1 Section One

- System of Care – How a Community Takes Care of Its Own
- History of the Utah Family Coalition
- Vision and Mission of the Utah Family Coalition
- System of Care Study and Review Questions
Section 1: System of Care
HOW A COMMUNITY TAKES CARE OF ITS OWN

**Definition:** System of Care has been defined as How a Community Takes Care of Its Own. A system of care defined as a broad flexible array of effective services and supports for a defined multi-system care management across multiple levels, is culturally and linguistically competent, builds meaningful partnerships with families and with youth at service delivery, management and policy levels, has supportive management and policy infrastructure, and is data-driven. (Primer, 2010)

**Purpose of System of Care:** To provide Family Resource Facilitators with knowledge and information about family involvement, support, and development at all levels; about partners in their community and for modeling values and principles of Systems of Care.

**Participant Objectives:**

- Understand the history of the Family Movement.
- Identify community partners in the system of care for his/her own child and family and briefly describe the role of each.
- Identify and describe values and principles of a system of care.
- Identify family involvement at all levels (i.e., policy level, management level, and service level).
- Understand cultural competence in the area of family culture.
What is a System of Care?

The term “System of Care” was first used in a book published in 1986: *A System of Care for Children and Youth with Severe Disturbances* written by Stroul and Friedman. Many of you have heard the term used around the State. It is used to describe an interwoven netting developed by a family, to provide services and supports for their child and family in partnership one with another. The word “system” may have a clinical, cold, agency sound to it in our world, but when we put it into personal experience, it becomes meaningful. The definition of System of Care is based on a set of values and principles which ALWAYS place the Child and Family at the Heart of any and all services. No matter how you look at it, the Child and Family are the hub of the wheel.

What does a System of Care look like? Here is one way to look at it:

What we know about infants and young children is that they are dependent upon adults…their family and, in some cases, caregivers. Think about the newborn infant. What can newborns do for themselves? They are completely dependent upon adults to meet their needs. As they develop, they gain skills to meet some of their own needs, but this is gradual.

When we think of a child who needs specialized services, who makes the decisions regarding the individual and family? Who does that decision impact? Answer: the child AND the family. The Child and Family are at the Heart of all services and decisions as partners.

The characteristics of the System of Care are summarized below:

- Child Centered
- Family Driven
- Culturally Competent
- Individualized
- Strength-Based
- Community Based
- Collaborative
- Inter-agency
- Cost Responsible

**ACTIVITY NO. 1:**
What does the System of Care look like for your child and family? Go to the Supplemental section of the manual under Activities. Activity 1 is a paper with a circle on it named: The System of Care for my child and family. Your task is to label and draw the System of Care for your child and family.
VALUES AND PRINCIPLES FOR THE
Community of Care (SYSTEM OF CARE)

Core Values: The System of Care should:

1. Be child centered and family focused, with the needs of the child and family dictating the types and mix of services provided.
2. Be community based, with the focus of services as well as management and decision-making responsibility resting at the community level.
3. Be culturally competent, with agencies, programs, and services that are responsive to the cultural, racial, and ethnic differences of the populations they serve.

Guiding Principles

1. Children with socio-emotional and developmental delays should have access to a comprehensive array of services that address their physical, emotional, social, and educational needs.

2. Children with socio-emotional and developmental delays should receive individualized services in accordance with the unique needs and potentials of each child and guided by an individualized service plan.

3. Children with socio-emotional and developmental delays should receive services within the least restrictive, most normative environment that is clinically appropriate.

4. The families and surrogate families of children with socio-emotional and developmental delays should be full participants in all aspects of the planning and delivery of services.

5. Children with socio-emotional and developmental delays should receive services that are integrated. These provide linkages between child-serving agencies, programs and mechanisms for planning, developing, and coordinating services.

6. Children with socio-emotional and developmental delays should be provided with case management or similar mechanisms to ensure that multiple services are delivered. These must be coordinated and therapeutic in supporting them to move through the system of services in accordance with their changing needs.

7. Early identification and intervention for children with socio-emotional and developmental delays should be promoted by the system of care in order to enhance the likelihood of positive outcomes.
8. Children with socio-emotional and developmental delays should be ensured smooth transitions to the adult services system as they reach maturity.

9. The rights of children with socio-emotional and developmental delays should be protected. Effective advocacy efforts for children and adolescents with emotional disturbances should be promoted.

10. Children with socio-emotional and developmental delays should receive services without regard to race, religion, national origin, sex, physical disability, or other characteristics. Services should be sensitive and responsive to cultural differences and special needs.


Key Components of a System of Care:

- Family Involvement at every level of activity (management, policy, and service delivery).
- An inclusive interagency agreement has been developed which indicates their support of the values and principles of the System of Care.
- Child and Family Teams are formed across community partners to create and implement individualized services and support plans.
- Support and service plan goals are monitored and measured with participant satisfaction emphasized.
- Sufficient funding is available to meet the service and support needs identified in the plan of care.
- Each family has access to Family Resource Facilitators.
- Training and regular interaction is provided to all participants across the community.
- Transition plans are ensured, including into adult life.

ACTIVITY NO. 1A:
Now that you know a little more about a System of Care: read the Family Resource Facilitator, System of Care in the Supplemental Activities section and draw a System of Care Model for Emma and her family. Think of the model we discussed earlier.
HISTORY OF THE FAMILY MOVEMENT
The mental health care system was not working for children. Following are events that began the family movement:

- Families suffered from blame and shame
- Families were labeled “dysfunctional”
- The service system was fragmented
- 1982: Jane Knitzer’s Unclaimed Children: The Failure of Public Responsibility to Children and Adolescents in Need of Mental Health Services
- 1986-1988: Training families as allies
- 1988: PSU “Next Steps” conference
- 1989: Steering Committee meeting and founding of the National Federation of Families for Children’s Mental Health
- 1992: The Federation received funding and the first executive director was hired
- 1999: “Family Involvement”
- 2000: “Family-professional partnerships”
- 2003: Key family contact FTE, youth coordinator FTE, support for family-run organizations, family and youth involvement in systems evaluation design, interpretation, and reporting of evaluation
- 2005: “Family Driven” and financial support to sustain family involvement throughout and beyond the Federal funding period
- 2003: The President’s New Freedom Commission on Mental Health issued Achieving the Promise: Transforming Mental Health Care in America
- Goal Two: Mental health care must be consumer and family driven.

SEE SUPPLEMENTAL – HANDOUTS – H-1
Handout No. 1: Family Driven Care – Federation of Families for Children’s Mental Health

FAMILY INVOLVEMENT, SUPPORT, AND DEVELOPMENT AT ALL LEVELS (i.e., Policy Level, Management Level, Service Level)

“In effective systems of care, families are partners at the policy making, management and service levels of the system with other key stakeholders. Effective systems do not simply invite families to be part of the process—although asking families if and how they want to be involved is a critical first step. They also actively support and engage families in a number of ways, for example, by providing tangible supports such as transportation, translation, and child care assistance; by recognizing and drawing on the knowledge and skills that parents bring to the table (e.g., utilizing parents as trainers of other stakeholders); by providing capacity-building support that gives families the information, skills, and confidence to partner such as training and peer and non-peer mentoring; and by asking families how they would like to be involved. Effective system builders recognize that families are diverse—racially, ethnically, linguistically, socio-economically, and in family composition, and thus they utilize multiple strategies and structures for family involvement and support.”
“There are increasing examples of how systems of care are structuring family involvement at the various levels of the system. At the policy level, for example, families may comprise the majority vote on governance bodies; they may be part of the team that writes and reviews Requests for Proposals and contracts; they may participate on system design workgroups and on system advisory bodies. At the management level, families may be actively involved in quality improvement processes, evaluating system performance, in helping to recruit and select personnel, and training activities. At the service level, in addition to the role that families play with respect to their own children, they may be service providers, care managers, family support workers, peer mentors, system “navigators,” and advocates on behalf of other families.” (Building Systems of Care – A Primer; Sheila A. Pires, Georgetown University Child Development Center, page 73.)

| How Systems of Care are Structuring Family Involvement at Various Levels of the System |
|---------------------------------|---------------------------------|
| LEVEL                      | STRUCTURE                                                                 |
| Policy                     | At least 51 percent vote on governing bodies                              |
|                            | As members of teams to write and review RFPs and contracts                |
|                            | As members of system design workgroups and advisory boards               |
| Management                 | As part of quality improvement process                                   |
|                            | As evaluators of system performance                                      |
|                            | As trainers in training activities                                       |
|                            | As advisors to selecting personnel                                       |
| Services                   | As members of the team for their own children                             |
|                            | As family support workers, care managers, peer mentors, system navigators or Family Resource Facilitators for other families |

(Utah Family Coalition of Family Involvement at all Levels:

- Three family organizations talked with families, agencies and community stakeholders about the need for using a common definition of what is “family involvement” in our communities.
- Designed a working model of a definition using our experience working with families in systems work.
- Reviewed a draft with families, agencies, and community partners to refine our view of this key system of care principles.
- Continue to share and refine based on the strengths, needs, and culture of the community.)
FAMILY INVOLVEMENT AT ALL LEVELS

A trained facilitator who has the core competencies to act as a guide for new families. Facilitate a team and work as a partner with professional to ensure a full range of treatment and support service programs are in place. (Paid staff)

Ready to change things and build a community that supports consumers and their families with complex needs. (Paid staff building and running community owned programs, this also includes community outreach to build relationships with key community partners and families and educating the public about Mental Health issues to reduce stigma). Service provision.

Ready to join with other parents to receive support from families in a similar situation. Education on how to help your family progress (support group)

Building Self Awareness and Advocacy - A youth/child/family comes into services (Personal Involvement / input into your individual service/team plan)

A Family is struggling looking for answers (intake and referral)

Continues - Families/Youth and Consumers are always receiving education and training, as well as advocating for system change with system partners and legislative partners.
ACTIVITY NO. 2 – Is It Too Much to Ask

FAMILY CULTURE:

If we are to be competent in family culture, we need to find out how a family operates. Possible questions to ask:

- What do parents like most about their children (looking for parent preferences and differences)?
- We ask what their goals are. What would life look like if things were better? We ask parents what their goals are for their children. We find out what they see as their biggest accomplishments.
- We find out what makes the parents and the child(ren) happy. We ask parents about their favorite memories of their own families.
- We find out how the parent is a parent – what they see as their best qualities.
- We find out if the family has special rules.
- We discover who their family’s friends are, who they call when they need help or want to talk, and who they consider to be supportive. We find out how the family has fun, what they prefer to do.
- We find out about special values or beliefs that they learned from their parents or others.
- We ask about their connections to the faith community or if and how they worship.

Working together a step at a time, this training will provide you with the basic knowledge and skills to get you on your way. Remember, one step at a time.

One child and family at a time.
HISTORY OF THE UTAH FAMILY COALITION
2008

The Utah Family Coalition is the joining of NAMI Utah, Allies with Families, and New Frontiers for Families. Combined they have over 30 years of experience in providing education, support, advocacy, information, training to families and professionals in the mental health field.

The purpose is to train and mentor Family Resource Facilitators (FRF). These are family members whose lives have been affected by a child with emotional, behavioral and mental health challenges. Located across the state, FRFs provide support to families and individuals faced with emotional, behavioral and mental health needs. Through the peer support of the FRF, families and individuals are provided the help they need. This support is designed to meet the needs of each family and can include: learning of and access to needed community resources; Wraparound facilitation, the gathering of those who can help; and ultimately supporting each family in developing a family voice. Ultimately, the family can positively impact not only their own treatment plans but the Local Mental Health Authority and their own community culture.

The Utah Family Coalition has developed standard competencies for the FRFs and has put in place mentoring programs to provide on-going, on-site coaching. This insures that the local FRFs have the supports they need to be successful and assure similar training and supervision across state.

The Coalition members provide training for staff at the local mental health centers as well as other community agencies and partners. These trainings are designed to help all partners understand “family involvement at all levels” and “family voice”.

THE UTAH FAMILY COALITION

VISION:

The Utah Family Coalition envisions a collaborative system of services that effectively supports and encourages authentic family voice and involvement at all levels of treatment. The vision includes a seamless service system that promotes family cohesiveness and effectively pools resources to meet the needs of children and families within their own homes and communities.

MISSION:

Our mission is to assist families and youth in accessing appropriate community based services and supports to develop an educated, authentic family-youth voice for advocacy and systems change utilizing the following strengths-based practices:

- Peer to peer coaching, mentoring and advocacy
- Community education and support
- Collaboration with community partners
- High Fidelity Wraparound