



A Good Life

from OK YLF



# WHAT IS A GOOD LIFE?

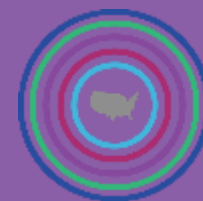


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*vimeo*

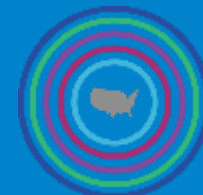
<http://supportstofamilies.org/what-is-a-good-life/>





# The LifeCourse Framework

Introduction





## Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities

### About the Community of Practice

The National Community of Practice for Supporting Families of Individuals with Intellectual and Developmental Disabilities will help five states develop systems of support for families throughout the lifespan of their family member with intellectual and developmental disabilities. The objective of the grant is to develop systems of supports for families throughout the lifespan of their family member.

### Facilitating the Community of Practice

Grant partners include

- National Association of State Directors for Developmental Disability Services (NASDDDS)
- University of Missouri-Kansas City – Institute for Human Development (UMKC-IHD)
- Human Services Research Institute (HSRI)
- National Association of Councils on Developmental Disabilities (NACDD)

### Goals of the CoP

The goals of the Community of Practice are:

- to create a model framework for supporting families that addresses the needs of families with a family member with I/DD across the lifespan and supports states to develop and sustain exemplary family support practices.
- to develop and facilitate a multi-level Community of Practice designed to build capacity within states and the nation to create policies, practices, and systems to better assist and support families that include a member with I/DD across the lifespan.
- to capture and share lessons learned and products to develop, implement and sustain exemplary practices to support families and systems

### The Goal of Supporting Families

The overall goal of supporting families, with all of their complexity, strengths and unique abilities is so they can best support, nurture, love and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members.



from Building a National Agenda for Supporting Families with Member with I/DD 2011

Learn about policies and practices for supporting families, find resources connect with the Community of Practice, and share your ideas about supporting families:



Visit our website at  
[www.supportstofamilies.org](http://www.supportstofamilies.org)



Like us on Facebook at  
[facebook.com/supportstofamilies](https://facebook.com/supportstofamilies)

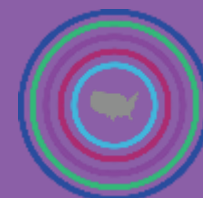


Sign up for our mailing list at  
[www.supportstofamilies.org](http://www.supportstofamilies.org)



Follow us on Twitter at  
[twitter.com/familieswithidd](https://twitter.com/familieswithidd)

The Community of Practice (CoP) Supporting Families throughout the Lifespan is operated under a five year grant awarded to NASDDDS by the Administration on Intellectual and Developmental Disabilities (AIDD) beginning October 2012.





# Connecticut's Accomplishments



## CONNECTICUT'S ACCOMPLISHMENTS



**Daily Living:** The CT Council on Developmental Disabilities has incorporated LifeCourse planning into its Customized Employment project.



**Community Living:** The CT ARC, through funding provided by the CT Council on Developmental Disabilities, developed a housing booklet that incorporated LifeCourse thinking throughout the guide.



**Safety & Security:** CT DDS has been meeting with Benefits Planners and Financial Planners across the state to assist them to incorporate LifeCourse Planning into their everyday practices.



**Healthy Living:** The CT Department of Public Health is in the process of applying the LifeCourse domains and other LifeCourse information into its planning tools.



**Social & Spirituality:** UCONN-UCEDD has incorporated LifeCourse practices into the activities that it has done with various religious organizations. A focus on using LifeCourse practices in community groups is a "next step" in CT's plan of action.



**Citizenship & Advocacy:** PATH has implemented a variety of activities to help youth groups, sibling groups and family mentor use LifeCourse practices and principles in the work they do. Many of the CT LifeCourse Ambassadors are family members who have been trained to help spread the word about LifeCourse planning.



**Services:** CT has trained family members, community members, private agency staff and DDS staff to become LifeCourse Ambassadors. Ambassadors help stakeholders to understand the LifeCourse principles and practices; to use the LifeCourse tools and to promote the use of technology by DDS stakeholders. Ambassadors have also participated in the DDS IP workgroup which is charged with making the DDS Individual Plan (IP) more person-centered.





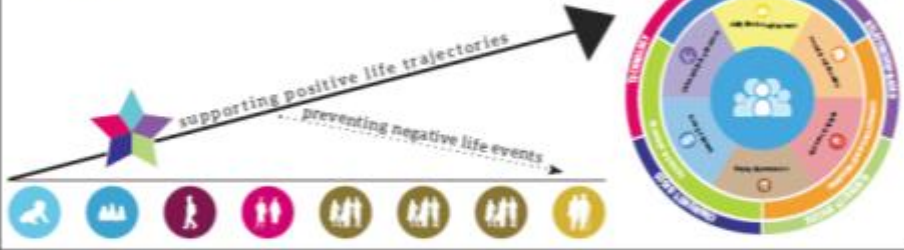
All people have the right to live, love, work, play and pursue their dreams in their community.



# Charting the LifeCourse

## Guiding Principles

**Core Belief:** All people have the right to live, love, work, play and pursue their life aspirations just as others do in their community.



## Focusing on ALL

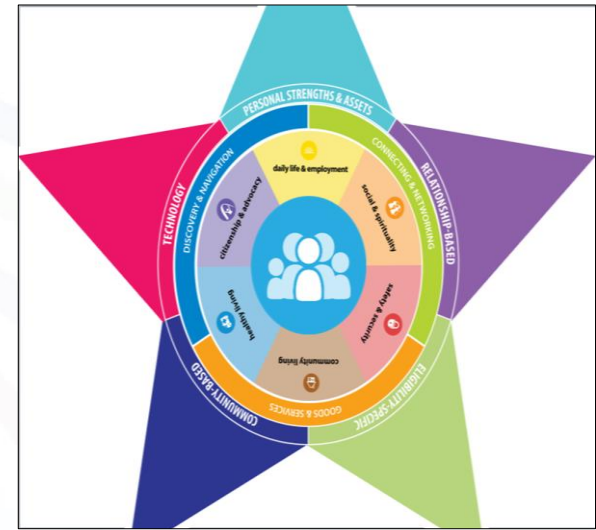


Based on 1.40% prevalence; US Census 2013; Braddock et al. State of the State 2013

## Life Stages and Life Domains

- |   |   |
|---|---|
| <p><b>Daily Life &amp; Employment:</b><br/>What you do as part of everyday life- school, employment, volunteering, communication, routines, life skills.</p> <p><b>Community Living</b><br/>Where and how you live- housing and living options, community access, transportation, home modifications.</p> <p><b>Safety &amp; Security</b><br/>Staying safe and secure- emergencies, well-being, guardianship options, legal rights and issues.</p> <p><b>Healthy Living</b><br/>Managing and accessing health care and staying well- medical, mental health, behavior, developmental, wellness and nutrition.</p> <p><b>Social &amp; Spirituality</b><br/>Building friendships and relationships, leisure activities, personal networks, faith community.</p> <p><b>Citizenship &amp; Advocacy</b><br/>Building valued roles, making choices, setting goals, assuming responsibility and driving how one's own life is lived.</p> | <p><b>Prenatal/Infancy</b><br/>Early years, wondering if meeting developmental milestones</p> <p><b>Early Childhood</b><br/>Preschool age, getting a diagnosis</p> <p><b>School Age</b><br/>Everyday life during school years</p> <p><b>Transition</b><br/>Transitions from school to adult life- Realizing school is almost over!</p> <p><b>Adulthood</b><br/>Living life as an adult</p> <p><b>Aging</b><br/>Getting older and preparing for end of life (parent/family/individual)</p> |
|---|---|

LifeCourse Infographic is a product of the Family to Family LifeCourse Network | UMKC IHD, UCEDD. More materials at [lifecoursetoolkit.com](http://lifecoursetoolkit.com) August 2016

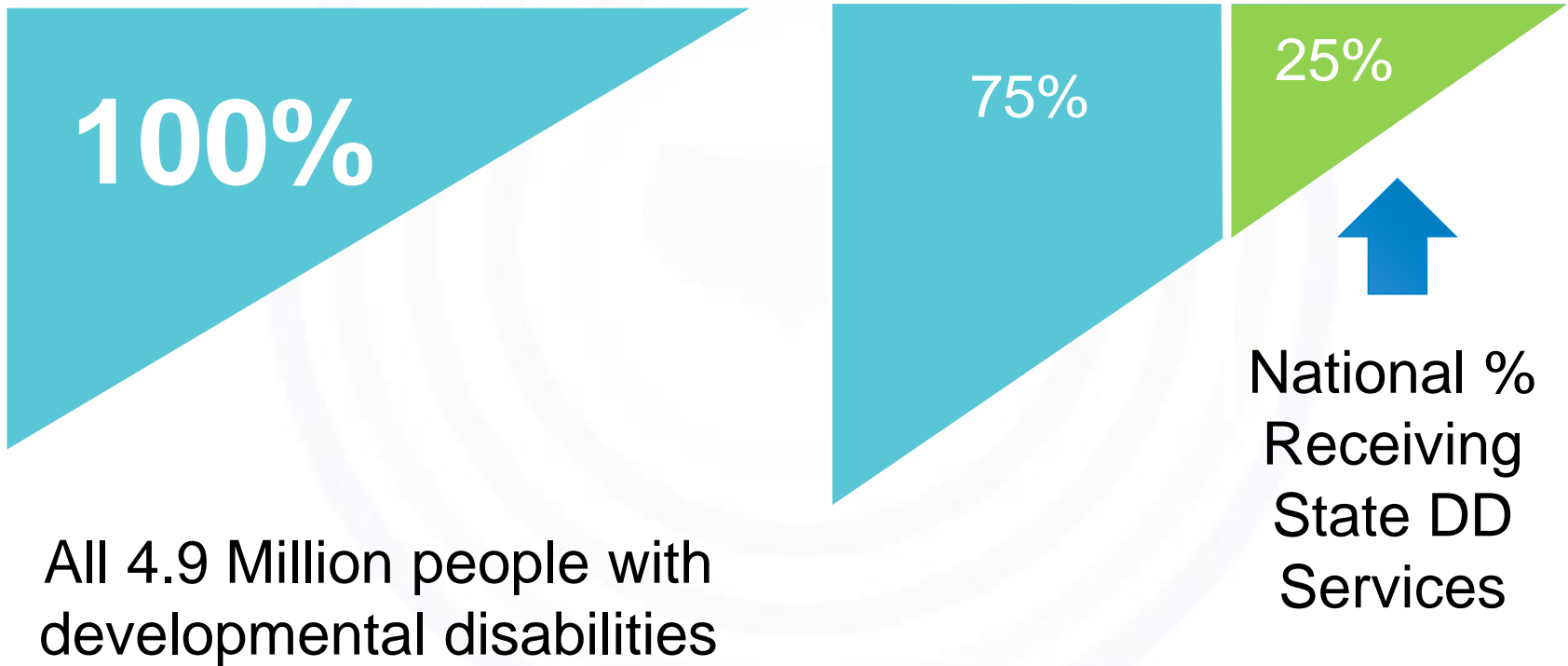


## CT DDS LifeCourse Link

National Supporting Families  
Community of Practice link  
<http://supportstofamilies.org/>



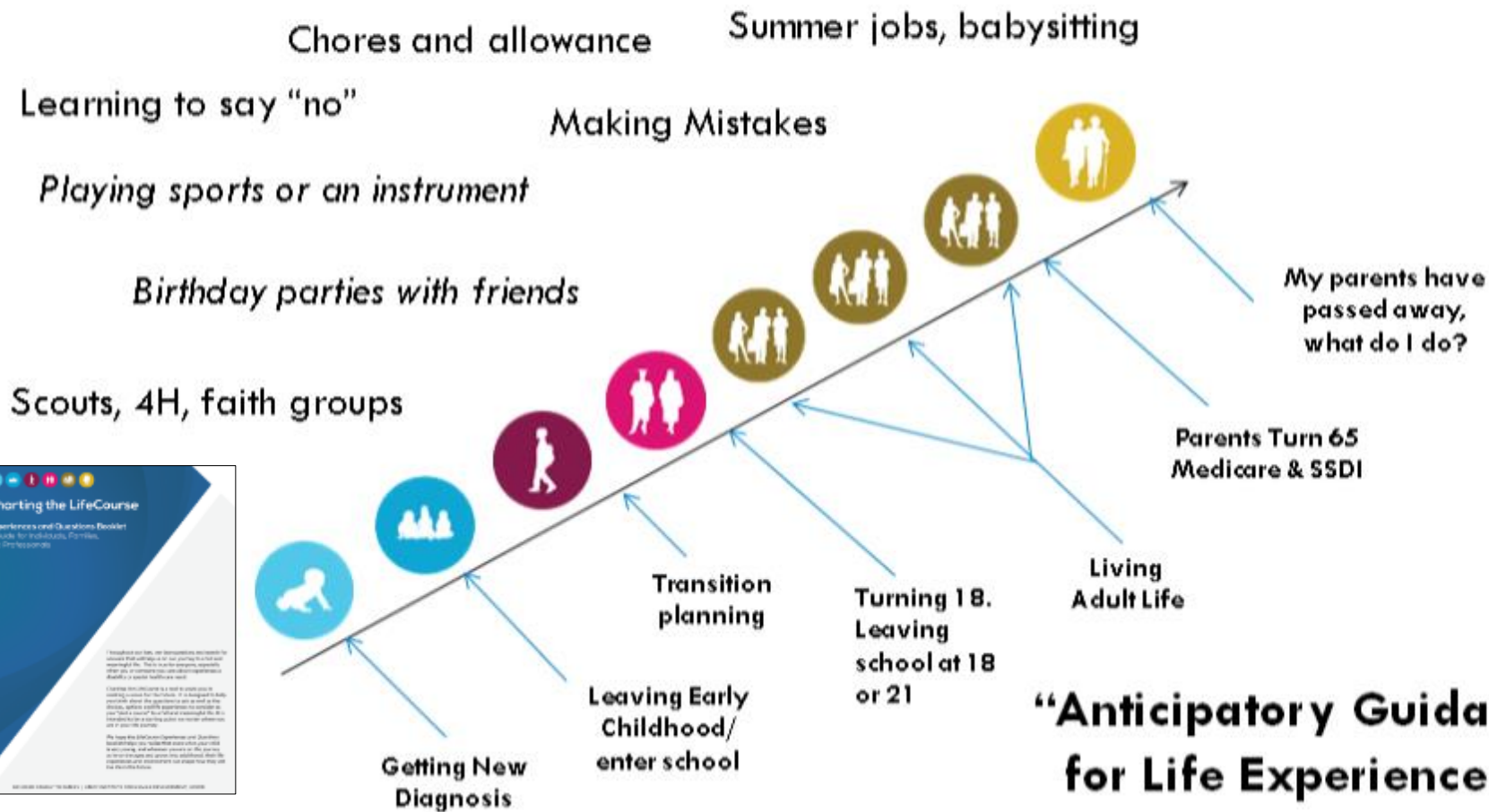
# Focus on “ALL”



*\*\* Based on national definition of developmental disability with a prevalence rate of 1.49%*



# Focusing on Life Experiences and Life Transitions



**“Anticipatory Guidance for Life Experiences”**





# LifeCourse Framework



# LifeCourse Framework



# LifeCourse Framework





# Focusing on Quality of Life Domains



**Community Living**  
(housing, living options, home adaptations and modifications, community access, transportation)



**Healthy Living**  
(medical, behavioral, nutrition, wellness, affordable care)



**Daily Life and Employment**  
(school/education, employment, volunteering, routines, life skills)



**Safety and Security**  
(emergencies, well-being, legal rights & issues, guardianship options & alternatives)



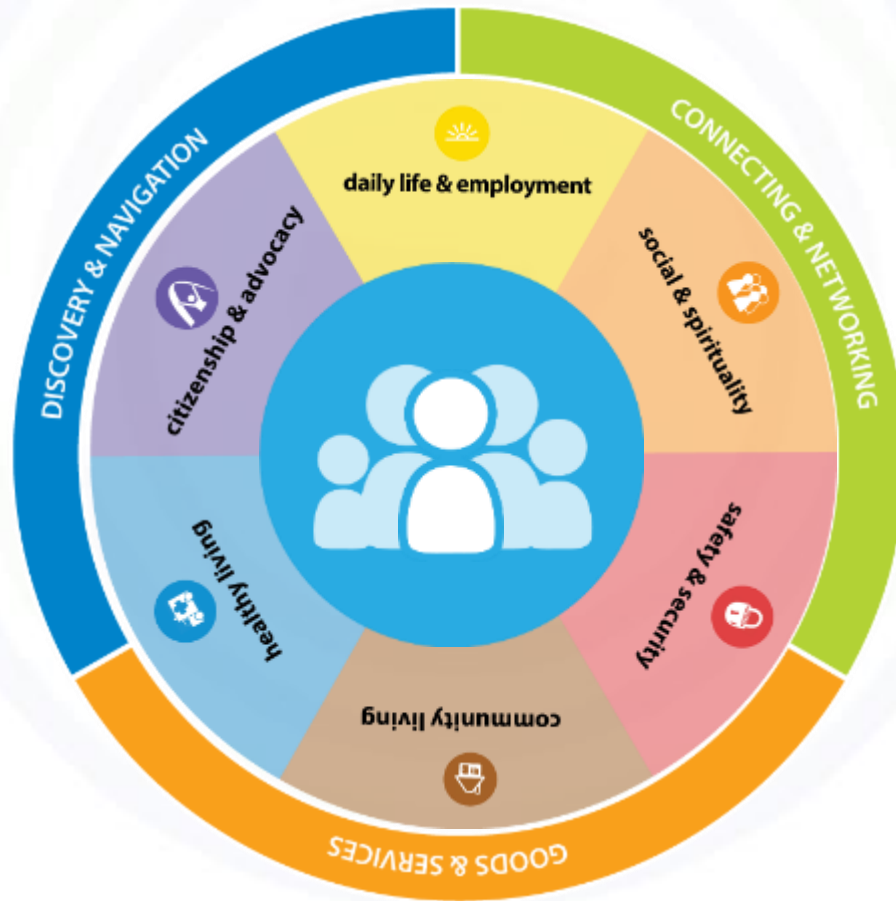
**Social and Spirituality**  
(friends, relationships, leisure activities, personal networks, faith community)



**Citizenship and Advocacy**  
(valued roles, making choices, setting goals, responsibility, leadership, peer support)



# LifeCourse Framework



# LifeCourse Framework



# LifeCourse Framework



# LifeCourse Framework



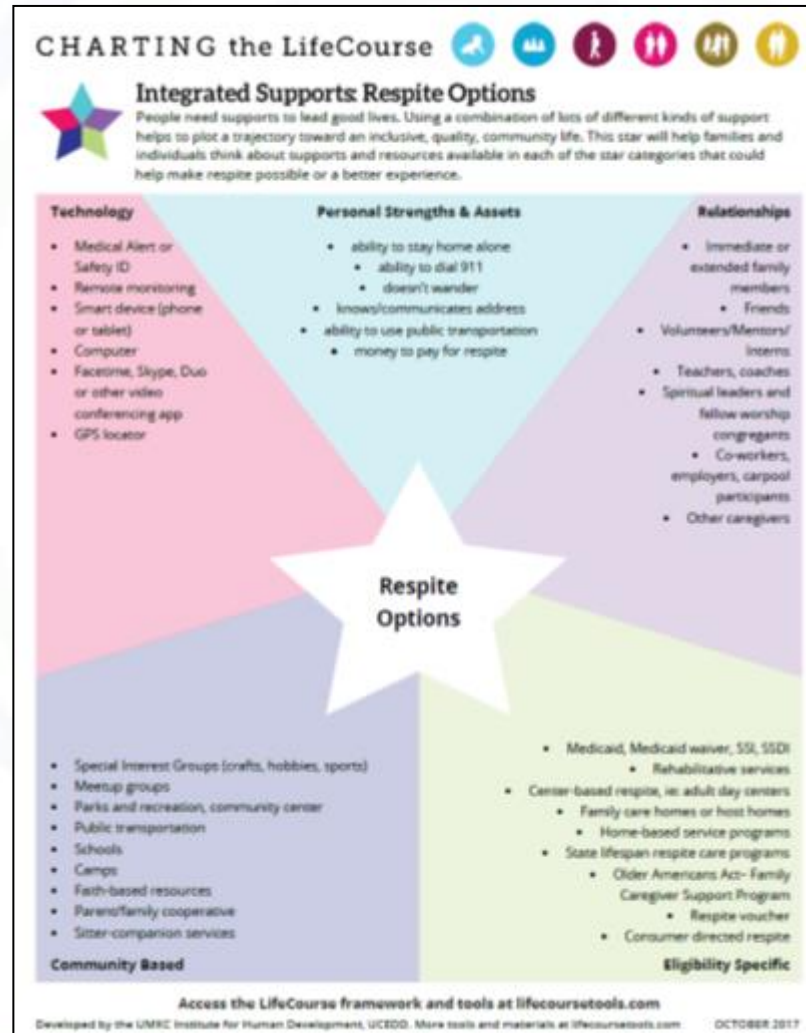


# LifeCourse Framework

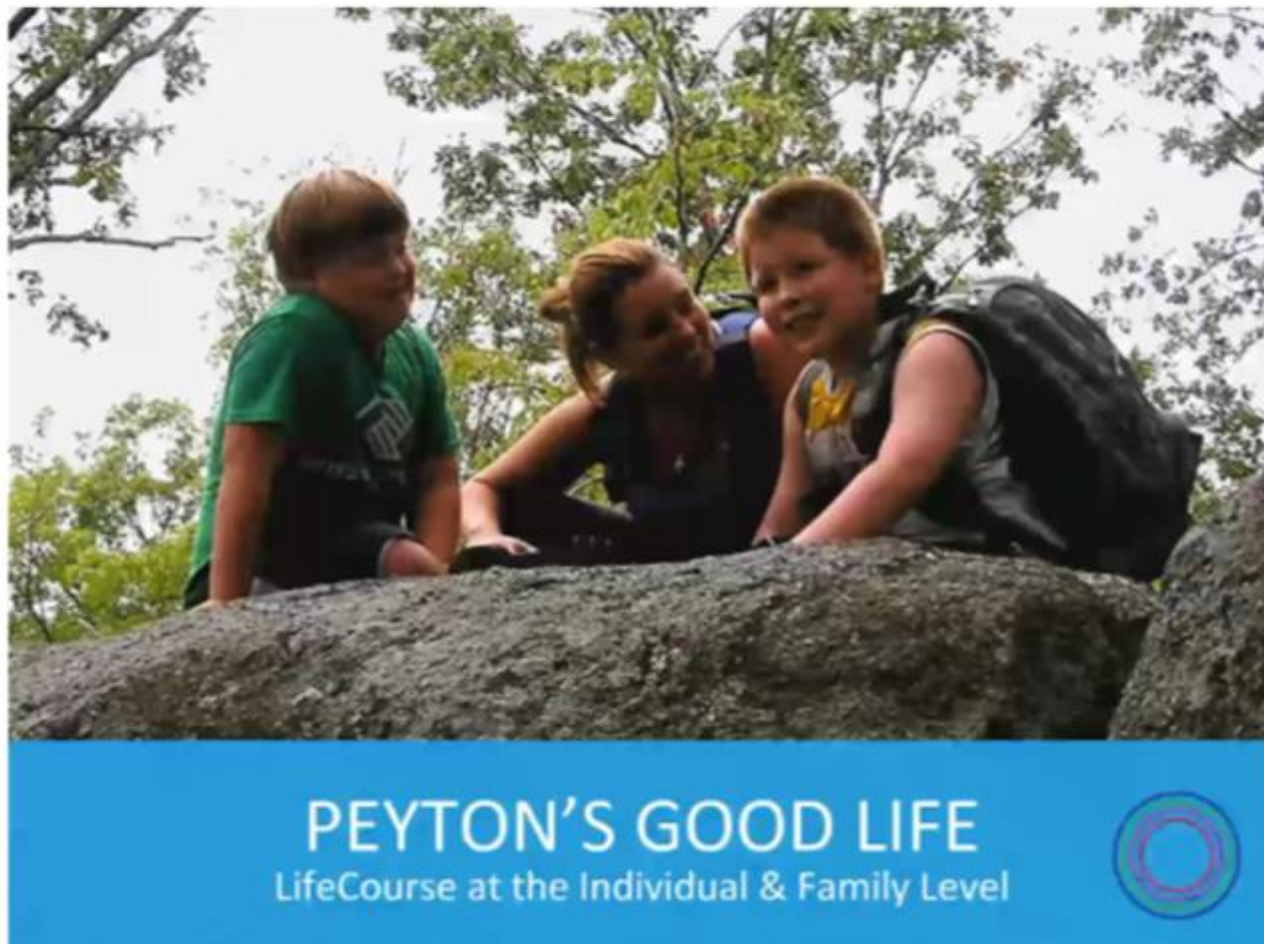
Strengths and Assets	Relationship Based Supports	Technology	Community Resources	Eligibility Based Supports
<p><b>Development:</b> There is growing momentum helping people with disabilities and their families to grow assets. The assumption is that individuals with disabilities, if supported, they will be able to overcome poverty and build better lives.</p> <p>The website below provides information on how to save and invest; to increase assets; to increase education and employment; and how to help people with disabilities use personal strengths to live a better life.</p> <p><b>Development:</b> The ABLE Act is federal legislation that aims to ease financial strains faced by individuals with disabilities by allowing tax-free savings accounts to cover qualified expenses such as education, health, and transportation. <a href="http://www.ablencr.org/">www.ablencr.org/</a></p> <p><b>Financial Independence Resource Center:</b> AIRC is a one-stop resource for information on options for Independence Accounts and on Individual Development Accounts (IDA). <a href="http://resources.acf.hhs.gov/">resources.acf.hhs.gov/</a></p>	<p><b>Relationship Based Supports:</b> Healthy relationships are a vital component of health and wellbeing. There is compelling evidence that strong relationships contribute to a long, healthy, and happy life. Helping people with disabilities to enhance personal relationships helps ensure a better life.</p> <p>The websites below provide information on how people with disabilities and their families can use expanded and enhanced personal relationships as a source of support for building a better life.</p> <p><b>Advocacy Groups/Organizations</b></p> <ul style="list-style-type: none"> <li>ARC CT: <a href="http://thearcct.org/">http://thearcct.org/</a></li> <li>CT Council on Developmental Disabilities: <a href="http://www.ct.gov/ctcdd/site/default.asp">http://www.ct.gov/ctcdd/site/default.asp</a></li> <li>CT Down Syndrome Congress: <a href="http://www.ctdownsyndrome.org/">http://www.ctdownsyndrome.org/</a></li> <li>CT Family Support Council: <a href="http://www.ct.gov/dds/cwp/view.aspx?q=427738">http://www.ct.gov/dds/cwp/view.aspx?q=427738</a></li> <li>CT Parent Advocacy Center: (CPAC) <a href="http://www.cpacinc.org/">http://www.cpacinc.org/</a></li> <li>CT Cross Disability Alliance: <a href="http://ctsilc.org/wp-content/uploads/2007/06/Access">http://ctsilc.org/wp-content/uploads/2007/06/Access</a></li> </ul>	<p><b>Technology:</b> There is a growing movement toward requiring that people with cognitive disabilities have equal access to technology and information. Access to technology is deemed key to helping people with disabilities realize full and equal participation and a better life.</p> <p>The websites below provide information on how people with IDD can use technology to stay safe; to make learning easier; to increase independence, and to live an empowered life.</p> <ul style="list-style-type: none"> <li><b>CT Tech Act Project:</b> Assessment, Demonstration Sites, Funding Ideas Loan Programs, Training <a href="http://cttechact.com/#sthash.pUtpqHm.dpbs">http://cttechact.com/#sthash.pUtpqHm.dpbs</a></li> <li><b>Center on Technology and Disabilities:</b> Assistive and Instructional Technology Supporting People with Learning Disabilities <a href="http://www.ctdinstitute.org/">http://www.ctdinstitute.org/</a></li> <li><b>Standard Technology Tools Checklist For Middle and High School</b> <a href="http://assistivetech.sf.k12.sd.us/middle_and_high.htm">http://assistivetech.sf.k12.sd.us/middle_and_high.htm</a></li> </ul>	<p><b>Community:</b> The Americans with Disabilities Act (ADA) has helped people with disabilities become more independent and involved in their world. Living, working, learning, and being engaged within a community is an essential way to help people with disabilities live a better life.</p> <p>The websites below provide information on ways to help make communities more accessible for people with IDD and provides information on accessible community-based social activities.</p> <ul style="list-style-type: none"> <li><b>CT ADA:</b> Knowledge of the ADA can be used to help communities become more accessible. <a href="http://www.iud.ct.gov/ADA/default.htm">http://www.iud.ct.gov/ADA/default.htm</a></li> <li><b>Connect Kids:</b> Special Needs Fun Stuff <a href="http://www.ct.gov/kids/cwp/view.aspx?q=4072&amp;q=478302">http://www.ct.gov/kids/cwp/view.aspx?q=4072&amp;q=478302</a></li> <li><b>Fun Things to Do in CT</b> <a href="http://www.wegoplaces.com/things-to-do-in-connecticut">http://www.wegoplaces.com/things-to-do-in-connecticut</a></li> <li><b>0-5 (Day Care/Pre-School) Office of Early Childhood (OEC) Childcare and Camp Information</b> <a href="http://www.ct.gov/oec/cwp/view.aspx?q=4542&amp;q=544636">http://www.ct.gov/oec/cwp/view.aspx?q=4542&amp;q=544636</a></li> </ul>	<p><b>Help for Those Who Are Eligible:</b> There are many agencies and other federal and state funded programs that provide support to people in need who are eligible for the services provided. These services are designed to help people with disabilities live better lives.</p> <p>The websites below are just a few of the organizations providing eligibility-based services. It is important that families are provided information about the services available.</p> <p><b>General Information</b></p> <ul style="list-style-type: none"> <li><b>211:</b> A one-stop connection to local services such as utility assistance, food, housing, child care, school programs, elder care, crisis intervention, and much more <a href="http://www.211ct.org/">http://www.211ct.org/</a></li> <li><b>Connecticut Association for Human Services:</b> Federal, state and local programs that help people in CT: <a href="http://cahs.org/publications/print-help-people/">http://cahs.org/publications/print-help-people/</a></li> <li><b>Connecting Connecticut Resource:</b> A Directory for Schools and Community Organizations Serving Families With Children Who Have Disabilities <a href="http://www.cpacinc.org/content/uploads/2014/03/Connecting-2012_Mar14_Interactive.pdf">http://www.cpacinc.org/content/uploads/2014/03/Connecting-2012_Mar14_Interactive.pdf</a></li> <li><b>CT Department of Social Services:</b> Programs for people with disabilities <a href="http://www.ct.gov/dss/cwp/view.aspx?q=04922&amp;dssNav=1">http://www.ct.gov/dss/cwp/view.aspx?q=04922&amp;dssNav=1</a></li> </ul>



# LifeCourse Problem Solving



# Peyton's Integrated School Story



<https://vimeo.com/153771378>



# Using LifeCourse Planning at a PPT

“My name is Owen and I will be attending Brown in the fall.

I am here to tell you what I need to be successful next year - using the LifeCourse framework.

Let’s start by me telling you about myself.”



**“Thank you  
for  
attending  
my PPT!”**

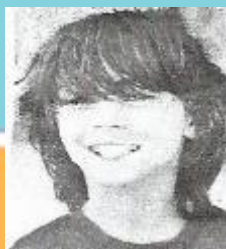


# My LifeCourse Portfolio

Owen's ONE-PAGE PROFILE

What people like & admire about me

I am hilarious, quick witted, treat others nicely. Sweet and kind, competitive. Really good at video games, entertaining



What's Important to ME

Family, friends, Milo, my dog, Ziggy, my guinea pig, getting things right the first time, free running, exercise, staying organized, Time People ask me what I want to do, drawing

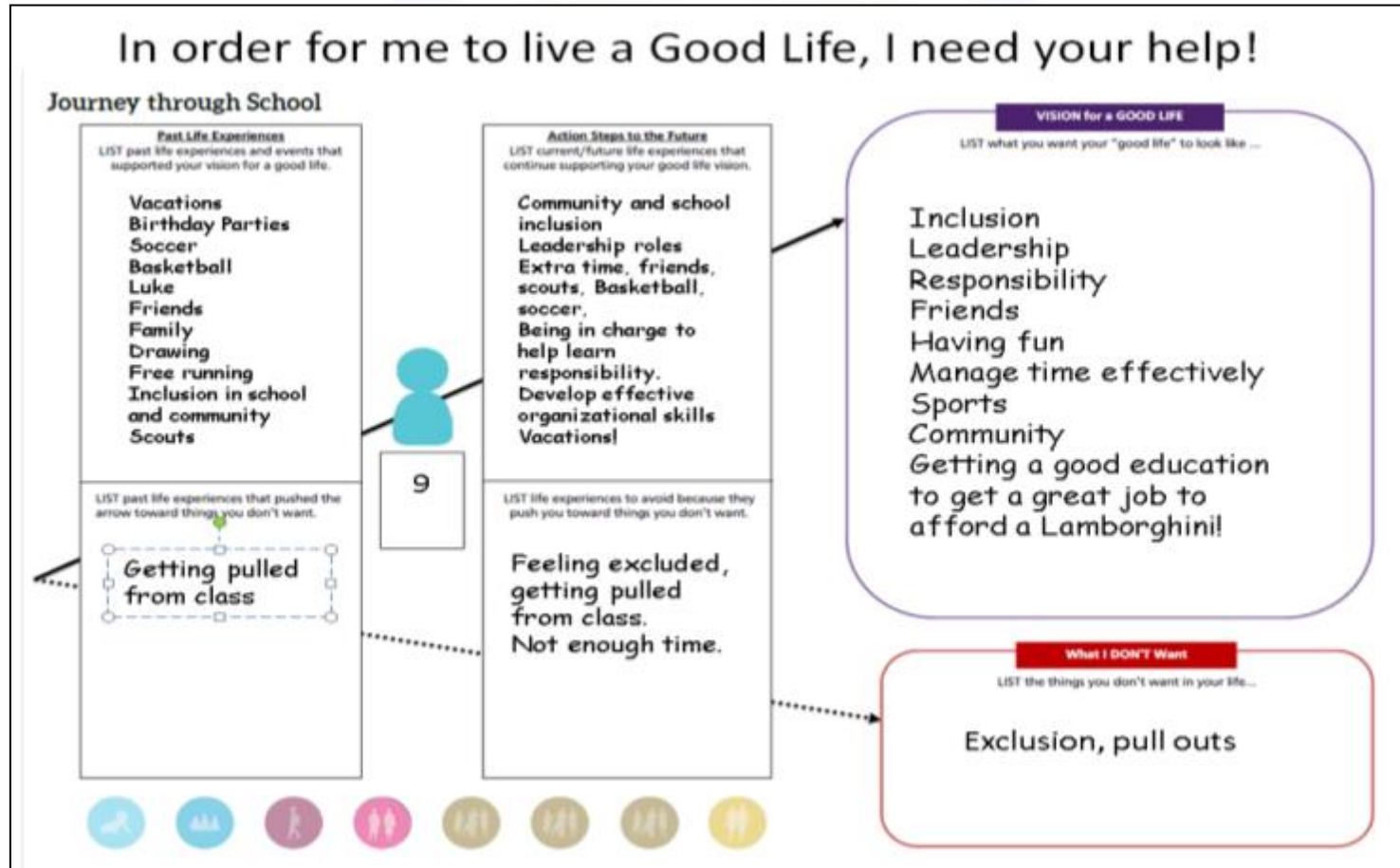
How to Best Support ME

Extra Time  
Organizers  
Gentle reminders

Adapted from The Learning Community for Person-Centered Practices and Roles, San Antonio Association, <http://rolecenteredpractices.com/one-page-profile/one-page-profile-templates/>



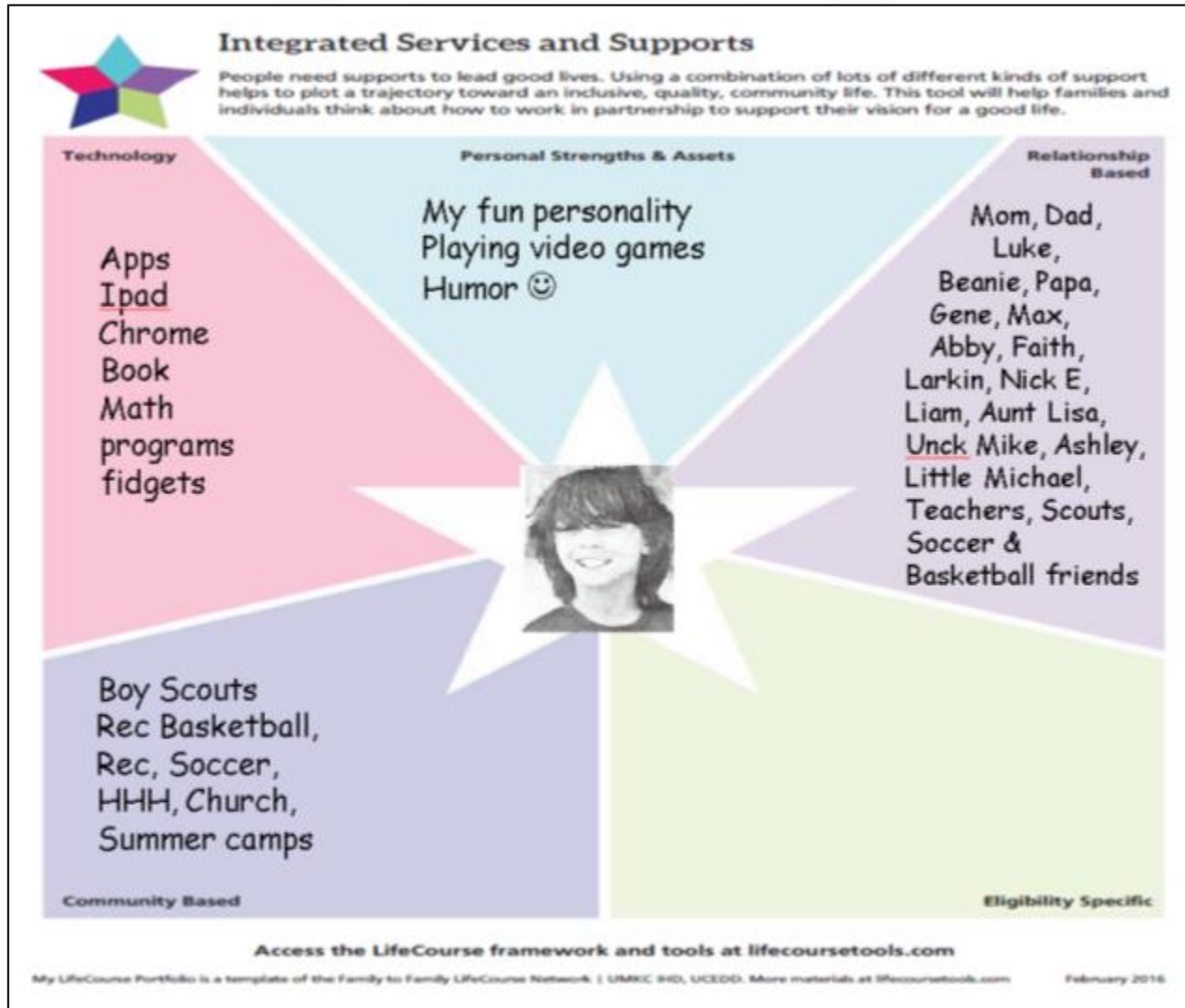
# My Vision of the Future



“On my Life Trajectory worksheet I have arrows that point up and arrows that point down. I always want my arrows to point up!”



# My Strengths



# LifeCourse Framework

## Meet Ben



He will help  
us put the  
Life Course  
Planning  
Tools  
into action





I PITY THE FOOL WHO DOESN'T LIKE



BEN'S ONE PAGE PROFILE!

### WHAT PEOPLE LIKE & ADMIRE ABOUT ME

- I like to make other people feel good and be happy.
- I have a great smile and a contagious laugh. I frequently "get the giggles"!
- I'm fun, silly and friendly!
- I am a dedicated volunteer in my community
- I am an Eagle Scout and an adult leader in scouting - been involved in service through scouting since first grade.
- I am a man about town!
- My tattoo!!
- My great hugs!
- I am willing to try new things...
- I remember songs and who sings them
- I am not usually a complainer, even though sometimes I am in pain or uncomfortable

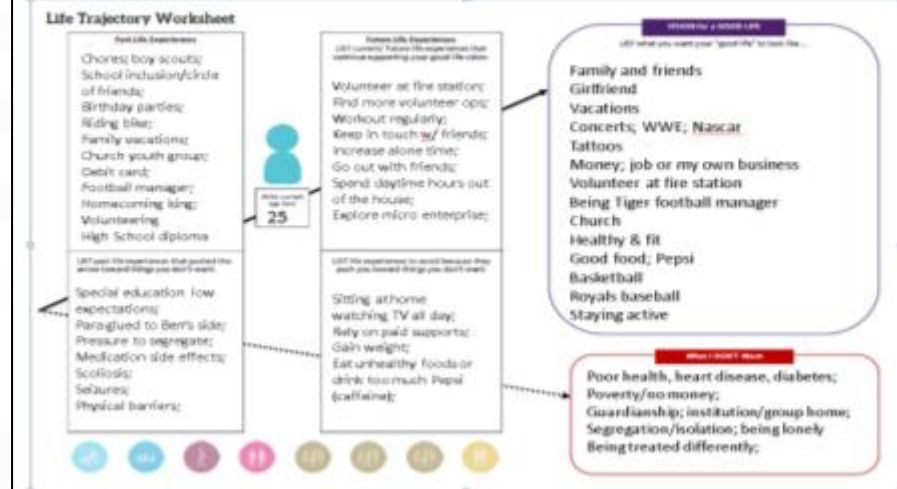
### HOW BEST TO SUPPORT ME

- I need help remembering things, like what I did or who I saw today.
- I get confused easily so I need help not getting lost or turned around when I am out and about.
- I know what times I am supposed to take my meds, but I need help getting them out and getting refills.
- I get anxious sometimes, need to be reassured that people I care about will be there for me.
- I don't like to spend time alone, but I am working on it, help me not be so anxious when I am alone for short periods of time.
- I sometimes need someone to steady me if I get off balance.
- I need to rest or extra support if I have to do a lot of walking or standing. If I am shopping, it helps if I am the cart-pusher.
- I need support keeping in touch with friends and family and practicing having good conversations.
- I'm friendly even though I may not look you in the eye at first

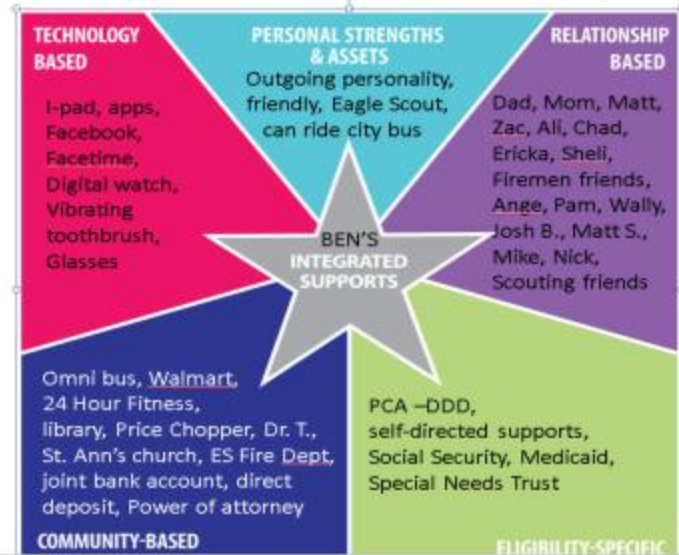
### WHAT'S IMPORTANT TO ME

- My family and friends
- Volunteering at the Fire Station, wearing my uniform and badge
- Going to the library
- Going to church
- My TV, DVR, and radio/CD player (I like to play them all at once sometimes)
- My iPad
- WWE wrestling – I love when my brother Matt takes me to live shows
- Nascar Racing (Jeff Gordon is my favorite driver)
- Going to country music concerts
- Feeling like I belong
- Being like everybody else, not being treated differently
- Getting a tattoo (already planning my next tattoo)
- Having control over my life as much as possible
- My Excelsior Springs Tigers – especially football
- Riding horses at NTRC
- Facebook friends
- Having an occasional beer with friends
- Having a purpose and being productive

## Ben's Life Trajectory



## Ben's Integrated Services and Supports Star



# LifeCourse Framework

## Long Term Support Needs – Before and After Integrated Support

Long Term Service and Support Needs

Time	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
6:45-7 AM	Parents get Ben out of bed, assist with breakfast, shower, getting dressed and ready for his day						
7:30-8 AM	Parents get Ben out of bed, assist with breakfast, shower, getting dressed and ready for his day						
8:30-9 AM	Waiver Self-Directed PCA					Parents are weekend support	
9:30-10 AM	Waiver Self-Directed PCA					Parents are weekend support	
10:30-11 AM	Waiver Self-Directed PCA					Parents are weekend support	
11:30-12 PM	Waiver Self-Directed PCA					Parents are weekend support	
12:30-1 PM	Waiver Self-Directed PCA					Parents are weekend support	
1:30-2 PM	Waiver Self-Directed PCA					Parents are weekend support	
2:30-3 PM	Waiver Self-Directed PCA					Parents are weekend support	
3:30-4 PM	Waiver Self-Directed PCA					Parents are weekend support	
4:30-5 PM	Waiver Self-Directed PCA					Parents are weekend support	
5:30-6 PM	Waiver Self-Directed PCA					Parents are weekend support	
6:30-7 PM	Mom and Dad provide all support, including meals, transportation and support for activities, etc.					Parents are weekend support	
7:30-8 PM	Mom and Dad provide all support, including meals, transportation and support for activities, etc.					Parents are weekend support	
8:30-9 PM	Mom and Dad provide all support, including meals, transportation and support for activities, etc.					Parents are weekend support	
9:30-10 PM	Mom and Dad provide all support, including meals, transportation and support for activities, etc.					Parents are weekend support	
10 PM-6 AM	Mom and Dad are overnight staff						

Long Term Service and Support Needs

Time	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
6:45-7 AM	Parents get Ben out of bed, assist with breakfast, shower, getting dressed and ready for his day						
7:30-8 AM	Parents support Ben						
8:30-9 AM	Waiver Self-Directed PCA	Volunteers Fire Dept Supported as needed by firemen	Waiver Self-Directed PCA	Volunteers Fire Dept Supported as needed by firemen	Waiver Self-Directed PCA		
9:30-10 AM							
10:30-11 AM						St. Ann's w/ mom	
11:30-12 PM						Home alone while Mom walks	
12:30-1 PM		Waiver Self-Directed PCA		Waiver Self-Directed PCA		Home alone while Mom walks	
1:30-2 PM							Home alone while Mom walks
2:30-3 PM	Volunteer at high school, supported by coaches and friends					Home alone while Mom walks	
3:30-4 PM	Volunteer at high school, supported by coaches and friends					Home alone while Mom walks	
4:30-5 PM	Volunteer at high school, supported by coaches and friends					Home alone while Mom walks	
5:30-6 PM	Mom and/or Dad prepare meal and assist as needed					Dinner w/ Roy & Carol & family	
6:30-7 PM	Home alone while Mom walks					Dinner w/ Roy & Carol & family	
7:30-8 PM	WWE with Matt		Horseback Therapy w/ Dad			Nick's Birthday with Matt and friends	
8:30-9 PM							Nick's Birthday with Matt and friends
9:30-10 PM						Nick's Birthday with Matt and friends	
10 PM-6 AM	Mom and Dad are overnight staff						



# Life Course in Action

How could you use the LifeCourse tools and thinking in your work?



Lifecoursetools.com

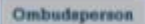
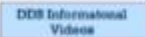




Jordan A. Scheff  
Commissioner

Office of the  
Commissioner

Acronyms



IN CASE OF A  
LIFE THREATENING  
EMERGENCY  
DIAL 911

## CHARTING the LifeCourse



### What is Charting the LifeCourse Planning?



The LifeCourse Framework was created by FAMILIES to help individuals and families of all abilities and ages develop a vision of a good life, think about what they need to know and do, identify how to find supports, and discover what it takes to live the lives they want to live. Even though it was originally created for people with disabilities, this universally-designed framework may be used by any person or family making a life plan, regardless of circumstances. LifeCourse Planning is built upon the core belief that people with disabilities and their families have the right to live, love, work, play and pursue their life aspirations just as others do in their community. [Read more](#)

### What are the benefits of using Charting the LifeCourse Planning tools?



**Personal Profile:** Planning works best when individuals and families are able to successfully communicate to others about what is most important in the person's life. Use of the One-Page Profile provides an at-a-glance way of knowing what really matters to the person, and can be taken with them as they move through services and come into contact with different people. The Personal Profile helps others to understand what to pay attention to and what works best to create positive change for the person. [Read more](#)



**Life Stage Trajectory:** LifeCourse Planning helps families to envision what matters most. The "Charting the LifeCourse Experiences and Questions Booklet" can help families to make sure that the right questions are asked on behalf of their loved one. Use of the LifeCourse "Tools for Developing a Vision" form and the "Life Stages Trajectory" form can help both the person and his or her loved ones to prioritize what is most important and to help guide decisions about current and future life experiences that will help move the person toward an inclusive, productive life in the future. [Read more](#)



**Integrated Supports:** In the past, conversations about supports for people with disabilities mainly revolved around the supports offered by the disability system. LifeCourse Planning helps individuals and families access an array of integrated supports to achieve an envisioned good life, including those that are publicly or privately funded and based upon eligibility; community supports that are available to anyone; relationship-based supports; technology, and supports that take into account the assets and strengths of the individual and family. LifeCourse Planning helps everyone realize that we ALL need an array of supports in our lives daily. [Read More](#)



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CT Charting the  
LifeCourse website  
[http://www.ct.gov/dds/  
cwp/view.asp?a=2042  
&q=591452](http://www.ct.gov/dds/cwp/view.asp?a=2042&q=591452)



# Re-evaluating current services – How many could we serve?

Type of Service	Cost per Person	Cost to Serve the Waiting List 122,870	People Served with \$5 M
ICF/MR	\$128,275 CT \$383,316	\$15,761,114,925	 39 CT 13
Non-family HCBS	\$70,133 CT \$140,199	\$8,617,241,710	 71 CT 36
Host Family	\$44,122 CT \$51,687	\$5,421,270,140	 113 CT 97
Own Family	\$25,072 CT \$30,390	\$3,080,596,640	 200 165

Data Source: Lakin, K.C. MSIS and NCI data from 4 states (1,240 Individuals)

NASDDDS

National Association of State Directors of Developmental Disabilities Services





Jordan A. Scheff  
Commissioner

Office of the  
Commissioner

Acronyms



DDS Informational  
Videos

Ombudsperson

PROJECTS



CAREER  
OPPORTUNITIES



## Employment and Day Services

[Employment First Overview](#)

[Understanding the DDS System: First Steps](#)

[Choosing and Managing your Day Service Supports](#)

### Employment Resources for:

Individuals

Families

Providers

Employers

Case Managers  
& Other DDS Staff

Services

[Frequently Asked Questions](#)

[Library](#)

Glossary, Presentations, Brochures, Videos and Helpful Links



Lara Ede is a phenomenal employee and she is a role model for all of us. She has the perfect job at the YMCA in Fairfield, CT where she works as a lifeguard and pool maintenance. She also has an additional job at the YMCA in her home town of Danbury, CT where she works as a lifeguard. The job is changing. Call 1-800-844-1000 or visit our website at [www.ct.gov/dds](#) to see the study. See how we can work together.

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