strategies to achieve preferred outcomes.
- ***Social Capital***: The network of social ties, supports, relationships, affiliations, and social-behavioral reciprocity that support one to achieve desired outcomes
 - ***Bonding***: Affiliating with others who share common characteristics
 - ***Bridging***: Affiliating with others who have different characteristics

Mediating Factors

- ***Social Inclusion***: societal acceptance of persons with disabilities in school, work, and community contexts.
 - Degree of inclusion has an impact on opportunities for self-determination

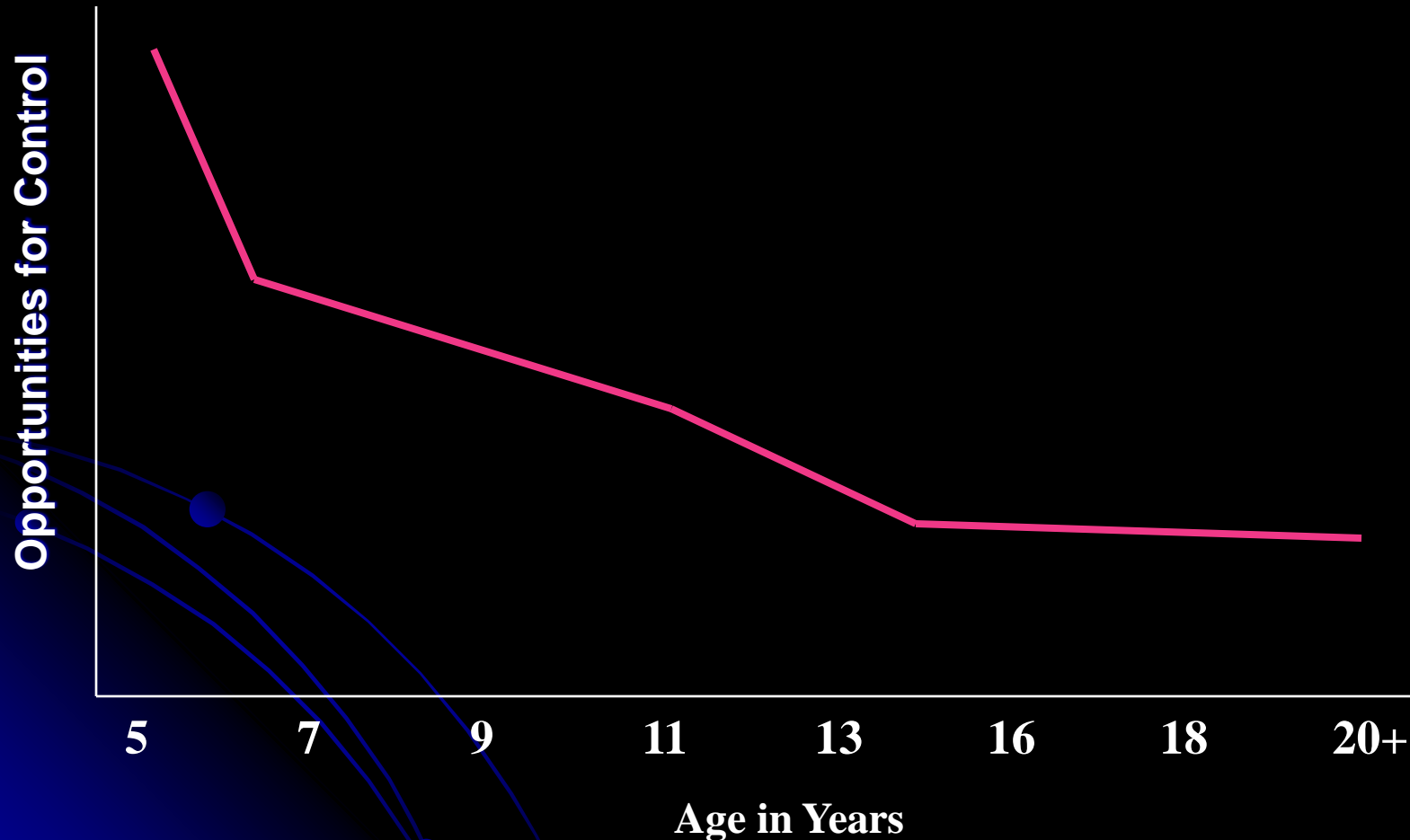


Self-Determination as a Moderating Factor

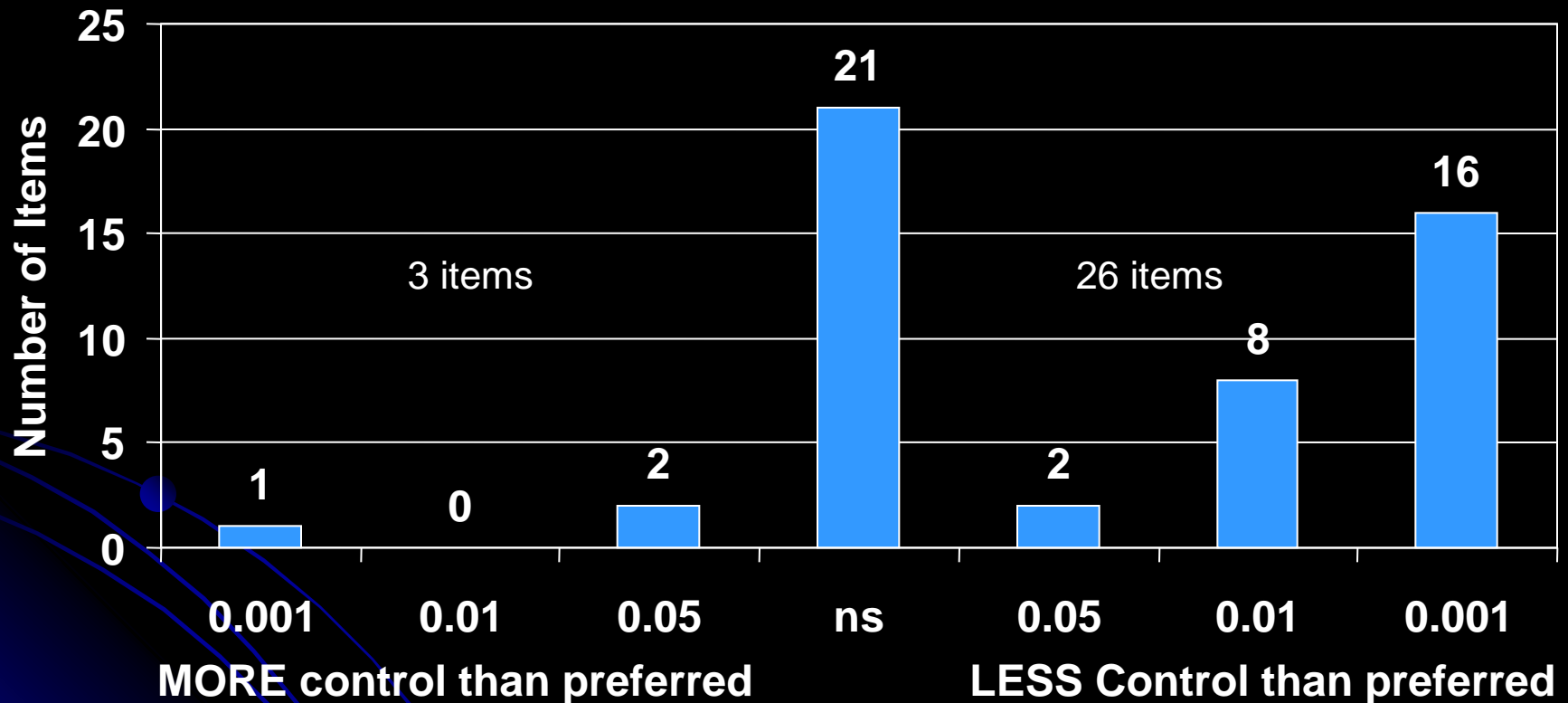
- Should self-determination be valued in and of itself or for what it helps us achieve:
 - Higher quality of life
 - Greater employment success
 - Enhanced levels of achievement in school
 - Encourages prosocial behavior
 - Increases responsibility
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Opportunities for Personal Control

Educational Context



Self-Determination: Assessed Item-by-Item Control Exercised vs. Preferred



Total # of items = 50

Less Control than Preferred ($p < .001$)

- Major decisions (where to live, housemates/roommates, pets)
- Decisions involving money
- What to do with free time
- Going out in the community (where, when etc.)
- Time alone with boyfriend/girlfriend
- Where they work
- What they did at their work site


What is Self-Determination?

- ***Educational Issue:*** teaching skills
- ***Psychological Issue:*** motivating persons with disabilities to take greater control
- ***Human Services Issue:*** providing better supports & services
- ***Civil Rights Issue:*** Guaranteeing the basic civil rights of persons with disabilities

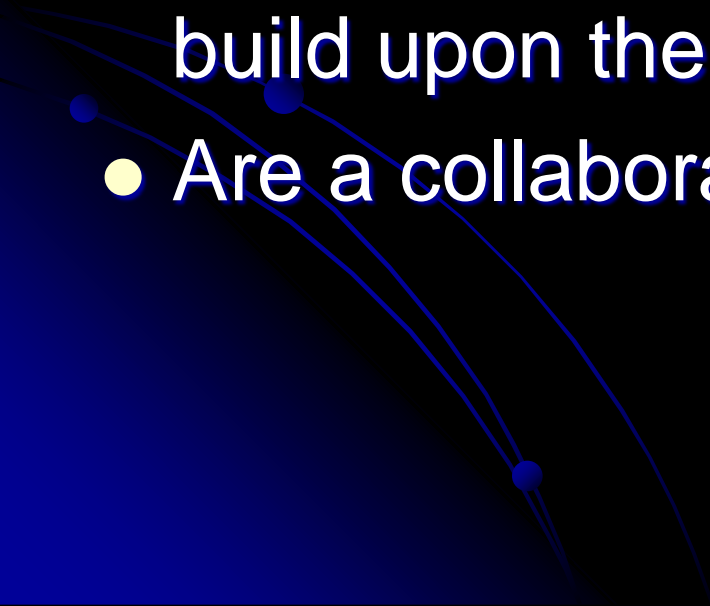
Typical Service Planning & Delivery

- Driven by available programs rather than the unique needs & interests of the individual
- Professionals are viewed as the sole “experts”
- Professionals have discussed and, at times, already made programming decisions prior to meeting with the consumer;
- Professional opinions outweigh those of the consumer and family members
- Person with disability may be present, but is rarely supported to actively participate.

Person-Centered Services are based on...

- A set of values and strategies used to assist a person in creating a vision for the future and working toward its realization;
 - A process that leads to a greater understanding of a person's:
 - Dreams and visions
 - Core values
 - Gifts and capacities
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Person-Centered Services...

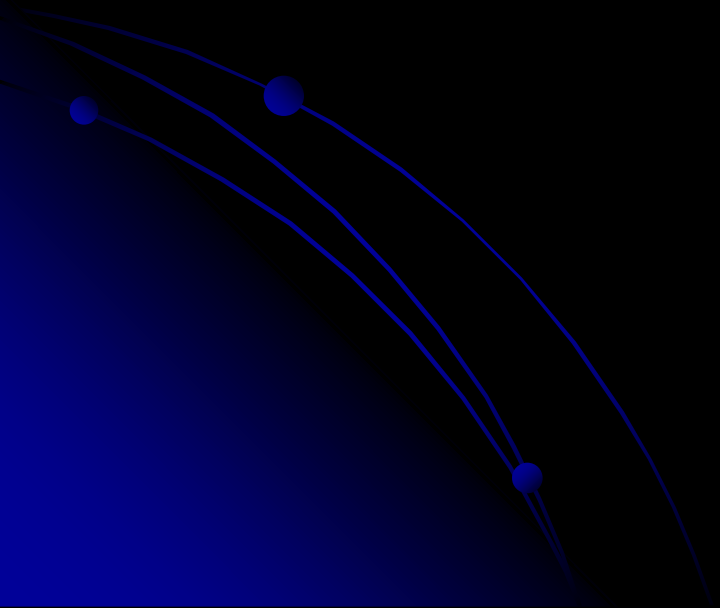
- Focus on persons rather than programs;
 - Are driven by the individual's unique vision, likes, and dislikes;
 - Recognize a person's capacities, and build upon them;
 - Are a collaborative community effort;
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Person-Centered Services Require...

- An understanding of a person's preferred lifestyle;
- Development of goals based upon the aspirations, preferences, and cultural background of a person;
- A commitment to outcomes that are meaningful for the person;
- A focus on and respect for the right of all persons to control their lives to the extent that they desire.

Person-Centered Services & Self-Determination

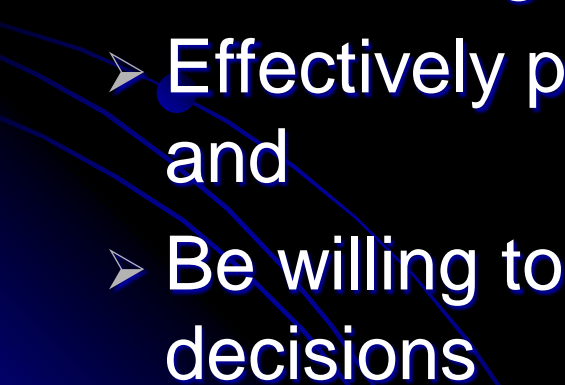
- Person centered planning and services have the *potential* to support self-determination *if* they support a person to follow their desired path in life.



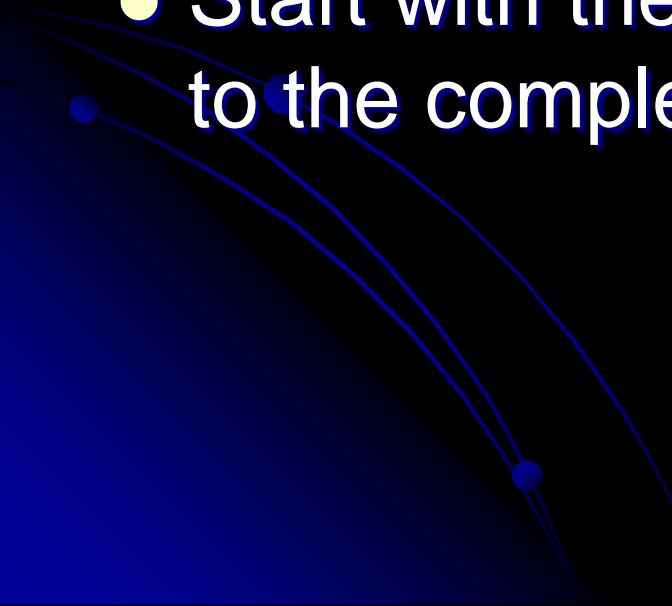
Person-Centered Services & Self-Determination

- Self-determined individuals are more likely to...
 - Create a personal vision for their future;
 - Effectively articulate that vision to others;
 - Consider the various paths they might take to achieve that vision;
 - Make informed decisions about the paths they desire to take;

Person-Centered Services & Self-Determination

- Self-determined individuals are more likely to...
 - Monitor their progress towards goals and make necessary adjustments (to both goals and strategies for reaching them);
 - Effectively problem-solve when necessary; and
 - Be willing to assume responsibility for their decisions
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When and How to Support Self-Determination

- Start as early as possible
 - Self-determination is not an issue of adolescence
 - Focus on a gradual transfer of control
 - Parent control > Shared control > Child control
 - Start with the simple and gradually move to the complex
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When and How to Support Self-Determination

- Provide opportunities for self-determination as part of daily routines;
 - Provide opportunities in as many contexts as possible;
 - Allow persons to, within reason, experience the natural consequences of their exercise of self-determination.
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