Outcomes for Today

- Basic overview of the Charting the LifeCourse Framework
- Practice using the Charting the LifeCourse Framework and tools
Setting the Stage
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.
Current Reality of Long Term Services and Supports

- Expectations, Values, Culture
- Federal Budget
- Demand for Services
- Capacity of Work Force
- Federal Policy

Circle Diagram:
- Community
- Family
- Services
- Person
WHY We Must Think Differently About Supports

ONLY 25% OF PEOPLE WITH IDD ACCESS FORMAL OR PAID SUPPORTS WITHIN THE DD SYSTEM

WHAT ABOUT THE OTHER 75%?
What We Want to See...

- **75%** People with I/DD not receiving formal DD services
- **25%** People with I/DD receiving formal DD services
- **100%** People with I/DD receiving integrated services and supports
Charting the LifeCourse....... 

IS:
- About having different conversations
- A different way of thinking
- Encouraging high expectations
- Having life experiences to move the trajectory in the desired direction
- Integrating LOTS of different kinds of support, and not just having an “all green life”

ISN’T:
- JUST about the “tools”
- A “program”

Is for ANYONE, regardless of AGE or ABILITY!
GUIDING PRINCIPLES OF THE CHARTING THE LIFECOURSE FRAMEWORK
Core Belief:
All people and their families have the right to live, love, work, play and pursue their life aspirations in their community.
Person Within Context of Family & 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

Family is anyone who loves you unconditionally.
Where do People with I/DD Live?

TOTAL 4.7 MILLION PEOPLE WITH IDD

- 89% living in own homes and/or are supported by family
- Own or With Family
- Residential Supports

# Reciprocal Roles of ALL Family Members

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<tr>
<th>Caring About</th>
<th>Caring For</th>
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<tr>
<td>Affection &amp; Self-Esteem</td>
<td>Provider of day-to-day care</td>
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<tr>
<td>Repository of knowledge</td>
<td>Material/Financial</td>
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<td>Lifetime commitment</td>
<td>Facilitator of inclusion and membership</td>
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<td>Advocate for support</td>
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*Adapted from Bigby & Fyffe (2012), Dally (1988), Turnbull et all (2011)*
Life Stages and Individual and Family Cycles

Individual Life Stages

Birth
Early child
School
Transition
Adulthood
Aging

Family Life Cycle

Single Adult
New Couple
Couple with Children
Launching Children
Family Later in Life
Lifelong Impact of Family on Individual

Biologically: Likes, dislikes, skills, abilities

Environmentally: Neighborhood, socio-economic, education

Socially: Family and friend network, connection with community members

Policy: Dreams, Aspirations, House rules, cultural rules, expectations
Siblings often juggle multiple roles for support and caregiving, which can seem overwhelming.
“Good Life for All”

The Individual will achieve self-determination, interdependence, productivity, integration, and inclusion in all facets of community life.

Families will be supported in ways that maximize their capacity, strengths, and unique abilities to best nurture, love, and support all individual members to achieve their goals.
Supporting All Team Members

Supporting Person’s Self-Determination & Self-Advocacy

Supporting Families Across the Lifespan

Supporting Person-Centered Planning
Policy, Systems & Community Change: Person-/Family- Centered and Driven
Partnering with People with Disabilities and their Families

So they can Engage, Lead, and Drive Policy and Systems Change
Life Trajectory, Experiences and Life Stages
What is YOUR Vision for a Good LIFE?

Vision of What I Want
What DON’T you want??

Vision of What I Don’t Want
Vision & Trajectory for a Good Life

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

Vision of What I Don’t Want

Trajectory towards Life Outcomes

Trajectory towards things unwanted
Ben’s Good Life Vision

Family  Friends  TATTOOS
Vacations  Girlfriend
Concerts  WWE  Nascar
Money  Job/own business
Fire Station  Church
Tiger Football  Royals
Good Food  Pepsi  Beer
Active  Healthy & Fit

Poverty/No Money
Poor Health  Diabetes
Heart Disease  Guardian
Isolated/Segregated
Institution/group home
Treated Differently
Trajectory Across Life Stages and Life Transitions

Life Transitions And Disability System Transitions

- Getting New Diagnosis
- Transition planning
- Leaving Early Childhood/enter school
- Turning 18. Leaving school at 18 or 21
- Living Adult Life
- Parents Turn 65 Medicare & SSDI
- My parents have passed away, what do I do?
Trajectory Across Life Experiences

Chores and allowance

Dating & Heartaches

Birthday parties with friends

Learning to say “no”

Scouts, 4H, faith groups

Playing sports or an instrument

Summer jobs, babysitting

Making Mistakes

“Anticipatory Guidance for Life Experiences”
Life Experiences = Life Outcomes

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)
### Looking at Life Possibilities

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<tr>
<th>Innovative</th>
<th>Very new or undiscovered</th>
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<tr>
<td>Islands of Excellence</td>
<td>Exists in a lot of places but not everywhere</td>
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<tr>
<td>Traditional Options</td>
<td>Services that have existed for a long time</td>
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Individualized Supports to Achieve a Good Life
Types of Support
The “3 Buckets”

- Discovery & Navigation
  (Info and Training)
- Connecting & Networking
  (Talking to someone that has been there)
- Goods & Services
  (Day to Day, Medical, Financial Supports)
Integrated Star for Problem Solving & Exploring Options
Charting the LifeCourse
Integrated Supports STAR

COMMUNITY

FAMILY

PERSON

100%

PERSONAL STRENGTHS & ASSETS
- Strengths: Things a person is good at or others admire or like
- Assets: Resources that are owned or can be accessed by the person
- Skills: Personal abilities, knowledge or experience

RELATIONSHIPS
- Family: People that love, care about, and are committed to each other
- Friends: People that enjoy spending time together, have things in common, and care about each other
- Acquaintances: People that come into frequent contact with the person but don't know them well.

TECHNOLOGY
- Personal Technology: Common technologies used by anyone
- Environmental Technology: Innovative technologies designed to help a person navigate or adapt their environment
- Assistive Technology: Low-tech or specialized devices that assist a person with day-to-day tasks

COMMUNITY RESOURCES
- Places: Businesses, faith communities, parks and recreation, health care facilities
- Groups: Civic and membership organizations
- Government Resources: Local services, i.e. public safety, legal, social programs

ELIGIBILITY SPECIFIC SUPPORTS
- Disability Specific: Supports received based on a diagnosis, i.e. Special Education, Government Funded Disability Supports
- Needs-based: Supports based on age, gender, geographics, income level or employment status

Developed by the UMKC Institute for Human Development, UCEDD, July 2016
Charting the LifeCourse Integrated Supports STAR

RELATIONSHIPS

Family:
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Charting the LifeCourse
Integrated Supports STAR

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Charting the LifeCourse
Integrated Supports STAR

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- Businesses
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- Parks and recreation
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Groups:
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Charting the LifeCourse Integrated Supports STAR

ELIGIBILITY SPECIFIC SUPPORTS

Disability Specific:
Supports received based on a diagnosis, i.e., Special Education, Government Funded Disability Supports

Needs-based:
Supports based on age, gender, geographics, income level or employment status
Focusing ONLY on Eligibility Supports

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

Poverty, loneliness, segregation, restrictions, lack of choice, boredom, institutions
Relying ONLY on Family & Friends

- Friends, family, enough money, job I like, home, faith, vacations, health, choice, freedom
- Poverty, loneliness, segregation, restrictions, lack of choice, boredom, institutions
LifeCourse Star to Calendar
Ben - BEFORE Integrated Supports

Personal Strengths & Assets

- Technology:
- Relationships:
- Community Based:
- Eligibility Specific:

DDD Self-Directed waiver PCA staff; Medicaid; Special Needs Trust

Mom, Dad

Ben’s Supports

Long Term Service and Support Needs

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Template by Missouri Family to Family @ UMKC@ UCEDD
December 2014

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Ben - AFTER Integrating Supports

**PERSONAL STRENGTHS & ASSETS**

Able to stay home alone for up to an hour; has & can use i-pad;

**TECHNOLOGY:**
i-pad when home alone; digital watch

**RELATIONSHIPS:**
Mom, Dad, Matt, Zac, Ali, Chad, Ericka, Roy, Carol, Nick, Spohn,

Ben’s Supports

**COMMUNITY BASED:**
Firemen at ESFD; coaches & staff at ES high school; Omni bus;

**ELIGIBILITY SPECIFIC**
DDD Self-Directed waiver PCA staff; Medicaid; Special Needs Trust

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**Long Term Service and Support Needs**

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*Template by Missouri Family to Family @ UMKC-HID, UCEDD*
Missouri Quality Outcomes

The Missouri Quality Outcomes (MOQO) were developed in the 1990's, in an effort to emphasize quality of life for individuals receiving services and supports from the Missouri Division of Developmental Disabilities.

In 2015 Missouri Division of Developmental Disabilities adopted the Charting the Life Course Domains into statewide Missouri Quality Outcomes.
MO Quality Outcomes were changed in 2015

- More user friendly and can be used in conjunction with “Charting the Life Course” guide developed by UMKC Institute for Human Development;

- New Federal regulations around Self-Determination and Home and Community Based Services

- Missouri Quality Outcomes
ISP Guidelines 2017

- Require the team to explore the Vision of a Good Life of each person
- Require the Missouri Quality Outcomes to be addressed in all ISP’s in Missouri
- Intentionally connect Personal Outcomes to the MO Quality Outcomes.
Charting the Life Course System Impact in Missouri

- **MO Quality Outcomes 2015**: Missouri Division of DD incorporates Domains into Missouri Quality Outcomes
- **MO ISP Guide 2017**: Missouri Division of DD integrates Trajectory and Domains into required components for ISPs
- **ISP Review and Monitoring 2019**: MO Quality Outcomes monitored monthly or quarterly by Support Coordinators
- **County Level Funding 2019**: MO Quality Outcomes used for measuring progress
Planning for Life Outcomes and/or Service Planning

Self-Advocate Tools & Resources

Family Perspective Tools

Formal Planning Tools and Forms

800-444-0821
Please fill out the Post-Survey and Evaluation - Thank You!