Charting the LifeCourse: A Community of Practice for Supporting Families

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All people are empowered to live, love, work, learn, play and pursue their dreams.
Establishing a Framework for Transformational Change
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.
“Change is not a threat, it’s an opportunity. Survival is not the goal, transformative success is.”
—Seth Godin
Everyone exists within the context of family and community

Traditional Disability Services

Integrated Services and Supports within context of person, family and community
When you point out kids' strengths, they grow in confidence. They know you see them. You see the whole individual, not just an empty vessel that needs to be filled with your knowledge.

~ Laura Lenz
Everybody is a genius. But if you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid.

~Albert Einstein
WHEN A CHILD IS LEARNING HOW TO WALK AND FALLS DOWN 50 TIMES, THEY NEVER THINK TO THEMSELVES, "MAYBE THIS ISN'T FOR ME."
Knowing and working with your natural strengths leads to:

1. **↑ HAPPINESS**
2. **↑ CONFIDENCE & SELF ESTEEM**
3. **↑ ENERGY & VITALITY**
4. **↓ STRESS**
5. **↑ RESILIENCE**
6. **↑ GOAL ACHIEVEMENT**
7. **↑ PERFORMANCE**
8. **↑ ENGAGEMENT**
Comprehensive, Integrated & Coordinated Systems Across Life Domains & Stages

- Pediatrician, Families and Friends, Faith based
- First Steps, Parents as Teachers, Health, Head Start
- School, Special Education, Health, Recreation
- Vocational Rehab, Health, Employment, College, Military
- Disability Services, Health, Housing, College, Careers
- Retirement, Aging System, Health
LIFECOURSE GUIDING PRINCIPLES

**ALL PEOPLE:** ALL people are considered in our vision, values, policies and practices for supporting people with intellectual and developmental disabilities.

**FAMILY SYSTEM & CYCLES:** People exist and have reciprocal roles within a family system, defined by the individuals. Roles adjust as the individual members change and age.

**LIFE STAGES & TRAJECTORY:** Individuals and families can focus on a specific life stage, with an awareness of how prior, current and future life stages and experiences impact and influence life trajectory. It is important to have a vision for a good, quality life, and have opportunities, experiences and support to move the life trajectory in a positive direction.

**LIFE OUTCOMES:** Individuals and families plan for present and future life outcomes that take into account all facets of life and have life experiences that build self-determination, social capital, economic sufficiency and community inclusion.
LIFE DOMAINS: People lead whole lives made up of specific, connected, and integrated life domains that are important to a good quality of life.

THREE BUCKETS: Supports address all facets of life and adjust as roles and needs of all family members change.

INTEGRATED SUPPORTS: Individuals and families access an array of integrated supports to achieve the envisioned good life, including those that are publicly or privately funded and based on eligibility; community supports that are available to anyone; relationship-based supports; technology; and that take into account the assets and strengths of the individual and family.

POLICY & SYSTEMS: Individuals and families are truly involved in policy making so that they influence planning, policy, implementation, evaluation and revision of the practices that affect them. Every program, organization, system and policymaker must always think about a person in the context of family.

Core Belief: All people have the right to live, love, work, learn, play and pursue their dreams in their community.
Trajectory Toward Positive Life Outcomes

Across the Lifespan

Trajectory towards Outcomes

Trajectory towards things unwanted

Vision of What I Don’t Want

Friends, family, self-determination, community living, social capital and economic sufficiency
Life Experiences & Life Transitions

- Learning to say “no”
- Playing sports or an instrument
- Birthday parties with friends
- Scouts, 4H, faith groups

Summer jobs, babysitting

Chores and allowance

Making Mistakes

- Summer jobs, babysitting
- Learning to say “no”
PERSON AND FAMILY LEVEL QUALITY OF LIFE DOMAINS

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

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

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

**Safety and Security**
(emergencies, well-being, legal rights and issues, guardianship options and 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)
TOOLS FOR ALL TEAM MEMBERS

Planning for Life Outcomes and/or Service Planning

Self-Advocate Tools & Resources

Family Perspective Tools

Formal Planning Tools and Forms
CHARTING the LifeCourse

Life Trajectory Worksheet: Family

Everyone wants a good life. The bubbles on the right will help you think about what a good life means for you or your family member, and identifying what you know you don't want. You can use the space around the arrows to think about current or needed life experiences that help point you in the direction of your good life.

VISION for a GOOD LIFE

What I DON'T Want

Developed by the UMKC Institute for Human Development, UCEDD. More materials at lifecoursetools.com

May 2016
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.

Access the LifeCourse framework and tools at lifecoursetools.com

My LifeCourse Portfolio is a template of the UNICEF, UCEDD. More materials at lifecoursetools.com
Charting the LifeCourse

- Is about having different conversations
- Is a different way of thinking
- Is about encouraging high expectations
- Is about having life experiences to move the trajectory in the desired direction
- Is about integrating LOTS of different kinds of support, and not just having an “all green life”
- Isn’t JUST about the “tools”
- Isn’t a “program”