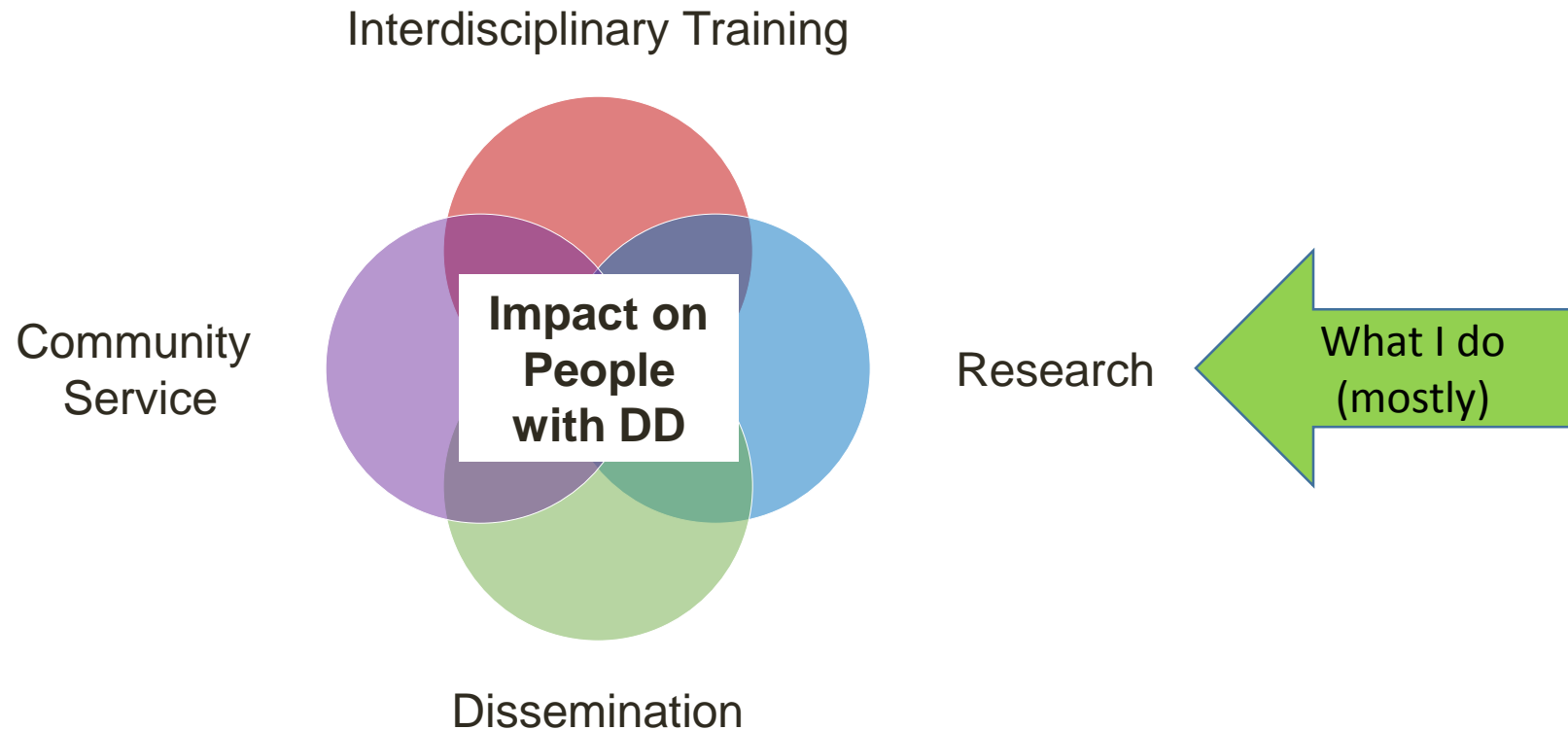


Developing Self-determination in Youth with Epilepsy

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Research Director

The Core Functions That Are the Building Blocks of the UConn Center for Excellence in Developmental Disabilities



This webinar is the second in a three part series:

Webinar 1:

Seamless Transitioning for Students with Epilepsy who have 504 Plans or IEPs: What Do Families Need to Know?

Friday, June 15, 1-2 p.m.

Webinar 3:

Issues in Transition from Pediatric to Adult Health Care for Youth with Epilepsy

Friday, June 29, 1-2 p.m.

After each live webinar,

PowerPoints will be available in *.PDF format on our website along with a taping of the webinar itself.

www.uconnucedd.org

Acknowledgement

- I want to thank Missy Wrigley for allowing me to adapt some of her slides from a presentation we had previously done together.

By the end of this session, you will be able to...

- Define self-determination
- State why self-determination is important for positive post-secondary transition outcomes
- Identify important skills in each of the areas (e.g., choice-making) leading to competency in self-determination
- Identify strategies and tools available to enhance teaching of self-determination skills at home and through the IEP process

Rule of thumb:

Can your child do this independently?

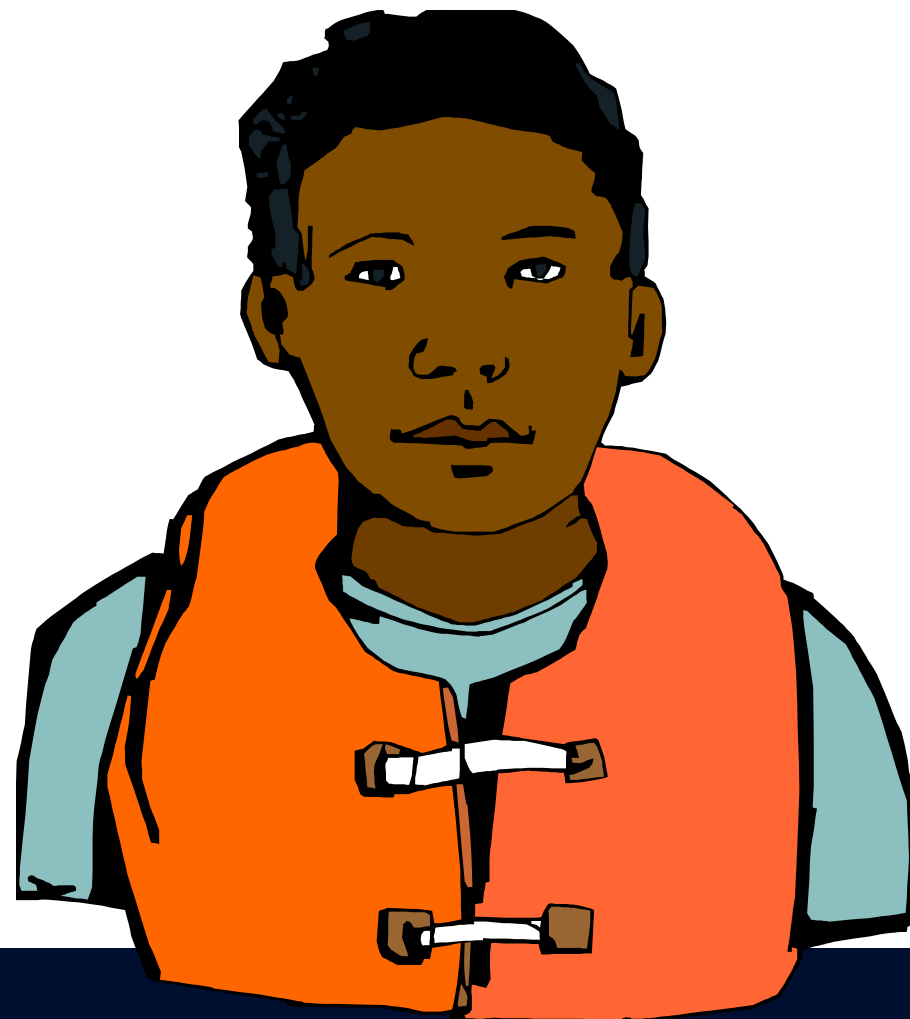
Can your child get an accommodation?

Can your child do this with support (natural or contrived)?

Why Self-Determination?

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

Amy Gaumer Erickson, Ph.D. 2007



Definition

“...disposition
in one’s life.
to freely choose
person to be the

Shogren, K.A., Wehmeyer,
functional model of self-de

1. Choose your own goals
2. Make choices that help you reach those goals
3. Do these with no undue influence
4. Improve your quality of life

causal agent
in service
enable a
et al., p. 17)
theory: Reconceptualizing a

Self-Determination

- Self-determination refers to an individual's awareness of personal **strengths** and **challenges**, the ability to **set goals** and **make choices**, to be assertive at appropriate times, and to interact with others in a **socially competent manner**.
- A self-determined person is able to make independent decisions based on his or her ability to use resources, which includes **collaborating and networking** with others.

Amy Gaumer Erickson, Ph.D. 2007

Goal for Self-Determination

“The Goal is NOT to make any one student independent.”

“The Goal is to enable students to make things happen in their life!”

Michael L. Wehmeyer, 2016

What is self-determination?

Self-Advocacy	Self-Determination
<p><i>“Self advocacy means speaking or acting for yourself. It means deciding what is best for you and taking charge of getting what you want. It means standing up for your rights as a person...”</i> (CT DDS)</p>	<p><i>“...refer(s) to a characteristic of a person that leads them to make choices and decisions based on their own preferences and interests, to monitor and regulate their own actions and to be goal-oriented and self-directing.”</i> (Nat’l Gateway to Self-Determination)</p>

Enhance Self-Determination Through Self-Advocacy

“I began to attend IEP meetings in the tenth grade, but the teachers did not ask me what I wanted. My dad asked me at home, and then he and my mom spoke for me in the meetings. At the end of the tenth grade, my guidance counselor, Mrs. Suter, asked me what courses I wanted to take next year. I picked my classes. Some of the classes got changed in the IEP meeting, but they asked me first. I liked that. At the end of 11th grade, Mrs. Suter asked me what classes I wanted to take in the 12th grade. I picked my classes. I got to take all of them that time. I felt great.”

Self-Determination and Transition Planning, Shogren, 2013

Component Elements of Self-Determined Behavior

- Goal setting and attainment
- Choice-making
- Decision-making
- Problem-solving
- Self-advocacy

Component Elements of Self-Determined Behavior

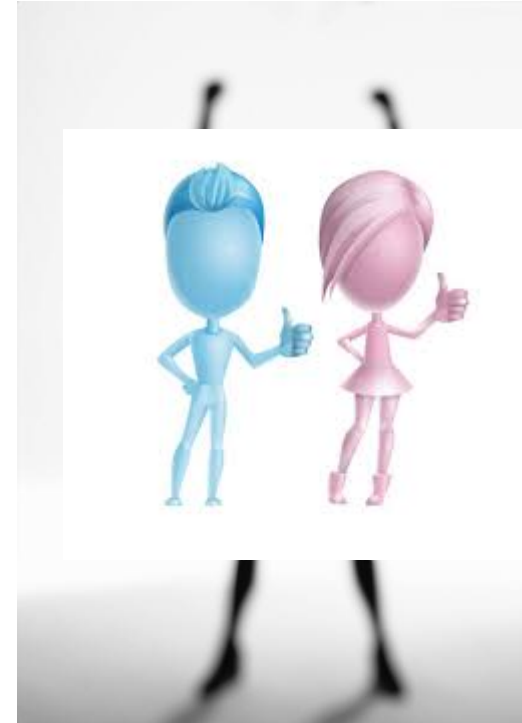
- Self-observation, evaluation and reinforcement
- Internal locus of control
- Positive attributions of efficacy and outcome expectancy
- Self-awareness
- Self-knowledge

Why is SD important?

What are you more invested in:
Goals you set for yourself or
goals others set for you?

We are **MORE INVESTED** in goals
WE set for ourselves

Do you think students with
disabilities relate to goals in the same way?



Why is SD important?

SD in students is associated with improved:

- ✓ Academic outcomes
- ✓ Transition outcomes
 - Positive employment
 - Independent living
 - Recreation and leisure
- ✓ Quality of life
- ✓ Life satisfaction



SD is IMPORTANT and the
foundation for building it starts early!

Why are these skills so important?

More successful transition to adulthood:

- Education or Training
- Employment
- Independent Living

Positive Outcomes

Improved or Increased...

1. Access to General Education
2. Academic & Study Skills
3. Financial Independence
4. Independent Living
5. Employment

Self-Advocacy

Self-Advocacy refers to the ability of an individual to effectively communicate, convey, negotiate, or assert one's own interests, desires, needs, and rights. It assumes the ability to make informed decisions. It also means taking responsibility for those decisions. Providing students with opportunities to learn and use decision-making and self-advocacy skills can help prepare them to become full participants in a democratic society.



Finding the Courage to Ask for Help

Allison Schwartz, a Ph.D. student, tells her own story of overcoming a fear of the stigma associated with extra time. She says, "I have two big regrets in college: not asking for extra time sooner, and letting labels dictate how I perceived myself."

http://dyslexia.yale.edu/article_print.php?a=extendedTime

Promoting Self-Advocacy Skills

- Skills needed to advocate on one's own behalf;
- Will focus on two common threads;
 - how to advocate;
 - what to advocate;
- Particularly important during secondary education, should be tied directly to educational planning meeting.

Promoting Self-Advocacy Skills

- How to advocate:
 - rights and responsibilities;
 - assertiveness vs. aggressiveness;
 - communicating effectively (one-on-one, small group)
 - negotiation, compromise and persuasion;
 - effective listening;
 - basic leadership and team skills

www.cpacinc.org



Chapter 2: Learning to Self-Advocate

Stepping Forward: A Self-Advocacy Guide for Middle and High School Students



*(Formerly "An Educational Journey from Self Discovery to Advocacy")
Revised 2013*

Schools help students develop self-determination skills when they:

- Support students in establishing their own transition goals, including postsecondary education, career, and independent living goals;
- Ensure that students are actively involved in IEP meetings and understand their IEPs, including their specialized instruction and related services, the accommodations they receive for instruction and assessments, if applicable, and supplementary aids and services to facilitate their education in the least restrictive environment;

Schools help students develop self-determination skills when they:

- Help students develop skills to direct their own learning;
- Use person-centered planning; and
- Create and maintain a system that supports family involvement and empowers families to support the self-determination of their sons and daughters.

A Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities, U.S. Department of Education,
2017

CT CORE Transition Skills-



To the maximum extent possible, **Each Student** with a disability will be able to:

- A. Explain his/her disability including individual strengths, needs, preferences and interests.
- B. Utilize effective self-determination skills including areas such as: choice-making, problem-solving, goalsetting, communication and self-advocacy.
- C. Strengthen his/her self-esteem and social-emotional awareness by analyzing his/her strengths and challenges in order to implement personal/vocational goals.
- D. Assist with the development of his/her Individualized Education Program (IEP).
- E. Attend, participate in and/or facilitate his/her Planning and Placement Team (PPT) meeting.

SD skill building

When you allow individuals to make choices for themselves, remember to allow for....

Dignity of Risk

What does that mean to you?

- Remember, they won't always make the BEST choice
- You want them to learn to make **A choice**
- Then **evaluate** that choice
- Let them know it's **ok to make a NEW choice** if the first one didn't turn out well

SD skill building

If you build your students' SD skills over time, they will grow in their ability to know

- what they want
- how to ask for it
- how to make choices
- how to set goals
- how to evaluate if those choices brought them closer to their goals
- how to ask for assistance
- how to advocate for themselves



“I believe self-determination is a familial thing, I think it is passed down in families. We talk about how to fine tune it to each disability, why not fine tune it to each culture and family.”

Self-Determination and Transition Planning, Shogren, 2013

Teaching Goal-Setting includes:

- Understand the process (SMART goals)
- Directly relate steps to desired outcome (goal)
- Practice Short-term vs. Long-term goal-setting
- Monitor progress
- Use both recognition and reinforcement
- Keep it simple!

Teaching Decision-Making includes:

- Research and understand the options
- Locate information and resources
- Narrow the field of possibilities
- Provide opportunities to experience options
- Teach situational assessment strategies

Teaching Choice Making includes:

- Be consistent
- Provide variety
- Offer many opportunities
- Progress from concrete and complex choices
- Allow for reinforcement and natural consequences

Teaching Problem-Solving includes:

- Identify the problem
- Offer possible solutions and/or alternative ideas
- Shift past experience from adult to student/child
- Assess strategies (what works?)
- Anticipate outcomes
- Reflect on results

Tips for Parents

- o Help your son or daughter learn about and understand his/her disability.
- o Keep records of the transition-related services and activities that occur.
- o Review your son or daughter's IEP goals.
- o Review graduation requirements and help make decisions about course of study, paths, and options for a high school diploma.

Self-Advocacy includes:

- Teach the difference between assertive vs. aggressive
- Identify opportunities to independently seek help, assistance, and clarity
- Teach and model active listening
- Teach and model perspective-taking (intentions vs. perception)
- Know your rights and theirs
- Provide everyday examples of how people “agree to disagree” respectfully

Questions to Consider

1. What is your vision for the future for your family and your child?
2. What do you think defines success in adulthood?
3. How does your child learn best?
4. What supports do you provide your child at home to promote success? What works and what does not work?
5. What does self-determination mean to you and your family?

What does self-determined behavior look like in your home?

- a. How does your family make decisions? Who is involved
- b. How does your family set goals? Who is involved?
- c. How does your child express his/her choices and goals? Do you talk about goals for the future at home?
- d. What types of roles does your child play at home?
- e. Have you had to advocate for your child? Does your child advocate for him- or herself? Is this important to you?

Schools help students develop self-determination skills when they:

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2017

Self- Directed IEP

PPT participation

When do students start participating in PPTs at your district?

- Students can and should be included in their PPT meetings starting at a young age

Self-Directed IEP

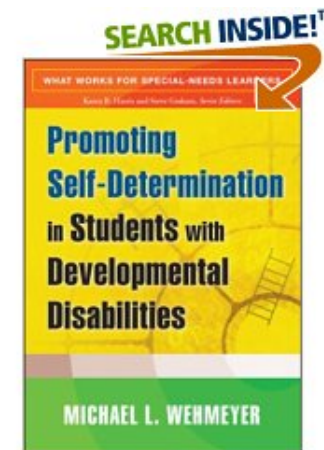
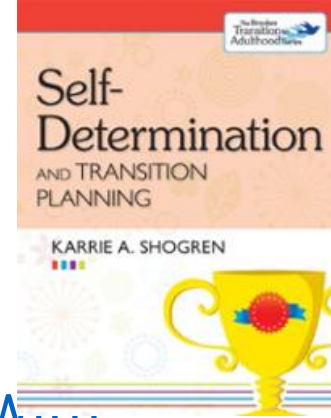
- <http://www.ou.edu/education/centers-and-partnerships/zarrow/choicemaker-curriculum/self-directed-iep.html>
- See also <http://hvsepc.org/student-draft-iep-interactive-tool/>

Resources

- National Gateway to Self-Determination
 - <http://www.ngsd.org>
- [OU Zarrow Center for Learning Enrichment](#)
- [KU Beach Center on Disability](#)
- [Accessing the Dream: Preparing Deaf-Blind Youth for a Self-Determined Life](#)
- [Self-Determination Inventory](#)
- [Paul V. Sherlock Center on Disabilities](#) at Rhode Island College

Resources: Books

- [Self-Determination and Transition Planning](#) (Shogren, 2013)
- [Promoting Self-Determination in Students with Developmental Disabilities](#) (Wehmeyer et al., 2007),
- [Self-Determination Instructional and Assessment Strategies](#) (Wehmeyer & Field, 2007), Corwin Press
- [Universal Design for Transition: A Roadmap for Planning and Instruction](#), Thoma, Bartholomew, Scott, Brookes Publishing



Comments or questions?

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THANK YOU! PLEASE COMPLETE YOUR EVALUATIONS
at [https://www.surveymonkey.com/r/EFCTSelf-
Determination](https://www.surveymonkey.com/r/EFCTSelf-Determination)

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