



FAMILIES SPEAK OUT
Iowa Family Choices Conference 1999

The First Iowa Family Choices Conference was held in Cedar Rapids, IA April 30-May 1, 1999. Families of children and youth with emotional and behavioral challenges met to share and create the following recommendations regarding state-of-the-art Iowa system of care based on their own field experience as a family and the unique insight, only they can render. The “Dream 2000” can become a reality!

SYSTEM OF CARE--FAMILY EMPOWERMENT

- Listen to children, youth and their families
- Talk with, not at or down to, families
- Begin with the strengths and vision of the child and family
- Respect and honor the vision of what the child, youth and family have for their future
- Recognize families as knowledgeable resources for their children and youth
- Utilize humor to help everyone feel equal and relaxed in the collaborative process
- Create a balanced view of the family; seeking input from all family members and service providers and reducing the likelihood that decisions will be made without enough information
- Maintain the integrity of the family with family reunification the primary goal for children and youth placed outside the home
- Acknowledge that families are experiencing normal reactions to their situations instead of being perceived as dysfunctional or at-risk when instead they are experiencing a serious lack of appropriate, accessible and affordable services
- Listen to families and validate the behavioral challenges they are experiencing with their children
- Honor the way families have developed and coped while offering new skills, tools and techniques to cope
- Promote families and professionals trusting one another
- Encourage families to bring an advocate to help, listen and support them
- Create environments that are conducive to collaboration
- Involve all family members in all meetings and all decisions regarding their child or youth
- Bring an open mind to all meetings and avoid preconceived notions or ideas about families
- Promote complete collaboration between families and professionals regarding every decision made about their child or youth and their family
- Actively brainstorm with all members of the team, including family members, and encourage each member to offer their ideas
- Proactively communicate; do not wait for problems to be solved

- Remove barriers and normalize honest communication i.e. police involvement, fear of recrimination, having a child removed from parental custody, abuse investigation, and parental access to records
- Stress the importance of confidentiality reducing the gossip about family issues
- Respect family privacy by providing interventions with the least amount of intrusion as possible
- Promote and offer family to family support and mentoring
- Promote and offer family to professional support and mentoring
- Understand that even the best solution to a problem can cause pain, grief and adjustment challenges for the family
- Make the safety of all family members a priority
- Ask the question, “Would this situation be treated the same way if it were a different disability?”
- Ask the question, “Would this situation be treated the same way if it were my child?”
- Ask the question, “Am I making an assumption finding the family at fault?”

SYSTEM OF CARE—GENERAL

- Allow families to designate a lead agency to coordinate services for their family rather than forcing predetermined service coordination
- Consider the family to be designated the “lead agency” to coordinate their own services
- Consider hiring personnel with personal family experience as case managers
- Hire creative professionals who are willing to dream and to take risks to improve the quality of available service and support options
- Place an emphasis on professionals that are effective rather than those with the most credentials
- Mandate families evaluate provider and system performance on a formal basis
- Offer professional sensitivity training reducing the stigma and judgements regarding families
- Recommend administrative professionals spend time with families to increase and renew their insight and understanding of family strengths and needs
- Train professionals—law enforcement personnel & emergency medical personnel—on how to deal with children and youth and families with emotional and behavioral challenges
- Develop one comprehensive plan working towards the family’s vision of their future
- Develop one comprehensive plan supporting the entire family rather than each agency involved and/or each individual having one or multiple plans
- Develop one comprehensive plan with the most effective services supporting the family as a whole rather than in pieces
- Empower families by promoting services that support families rather than taking control of the family

SYSTEM OF CARE—CULTURE CONSCIOUSNESS

- Understand and respect culture uniqueness
- Offer true friendship and a willingness to learn a culture and its heritage
- Think through your own limitations in regard to understanding, knowledge, and acceptance of another culture
- Offer a true appreciation of feeling “left out” and not being part of a full community

- Beware of your own judgements associated with cultures
- Beware of the tendency of “over-identification” in regards to children and youth of culture

SYSTEM OF CARE--ECONOMIC

- Seek family and individual recommendations on how best to use the money available to serve them and to provide a continuum of care for their families
- Provides services or supports to families based on need rather than on the family’s ability to pay for them
- Provide entitlement to a range of services that enable families to keep their children at home rather than being compelled to use out-of-home placements
- Allow families to utilize a provider of choice with proper credentials
- Provide funding to support families comprehensively rather than narrowly funding specific disorders, dysfunction, problems, or at-risk categories
- Increase funding available for prevention, early identification, early treatment options and wrap-around services
- Reduce service gaps that occur when a family is deemed ineligible for funding
- Fund ongoing parent/caregiver support groups without requiring professional facilitators
- Increase funding for advocacy training as well as other programs that promote families advocating for their child and their family
- Expand programs such as the Family Development Fund, which allows families to save money and get matching funds to support the family in their goals

SYSTEM OF CARE—EDUCATION

- Rigorously monitor the implementation of IEP’s and student progress with authentic functional behavior assessments rather than arbitrary standardized measures
- Develop a blueprint to help teams determine how to apply the concepts of Free Appropriate Public Education (FAPE) and Least Restrictive Environment (LRE) for each children and youth with behavior challenges and mental health needs
- Expedite due process and create measures to provide interim educational placements so children and youth do not lose skills while waiting for legal outcomes
- At no time bring an IEP to the team meeting as a finished product
- Develop an Individual Training Plan for every school to ensure professionals are well trained in the laws pertaining to IDEA, IEP development, and Section 504

SYSTEM OF CARE—HEALTH AND HUMAN SERVICES

- Organize the system to help children and youth and their families feel good about themselves, feel competent to make decisions and direct the life of their family
- Create a system with a general framework and fewer specific rules and funding sources
- Provide increased flexibility in policies and practices of the different systems that serve children and youth and their families
- Facilitate service teams to work in collaboration with families to identify and provide services that fulfill the real needs of the family

- Provide families tools to document behaviors to get a true picture of their child's behavior with a minimum amount of intrusion into the family and child's environment
- Create support groups for children and youth with behavior, emotional and mental health challenges
- Help children and youth before they have done something drastic or illegal or families are in crisis before they can get help
- Develop mechanisms to provide services to children and youth within their family
- Consider not "pulling" services when a child or youth begins to experience success, but instead support and maintain for a measured period to preserve success
- Avoid having families surrender parental control of their child and having to sign Child In Need of Assistance (CINA) petition
- Examine all the options
- Develop and coordinate quality community-based, accessible and affordable respite care with a variety of alternatives
- Encourage collaboration among community groups to provide needed services utilizing existing staff and resources in new ways
- Target key under-served rural areas for service development
- Emphasize the development of quality, accessible services in rural areas
- Provide development resources in rural areas to assist communities in creating needed services with a special focus on preventive services for teens to reduce substance abuse and vandalism
- Emphasize a special focus on preventive services for teens both rural and urban

FAMILY CHOICE—DREAM 2000

By Carla R. Lee-Lawson

Help us to help our child
 Ask us what our family truly needs
 Go beyond what your rules offer
 Be someone to make a mark in our life
 Help our family go into a strange New World

Into a world of uncertain strangers, blind and unknowing,
 Our family meets many strangers, a whole world of strangers
 Many strangers coming into our home
 Many strangers passing us on the street
 Many strangers of imagined fear
 Many strangers never imagined

Not wanting to meet the strangers
 No choice, they come into our family's life
 Bit by bit, meeting the strangers, one by one
 Systems full...
 Counselors, police, psychologists, lawyers, judges,
 social workers, teachers, probation officers...
 A million judges dictating our family's life
 What our family should do or should not do

So the isolation sets in once more

Once more filling us up with torrential pain
No one to talk with...
No one to be with...
No one to know with...
The questions abound
 What could we do?
 What should we do?
 What could we have done?
 What should we have done?
Doing everything imagined, the questions keep coming
 With few answers

So they try this and they try that
Taking our child into a program
 To cure
 To find all the answers
But there is guilt with our child leaving
 Guilt because our family did not have the answers
 Guilt because there is relief
 Guilt because there is peace
 Guilt because there is one tiny answer
If not for our child, temporarily for ourselves, our family

But then we learn there is no cure
 No one answer for our child
 No one who can make a lifetime commitment to our child
 No one but us
 Our family

So help us help our child
Ask us what our family truly needs
Go beyond what your rules offer
Be someone to make a mark in life
On our life
Forever

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