National Community of Practice on Supports to families

Dr. Michelle “Sheli” Reynolds, Co-Project Director
UMKC-Institute for Human Development, UCEDD
Barb Brent, Co-Project Director
NASDDDS
About Barb

• Director of State Policy, NASDDDS

• Co-Director of National Community of Practice on Supports to Families

• State Director of DD in 2 States
About Sheli

• Sibling of three brothers, one who is 32 years old with developmental disability

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

• Director of Individual Advocacy and Family Support, UMKC UCEDD
  o Supported the Self-Advocacy Movement for 12 years
  o Director of Mo Family-to-Family Health Info Center
  o Co-Director of National CoP on Supports to 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 than include a member with intellectual and developmental disability across the lifespan.
Project Outcomes

• 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 Service and Supports

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

Diagram:
- Community
  - Family
  - Services
  - Person
Families Support Members with I/DD

89% of People I/DD receiving services are living outside of residential supports

Defining Supports to Families

**GOAL**

**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 the individual to achieve their goal

Recognition that individuals exist within a family system

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**DISCOVERY AND NAVIGATION**
Knowledge & Skills

**CONNECTING & NETWORKING**
Mental Health & Self-Efficacy

**GOODS & SERVICES**
Day-to-Day & Caregiving/Supports
### Moving to Supporting Families

<table>
<thead>
<tr>
<th>Family Support</th>
<th>Supporting Families</th>
</tr>
</thead>
<tbody>
<tr>
<td>Defined by eligibility, services or programs available, or funding</td>
<td>Not a program or based on eligibility, it is needs defined by the families across the lifespan regardless of service provision</td>
</tr>
<tr>
<td>Caregiver or parent</td>
<td>Family is defined functionally; inclusive of siblings, parents with disabilities, grandparents</td>
</tr>
<tr>
<td>Tension between self-advocacy and family support</td>
<td>Enhances opportunities for self-advocacy and self-determination</td>
</tr>
<tr>
<td>Crisis, immediate response</td>
<td>Preventative, long-term planning</td>
</tr>
<tr>
<td>Supporting caregiver in order to decrease demand on long-term services</td>
<td>Creates a quality of life for person with DD and their family by supporting their many roles</td>
</tr>
</tbody>
</table>
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
Everyone exists within the context of family and community

Traditional Disability Services

Integrated Services and Supports within context of person, family and community
Core Belief:
All people and their families have the right to live, love, work, play and pursue their life aspirations in their community.
“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.
1 in 4 Persons with I/DD Receive Formal State DD Services

100%

4.7 Million people with developmental disabilities

75%

25%

National % Receiving State DD Services

** Based on national definition of developmental disability with a prevalence rate of 1.58%
Ohioans with Disabilities

183,188 estimated Ohioans with Developmental Disabilities

49% (89,737)

29%

20%

2%

Based on 1.58% prevalence of 3.815 million citizens, US Census
Connecticut Data

52,786 estimated Connecticut's with Developmental Disabilities

Based on 1.58% prevalence of 3.59 million citizens, US Census
Recognizing Lifelong impact of Family: Person Centered Supports within the context of family
Trajectory towards Life Outcomes

Focusing on Past, Present and Future Life Experiences

Friends, family, self-determination, community living, social capital and economic sufficiency

Vision of What I Don’t Want

• Adapted from “Life Course Theory” and Rethinking MCH: The Life Course Model as an Organizing Framework, HRSA, Maternal and Child Health Bureau
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)
Three Types of Supports

Discovery & Navigation
(Info and Training)

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

Goods & Services
(Day to Day, Medical, Financial Supports)
LifeCourse Integrated Supports STAR

**PERSON**

**FAMILY**

**COMMUNITY**

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

**Relationships**
- Family, friends, neighbors, coworkers, 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

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100%
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
Daily Activity Problem Solving

Focus Area

- Personal Strengths & Assets
- Technology
- Relationships
- Community Based
- Eligibility Specific
The Arc StL

Problem Solving for Info and referral
Focusing on Services and Supports
Mapping Services and Supports

**PERSONAL STRENGTHS & ASSETS**

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

**TECHNOLOGY:**
- i-pad

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

**COMMUNITY BASED:**
- Ben’s Services & Supports
- 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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<tr>
<th>Time</th>
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<th>Tues</th>
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<th>Thurs</th>
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Template by Missouri Family to Family "WAXC-WHD, UCEDD January 2015"
Calendar to Star/Planning

CHARTING the life course

Long Term Support Needs

<table>
<thead>
<tr>
<th>TIME</th>
<th>MON</th>
<th>TUES</th>
<th>WED</th>
<th>THURS</th>
<th>FRI</th>
<th>SAT</th>
<th>SUN</th>
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<tbody>
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<td>Dines, writes</td>
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<td>8:30 AM</td>
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<td>Breakfast, news, Church</td>
<td>Breakfast, news, Church</td>
<td>Breakfast, news, Church</td>
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<td>Breakfast, news, Church</td>
<td>Breakfast, news, Church</td>
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<tr>
<td>9:30 AM</td>
<td>House cleaning, grocery shopping</td>
<td>House cleaning, grocery shopping</td>
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<td>10:00 AM</td>
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<td>11:00 AM</td>
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<td>12:00 PM</td>
<td>Lunch, books</td>
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<td>2:00 PM</td>
<td>TV, Sports on TV</td>
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</table>

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.

Debbie

- Has
  - Great cook
  - Likes to read
  - Awesome garden
  - Her own home
  - Very knowledgeable
  - Does dishes
  - Jeans
  - Goes to church

- Wants
  - Computer
  - Internet
  - Cell phone

- Community Based
  - East Hills Church of Christ
  - TOPS
  - CABS
  - Somewhere she can be around cattle

- Eligibility Specific
  - Has
    - Social Security Administration
  - Wants
    - None to add

MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD
Ben’s Safety & Security Star

Focus on Supported Decision Making
Problem Solving:

- Employment is decreasing from 30 to 15 hours a week
- Parents are worried about who will provide supports during 15 hours not working
- Concerned about losing eligibility of services
Partnering with People with Disabilities and their Families so they can Engage, Lead, and Drive Policy and Systems Change
Supporting Families in Connecticut
What is Connecticut’s Vision for Supported Families?

Write down your responses on your worksheet & discuss with your table
What DON’T you want??

What happens when families aren’t supported?

Write down your responses on your worksheet & discuss with your table
Constructing Universal Strategies for Supporting Individuals with Disabilities and Families Across the LifeCourse

Community Resources

- Public-Private Partnerships
- Government

Accessed by all citizens:
- Faith based communities
- Parks and Recreation
- Businesses
- Emergency Personnel

Long Term Services and Supports

- Family and Self-Advocacy Networks
- Aging and Disability Resource Centers
- No Wrong Door Initiatives
- Area Agencies on Aging
- Parent Training Info Centers for Education
- United Way 211
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
Reframing for All Stakeholders: Disseminating Broadly
Reframing for All Stakeholders: Focused Education and Training

- Self-Advocates and Families
- Partners in Policymaking Classes
- Person Centered Planners
- Teachers and School Professionals
- Employment Professionals
State Structures
Connecting Families to Support at the Front Door

State DD Agency
- Intake and Eligibility for State Division of DD and Medicaid Waiver services
- Person Centered Target Case Management and Support Coordination
- Provision and oversight of long term services and supports
- On-going quality enhancement and data collection of services and supports

Missouri F2F Resource Center
Parent-to-parent peer support for families of CYSHCN:
- Recruits and trains family mentors
- Maintains a pool of over 400 trained mentors
- Assists with creating timely and effective peer matches
- Provides follow-up support
- Evaluates outcomes
- Provides information on community resources
State Structures
Support Coordinator Training

Person Centered Planning

- Eligibility Services
- DDS Services
- Community
- Assistive Technology
- Strengths & Assets Planning
State Structures
Person Centered Planning and HCBS Rules

Learning Opportunities Quality Works, Inc.
Initial and Annual Assessment

Consumer Name (first, middle initial, last name):  
LOQW, Inc.  Date of birth:  

Instructions for use: Mark if this assessment is annual or initial assessment. Meet with the individual and support members of their choice, ask each question in sequence. Answers should be recorded in full sentence form so that when they are read to someone the answer makes sense, and should not be automated.

Initial Assessment  Annual Assessment

Contributing staff or family:  

Community Living
Living Arrangement:
Do you like where you live and who you live with? Are there any modifications to your home needed to carry out, stuff, tasks, etc.? Do you feel safe when you are at home?  

Transportation and Community Access:
Are there nearby places you like to go and how do you get there? What support do you need, if any, to access your community?  

Is there anything you would like to learn how to do as a hobby or a special interest to you?  

Social and Spirituality
Communication:
Who are your family and friends that are most important to you and what do they enjoy doing together?  

How do you communicate with your family and friends (Verbal/Nuverbal, letters, phone, email, sign language, communication devices) and is there a way you could make more frequent contact?  

Missouri Quality Outcome
Citizenship & Advocacy
People Have Opportunities to Advocate for Themselves, Others and Causes They Believe In, including Personal Goals and Dreams

About This Outcome
This outcome emphasizes the importance of self-advocacy. Training and ongoing support are often time requires to assist an individual in developing their self-advocacy skills.

Icons:
- Daily Life
- Community Living
- Social Spirituality
- Healthy Living
- Safety & Security
- Citizenship & Advocacy
- Supports to Families

All Charting the Life Course category logos and graphics from the Missouri Family to Family Resource Guide, and can be found at: http://mhdss.mo.gov/family/resources
Draft ISP Template
Integrating Systems and Initiatives: Youth Transition and Employment

SUPPORTING FAMILIES of individuals with intellectual & developmental disabilities
THE NATIONAL COMMUNITY OF PRACTICE FUNDED BY THE ADMINISTRATION ON INTELLECTUAL DEVELOPMENTAL DISABILITIES

SHOW-ME-CAREERS MISSOURI'S TRANSITION TO EMPLOYMENT COLLABORATIVE

Statewide Employment Leadership Network (SELN)

Employment First State Leadership Mentor Program
Adult Employment Trajectory

**Employment Trajectory Worksheet:**

- Contributions:
  - Skills, Experience, Attributes, Talents
  - Hard Working
  - On time / prompt / reliable
  - Wakes up around 6 am
  - Motivated by money
  - Will pick up extra shifts
  - Knows what cleaning supplies are used while cleaning the restroom and how to use them safely
  - Showers and wears clean clothing each day
  - Will work weekends

- VISION for good employment and a GOOD LIFE
  - Long term employment desires and goals:
    - Kenny would like to find a job that he is good at and enjoys for long term employment. Kenny enjoys custodial work and finds that it is a good match for him. He finds it very important that the factors under "What I DON'T Want" are respected when job seeking.
    - Kenny’s ultimate goal is to find full time employment with benefits and to live independently. Kenny understands that this can only happen when it is considered safe for himself and everyone else.

- Conditions:
  - Part-time employment
  - Line-of-site supervision at all times
  - Make at least minimum wage
  - Co-workers / staff are respectful to him

- Preferences:
  - Would like to work indoors when the weather outside is too hot
  - Custodial employment
  - Cutting grass

- Support Needs:
  - Assistance learning the routine and new job tasks
  - Reminders to be clean shaven
  - Transportation to and from work from Carrs
  - Audio learner with demonstration as needed

(May include: Schedules, Salary, Benefits, Appearance, Learning Style, Supervisor Interaction, Environment, etc.)

MISSOURI FAMILY TO FAMILY | UMKC-IHD, UCEDD

MAY 2014
No Wrong Door SYSTEM

Focus of CoP Supports to Families and DD System:
- Support Coordination
- Person Centered Thinking, Planning, and Facilitation
- Family Navigation and Family Networks
- LifeCourse Framework and Tools
- Responding to new CMS HCBS rule
- Focusing on Front Door of DD Services
State Structures
State Waitlists

Strategies:
1. Strengthen Information Access
2. Provide Resource Navigation and Improve Inter-Agency Service Coordination
3. Provide family-to-family support to individuals and families who are currently on the Waiting List or who apply for Waiver Services.
4. Assess needs of families currently on the Waiting List.
5. Build capacity of services and supports outside of those provided through DDS waivers.
Organizational Strategic Thinking: Evolving Day Habilitation Services

**Community Center Trajectory Worksheet:**

**Organizational Contributions:**
- Skills, Experience, Attributes, Talents that contribute to the culture.
- 30 plus years providing services and supports.
- Experience in Targeted Case Management (TCM).
- Experience in networking and partnering.
- Early adopters of new ideas.
- Active in the Community.
- Embraces change.

**Vision for the New Community Center and its role in a GOOD LIFE for people in our community:**

**Long term desires and goals:**
- It is our long term goal that the new Community Center be a hub for community life engagement activities in Monroe City. Promoting personal growth through opportunity, experience and exposure.
- It is our vision that the Community Center will become part of the larger community, viewed as a resource and a valuable part of the inclusive diverse community that people engage in and promote to others.

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

**Preferences:**
- Wide variety of activities, classes, etc. to engage diverse group of people (ages, etc.)
- To access classes outside the center
- Engage volunteers to teach some classes in the center and utilize talents in the Community
- Financial Support to assist in Center operation

**Vision:**
- Fun Activities
- Participation by Individuals
- Participation by the Community
- Community Engagement
- Real Life Experiences

**Integrated Services and Supports for Community Center**

**Technology**
- Social Media
- Facebook, Pinterest
- YouTube Videos & TED Talks
- Comfortable using laptops, iPad, Projectors, and other devices.

**Personal Strengths & Assets**
- Enthusiastic & Motivated
- Wants to have fun & likes others to have fun!

**Relationship Based**
- Advocacy Skills
- Values Community
- Values relationships with community and others
- Support People First and Serve as local Chapter Advisor for Monroe City
- Recruit & Organize Volunteers
- Provide outreach and Motivate people to join in

**The Hub**
- Be a Part of the Center!

**Community Center Culture and Expectations**

**Community Based**

**Eligibility Specific**

**Planning and Research for Center**
- Identify needs and how to meet them
- Comfortable with a diverse group of people
- Celebrates differences and diversity in a group.
- Comfortable utilizing Tools for Choice and other tools to support people with challenging behaviors
- Communicates in a comfortable way to all visiting: People who Need Support / Bring Support!
2015 Outcome Trajectory

Staff who are having success:
- Coley, Jan, Molly, & Suzanne - 100% LOC Completion
- Jill - 100% ISP Implementation
- Jill & Molly - 100% accuracy on Logging Audits
Judy was the only staff to bill 69% in a quarter
- Suzanne, Jan, Jill, Molly, Judy & Amy got 100% satisfaction feedback from individuals served.

What’s Working:
- Team work! (Google Chat) - We’re a small team with many skills
- Our new ISP which focus more heavily on quality of life
- LifeCourse tools developing more valuable monthly visits
- Further connections with schools through Job Clubs
- Team meetings

Projected Outcomes for TCM
- 95% of ISP’s will be approved by the consumer/guardian and SCS prior to implementation date
  Met at 93.47%
- 69% of Service Coordination time will be directly with or for consumers
  Met at 65.75%
- 100% of LOC’s will be completed within 365 days of previous LOC.
  Met at 93.98%
- Logging entries will be completed within 72 hours of the time the activity was completed. 100% of the time.
  Met at 99.01% (July-Dec)

Obstacles/ What is not working
- Only 1 person met our goal of billing 69% in one quarter throughout the entire year
- Documenting indirect time
- Tracking to ensure individuals are seen regularly – need examples of what works
- Need to keep SC’s updated on feedback from Satisfaction surveys
- SM form
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
What does K Plan: Community First Choice change about our current system?

**Current:**

- **Entitlements (State Plan):**
  - Institutional
  - Home and Community-Based
- **Other Medicaid:**
  - Medicaid Personal Care: *Personal Care*
  - Waivers:
    - Personal Care
    - PERS
    - Equipment
    - Assistive Technology
    - Home Modifications
    - Respite
    - Therapies
    - Habilitation
    - Employment Support
    - Other

**Future:**

- **Entitlements (State Plan):**
  - Institutional
  - Home and Community-Based
- **Other Medicaid:**
  - New - Community First Choice:
    - Personal Care
    - Required CF CO Services
    - Optional CF CO Services?
    - More Flexibility?
    - Improved outcomes
  - Waivers:
    - Will look different in some cases
    - May become more of a wrap-around service to CF CO?

*Current: client is eligible for one or the other*

*New: A client is potentially eligible for both*
Connecticut Community of Practice
Celebrating the Last Four Years
Connecticut Successes

- Promotion of use of Charting the LifeCourse materials and tools across systems and organizations
- LifeCourse Ambassadors
- Family members are disseminating LifeCourse materials to other families
- CT DDS Integrated Supports Options document
- IP Committee is working to incorporate LifeCourse materials in the DDS IP
Connecticut Successes
Flyer on Transition Stages
CT Life Experience Booklet
CT Daily Life & Employment Booklet
Front Door Experiences: Eligibility & HelpLine
Connecticut Successes

- Advocates Corner provides self-advocates with information about self-advocacy and self determination
- The Family to Family Connections brochure provides information about family groups that can be useful allies to families.
- The Connecticut Sibling Connection is an organization with the mission to support siblings of individuals with disabilities.
- Peer to Peer Supports is a new waiver service offered to people served by CT DDS. This empowering service allows DDS consumers to get paid to help mentor and support their peers.
- Family Mentoring Group formed to bring together family organizations for communication exchange
Connecticut Successes

- SERC is using LifeCourse materials in teacher trainings
- LifeCourse training has been provided at all of the CONNCASE regional meetings
- Teachers and transitional staff are beginning to use LifeCourse materials in schools
- LifeCourse trainings have been provided to DSS staff
• The DD Council, UCEDD, OPA, and CT Tech Act staff are partnering with DDS in implementing the DDS Good Life Technology Campaign

• SERC and the Tech ACT demonstration sites have expanded to include technology for people with IDD

• An AT lifespan brochure has been created to help people understand their rights regarding AT

• DDS has contracted with TYZE so that families can access this service free of charge
A Positive Behavior Support brochure and PBS family video has been developed to help families understand how positive behavior supports can be beneficial across the lifespan.

A Respite Brochure has been developed to help families understand the variety of types of respite supports that are available to families.

An In-Home Supports COP committee has developed training materials for providers.

A recreation COP committee has developed a social skills pilot at a DDS respite center.
Mapping Connecticut’s Successes
Reframing at All Levels
Next Steps for Year 4/5
Reframing at All Levels
National CoP Next Steps: Supporting Families Focus Areas Year 4 & 5

Providers Partnering with Families
Self-Directed Supports and Families
Goods and Services Specific to Family or Caregiver
Building Capacity of Community to Support Families
Ways to Get involved!

NASDDDS June 2016 Conference Website
State Updates
LifeCourse Framework Resources
Listserv for Project Highlights
Webinars (Quarterly Live and Archived)

supportstofamilies.org
Contact Information

Sheli Reynolds
reynoldsmc@umkc.edu

Barb Brent
bbrent@nasddds.org