Charting the LifeCourse
Path to the Good Life
About Our Organization

- Housed at UCEDD/LEND with longstanding focus on Family Support, Self-Advocacy and Self-Determination
- State and National Systems and Policy Change
- Statewide Family Resource Center, Family-to-Family HIC, for over 25 years, with evolving and on-going statewide partnerships
About Crystal …

• Mom to Peyton, Conner and Lilly

• Missouri Family to Family -Coordinator

• UMKC-IHD -Family LifeCourse Specialist

• CtLC Certified Trainer

• AMCHP -Family Delegate

• Partners in Policymaking Graduate
National Community of Practice for Supporting Families

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.
Setting the Stage
Current Reality of Services and Supports

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

Everyone exists within the context of family and community.

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.
Guiding Principles of the Supporting Families LifeCourse Framework
ALL People
1 in 4 Persons with I/DD Receive Formal State DD Services

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

- 100%: 4.7 Million people with developmental disabilities
- 75%
- 25%

National % Receiving State DD Services

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Kansans Living With DD

45,978 estimated people in Kansas living with Developmental Disabilities*

- 75%: ~33,600 Not Known to DD State System
- 8%: ~3,500 Wait list
- 17%: ~8,880 Paid DD Services

*Based on 1.58% prevalence of 2.92 million citizens, US Census (2015)
Person Within Context of Family and Community
ALL Individuals Exist Within the Context of Family

- Family is defined by the individual
- Individuals and their family may need supports that adjust as roles and needs of all members change
- Not dependent upon where the person lives
Lifelong Impact of Family on Individual

Biologically: Likes, dislikes, skills, abilities

Environmentally: Neighborhood, socio-economic, education

Socially: Family & friend network, community

Policy: Dreams, Aspirations, House rules, cultural rules, expectations
# Reciprocal Roles of ALL Family Members

<table>
<thead>
<tr>
<th>Caring About</th>
<th>Caring For</th>
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<tbody>
<tr>
<td>Affection &amp; Self-Esteem</td>
<td>Provider of day-to-day care</td>
</tr>
<tr>
<td>Repository of knowledge</td>
<td>Material/Financial</td>
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<tr>
<td>Lifetime commitment</td>
<td>Facilitator of inclusion and membership</td>
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<tr>
<td>Advocate for support</td>
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siblings often juggle multiple roles for support and caregiving, which can seem overwhelming
Good Life, Vision, Trajectory, Life Stages and Experiences
What is YOUR Vision for a Good LIFE?

Vision of What I Want for a Quality of Life
The future is not something we enter. The future is something that we create. And creating that future requires us to make choices and decisions that begin with a dream.

- Leonard L. Sweet
Life Experiences and Life Transitions

- Getting New Diagnosis
- Parents Turn 65
- Medicare & SSDI
- Leaving Early Childhood/Enter school
- Transition planning
- Turning 18. Leaving school at 18 or 21
- Living Adult Life
- Chores and allowance
- Summer jobs, babysitting
- Learning to say “no”
- Making Mistakes
- Playing sports or an instrument
- Birthday parties with friends
- Scouts, 4H, faith groups
- My parents have passed away, what do I do?
Life Experiences = Life Outcomes

What We DON’T Want

Experiences at age 5

Experiences at age 13

Experiences at age 65

What We Want

Friends, family, enough money, job I like, home, faith, vacations, health, choice, freedom

What We DON’T Want
Dignity of Risk and Mistakes

Never be defined by your past. It was just a lesson, not a life sentence.

Friends, family, enough money, job I like, home, faith, vacations, health, choice, freedom

Poverty, loneliness, segregation, restrictions, lack of choice, boredom
Life Domains, Life Outcomes and Life Possibilities
Achieving Outcomes for Connected Life Domains

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

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

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

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

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

- **Citizenship and Advocacy**
  (valued roles, making choices, setting goals, responsibility, leadership, peer support)
Integrated Star for Problem Solving & Exploring Options
Three Types of Supports

- Discovery & Navigation
- Goods & Services
- Connecting & Networking
LifeCourse Integrated Supports

STAR

Personal Strengths & Assets
- Technology: i-pad/smart phone apps, remote monitoring, cognitive accessibility, Adaptive equipment
- Resources, skills, abilities characteristics

Relationships
- Family, friends, neighbors, co-workers, church members, community members

Community Based
- School, businesses, church faith based, parks & rec, public transportation

Eligibility Specific
- SHS services, Special Ed, Medicaid, Voc Rehab, Food Stamps, Section 8

100%
Brighter Futures, Positive Trajectories and Transformational Family Change
Before Charting the LifeCourse
Before Charting the LifeCourse

WHAT DOES THIS JOB PAY??
WHAT WILL I DO IF MY CAR BREAKS DOWN??
WHAT IF MY HOURS GET CUT???
WHAT IF MY NEXT SPOUSE MAKES TOO MUCH??
WHERE WILL WE HAVE TO LIVE??
ARE MY KIDS "BAD ENOUGH" TO QUALIFY??
WHAT IF MY PROGRAM DOESN'T GET FUNDED??

FEAR
Peyton’s Plan for Inclusion in School

Using the LifeCourse Tools to Transform the Way the School Thinks about Inclusion for Peyton
Transformational Changes in Thinking
Transformational Changes in Thinking

My Good Life

- Challenger Sports
- Basketball
- Being Healthy
- Cheerleaders
- Swimming
- Woody and Big Bird

Peyton Bell
A GOOD LIFE!!!
A GOOD LIFE!!!
The Gift of Self-Advocacy
Conner’s Journey

Discovery

Self-Advocacy
A GOOD **LIFE!!!**
What about THE BUMPS!!???

- No Friends
- People laugh at me
- People think I’m stupid
- No understanding
- Poor
- No job

Acceptance
Popular
On TV and YouTube
Rich
Family
Girlfriend

Inclusion

Aggression
Isolation
Loss of Freedom
Depression
Everyone has a different path
Impacting ALL
Impact on All Family Members
A GOOD LIFE!!!
Thank You!

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