Initiative Implementation for Improved Transition Outcomes
Project Goal
To build capacity through a community of practice across and within States to create policies, practices and systems to better assist and support families that include a member with I/DD across the lifespan.

Project Outcome
- State and national consensus on a national framework and agenda for improving support for families with members with I/DD.
- Enhanced national and state policies, practices, and sustainable systems that result in improved supports to families.
- Enhanced capacity of states to replicate and sustain exemplary practices to support families and systems.
Funded in 2012 by National Partners
Guiding Principles of the Supporting Families LifeCourse Framework
Current Reality of Services and Supports

- Expectations, Values, Culture
- Demand for Services
- Federal Budget
- Federal Policy
- Capacity of Work Force
Services and Supports are Evolving

Integrated Services and Supports within context of person, family and community enables us to serve The ALL

Traditional Disability Services wrap supports around a person
Type of Change that is Needed

Transitional Change

- “Retooling” the system and its practices to fit the new model
- Mergers, consolidations, reorganizations, revising systematic payment structures,
- Creating new services, processes, systems and products to replace the traditional one

Transformation Change

- Fundamental reordering of thinking, beliefs, culture, relationships, and behavior
- Turns assumptions inside out and disrupts familiar rituals and structures
- Rejects command and control relationships in favor of co-creative partnerships

Creating Blue Space, Hanns Meissner, 2013
Core Belief:
All people and their families have the right to live, love, work, play and pursue their life aspirations in their community.
Applying the Public Health Framework to Long Term Services and Supports

Medical System

Flu Shot

Hand Washing
Anti-Bacterial Soap
1 in 4 Persons with I/DD Receive Formal State DD Services

4.7 Million people with developmental disabilities

75% National % Receiving State DD Services

25%

** Based on national definition of developmental disability with a prevalence rate of 1.49%
Supports that focus on Life Experiences

Birth----Early Child----School----Transition----Adulthood-------Aging

“Anticipatory Guidance”
Comprehensive, Integrated & Coordinated Systems Across Life Domains & Stages

- Pediatrician, Families and Friends, Faith based
- IDEA Part C, Parents as Teachers, Health, Headstart
- School, Special Education, Health, Recreation
- Vocational Rehab, Health, Employment, College, Military
- Disability Services, Health, Housing, College, Careers
- Retirement, Aging System, Health

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LifeCourse Tools

LifeCourse Educational Materials

Lifecoursetools.com
Information and Referral

- Ordered by LifeCourse domains
- Meets reporting requirements for F2F and UCEDD
- Customized to include most frequent referrals
- Can help guide conversations
- Use in concert with LifeCourse portfolio
Using the LifeCourse Portfolio during Intake

- Explain framework within context of intake call
  - Some requestors are very open to thinking outside the box and ready to discover the LifeCourse framework
  - Others are hesitant to dream but respond well and are curious about the tools

Integrated Services and Supports

- Enter information gained from conversation
- Briefly explain supports star
- Attach draft to follow up email with link to LifeCourseTools.com
Using the LifeCourse Portfolio during Intake

One page profile
- Enter information gained from conversation
- Briefly explain Portfolio
- Attach draft to follow up email

Life Trajectory Worksheet
- Enter information gained from conversation
- Briefly explain trajectory
- Attach draft to follow up email
Life Trajectory Worksheet

**Past Life Experiences**
LIST past life experiences and events that supported your vision for a good life.
- Knows and uses some sign language

**Future Life Experiences**
LIST current/future life experiences that continue supporting your good life vision.
- Functional Behavior Assessment
- Alternatives to negative behaviors
- Picture Exchange System
- Early Childhood Special Education

**VISION for a GOOD LIFE**
LIST what you want your "good life" to look like...
- School ready
- Have friends
- Be comfortable in the community

**What I DON’T Want**
LIST the things you don’t want in your life...
- Aggressive behaviors

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About me......

• Mom to Peyton, Conner and Lilly
• UMKC IHD
• AMCHP Family Delegate
• MO Family Partner with Bureau of Special Healthcare Needs
• Trainings:
  • Partners in Policymaking Graduate
  • SOS Trained Peer Mentor
  • MPACT Trained Parent Mentor
  • Tools of Choice
  • Family Leadership Certificate Series
  • Family to Family Volunteer
Peyton’s Plan for Inclusion in School

Using the LifeCourse Tools to Transform the Way the School Thinks about Inclusion for Peyton
Peyton's Good Life Trajectory

Friends
Family
Productive Employment
Happiness
Living Independently
Meaningful Relationships
Love
Community Involvement & Inclusion

Sheltered Workshop
Group Home
Isolation
Dependency on paid supports
Lonely
Unhappy, unproductive, bored
Poverty
Peyton’s Integrated Supports

CHARTING the life course

Integrated Services and Supports

Personal Strengths & Assets
- Sociable
- Helpful
- Strong
- Loves to Run & Play
- Wants to Communicate
- Silly/Wants to make others laugh
- Reads others emotions well
- Routine oriented
- Imaginative

Relationship Based
- Mom
- Conner
- Scott
- Grandparents
- Dad & Kristy
- Perry

Peyton Bell

Long Term Support Needs

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<th>MON</th>
<th>TUES</th>
<th>WED</th>
<th>THURS</th>
<th>FRI</th>
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Peyton Bell

My Good Life

Basketball
C. U. A. R. H. T. S.
Cheerleaders
Being Healthy

Swimming
Woody and Big Bird

self-leading
IEP
Peyton Current School Year

Integrated Services and Supports

People need supports to lead good lives. Using a combination of lots of different kinds of support helps to plot a trajectory toward an inclusive, quality, community life. This tool will help families and individuals think about how to work in partnership to support their vision for a good life.

Technology
- IPad
- DVD Player
- iPhone
- Computer
- TV
- Wii
- Nintendo
- Microwave
- Radio
- Toaster
- Vacuum

Personal Strengths & Assets
- Funny
- Good Dancer
- Determined
- Routine-Oriented
- Playful
- Helpful
- Strong
- Reads emotions well

Relationships
- Based
- Dad
- Mom
- Kristy
- Scott
- Susan
- Dale
- Grandpa Ralph
- Grandma Kathy
- Conner
- Lilly
- Perry
- Abi
- MamMaw
- PapPaw
- Grandpa
- Granny
- Trey
- Elizabeth

My LifeCourse Portfolio

Peyton’s ONE-PAGE PROFILE

What people like & admire about me
- Funny
- Determined
- Good Dancer
- Imaginative
- Good Basketball Player
- Compassionate
- Forgiving

What’s important to ME
- Movies
- Big Bird & Woody Dolls
- Wii
- Basketball
- Football
- Playing Sports
- Family
- Friends (Abi, Trey, Logan)
- Being included
- Joking

How to best support ME
- Give Clear Expectations
- Keep the mood light/joking with me
- Give lots of praise and encouragement
- Respect my space
- Let me approach you
- Give me time to warm up to you/new situations
- Prepare me for transitions
- Using “reverse psychology” can often convince me to cooperate in difficult situations

Access the LifeCourse framework and tools at lifecoursetools.com

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Peyton Current School Year

Life Trajectory Worksheet

Past Life Experiences
LIST past life experiences and events that supported your vision for a good life.
- Being included in areas that work for me
- Being given time to warm up to people/situations
- Trying different ways to help me learn
- People having patience giving me time to communicate in my own way
- Riding the Reg. Ed. bus with my brother and now on my own
- Participating in gen. ed. classes and after school programs
- Giving me chores so I can feel successful and a part of a team
- Immediate consequences/rewards for my actions
- Giving me choice over things in my life
- Learning how to take care of my own needs

LIST past life experiences that pushed the arrow toward things you don’t want.
- Rejection
- Low expectations
- No accountability
- Riding Spec. Ed Bus
- Learned Helplessness
- My opinions/wants not being valued
- Not being part of decisions that affect me
- Not being given enough time to warm up to a situation before it was abandoned
- Always having an adult/caregiver looking over my shoulder
- Not being allowed to take risks in order to learn

Future Life Experiences
LIST current/future life experiences that continue supporting your good life vision.

Friends
Watching movies
Playing sports, especially basketball
Having a routine
Knowing what’s expected of me
Being given time to play with my favorite toys
Feeling like I have accomplished something
Being treated like my peers/being one of the group
Having people value my conversation

Stable and gainful employment
Independence
Real choice in living situations
Happiness
Good Health
Ability to negotiate transportation within my community
Knowing how to stay safe
Loving relationship/my own family
Seeing my family

What I DON’T Want
LIST the things you don’t want in your life...
- Unfulfilling/Underpaid employment/sheltered workshop
- Group home/no choice in living
- Predetermined schedules/no choice
- Unhealthy/sickness
- Dependence on paid support
- Poverty
- Loneliness
- Boredom
- Being controlled/choices made for me
Conner’s Portfolio
Conner’s Trajectory

Journey through School

Past Life Experiences:
- LIST past life experiences and events that supported your vision for a good life.
- Inclusion in Gen Ed Learning
- Education of support staff and students to provide understanding
- Participation in community events
- Exposure to various activities
- Riding the Reg Ed bus
- Providing schedules and set expectations.
- LIST past life experiences that pushed the arrow toward things you don’t want.
  - Seclusion in special ed classrooms
  - Riding the special education bus
  - Being punished for behaviors
  - Making excuses for behaviors.

Action Steps to the Future:
- LIST current/future life experiences that continue supporting your good life vision.
- Write current age, grade, or school year here 2016-17 5th grade
- LIST life experiences to avoid because they push you toward things you don’t want.

VISION for a GOOD LIFE

LIST what you want your “good life” to look like...

Have a job (Gainfully employed)
Make friends (Have quality relationships)
Make money (Be financially independent)
Have a girlfriend (Find love)
Have kids
Live on my own (independently)
Go bowling (Participate in community)
Build things in the forest next to New York City (Have hobbies he enjoys)

What I DON’T Want

LIST the things you don’t want in your life...

No friends (unhealthy relationships)
Get fired (unstable employment)
No girlfriend (isolation)
No kids
My LifeCourse School Portfolio

Conner’s ONE-PAGE PROFILE

What people like & admire about me

- I like to laugh
- I’m inventive and very creative
- I like to go places
- I want to learn about things
- I love my sister
- I’m a very kind person
- I’m honest
- I’m very attentive to details

What’s Important to ME

- Toy cars
- Racing video games
- Play time
- LEGO
- Lincoln Logs
- Stuffed animals
- Drawing
- Cheese or pepperoni pizza
- Pretzels
- Goldfish
- Swingling
- Building things
- Kickball
- Basketball
- Baseball
- Soccer
- Dodgeball
- Cats
- The Library
- Computer

How to Best Support ME

- Get me to a safe, quiet place
- Give me a short explanation of the situation and resolutions then walk away
- Listen when I say I’ve had enough
- Let me take a break and come back when I’m calm
- Have me write/type a letter when I’m upset
- Give me clear expectations
Impact on All Family Members
Contact Information

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Susan Bird
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Using the LifeCourse Framework to Engage Families & Transform Systems

TASH: Gateway to Equity Initiative Implementation for Improved Transition Outcomes
November 30, 2016
About Us

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D.C. Project Action!
Co-Vice President

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DC Department on Disability Services
Sibling & Family Planning Together Trainer
alison.whyte@dc.gov
DC Supporting Families CoP
Core Team Members

[Logos of various organizations]
Capacity building and braiding of initiatives

2012-2013
- Launched PCT Initiative
- PCT Training, TA & coaching
- Changed employee orientation
- Applied for Supporting Families Community of Practice

2013-2014
- PCT trainers
- PCT Phase II Training: PCT tools in practice
- Trained SF CoP in PCT
- Introduced stipend authority

2014-2015
- Changes to waiver, regulations, & ISP
- Families & Self-Advocates become PCT trainers
- Providers become PCOs
- Family Support Council
- NWD Planning Grant
DC Supporting Families CoP: Not Just a Grant!

Dedicated group coming together to design a system that supports people with intellectual and developmental disabilities and their families across the lifespan.
Comprehensive Supports for People with DD

- Self-Determination & Supported Decision Making
- Peer Support
- Person and Family Centered Supports
- Coordinated Lifespan Supports

Resulting priorities for systems change & sustainability in D.C.

Principles embraced by NWD partners for LTSS system at large
Person-Centered Planning starting at intake
  – *Like and Admire* to determine strengths
  – *Working/ Not Working* to identify LTSS needs
  – *Trajectory* to identify goals
  – *Integrated Supports Star* to match to supports
  – Start eligibility for public LTSS, only if needed

Aligns with Initial ISP at DDA

Will have common elements that map to service planning across LTSS (No Wrong Door)
Pathway to Employment

Assessment & Exploration

Training & Education

Active Job Search

Job Retention

Job Advancement
CHARTING the life course
Life Trajectory Worksheet: Family Focus on Employment
Families discussed, what works to support employment?
Believe, Encourage, Be Creative

VISION for the Life I WANT
- Employment – a good job that creates meaning and economic self-sufficiency
- Independence – doing as many things independently as possible and as desired
- Self-determination – making one’s own decisions
- To have a mentor - someone to look up to who understands each person’s experience.
- To contribute to other family members

What I DON’T Want
- To be discouraged by professionals
- To give up hope
- Boredom
- To not have a social network of friends or employment contacts
- Negativity and low expectations

-Being a part of the discovery process – communicate to professionals what a person’s interests and skills are.
-Find things in the community to stay busy – volunteer as a family.
-Staying connected – have a social network, talk with people you know about jobs.
-Learn about disability rights and parent rights.
-Exposure: bring children to work, go to different places of business and talk about work, etc.
-Advocating at school meetings to focus on employment.
-Talking about money.
-Teaching interview skills.
-Asking, “what do you want to be when you grow up?”
-Giving ALL children chores, including those with disabilities.
-Reading to children from an early age.
PCT & LifeCourse in Service Planning

- PCT & LifeCourse tools at ISP Pre-Planning
- Discovery *Positive Personal Profiles*
- Use *Trajectory* to talk about vision for a good life and employment
- Use *Integrated Support Star* to identify supports to help achieve goals and meet LTSS needs
Collaboration

• DC Secondary Transition Community of Practice is a city wide cross-section of stakeholders who come together to support DC youth with disabilities as they transition into a self-directed life.

• Reignited Effort: Exploration of supporting families to improve their engagement throughout the transition process.
DC Annual Secondary Transition Forum-Parent Session

- Parent-Led Forum - Questions & Answers: 16 panelists with representations from government agencies, local organizations and key educational representatives
- What is Secondary Transition?
- Where does a Parent Start? ... Introduction of Support Star as a Transition Tool
DC Secondary Transition Meeting - Parent/Family Engagement

- Stakeholder representation-school system, local advocacy groups, community organizations, parents, etc.
- Introduction of DC CoP Supporting Families
- Importance of a Vision of a Good Life-Trajectory Tool
- Small Group Exercise – Integrated Support Star
DC Secondary Transition Meeting - Parent/Family Engagement

How are you supporting the youth and their families in each one of the points of the integrated support star?
Meet Steven Powe

- Advocate
- Artist
- Board Member
- Brother and Son
- Employee
- Friend
- Trainer

Picture of Steven Powe in a meeting
Steven’s Story

Grew up at home with his family

Lived with his family for more than 50 years

Lives in his own apartment with drop in supports
Steven’s trajectory using the life course

**VISION for a GOOD LIFE**
- Promotion at work
- Own a book store
- Own a home
- Get married
- Advocacy leader
- Friends and quiet time

**What I DON'T Want**
- People treating me like a child/ lack of respect
- No personal space
- Being separated from family
Thank you for attending! If you’d like to learn more please visit:

- DC Supporting Families Community of Practice
Thank you!!

Questions?
Supporting Families in TN

Emma Shouse
Director of Communications
TN Council on Developmental Disabilities
About me ...

Communications Director at TN Council on Developmental Disabilities

Lead Council staff for Supporting Families

Sibling – twin 21-yr old brothers, 1 with autism
  Very involved in TN’s sibling support network, TABS (TN Adult Brothers and Sisters)
TN CoP Team Focus Areas

• Sharing information about Lifecourse framework & tools with individuals and families

• Building capacity among state agency and community partners to understand & use Lifecourse concepts with those in “formal services” and those not receiving services (“the 100%”)

• Creating & strengthening partnerships to reach families not already connected to disability service system
Benefit of DD Council Role

- Key role of Councils – create structural change with long-term impact
- Statewide reach
- Disability across the lifespan
- Involving individuals and families in policy
- Located in state government but independent of disability service system
- Building public/private partnerships is part of all our work
Supporting Families Lunch & Learns

Targeted towards state agency stakeholders

Facilitates cross-agency discussion about improving supports to families

Topics -

• Peer supports/mentoring
• Information & service system navigation for families
• Technology supports
• Involving families in planning, policy, program evaluation
Sharing LifeCourse framework & tools

- Training professionals in LifeCourse thinking
- Statewide special education conference
- Arc TN Summit for Supporting Families (Aging & Disability)
- DD agency’s Planning and Policy Council
- Undergrad/grad students in disability-related fields
- DD agency case managers, intake staff & support brokers
- State Leadership Academy for Excellence in Disability Services (Dec. 2016)
Sharing LifeCourse framework & tools

Training families & self-advocates
- TN Disability MegaConference
- TN Family Coalitions on employment
- DD Council members, Partners in Policymaking
- TennesseeWorks Employment Summit
- + lots of other family-focused events (transition fairs, disability-specific conferences, etc.)
Sharing LifeCourse framework & tools

Information dissemination

• Supporting Families e-newsletter, other agencies’ newsletters

• Council magazine, website

• Resource folders

• Supporting Families Kindred Stories
Connecting to Community Partners that Support Families

• Presented LifeCourse tools to disability community organizations, asked for feedback

• Discussed their staff’s information/training needs, information/training needs for families they serve

  Answers included ...

  • How families can support independence, self-advocacy
  • Self-care and support for caregivers
  • How to develop and nurture high expectations for a family member with a disability
Building New Partnerships

• University Extension
  • Resource folder distribution
  • Training family agents in every county
  • Partners in Policymaking

• KidCentralTN / Gov.’s Children’s Cabinet
  • Online ‘one-stop shop’ for info for ALL Tennessee families
  • Led by Gov.’s Children’s Cabinet
  • Partnering to expand content relevant to families with a member with a disability
Next Steps for TN

Dec. 2016 …

State Leadership Academy training in LifeCourse framework

Case manager conference; continuing to build capacity to utilize LifeCourse thinking and tools among DD system staff

Strategic planning for embedding LifeCourse principles and tools in goals/activities related to promoting employment for ALL Tennesseans with disabilities who want to work
Contact

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Tennessee Council on Developmental Disabilities
emma.shouse@tn.gov