

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



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, ttegration, and inclusion in all facets of community



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



Like us on Facebook at facebook.com/supportstofamilies



Sign up for our mailing list at www.supportstofamilies.org



Follow us on Twitter at twitter.com/familieswithidd

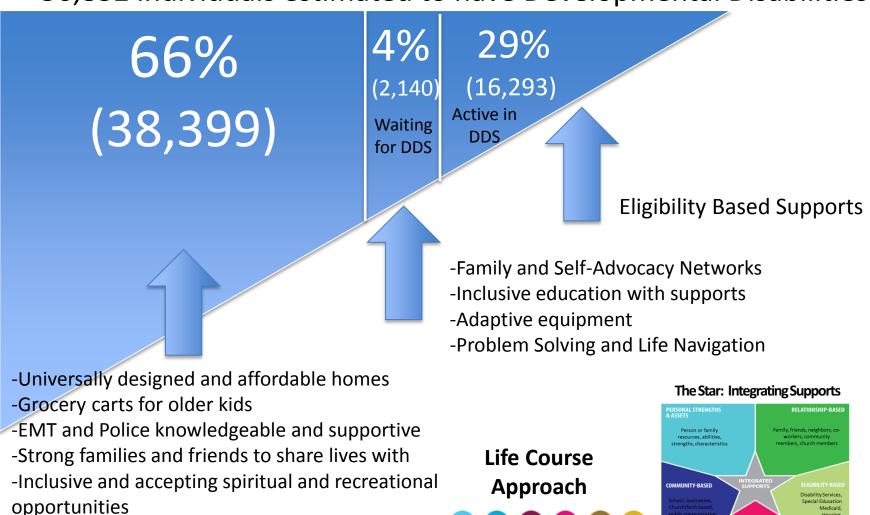
The Community of Practice (CoP) Supporting Families throughout the Lifespan is operated under a five year grant awarded to NASDDDS by the Administration on Intellectual and Developmental Disabilities (AIDD) beginning October 2012. Goal: To create a model framework for supporting families that addresses the needs of families with a family member with ID/DD across the lifespan.

Wingspread Report http://www.ct.gov/dds/cwp/v iew.asp?a=2042&Q=537862

GRANT STATES\*
CONNECTICUT
DISTRICT OF COLUMBIA
\*MISSOURI
OKLAHOMA
TENNESSEE
WASHINGTON

## **Changing Our Focus**

56,832 individuals estimated to have Developmental Disabilities\*



<sup>\*</sup>Based on 1.58% prevalence of 3.597 citizens, US Census (2014)

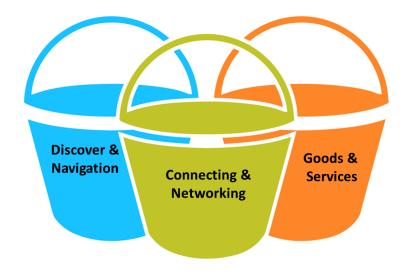


# Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities

### Discovery & Navigation:

Helping families find and understand the information they need to better support their child

## Mapping Strategies for Supporting Families Across the LifeCourse



#### **Goods & Services:**

Helping families get the supports they need for their child

#### **Connecting & Networking**

Helping families connect to other families for support & mentoring



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

#### **Partners**







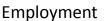






#### **Core Team Activities**







Family to Family



**Healthy Living** 



Housing



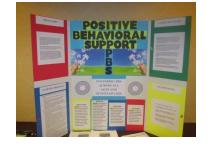
**Information Navigation** 

#### **COP COMMITTEES**



Person-Centered Planning





**Positive Behavior Support** 



**Self Directed Supports** 



**Social & Respite Supports** 



Technology



#### Year 1 & 2 Goals

Year 1

Culture Shift: Getting agencies to work from the outside in, to research best practices, & to partner with community-based groups

Year 1: Assist COP Committees to become "Community-Based Learning Communities"







Year 2

Messaging Shift: Life Course Planning is the best way to build a broad foundation of supports. We need to think about new ways of support.

Year 2: Assist COP Committees to develop marketing message



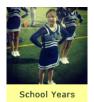


## Accomplishments

#### Life Span Approach













Improved Collaborations







**Education** Partners



Family Partners



State Agency Partners

New Support Options



New Waiver Services



**Technology** 





**PWCL** 

Supports

Peer Supports







#### **COP COMMUNITY COMMITTEES**

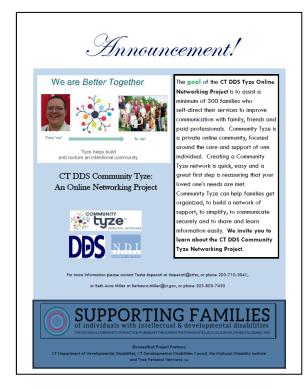
- Employment
- Family Mentoring
- Healthy Living
- Housing
- Information Dissemination
- In-Home Supports
- Person-Centered Planning
- Positive Behavior Supports
- Respite
- Self Directed Supports
- Social/Recreation

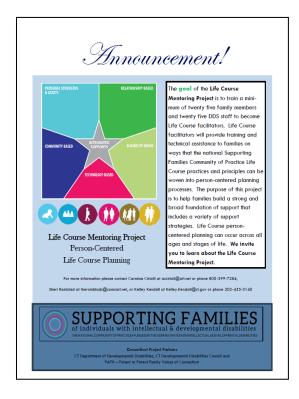


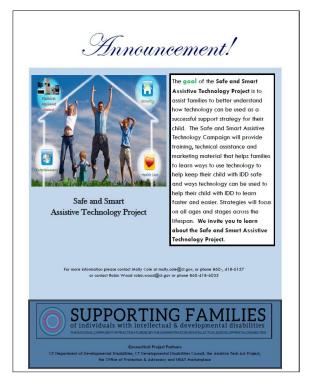
Self Advocates, Families, Providers, DDS Staff, Other State Agency Staff and Community Members All Working Together



### What's Next? Year 3 Goals

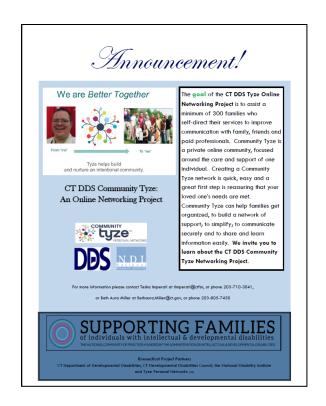








### What's Next? Year 3 Goal





**Discovery and Navigation Activities** 



### **Tyze**

### We are Better Together



Tyze helps build and nurture an intentional community.

Goal: 100 self-direction families in each region use Tyze to enhance their network of support.



# Tyze Online Networking



https://www.youtube.com/watch?v=WppiMkaeNsA

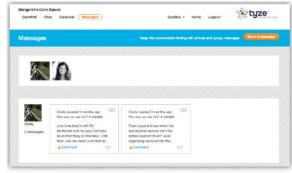


#### **Discovery and Navigation Activities**



# Tyze Online Networking

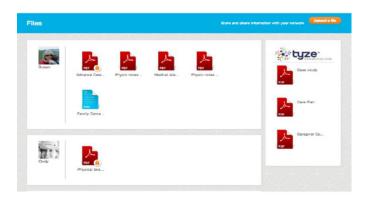






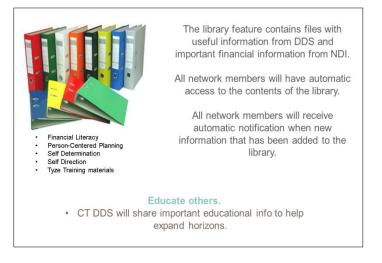
#### Send Messages.

 Send information to all network members at once, or decide who gets the message.



#### Store files.

 Share documents and store important info in a secul vault. You decide who has access to each file.





#### **Benefits of Tyze**

**Convenience** Update everyone at once.

**Empowerment** Increased feelings of belonging = better health outcomes.

**Share the Care** Lifts some of the burden of care off of the primary caregiver.

All information in One Safe Space Family, friends and professionals caregivers have one central hub to store information, sensitive files and communication updates.





**Discovery and Navigation Activities** 

#### **Starting A Tyze Network**



Basic Requirements

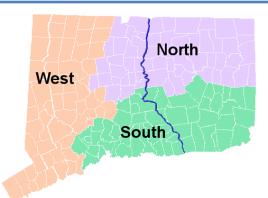
- Is the Tyze network being developed for someone who is eligible to receive support from DDS?
- Does the person managing the Tyze network (concierge) have access to a computer and an email address?

Getting in Touch

- Where does the Tyze focus person live? Which CT DDS region?
- Send an email to the DDS Self Determination Director in your area and request that you get connected to Tyze.

Starting your Tyze Network

- The Regional Self Determination Director will send an invitation to start a network and Quickstart information to the interested party.
- The network concierge creates the network and invites others to join the network.



South Gregory McMahon, <u>gregory.mcmahon@ct.gov</u>
North Amy Blazawski, <u>amy.blazawski@ct.gov</u>
West BethAura Miller, bethaura.miller@ct.gov

### **Help Build Networks**





Share Information about Tyze with a Friend!



**Discovery and Navigation Activities** 



#### **Facebook**





**Discovery and Navigation Activities** 



# Other Discovery & Navigation Activities



Caregivers take care of themselves and they feel supported by others.



## Discovery & Navigation Contacts

Want more information about Discovery & Navigation activities?



#### Please contact:

Tesha Imperati at <a href="mailto:timperati@ctfsn.org">timperati@ctfsn.org</a>, or call 203-710-3041

Beth Aura Miller at <a href="mailto:bethaura.miller@ct.gov">bethaura.miller@ct.gov</a>, or call 203-806-7430









Planning Across the Life Span

In a Person-Centered Way

Goal: 25 Family Members & 25 DDS Staff Trained to be Life Course/PCP Mentors



### Making the Connection Between Life Course Planning and Person-Centered Planning

Person-Centered Planning occurs across the lifespan at any age or any stage













Life Course Planning provides specific information about things to consider at each developmental stage.



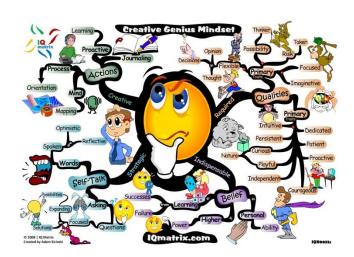
http://supportstofamilies.org/resources/lifecourse-toolkit/





### Making the Connection Between Life Course Planning and Person-Centered Planning

All person-centered planning processes are designed to enhance creative thinking.



Life Course planning provides more detailed information about a variety of support strategies that can be considered.





### Making the Connection Between Life Course Planning and Person-Centered Planning





Person-Centered planning processes emphasize

helping the focus person to communicate his or her wants and needs

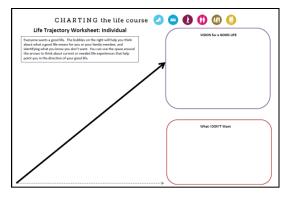
AND helping the person to include family, friends and other important people in the planning process. Life Course Planning emphasizes family planning AND person-centered planninh.

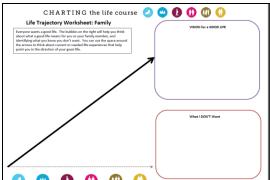


### Making the Connection Between Life Course Planning and Person-Centered Planning









Life Course Planning helps ensure that the individual and their family are on the same trajectory.

### FAMILY MATTERS





#### **Making the Connection Between Life Course Planning and Person-Centered Planning**

#### Types of Person-Centered Planning



What process is right for you?

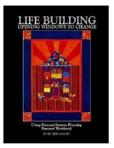


**PATH** 



A GOOD LIFE

MAPS



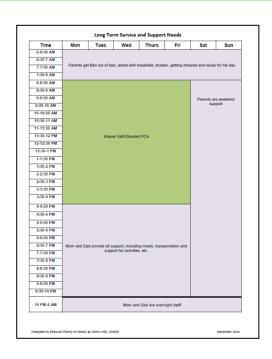


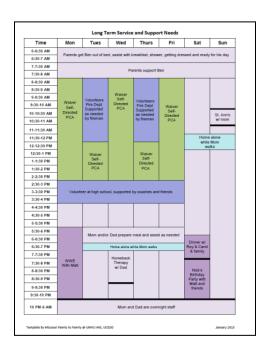
All planning processes have different strengths and weaknesses. It's important to select the right tool for your needs.





### Making the Connection Between Life Course Planning and Person-Centered Planning





All Planning Processes Should Result in a Better Life!



### Making the Connection Between Life Course Planning and Person-Centered Planning

Life Course
Person-Centered
Planning
is an
Ongoing Process







**Results Occur** 



And
Continuous Improvement
is Expected



# Family-to-Family Connections





Growing stronger through family-to-family connections



## Other Family-to Family Connection Activities

#### **College of Direct Support**



#### **Siblings**





# Family-to Family Contacts

Want more information about Family-to Family Connection activities?

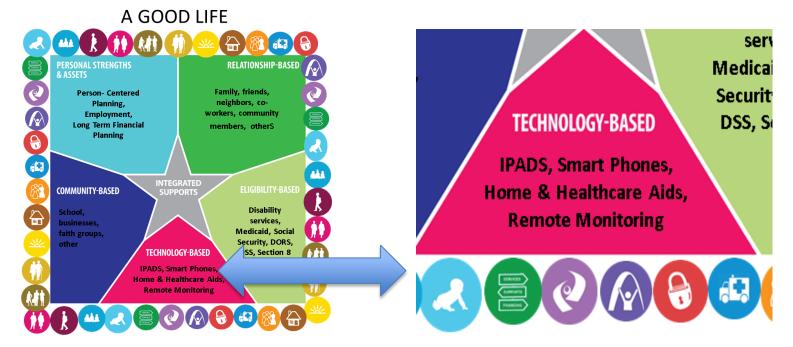


#### Please contact:

Carmina Cirioli at ccirioli@pathct.org, or call 203-234-9554.

Sheri Romblad at <a href="mailto:theromblads@comcast.net">theromblads@comcast.net</a>
Kelly Kendall at <a href="mailto:kelly.kendall@ct.gov">kelly.kendall@ct.gov</a>, or call 203-455-3140



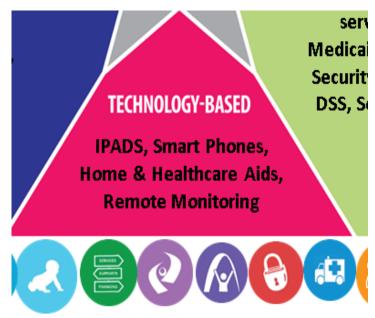


#### **Outcome**

Promote the use of technology and document success stories of people with IDD or autism who are using technology to create a good life.







http://wtnh.com/2014/01/27/high-tech-homes-for-the-disabled/





Using Technology to Create A Good Life
Through Enhanced Communication

**Carly's Story** 





Low tech

Using Technology to Create A Good Life
Through Enhanced Communication



????? What ????? communication technology is right for you?



Old Tech



**New Tech** 



High tech



**Using Technology to Improve Team Communication and Supervision** 







Monitoring

Flexible Communication



**Using Technology to Improve Team Communication and Supervision** 



Low Tech

What team communication and supervision technology is right for you?



Old Tech



High Tech



**New Tech** 



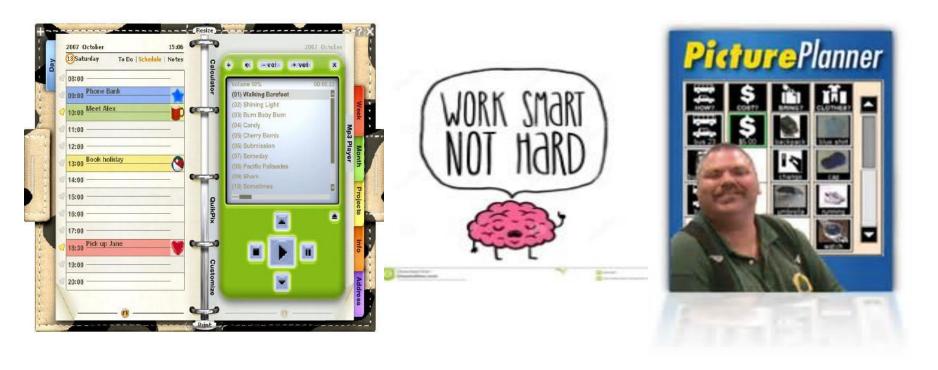
**Using Technology to Enhance Learning and Organization** 



**Chris's Story** 



Using Technology to Enhance Learning and Organization



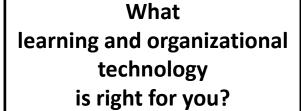
Organization, Learning, Reading, Math, Time Management



**Using Technology to Enhance Learning and Organization** 



Low Tech





Old Tech



High Tech



**New Tech** 

Organization, Learning, Reading, Math, Time Management



Using Technology at Home, School, Work and in the Community



What technology is right for you in your life?











# Assessment, Funding, Maintenance of Technology

Assessment

- Do I need technology?
- What technology is best for me?

**Funding** 

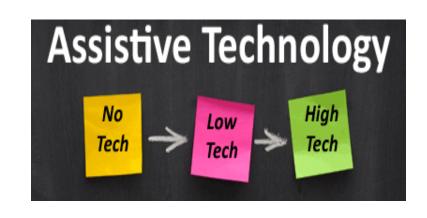
- What resources do I have to pay for technology?
- What other funding resources are available to help me pay for the technology I need?

Maintenance

- How can I be safe using technology?
- How do I keep my technology secure and well maintained?
- How do I keep my technology updated so that it remains useful?



Want more information about Assistive Technology activities?



**Please contact:** 

Arlene Lugo at Arlene.Lugo@ct.gov, or call 860-424-4881

Robin Wood at robin.wood@ct.gov, or call 860-418-6035



### **CCH Out-of-Home Respite**



http://www.ct.gov/dds/cwp/view.asp?a=3&q=527308



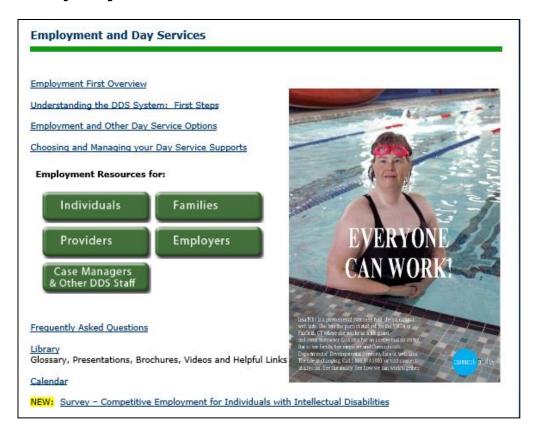
Goal: CCH Homes are used for out of home respite opportunities for families.

Goal: Families make informed decisions about CCH Homes as a supported living option for their son or daughter.

For more information please contact Robin.Wood@ct.gov or call 860-418-6035.



### **Employment**





For more information please contact Amy Blazawski at <a href="mailto:amy.blazawski@ct.gov">amy.blazawski@ct.gov</a>, or call 860-263-2449

ODEP EMPLOYER ENGAGEMENT

http://www.ct.gov/dds/cwp/view.asp?q=492514



# Healthy Living Newsletter



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

#### HEALTHY LIVING TACKLING OBESITY

#### What is Obesity?

Obesity is defined by the Center for Disease Control as both labels for ranges of weight that are greater than what is generally considered healthy for a given height. The terms also identify ranges of weight that have been shown to increase the likelihood of certain disease and other health problems. Obesity is a medical condition that is rapidly growing in Connecticut and across the nation. The estimated annual medical cost of obesity in the U.S. was 5147 billion in 2008 U.S. doilars; the medical costs for people who are obese were \$1,429 higher than those of normal weight.

#### OBESITY and DISABILITY:

For individuals with disabilities the prevalence of obesity is even more concerning. Obesity (41.6%) and extreme obesity (9.3%) prevalence among those with disabilities were significantly higher than they were among those without disabilities (29.2% and 3.9%, respectively). People with disabilities at all weight categories are significantly more likely to report being told they have hypertension, high cholesterol, or diabetes and to have been prescribed antihypertensive and lipid-lowering medications.



#### CHILDREN AND ADOLESCENTS

A child or adoles cent 2 to 19 years, is considered obes effihere body mass index (BMI) is at or above the \$5.50 paggentile. Obes ity is just as much a health problem amongst youth with IDD as in the general population and for some disorders the rate of obesity is even greater. Obesity rates for children without billities are 98% higher than for children without disabilities. Adoles cents with Autism and Down syndrome were 2-3 times more likely to be obes than adoles cents in the general population. Studies of children with ID also generally report higher levels of sedentary behavior and greater use of electronic media, compared with tyoically developing hildren.

Best Practice Recommendations for combating Child and Adolescent Obesity and IDD.

- 1. Behavior modification techniques to increase food acceptance has shown some success
- A structured physical activity routines hould be in place for the child and family. Parents and Care
  providers often control the environments of they need to be engaged and supported in healthy living
  propries.
- The use of motivational strategies, child direction in activities, and incremental increæs in workload all
  appear promising approaches, yet require further evaluation.
- 4. Ensures chool wellness programs have considered the uniqueneeds of the child's disability. Provide training for teachers and other school personnel on how to include children with disabilities in physical activity programs, recess, and active learning. Include healthy eating/nutrition goals and physical activity goals in Individualized Education Plans (IEPs).
- 5. GET MOVING, GET MOVING!!!

1



For more information please contact <u>Lakisha.Hyatt@ct.gov</u>, or call 860-418-6083





### **In Home Supports**



#### Family Support Staff Training

An educational series for staff supporting individuals living with their family.

Where: CT Behavioral Health Partnership, 500 Enterprise Drive, Rocky Hill, CT 06067 Third Floor, Suite 3D (860) 263-2000

Registration: Contact Diane Gill at dianne.gill@ct.gov or 860-418-6091. Please register by August 14, 2015. Space is limited. Trainees are encouraged to attend all 6 sessions but it is not mandatory.

#### Module 1 Presenter: Molly Cole

Date: September 3, 2015 Time:1:00-4:30pm

In-Home Support Staff & Values: Direct Support Staff who work independently in family homes and in the community must be able to adhere to a high standard of professionalism. This module describes the ethics and values staff are expected to understand and implement in their daily role as a family Direct Support Professional.

#### Module 2 Presenters: Robin Wood & Scott Wolfe Date: September 10, 2015 Time:1:00-4:30pm

Person Centered and Family-Centered Supports: Working with families is different than working with other types of support teams. This module describes the knowledge and skills that staff need to successfully work in family homes and in their local communities. Trainees will also learn ways to help the family obtain other types of supports that may be needed: how to expand personal networks, use of assistive technology, how to find community supports and how to navigate other eligibility supports.

#### Module 3 Presenter: BethAura Miller

Date: September 17, 2015 Time:1:00-4:30pm

Professional Judgment: Making Wise Decisions Quickly! Staff working in family homes and in the family's local community often need to make quick, on the-spot decisions that require good judgment. This module assists staff in understanding how personal values and biases impact judgment. Through this module staff will also learn strategies to enhance their professional judgment skills and to successfully apply the concept of "dignity of risk" in their daily work.

#### Module 4 Presenter: Lakisha Hyatt

Date: October 1, 2015 Time:1:00-4:30p

Health and Wellness: Never Assume! It is important staff are alert to health issues that may be impacting the individual they support. It cannot be assumed that the family is always aware of, or is addressing, important medical needs of the person. This module assists staff to recognize Signs and Symptoms of illness and to know how to help the individual and family use positive Wellness Practices in their daily routines.

#### Module 5 Presenters: Peter Tolisano & Pam Lyle Date: October 8, 2015 Time: 1:00-4:30pm

Positive Behavior Support: Collaborating with Families to Support the Use of Positive New Behavior. Families often need support to help manage their family member's behavior. This module assists staff to coach families on ways to incorporate Positive Behavior Support strategies into the family's daily routines.

Module 6 Presenter: Tacie Lowe, Richard Joseph and Damian Parker Date: October 15, 2015

Promoting Independence: Direct Support Professionals as Educators. Families often need assistance to teach their family member how to be more independent at home and in the community. This module assists staff to develop the skills to know what to teach and how to teach independent living skills to the individuals they support.

The In-Home Supports Committee is piloting a training curriculum for direct support staff who are new to providing supports in family homes or in community settings.

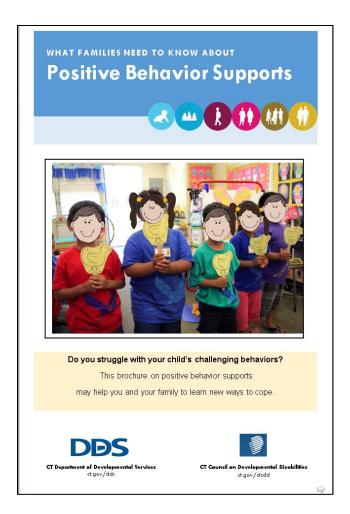


For more information please contact Lorraine Gendron at Lorraine.Gendron@ct.gov, or call 203-806-8726





### **Positive Behavior Supports**



For more information please contact Peter.Tolisano@ct.gov or call 860-418-6086





### **Social Opportunities**

- Data has been collected from the social/respite surveys completed by individuals and families.
- Life skills and social opportunities were identified as the greatest need.



Increase the utilization of statewide respite centers for individuals to work on social and residential life skills with individualized goals of (1) increased independence in activities of daily living and (2) presence and participation in community life.



DDS North Region Pilot Program: develop modified curriculum, secure community assistance, register participants for classes beginning February 2016

For more information please contact:

donna.haley@ct.gov 860-331-2042 elisa.marcoux@ct.gov 860-331-2039



# What We've Learned

Change takes time



We MUST listen to and include families in all that we do



People need time to adapt



It's easy to revert to old behavior



have more to offer than we think



## **Thank You!**

