About Sheli

• Sibling of three brothers, one who is 35 years old with developmental disability

• Member, Presidents Committee for Persons with Intellectual Disabilities Appointed by President Obama

• Associate Director, UMKC Institute for Human Development
  o Lead Developer of Charting the LifeCourse framework and tools
  o Co-Director of National CoP on Supports to Families
  o Director of Mo Family-to-Family Health Info Center
  o Supporter of the Self-Advocacy Movement for 12 years
Introducing Ben

I PITY THE FOOL WHO DOESN'T LIKE

BEN'S ONE PAGE PROFILE!

WHAT PEOPLE LIKE AND ADMIRE ABOUT ME

- I like to make other people feel good and be happy.
- I have a great smile and a contagious laugh. I frequently "get the giggles!"
- I'm fun, silly and friendly!
- I am a dedicated volunteer in my community
- I am an Eagle Scout and an adult leader in scouting - been involved in service through scouting since first grade.
- I am a man about town!
- My tattoo!
- My great hugs!
- I am willing to try new things...
- I remember songs and who sings them
- I am not usually a complainer, even though sometimes I am in pain or uncomfortable

WHAT'S IMPORTANT TO ME

- My family and friends
- Volunteering at the Fire Station, wearing my uniform and badge
- Going to the library
- Going to church
- My TV, DVR, and radio/CD player (I like to play them all at once sometimes)
- My iPad
- WWE wrestling – I love when my brother Matt takes me to live shows
- NASCAR Racing (Jeff Gordon is my favorite driver)
- Going to country music concerts
- Feeling like I belong
- Being like everybody else, not being treated differently
- Getting a tattoo (already planning my next tattoo)
- Having control over my life as much as possible
- My Excelsior Springs Tigers – especially football
- Riding horses at NTRC
- Facebook friends
- Having an occasional beer with friends
- Having a purpose and being productive

HOW BEST TO SUPPORT ME

- I need help remembering things, like what I did or who I saw today.
- I get confused easily so I need help not getting lost or turned around when I am out and about.
- I know what times I am supposed to take my meds, but I need help getting them out and getting refills.
- I get anxious sometimes; need to be reassured that people I care about will be there for me.
- I don't like to spend time alone, but I am working on it; help me not be so anxious when I am alone for short periods of time.
- I sometimes need someone to steady me if I get off balance.
- I need to rest or extra support if I have to do a lot of walking or standing. If I am shopping, it helps if I am the cart-pusher.
- I need support keeping in touch with friends and family and practicing having good conversations.
- I'm friendly even though I may not look you in the eye at first.
Outcomes

- Learn about the Charting the LifeCourse framework and tools
- Discover how the Charting the LifeCourse tools are being used to support exploration, planning, decision-making, and problem-solving at all levels of change.
- Explore the many different implementation strategies within education and school systems, transition and employment, long term services and supports, health care and strategic policy changes.
Setting the Stage
Development of Framework and Tools for Multi-Level Transformation
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%
Missourians with DD

96,122 estimated Missourians with Developmental Disabilities*

65%
(62,087)
Not Known to DD State System

17%
Targeted Case Management

18%
Paid DD Services

As Reported by MoDDD (May 2016)

Total State DD: 33,315
  TCM Only: 16,210
  TCM Plus Paid DD: 17,107
  Of Paid DD, Residential: 7,012
  Of Paid DD, State ICF/DD: 360

Where People with I/DD Live

4.7 million estimated People with Developmental Disabilities*

75%
3,500,000
Not Known to Services

12%
672,000
Living at Home

11%
528,000
Out of Home Services

Current Reality of Services and Supports

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

COMMUNITY
FAMILY
SERVICES
PERSON
Services and Supports are Evolving

Everyone exists within the context of family and community

Traditional Long Term Services and Supports

Integrated Services and Supports within context of person, family and community
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.

National Association of State Directors of Developmental Disability Services

Original Funding Source
Administration for Community Living
The significant problems we face cannot be solved at the same level of thinking we were at when we created them.

Albert Einstein
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
History of Development

Charting the LifeCourse Framework and Tools
Thinking that Guides the Framework
Building on the Life Course Perspective

- Looks at areas across the life span
- Not disconnected stages
- Each life stage influences the next

- Complex interplay of
  - Biological
  - Behavioral
  - Psychological
  - Social
  - Environmental factors

Policy Brief: A New Agenda for MCH Policy and Programs (2009)
What is Charting the LifeCourse??

- **Guiding Framework**: Guides thinking and problem-solve
- **Practices**: Specific Area (action, policy, procedure) to enhance or change
- **Tools**: Educational Resources Planning & Problem-solving Worksheets

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Reframe Change at Every Level

Based on Social-Ecological Model
What We Have Learned: Universal Framework for “All”

100%

• Early Childhood
• Children in Foster Care
• High School and College Students
• Community Health Workers
• Managed Care Organizations
• Electronic Record Keeping Systems
• Aging Caregivers
• Support/Care Coordination
• Informational and Referral
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.
All People

ALL people, regardless of age, ability or family role, are considered in the framework.

ALL people with disabilities and their families have choices and access to supports they need, whether they are known to the disability service.

1 in 4 Persons with I/DD Receive Formal State DD Services

75%

25%

National % Receiving State DD Services

** Based on national definition of developmental disability with a prevalence rate of 1.49%
Individuals live within the context of their Families 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 and friend network, connection with community members

Policy: Dreams, Aspirations, House rules, cultural rules, expectations
Connected Stages and Cycles

Individual Life Stages

A Traditional Family Life Cycle
## Reciprocal Roles of ALL Family Members

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<tr>
<th>Caring About</th>
<th>Caring For</th>
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<td>Affection &amp; Self-Esteem</td>
<td>Provider of day-to-day care</td>
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<td>Repository of knowledge</td>
<td>Material/Financial</td>
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<td>Lifetime commitment</td>
<td>Facilitator of inclusion &amp; membership</td>
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<td>Advocate for support</td>
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Family Members Are
Cared about and Loved
Self-determined
Independent/interdependent
Integrated and Included
Productive

Changing Roles of Family

Family Roles
Caregiver and Family
Behavior Therapist
Spiritual Guider
Psychiatrist or Counselor
Social Planner
Life Coordinator
Protector and Advocate

Birth-----Early Child---School-----Transition----------------------Adulthood---------------------------Aging
Sibling Leadership Network

Siblings: The ‘Club Sandwich’ Generation

Siblings often juggle multiple roles for support and caregiving, which can seem overwhelming.

-Sibling Leadership Network
Families are complex, but we know that families.....

- Help each other; they sacrifice for one other;
- Hurt each other; they apologize and forgive;
- Have fun and celebrate with each other;
- Have routines, customs and habits – they have their way of doing things;
- Have secrets and things they don’t talk about;
- Have troubles, get tired and discouraged;
- Do the impossible;
- Might commit abuse and take advantage of other families members;
- Can’t do everything;

*The family is the context for the person; personal outcomes are influenced by the family*
Challenging Our Thinking About Families

- “the families I work with are often a barrier”
- “families are too tired and overwhelmed”
- “families expectations are too high”
- “families expectations are too low”
- “the people I support don’t have any family”
The focus is on the “person with a disability” this does NOT mean that “Family Engagement” supersedes the INDIVIDUAL.

It is not family involvement VS person centered.

**Family Engagement** is a component of a holistic approach to person centered supports that recognizes the context and impact of the family in practice and policy implementation.
Supporting the Needs of the Person and Family

Individual and family supports address all facets of life and adjust as roles and needs of all family members change.

Discovery & Navigation
(Info and Training)

Connecting & Networking
(Talking to someone that has been there)

Goods & Services
(Day to Day, Medical, Financial)
<table>
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<tr>
<th>Overarching Area (3 Buckets)</th>
<th>Focus Area of Enhancement</th>
<th>Examples of Services or Supports</th>
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<tr>
<td>Discovery and Navigation</td>
<td>Informational Support</td>
<td>• Informational Support (specific disability or health condition, options and possibilities for employment, community living, relationships, recreation, future planning)</td>
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<td>Instructional Skills Development</td>
<td>• Skill Building Support (navigating and access services, behavioral supports, medical tasks)</td>
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<td>Navigation and Advocacy Skills</td>
<td>• Interventions that enhance the ability to advocate for services and policy change</td>
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<td>Connections and Networking</td>
<td>Emotional Support</td>
<td>• Support Groups</td>
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<td>Affirmational Support</td>
<td>• Professional Counseling</td>
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<td>Relationships and Social Capital</td>
<td>• Peer-to-peer interventions and programs (Parent-to-Parent, Sib-shops, Self-advocacy organizations)</td>
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<tr>
<td>Goods and Services</td>
<td>Physical Support</td>
<td>• Individual and Family-Directed Supports</td>
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<td>Financial Material/Instrumental</td>
<td>• Cash Subsidies and Financial assistance</td>
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<td>• Transportation</td>
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<td>• Respite/Childcare</td>
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<td>• Adaptive equipment and Home modifications</td>
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Elizabeth’s Health Trajectory
As Told by Her Mother

5 Months…………….1 year…………………2 years

Vision for a Good Life
Self determination
Choice
Privacy

What I DON’T Want
Unnecessary medications
Unnecessary procedures
Limiting choices
Limiting self-determination

Charted trajectory stoma
Peer Support / Research / Advocacy
Charted trajectory ditropan
Uncharted trajectory self-cath
Peer Support / Research / Advocacy

5 Months..................1 year.....................2 years
Focusing on Quality of Life

People lead holistic lives made up of connected and integrated life domains that are important to their quality of life.

Focus on self-determination, interdependence, inclusion, social capital and economic sufficiency of individuals and families.
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)
<table>
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<tr>
<th>LifeCourse Domains</th>
<th>Social Determinants of Health Domains (Healthy People 2020)</th>
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</table>
| Education:        | High School Graduation  
|                   | Enrollment in Higher Education  
|                   | Language & Literacy  
|                   | Early Childhood Education & Development  
| Economic Stability:| Poverty  
|                   | Employment  
|                   | Food Security  
|                   | Housing Stability  
| Neighborhood & Built Environment: | Quality of Housing  
|                     | Environmental Conditions  
|                     | Access to Healthy Foods  
| Neighborhood & Built Environment: | Crime & Violence  
|                     | Social & Community Context  
|                     | Discrimination  
| Health & Health Care: | Access to Health Care  
|                     | Access to Primary Care  
|                     | Health Literacy  
| Economic Stability: | Food Security  
| Neighborhood & Built Environment: | Access to Healthy Foods  
| Social & Community Context: | Social Cohesion  
|                     | Incarceration  
| Social & Community Context: | Civic Participation  
|                     | }
Individuals and families can reflect on prior and current life stages and experiences while focusing on the future.

A vision creates opportunities for life experiences along the life trajectory.
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
What is YOUR Vision for a Good LIFE?

Vision of What I Want for a Quality of Life
What DON’T you want??

Vision of What I Don’t Want
“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.
Trajectory towards Good Life

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

Vision of What I Don’t Want
Trajectory towards 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

WHAT I DON'T WANT
- Poverty/No Money
- Poor Health
- Diabetes
- Heart Disease
- Guardian
- Isolated/Segregated
- Institution/group home
- Treated Differently
Trajectory Across Life Transitions

“Anticipatory Guidance for Life Experiences”

**Life Stages & Life Experiences**

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

**Making Mistakes**

- Chores and allowance
- Summer jobs, babysitting

**Getting New Diagnosis**

- Transition planning
- Turning 18. Leaving school at 18 or 21
- Leaving Early Childhood/enter school

**Parents Turn 65 Medicare & SSDI**

**Living Adult Life**

**Disability System Transitions**

- My parents have passed away, what do I do?
Life Experiences = Life Outcomes

What We WANT

Experiences at age 65

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

What We DON’T WANT

Experiences at age 5

Experiences at age 13
**Ben’s Life Trajectory**

### Life Trajectory Worksheet

#### Past Life Experiences
- Chores; boy scouts;
- School inclusion/circle of friends;
- Birthday parties;
- Riding bike;
- Family vacations;
- Church youth group;
- Debit card;
- Football manager;
- Homecoming king;
- Volunteering;
- High School diploma

#### Future Life Experiences
- Volunteer at fire station;
- Find more volunteer ops;
- Workout regularly;
- Keep in touch w/ friends;
- Increase alone time;
- Go out with friends;
- Spend daytime hours out of the house;
- Explore micro enterprise;

### What I DON'T Want
- Poor health, heart disease, diabetes;
- Poverty/no money;
- Guardianship; institution/group home; Segregation/isolation; being lonely
- Being treated differently;

### Vision for a GOOD LIFE
- Family and friends
- Girlfriend
- Vacations
- Concerts; WWE; Nascar
- Tattoos
- Money; job or my own business
- Volunteer at fire station
- Being Tiger football manager
- Church
- Healthy & fit
- Good food; Pepsi
- Basketball
- Royals baseball
- Staying active

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**Ben's Life Trajectory**

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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
Integrated Service and Supports

Individuals and families utilize an array of integrated services and supports to achieve the envisioned good life.
Integrating Services and Supports
Integrated Supports STAR

- **Personal Strengths & Assets:** resources, skills, abilities characteristics
- **Technology:** i-pad/smart phone apps, remote monitoring, cognitive accessibility, Adaptive equipment
- **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
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
Integrated Supports: Daily Routine

- Personal Strengths & Assets
- Technology
- Relationships
- Community Based
- Eligibility Specific

Morning or Evening
Integrated Supports: Domain Specific
Focus on Social and Spirituality

**PERSONAL STRENGTHS & ASSETS**

- Happy, Funny and loving
- Likes to help people
- Likes to try new things
- Police cars, tow trucks, fire engines and racecars

**TECHNOLOGY:**
- I-pad
- Smart Phone

**RELATIONSHIPS:**
- See his girlfriend more
- Connect with his family
- Spend more time with friends

**COMMUNITY BASED:**
- Scouts
- Red Robin
- Race Tracks

**ELIGIBILITY SPECIFIC**
- Companion Supports day-to-day
Elizabeth’s Integrated Star: Mapping Supports
BEFORE: Integrated Supports

- **PERSONAL STRENGTHS & ASSETS**
- **TECHNOLOGY:**
- **RELATIONSHIPS:** Mom, Dad
- **COMMUNITY BASED:** Ben’s Services & Supports
- **ELIGIBILITY SPECIFIC** DDD Self-Directed waiver PCA staff; Medicaid; Special Needs Trust

![Long Term Service and Support Needs](image)
AFTER: Integrated 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,

**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-IRD, UCEDD January 2015
Ben's Safety & Security Star

Focus on Supported Decision Making

NOW
- Carries ID
- Uses Debit Card
- Can call 911

FUTURE
- Communicate wants & needs better
- Spend more time on his own
- Call 911 only if emergency

Relationships
- Joint bank account with mom
- Power of Attorney (mom & dad)
- SN Trust Committee (Matt, Zac, Ali, Mike, Tracy)

NOW
- Remote Monitoring
- Learn to use FaceTime or Skype

FUTURE
- Add more Power of Attorney successors
- Supported (shared) decision making

NOW
- Automatic Bill Pay
- Direct Deposit
- Well known at:
  
  Library, church, Fire station, restaurants, stores, bus
- Community Based

FUTURE
- Limited bank account
- Senior Center
- Meals on Wheels
- Expand community contacts

Eligibility Specific
- Has DDD/SDS Personal Care Attendant
- Supplemental Special Needs Trust
Safety and Security

Focus on Supported Decision Making
Every program, organization, system and policy maker must always think about a person in the context of family.

Individuals and families are satisfactorily involved in policy making so that they influence planning, policy, implementation, evaluation and revision of the practices that affect them.

Person with Disability and their Families Engage, Lead, and Drive Policy, Practice and Community Change
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
Reframing for All Stakeholders: Developing Materials

- Family to Family at Missouri UCEDD
- Early Childhood, Part C
- School Districts, Special Education
- PNS Show Me Career Grant Pilot Sites
- State Division of Developmental Disability
- Special Health Care Needs
- Dept. Health and Senior Services
- Vocational Rehabilitation
Tools for All Team Members

Planning for Life Outcomes
and/or
Service Planning

Self-Advocate
Tools & Resources

Family Perspective
Tools & Resources

Support Team
Tools & Resources
Specific Life Domain Planning
LifeCourse at ANY Age
Person-Led Planning Meetings

![Diagram of Person-Led Planning Meetings]

- Charting the life course
- Life Trajectory Worksheet: Family
- Individual
- Vision for a Good Life
- Live Independently
- Find a Career
- What I DON'T Want
- To Get Angry
- Not Stay Safe
- Mission Family to Family | UMKC-IHD, UCEDD

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Hiring Self-Directed PCA

CHARTING the life course

Strengths & Assets:
- Enjoys health & fitness and is determined to live a healthy lifestyle.
- Loves music, especially Rock music. The louder the music, the better!
- Is a great communicator one on one.
- Enjoys online searching to review sports facts.
- Movie critic – especially Sci-Fi.
- Dabbled in writing stories.
- Chicago Bears Fanatic.
- Spends spare time playing K-box.
- Interested in helping others & sharing stories of those who experience depression.

Build Relationships:
- Join the YMCA & find someone to work out with.
- Meet friends at Java Live or other hot spots for coffee.
- Friends who value eating healthy.
- Find a Chicago Bears fan!
- Meet other movie critics.

VISION for a GOOD LIFE

Pat wants to move into his own apartment, increase relationships, improve his mental and physical health and decrease formal supports. He wants to increase his independence in his home and community and wants to take steps toward being his own guardian.

Technology:
- Cell phone.
- Laptop.
- K-box.
- Stereo.
- License – but no car yet.

Community-Based:
- Music Under the Stars.
- Down by the river.
- Farmer’s Market.
- Mississippi Market Place.
- YMCA.
- Music Stores.
- Game Stop.
- Walk around town.
- Find a volunteer site.

What he DOESN’T Want:
- To have more formal supports than what he needs.
- His mom to have guardianship of him.
- To participate in activities that are disability specific.
- Others to see him differently or have lower expectations for him.

NOW HIRING: Self-Directed Services staff
Who have common interest: around 8 hours a week
Contact Stephanie: 573 248 4130

MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD

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Enhance Person Centered Planning and Individual Support Planning
Support Coordination

- Building skills and knowledge for exploring, planning and problem-solving with person with DD and their families
- Building into required policy and procedures for person centered planning guidance and ISP templates
Implementing CMS HCBS Rules

- Service plans for HCBS must be developed through a person-centered planning process that provides necessary information and support so that the individual can direct the process and make informed choices.

- The process must be directed by the individual and the individual’s freely chosen representative and must reflect individual preferences and goals.

- The plan must be written so that the individual can understand the plan.

Integrating into State System Procedures

Learning Opportunities Quality Works, Inc.
Initial and Annual Assessment

Customer Name: [Insert name]
Date of birth: [Insert date]

Instructions for use: Mark if this statement is accurate or not. Write a comment in the space below if you need to explain when they are not accurate. Initial Assessment

Contributing staff or family: [Insert name]

Community Living
Living Arrangement: Do you like where you live and who you live with? (family, staff, etc.) If you do, please mark yes. If not, please mark no.

Transportation and Community Access: How does this help you get to where you need to go? (subway, access to community, etc.)

In what other ways would you like to learn more about?

Social and Spiritual
Communication: Who are your family and friends that you see together?

How do you communicate with your family? (language, communication device, etc.)

Outcome: A. I will participate in meaningful daily activities of my choice.
What is Going To Be Done: A1. I will receive 180 hours per month with an average of 15 hours per month of Community Integration Individual Services (CIIS). Funded by Medicaid Waiver and provided by LOOW.
What: [Insert details]
Who: [Insert name]
Start Date: [Insert date]
Stop Date: [Insert date]
Training Plan Needed from Provider: [Yes/No]

Outcome: B. I will have opportunities to advocate for myself, others, and causes that I believe in, including personal goals and dreams.
What is Going To Be Done: B1. I will have a list of resources/people to call when I need help. Use Charting the Life Course Tools to discuss future goals.
Where: [Insert location]
Who: [Insert name]
Start Date: [Insert date]
Stop Date: [Insert date]
Training Plan Needed from Provider: [Yes/No]

Outcome: C. I will be treated with respect and dignity.
What is Going To Be Done: C1. I will have a written plan of care.
Where: [Insert location]
Who: [Insert name]
Start Date: [Insert date]
Stop Date: [Insert date]
Training Plan Needed from Provider: [Yes/No]

Outcome: D. I will be free from abuse.
What is Going To Be Done: D1. I will have support from my support team if I experience abuse.
Where: [Insert location]
Who: [Insert name]
Start Date: [Insert date]
Stop Date: [Insert date]
Training Plan Needed from Provider: [Yes/No]

Outcome: E. I will be free from neglect.
What is Going To Be Done: E1. I will have access to support from my support team if I experience neglect.
Where: [Insert location]
Who: [Insert name]
Start Date: [Insert date]
Stop Date: [Insert date]
Training Plan Needed from Provider: [Yes/No]

Outcome: F. I will have opportunities to be active and engaged in the community.
What is Going To Be Done: F1. I will have access to community resources and opportunities.
Where: [Insert location]
Who: [Insert name]
Start Date: [Insert date]
Stop Date: [Insert date]
Training Plan Needed from Provider: [Yes/No]

Outcome: G. I will have opportunities to develop and use skills.
What is Going To Be Done: G1. I will have access to educational and vocational opportunities.
Where: [Insert location]
Who: [Insert name]
Start Date: [Insert date]
Stop Date: [Insert date]
Training Plan Needed from Provider: [Yes/No]

Outcome: H. I will have opportunities to explore, participate, and express my wants and interests.
What is Going To Be Done: H1. I will have access to a variety of activities and opportunities.
Where: [Insert location]
Who: [Insert name]
Start Date: [Insert date]
Stop Date: [Insert date]
Training Plan Needed from Provider: [Yes/No]

Outcome: I. I will have opportunities to express myself and my interests.
What is Going To Be Done: I1. I will have a written plan of care.
Where: [Insert location]
Who: [Insert name]
Start Date: [Insert date]
Stop Date: [Insert date]
Training Plan Needed from Provider: [Yes/No]

Outcome: J. I will have opportunities to develop and use my relationships.
What is Going To Be Done: J1. I will have access to social and recreational opportunities.
Where: [Insert location]
Who: [Insert name]
Start Date: [Insert date]
Stop Date: [Insert date]
Training Plan Needed from Provider: [Yes/No]
Enhance monitoring to focus on quality outcomes
Organize Intake Conversations
Employee Training

<table>
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<tr>
<th>Integrated Supports</th>
<th>Life Trajectory</th>
<th>Life Domains</th>
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**Final Jeopardy**

ONE PAGE PROFILE – SHARON SPURLOCK

People like my creativity and my positive energy. I am genuinely interested in other people's success and try to share useful tools. I am loud & funny! I'm not afraid of a challenge and won't be offended if you don't like my first idea.

What's important to me?

- Getting to know people personally.
- Being included in decision making – large & small!
- Connection & contribution to my community.
- A really good need and a glass of wine.
- Time to be by myself after being with other people.

How to Support Me

- Recognize that I am being negative. I am overwhelmed and need some time for me.
- Give me the big picture goal and let me have some fun and be creative in accomplishing it.
- Support development of my leadership skills.
- Help me manage stress.
- Help me create a support network.
- Help me manage roles & relationships.
Employee Training
Person Centered Planning
Integrated Support Star
Other Examples of LifeCourse Application

- Job Descriptions
- New Positions
- Hiring & Interviews
- Performance Reviews
- Team Meetings
Job Descriptions

Intake Specialist Job Description
This tool will help define the search for the person Progressive Community Services needs to help coordinate and guide the Intake Specialist to P/CIS. Ensuring that the Intake Specialist develops a culture that supports individuals and families think about how to work in partnership to support their vision for a good life.

Technology
- Email
- Internet Awareness
- Proficient in Microsoft Word and Excel
- Develop a tracking system or a way to monitor tasks and deadlines
- Marketing
- Social Media
- Assistive Technology
- PSV

Personal Strengths & Assets
- Great Listener
- Supportive
- Creative
- Lifelong learner
- Follow systems that have been developed and provide options for improvement
- Develop/Utilize skills
- Excellent communication skills
- Very Organized
- Work independently & with a group
- Above average problem-solving skills
- Self-Directed and Motivated
- Flexible
- Multitask
- Advocate

Relationship-Based
- Make decisions independently and also know when to ask for assistance if needed
- Develop relationships with a diverse group of people
- Value all people, their vision of a good life and their sense of urgency
- Develop/Maintain Partnerships
- Collaborate with peers and other agencies

INTAKE SPECIALIST

Active in Community
- Market agency to others, both formally and informally
- Use personal networks to support people in being included in their community

Community Based
- Know and utilize best practices
- Be familiar with the DD systems (DMH, Special Ed., VR, etc.)
- Assist in completing applications
- State and Federal Laws applicable to the intake process

Eligibility Specific

VISION for Intake Specialist
- People will receive personalized support with the Intake process to DMH/DD Supports
- More people will complete the process in a shorter amount of time
- The process will be easier for individuals/families
- Work closely with the Family Navigator to address immediate needs

What to avoid
- Individuals and families feeling overwhelmed and/or confused by paperwork
- Individuals/families not finishing the process
- The process taking so long that people are frustrated
Human Resource:
Hiring and Performance Reviews
Organizational Communication Plan for Conflict Free Case Management
Organizational Strategic Thinking: Evolving Day Habilitation Services

Community Center Trajectory Worksheet:

- **Organizational Contributions:**
  - Skills, Experience, Attitudes, Talents that contribute to the culture.
  - Work experiences, years of service, and experience.
  - Experience in Targeted Case Management (TCM).
  - Experience in networking and garnering.
  - Early adopters of new ideas.
  - Active in the community.
  - Emphasis on change!

- **Timeline:**
  - Early 2015
  - Summer 2015
  - 5/15
  - 9/15
  - 11/15
  - 11/23
  - 11/23 2016

- **Vision for the New Community Center and initiative to help people in our community:**
  - Long-term care of their own.
  - To develop a hub for community life engagement activities in Monroe City.
  - Promoting personal growth through opportunity, experience, and exposure.

- **Conditions:**
  - Good leadership
  - Talented Staff
  - Training & Skill Development
  - Access to Technology & Staff interest to use it

- **Preferences:**
  - Wide variety of activities, classes, etc. to engage diverse groups of people; elderly, etc.
  - To access classes outside the center.
  - Engage volunteers to reach more people in the center.
  - Be a part of the community.

- **Strategic Focus:**
  - The Hub
  - Be a part of the Center!

- **Community Center Culture and Expectations:**
  - Missouri Family to Family
  - UMKC, HCED, UCEDD

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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.

Find a mentor.

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.

Giving ALL children chores, including those with disabilities.

Teaching interview skills.

Asking, “what do you want to be when you grow up?”

Reading to children from an early age.
National Community of Practice
For Supporting Families – Phase II

- 17 States believe in this
- New LC Ambassador Level Partners scattered across the country
- “IT” is built more (than in the beginning of Phase I)
- Now implementing more than Building
- More awareness of pressure points and strengths

VISION for Supporting Families Community of Practice (SF-CoP)
(What it IS)

- Space for INNOVATION to think differently
- Process for LEARNING
- Shared (equal) COLLABORATION to change and be changed
  - Healthy collaboration of all stakeholders (healthy tension)
  - Important roles of ALL/Important Place at the Table
- Change in Culture/Beliefs/Values that leads to Changed Behavior
- Driven by OUTCOMES (not outputs)
- Sustainable, embedded infrastructure for change
- Enhance work on existing issues/initiatives while learning LC Framework to think about person/family
- Connects with other initiatives (NOT just another project)
- CULTURE, VALUES, BELIEFS
- Balance where states are (current needs/issu(e)s) with LC Framework--- nudging one step

What It ISN’T/Don’t Want

- Train the Trainer
- Another Project or Program
- Only focused on Family/Family Support
- The answer, without the process of learning
- Tool to FIX something
- A template, a “thing”
- National Staff do the WORK
- Easy
- Only the State DD agency that needs to change

Developed by Missouri Family to Family at the UMKC Institute for Human Development, UCEDD mecfamilytofamily.org
Reframing the Conversation

Focus on the All

73%
(44,515)

11%
(6,980)

16%
(9,777)

Waiting for DDS services

Served by DDS

Inside the State System

- State Funded (group homes, assisted living, employment & respite) 1244
- Homeward Bound (class members) 683
- Community Waiver 3026
- In-Home Supports Waiver (Adults & Children) 1870
- Family Support Assistance Payment ($250) 2077
- Money Follows the Person (recent transitions) 211

27% under 21 yrs.
73% 22 yrs. + (estimated)

*Based on 1.58% prevalence of 3.878 citizens US Census (2014)
# Oklahoma: Waiting – Life Stages

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State Structures
Medicaid State Plans and Waivers

Employment and Community First CHOICES Waiver for Tennesseans with I/DD (Amendment 2)

- Family Caregiver Education and Training
- Community Support Development, Organization and Navigation
- Peer-to-Peer Self-Direction, Employment and Community Support and Navigation
3rd Annual Charting the LifeCourse
SHOWCASE 2019
WESTIN KANSAS CITY AT CROWN CENTER | KANSAS CITY, MO.
MAY 1–2, 2019
WEBSITE: LifeCourseTools.com
Contact Information
Sheli Reynolds
reynoldsmc@umkc.edu
816-235-1770