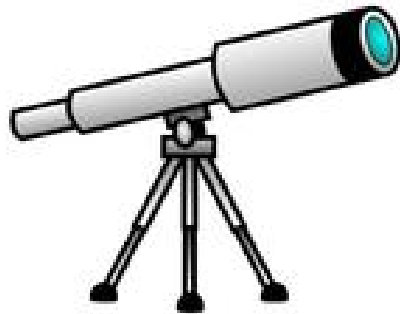


# Seamless Transitioning for Students with Epilepsy who have 504 Plans or IEPs: What Do Families Need to Know?

June 15, 2018

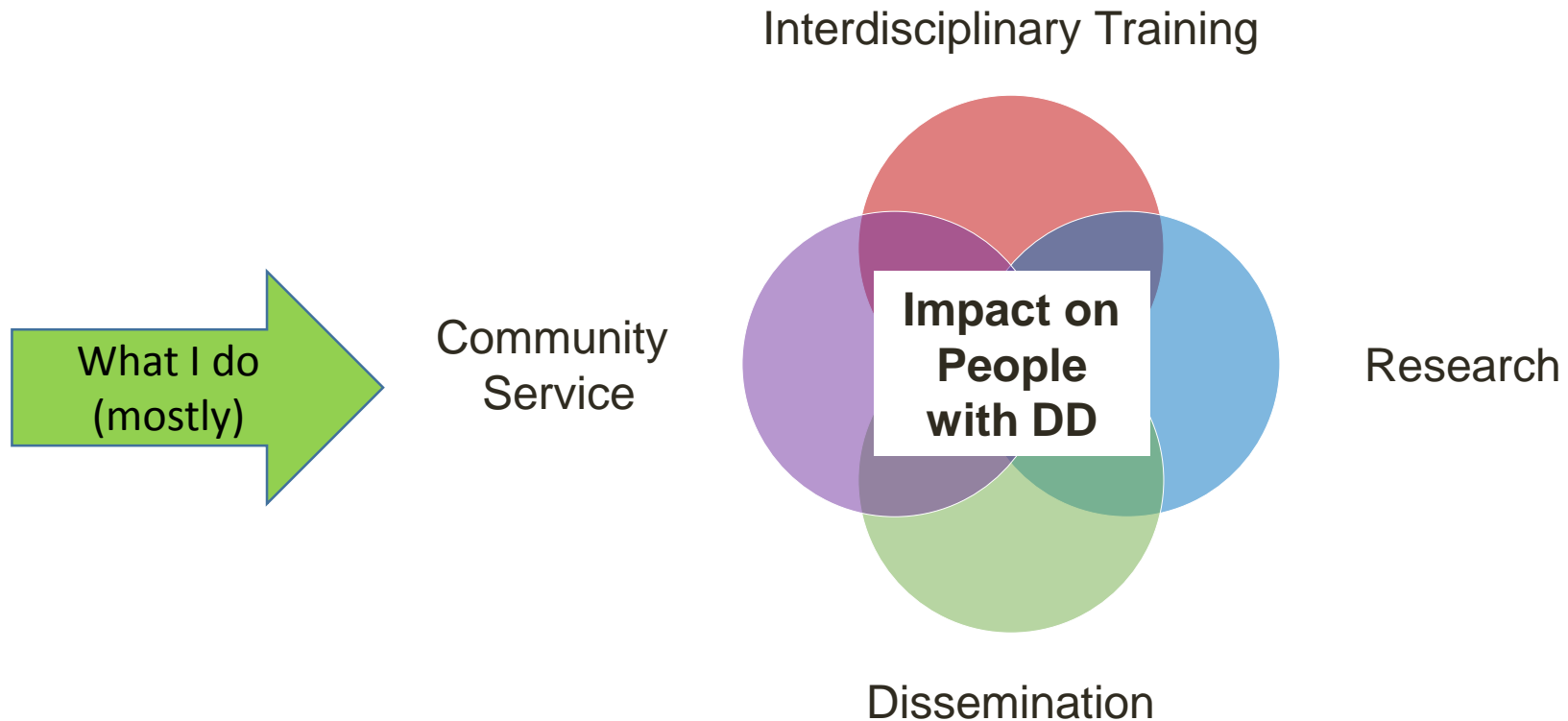
by Linda Rammler, M.Ed., Ph.D.



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DISABILITIES

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



# **This webinar is the first in a three part series:**

**Webinar 2:**

**Developing Self-  
determination in Youth  
with Epilepsy**

**Friday, June 22, 1-4 p.m.**

**Webinar 3:**

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

**Friday, June 29, 1-4 p.m.**

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# After each live webinar,

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

[www.uconnuceedd.org](http://www.uconnuceedd.org)

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# Today' webinar will address

- Big adjustment (whether on to post-secondary schooling or the world of work) when grade school days are over
- Extra steps often needed for students with 504 Plans or Individualized Education Programs,
- Overview of what parents of adolescents and young adults with epilepsy can do to facilitate a seamless transition from school to adulthood.

# What does “transition” as you hear it from schools really mean?

Secondary transition = Thoughtfully planned movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment); continuing and adult education, adult services, independent living, or community participation.



# High School completion means:

- If NO IEP or 504 plan:

Academic requirements met = diploma awarded

- If 504 plan only:

This can follow the person to post-secondary education or training programs, BRS, or even work as “reasonable accommodations”

Academic requirements met = diploma awarded

If IEP w/academic requirements (i.e., minimum credits earned) met

- AND no other IEP Goals/objectives = diploma awarded
- BUT transition goals/objectives **not** met = diploma not awarded until non-academic IEP G's/O's met OR “ages out”

*“Ages out” = end of SY in which student turns 21 years of age*



# IF IEP and has not met academic requirements by age 18-19ish:

- Still focus on transition goals/objectives to maximize independent living/employment opportunities UNTIL:
  - these G's/O's met OR
  - “ages out” with “turnkey” to adult services/supports
- *Some* additional credits but seek alternatives (e.g., credit recovery, adult ed) if HS diploma important

# If my child is not in his/her teens yet, does transition planning matter?

- Chores
- Playmates and playdates
- Community exposure and inclusion
- HIGH EXPECTATIONS
- Encourage dreams
- Identify and stay on top of changes in interests, preferences, likes, dislikes, talents, unique skills
- Savings account, hope chest, whatever you're doing for the siblings
- Connect to YOUR community
- Ask other kids your child's chronological age



# Avoid “The Cliff”



# Today's Objectives

At the end of this webinar, you will be able to:

1. State the unique needs that students with epilepsy (with or without co-occurring diagnoses) have that need to be taken into account before school years end
2. Identify personal strengths to develop to facilitate a quality adult life
3. Develop personal and community connections for support
4. Access assistive technologies to facilitate independence
5. State the legal opportunities under Section 504 of the Rehab Act of 1972, the Individuals with Disabilities Education Act of 2004, and the Workforce Incentives and Opportunities Act of 2014
6. Identify additional resources to assist in the transition journey

# Objective 1: Unique Needs

- May still need to learn skills “differently acquired” or unique (Nordli, 2004), e.g.:
  - Age-appropriate social-emotional skills
  - Self-management (e.g., avoid triggers, dangerous medication interactions)
  - Time management (e.g., to accommodate sleepiness, stress)
  - Self-esteem/self-confidence
  - Age-appropriate independence

# Unique needs, cont.

- Medical and medication management (Dr. Schramm)
- Possible cognitive impact, e.g.,
  - Overall learning
  - Memory (short- or long-term)
- Possible co-occurring conditions (e.g., ID, ASD, physical challenges)

*May have 504 Plan or IEP (Individualized Education Program) at school*

# Unique Needs, cont.

Life  
Liberty  
Happiness  
**Know your  
rights**

+ ADA  
504  
IDEA

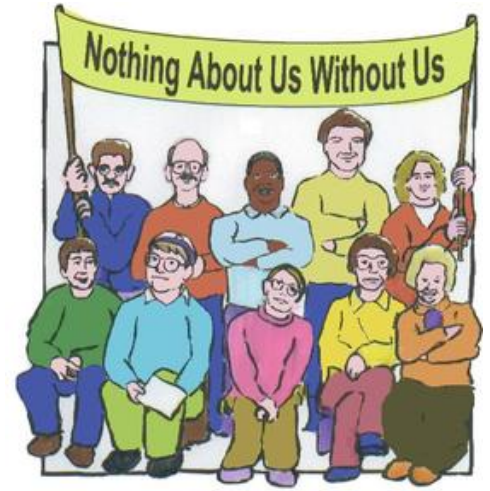


**ASK QUESTIONS**

**“ As a  
parent, you  
know your  
child better  
than anyone  
else. ”**

**You are equally if not  
more important to  
your child’s future  
than any  
“professional”**

**SELF-  
DETERMINATION  
AND SELF-  
ADVOCACY**



# Unique need = particular importance of self-advocacy and 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 <b>characteristic of a person</b> that leads them to <b>make choices</b> and <b>decisions</b> based on their own <b>preferences</b> and <b>interests</b>, to monitor and regulate their own actions and to be <b>goal-oriented</b> and <b>self-directing</b>.”</i> (Nat’l Gateway to Self-Determination)</p>



But having unique needs should not affect *Quality of Life*.

With good planning and needed supports in place, people with ANY kind of disability or disabling condition can still lead an enviable life!

# Objective #2: Personal Strengths

Start with the end in mind:

What vision of a POSITIVE future do you have for your son/daughter?

What do you want to avoid in his/her future?

# Achieving Valued Life Outcomes are possible for EVERYONE

*Valued life outcomes are the same types of outcomes we would want for any of our loved ones who do not have a disability.*

A Place of One's Own to Call Home



*Family*



*Friends*

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# More Valued Life Outcomes



"Sometimes the hardest part of the journey is believing you're worthy of the trip."

Guardianship Alternatives:  
Supported Decision-Making



**How much more feasible are these if you are employed and earning a living rather than living in poverty?**



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# Raising Expectations

- You raise expectations by having high expectations
- Raising expectations does not mean having unrealistic expectations



“If you reach for the stars, you can settle for the moon. If you only reach for the moon, you may never get off the ground.” (RWC, 1995)

# STEP 1: Moving away from “what’s wrong”

- Prejudices
- Over-protectiveness
- Thinking in terms of “mental age”
- Thinking in terms of deficits, weaknesses, and what doesn’t work
- Hoping for a “cure”
- “It’s not realistic”
- “S/he is too \_\_\_\_\_”
- Waiting for someone else to “do it”

**To paraphrase Thomas Jefferson:**

**Nothing can stop a family and individual with the right mental attitude from achieving their goal; nothing on earth can help those with the wrong mental attitude.**

# Step 2: Wipe YOUR board clean of deficit thinking.

## Examples:

- Will never \_\_\_\_\_
- Can't \_\_\_\_\_
- Is \_\_\_\_\_  
(insert negative adjective)
- Diagnoses \_\_\_\_\_
- You must be/have done \_\_\_\_\_  
\_\_\_\_\_ to deserve \_\_\_\_\_
- Surely a cure is just  
around the corner
- Other unhelpful advice

- Accept the reality of discriminations based on race, ethnicity, gender, social class, and other -isms
- Take a sheet of paper and write down everything negative you can say about the young person of concern to you.

WRITE DOWN ALL THE NEGATIVITY



NOW GET RID OF IT!

- Now take that sheet of paper, crumple it up and throw it away.

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# STEP 3: Strengths-Based Person-Centered Planning is Essential

## Examples of strength-based person-centered thinking

- *Inclusion; celebrate differences*
- *Support not control*
- ***Do with** because community is important*
- *Balance of power belongs with the person*
- *It's okay to learn from mistakes*

## Examples of the deficit model of “traditional” interactions

- *Exclusion; ignore or hide differences or “fix”*
- *Control and manage*
- ***Do for** if they can't do themselves*
- *Balance of power belongs with caretakers/caregivers*
- *“They” must be protected*

## Non-examples of strength-based person centered descriptions:

- Perseverates/Fixates on \_\_\_\_\_.
- Displays attention-seeking behavior.
- Frequently off task or avoidant.
- Is non-compliant.
- Perseverates.
- No self-control
- Is dependent on others. Can't \_\_\_\_\_.
- Tantrums.
- Short attention span.
- Splinter skills.
- Isn't smart
- Has lots of problems including but not limited to \_\_\_\_\_.

## Examples of strength-based descriptions:

- Perseveres, Really seems to like/be interested in \_\_\_\_\_.
- Wants to have relationships with \_\_\_\_\_.
- Takes breaks to “regroup” or expresses disinterest independently.
- Has survived
- Self-advocates
- Does best when supported for \_\_\_\_\_.
- Knows what s/he likes.
- Able to change his/her mind.
- Talents. Really good at \_\_\_\_\_.
- Is smart in ways others don't always recognize like \_\_\_\_\_.

# After this webinar, work with your son/daughter to write down:

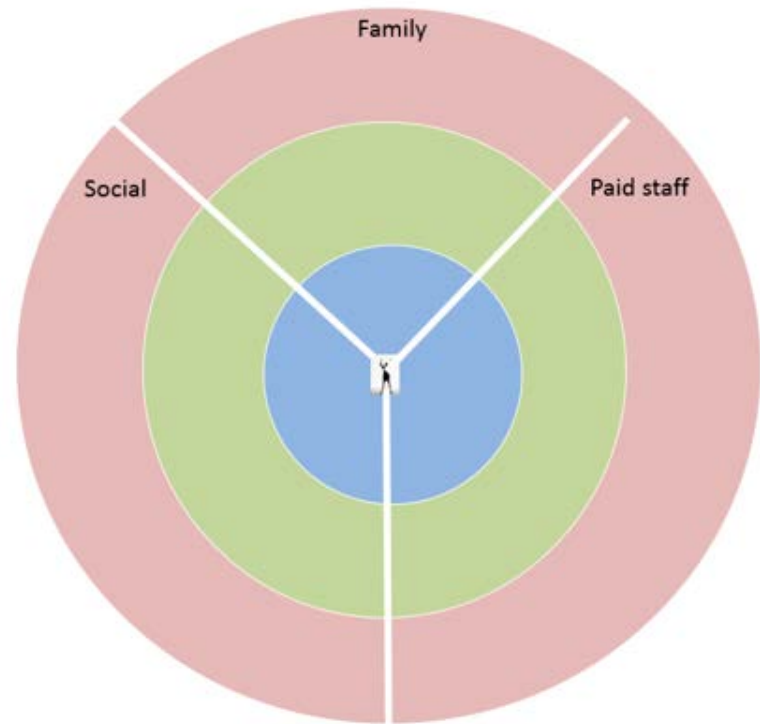
What people admire about me/my strengths

What's important to me  
(my preferences, interests, passions)

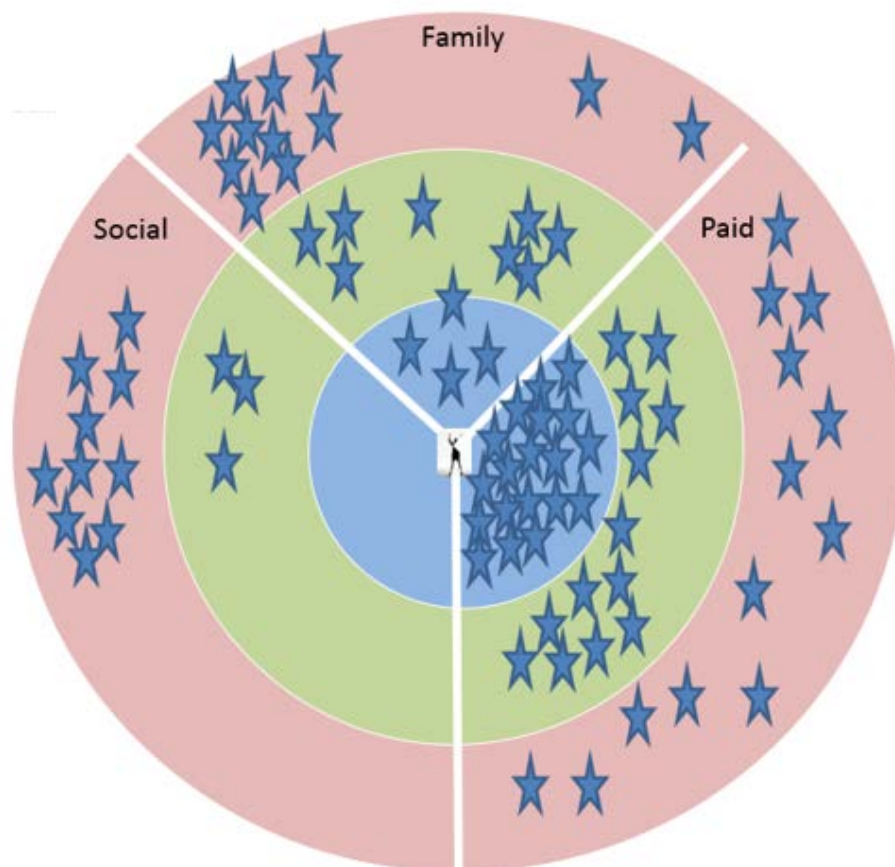
# Objective #3: Personal and Community Connections

Adult services are NOT mandated!

Who is in you child's and your Circles of support?



# What we often see:



# How to build personal and community connections:

<http://www.inclusion.com/downloads/actions-that-build-community.pdf>

**75 Actions that Build Community-**  
*connect with others • build trust • get involved*

SOURCE: <http://www.inclusion.com/downloads/actions-that-build-community.pdf>  
BY John O'Brien  
(Adapted from www.bettertogether.org which identifies 150 social capital building actions)

Community grows stronger through hundreds of little and big actions citizens take every day. As you scan the list put a mark next to any of these actions that you or a family member has done either in the past month or so, or for more occasional actions, in the past year or so.

<input type="checkbox"/> Invite neighbors over for a meal or barbecue	<input type="checkbox"/> Start or join a carpool
<input type="checkbox"/> Attend a political meeting	<input type="checkbox"/> Plan a "Walking Tour" of a local historic area
<input type="checkbox"/> Support local merchants	<input type="checkbox"/> Tutor or read to children or have children read to you
<input type="checkbox"/> Volunteer your special skills to a community organization	<input type="checkbox"/> Run for public office
<input type="checkbox"/> Donate blood (with a friend)	<input type="checkbox"/> Host a party
<input type="checkbox"/> Work in a community garden	<input type="checkbox"/> Offer to serve on a committee outside of work
<input type="checkbox"/> Mentor a person of a different ethnic group	<input type="checkbox"/> Form a walking group (or a swimming group) with at least one other person & encourage each other
<input type="checkbox"/> Surprise a new or favorite neighbor by taking them food	<input type="checkbox"/> Play a sport
<input type="checkbox"/> Avoid destructive gossip or help someone else avoid it	<input type="checkbox"/> Go to church and connect with people and activities
<input type="checkbox"/> Help another person outside your home fix something	<input type="checkbox"/> Ask an elder or a young person to teach you something
<input type="checkbox"/> Attend local school or children's athletics, plays, & recitals	<input type="checkbox"/> Host a potluck supper
<input type="checkbox"/> Get involved with scouts	<input type="checkbox"/> Take dance lessons with a friend
<input type="checkbox"/> Sing in a choir	<input type="checkbox"/> Become a trustee
<input type="checkbox"/> Attend a party in someone else's home	<input type="checkbox"/> Join a campaign & take action that brings you into contact with others (not just a donation)
<input type="checkbox"/> Get to know the clerks and salespeople at your local stores	<input type="checkbox"/> Gather a group to clean up a local park, cemetery or waterway
<input type="checkbox"/> Audition for community theatre or support a production backstage or volunteer to usher	<input type="checkbox"/> Bake something for neighbors or work colleagues
<input type="checkbox"/> Attend a lecture or concert	<input type="checkbox"/> Plant trees
<input type="checkbox"/> Give to your local food or clothing bank	<input type="checkbox"/> Volunteer at the library or primary school
<input type="checkbox"/> Play cards or games with friends or neighbors	<input type="checkbox"/> Call an old friend
<input type="checkbox"/> Walk or bike to support a cause and meet others	<input type="checkbox"/> Sign up for a class & meet your classmates
<input type="checkbox"/> Participate in a political campaign	<input type="checkbox"/> Accept or extend an invitation
<input type="checkbox"/> Attend a local festival or parade	<input type="checkbox"/> Log off and go to the park
<input type="checkbox"/> Find a way to show personal appreciation to	

<input type="checkbox"/> someone who builds your local community	<input type="checkbox"/> Say hello to strangers
<input type="checkbox"/> Coach or help out with local (youth) sport	<input type="checkbox"/> Find out more by talking with a neighbor you don't know very well yet
<input type="checkbox"/> Offer to help a neighbor with garden work or shopping or a ride	<input type="checkbox"/> Host a movie night
<input type="checkbox"/> Start or participate in a discussion group or book or film club	<input type="checkbox"/> Help out with or create a newsletter
<input type="checkbox"/> Cut back on TV & interact with people instead	<input type="checkbox"/> Collect oral histories to discover the interesting things people have done
<input type="checkbox"/> Join in to help carry something heavy	<input type="checkbox"/> Offer to watch a neighbor's home while they are away
<input type="checkbox"/> Make gifts of time	<input type="checkbox"/> Help out with recycling
<input type="checkbox"/> Greet people	<input type="checkbox"/> Ask to see a friend's photos
<input type="checkbox"/> If you think someone needs help, ask to find out & do what you can	<input type="checkbox"/> Invite a local politician or official to speak to a group you belong to
<input type="checkbox"/> Fix it even if you didn't break it	<input type="checkbox"/> Start talking to people you see regularly
<input type="checkbox"/> Pick up litter even if you didn't drop it	<input type="checkbox"/> Listen to the children you know and find out what matters to them
<input type="checkbox"/> Attend gallery openings & art exhibits	<input type="checkbox"/> Plan a reunion of family, friends, or people with whom you had a special connection
<input type="checkbox"/> Organize a neighborhood yard sale	<input type="checkbox"/> Hire local young people for odd jobs
<input type="checkbox"/> Read or listen to the local news faithfully	<input type="checkbox"/> Write a letter to the editor
<input type="checkbox"/> Attend a public meeting or hearing & speak up	<input type="checkbox"/> Join a group that is likely to lead to making new friends of different ethnicity, or religion, or income, or life experience
<input type="checkbox"/> When inspired write a personal note or send a card to friends	

What can we learn about community building from our own patterns of action?

John O'Brien



version 2.0

# Personal and community connections, cont.

<http://learningcommunity.us/documents/connections.pdf> pp. 10-11

## A Guide to Developing Community Connections



### An Associational Map

Prepared by John McKnight  
Northwestern University  
Center for Urban Affairs and Policy Research

*Associational life is rich in all of our communities. Learning about where the community networks are & useful information to have on hand. This is a guide to help you learn about the possible associations in your community. Use this list to think about the various organizations people belong to. You can identify groups in your area in a number of ways - talking to others, looking in the phone book, reading area and neighborhood newspapers, surveying churches and existing groups, checking with the Chamber of Commerce, etc. Make your own listing and use it as a resource as you think about connecting specific people.*

Associations (examples)	Your Area
<b>Artistic Organizations</b> choral, theatrical, writing	
<b>Business Organizations</b> Chamber of Commerce, business associations	
<b>Charitable Groups &amp; Drives</b> Red Cross, Cancer Society, United Way	
<b>Church Groups</b> service, prayer, men's, women's, youth, seniors	
<b>Civic Events</b> July 4th, art fair, festival, Halloween	
<b>Collectors Groups</b> stamp collectors, flower dryers, antiques	
<b>Community Support Groups</b> Friends of the Library, nursing home, hospital	
<b>Elderly Groups</b> Senior Citizens	
<b>Ethnic Associations</b> Sons of Norway, Black Heritage Club, Hibernians	
<b>Health &amp; Fitness Groups</b> bicycling, jogging, exercise	
<b>Interest Clubs</b> poodle owners, antique car owners	

## A Guide to Developing Community Connections

Associations (examples)	Your Area
<b>Local Government</b> town, fire department, emergency units	
<b>Local Media</b> radio, newspaper, local access cable TV	
<b>Men's Groups</b> cultural, political, social, educational, vocational	
<b>Mutual Support (Self Help) Group</b> Alcoholics Anonymous, LaLeche League	
<b>Neighborhood &amp; Block Groups</b> crime watch, beautification, Christmas decorations	
<b>Outdoor Groups</b> garden clubs, conservation clubs	
<b>Political Organizations</b> Democrats, Republicans, caucuses	
<b>School Groups</b> parenting club, PTA, child care	
<b>Service Clubs</b> Zonta, Kiwanis, Rotary, AAUW	
<b>Social Cause Groups</b> peace, rights, advocacy, service	
<b>Sports Leagues</b> bowling, swimming, baseball, fishing, volleyball	
<b>Study Groups</b> literary clubs, bible study groups	
<b>Veterans Groups</b> American Legion, Veterans of Foreign War	
<b>Women's Groups</b> cultural, political, social, educational, vocational	
<b>Youth Groups</b> 4H, Future Farmers, Scouts, YMCA	

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# Objective #4: Assistive Technology



Including  
wearable or  
mattress  
seizure  
detection  
devices and  
alarms



# If portable electronics typically trigger seizures, consider:

- Flicker-free monitors
- Monitor Glare Guards
- Set up browser features to disable animation and audio in web sites
- Key grids for “touch screen” options

# If electronics trigger still seizures, what low-tech can be used?

- Bracelets/necklace
- To-do lists
- Pocket calendar
- Emergency communication/contact information
- Wrist watch alarms
- PECS (Picture Exchange Communication System)
- Automatic dialing, etc.

# AT in transition:

- Assessed for appropriate independence-facilitating low- and high-tech assistive technology when in school
- Learn how to use appropriate AT when in school
- Access AT across settings so usable as an adult

**For more information on AT:**

**<https://oakhillct.org/NEAT-Center>**



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# Objective #5: Legal Opportunities



**DISABILITY RIGHTS  
CONNECTICUT**  
Justice. Community. Inclusion.

<https://www.disrightsct.org/>

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# How do the federal Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and the Individuals with Disabilities Education Act differ?



	<b>504</b> 1973	<b>IDEA</b> 1975 last amended 2004
<b>Purpose</b>	Prevent discrimination	Direct assessment, planning, educational provisions/services
<b>Funding</b>	None	Provides state funding
<b>Age served</b>	Lifetime	Birth to acceptance of high school diploma or age 21
<b>Population</b>	All federally funded programs	Schools
<b>Procedural regulation</b>	Not strictly regulated	Specific due process requirements

## ADA v. 504 v. IDEA, cont.

- ADA “...guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, State and local government services, and telecommunications.” (No change for public entities)
- Section 504 "No otherwise qualified individual with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance . . . ."

<http://www.greatschools.org/gk/articles/section-504-2/>



## ADA v. 504 v. IDEA, cont.

- “IDEA requires that the disability adversely affect a child’s educational performance...(and) that the purpose of education is to enable the child to develop skills toward independence and meaningful community involvement as an adult.”

<https://ed.gov/parents/needs/speced/iepguide/index.html> OR <http://idea.ed.gov/explore/home>



# Is my child eligible for transition services or protections under any of these laws?

- SHORT ANSWER: It depends.
- Must meet eligibility criteria. But according to whom?
- Due process **only** under IDEA
- Administrative relief if rights violated under any act
- Egregious violations may result in compensatory damages by violators but only at plaintiff's expense of taking case to court

***ONLY THE IDEA PROVIDES FOR SECONDARY TRANSITION SERVICES.***

# New Laws



## A.B.L.E.

*Achieving a Better Life  
Experience Account*  
<http://ablenrc.org/>



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# Objective 6: Additional Resources

<https://www.cttransition.org/>

The screenshot shows the homepage of the CT Transition Community of Practice. At the top, the title "CT Transition Community of Practice" is displayed in white on a dark blue background. Below the title is a navigation menu with five items: "Home", "What's New?", "Upcoming Events", "Resources", and "More Links", each in a dark red box. The main content area features a grid of buttons and images. On the left, there is a circular icon of a calendar. To its right are three images of people, each with a corresponding button: "Students", "Families", and "Professionals". Below these is a "Join a Practice Group" button. To the right of the main content is a vertical sidebar with four buttons: "Submit a Resource", "Submit an Event", "About Us", and "Contact Us". At the bottom of the main content area are three red buttons: "Transition Bill of Rights", "Guideposts for Success", and "Transition Timeline". The footer contains the "CONNECTICUT TRANSITION Community of Practice" logo, which includes a stylized signpost with three arrows pointing left, right, and up. Below the logo is a small disclaimer: "CT's Community of Practice Disclaimer: Thank you for visiting the CT Transition Community of Practice (COP) website. The resources and events on this site link to federal, state and local agencies and private and public organizations and are provided for the convenience of users. CT Transition COP does not create or maintain these websites, and does not accept responsibility for their content or accuracy. Information on this website is not reviewed by federal, state, or local agencies. Reference to any specific commercial product, event, process, service, manufacturer, publisher, or company does not constitute endorsement or recommendation by the CT Transition COP or any of its members. (4-2-15)"

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# Ability Beyond Transition Resource Center

TRANSITION RESOURCES

MEMBER LOGIN

<http://abilitybeyond.org/resource-center/transition-resources/>



Welcome. Transition is a Journey.

It is never too early to [start](#) planning for your child's future even if just getting through one day at a time can seem overwhelming. Learn what you, as a parent, can do to maximize your child's independence now and plan for a future that is secure and full of opportunity.

The Transition Resource Center provides **eight informative videos** covering all key areas of transition including:

- IEP's & School Based Supports
- Employment First
- Housing & Daily Life
- College & Post-Secondary Education
- Social Connections & Relationships
- Healthy Living
- Legal Matters & Advocacy
- Finances & Eligibility

Developed in Partnership with:







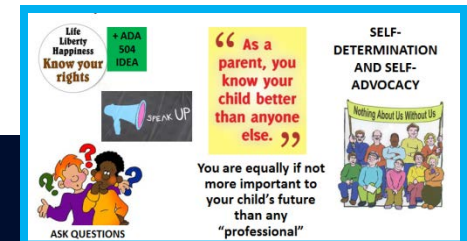
In addition, we offer worksheets tailored to the topic of each Module to guide the planning process.

Start by signing up to [join](#) the Transition Resource Center. Membership and all resources are free to the public.



# What are things to think about today?

- Transitions in the future **PLAN PLAN PLAN PLAN PLAN**  
*(no shoulda/woulda/coulda allowed!)*
- *Refocus your own goals*    
- Think POSITIVE FUTURES and dare to dream
- Recognize that getting the support one needs to live a meaningful life is different from being “in a program”
- Maximizing EMPOWERMENT (yours and your child’s)
- Maximize “natural supports”



# Today's Objectives

Are you now able to:

1. State the unique needs that students with epilepsy (with or without co-occurring diagnoses) have that need to be taken into account before school years end?
2. Identify personal strengths to develop to facilitate a quality adult life?
3. Develop personal and community connections for support?
4. Access assistive technologies to facilitate independence?
5. State the legal opportunities under Section 504 of the Rehab Act of 1972, the Individuals with Disabilities Education Act of 2004, and the Workforce Incentives and Opportunities Act of 2014?
6. Identify additional resources to assist in the transition journey?

# Comments or questions?

How to contact me:

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Community Education Director

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Disabilities | UConn Health

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Office: 860.679.1585 | Fax: 860.679.1571

[www.uconnucedd.org](http://www.uconnucedd.org)

**THANK YOU! PLEASE COMPLETE YOUR EVALUATIONS at**

**<https://www.surveymonkey.com/r/EFCTWebinar1Eval>**

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