



**Iowa Families Choices
Conference
Families
Recommendations
May 1999, 2000 &
2001**

Families Dare to Dream

Iowa Family Choices Conference 2001

The Third Iowa Family Choices Conference was held in Cedar Rapids, IA May 5-May 7, 2001. 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. These are their statements about what the service system would look like when the "dream" comes true. With all of us working together our dream can become a reality!

- Collaboration is the norm rather than the exception. Strong diverse teams work together to design, create, and implement the systems, programs, and services that are necessary to ensure that every child and family is supported and successful.
- Flexible family centered, family defined services are in place. Our families need someone to come in and teach us how to de-stress and de-escalate together.
- Parents, schools, service systems and communities work together to meet the needs of our kids, because it does take a village to raise a child.
- There are no second-class kids. Children with special needs are treated as valuable members of school, family and community.
- Hierarchical structures are eliminated so all members of the team are valued for the information and expertise they bring to the process.

- The complete service/educational plan including disciplinary issues is based on the needs of the individual rather than one community standard.
- All children have equal opportunity and equal access to services.
- Parents would always have the skills, courage, and tenacity to stand up for their families, children, and themselves.
- Every family has an advocate.
- Families, educators, and service providers maintain a positive attitude and look toward the future to make the system work for every child.
- When the system works praise it and replicate it.
- Families don't feel as though they, or their child, will be penalized if they disagree with service providers or demand services for their child.
- Families, educators and the public all know about the options available to children with special needs such as 504 and IDEA.
- Education and support is available for all parents to assess their children's physical, developmental, and mental needs from the beginning.
- There are abundant opportunities for parent education.
- Educators are knowledgeable about 504 including what it is and who is responsible for implementation.
- Schools meet the social, developmental and educational needs of all children.
- Teachers are competent not just certified.
- Administrators are competent and open to recognizing mental health issues in children.
- During teacher training, students get training regarding special education, recognizing special needs including mental health concerns in children and the needs of families including organizations that provide parent advocacy.

- Federal laws improve special education programs.
- General education classrooms are equipped to meet the needs of children with special needs.
- Teachers and administrators recognize the mental health concerns that affect children.
- Individual school districts are accountable for following the letter and spirit of the law. Districts that do not comply face repercussions from the state and federal departments of education.
- Families, children, and communities have opportunities to provide meaningful evaluation of schools, teachers, and administrators.
- Administrators and Unions don't protect incompetent teachers.
- Teachers and parents can identify early signs of mental health issues with young children.
- There is an educational revolution, and education "thinks outside the box". Every child is looked at as a special child. Each child's unique learning, developmental, and social needs are considered in planning for their education.
- Parents receive an information packet at the time their child's special needs are identified or diagnosed that provide them with information about the diagnosis and resources/key contacts to find the services and support for their child and family.
- Social and recreational opportunities are available for children with special needs and to families. Social opportunities build skills and friendships for our children. Social and recreational opportunities for families allow us the opportunity to escape the pressure and stress of our everyday life.
- More programs such as "Connections" (Linn-Mar schools) exist to address the social and emotional needs of children

- outside the school system while teaching them the skills they need to be successful within the educational system.
- All state agencies, not just educational agencies, work together to eliminate contradictory policies and procedures - eliminate red tape.
 - The Adult and Children's Mental Health advocacy organizations collaborate together to benefit families with children of all ages.
 - The Iowa Federation of Families for Children's Mental Health has wider recognition and serves everyone in the state who needs them.
 - Consistent, accessible services are available throughout the state.
 - Services and funding is balanced for children of all ages. Services are available for children from birth through adulthood.
 - Flexible funding wraps itself around the family rather than making the family fit into a particular funding stream.
 - Advocacy and parent education organizations have adequate funds to provide services to all the families who need them.
 - A program also for adults to have health and mental health insurance assistance along with the children. It's most important for the children but the parents need to stay healthy also. Especially for the ones who do not have health insurance.
 - Private and federal/state insurance companies/ HMO's need to acknowledge and provide coverage for all levels of mental illness, without caps.
 - Organizations like CHADD etc need to be brought to the attention of the parents as support groups/resources available to all people.

- School administrators, all teachers and faculty need to know what mental health & disabilities are, how to recognize them and who to direct parents and children to.
- We have come a long way, but there is still a long way to go. When you know where to go and what services are available then you can make a lot of progress.
- There needs to be affordable daycare and respite to all families regardless of financial situations, 24 hours a day, 7 days a week, 365 days a year. Daycare and respite care for all special needs children, and make it easily accessible in all communities/counties. For the WHOLE state, Rural & City.
- Title 19 Medicare should be accepted across state lines.
- HAWK-I needs to include parents, adults as well as single adults.
- There needs to be more accessible respite care and financial support for parents or special needs children, especially single parents, so that in times of illness parents are not financially punished.
- That school disciplinary policies would be adjusted to fit special needs children rather than taking away extra curricular activities or sports.
- That a family resource center be established in each school district so parents can get access to all resources available.
- That families receive transportation assistance to get to the resources when necessary.
- Educators understand behavior disorder and why behaviors occur not just behavior management.
- Schools and communities in partnership address the social emotional & behavioral development of all children and youth in Iowa.

**IOWA FAMILY
CHOICES CONFERENCE
2000
FAMILY
RECOMMENDATIONS**

On the Day the Dream Comes True For Families:

- All families and children are treated with dignity and respect.
- The strengths of all children and families are respected and celebrated.
- Families/Parents are empowered not blamed. Empowered families have increased ability to cope and respond to their child's needs. Empowered families are ready and able to participate in building successful futures for their children.
- Families and professionals make a sincere effort to understand each other and engage in open dialog about their respective roles in the system.
- Families have the tools and encouragement to take care of themselves.
- Mental Health Services have complete parity with all other health and educational issues.
- Families, professionals and services systems communicate openly, honestly and without fear in positive partnerships.
- Every child receives services to help them transition into adult life and services as needed.
- Parents participate in all levels of policy and decision-making.
- The different abilities, experience levels, and skills of parents and families are recognized, appreciated and utilized.
- Families and individuals are recognized as distinctive and unique. Parents are offered specific answers and alternatives to find the solution that works for their family.
- Training is developed and targeted at "new" families who need the basics and at "experienced" families that need advanced, ongoing training.
- Families have the time, space and encouragement to network and support one another.
- Parent's expertise in matters regarding their child and family are sincerely honored.
- Parents keep their own records/journal of important information regarding their child including medical info, doctor visits` therapies and medications, school records and meetings, history of the child including development etc.

On the Day the Dream Comes True In Schools

- Parents and students have opportunities to evaluate and offer feedback on teacher and special education department performance.
- All school employees, nurses, bus drivers, lunchroom attendants, etc are familiar with children's mental health issues, and understand how to provide support to children with special needs.
- Teachers focus their time, energy, and talents on facilitating learning.
- A Child's mental health needs are acknowledged and addressed in the child's IEP

- IEP development is done in a collaborative environment with the input of the family, child and all other team members involved with the child. The IEP is never brought to the meeting as a pre-prepared finished product.
- All educators provide "Special Education".
- Educators have training and understanding to work with the special needs of their students.
- Families, Educators and Administrators communicate openly and respect that some teachers do not want or are not equipped to deal with kids with special needs in their classroom.
- Education, Service Systems and the providers of education and services are adequately funded.
- Children are not *punished*, by taking away after school activities because of poor academic performance.
- The atmosphere of the IEP meeting fosters collaborative relationships and all members of the team are equal partners in the process.
- In IEP meetings, unlike in other *negotiation process*'s, families are not asked to give up on one point to win another point.
- IEP team members truly listen and speak to one another as equal partners in the process.
- Parents come to IEP meetings etc. with a list of questions and concerns that they want to see addressed in the meeting.
- Parents are offered information and support in advance of the IEP meeting so that they can consider it and deal with the emotional impact before they come to the IEP meeting. So they are prepared to make decisions and participate in the process.
- Parents have access to the same IEP development resources that professionals have available.

On the Day the Dream Comes True In Communities

- All children have friends.
- All children and community members are knowledgeable about and understand children with mental health needs.
- Community activities include all children.
- Communities are involved in all children's care and welfare and make children their number one priority.
- Children with behavioral challenges are included in the community.
- Every community has quality respite care alternatives that are accessible and affordable. A variety of alternatives are offered including in-home, drop-in, and short term out of home options.

On the Day the Dream Comes True In Service Systems

- Families have one place to go to help them access the resources and services they need.
- Parents and professionals have ongoing opportunities to sit together and engage in meaningful dialog about how the system works and how to improve it.
- Home and Community Based Waiver services include children with mental health needs.
- Parents are informed about what wrap around services are and how services can assist their family and child. Parents have specific information and assistance in accessing wrap around services.
- In home counselors are focused on the needs of the family not just the "troubled child".
- Services continue after families or situations are "stabilized", ensuring that families will receive services needed to maintain their improved situation.
- Families are offered a range of treatment alternatives beyond residential care.
- Parents are kept informed of all developments related to their child and family.
- Parents, especially parents new to the system are given information and assistance to understand the process as well as support to know what is expected of them and how to participate in the process.
- Parents have the option to be paid Case Managers for their child/family.

**IOWA FAMILY
CHOICES CONFERENCE
1999**

**FAMILY
RECOMMENDATIONS**

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
- Provide opportunities for families evaluate provider and system performance on a formal basis
- Offer professional sensitivity training reducing the stigma and judgments 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 judgments 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
- Provide support and help for children and youth before they have done something drastic or illegal or families are in crisis
- 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

Iowa Federation of Families for Children's Mental Health is a statewide organization, which provides support, information and referral and training for parents/families of emotionally, mentally and behaviorally challenged children.
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These statements have been made by families from across the State of Iowa. Iowa Federation of Families for Children's Mental Health does not necessarily agree or disagree with these statements.

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