

Focusing on Families:

A Priority of DMH

Division of Developmental Disabilities



Michelle "Sheli" Reynolds, SIBLING, PhD
Director of Individual Advocacy and Family Support
University of Missouri- Kansas City
Institute for Human Development
University Center on Developmental Disabilities
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About Me

- **Sibling of 29 year old brother with developmental disability**
- Director of Individual Advocacy and Family Support at UMKC Institute for Human Development, *University Center on Excellence in Developmental Disabilities*
 - 12 years supporting the **self-advocacy movement** (People First of MO and SABE)
 - Director of Mo **Family-to-Family** Disability & Health Information Center (formerly MODDRC)

Family Support and My Family



My Role with DMH DDD

- Contracted by DMH Division of Developmental Disabilities to identify strategies to “support families across the lifespan” in their role in the lives of individuals with developmental disabilities
 - Support Key DMH-DDD staff to develop a plan and a consistent message
 - Share Message with DMH DDD staff and stakeholders
 - Build capacity of Family Support Coordinators
 - Assist in hosting March DMH DDD Conference



HISTORY OF THE FIELD AND THE ROLE OF THE FAMILY

Why Unchartered Waters??

- ❑ **Journey:** Recognizing life is not static
- ❑ **Exploring:** identifying new options and possibilities
- ❑ **Navigating together:** Sharing responsibility
- ❑ Our overall compass is “**dignity**” and “**quality of life**”



Charting the Life Course

Charted

Slightly Charted

Uncharted

- *Removes value judgments and blame*
- *Not a continuum, but current or historical options*
 - *Does not imply a state is or isn't doing*
- *Allows for comparison of where you are and where to go*



Factors that Impact Evolution

- Societal
 - Beliefs and Values
 - Federal Laws and Policy
- Economic
- Theory and Practice

EVOLUTION OF Understanding

Era	On Family	On Disability Services
1800s	Moral blame assigned to parents	Removal from Society
1900s	Child damaged families	Removal from Family
1950s	Burden of Care-giving	Specialized Services
1980s to Now	Families seen as system Positive Coping, adaptation and Resiliency	Inclusion and Integration Self-Determination Community Membership Family Support Services

Charting the Future of Disability Services





**MISSOURI DEVELOPMENTAL
DISABILITY SERVICE SYSTEM**

Missouri DMH DDD

Roadmap to Supports and Services

- ❑ Implementing contemporary best-practices
- ❑ Improving communication between all stakeholders
- ❑ Build comprehensive quality assurance and management system focusing on outcomes
- ❑ Restoring a focus on flexible individualized supports
- ❑ Local service delivery

*Simon, Bernard (April, 2009)

MoDDD Five Year Priorities

- Individual Advocacy and Family Supports
- Employment
 - Integrated, Community Employment
- Housing Options
 - Affordable and Accessible
 - Environmental Adaptations
- Individualized Service Options
 - Self-Directed Services
 - Shared Living

DDD 5 Year Priority	Goal	Regional Office Restructure Positions
Individual Advocacy & Family Supports	Connect individuals with I/DD and their families to information and training, peer support and other goods and services.	Advocacy Specialists Family Supports Coordinator Autism Navigators
Housing	Enhance access and connect individuals with I/DD to person-focused environments and/or affordable and accessible housing in the community.	Community Living Coordinators
Employment	Enhance access and the connect individuals with I/DD successfully employed in integrated community employment leading them to become economically self-sufficient.	Employment-Youth Transition Coordinators
Individualized Supports	Enhance capacity of service coordination to connect to individualized supports and services that are person- and family-centered, foster natural supports, and utilize community resources.	Target Case- Management Technical Assistance
	Enhance awareness, access and capacity of self-directed options.	Self-Directed Supports Coordinators
	Enhance capacity of providers to provide individualized supported living, emphasizing shared living and technology-based options.	Provider Relations
	Build the capacity of disability service system to provide person-centered tiered supports, focusing on behavior prevention and intervention.	Behavior Resource Teams



Stakeholders

People First of Missouri
Mo Family-to-Family Stakeholders
The Arc of Missouri
Mo Commission Autism
Autism Centers on Excellence
Missouri Autism Advisory Committee
Mo Parent Advisory Councils on Autism
Autism Rapid Response Statewide/Local
Mo Housing Corporation
Statewide Employment Leadership Network
APSE-MO
Community Transition Teams
Rehab Service Council
MACDDS
Self-Directed Stakeholders Group
Mo Self-Determination
New Fiscal Intermediary Advisory Group
MARF
Mo Developmental Disability Council
Regional Advisory Councils
Statewide Quality Advisory Council
SAFE



**FOCUSING ON FAMILIES
ACROSS THE LIFECOURSE**



Using DATA to Refocus

- National
- State
- DMH Division of Developmental Disabilities

History of Supports to Families

<i>Chartered</i>	<i>Slightly Chartered</i>	<i>Unchartered</i>
<p><i>Programs provided by services system to person:</i></p> <p><i>Case-management</i></p> <p><i>Providers</i></p> <p><i>Group homes</i></p> <p><i>Independent Supported Living</i></p>	<p><i>Services provided in the family home:</i></p> <p><i>Person-centered planning</i></p> <p><i>Cash-Subsidies</i></p> <p><i>Respite</i></p> <p><i>Home Modification</i></p>	<p><i>Supporting the Family System:</i></p> <p><i>Instrumental Services</i></p> <p><i>Emotional and Self-Efficacy Support</i></p> <p><i>Information and Training</i></p>

Supports to Families

Instrumental Supports: <i>Day-to-Day Needs</i>	Emotional Supports: <i>Mental Health and Self-efficacy</i>	Information and Training Supports: <i>Knowledge and Skills</i>
<ul style="list-style-type: none">• Respite/Childcare• Adaptive equipment• Home modifications• Financial assistance• Service Coordination• Cash Subsidies• Person/family-centered planning	<ul style="list-style-type: none">• Parent-to-Parent Support• Self-advocacy organizations• Sib-shops• Support Groups• Professional Counseling• Non-disability community support	<ul style="list-style-type: none">• Information on disability• Knowledge about best practices and values• Skills to navigate and access services• Ability to advocate for services and policy change

Objective of Supporting Families

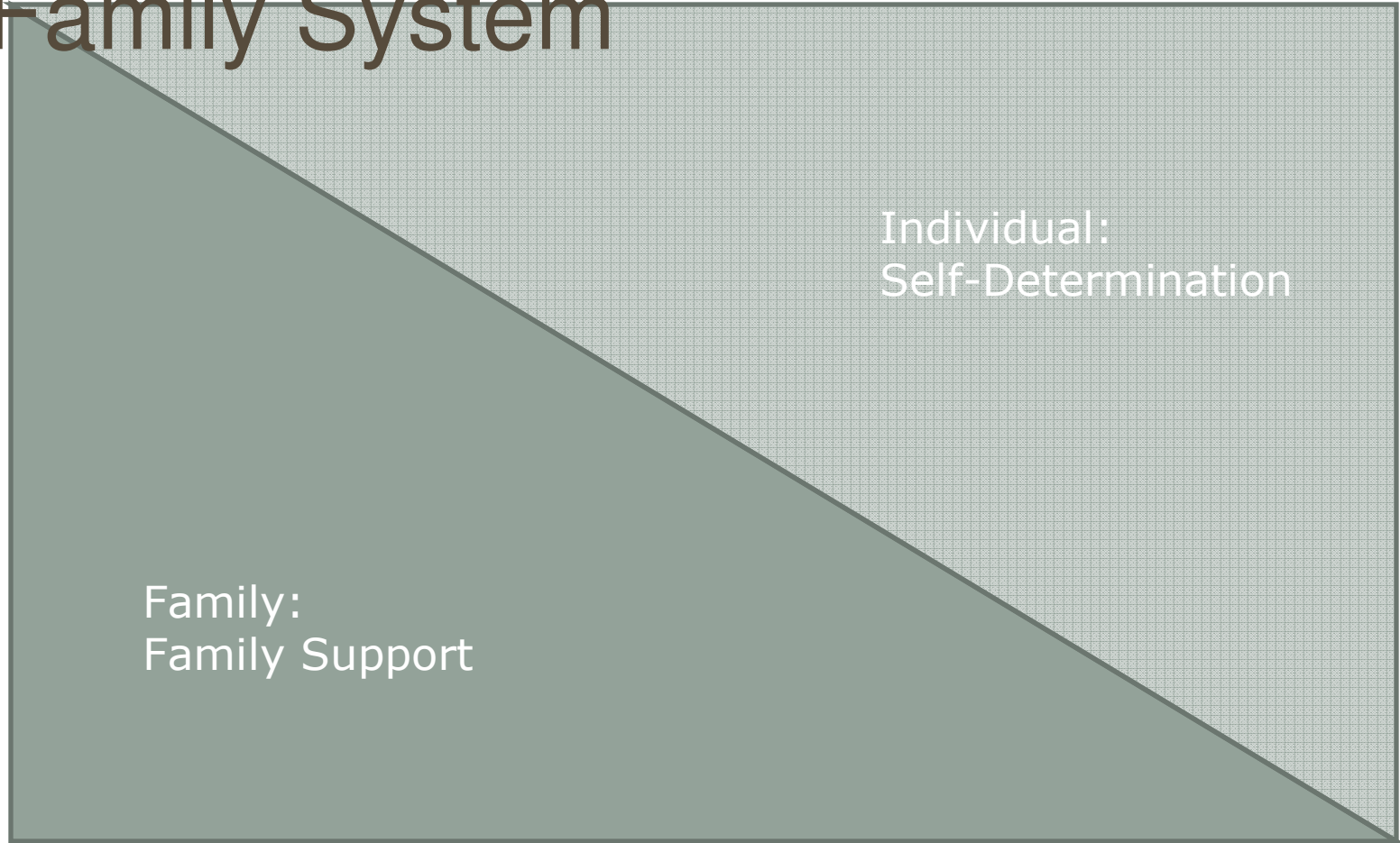
To support families, with all their complexity and diversity, in ways that maximizes their capacity, strengths and unique abilities

so they can best support, nurture, love and facilitate

- ▣ the achievement of self-determination, interdependence, productivity, integration and inclusion in all facets of community life for their family members.

▣-definition from National Agenda on Family Support Conference, 2011.

Supporting the Individual in the Family System



Birth-----School-Age----Transition-----Adulthood-----Aging-----Death

Eric's Uncharted Life



***Life isn't
about how to
survive the
storm, but
how to dance
in the rain.***

-unknown



Contact Information

Department of Mental Health

<http://dmh.mo.gov/dd/>

Bernie Simons, Director

UMKC-Institute for Human Development

Sheli Reynolds

reynoldsmc@umkc.edu

816.235.1759