

**REPORT OF THE CHILDREN'S SED/MR/DD/BI OVERSIGHT COMMITTEE**

**SUBMITTED TO THE MH/MR/DD/BI COMMISSION**

**JULY 10, 2006**

**MH/DD/MR/BI OVERSIGHT COMMITTEE MEMBERS**  
**6/15/04**

**Jim Rixner Co-Chair**  
Executive Director  
Siouxland Mental Health Center

**Ann Riley, RN Co-Chair**  
Disability Policy Manager  
Center for Disabilities and Development,  
University of Iowa Hospitals and Clinics

**Bob Bacon**  
Director, University Center for Excellence on  
Disabilities, University of Iowa

**Mary Ellen Becker, Ph.D.**  
Director of Special Education,  
Southern Prairie AEA

**Ed Boll**  
Program Manager  
Brain Injury Association of Iowa

**Nancy Christopherson**  
Behavioral Care Clinical Manager  
Mercy Medical Center

**Paula Connolly**  
Family Advocate, Family Voices of Iowa  
*Parent*

**Patricia Crosley**  
Family Advocate, Magellan Health Services  
*Parent*

**Tom Daniels**  
Executive Director  
Faith, Hope, and Charity Inc.

**Mary Gannon**  
Attorney  
Iowa Association of School Boards

**Gary Lippe**  
Service Area Manager  
Department of Human Services

**Jeffrey Lobas M.D.**  
Medical Director, Child Health Specialty Clinics  
Medical Director, Division of Health Promotion and  
Chronic Disease Prevention,  
Department of Public Health

**Lana Michelson**  
Bureau Chief, Children, Family, & Community  
Services, Department of Education

**Eric Sage**  
Policy Manager, Criminal and Juvenile Justice  
Planning Iowa Collaboration for Youth Development

**Deb Schildroth**  
Central Point of Coordination (CPC), Story County

**Beth Troutman, Ph.D.**  
Child and Adolescent Psychologist  
University of Iowa Hospitals and Clinics  
Iowa Consortium for Mental Health

**Sonya Wills**  
Family Advocate, Autism Society of Iowa  
*Parent*

**Acknowledgements:**

Many other individuals participated as occasional substitutes for appointed members at Oversight committee meetings to maintain communication and representation of their constituency. We also wish to acknowledge the many people who attended work group meetings.

**Staff:**

Becky Flores,  
Department of Human Services

Kay Leeper,  
Center for Disabilities and Development  
University of Iowa Hospital and Clinics

July 10, 2006

To members of the MH/MR/DD/BI Commission

Dear Commissioners:

On behalf of the Oversight Committee, I am pleased to send you this blueprint for building a new system of care for Iowa's children and youth with serious emotional disturbances, mental retardation, developmental disabilities, and brain injury and their families.

During the past two years, we have talked to many families and youth about their experiences accessing services under the current structure. We met with providers across multiple disciplines that are passionate about the care they provide children, youth and families, yet are looking for ways to improve how things work. And, we reviewed the literature searching for those practices that have been successful for others.

Now, together with work group participants, we are more convinced than ever that there is a need for a comprehensive system that builds on family strengths, provides the catalyst to build linkages that maximize our precious resources, and includes a new governance framework for communication and the ability to make data driven policy improvements. In such a system, the whole can truly be greater than the sum of its parts.

The result of our work is a plan for building a comprehensive system of care that is focused on the needs, assets and preferences of children and youth--a system of care that is family driven. It will build on the strengths of the current structures and be accountable to the children and youth it serves, to their families and to the people of Iowa.

We thank you for the opportunity to bring this plan to you for your consideration and look forward to continuing to work with you to improve outcomes for children and youth with SED/MR/DD/BI and their families.

Sincerely,

Ann Riley  
Co - chair  
SED/MR/DD/BI Oversight Committee

## Table of Contents

<b>Executive Summary .....</b>	<b>6</b>
<b>Introduction.....</b>	<b>13</b>
<b>Vision.....</b>	<b>14</b>
<b>Target Population.....</b>	<b>15</b>
<b>Expected results .....</b>	<b>15</b>
<b>The Challenge .....</b>	<b>16</b>
<b>Prevalence of need.....</b>	<b>16</b>
<b>Climate for change .....</b>	<b>17</b>
Need for information about services .....	17
Need for service options for families.....	19
Need for coordinated care plans .....	19
Need for training .....	19
Need for additional service providers .....	20
Need to take action .....	21
Current initiatives .....	22
<b>State resources.....</b>	<b>26</b>
<b>Framework for Iowa’s Child SED/MR/DD/BI system.....</b>	<b>27</b>
<b>Overarching values and principles for the system of care.....</b>	<b>29</b>
<b>Key Processes .....</b>	<b>31</b>
<b>Building blocks for the system of care .....</b>	<b>31</b>
<b>Iowa’s Lighthouse Model .....</b>	<b>34</b>
<b>Overview .....</b>	<b>34</b>
<b>Information and Referral.....</b>	<b>35</b>
Information and Referral functions .....	36
Implementation guidelines.....	37
Information and Referral Competencies .....	38
<b>System Navigator .....</b>	<b>38</b>
Navigator functions.....	40
Implementation guidelines.....	41
Navigator competencies.....	42
<b>Coordinated Care Plan of Services, Supports and Resources .....</b>	<b>43</b>
Functions of the Coordinated Care Plan of Services, Supports and Resources	45
Coordinated Care Plan of Services, Supports and Resources guidelines.....	46
Care Plan Coordinator Competencies.....	47
<b>Governance .....</b>	<b>48</b>
Responsibilities of the Governance structure .....	48
Suggested committees of the governance structure .....	48
Membership.....	49
Lead Agency .....	49

The System Today and Tomorrow as seen through the eyes of Iowa Families ...	50
Recommendations .....	61
5 Year Implementation Plan .....	62
Budget .....	66
 <u>Appendix</u>	
A - Framework.....	67
B - Iowa's Lighthouse System of Care Model .....	69
C - Entities currently providing information and referral services, assisting families to access services or developing plans of care .....	70
D - Glossary of Terms and Acronyms.....	72
E - Need for services, providers, and training of direct care workforce for children and adolescents with SED.....	79

# Report of the Children's SED/MR/DD/BI Oversight Committee

*Iowa's Lighthouse: A system of resources, services and supports for Iowa children and youth with disabilities and their families.*

## EXECUTIVE SUMMARY

### VISION STATEMENT

All Iowa children<sup>1</sup> with serious emotional disorders, mental retardation, developmental disabilities and brain injury<sup>2</sup> (SED/MR/DD/BI) and their families will have access to a statewide system of care that is child-focused, family-driven, flexible and coordinated with effective, quality services supported by sufficient funding and a structure to assure families are supported and children reach their greatest potential.

In 2004, Iowa's Mental Health, Mental Retardation, Developmental Disabilities, and Brain Injury (MH/MR/DD/BI) Commission appointed an Oversight Committee, consisting of families of children with disabilities, representatives of key state agencies and other public and private stakeholders to study the issues of the children's serious emotional disturbance, mental retardation, developmental disabilities, and brain injury (SED/MR/DD/BI) system and make recommendations to achieve a major redesign of Iowa's system of care for children with SED/MR/DD/BI.

The Oversight Committee confirms that the children's SED/MR/DD/BI system is comprised of multiple elements that are not coordinated in ways that are most efficient and effective for children and their families. The youth, families and providers who participated in Oversight Committee activities characterized the current systems that support children as fragmented and inflexible, leading them to participate in services that may not be most effective and prohibiting them from utilizing other services that may be more effective. The Committee found that multiple initiatives in Iowa are working to

*Iowa lacks a formalized statewide system for pulling together all initiatives and services for children with disabilities.*

<sup>1</sup> In this report, whenever child or children is used, it is understood that it includes youth and their families.

<sup>2</sup> In this report all references to children and youth with serious emotional disorders, mental retardation, developmental disabilities and brain injury are meant to be all inclusive. Any child or youth may have one or multiple conditions. It is the intent that all system decisions and services are applicable to all children or youth with diagnosed or diagnosable SED/MR/DD/BI.

improve services for this target group especially in young children. Many of these initiatives are housed in State or county agencies with a rich history and strong passion for the particular program or service for which they are responsible. Many of their initiatives are based in recognized best practices and can be considered strengths upon which the State can expand and build. However, Iowa lacks a formalized statewide system for pulling together all initiatives and services for children with disabilities and individual communities may lack the scope of services and supports necessary to meet the needs of children and families seeking care.

Current services are multifaceted and complex, involving multiple individuals, agencies and organizations, including public and private providers, primary care providers, specialty providers, education, juvenile justice, and social welfare, each working to meet similar outcomes for children and families but having minimal linkages to one another. Multiple funding streams from state, federal, and local sources increase the complexity and potential for confusion.

To address these system issues, the Oversight committee proposes a framework for a system of care that builds formal linkages among all these disparate elements and funding sources (Appendix A). A system of care will significantly reduce gaps in services for children, youth and their families and increase service options and flexibility. The new system must be guided by agreed upon principles and values and must be supported by a strong statewide infrastructure. The proposal stresses the need for a governance structure that provides an umbrella of oversight and accountability for the system.

The children's SED/MR/DD/BI system of care services focus on six life domains that promote the quality of life experiences: 1) physical, emotional, and behavioral health; 2) education; 3) social; 4) safety; 5) vocation/employment; and 6) life settings. Services within each of these domains range from prevention and early identification, to intervention and will vary in intensity and scope based on the unique needs of the child, youth or family. The children's SED/MR/DD/BI system of care requires multiple public and private resources and supports to carry out its vision. Activities within these domains for all Iowa children, referred to as population-based services, are the responsibility of the broader child service system in Iowa. Activities of the system directed toward children, youth or families with SED/MR/DD/BI are provided by the SED/MR/DD/BI system of care.

The key to successful outcomes for Iowa children and youth with SED/MR/DD/BI lies in Iowa's commitment to all children. The SED/MR/DD/BI system of care relies on Iowa communities being

***A system of care that builds formal linkages among all these disparate elements and funding sources will significantly reduce gaps in services for children, youth and their families and increase service options and flexibility.***

***The SED/MR/DD/BI system of care relies on Iowa communities being places where all children, including those with disabilities, can receive the services and supports they need to help them grow to be healthy and successful.***

places where all children, including those with disabilities, can receive the services and supports they need to help them grow to be healthy and successful.

Using the system of care framework, the Oversight Committee recommends building on the strengths of the current system and stakeholders to transform the system to one that ensures children, youth and their families receive the services they need in a system that is accountable, coordinated, based on research or best practices and focused on the needs of children and youth. This model may require major changes in the way services are delivered. Current structures, positions and funding streams may also need to be enhanced and reorganized.

The proposed model, called “*Iowa’s Lighthouse: A system of resources, services and supports for Iowa children and youth with disabilities and their families,*” includes four major components (Appendix B):

1. **Information and Referral (I&R)** - I&R is an enhanced network of information resources for the national, state and local system of supports and services for individuals with SED/MR/DD/BI, their family and providers. Information and referral resources are available to all people seeking information. In this new enhanced model, information and referral sources will be offered through a web-based internet format 24 hours a day, 7 days a week, as well as through a state level toll free family help line. Any individual who does not prefer to seek information by internet or telephone may enter any system provider location, displaying the system logo, and be assisted to connect to the system of services and supports or be connected to a Navigator as needed. The information and referral tools will include a template for a folder called “My File,” a resource locator that matches options to the individuals identified needs and a tool to begin an electronic application process.
2. **System Navigator** - Navigators assist the child, youth and/or family with the process of exploring, discovering and identifying options to make informed choices and to link to supports and services based on their needs, assets, and preferences. Navigators enhance the information and referral network’s capacity to connect families to informal supports or services in local communities, advocate for families as needed and work to smooth the pathways between services. Currently, there are multiple programs that help families access services for specific funding streams and programs, but this approach leads to fractured service and missed opportunities for families. Families asked for a person who will “take my hand and

***Early detection and linkages to appropriate supports and services can improve outcomes, decrease co-occurring conditions and prevent conditions from worsening.***



walk me through, somebody that is going to be there for a period of time so I don't need to continually retell my story." In this new model, Navigators will have knowledge of the broader picture and will be required to work in partnership with individuals and their communities to maximize the resources available from multiple programs and sources and tailor them to the child, youth and family in a way that fits their individualized needs, assets and preferences. A Navigator is a neutral entity to reduce conflict of interest and help to maintain the broader perspective. Families and youth are encouraged to access Navigators during the times they are not eligible for a care planner. This includes before the child or youth formally enters the system and during times of transition when the care planner services may not be covered.

*Families asked for a person who will "take my hand and walk me through, somebody that is going to be there for a period of time so I don't need to continually retell my story."*

3. **Coordinated Care Plan of Services, Supports and Resources of Supports and Services** (including transition planning) - This component of Iowa's Lighthouse assures a system of supports, services and resources that are coordinated through ONE universal plan to meet the unique needs, assets and preferences of the child, youth and family. Currently, families may have multiple planning teams and plans designed around specific program requirements. Because children and youth with SED/MR/DD/BI and their families have needs which cross multiple providers and programs, services must be designed to wrap around the child or youth - not the needs of the system. This approach recognizes that children, youth and their families have needs in all of life's domains that do not necessarily match specific programs, funding sources or eligibility requirements. Iowa's Lighthouse acknowledges six overlapping domains from the child or youth's perspective to promote the quality of life experiences: physical, emotional, and behavioral health; education; social; safety; vocation/employment; and life settings.

*Iowa's Lighthouse acknowledges six overlapping domains from the child or youth's perspective to promote the quality of life experiences: physical, emotional, and behavioral health; education; social; safety; vocation/employment; and life settings.*

4. **Governance** - The new Governance structure provides interagency accountability, oversight, monitoring and guidance to the system. It is structured as a collaborative among stakeholders including families, public and private providers, policymakers, and the public at large. The governance model must be a new entity in order to promote building new infrastructures to maximize existing resources in new ways. A lead agency has administrative responsibility to provide permanence and stability for the system. To create a system between state and local agencies a collaborative structure must encompass shared

responsibilities and authority with decisions driven by family and youth input.

***Families must be full partners in the system of care.***

A strong infrastructure for the system of care is a critical first step to assure system success and sustainability. This requires that the state and community structures be strengthened and reorganized utilizing a strategic planning process. This infrastructure requires development of new policies and procedures to guide system implementation and provide clear definition of intent; clarification of interagency and private and public partnership roles and responsibilities; and development of a plan for comprehensive financing to maximize fiscal resources and for training the workforce.

Family involvement is a key factor in the implementation and sustainability of the system. Family voice ensures that the system is responsive to those it serves and also contributes to family support of the system. Families must be full partners in the system of care. They bring a broader perspective that reflects the population being served in terms of its ethnic, religious, geographic and cultural diversity.

New technology will need to be explored that improves communication and data sharing between multiple entities. There must also be support for exploring new emerging technologies to support other needs of the system such as tools to improve collaboration over geographic distances and between service providers.

Finally, strong community organizational skills are needed to bring together a variety of local interests whose agenda may not at first appear to coincide with the goals of the system, but who may actually share a common interest.

## **EXPECTED RESULTS**

- 1) Improved opportunities for the children to achieve their goals or dreams;
- 2) Increased ability to access information about services from multiple arenas leading to more informed comprehensive choices;
- 3) Assurance that no child or family needs go unidentified;
- 4) Coordinated service plans with all key partners working together leading to:
  - a) more efficient and effective use of the family's time, and
  - b) more efficient and effective use of providers' and other care plan team members' time;
- 5) An increased ability to identify the unique supports needed for each child, family and community;

- 6) Respectful identification of funding and outcome requirements from each participating entity;
- 7) Improved capacity for the community to be inclusive;
- 8) Increased use of appropriate supports for children and their families;
- 9) Seamless transitions both horizontal and vertical;
- 10) Increased community awareness of capabilities of people with disabilities;
- 11) Increased number of trained competent providers in the SED/MR/ DD/ BI child system of care;
- 12) Decreased disparities in ability to access supports;
- 13) Increased system accountability to families and lowans assuring;
  - a) Identification and elimination of gaps and duplication in services;
  - b) Identification and elimination of gaps and duplication in funding;
  - c) Identification of policy changes for improved care for children, youth and families.

## RECOMMENDATIONS

To achieve the vision of a system of care for children and youth with SED/MR/DD/BI and their families, the Oversight Committee forwards these recommendations to the MH/MR/DD/BI Commission:

1. Implement the "Iowa's Lighthouse" model over a five year phase in period to: improve access to information and referral; assist families to navigate the system of services; coordinate services, supports and resources through a plan of care; and to plan smooth transitions (see page 38). The first two years of the Iowa's Lighthouse Implementation Plan will be used to build the infrastructure for the system. During this time the details for the system will be clarified, memorandums of agreement signed, and training of the workforce begun. In year three the Iowa's Lighthouse model components will be implemented with year four being a time for system evaluation and improvements with full implementation in year five.

2. Acknowledge and support initiatives that include activities for prevention and early intervention services for children and youth with diagnosed or diagnosable SED/MR/DD/BI to prevent known problems from worsening and to decrease co-occurring disorders.

3. Continue to identify areas in need of improvement within the SED/MR/DD/BI system of care and identify strategies to enhance the system.

4. Endorse and collaborate with efforts to improve screening for social, emotional, developmental and mental health for all infants, children and youth that are consistent with the SED/MR/DD/BI system of care vision.

5. Endorse activities of other initiatives, consistent with the SED/MR/DD/BI system of care vision, that include promotion, prevention, and early intervention services for all children and youth to prevent or ameliorate social, emotional, developmental or behavioral disorders or disabilities.

## Report of the Children's SED/MR/DD/BI Oversight Committee

*Iowa's Lighthouse: A system of resources, services and supports for Iowa children and youth with disabilities and their families.*

### INTRODUCTION

In 2004, Iowa's Mental Health, Mental Retardation, Developmental Disabilities, and Brain Injury (MH/MR/DD/BI) Commission appointed an Oversight Committee, consisting of families of children with disabilities, representatives of key state agencies and other stakeholders "to knit together a statewide system of care focused on children with developmental and behavioral needs and their families."<sup>1</sup> In the charge to the committee, the Commission directed its members to study the issues of the children's SED/MR/DD/BI system and make recommendations to achieve a major redesign of Iowa's system of care for children with serious emotional disturbance, mental retardation, developmental disabilities, and brain injury (SED/MR/DD/BI).

To determine the scope of the issues facing children, youth and their families, the Oversight Committee held multiple statewide events to seek input on the issues and possible solutions to improve the system, including: a statewide kick off event; the "Touch the Lives of Children with Disabilities Conference" in October, 2004; twenty-two community listening events in fall 2005; the Lighthouse/Navigator and Community Care Planning workgroups from December 2005 through May 2006; and the "Touch the Lives of Children with Disabilities II" in April 2006. Attendance at these events totaled over 900 participants.

The Oversight Committee study confirms that the multiple elements of the current system are not effectively coordinated. Youth, families and providers who participated in Committee activities characterized the current system as fragmented and inflexible, forcing them to participate in services that may not be most effective and prohibiting them from utilizing other services that may be more effective. Oftentimes, it appears that funds could be more efficiently spent if families had the flexibility to develop a care plan focused on their needs, assets and preferences.

Data collected in the study relating to service gaps, provider shortages, and specific barriers to services were incomplete,

*Oftentimes, it appears that funds could be more efficiently spent if families had the flexibility to develop a care plan focused on their needs, assets and preferences.*

anecdotal, and differed based on location in the state. This made specific problem focused recommendations premature. What is evident is that youth and families need assistance to identify what services are available and appropriate for them. They need guidance to explore and discover the options that best fit their needs and preferences, and they need a system that coordinates the requirements of multiple programs into one plan.

Therefore, to improve care for children and youth, the Oversight Committee recommends a new model of care to begin the transformation of the system: one that builds on the strengths of the current services; ensures children, youth and their families receive the services they need in a system that is coordinated, collaborative and focused on the needs of the child and youth. It is critical that the model include a body responsible for system accountability that will systematically collect data to more clearly identify gaps in service, the needs of providers and the barriers to care. This data will be used to establish clear recommendations for changes or policies and improvements in the system.

This model may require major changes in the way services are delivered. Current structures, positions and funding streams will need to be enhanced and may need to be reorganized. The proposed system of care model clearly reflects the vision of the adult MH/MR/DD/BI system:

*To transform [Iowa's] system to one that reflects choice, empowerment, and community -- where individuals receive necessary, high quality services and supports on an equitable, timely and convenient basis, enabling them to live, learn, work, recreate and otherwise contribute in their chosen communities.*

***National studies indicate that among children and adolescents with SED, parents typically first noticed emotional or behavioral difficulties during early childhood but services did not begin until approximately two years after problems were first noticed.***

Multiple key initiatives are already underway in Iowa that will improve the lives of children with SED/MR/DD/BI and their families. The Oversight Committee plans to seek ways to link its efforts to these existing initiatives and avoid building parallel systems.

## **VISION STATEMENT**

All Iowa children with serious emotional disturbances, mental retardation, developmental disabilities and brain injury (SED/MR/DD/BI) and their families will have access to a statewide system of care that is child-focused, family-driven, flexible and coordinated with effective, quality services

supported by sufficient funding and a structure to assure families are supported and children reach their greatest potential.

## **TARGET POPULATION**

Children and youth, birth to age 21, who have diagnosed or diagnosable serious emotional disturbances, mental retardation, developmental disabilities or brain injury and their families.

## **EXPECTED RESULTS**

- 1) Improved opportunities for the children to achieve their goals or dreams;
- 2) Increased ability to access information about services from multiple arenas leading to more informed comprehensive choices;
- 3) Assurance that no child or family needs go unidentified;
- 4) Coordinated service plans with all key partners working together leading to:
  - a) more efficient and effective use of the family's time, and
  - b) more efficient and effective use of providers' and other care plan team members' time;
- 5) An increased ability to identify the unique supports needed for each child, family and community;
- 6) Respectful identification of funding and outcome requirements from each participating entity;
- 7) Improved capacity for the community to be inclusive;
- 8) Increased use of appropriate supports for children and their families;
- 9) Seamless transitions both horizontal and vertical;
- 10) Increased community awareness of capabilities of people with disabilities;
- 11) Increased number of trained competent providers in the SED/MR/ DD/ BI child system of care;
- 12) Decreased disparities in ability to access supports;
- 13) Increased system accountability to families and lowans assuring:
  - a) Identification and elimination of gaps and duplication in services;
  - b) Identification and elimination of gaps and duplication in funding;
  - c) Identification of policy changes for improved care for children, youth and families.

## THE CHALLENGE

### PREVALANCE OF NEED

*Research has found that the prevalence of mental disorders among youth in the juvenile justice system is two to three times higher than youth in the general population.*

It is important to note that the types of disabilities children face vary widely as do the associated services and supports they and their families need. These services and supports are funded through a variety of sources. Therefore, some of the data cited below may be duplicated or represent children with dual diagnoses.

Approximately 5 to 9 percent of all children in the United States have a serious emotional disturbance<sup>2</sup> and approximately 15 to 18 percent of U.S. children have a developmental or behavioral disability.<sup>3</sup> In Iowa, there are an estimated 85,000 children in need of mental health intervention<sup>4</sup>. In 2005, 27,125 children enrolled in Medicaid received mental health treatment through the Iowa Plan for Behavioral Health. There are approximately 90,000 children with some type of diagnosed disability, birth to 21 years of age, receiving services from the Department of Education.

National studies indicate that among children and adolescents with SED, parents typically first noticed emotional or behavioral difficulties during early childhood but services did not begin until approximately two years after problems were first noticed.<sup>5</sup> The 2000 Iowa Child and Family Household Health Survey reports that eight percent of Iowa children needed care for a behavioral or emotional problem in the previous year. Of those, one in ten (10%) experienced a time when they were not able to get the care they needed.<sup>6</sup> There are 285 children enrolled in the Children's Mental Health Home and Community Based Waiver program, with over 220 on the waiting list.

Research has found that the prevalence of mental disorders among youth in the juvenile justice system is two to three times higher than youth in the general population and most youth in the juvenile justice system qualify for at least one mental health diagnosis.<sup>7</sup>

Brain injury data are more difficult to extrapolate. In a 1996 study, the Iowa Department of Public Health (IDPH) found 879 individuals under age 22 were hospitalized with brain injury.<sup>8</sup> However, the outcome of the hospitalization is not apparent, but it can be assumed that some of these children and youth may have varying degrees of permanent disability.

In a 2003 National Survey of Children's Health, parents reported the most commonly diagnosed emotional, developmental and behavioral problem among children 6-17 were learning



disabilities (11.5%); attention- deficit/hyperactivity disorder (8.8%); and behavior problems (6.3%). The most common diagnoses reported for children age five years and under were speech problems (5.8%) and developmental delay (3.2%). One in 200 children were diagnosed with Autism. Notable in this report is that parents reported concerns about their child's problems at a much higher rate than diagnosed suggesting, in part, that children's problems may be under-diagnosed. Compared to other children, those with chronic problems had diminished family functioning, more school absences, and less participation in community activities. Similarly, their parents reported more difficulty with child care, employment and parenting skills.<sup>9</sup>

*A system of care that builds linkages between funding sources and providers will reduce service gaps.*

## CLIMATE FOR CHANGE

The climate in Iowa for children's mental health and disability services is primed for change. Multiple initiatives in Iowa are working to improve services for this target group, especially in young children. Many of these initiatives are housed in state or county agencies with a rich history and strong passion for the particular program or service for which they are responsible. Many of their initiatives are based in recognized best practices and can be considered strengths upon which the state can expand and build.

Iowa now has an opportunity to pull these various initiatives together into a formalized statewide system for mental health and other disability services for children and communities that will support a wide array of service options for children and families seeking care. The current services are multifaceted and complex, involving multiple individuals, agencies and organizations, including public and private providers, primary care providers, specialty providers, juvenile justice, and social welfare, each working to provide and ensure similar outcomes for children and families despite a lack of formal linkages to one another. Multiple funding streams from federal, state, and county sources increase complexity and the potential for confusion. A system of care that builds linkages between funding sources and providers will reduce service gaps. Therefore, at this point, rather than to "redesign" the system it makes sense to "design" the system, or, as the President's New Freedom Commission choose to do - "transform" the system.

*Family members emphasize that support must be more than just the services offered through HCBS waivers.*

### Need for information about services and how to access services

Currently, families report their ability to identify what types of supports or services are available for their child often depends on whom they know, where they seek the services first, or where they live. Yet the increase in internet accessibility is providing a way to reach more families than ever before. When asked in

***Currently, families report their ability to identify what types of supports or services are available for their child often depends on whom they know, where they seek the services first, or where they live.***

***Currently, when a child is determined to have a disability the family begins to search for services, but Case Managers are not assigned until the eligibility assessment is completed.***

Iowa Plan Client Satisfaction Surveys about access to a computer and the ability to connect to websites, 38-66% of Medicaid clients said they could do so.<sup>10</sup>

Families strongly endorse the creation of a system that recognizes their unique situations and honors the principle that decisions are driven by the child, youth and family needs and assets. They are seeking information about the services they are unaware of. Families want to be able to make informed decisions based on the full scope of options available to them.

The Health and Resource Service Administration (HRSA) believes a system for resource facilitation should be available nationwide regardless of age, culture or income.<sup>11</sup> Data from a 2000 HRSA analysis of services for people with brain injury demonstrated that with a coordinated approach to resources and supports access to services becomes more accessible, dollars are maximized and people are given choice which leads to independence and better quality of life. The study further supported the notion that improving access to information stimulates the development of community support services for individuals with brain injury.<sup>12</sup>

Often families need someone to help them access services before the child or youth is able to access formal supports. Currently, when a child is determined to have a disability the family begins to search for services, but Case Managers are not assigned until the eligibility assessment is completed. Multiple eligibility requirements for multiple programs and services create a maze that is enormously confusing and convoluted, particularly for families new to the system. Families need assistance when the child is still in the “diagnosable” phase of eligibility determination.

It often takes 18 months to two years for a child go through the disability determination process, Medicaid, SSI or waiver application and sometimes there are waiting lists for waivers. Case management and service coordination is not available during the waiting process.

Under the Iowa Care Act, 2005, families no longer are required to identify their child as a “Child in Need of Assistance” in order to be eligible for the Mental Health Waiver. These families are finding they no longer have access to a case manager and are seeking assistance to navigate the system.

Once in the system, families say additional assistance is needed to provide a “safety net” during times of transition and to assist them to build a team of informal supports that can fill in when the formal supports are not available or and not accessible. This

is especially important as the family waits for their name to rise to the top of long waiting lists.

#### Need for coordinated care plans

Parents report they often use vacation and sick time to attend multiple service plan meetings from different entities. They must also spend many hours of precious personal time coordinating various service plans. Transition planning between systems which should be seamless and smooth, is often poorly addressed.

A lack of coordinated care planning also fragments care, leads to duplication of services, often does not adequately address cultural needs of families, and allows the development of potentially dangerous situations when the child is receiving a complex medication routine.

#### Need for service options for families

While comprehensive service options are in place for children or youth enrolled in the Iowa Pan through Medicaid or eligible for Home and Community Based Waiver services, the same can not be said for all children with disabilities. Sometimes a family will elect to not apply for a HCBS (Home and Community Based Services) waiver because their child is covered under their current insurance program and they do not want to access Medicaid. Children who do not have mental health issues or mental retardation and do not meet the institutional level of care remain another group of children unable to access Medicaid or HCBS waiver services. This includes children with autism and many children with chronic health conditions.

Family members emphasize that support must be more than just the services offered through HCBS waivers. Support includes the ability to connect to mentors and support groups at the time an individual is ready to reach out for help. Shortages in funding or restrictions in the definitions of fundable services continue to hinder access to supports for many families.

#### Need for training

At the 2005 community listening events, Iowa service coordinators, community providers and case managers cited a lack of training and knowledge of options as a major need. They report they often do not have sufficient knowledge about possible services or support programs when these are funded outside their usual funding stream. Also, they find that success using the internet to search for information is often dependent on their familiarity with the terminology and jargon of other disciplines or programs.

*Data from a 2000 HRSA analysis of services for people with brain injury demonstrated that with a coordinated approach to resources and supports access to services becomes more accessible, dollars are maximized and people are given choice which leads to independence and better quality of life.*

Research based or evidence based practices provide the foundation to assure supports and services are working together and provide built in measures of quality associated with results. But many providers are not informed about these practices or how to incorporate evidence based practices into their services. Training is critical in order for providers to offer services that are cutting edge practice. Training keeps the workforce competent, knowledgeable about research based practices and culturally aware and gives children the opportunity to benefit from the latest research.

*Case Managers are not assigned until the eligibility assessment is completed.*

#### Need for Additional Service Providers

There is a severe maldistribution of child psychiatric services in the United States and data suggests children in rural areas and areas of low social economic status have limited access to trained professionals.<sup>13</sup> An alarming fact for Iowa is that the number of child and adolescent psychiatrists has decreased from 42 per 100,000 youth in 1995 to 35 per 100,000 youth in 2001. Iowa currently has 45% of the national average in psychiatrists per capita but there is no method to determine how many of the child psychiatrists actually have child focused practices or how many are practicing full time. Currently there is only one board-certified clinical child and adolescent psychologist and one board-certified school psychologist in Iowa.<sup>14</sup> In addition, no approved child psychology internships are approved in Iowa by the American Psychological Association.

Because of the lack of availability or lack of knowledge about treatment and local resources, more of Iowa's children and youth are receiving psychiatric care at Iowa's urban based centers. Other families are seeking care through local pediatricians or family practitioners who may lack specialty training or knowledge of best practices in psychiatric care. With the high cost of gasoline, families now wait until there is a crisis before seeking long distance care.

The Iowa Department of Public Health recently conducted a survey of the mental health workforce in Iowa in response to media reports of a shortage of mental health providers throughout the state. This survey confirmed the shortage of mental health providers in Iowa with hospitals, agencies, and private providers reporting unfilled vacancies for all types of mental health providers. Although this survey did not specifically address shortages of mental health providers for children and adolescents, a number of respondents indicated a need for psychiatrists who could treat children and adolescents.<sup>15</sup> (For a more in depth discussion of the *Need for services, providers, and training of direct care workforce for children and adolescents with SED* see Appendix E).

### Need to take action

Issues surrounding children's health impact all sectors of society: personal, economic and societal. Multiple federal and state reports support the urgent need to take action to improve systems outlining specific actions that promote the social, emotional and physical well being of children with disabilities.

The President's New Freedom Commission on Mental Health characterized the current mental health care system in America as fragmented and in disarray, a situation that leads to unnecessary and costly disability, school failure and incarceration.<sup>16</sup> The President's Commission recommendations related to children's mental health include:

- Improving access to quality care and services that promote self-monitoring and accountability;
- Developing an individualized plan of care for managing care;
- Bringing current research-based practices to the community-based practice;
- Providing early detection, assessment and links with treatment and supports in low-stigma settings such as with primary health care providers, schools, and in settings in which a high risk for mental health problems exist such as juvenile justice, and child welfare systems;
- Screening for mental health during routine physical exams;
- Advancing communication and information technology tools to empower consumers and families to access information, link to multiple service systems, maintain electronic records, and communicate with remote providers;
- Involving consumers and families fully in orienting the mental health system toward recovery; and
- Creating accountability for services.<sup>17</sup>

Iowa has identified multiple opportunities to collaborate to improve the status for children with mental and developmental disabilities as described in *Healthy Iowan's 2010*. This document is the blue print for action to improve the health of Iowan's of all ages and represents a collaborative effort of multiple stakeholders who are committed to carrying out the goals. Action to build collaborative community-based systems of services for children and adolescents in need of mental or behavior health care is supported in Goal 11-11, 11-18. Chapter 12 calls for a strengthening of the role of families in designing the system of care for children and adolescents with mental health needs (12-3); creating a point of responsibility for children's services in state government that will integrate available financing along with staffing necessary to establish and implement a coordinated system of care for behaviorat, mentally

*Parents report they often use vacation and sick time to attend multiple service plan meetings from different entities.*

and emotionally ill children and their families (12-4); funding initiatives to increase children's mental health services and supports (12-7); and providing services and supports for children and youth in the juvenile justice system (12-9).<sup>18</sup>

At the "Off to a Good Start" leadership workshop in 2005, more than 100 Iowa health, education, social service professionals, business leaders, and elected officials used the Early Childhood Iowa Strategic Plan to outline strategies to improve child health outcomes in Iowa. Among recommendations from this workshop, the leaders called for increasing access to and utilization of social, emotional, and mental health services by: expanding the role of mental health centers to serve children birth to age five; expanding telehealth services to children in communities that lack appropriately trained health care providers; promoting and developing strong public/private partnerships among all infant and child health, education and social service providers; providing education to the public about social emotional development and support programs to foster healthy development of children; and supporting funding for Iowa specific curricular materials for all health care, education, social service and public policy personnel to promote understanding of the critical need for infant and young children's mental health.<sup>19</sup>

The Oversight Committee and the Iowa Chapter of the American Academy of the Pediatrics support recent legislation to provide incentives to attract psychiatrists to practice in underserved areas, increase the use of "Physician extenders" such as Physician Assistant and ARNP programs and to promote the use of innovative practices to extend the reach of existing practitioners such as telehealth models.

### Current Initiatives

Multiple initiatives are currently being developed or are in place to meet some of the needs that make up a comprehensive system of care for children and youth. Each is developing or improving a part of the advocacy, infrastructure and supports upon which the evolving system can build. Care must be taken to preserve the integrity of these initiatives by enhancing them, not draining them of resources. To follow are a few examples of those many good initiatives.

The Governor signed two bills of significance to children's mental health services in Iowa from the 2006 session of the General Assembly. HF 2780 supported a greater effort to assure close coordination and continuity of care for those persons receiving publicly supported disability services in Iowa. In that bill the General Assembly emphasized that if person's with disabilities are to "exercise their own choices about the amount and types of services received," it is critical for them to have

knowledge of their options from all the formal support systems. The second bill, the Brain Injury Services Bill, HF2772, addressed the state's need for brain injury services by creating a new program for resource facilitation within the Department of Public Health and providing resources for individuals not currently eligible for Medicaid services.

The newly established Mental Health and Disability Services Division within the Department of Human Services will provide additional structure for the system services supported by DHS once operationalized.

Iowa's enhanced information and referral (I&R) network is being developed through combined efforts of a Department of Human Services "Family 360" grant, the Department of Elder Affairs', "Aging and Disability Resource Center" grant and Iowa Medicaid Enterprise's "Real Choices Systems Transformation" grant. The new software with electronic capability for shared case plans, on line applications and resource locator service will be available by the end of FY 2007. The children's system can utilize the developing I&R network to increase the ability of youth and families to make informed choices and to assist service providers and navigators in their roles.

Early ACCESS is an integral partner for identifying and serving children birth to three with developmental disabilities or at risk for developmental disabilities. This system has successfully demonstrated an interagency collaborative governance structure, development of interagency coordinated care plans, and interagency agreements for shared resources.

The Iowa Collaborative for Youth Development is another example of a state-led interagency initiative that has demonstrated successful collaboration among multiple state and community agencies, youth and their families to align policies and programs for youth. The Iowa Collaboration for Youth Development is working to make certain that youth have opportunities to be involved, practice healthy behaviors and are socially competent, achieve success in school, and are prepared for a career and a productive adulthood.

ABCD II, Iowa's Assuring Better Child Health and Development II initiative is focusing on implementing prevention, early recognition, and early intervention practices that promote the healthy mental development of all children from birth through age three. The ABCDII Healthy Mental Development Clinical Panel is completing a report of its recent study and has discussed opportunities to support healthy mental development including early and periodic screening, early assessment and diagnosis, prevention and intervention services, as well as referral, care

coordination and case management. In order to provide an age-appropriate mental health diagnosis for young children, Iowa Medicaid is recommending a "crosswalk" between the Diagnostic classification of mental health and developmental disorders of infancy and early childhood revised edition (DC:0-3R) and DSM-IV and ICD-10 diagnostic codes.

The Integrated Evaluation and Planning Clinics (IEPC), a service of Child Health Specialty Clinics, are designed to provide services for children with health-related developmental and behavioral problems. This initiative demonstrates successful use of collaborative teams to work with families to develop individualized care plans that are implemented across multiple settings.

The Iowa Plan for Behavioral Health, administered by IDHS and IDPH through Magellan Behavioral Care of Iowa, coordinates mental health and substance abuse treatment services for Medicaid enrollees as well as substance abuse treatment services funded by the Substance Abuse Block Grant. The Iowa Plan has been cited as a national model for innovative and effective implementation of a quality behavioral healthcare system. To monitor access for Iowa Plan Medicaid enrollees, DHS has set specific standards for access to mental health treatment. In May 2006 100% of Iowa Plan Medicaid children and youth living in rural areas were within 35 miles of an outpatient mental health provider and 45 miles of an inpatient facility. In order to meet those statewide standards, Iowa Plan supports service delivery through a variety of professionals in addition to psychiatrists: psychologists, nurse practitioners, physician assistants, social workers, counselors, and therapists. These professionals may work in hospitals or Community Mental Health Centers or in agencies or group or individual practices. In addition, the Plan Medicaid funds a project that brings child psychiatry services to rural families through the University of Iowa's Child Health Specialty Clinics and the use of telehealth technology.

Iowa's Department of Public Health newly developing Resource Facilitation Service will enhance facilitation of resources to help families of children with brain injury to identify and access the system of services. This will provide additional information on implementation of a Children's System "Navigator" for a single targeted population.

Iowa's Chapter of the American Academy of Pediatrics (AAP) newly forming Children's Council could potentially become a strong partner in identifying gaps in the system, promoting public/private collaboration, evidence-based primary health care practices, and advocating for system structures including private and public funding for services. The Iowa AAP is



committed to the development of a diverse, trained workforce that delivers the highest quality of services and care and has demonstrated success advocating for children by promoting the utilization of outcome data for improving care for children and their families.

Iowa's reapplication for the Substance Abuse and Mental Health Services Administration (SAMHSA) grant through Iowa's Department of Human Services in partnership with Child Health Specialty Clinics could potentially provide another avenue to explore strategies for a community-based children's system of care.

There are several successful models of the concept of "flexible resources" in Iowa. Flexible resources uses the concept of family centered and family-driven consumer choice options, individualized budgets, blended and braided dollars, Micro Boards and Micro Enterprises. Models such as De Categorization, Consumer Choices Option, Empowerment, and Children at Home all utilize this concept to maximize resources to individuals and families. Resource representatives have proven to be crucial to bringing the coordinated care plan alive under this type of structure.

#### **Potential Entry Doors into Supports and Services for children with SED/MR/DD/BI and other Key Stakeholders**

Currently multiple potential partners are providing formal or informal services and supports to children, youth and families with SED/MR/DD/BI. Relationships need to be established with many current providers of services for children with SED/MR/DD/BI encouraging them to enter into formal agreements to participate in the system. The following are a few examples of existing services and initiatives.

# Potential Entry Doors into Supports and Services for Children with SED/MR/DD/BI and Other Key Stakeholders

Iowa Department of Human Services	Juvenile Justice	Iowa Department of Education	Iowa Department of Public Health	Other Key Stakeholders	
<b>Child Welfare</b> <ul style="list-style-type: none"> <li>Abuse Investigations</li> <li>Foster Care</li> <li>Therapeutic Foster Care</li> </ul>	<ul style="list-style-type: none"> <li>Court Ordered Services For Juveniles</li> <li>Juvenile Accountability Incentive Project</li> <li>County Run Juvenile Detention Centers</li> <li>Two State Run Juvenile Homes</li> <li>Local Shelters For Juveniles</li> <li>Supervised Community Treatment for Adjudicated Youth</li> <li>Assessment and Treatment Programs for Juveniles</li> </ul>	<ul style="list-style-type: none"> <li>IDEA Part C Early ACCESS</li> <li>IDEA Part B (ages 3-21 years)</li> <li>AEA Services</li> <li>504 Plans</li> <li>365 School Districts</li> <li>Iowa Behavioral Alliance</li> <li>Parent Education Connection</li> <li>Parents as Teachers</li> <li>Division of IOWA Vocational Rehabilitation</li> <li>Integrated Behavioral Health Project</li> <li>Learning Supports</li> <li>Student Disability Services at universities and colleges</li> </ul>	<ul style="list-style-type: none"> <li>HOPES - Parenting Supports</li> <li>Prevention of Secondary Conditions</li> <li>Living Well w/Disability</li> <li>Emergency Preparedness</li> <li>Brain Injury supports</li> <li>ABCD II Early Referral</li> <li>Healthy Child Care - IA Nurse Consultants</li> <li>EPSDT Care Coordination</li> <li>Title V Maternal and Child Health Providers</li> <li>Early Hearing Detection &amp; Intervention</li> <li>Success by Six</li> <li>HCBS/MR Waiver Specialists</li> </ul>	<ul style="list-style-type: none"> <li>CHSC - 14 clinics</li> <li>Integrated Evaluation &amp; Planning Clinics 2</li> <li>IA Respite Coalition</li> <li>FIND (Family Information Network on Disabilities)</li> <li>ASK Resource Center</li> <li>Iowa Federation of Families for Children's Mental Health (IFFCMH)</li> <li>Iowa Foster Parent Association (IFPA)</li> <li>Many Family Advocacy or Support Organizations</li> <li>SSI/SSDI</li> <li>Dept. of Human Rights - Division of Persons with Disabilities</li> <li>DD Council Projects</li> <li>P &amp; A</li> </ul>	<ul style="list-style-type: none"> <li>Teachers in childcare and public school systems</li> <li>Primary Care Providers: Family Practice, Physicians, Nurse Practitioners, Pediatricians</li> <li>Tertiary Medical Care Hospitals and Clinics</li> <li>Private Insurers</li> <li>Empowerment Council</li> <li>Iowa Early Care and Education</li> <li>Head Start</li> <li>Life Long Links/ Aging &amp; Disability Resource Center</li> <li>Iowa Department for the Blind Transitions Project</li> <li>CDD</li> <li>Collaboration for Youth Development</li> <li>Information and Referral</li> </ul>
<b>Special Needs Assistance</b> <ul style="list-style-type: none"> <li>Subsidized Adoption</li> <li>Family Support Subsidies</li> <li>Children at Home</li> <li>4MHI - 2 enroll children</li> <li>12 PMIC's</li> <li>2 Resource Centers</li> </ul>					
<b>Medicaid</b> <ul style="list-style-type: none"> <li>State Plan</li> <li>7 HCBS Waivers</li> <li>Magellan Iowa Plan</li> <li>Hawk I</li> <li>EPSDT</li> <li>RTSS</li> </ul>					
<b>ABCD II Prevention Early Referral</b>					
<b>County Level System</b> <ul style="list-style-type: none"> <li>Income Maintenance Workers</li> <li>Social Workers</li> <li>Case Managers</li> <li>Targeted Case Managers</li> <li>DeCat Funded Projects</li> </ul>					
<b>Mental Health and Disability Services Division</b>					
<b>MH Block Grant</b>					

## FRAMEWORK FOR IOWA'S SED/MR/DD/BI SYSTEM

Recognizing that services and supports for children and youth with SED/MR/DD/BI are not provided in isolation, but are part of a broader environment of care; and, acknowledging that the whole is more than the sum of its parts, the organizing framework for Iowa's SED/MR/DD/BI system is the concept of a "system of care" (Appendix A). A system of care is defined as a *range of services and supports that is guided by a widely agreed upon philosophy supported by an infrastructure.*<sup>20</sup>

The system of care concept has been a focus of children's mental health policy reform since 1982 and today represents the largest federal investment focused on children with mental health problems.<sup>21</sup> However, the system of care concept has been applied more broadly than in mental health including initiatives from the federal Maternal and Child Health Bureau, federal Bureau of Children's Services, and several initiatives that foster collaboration between mental health and education and juvenile justice.<sup>22</sup>

The children's SED/MR/DD/BI system of care services focus on six life domains to promote the quality of life experiences: 1) physical, emotional, and behavioral health; 2) education; 3) social; 4) safety; 5) vocation/employment; and 6) life settings. Services within these domains range from prevention and early identification, to intervention and will vary in intensity and scope based on the unique needs of the child, youth or family. The children's SED/MR/DD/BI system of care requires multiple public and private resources and supports to carry out its vision. Activities within these domains for all Iowa children, called population-based services, are the responsibility of the broader child service system in Iowa. Activities of the system directed toward children, youth or families with SED/MR/DD/BI are provided by the SED/MR/DD/BI system of care.

The key to successful outcomes for Iowa children and youth with SED/MR/DD/BI lies in Iowa's commitment to all children. The SED/MR/DD/BI system of care relies on Iowa communities being places where all children, including those with disabilities, can access the services and supports they need to grow to be healthy and successful.

This framework recognizes *that for adults and children alike early detection, assessment and linkages to treatment and supports can prevent mental health problems from worsening.*<sup>23</sup> For children, research suggests that many developmental disorders as well as mental health problems might be prevented

*Recognizing that services and supports for children and youth with SED/MR/DD/BI are not provided in isolation, but are part of a broader environment of care; and, acknowledging that the whole is more than the sum of its parts, the organizing framework for Iowa's SED/MR/DD/BI system is the concept of a "system of care."*

*Activities within these domains for all Iowa children, called population-based services, are the responsibility of the broader child service system in Iowa. Activities of the system directed toward children, youth or families with SED/MR/DD/BI are provided by the SED/MR/DD/BI system of care.*

***The SED/MR/DD/BI system of care relies on Iowa communities being places where all children, including those with disabilities, can access the services and supports they need to grow to be healthy and successful.***

***For children, research suggests that many developmental disorders as well as mental health problems might be prevented or improved with prevention, early identification, and intervention services.***

or improved with prevention, early identification, and intervention services. Prevention with early identification and early intervention efforts for children with social-emotional risk factors and disabilities have been shown to improve school readiness, health status, and academic achievement and reduce the need for more costly interventions such as grade retention, special education services, and welfare dependency.<sup>24</sup> The return on investment for addressing children's issues early, saves seven dollars for every one dollar spent by reducing the need for crisis services<sup>25, 26</sup>. Without such a system, children and families will suffer because of missed opportunities, fragmented services, and low priorities for resources.

Prevention services are activities designed to avert the occurrence of SED/MR/DD/BI in children or to interrupt the progression of disabilities once a diagnosis has been made. Prevention includes reducing risk or exposure to threats and alleviating the effects of a disorder, injury or disability and might include such activities as promotion of healthy behaviors, injury prevention, or screening for social emotional problems and developmental delays. Prevention activities provided through the SED/MR/DD/BI system of care are specific to the individual child or youth with SED/MR/DD/BI and the family and are designed to promote the health and well-being of those individuals. These activities prevent secondary conditions and co-occurring conditions.

Population-based prevention activities (e.g. those targeting *all* children and youth) are the responsibility of the broader child system of which the SED/MR/DD/BI system of care is a part. These activities incur a low-cost per individual program to provide universal supports and avert the need for high-cost services and intervention later. This primary investment to support the healthy development of all children and to prevent injury is the most cost effective of all services and substantially reduces the need for intensive and expensive "downstream" services (such as juvenile justice or intensive mental health or rehabilitation services) that may become necessary in the absence of universal preventive services and supports.

Early Identification activities identify children in need of SED/MR/DD/BI services and lead to timely referral to critical interventions. Children may be identified through more population-based activities of the broader system for all children or may be children already in the system that are identified as requiring additional evaluation for the possibility of secondary or co-occurring conditions. Early identification services might include informal ongoing observation by parents, child care providers and teachers, to the more formal screening by primary care health providers. Early identification also includes

assessment by qualified professionals and accurate diagnosis leading to early provision of appropriate interventions.

Intervention services provide a coordinated system of comprehensive, developmentally appropriate, research/evidence based treatment services specifically tailored to meet the needs, assets and preferences of children and youth with SED/MR/DD/BI and their families. Intervention services include multiple levels of care from the six life domains that promote the quality of life experiences.

Intervention services within the SED/MR/DD/BI system of care will be guided by a comprehensive plan to meet the child, youth or family goals within each of the six life domains. The plan is guided by the system principles. Such a plan must take a comprehensive, community-based approach which emphasizes a wide array of services across the full continuum of care. Services must be delivered in the least restrictive environment, with full participation of families and include coordination among child-serving providers. A system of care presumes that all key partners must come together to plan, fund and deliver services.<sup>27</sup>

*Prevention activities provided through the SED/MR/DD/BI system of care are specific to the individual child or youth with SED/MR/DD/BI and the family and are designed to promote the health and well-being of those individuals.*

## **OVERREACHING VALUES AND PRINCIPLES FOR THE SYSTEM OF CARE**

The following principles guide all decisions for development and implementation of the system of care. The system is

- 1) Child-focused
  - a) Individual and family needs and assets drive the decisions
  - b) Service delivery is consumer directed
  - c) Services are appropriate may vary in intensity
  - d) Access to services is based on identified child and family needs and strengths
- 2) Family-driven
  - a) Families are full partners in system development, implementation and monitoring of the system
  - b) Individual and family needs, assets and preferences drive the decisions
  - c) Service delivery is consumer directed
- 3) Comprehensive
  - a) Services and supports are broad-based including families
  - b) Services and supports promote seamless successful transitions
  - c) Services must be broad enough to meet the diverse needs of the developing child
- 4) Coordinated/Collaborative
  - a) Assessment of strengths and needs are standardized
  - b) Varying entry points assure “no wrong door” for accessing services and supports

- c) Services between agencies/programs/initiatives are seamless
- d) Memorandums of agreement specify how multiple agencies and programs work together
- e) There is participation of a broad-base of stakeholders in the system design, implementation and monitoring.
- 5) **Culturally competent**
  - a) Policies, values, structures and services are designed to meet the cultural, social and religious beliefs and values of the child and family
  - b) Workers consider the cultural, social and religious beliefs and values of the child and family in their interactions
  - c) Coordination of services includes supports that improve an individual's whole life
  - d) There is institutionalization of cultural knowledge
- 6) **Infused into natural settings and services**
  - a) The new system of integrated services is provided within the current settings
  - b) Services are community based as appropriate
  - c) The system of services is designed to be minimally intrusive in the normal day to day routine of the child, youth or family.
- 7) **Grounded in research/evidence-based practices or best practices**
  - a) Research/evidence-based or best practices are the foundation for the service system
- 8) **Delivered by a prepared workforce based in the community** (Workforce includes formal and informal service providers and supports including parent groups)
  - a) Training is provided to improve skills of all providers and to increase knowledge of system protocols and best practice along a continuum from pre-service to continuing education
  - b) Expert mentors and consultants are available to the child, youth and family as supplement to local care providers
  - c) Consultation/Technical Assistance is available to communities for building system capacity
  - d) The community is educated about children with disabilities
- 9) **Accountable**
  - a) Planning, assessment and transition are filters used to assure change is embraced and valued within a shared case plan
  - b) Data from quality assurance (QA), monitoring, evaluation and improvement processes guide the system
  - c) System meets privacy and confidentiality regulations (e.g. State, FERPA and HIPAA);
  - d) System is meeting the child's needs
- 10) **Resource flexible**
  - a) Sustained resources support the system

- b) Resources are maximized through sharing of staff, funds, equipment, etc
- c) Partnerships between private and public funding sources support the system

## KEY PROCESSES

To be successful the service system model must include unified processes that improve the efficiency and effectiveness of the system to achieve the system goals. Key processes for the system are:

### Information and referral

Methods to access information about services that indicates clear referral paths into the system.

### Determination of eligibility

Clearly defined parameters and methods for determining the population served by the system.

### Family support & advocacy

Processes to assure families are provided services that assist them to access and move through the system, provide encouragement, provide a means for conflict resolution, and promote and protect the rights of children and youth with SED/MR/DD/BI.

### Coordinated plan of care

Resources of multiple providers and funders are brought together to together to meet the unique needs and preferences of the child and family.

### Delivery of services

Processes for service delivery include entry into the service system, service planning, service provision, and case monitoring and review.

### Continuous monitoring and improvement

Child, youth, family, organizational and financial outcomes are monitored continually to provide direction for system improvements and to identify service gaps.

## BUILDING BLOCKS FOR THE SYSTEM OF CARE

Building a strong infrastructure for the system of care is critical to success and sustainability. This requires that the state and community structures be strengthened and reorganized utilizing a strategic planning process. Major building blocks for sustaining the system include:

*Studies show that one of the most fundamental measures of success and sustainability is development of a strong, and “real,” interagency collaboration.*

### Policies and procedures

Written policies and procedures guide system implementation and provide clear definition of intent. New policies and procedures supporting the system principles, values and new processes will need to be developed along with memorandums of agreement between agencies to specify the responsibilities and contributions of each to the system.

### Interagency collaboration/partnerships

State-level interagency collaboration is essential to secure state level policy changes and to support local systems. Studies show that one of the most fundamental measures of success and sustainability is development of a strong, and “real,” interagency collaboration.<sup>28</sup> *To ensure meaningful collaboration on financial issues, the [State’s] sustainability plan must be developed with, and not for, its collaborating partners.*<sup>29</sup> Fiscal accountability for all partnering agencies is fostered through the development a single plan of care.

### Blended or braided, flexible funding

A comprehensive financing plan is an important contributing factor in the successful implementation of a system of care. The plan should identify fiscal needs, utilize multiple sources of funding, promote flexibility, maximize federal entitlements, and redirect spending from restrictive placements to community-based services.<sup>30</sup> Blended funding brings resources together forming a pool of resources to meet the system fiscal needs and gives all partners a role in determining how funds will be spent. This approach has been successful in several states.<sup>31</sup> Collaborative partners can also bring in new resources for funding, adding additional flexibility.

### Prepared workforce

Training is critical for implementing and sustaining a new system. Service providers and staff must be aware of the changes in the system, the new principles and values of the system, new policies and procedures, and how the changes affect the way they do business. Training plan development and implementation must be considered in the fiscal plan, as well as evaluation of the training program itself. Training is based on competencies required to carry out the functions of the system.

### Flexible and accessible services

Services and supports work best for children, youth and families when they include a broad range of care options that represent a package of services that are individualized to the child or youth and the community of service. Approaches will vary from community to community, child to child and change with the child over time. This requires flexibility of policies, funding and provider protocols.

*Families should be full partners in the system of care.*



### Family involvement

Family involvement is a key factor in implementation and sustainability. Family voice not only ensures that the system is responsive to those it serves, but it provides a vehicle for family support of the system.<sup>32</sup> Families should be full partners in the system of care. They bring a broader perspective to the table that reflects the population being served in terms of its ethnic, religious, geographic and cultural diversity.

### Accountability

The system of care must be accountable to children, youth and families with ED,MR/DD/BI and to the citizens of Iowa. System providers will be licensed professionals or trained personnel who possess the skills to provide services and supports that are consistent with the system philosophy, values and principles.

### Technology compatible with system needs

New technology will need to be explored that improves communication and data sharing among multiple entities, including a comprehensive data base to track outcomes. There must also be support for exploring new emerging technologies to support other needs of the system such as tools to improve collaboration over geographic distances and between service providers.

### Governance

A governance structure is essential to maintain the focus on the system of values, goals and theory of change. In addition, the governance structure uses systematic data and family and stakeholder inputs to continuously strengthen the system and provide for clear and efficient decision making about the system direction. The governance body provides oversight for the system and monitors system outcomes.

### Transformational Leadership

Strong community organizational skills are needed bring together a variety of local interests whose agenda may not at first appear to coincide with the goals of the system, but whom actually may share a common interest.<sup>33</sup> For transformation to occur a leader must be able to create high level partnerships that tie together multiple processes and functions into a system of care that makes sense and works at the community level.<sup>34</sup>

*The governance structure uses systematic data and family and stakeholder inputs to continuously strengthen the system and provide for clear and efficient decision making about the system direction.*

## IOWA'S LIGHTHOUSE MODEL

*Iowa's Lighthouse: A system of resources, services and supports for Iowa children and youth with disabilities and their families.*

### OVERVIEW

The model chosen to deliver the system of care to Iowa children and youth with SED/MR/DD/BI and their families is *Iowa's Lighthouse* ( Appendix B). This model utilizes the system of care framework and builds upon the strengths of the current structures and resources of multiple stakeholders to transform the system to one that improves access to services and ensures children and youth with SED/MR/DD/BI and their families receive the services and supports they need (Appendix C). The model includes an enhanced information and referral network to improve access to information about the system, a person to help families navigate the system and a process for development of a coordinated care plan in a system that is accountable to children and youth with SED/MR/DD/BI and their families as well as to the citizens of Iowa. Once operational, data collected regarding child and youth outcomes, consumer satisfaction, and the processes of the system will be used to determine the gaps and barriers to care. This data will be utilized to recommend policy changes as well as to make system improvements.

The model may require major changes in the way services are delivered. Current structures, positions and funding streams may need to be enhanced and reorganized.

The proposed model, called "*Iowa's Lighthouse: A system of resources, services and supports for Iowa children and youth with disabilities and their families,*" includes four major components: 1) Information and Referral; 2) System Navigator; 3) Coordinated Care Plan of Services, Supports and Resources; and 4) Governance.

There is no wrong door into Iowa's Lighthouse. A child, youth or their family may enter the system at any point and expect to have access to the full system of supports and services that meet their unique needs. Wherever the system is accessed, the youth or family is given information about the entire system of care services and how to access those services.

System providers must enter into agreements and meet the system criteria in order to be considered a "Lighthouse"

provider. As such, a provider will display an Iowa's Lighthouse logo indicating they are a system provider. Staff providing I&R Specialist, Navigator and Care Plan Coordinator functions will be required to meet the competencies related to providing those functions and will receive skill trainings to help them meet and maintain those competencies.

The system of services is fluid. Services flow in a circular, rather than linear fashion. Families drive the system and are able to access all components at any time they need assistance. For instance, if a youth is concerned about his upcoming adult transition, he may contact the Navigator for assistance or surf the I&R web for options. System providers are also expected to have open communication with each other as needed. For instance, there may be times when the Care Plan Coordinator is in need of information or assistance from the Navigator or needs to access additional information and referral or other Care Plan Coordinators.

*The system of services is fluid.*

Common language facilitates consensus building. For consistency, this model refers to individuals who provide information and referral services as *I&R Specialists*; individuals who provide assistance to access the various services and supports as *Navigators*; and individuals who manage or coordinate care plans as *Care Plan Coordinators*.

## **INFORMATION AND REFERRAL (I&R)**

I&R is a source of information for the local, state and national system of supports and services for individuals with SED/MR/DD/BI, their family and providers. Information and referral resources are available to all people seeking information.

In this new enhanced model, information and referral sources will be offered through a web-based Internet format 24 hours a day, 7 days a week, as well as through a state level telephone state level toll free family help line. Any individual who does not prefer to seek information by internet or telephone may enter any system provider location, displaying the system logo, and be assisted to connect to the system of services and supports or be connected to a Navigator as needed.

The information and referral tools will include a template for a folder, called "My File," a resource locator that matches options to the individuals identified needs and a tool to begin an electronic application process.

Many families have requested the internet format to explore their options during non-traditional work hours and before they

meet face to face with a provider or navigator, so they are prepared to ask questions and make informed choices. The enhanced I&R component of the model will assure that information about the full array of supports and resources available to Iowa youth and families is easily accessible.

*I&R specialists are skilled professionals housed within information and referral networks to assist individuals to find the help they need.*

The web-based information and referral source will provide a seamless network of information on the Internet regardless of the point of entry. It will connect to general information and referral such as 211, to crisis hot lines, or other specialty information and referral sites such as the Disability Housing Registry. It will be housed in one location with electronic networking from multiple sources. This allows the searcher to enter through one URL and link to another by the click of an electronic link. Similarly, the telephone-based information and referral source allows one "help line" to connect to another without the caller hanging up and redialing. It also allows the information and referral specialist to automatically seamlessly link to a system Navigator or a designated local source of coordination.

I&R specialists are skilled professionals housed within information and referral networks to assist individuals to find the help they need. They identify needs and help determine options and the best course of action based on the family needs, preferences and assets. I&R specialists meet national certification standards and work to assure the data is accurate, in addition to providing technical assistance to all users of the web based tools.

#### Information and Referral Functions

- Maintains a database of current continuum of formal resources and links to informal resource contacts;
- Provides information and referral assistance to service providers in addition to families and individuals;
- Identifies entry level needs, preferences and assets of child/youth and/or family to assure maximum quality of life in the community;
- Assists child/youth and family to identify potential services and supports;
- Provides basic unbiased information on services available;
- Provides contact information to reach those services;
- Makes appropriate referrals to connect child/youth or family to specific services or supports or a navigator;
- Empowers families with knowledge to make informed choices;
- Offers an electronic "MY FILE" template for child/youth or family;

- Collects family intake data and customer satisfaction and outcome data to evaluate if family sought or applied for supports or services;
- Collects data so that service gaps can be identified and filled.

### Implementation Guidelines

The following will provide guidance for design and implementation of the I&R system:

- The expertise provided by the I& R service will identify the basic issues, and provide information and referral within approximately 10-20 minute contact;
- The model provides flexibility for each community to define how many lighthouse entities are available to the community -
  - In large communities there could be many lighthouses with several providers and various agencies trained, in small rural communities there might be only one trained lighthouse;
  - In rural areas there are fewer formal services, but families report some smaller communities have more informal networks;
- The I&R system will promote awareness of local family support networks that improve access to informal supports;
- The system is networked for automatic connection to multiple funding sources as needed;
- Service is accessible during non-traditional hours;
  - Web-based service is available for twenty-four hours, seven days a week;
  - Person-to-person hours of operation includes peak times of need, such as one evening a week and weekends, based on community needs;
- Provides a rapid response for translation services during use of both the phone and web-based services;
- Location of local I&R provider is unique in each community;
- Electronic format is user-friendly
  - Is accessible to families and does not depend on a “professional” to deliver information;
  - I&R specialist is available to assist as needed (per hours noted above);
  - Is accessible for a wide range of cultural and disability needs including accessible formats for the vision and hearing impaired, basic reading levels, cultural competency, ethnicity, poverty (i.e. May use pictures that are available for passwords);
- I &R questionnaires to identify needs and assets are brief and easy to complete;

- Information from the web based “MY FILE” folder could be used, if directed by the family or youth, to pre-populate eligibility forms for multiple agencies and program applications;
- Connections to crisis centers or services are prominent on the web site and on phone answering machines;
- Referrals needing additional connections are kept to a minimum;
- The local I&R specialist must be knowledgeable about local information and referral options across multiple programs (education, medical, court, juvenile justice, child welfare);
- Staff must demonstrate the competencies for I&R specialists;
- Training is available to help I&R specialists meet and maintain the required competencies;
- I&R staff are well supported with sufficient funding and training.

#### Information and Referral Competencies

In order to be a designated Iowa’s Lighthouse I&R specialist, an individual must be able to demonstrate the following:

- Ability to listen objectively and identify needs and preferences of the person seeking information;
- Excellent communication skills with the ability to help people clarify needs;
- Knowledge of best practice standards for a statewide information and referral service;
- Excellent knowledge of etiquette for good customer service;
- Ability to communicate with people of diverse cultures;
- Ability to skillfully utilize the I&R software or web page for information and referral tasks;
- Knowledge of the Iowa’s Lighthouse and SED/MR/DD/BI services language and acronyms.

#### SYSTEM NAVIGATOR

*Navigators provide information to link families and youth to sources for further assessment and evaluation to establish specific needs or diagnoses.*

Navigators assist the child, youth and/or family with the process of exploring, discovering and identifying options to make informed choices and to link to supports and services based on their needs, preferences and goals. They utilize the information and referral network as a tool to identify services needed, advocate for the family and youth as needed and work to smooth the pathways between services. Navigators provide information to link families and youth to sources for further assessment and evaluation to establish specific needs or diagnoses.

Currently, there are multiple programs that help families access services for specific funding streams and programs, but this

approach leads to fractured service and missed opportunities for some families, while providing duplication for others. Families asked for a person who will “take my hand and walk me through, somebody who is going to be there for a period of time so I don’t need to continually retell my story.” In this new model, Navigators will have knowledge of the broader picture and are required to work in partnership with individuals and their communities to maximize the array of resources available from multiple programs and sources and tailor them to the child, youth and family in a way that fits their individualized needs, assets and preferences.

Maintaining a Navigator as a neutral entity will reduce conflict of interest and help to maintain the broader perspective of the full array of services available. Families and youth are encouraged to access navigators during the times the child or youth are not eligible for a care plan coordinator. This includes before the child or youth formally enters the system and during times of transition when a care plan coordinator is not assigned or when care planning may not be a covered service.

Navigators will enhance the I&R network’s capability to connect families to supports or services in local communities. Embedded in the community, they will be aware of community-specific informal supports for families and will be able to monitor changes in resources and inform the I&R in a timely fashion when changes occur. Even formal provider networks change as funding streams or community needs change. Some services, such as pilot projects, may have a short time span and may not be entered on the formal information and referral network, or will only be available for a short time and then change.

As with all parts of the system, a navigator is an optional support and the intensity of the service will vary based the unique situation of the family. For instance, a family not in the system may be exploring the options available to help them meet emerging needs of their child. Or, a family may already be in the system and may need an advocate or contact to begin transition from one service to another. Sometimes individuals are simply in need of temporary support as they wait for eligibility for long term supports. The navigator assists the individuals in identifying the informal or public private partnership needed to address short term needs.

Because at times families need help before or during the coordinated care planning process, Navigators act as the bridge to the care planning team. They may assist the family complete the Lighthouse “My File”, including the release of information forms. Navigators facilitate communication between all members of the service and support team the family has

***As with all parts of the system, a navigator is an optional support and the intensity of the service will vary based the unique situation of the family.***

selected and follow up to make sure needs are met or that services have been initiated when the family is not eligible for or simply does not have a care plan coordinator; or advocating for the family when needed to provide an objective view of needs and resources available. Similarly, Navigators provide a feedback loop for follow up including collection of data on system gaps and individual satisfaction with services.

Although the service is community-based, provided in an area or region close to the where the family resides, Navigators may also be available by telephone, electronic mail, web cam or through other technology as appropriate. This is particularly important when the “community” may not be a geographic location but a community of interest, such as in the case of a rare condition or disability. In this instance there may be Navigators in other parts of the state that are “specialists” for those rare conditions. Contact information and referral for the system Navigators will be available through the I&R network with “hot links” directly to the Navigator to maintain a seamless connection for families. Regardless of where the family contacts the system, they are given information about a Navigator to assist them. There is no wrong door into the system.

Navigators are skilled individuals that must meet the competencies required by the system. Training is a major element of this model to help Navigators maintain skills and competencies of the job.

#### Navigator Functions

- Identifies youth and family needs, assets and preferences to maximize the child’s potential and improve the child or youth’s quality of life in the community;
- Links child, youth and families to the system of supports and services based on their needs, assets and preferences to meet their goals;
- Provides a direct link to peer to peer or family to family mentors as requested;
- Serves as a “point” person between the various programs and services available;
- Helps the family and youth link to sources for evaluation and assessment;
- Helps youth and families become self-advocates;
- Advocates for child, youth and family as needed based on family, child or youth circumstances;
- Assists child, youth and family in problem solving and guides them to potential resources;
- Empowers child, youth and families to more effectively use the information for decision-making, and to take steps needed to achieve satisfaction and independence;



- Maintains contact at established times for identification of emerging needs;
- Assists the youth and family to complete forms and applications as needed to access supports and resources;
- Assists the youth/family to complete a Lighthouse “My File” as needed;
- Participates as a “bridge” in the first meeting of the care planning team;
- Empowers child, youth or family to take the steps needed to achieve satisfaction and independence;
- Anticipates transition times for the child, youth or family and initiates contact with them to discuss transition planning options;
- Provides a safety net to the child, youth or family when the system fails to address their needs;
- Provides follow-up on referrals made to assure connections and satisfaction;
- Guides youth and family to resources for dispute or conflict resolution;
- Seeks information needed to facilitate communication between providers;
- Facilitates the family and youth in anticipating the “next step” to help them make informed decisions;
- Collects data on service gaps identified during navigation process;
- Collect outcome data to document what works in the system and what does not work;
- Reports aggregate data back to the Governance structure regarding needs, preferences and needs met.

### Implementation Guidelines

The following will provide guidance for design and implementation of the System Navigator:

- Initial intake time is expected to be approximately 60 minutes to identify needs, assets and preferences;
- Level of intensity (or frequency) of support varies with child/youth and family need and assets;
- Model includes a community of families that link to each other;
- The system will have standards and competencies that must be met by navigators;
- Service may be provided by parents or nonprofessionals if they demonstrate the competencies of the system;
- Navigator is separate from the system Care Plan Coordinator so the family has a place to turn when transitions occur;
- Navigator is a neutral entity
  - Families have indicated that they need a neutral navigator to sidestep the bottlenecks in the

system, service delivery or to resolve disputes with Care Plan Coordinators;

- Navigator is available over an extended period of time;
- Navigators connect the family to the appropriate expert but do not necessarily have to be the expert;
- Navigator is a local person who is very familiar with the services in local area
  - In some instances a Navigator could be an Internet peer, especially for teens
  - Support can be over the Internet, phone, or face to face- but needs to be accessible;
- Navigator may not always be the same person but perhaps an entity and may need to change as needs change;
- Navigators must be well supported with appropriate funding and on-going training;
- Navigator uses a data base/tickler system for tracking follow dates with youth/family;
- Navigators meet core competencies and are certified in use of the systems search tool.

#### **Navigator Competencies**

In order to be a designated Iowa's Lighthouse Navigator, an individual must be able to demonstrate the following:

- Ability to patiently listen objectively and identify needs of the person seeking information and/or assistance;
- Knowledge of how to connect to the system of supports and services from multiple local service and supports providers in Iowa;
- Ability to utilize Information Technology software for information and referral in addition to knowledge of informal local supports or services;
- Knowledge of best practice standards for navigator services and disability service models. (e.g. Consumer Choices Option)
- Good coaching skills to provide guidance and support;
- Basic skills in questioning techniques that empower the individual and family to make choices;
- Ability to communicate with people of diverse cultures;
- Ability to build trust;
- Skills in assisting others in problem solving and conflict resolution;
- Ability to help, mentor and advocate without "doing it" for the youth/family;
- Good communication etiquette for customer service;
- Knowledge of the system language and acronyms;
- Basic knowledge of disability and advocacy systems and services;

- Knowledge of appropriate methods for data collection with an ability to identify appropriate data and monitor trends;
- Familiarity with processes to link with informal support networks;
- Clear and concise writing skills.

## **COORDINATED CARE PLAN OF SERVICES, SUPPORTS AND RESOURCES**

This component of Iowa's Lighthouse assures a system of supports, services and resources are coordinated through ONE universal plan to meet the unique needs, assets and preferences of the child, youth and family. Currently, families may have multiple planning teams and plans designed around specific program requirements. Because children and youth with SED/MR/DD/BI and their families have needs which cross multiple providers and programs, services must be designed to wrap around the child or youth - not the needs of the system. This requires a public/private approach using an integrated, multi-agency network that blends or braids the resources of state agencies with family organizations, community-based primary health care providers, provider associations, local government and other child service entities.

*Services must be designed to wrap around the child or youth - not the needs of the system.*

This approach recognizes that children, youth and their families have needs in all of life's domains that do not necessarily match specific programs, funding sources or eligibility requirements. Iowa's Lighthouse acknowledges six overlapping domains from the child or youth's perspective to promote the quality of life experiences: physical, emotional, and behavioral health; education; social; safety; vocation/employment; and life settings.

Advocacy and self-determination skills are not given a separate domain, but are critical components to be addressed as a part of every domain. Conversely, safety is given emphasis as a separate domain although safety needs most likely overlap in all domains. At any point in the life of the child or youth, one of these domains may take on more importance than others, but care must be taken to ensure that the plan does not become too narrowly focused.

*Clear processes for smooth transitions at times of significant changes in the child or youth's life are a critical component of the care plan.*

Although these domains provide a broad framework for the care plan goals and activities, the plan cannot be all encompassing. Rather, it should focus on specific goals the child, youth and family want to accomplish in each of the domains. Care plan activities should be designed to be minimally intrusive in the normal day to day routine of the child, youth or family. The coordinated care plan is initiated anywhere within the circle of

supports and services regardless of where the child, youth or family entered the system.

Clear processes for smooth transitions at times of significant changes in the child or youth's life are a critical component of the care plan. Children, youth and their families move through multiple times of change as the child grows, as family circumstances change and as the child or youth's unique needs change. The child, youth, family and system transitions must be recognized, addressed and valued within a shared care plan. Transitions include times when the child grows older, family circumstances change, the child's unique needs change, and when formal and predictable changes in the system occur. System changes are often formal and predictable and include policy driven changes and as well as institutional changes.

Key system transitions may include moving from:

- Early ACCESS (IDEA Part C) to preschool and school age special education services (504 and IDEA Part B);
- Kindergarten to elementary school educational settings to secondary to post-secondary and adult education or vocational programs;
- The youth to the adult MH/MR/DD/BI system of care;
- The foster care system to home or adoptive home (or home to foster care), institutions or to adult life situations;
- Out-of-home placement to home and back again such as occurs when youth move from group-home care, shelter, detention, the State Training School, PMIC's and ICF/MR programs back to the community;
- Differing financial eligibility levels such as EPSDT eligibility to private insurance or no insurance due to age or financial status;
- Hospital to home; and
- Family transitions which may include a geographic move, divorce, remarriage, deaths, adoptions, sibling leaves home, or moving to or from foster care.

***In this model of care planning, the youth and family drives the care planning process and has shared responsibilities as members of the planning team.***

In this model of care planning, the youth and family drives the care planning process and has shared responsibilities as members of the planning team. Providers will collaborate to offer the best plan for the child using a results-based approach that meets the requirements across service providers and funding sources. When the child, youth or family enters Iowa's Lighthouse system, "My File" will be further developed as needed. This may include a more advanced assessment and evaluation of the child or youth's status in all the designated life domains and a determination of needs, assets, and preferences that will be utilized for plan development. All assessments and information previously attained and made available by the family will be built upon, not

repeated. At all times the youth and/or family choice will guide the process in concert with knowledgeable service and support providers.

The family chooses a Care Plan Coordinator from a provider, a system trained neutral party, or they may choose to coordinate the care plan themselves. As the child grows and develops and needs change over time, it is expected that the designated Care Plan Coordinator may also change. The family, together with the Care Plan Coordinator, determines who is at the planning table. Examples of possible team members include:

- Child, youth and family
- Other relatives
- Representatives of the multiple agencies providing staff and funding resources
- Teachers
- Primary Care Providers
- Private specialty care providers
- Lighthouse Navigator
- Juvenile Court officers
- Direct care staff
- Child care providers
- Respite providers
- Friends of the child and family

Care Plan Coordinators are skilled individuals that must meet the competencies required by the system. Training is a major element of this model to help Care Planners maintain skills and competencies of the job.

#### **Functions of Coordinated Care Plan of Services, Supports and Resources**

- Assures appropriate assessment for service eligibility based on the needs, strengths and preferences of the child and family;
- Assures cultural needs are met for the child, youth or family members.
- Assures the responsibilities for the comprehensive care plan will be shared between providers as appropriate;
- Coordinates and expedites eligibility processes for all identified formal services;
- Empowers the child, youth and families with information or mentoring they need to:
  - Develop self advocacy skills
  - Make informed choices about the formal services best suited to their situation
  - Drive the care coordination
  - Know who to turn to if the system isn't working for them

*The family chooses a Care Plan Coordinator from a provider, a system trained neutral party, or they may choose to coordinate the care plan themselves.*

- Understand the system language
- Anticipate upcoming transitions and drive care coordination accordingly
- Be empowered to become leaders
- Be empowered to be own care plan coordinator
- Assures that releases of confidential information are in place for sharing information among providers;
- Manages shared care files with a secured web base and electronic files;
- Assists parents who have challenges working with the system including those with intellectual disabilities, mental illness, exhaustion, or parents that are otherwise challenged to drive their own care coordination by providing options for a navigator, or other support person to assist in the decision making (may involve guardians if there is a guardian for the parent);
- Assures that all essential members of the planning team are involved in the plan development and implementation, especially as required by law or funding entity;
- Builds a bridge between the planning team and the Lighthouse Navigators, as necessary;
- Provides vehicles for communication among the various providers and coordinators, agencies and entities, including primary health providers;
- Assures that Care Plan Coordinators are trained and supported to meet the established competencies;
- Provide systematic collection of data for accountability.

### **Coordinated Care Plan of Services, Supports and Resources Guidelines**

The following will provide guidance for design and implementation of the System

- The care plan is controlled by the youth and family;
- The family has assistance of a system provided Care Plan Coordinator for plan development;
- The plan is based on a single plan concept with various entities responsible for specific pieces;
- The template for plan development includes all six domains with the expectation that there is a minimum of one goal for each domain;
- Care plan meetings occur in timely fashion and within preset time constraints;
- Rules of engagement are in place for team meeting;
- Family is supported as needed before and during meetings;
- Compensation available for care providers as needed for participation in the care planning meetings;
- There is a central family-controlled electronic location for the Lighthouse “My File” that can be shared and used

- by the care planners that is compliant with the laws assuring confidentiality ( i.e. HIPAA and FERPA);
- The care plan is electronically accessible to, and maintained by, all providers responsible for carrying out activities of the plan.
  - Case load for the Care Plan Coordinator must be limited to a level that supports quality service.

### Care Plan Coordinator Competencies

The Care Plan Coordinator demonstrates:

- Ability to listen objectively, identify and use assets, needs and preferences of the child, youth and family to build the care plan;
- Ability to facilitate family involvement;
- Knowledge of the system of supports and services of multiple local agencies and state agencies;
- Trained in neutral facilitation skills;
- Ability to utilize Iowa's Lighthouse Information and Referral software to assist families and providers to identify contact persons for services and supports for meeting child and youth goals;
- Ability to guide decisions based on best practice and emerging standards for children and youth with SED/MR/DD/BI;
- Ability to link families to their lighthouse navigator or to an appropriate conflict resolution process if the system isn't working for the family;
- Ability to advocate for the family as opposed to advocating for the services of a specific program or agency;
- Ability to assist the child and family to anticipate and manage upcoming transitions;
- Cultural competence;
- Leadership skills for facilitating meetings of multiple entities providing services;
- Trustworthiness;
- Skills in assisting others in problem solving and conflict resolution;
- Ability to help, mentor and advocate without assuming complete control and responsibility and "doing it" for the youth and family;
- Good communication and listening etiquette for customer service;
- Knowledge of the system language and acronyms.
- Good verbal, written and computer skills.

## GOVERNANCE

*The new Governance structure provides interagency accountability, oversight, monitoring and guidance to the system.*

The new Governance structure provides interagency accountability, oversight, monitoring and guidance to the system. It is structured as a collaborative among stakeholders including families, public and private providers, policymakers and the public at-large. The governance model must be a new entity to promote building new infrastructures to maximize existing resources in new ways. The lead agency will hold administrative responsibilities that provide permanence and stability for the system. To create a system among state and local agencies a collaborative structure must encompass shared responsibilities and authority with decisions driven by family and youth input.

The body will operate under the state Sunshine Rules (Open Meetings, Iowa code chapter 21) and must be depoliticized. The chair of the governance body will rotate at least every two years between member partners. Agendas will reflect system priorities and gaps in services.

### Responsibility of the Governance Structure

The governance component of the model will act as an umbrella for the system.

*A lead agency will hold administrative responsibilities that provide permanence and stability for the system.*

The Governance Structure will be charged with the following responsibilities:

- Oversight for the system;
- Create policy to meet system standards ensuring that policy decision making is transparent;
- Promote formal agreements to clarify system partner responsibilities;
- Provide assurance functions
  - Monitor the system outcomes, including gaps analysis, and
  - Make corrective changes as needed;
- Develop grievance process;
- Provide guidance for the training plans;
- Guidance/ implementation for a certification process;
- Create and guide a funding plan that is based on needs rather than merely funding existing services. Transparency in funding decisions is needed.

### Suggested committees of the governance body will include

- Standards committee
- Training and certification committee
- Accountability committee
- Data collection and management committee



### **Membership (key stakeholders)**

Membership will be appointed by the Governor and should be balanced by gender, race, political affiliation, and geography to mirror that of the population characteristics of the state.

Representatives are suggested from the following constituencies:

- 50% Families balanced by the diagnosis of the child or youth.
- Legislator
- MH/MR/DD/BI Commission member
- State agency representatives responsible for system components
  - The agency programs need to be represented to share practical experience and ongoing service gaps and interpretation of the data received from the system thus providing a feedback and validation process
- Public providers
- Private providers
- Advocacy groups
- Funding entities
- College or University (for training guidance)
- Public

There must be paid supports for parents to assure participation. These include honorariums/stipends, mileage, travel expenses and childcare.

### **Lead Agency Responsibilities include**

- Braid federal and state funds;
- Employ staff to implement and coordinate the components of the system;
- Administer policies to assure standards are met;
- Maintain a repository for data;
- Provide the mechanism for administration funds;
- Assure data for accountability is collected statewide, coordinated and reported.

## SED/MR/DD/BI SERVICES AND SUPPORTS TODAY AND TOMORROW AS SEEN THROUGH THE EYES OF IOWA FAMILIES

The following tables compare stories about the barriers some families experience under the current structure of services and supports (left hand column) and how their experience could be different using the proposed Iowa's Lighthouse (right hand column). The names and settings have been changed to protect the privacy of those who shared their stories.

Miranda's Story	
Experiences and outcomes using the existing structure	Experiences and outcomes using the proposed Iowa's Lighthouse
<p>Miranda was a shy, moody preschooler who had difficulty separating from her parents to attend preschool. Entering Kindergarten, school personnel and Miranda's pediatrician gave her parents suggestions for how to manage her behavior. Her functioning improved and she did well in Kindergarten.</p> <p>However, after the sudden death of her favorite uncle when she was seven, she began having severe mood swings and return of the separation anxiety. Miranda's parents attempted to find a mental health professional to diagnose and treat Miranda's serious emotional disturbance. They had difficulty finding a mental health provider in their area who treated mood disorders in children of Miranda's age and was a provider for their insurance.</p> <p>Miranda's family was eventually able to find a therapist (Dr. A.) at a community mental health center an hour away. The therapist recommended weekly therapy for Miranda and her family given the severity of Miranda's symptoms. However, due to the therapist's caseload, she was only able to see Miranda and her family twice a month.<sup>3</sup> The therapist arranged an appointment with a local psychiatrist (Dr. B) who prescribed an antidepressant and began seeing Miranda every four months. Miranda's teacher (Ms. C) continued to have concerns about Miranda's functioning at school. She discussed her concerns with Miranda's parents and, with their permission, made arrangements for Miranda to be evaluated by the school's child study team. The child study team determined that Miranda should begin seeing the school</p>	<p><i>Miranda's family would be able to identify mental health resources for Miranda when her symptoms reappeared and became more severe. They would not have to waste valuable time trying to find a mental health provider as her problems worsened.<sup>1</sup></i></p> <p><i>School personnel and mental health specialists would utilize a coordinated care plan to communicate and implement consistent interventions across all settings for Miranda. The parents would receive consistent guidance and there would be a mechanism for resolving conflicting recommendations.<sup>2</sup></i></p>

counselor (Ms. D) twice a month. The mental health professionals working with Miranda and her family communicated with each other infrequently due to their busy schedules. Miranda and her family found themselves repeating the same information to each provider and sometimes receiving conflicting advice about how to address Miranda's mood swings and separation anxiety. Miranda's mother, who was also grieving the sudden death of her brother, found herself feeling increasingly stressed by Miranda's mood difficulties and the conflicting advice from providers. She randomly applied the various interventions according to her ability to cope on a particular day.

After an argument with another student at recess one day, Miranda told her teacher she wanted to kill herself. Miranda's teacher contacted the school counselor who recommended Miranda be taken to the local Emergency Room to be evaluated. It was determined that Miranda needed to be psychiatrically hospitalized. During the psychiatric hospitalization, hospital staff expressed concern about Miranda's failure to respond to outpatient treatment. It was recommended she be placed in a residential treatment setting so she could receive consistent therapy from a small group of providers who communicated with each other on a regular basis.

Miranda responded positively to the coordinated treatment she received during residential placement. Although she continued to experience depression and anxiety, she was able to talk with staff members about her thoughts of hurting herself or others and to develop strategies for coping with her unstable moods. Miranda was discharged home and resumed therapy with local providers.

Despite her positive response to treatment during her residential placement, Miranda's reentry to her home, school, and community was fraught with difficulties. Other children in her class teased her about her time in residential care referring to her as a "psycho". Miranda expressed anger at her family and therapists for sending her away the first time and expressed reluctance to discuss her mood problems for fear of being sent away again.

*Miranda's mother would receive the services she needed to support her during this difficult time.<sup>4</sup>*

*Miranda's family and providers would revise her coordinated care plan to address her suicidal ideation. She would receive more intensive services at school and in the community rather than placing her in a residential treatment setting.<sup>5</sup>*

*By providing Miranda with intensive services at school and in the community, her symptoms would be addressed in her natural environment reducing the possibility of experiencing difficulties transitioning back to her home, school, and community.<sup>6</sup> If Miranda required residential treatment despite intensive community interventions, her coordinated care plan would help her and*

	<i>her family plan for this transition.</i>
--	---

Annotation - how the proposed model would lead to improved outcomes.

<sup>1</sup>*Miranda's family would have assistance in locating appropriate services for Miranda and their family as soon as Miranda's symptoms reappeared and became more severe through the use of Information and Referral services and a System Navigator. Information and Referral would provide them with information about services for children and adolescents. In addition, the information and referral service would allow them to access a system navigator who would help them identify and access appropriate services given Miranda's age and the type of problems she was exhibiting. Since Miranda did not have a previous mental health diagnosis, the system navigator would assist her family in finding a mental health professional that could diagnosis and treat affective and anxiety disorders in children.*

<sup>2</sup>*A Coordinated Care Plan of Services, Supports and Resources would be developed that would address Miranda's functioning at home, school, and in the community. All providers working with Miranda and her family (e.g. school personnel, mental health specialists, and pediatrician) would be familiar with the coordinated care plan developed to address the needs of Miranda and her family.*

<sup>3</sup>*The shared Governance of the proposed system would provide data on gaps in services (e.g. lack of providers near Miranda's home with expertise specific to Miranda's symptoms; lack of sufficient therapist time to meet Miranda's needs for weekly therapy). This oversight would be used for long-range planning to address service gaps. All navigators report aggregated data on gaps in services and unmet needs from all their cases to the governmental body for the Children's system. The governance body makes data driven recommendations for systematic changes to address gaps in services and supports statewide.*

<sup>4</sup>*The System Navigator would help Miranda's mother identify local resources for parents of children with SED and coping with grief.*

<sup>5</sup>*When community systems of care are improved for youths with SED, youths exhibit improved functioning, an increased use of community-based services, and a reduction in use of residential placements and hospitalizations (Knitzer & Cooper, 2006).*

Knitzer, J., & Cooper, J. (2006). Beyond integration: Challenges for children's mental health. *Health Affairs*, 25(3), 670-679.

### Joe's Story

Experiences and outcomes using the existing structure	Experiences and outcomes using the proposed Iowa's Lighthouse
<p>Joe is a 17 year old with mental retardation and mental illness. He lives in the parental home with only those support services offered in the special education school setting. His mother is the primary caregiver as his father has been transferred to another location for his job.</p> <p>Over a short period of time, there were several occasions where Joe became combative with his mother and assaulted her. He was court committed and hospitalized several times. Discharge planning following hospitalization was insufficient. The only recommendation given to the family was to commit Joe to a state psychiatric facility.</p> <p>Joe is in that "transition age" for moving from the youth system of care to the adult system of care. Because he has less than 12 months before turning eighteen, funding for needed services is very difficult to secure. A DHS social worker became involved and Joe was put on the waiting list for the MR waiver program. He also meets eligibility requirements to receive targeted case management, but those services can't be implemented until Joe is authorized for a state slot under the MR waiver program. It can take several months to a year before someone moves off this waiting list.</p> <p>The county CPC explored the possibility though DHS of granting an exception to policy for Joe to receive services from Medicaid before he was 18 years old or moving onto the MR waiver program more rapidly. The county is willing to grant an exception to their funding policy if the state would provide the exception for early enrollment into adult services. DHS suggested that an exception to policy be filed - but reminded the county worker it can takes months to go through the process. <i>Children at Home</i> funds were accessed to help cover in-home services for Joe. Due to Joe's combative behavior with staff, two agencies stopped providing services. In the meantime, Joe's mother's health deteriorated and her abilities to meet Joe's needs by herself decreased.</p>	<p><i>When Joe first began showing combative and aggressive interactions at home Joe's mother would receive assistance in identifying supports and services to address Joe's behaviors. Joe's parents would not have to hospitalize him to receive guidance on how to deal with his aggressive behaviors.<sup>1</sup></i></p> <p><i>School personnel, mental health specialists, the hospital discharge team and community providers would utilize the coordinated care plan to communicate and implement consistent interventions at home and in school for Joe's aggressive behaviors. Joe's mother would receive respite services to allow her time to manage her own deteriorating health status.<sup>2</sup></i></p> <p><i>When Joe's aggressiveness became focused on his respite workers, the Navigator worked with the respite agency to locate training and resources that would enhance his direct care workers abilities to effectively address Joe's behaviors.<sup>3</sup></i></p> <p><i>When Joe became eligible for the MR waiver and case management that manager began participating in Joe's coordinated care plan. This plan included helping Joe and his mother make arrangements for relocating to the area where Joe's father was working and living.<sup>4,5</sup></i></p>

After several weeks, a state slot became available for the MR waiver program, and Case Management assisted with lining up services for the family. Before services could start, the case manager learned that Joe's parents had purchased a home closer to where his father worked and they would be moving in less than a month. The case manager made a referral to the case management agency in the family's new location. During the process of establishing new providers in his new town Joe is again hospitalized for aggressive behaviors. The DHS social worker decides an out of home placement needs to be sought because the parents seem incapable of handling Joe's outbursts and these outbursts are becoming more frequent. The worker arranges placement at a state resource center which will be approximately 2.5 - 3 hours away from the family's new home.

Annotation- how the proposed model would lead to improved outcomes.

<sup>1</sup> *Joe's mother would have assistance in locating appropriate supports to help her decrease Joe's aggressive behaviors as soon as Joe began acting out at home. His school personnel would use the Information and Referral Network to locate a System Navigator to assist her. The Navigator would work with Joe's mother to determine their needs and accurately identify the supports and services available to Joe and his family in their home. Since Joe did not have a case manager the navigator would assist the family through the process of connecting to services they select. One of the most critical needs identified during the intake process was respite care. The Navigator would provide emotional support to Joe's mother until respite services were actually in place. This action could reduce the need for costly hospitalization and help his mother more effectively manage her own physical illness*

<sup>2</sup> *A Coordinated Care Plan would be developed that would address Joe's functioning at home, school and in the community. The care planning team would also identify steps needed to transition Joe into adult services.*

<sup>3</sup> *The System Navigator would help Joe's family retain consistent qualified workers by assisting the respite agency in locating training and resources that enhance his direct care workers ability to effectively address Joe's behaviors. The Navigator also assisted Joe and his mother with pursuing the MR waiver.*

<sup>4</sup> *The Navigator transferred Joe to his new Case Manager when he became eligible for the MR home and community based waiver. The Case Manger became a member of Joe's coordinated care planning team. Because services were ready to begin when the family relocated Joe was able to remain with his family and institutional placement was avoided*

<sup>5</sup> *The shared Governance of the proposed system would assure all providers working with children that have disabilities are knowledgeable about their roles and responsibilities. This would have resulted in the school personnel referring Joe to a navigator at age 14 to assist the family in planning*

*a smooth transition from school to a work environment and adult services, instead of beginning the transition steps at age 17 when his transition to adult services was eminent.*

Kyle's Story	
Experiences and outcomes using the existing structure	Experiences and outcomes using the proposed Iowa's Lighthouse
<p>One Friday in mid-July, about 6 weeks after I became two year old Kyle's foster mother, I got a phone call from his child care provider that his biting of other children had gotten out of hand.</p> <p>Reducing his biting incidents was something we had been working on for a few weeks but we weren't really getting anywhere. The child care teacher wanted to give me a heads up, that if the biting didn't get better soon, we'd need to get a new child care provider.</p> <p>Kyle is a child who had been severely physically abused and neglected before he was finally removed from his family after the third founded incident. While the child care provider was more than empathetic, most parents were not and were upset when their children came home with bite marks.</p> <p>I called my social worker, but she was out of the office. I then called her supervisor as her voice message directed. She, too, was gone. So, the only other option on her voice message was to call the DHS emergency number. I placed the call but didn't receive a return call from them until the following Wednesday, seven days after my initial contact.</p> <p>In the meantime, I'd worked with the child care teachers to solve the problem and we did. He didn't need to go to another child care. But, it was clear something was wrong with this child and we needed to work on his anger management. It took six months until I finally got Kyle into a play therapy program at Lutheran Services. It took that long because we went through three social workers in that time period. Each time a worker left we seemed to fall through the cracks and had to orient the new worker about Kyle's issues and advocate for him to access the assistance he needed.</p> <p>Luckily for him, I'm a strong advocate for my child and wouldn't back down. After about five months of therapy for him (and me!) we were released and haven't needed to go back.</p>	<p><i>Kyle's foster mother and the social worker meet to identify a variety of evaluation and intervention resources for Kyle to determine his developmental level and social emotional skills after being removed from an abusive and neglectful home environment. Valuable time would not be wasted waiting to seek permission to have the child evaluated and locate a mental health provider as his social and emotional problems worsened.<sup>1</sup></i></p> <p><i>The foster mother and child care staff would receive early guidance to help Kyle resolve his biting issue in addition to learning how to help him with his post traumatic stress syndrome and provide him with appropriate guidance in anger management. Kyle would develop friendships with his new peers in the child care setting. His new foster parents would be better prepared to assist Kyle during his transition away from his birth parents.<sup>2</sup></i></p>



--	--

Annotation - how the proposed model would lead to improved outcomes.

---

<sup>1</sup> *All social workers are trained members of the Iowa's Lighthouse and have knowledge of the Information and Referral network to help identify appropriate services for foster care children demonstrating diagnosable mental health issues. Foster parents would also be able to utilize the web based tool to search for information during times the social worker was not accessible to them. After Kyle was evaluated and determined to have post traumatic stress syndrome, a learning disability and ADHD, the foster parent would be connected to an Iowa's Lighthouse Navigator that could provide guidance during the times the social workers were changing.*

<sup>2</sup> *A Coordinated Care Plan of Services, Supports and Resources would be developed that would address Kyle's functioning at home and child care. His foster family, child care personnel, mental health specialists, social worker and pediatrician would be partners in the coordinated care plan developed to address the needs of Kyle and his family. Kyle would receive appropriate supports during the transition time into the foster care system.*

### The Hill Family Story

Experiences and outcomes using the existing structure	Experiences and outcomes using the proposed Iowa's Lighthouse
<p>Sally Hill is a 39 year old mother with four children. Sally has mild mental retardation but does not receive any services and supports because her parents and husband do not want her to be viewed as mentally retarded. They don't see the need for any additional supports outside of what they provide Sally.</p> <p>The call to find someone to help Mrs. Hill address her children's needs came from the principal of her oldest child's school. For the fourth time Mrs. Hill had just been told all of her children could not attend school until after they had all been treated for head lice. Mrs. Hill informed the principal she had followed all of the instructions the nurse had given her in the past but the treatments just did not seem to working. She broke down in tears and refused to leave the office because she did not know what she should do to make the lice go away.</p> <p>The principal had interacted with Mr. and Mrs. Hill on previous occasions because their eight year old daughter was diagnosed with moderate developmental delays and had been attending his school since first grade. He knew the Hills also had a six year old son diagnosed with autism attending a specialized classroom across town, a five year old daughter in Head Start and two and a half year old with noticeable speech and motor skill delays that was always with Mrs. Hill.</p> <p>On several occasions the school staff had reported being frustrated with the parent's lack of communication and follow through on any of their recommendations.</p> <p>The staff working with the five year old daughter in the collaborative Head Start/ school district preschool also had been encouraging Mrs. Hill to have her youngest child evaluated by the AEA Early Access team. But, Mrs. Hill seemed reluctant to seek an evaluation and told the teachers her son is still just a baby. Mr. Hill has shared he is particularly opposed to having his youngest son evaluated.</p>	<p><i>The Hill family receives a Navigator when Sara, their first child, is diagnosed with moderate developmental delay. When the family is notified of the head lice problem, Mrs. Hill calls her Navigator and asks what she can do since the treatment did not work in the past. The Navigator contacts the school nurse to advocate for Mrs. Hill. The Navigator works together with the school nurse to help the school understand the difficulties Mrs. Hill faces understanding directions and how to help her complete the treatment steps for head lice.<sup>1</sup></i></p> <p><i>When the Hills begin to suspect their second child, Sam, has developmental delays they ask Sara's teacher what they should do. The teacher utilizes the information and referral system to help the family locate services that will evaluate Sam and determine if he has a formal diagnosis. Once Sam is diagnosed a Coordinated Care Plan is developed. A time is set up for a family team meeting and the decision is made with Mr. and Mrs. Hill to ask their pastor to facilitate the meeting.<sup>2</sup></i></p> <p><i>Mrs. Hill periodically calls her Navigator when she begins to feel overwhelmed and wants to explore her options for additional services that may assist her in meeting her family needs. Mrs. Hill also asks her Navigator to attend both of her children's initial coordinated care plan meetings.<sup>3</sup></i></p> <p><i>During the Coordinated Care Plan meetings the team discusses additional supports the Hill family might access. These include the Respite Coalition and Home and Community-based waivers for Sara and Sam. The Coordinated Care Planner assists Mrs. Hill through the applications process for these services.<sup>4</sup></i></p>

<p>The principal was concerned about Mrs. Hill and could see she really was trying to be a good mother and help her children be successful in school. She regularly attends parent-teacher conferences as well as other school activities but seemed to need help with follow through on any recommendations. It was clear Mrs. Hill was very tired, under a lot of stress, and simply overwhelmed trying to keep up with the needs of all her children.</p> <p>The principal wasn't sure who should be called or what community resources were available. It was evident the family needed some help beyond what school resources could provide. He wondered who could help from other organizations and agencies. The only programs the principal knew about were through the child welfare system. The principal decided to report the family to DHS because they were not addressing the youngest child's obvious needs or to effectively treat the head lice.</p>	<p><i>The Hill family was able to access supports and services at the time they needed them. The children's needs were met and the team members working with the family did not feel the need to report the family to the Department of Human Services because the parents, with occasional support, is able to meet their children's needs.<sup>5</sup></i></p>
--	--

Annotation - how the proposed model would lead to improved outcomes.

<sup>1</sup> *The Navigator contacts the school nurse to advocate for Mrs. Hill. She discusses how the school can best help Mrs. Hill follow through on the instructions given. The school nurse is able to draw on community resources to further assist Mrs. Hill treat the head lice. The Navigator assists Mrs. Hill to begin to create a Lighthouse "MY File" to identify resources and to provide a basis for future service applications. By advocating for the family, the Navigator assists the school personnel to improve their understanding of the family situation to better assist the children in the future.*

<sup>2</sup> *The school is part of the Iowa's Lighthouse. The Iowa's Lighthouse Governance structure assures each provider is trained and knowledgeable about their roles within the system. Each provider's role includes the utilizing the information and referral network when a child, youth or family need is not within their array of services. Because Sam receives a formal diagnosis of Autism a Coordinated Care Plan meeting is scheduled. This process is family driven based on Sam's and the Hill's need, assets and preferences. The Hills request their pastor facilitate the meeting because they trust him and because he has been coordinating assistance for the family for several months. They also request their Navigator attend the initial care plan meeting to help them deal with the multiple recommendations. A Coordinated Care Planner is assigned to help the family meet the needs of the multiple goals and service providers for the child and family plan of care.*

<sup>3</sup> *The Navigator helps the family access both formal and informal supports. Mrs. Hill mentions she is worried about the youngest child but is still hoping he is going to learn to talk clearly and be more independent soon because it is too overwhelming to think another one of her children might have a disability. The Navigator helps connect Mrs. Hill with another mother who has several children with special needs. They talk about their emotions and how to deal with having not only one child but several children with disabilities. After several phone exchanges, Mrs. Hill asks her parent support mentor if she would attend an Early Access evaluation appointment for her son.*

<sup>4</sup> *During the Coordinated Care Plan meeting, arrangements are made to help the family contact needed services. The Care Planner assists the family to complete applications using information*

*available in "My File" plus some additional information as needed. As the children become eligible for multiple services, the various programs must maintain one lead care planner. Under the new Iowa's Lighthouse, the infrastructure will be in place for multiple entities to coordinate care through one care planner.*

<sup>5</sup> *The System of Care reduces the number of inappropriate referrals when providers are attempting to help children, youth and families locate the supports they need at the time they need them. In this case the child welfare system was not contacted thus reducing the time needed by the investigation team. Mr. and Mrs. Hill also did not receive the message they were irresponsible parents during a time when they were feeling overwhelmed.*

## RECOMMENDATIONS

Building a system of care takes time and patience. It requires considerable negotiation among partners to build new infrastructures and determine how collaboration will occur at state and local levels as well as among private and public entities. The Oversight Committee is proposing a transition team to bridge the work between the current committee and new governance structure. This team is a critical link to sustain current momentum, maintain continuity of the plan and continue work toward a new system of care for Iowa children with SED/MR/DD/BI.

To achieve the vision of a system of care for children and youth with SED/MR/DD/BI and their families, the Oversight Committee forwards these recommendations to the MH/MR/DD/BI Commission:

1. Implement the “Iowa’s Lighthouse” model over a five year phase in period to: improve access to information and referral; assist families to navigate the system of services; coordinate services, supports and resources through a plan of care; and to plan smooth transitions (see page 38). The first two years of the Iowa’s Lighthouse Implementation Plan will be used to build the infrastructure for the system. During this time the details for the system will be clarified, memorandums of agreement signed, and training of the workforce begun. In year three the Iowa’s Lighthouse model components will be implemented with year four being a time for system evaluation and improvements with full implementation in year five.
2. Acknowledge and support initiatives that include activities for prevention and early intervention services for children and youth with diagnosed or diagnosable SED/MR/DD/BI to prevent known problems from worsening and to decrease co-occurring disorders.
3. Continue to identify areas in need of improvement within the SED/MR/DD/BI system of care and identify strategies to enhance the system.
4. Endorse and collaborate with efforts to improve screening for social, emotional, developmental and mental health for all infants, children and youth that are consistent with the SED/MR/DD/BI system of care vision.
5. Endorse activities of other initiatives, consistent with the SED/MR/DD/BI system of care vision, that include promotion, prevention, and early intervention services for all children and youth to prevent or ameliorate social, emotional, developmental or behavioral disorders or disabilities.

# IMPLEMENTATION PLAN

## GOALS

- Year 1 & 2 Build the infrastructure for the system of care
- Year 3 Implement the I&R, Coordinated Care Plan of Services, Supports and Resources and Navigator Components of the System
- Year 4 Evaluate implementation processes and take corrective actions
- Year 5 Fully implement the system - Report on system gaps and recommend policy to improve services.

## YEAR 1 & 2 Build the infrastructure for the system of care

### STRATEGIES

#### Resources

Lead agency staff, coordinator/facilitator, meeting location, family liaison, transition team members (consumers, state agency representatives, public and private providers) time and resources - contractors as required.

#### Build the infrastructure for the system of care

- 1) Convene an interim SED/MR/DD/BI System Transition Team to provide direction and governance for the implementation phase until the formal governance body is established.
- 2) Develop the policies for the system
- 3) Create a structure to finance the system
- 4) Develop the training plan for Iowa's Lighthouse workforce to carry out the duties of Information and Referral, Navigators and Care Planners
- 5) Develop a monitoring plan
- 6) Develop a communication plan
- 7) Develop a marketing plan
- 8) Develop a plan to address areas for system improvement identified in the Oversight Committee study and from the experience with the system.

#### Strategy 1

Convene an interim SED/MR/DD/BI System Transition Team to provide direction and oversight for the implementation phase of the model until the formal Governance Body is established.

#### Rationale

There is an entity that is accountable for the system implementation in a timely manner. Momentum established and the work of the Oversight committee is sustained.

Tasks	Responsible Party
1) Designate a coordinator/facilitator, family liaison, public private connector and agency staff	Signatory Agencies
2) Convene an interim transition team based on membership, reporting relationships, and specific charge and timelines as	Lead Agency, Facilitator

specified by the MH/MR/DD/BI Commission. Team may meet monthly for the first year and have subcommittees as needed.	
3) Advise and assist in the development of policies to forward implementation and to sustain the Iowa's Lighthouse model principles and design.	Transition Team
4) Develop a plan (and mechanism) to monitor the system wide reports of family needs, assets, and preferences to provide guidance to the system for structures and policies that enhance access to formal and informal services and supports.	Transition Team
5) Encourage full participation, coordination and cooperation of key entities providing supports and services to children/youth and families in the system.	Transition Team
6) Identify sources of funding for services and supports and encourage braiding of resources to promote a seamless system.	Transition Team

### Strategy 2

#### Develop the standards and policies for the system

#### Rationale

System standards and policies provide a clear direction for implementation, support interagency and public/private collaboration, and provide a strong base for implementation.

Tasks	Responsible Party
1) Identify where & how the model links to the broader system of services including new initiatives that are underway.	Transition Team
2) Seek commitment from key state agencies to continue to explore strategies that move the system forward.	Transition Team
3) Seek commitment from key stakeholders to continue to explore strategies that move the system forward.	Transition Team
4) Review state and federal code and policies for inconsistencies with the model and seek legislation or other action as necessary to support the change.	Transition Team/staff
5) Develop system standards	Transition Team/staff
6) Establish outcomes and measures	Transition Team/staff
7) Negotiate formal and informal partner agreements for the collaborative <ul style="list-style-type: none"> <li>a) Determine who is a part of the system collaborative</li> <li>b) Determine responsibilities of each party</li> <li>c) Develop a template for local use for formal and informal agreement</li> <li>d) Identify the resources of each partner and how those resources will be utilized in the model</li> <li>e) Review existing policies and protocols of each partnership to insure they will support the collaborative model</li> </ul>	Transition Team/staff

### Strategy 3

Create a structure to finance the system

#### Rationale

A clear framework and flow for blending and braiding of funding streams, and resources supports the system, and guides efforts to eliminate duplication.

Tasks	Responsible Party
1) Leverage existing federal, state and local resources and funding streams to finance the model. Include public and private sources and mechanisms and maximize the federal match.	Transition Team
2) Identify new resources for financing or supporting the system.	Transition Team
3) Develop planning and administrative mechanisms and frameworks that maximize utilization of resources from multiple sources to serve children and families through the system of care model in a variety of settings.	Transition Team

### Strategy 4

Complete training for Iowa's Lighthouse workforce to carry out the responsibilities of Information and Referral, Navigators and Care Planners.

#### Rationale

The workforce for Iowa's Lighthouse will be prepared to implement the services based on standards for the system.

Tasks	Responsible Party
1) Designate, or contract with, a curriculum development specialist	Lead agency
2) Agree upon core competencies for certification and methods for training	Transition Team
3) Determine training methodology and processes	Transition Team
4) Develop curriculum	Transition Team

### Strategy 5

Develop a monitoring plan.

#### Rationale

Mechanisms for effectively collecting, sharing, and analyzing data generated by the system are critical to system monitoring and improvement and to successful advocacy efforts. Data driven actions encourage momentum and sustainability.

Tasks	Responsible Party
1) Designate staff, or contract, to set up the electronic data system.	Lead agency
2) Establish the systems for decision oriented, collaborative	Transition



data collection and sharing between partners.	Team/Staff
3) Identify method for continual assessment/monitoring of outcomes.	Transition Team/Staff
4) Develop a method for resetting the course based on outcomes.	Transition Team/Staff

**Strategy 6**

Develop a communication plan

**Rationale**

A clear communication of the model to the public, policy leaders, and community leaders is essential to secure support to mobilize resources, build partnerships, substantiate collaboration and maintain the system.

Tasks	Responsible Party
1) Designate staff to facilitate the development of a communication plan.	Lead Agency
2) Determine the message and methods for communication of the model.	Transition Team
3) Identify formal and informal leaders to “champion” the implementation.	Transition Team
4) Identify leaders from the Oversight Committee to provide continuity.	Transition Team
5) Build new leadership to sustain the vision.	Transition Team
6) Prepare fact sheets for spreading a consistent message.	Transition Team
7) Train parents, providers and staff of all collaborative partners about the model structure, principles and vision.	Transition Team
8) Provide information to policymakers regarding the system throughout the 2007 Legislative session.	Transition Team

**Strategy 7**

Develop a marketing plan

**Rationale**

A strong marketing plan assures that families, as well as community providers, are aware of the services and how to access them. Providers will be aware of how to refer children, youth and families into the service system.

Tasks:	Responsible Party
1) Designate a marketing specialist	Lead agency
2) Establish a name for the system that is easily recognized and marketable	Marketing specialist/Transition Team
3) Identify the target audience	Transition Team
4) Create a logo for the local system “Iowa’s Lighthouse” providers to use to advertise their service (or the logo for the system)	Marketing specialist/Transition Team

5) Use social marketing techniques in development of the marketing plan (focus groups)	Marketing specialist/Transition
--	---------------------------------

**Strategy 8**

Develop a plan to address areas for system improvement identified in the Oversight Committee study and from the experience with the system.

**Rationale**

It is essential that areas for system improvement identified by the Oversight Committee study, as well as improvements identified through evaluation of the new system, not be lost but be considered through a strategic planning process.

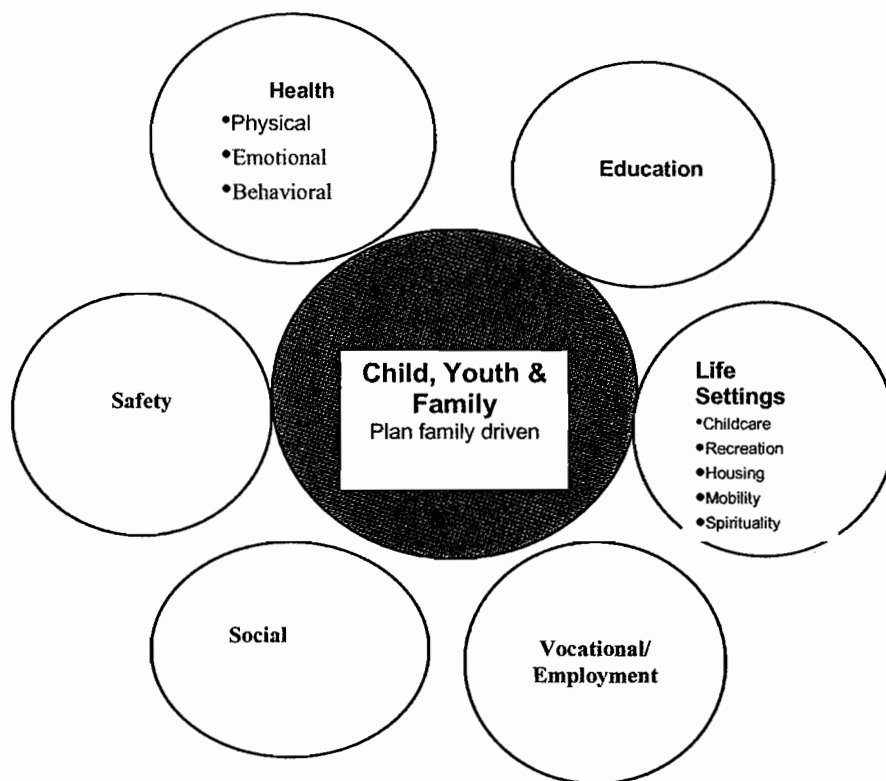
Tasks:	Responsible Party
1) Review the reports of the Oversight Committee studies to determine any system improvements that need to be addressed that haven't been met in the current system model.	Transition Team
2) Continuously monitor the results of system evaluation and address areas for improvement.	Transition Team
3) Prioritize system needs.	Transition Team
4) Determine a plan for meeting the system improvement needs.	Transition Team

**BUDGET**

To meet the infrastructure building goal for year one, the SED/MR/DD/BI Oversight Committee is seeking \$800,000. Estimated costs include \$ 400,000 for four FTE staff to: convene and carry out the responsibilities of the Transition Team, \$200,000 to develop a marketing plan and \$200, 000 to develop curriculum for training the Iowa's Lighthouse workforce.

## Appendix A

### FRAMEWORK FOR THE SED/MR/DD/BI CHILDREN'S SYSTEM SERVICES AND SUPPORT DOMAINS



ALL DOMAINS INCLUDE ACTIVITIES FOR  
PREVENTION      EARLY IDENTIFICATION      INTERVENTION

#### Principles of the System

1. Child/youth focused
2. Family driven
3. Comprehensive
4. Coordinated/Collaborative
5. Culturally competent
6. Infused into natural settings and services
7. Grounded in research/evidence-based or best practice
8. Delivered by a prepared workforce (including volunteers) in the local community
9. Accountable
10. Resource flexible

#### Key Processes

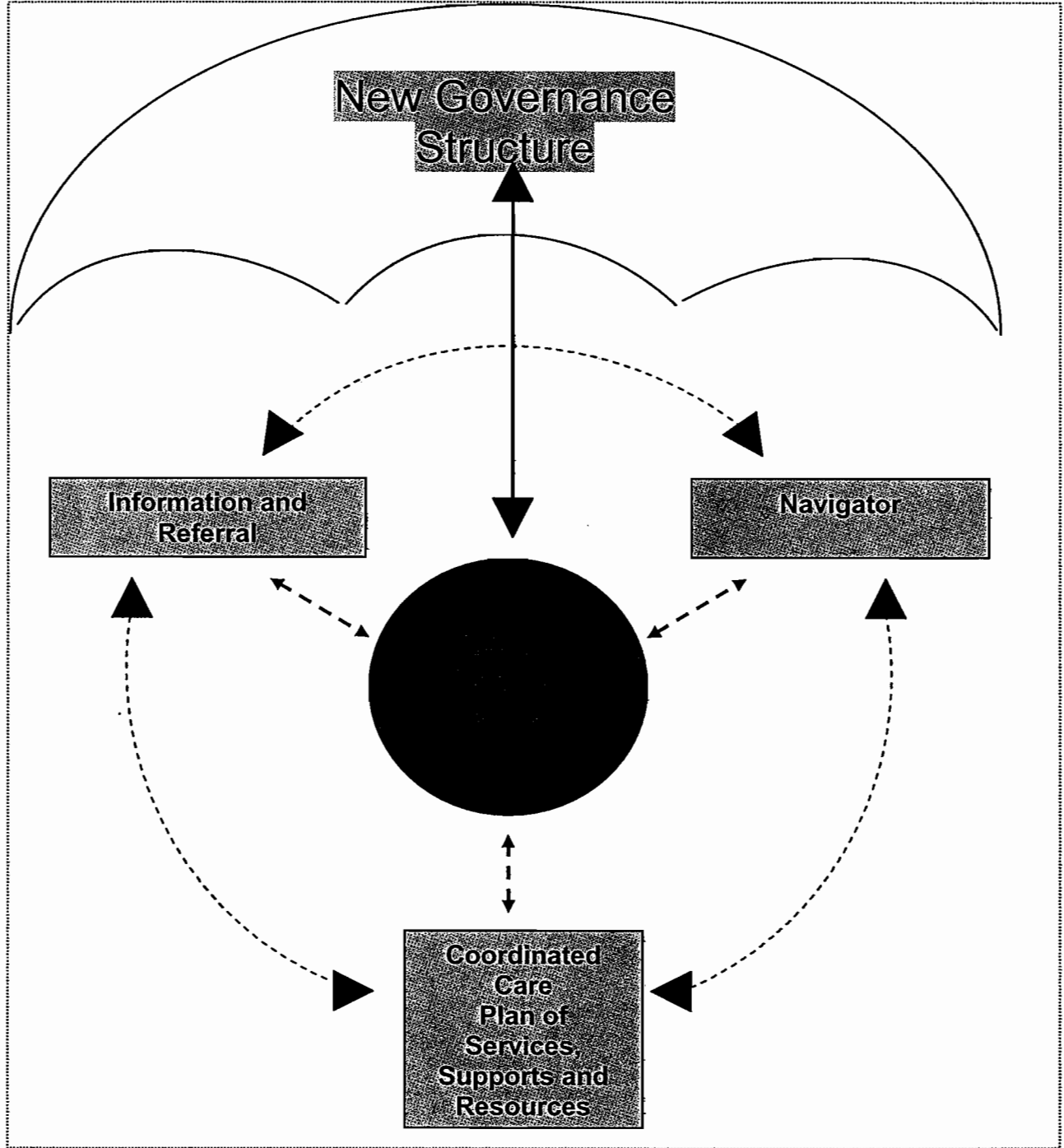
1. Information and referral

2. Determination of eligibility
3. Family support & advocacy
4. Coordinated plan of care
5. Delivery of services
6. Continuous monitoring and improvement

**Building Blocks for the System of Care**

1. Strategic planning, policies and procedures
2. Interagency collaboration/partnerships
3. Braided, flexible, funding
4. Prepared workforce
5. Flexible and accessible services
6. Family Involvement
7. Accountability to children, youth and families with ED,MR/DD/BI and the citizens of Iowa
8. Technology compatible with system needs
9. Governance
10. Transformational Leadership

### IOWA'S LIGHTHOUSE SYSTEM MODEL



## Appendix C

### **Entities currently providing information and referral services, assisting families to access services or developing plans of care (Not all inclusive)**

#### **GENERAL INFORMATION AND REFERRAL OR HOTLINE SERVICES**

- 211
- ISU extension
- Healthy Families Line
- Teen Line
- IDPH Child Health Care Coordinators

#### **SPECIALTY INFORMATION AND REFERRAL SERVICES**

- COMPASS
- ISU HCBS Specialists
- Waiver Case Managers
- Vocational Rehabilitation Services
- Health care providers and discharge planners
- Child Care resource and Referral
- Brain injury resource network and new State level Resource Facilitators
- Iowa family support Network
- County Central Points of Coordination (CPC)
- Child Health Specialty Clinics

#### **ASSISTING FAMILIES TO ACCESS SERVICES**

- Parent Educator Connection
- Targeted Case Managers - Child Welfare Case Managers (DHS/Juvenile Justice)
- AEAs - Early ACCESS Service Coordinators
- Child Health Specialty Clinic
- IDPH Child Health Screening Center Care Coordinator
- Magellan care coordination for children with mental health problems
- NAMI
- ASK Resource
- Children at Home coordinators
- Mental Health, Foster Care, Juvenile Court emerging navigators
- Brain Injury Resource Facilitators
- Parent Consultants in education and health service system
- Workforce Development Navigators
- Home Health Agencies
- Medical Social Services
- Guardian ad Litem
- Advocacy groups

**DEVELOPING PLANS OF CARE:**

- Families/Parents
- Child Welfare/ Juvenile Justice
  - Rehabilitative, Treatment, Services and Supports System (RTSS)
  - Court/Legal (CINA or Delinquency cases)
- Medicaid
  - HCBS Waiver Services, including Children's Mental Health Waiver
  - Iowa Plan for Behavioral Health
- Education: Early ACCESS(IFSP) and Special Education(IEP)
- Medical
  - Child Health Specialty Clinics
  - Medical Home
  - Primary care providers
  - Specialty care providers
  - Psychiatric, primary to tertiary
- Vocational Rehabilitation
- CPC s
- IDHS Case Managers
- Juvenile Court Services
- Private system entities (may have contract with the above)
- Insurance providers

## Appendix D

### GLOSSARY OF TERMS AND ACRONYMS

**Assets:** resources or strengths

**ASK Resource Center:** a family and youth advocacy and support program when the child or youth has a diagnosable or diagnosed disability.

**Brain Injury Lead Agency:** the Bureau of Disability Prevention, Iowa Department of Public Health, provides supports and training to individuals and family members to help them achieve or maintain independence after a traumatic brain injury event. They work collaboratively with Iowa Medicaid to match the state contributions for individuals on the brain injury home and community waiver waiting list and offer a sliding scale for supports and services if the individual does not meet the eligibility guidelines for the waiver. The department also works to build community capacity by training providers on best practices for working with an individual with brain injury.

**Care Plan Coordinators:** individuals who assist children and families to manage coordinated care plans of the system of services, supports and resources.

**Child:** in this report, whenever child or children is used, it is understood that it includes youth and their families.

**Collaboration:** the process of individuals or organizations jointly sharing resources and responsibilities to plan, implement and evaluate programs to achieve common goals.

**Community:** the boundaries, within which a problem can be defined, dealt with, and solved; (e.g., political boundaries, county boundaries, catchment areas, neighborhoods, school district boundaries, or cultural boundaries of a group of people.) This may be the political lines of county boundaries, service areas in which a contractor provides services, or it may be defined by the presence of significant numbers of a particular cultural group. (Definition from the National Commission on Community Health Services, 1960.) Community may be defined by a needed specialty service, rare diagnosis, or age of the target population (i.e. adolescents). It may be small as a neighborhood.

**Community-based:** coming from within the community, or ideas, services, or programs that are shaped by the unique characteristics, culture, and resources present in a community.

**Culturally competent:** organizing systems to be culturally sensitive to diverse groups so they can be better served through recognition and inclusion of their differing values, beliefs and practices at the program level. This must first be accepted and incorporated at the policymaking and administration levels.

**De Cat Funded Projects:** decategorized dollars at county and local level used to fund unmet needs in their communities

**Developmental Disability:** This term refers to a severe and chronic impairment, which can be attributed to one or more mental or physical impairments which will require specific and lifelong or extended care that is individually planned and coordinated, and which had an



onset before age 22, and which is likely to continue indefinitely. The condition or conditions must create substantial functional limitations in three or more of the following areas of major life activity: 1) self care, 2) language skills, 3) learning, 4) personal mobility, 5) self-direction, 6) potential for independent living and 7) potential for economic self-sufficiency as an adult.

**Diagnosable:** has the potential for diagnosis under the diagnostic criteria specified in the DSM -IV.

**DSM-IV:** The *Diagnostic and Statistical Manual of Mental Disorders Fourth Edition* (DSM-IV) is a publication of the American Psychiatric Association while the *International Classification of Diseases, 10<sup>th</sup> revision* (ICD-10) is a publication of the World Health Organization.

**Early ACCESS:** provides early identification and intervention services for infants and toddlers up to three years old identified as at risk for developmental delays under part C of the Federal IDEA Law.

**Early Hearing Detection and Intervention:** program works to assure hearing tests are implemented for all newborns and referrals are made to appropriate services as needed.

**Family:** the persons who are primarily responsible for the care and nurturing of the child including birth parents, guardians, persons acting as parents, foster parents or siblings.

**Fiduciary:** the concept of trust and responsibility that members of a governing board must have to make decisions on behalf of another human being. It requires that reasonable care, skill, and diligence be used in every decision made by the board.

**hawk-i:** Healthy and Well Kids in Iowa, the state's child health insurance program as authorized in Title XXI of the Social Security Act.

**Healthy Child Care Iowa:** trains nurses statewide to assist child care providers in improving the health and safety components of child care programs. The nurses also provide assistance to the child care workers to help them identify resources and training they may need to provide appropriate care to children with disabilities enrolled in their programs.

**I&R Specialist:**certified individuals who provide information and referral services.

**Infrastructure building:** activities to provide support for the development and maintenance of comprehensive services systems including development and maintenance of policies and procedures, standards or guidelines, training, data, and planning systems.

**Iowa Respite Coalition** provides respite services to individuals with disabilities that live in communities through out Iowa that are not receiving home and community based waiver services.

**Mental Health and Disability Services Division (MH/DD Division)** being reinstated within the Department of Human Services to guide policy development and the services system for individuals with mental health, mental retardation, or developmental disabilities.

**Mental Health Block Grant** is Federal dollars allocated to help support mental health services in local communities through out Iowa.

**Memorandum of Agreement (MOA) or Memorandum of Understanding (MOU):** a mutually signed agreement by individuals or organizations to share resources and/or responsibilities to jointly plan, implement, or evaluate programs to achieve common goals.

**Monitoring:** ongoing assessment and evaluation of an intervention that provides continuous feedback on performance.

**Navigators:** individuals who provide assistance to families to help them access the various services and supports.

**Partner:** an individual or organization working with others to accomplish a common goal with a shared sense of purpose and sharing responsibility for the outcome.

**Partnership:** individuals or organizations working together in a side-by-side effort to accomplish a common goal with a shared sense of purpose and a shared responsibility for the outcome.

**Population-based Services:** activities and services developed for, and available to, the entire population in the state rather than for individuals in a one-on-one situation. Disability and injury prevention, promotion, and statewide outreach are examples of activities.

**Target population:** the people identified as needing, requiring, or desiring a particular product or service. In the SED/MR/DD/BI system, the target population refers to children and youth, birth to age 21 years, who have diagnosed or diagnosable serious emotional disturbances, mental retardation, developmental disabilities or brain injury and their families.

**Title V:** of the Social Security Act. Federal requirements contained in the Omnibus Budget Reconciliation Act of 1989 (Public Law 101-239), deals with the Maternal and Child Health program administered by the IDPH.

**Traumatic brain injury (TBI):** is an insult to the brain, not of degenerative or congenital nature but caused by an external physical force that may produce a diminished or altered state of consciousness, which results in an impairment of cognitive abilities or physical functioning. It can also result in the disturbance of behavioral or emotional functioning. These impairments may be either temporary or permanent and cause partial or total functional disability or psychosocial maladjustment. (Brain Injury Association)

**Serious emotional disturbance (SED):** is defined as a mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified in the DSM-IV that results in functional impairment that substantially interferes with or limits one or more major life activities in an individual up to 18 years of age. Examples of functional impairment that adversely affect educational performance include an inability to learn that cannot be explained by intellectual, sensory, or health factors; an inability to build or maintain satisfactory interpersonal relationships with peers and teachers; inappropriate types of behavior or feelings under normal circumstances; a general pervasive mood of unhappiness

or depression; or a tendency to develop physical symptoms or fears associated with personal or school problems.<sup>35</sup>

**Diagnosable:** has the potential for diagnosis under the diagnostic criteria specified in the DSM -IV.

**DSM-IV:** The *Diagnostic and Statistical Manual of Mental Disorders Fourth Edition* (DSM-IV) is a publication of the American Psychiatric Association while the *International Classification of Diseases, 10<sup>th</sup> revision* (ICD-10) is a publication of the World Health Organization.

**Service Providers:** formal and informal workforce that provide services and supports.

**System of Care:** a range of services and supports guided by a widely agreed upon philosophy and supported by an infrastructure.

**Toledo Juvenile Facility:** provides services to delinquent boys and girls between the ages of 12 and 18 years. The facility's capacity is 100 beds.

**Eldora Juvenile Facility:** provides services to delinquent boys between the ages of 12 and 18 years. All of the admissions are adjudicated delinquents. The facility's capacity is 189 beds.

**State Plan Services:** are Medicaid services for adults and children meeting 150% of Federal poverty guidelines

**Magellan Iowa Plan:** provides managed care service options for individuals with mental health diagnosis and meeting Federal poverty level of income.

## ACRONYMS

**ABCD II:** Assuring Better Child Health and Development Initiative focuses on implementing prevention, early recognition, and early intervention practices that promote the healthy development of children from birth through age 3 who participate in Iowa's Medicaid system.

**AEA:** Area Education Agency services provided to local school districts for developing and implementing individualized education plans for children with diagnosed disabilities.

**CYD:** Collaboration for Youth Development consists of a partnership of multiple state agencies focused on assisting local communities to develop a single unified community plan for youth development. The state team offers community partners a results matrix and targeted outcomes for youth to be: Safe, Healthy, Prepared for productive adulthood, and Successful in School.

**CDD:** Center for Disabilities and Development, University of Iowa Hospitals and Clinics

**CHSC:** Child Health Specialty Clinics, Iowa's Title V agency for children with special health care needs. Services include clinical visits, professional consultation and case management services for children that are medically fragile, have cardiac conditions, cystic fibrosis, Ear, Nose and Throat anomalies and generalized pediatric social emotional issues.

**CMS:** Center for Medicare and Medicaid Services

**CMH Waiver:** The Children's Mental Health Waiver provides funding and individualized support that allows eligible children to live in their own homes and communities who would otherwise require support in a medical institution. A child who may benefit from this Medicaid waiver has been diagnosed with a serious emotional disturbance as verified by a psychiatrist, psychologist or a mental health professional.

**DD Council:** Governor's Developmental Disability Council provides funding for targeted activities that promote advocacy, inclusion and choice for Iowans with developmental disabilities.

**EPSDT:** the Early Periodic Screening, Diagnosis, and Treatment program for children birth to 21 under Medicaid.

**FERPA:** Family Educational Rights and Privacy Act (20 U.S.C. § 1232g; 34 CFR Part 99) is a Federal law that protects the privacy of student education records.

**FIND:** Family Information Network on Disabilities provides training and advocacy supports for families of children with disabilities.

**HCBS:** Home and Community Based Services Waiver is a Medicaid program designed to maintain an eligible individual at home or in the community. In order to extend eligibility for the program, the federal government must "waive" certain Medicaid regulations.

**HIPAA:** Health Insurance Portability and Accountability Act. This includes provisions that protect the confidentiality and privacy of medical records.

**HOPES:** Healthy Opportunities for Parents to Experience Success works with high risk families to help strengthen them and provide guidance that reduces the incidence of child abuse and neglect.

**HRSA:** The Health Resources and Services Administration (HRSA), an agency of the U.S. Department of Health and Human Services, is the primary Federal agency for improving access to health care services for people who are uninsured, isolated or medically vulnerable.

**ICF/MR:** Intermediate Care Facility for people with mental retardation provides services to both adult and children Medicaid recipients.

**IDM:** Iowa Department of Management

**IDE:** Iowa Department of Education

**IDEA:** Individuals with Disabilities Act Part B provides supports for an individualized education plan for children with disabilities between the ages of three to twenty one years.

**IDHS:** Iowa Department of Human Services

**IDPH:** Iowa Department of Public Health

**IEPC:** Integrated Evaluation and Planning Clinics, a service of Child Health Specialty Clinics, are designed to provide services for children with health-related developmental and behavioral problems. The clinic physician provides diagnostic and evaluation services. Professional examiners from the community provide consultation in nursing, psychology, and social services.

**IFPA:** Iowa Foster Parent Association provides advocacy, training and support to foster parents.

**IFFCMH:** Iowa Federation of Families of Children with Mental Health provides statewide advocacy and support to families that have children with behavioral or mental health issues.

**MH/MR/DD/BI:** Mental Health, Mental Retardation, Developmental Disabilities, and Brain Injury

**MR Waiver:** Mentally Retarded Waiver program is a Medicaid program designed to maintain an eligible individual at home or in the community. In order to extend eligibility for the program, the federal government must “waive” certain Medicaid regulations.

**P & A:** Protection and Advocacy provides advocacy and legal guidance for individuals with a disability and their families.

**PAT:** Parents as Teachers provides training and assistance to parents wanting to co-present during pre-service and in-service education for future and existing professionals.

**PEC:** Parent Educator Connection provides a core of trained parent advocates to assist parents of children with disabilities to access the supports and services their child may need within their individualized education plan.

**PMIC:** Psychiatric Mental Health Institutions for Children under the age of 21 needing long term residential care.

**RTSS:** Rehabilitative treatment supports and services for children needing assistance to live safely within their families and communities.

**SAMHSA:** Substance Abuse and Mental Health Services Administration

**SECTION 504 of the Rehabilitation Act of 1973:** Protection for children with disabilities who may not be eligible for IDEA services.

**504 Plans:** provide individualized supports to children that have behavioral issues that impact their success within the classroom in public schools. These children do not have a 25 % or more developmental delay.

**SED/MR/DD/BI:** Serious Emotional Disturbance, Mental Retardation, Developmental Disabilities, and Brain Injury

**SSI:** Social Security Income

**TBI:** Traumatic Brain Injury

## Appendix E

### Need for services, providers, and training of direct care workforce for children and adolescents with SED.

While comprehensive service options may be available through some current programs, they may not be all inclusive and may not cover all children with disabilities. Both national and available state data indicate a shortage of providers with specific expertise in providing evidence-based interventions for mental health problems in children and adolescents.

Providers who treat mental health problems in children and adolescents come from a number of different disciplines. These disciplines require different levels of training and offer different types of expertise. A recent review of national trends in the provision of mental health services to children and adolescents noted that “there is a striking trend toward the use of professionals who lack specialty training in child mental health” and “Experts across the professions generally agree that non-specialists are not trained appropriately to be providing this type of care. But they do not agree on the extent to which more specialists should be trained, or generalists should retool, to offer children effective mental health care” (Koppelman, 2004).

The two types of interventions for children and adolescents with SED, broadly defined, are psychotropic medication and psychosocial interventions (e.g. psychotherapy, behavior therapy).

Child and adolescent psychiatrists are the providers with the most training in treating youth’s mental health problems with psychotropic medication. In Iowa, other providers who prescribe psychotropic medications for children and adolescents include pediatricians, family physicians, advanced practice nurses, and physician assistants. Two states (New Mexico and Louisiana) allow psychologists who have completed specialized training to prescribe psychotropic medications and several other states are considering allowing psychologists prescription privileges (Koppelman, 2004). National data indicates that the majority of psychotropic medications for children and adolescents (85%) are prescribed by pediatricians and family physicians (Goodwin, Gould, Blanco, and Olfson, 2001). The American Board of Pediatrics created a formal subspecialty called developmental and behavioral pediatrics in 2002 to provide pediatricians with increased training and specialization in mental health problems. However, there are currently only 300 board certified developmental and behavioral pediatricians in the United States (Koppelman, 2004).

Psychosocial interventions for children and adolescents with SED are provided by psychologists, marital and family therapists, mental health counselors, and social workers. The amount of training specific to interventions for mental health disorders in children and adolescents differs between disciplines. In addition, there is variability within disciplines depending on the emphasis of the specific training program where the provider was trained.

Psychologists have the most training in evidence-based psychotherapies and conducting standardized psychological assessments and spend an average of seven years in post-graduate training (Koppelman, 2004). The American Board of Professional Psychology recognizes two specialties with training specific to the assessment and treatment of mental health disorders in children and adolescents: clinical child and adolescent psychology and

school psychology (American Board of Professional Psychology, 2006). Specialists in these areas complete additional coursework and clinical practica focused on mental health problems in children and adolescents during their graduate training in psychology. In addition, they complete two years of specialized training focusing on assessment and treatment of children and adolescents with SED (a one year predoctoral internship and one year of postdoctoral training). Nationally, there are 209 internships approved by the American Psychological Association (APA) with a major emphasis on providing specialized training in assessing and treating children and adolescents with SED. Currently there are no APA-approved internships in Iowa offering specialized training in child and adolescent mental health (Association of Psychology Postdoctoral and Internship Centers, 2006). Nationally, there are currently 75 board-certified clinical child and adolescent psychologists and 133 board-certified school psychologists (American Board of Professional Psychology, 2006). Currently there is only one board-certified clinical child and adolescent psychologist and one board-certified school psychologist in Iowa (American Board of Professional Psychology, 2006).

#### References:

*American Board of Professional Psychology (2006). Directory of the American Board of Professional Psychology. Retrieved from [www.abpp.org](http://www.abpp.org) on 6/28/06.*

*Association of Psychology Postdoctoral and Internship Centers (2006). Directory of the Association of Psychology Postdoctoral and Internship Centers. Retrieved from [www.appic.org](http://www.appic.org) on 6/28/06.*

*Goodwin, R., Gould, M., Blanco, C., & Olfson, M. (2001). Prescription of psychotropic medications to youths in office-based practice. *Psychiatric Services*, 52, 8, 1081-1087.*

*Koppelman, J. (2004). The provider system for children's mental health: Workforce capacity and effective treatment, National Health Policy Forum. Washington, DC. Retrieved from [www.nhpf.org](http://www.nhpf.org) on 6/21/06.*

*Thomas, C. & Holzer, C. (in press). The continuing shortage of child and adolescent psychiatrists. *Journal of the American Academy of Child and Adolescent Psychiatry*.*



## FOOTNOTES

- <sup>1</sup> Iowa MH/MR/DD/BI Commission. *System Redesign Progress Report to the Governor, January 20, 2005.*
- <sup>2</sup> New Freedom Commission on Mental Health. *Achieving the Promise: Transforming Mental Health Care in America. Final Report.* DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003, page 2.
- <sup>3</sup> Healthy Iowans 2010 chapter 12 page 1.
- <sup>4</sup> Glascoe FP. "Early Detection of Developmental and Behavioral Problems." *Pediatrics in Review.* 2000: Vol. 21, No. 8: 272-280.
- <sup>5</sup> Kutash, K.; Duchnowski, A.; Friedman, R., *The system of care 20 years later. In Outcomes for children and youth with emotional and behavioral disorders and their families, Second ed.; Epstein, M.; Kutash, K.; Duchnowski, A., 'Ed.' Eds.' pro-ed: Austin, Texas, 2005; 'Vol.' p^pp 3 - 22.*
- <sup>6</sup> Public Policy Center, Iowa Department of Public Health, *Child Health Specialty Clinics, 2000 Iowa Child and Family Household Health Survey, Oct 2001.*
- <sup>7</sup> National Center for Mental Health and Juvenile Justice, *Key Issue Brief,* [www.ncmhjj.com/faqs/default.asp](http://www.ncmhjj.com/faqs/default.asp)
- <sup>8</sup> *Brain Injury News, Spring 2005, Center for Disabilities and Development, University of Iowa Hospitals and Clinics, www.biaia.org.*
- <sup>9</sup> Blanchard, L, Gurka, M, & Blackman J. *Emotional, Developmental, and Behavioral Health of American Children and their Families: A report from the 2003 National Survey of Children's Health. Pediatrics Vol. 117 No 6 June 2006, pp e1202-1212.*
- <sup>10</sup> Iowa Plan Medicaid Mental Health / Substance Abuse Client Satisfaction Survey Reports, 2003-2004. Magellan Behavioral Care of Iowa.
- <sup>11</sup> Conners, S. (2001) *Resource Facilitation: A Consensus of Principles and Best Practices To Guide Program Development and Operation in Brain Injury.* BIA Inc. Alexandria VA.
- <sup>12</sup> *Ibid*
- <sup>13</sup> Kuperman, Samuel. *Child Psychiatry an Overview of State Needs, Presentation at the Iowa's Children: Our Future, Our Promise, May 12, 2006.*
- <sup>14</sup> American Board of Professional Psychology (2006). *Directory of the American Board of Professional Psychology.* Retrieved from [www.abpp.org](http://www.abpp.org) on 6/28/06.
- <sup>15</sup> Iowa Department of Public Health Center for Health Workforce Planning (2006). *A summary of four mental health workforce surveys in Iowa.* Retrieved from [www.idph.state.ia.us/hpcdp](http://www.idph.state.ia.us/hpcdp) on 6/26/06.
- <sup>16</sup> New Freedom Commission on Mental Health. *Achieving the Promise: Transforming Mental Health Care in America. Final Report.* DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003, p 3.
- <sup>17</sup> New Freedom Commission on Mental Health. *Achieving the Promise: Transforming Mental Health Care in America. Final Report.* DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003, p 11 -15.
- <sup>18</sup> Iowa Department of Public Health. *Healthy Iowans 2010 Mid-Course Revision.* Des Moines IA. July 2005. Found at [www.idph.state.ia.us/bhpl/common/pdf/healthy\\_iowans\\_2010\\_chapters/Healthy\\_Iowans\\_2010\\_Complete.pdf](http://www.idph.state.ia.us/bhpl/common/pdf/healthy_iowans_2010_chapters/Healthy_Iowans_2010_Complete.pdf)
- <sup>19</sup> Report of the "Off to a Good Start Framing Policy for Early Childhood Systems Integration Workshop" (2005). *Early Childhood Health Systems Integration- Principles for Consideration.* Report published at [www.public-health.uiowa.edu/umphtc/products/ecd-conf/](http://www.public-health.uiowa.edu/umphtc/products/ecd-conf/)
- <sup>20</sup> Stroul, B. (2002) *Issue Brief, Systems of Care: A framework for system reform in children's mental health.* Washington D.C.: Georgetown University Child Development Center, National Technical Assistance Center for Children's Mental Health, p5.
- <sup>21</sup> Knitzer, J. *Building Services and Systems to Support the Healthy Emotional Development of Young Children* (New York, NY: National Center for Children in Poverty, 2002). Also see Jane Knitzer. "Early Childhood Mental Health Services Through a Policy and Systems Development Perspective." In S.J. Meisels and J.P. Shonkoff (Eds.), *Handbook of Early Childhood Intervention* (2nd ed.) (New York: Cambridge University Press, 1997).
- <sup>22</sup> Knitzer, J. & Cooper, J. (2005). *Beyond Integration: Challenges for children's mental health.* *Health Affairs, 29(3), 670-679.*

- 
- <sup>23</sup> New Freedom Commission on Mental Health. *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003, page 58.
- <sup>24</sup> Knitzer, J. *Building Services and Systems to Support the Healthy Emotional Development of Young Children* (New York, NY: National Center for Children in Poverty, 2002). Also see Knitzer, J.. "Early Childhood Mental Health Services Through a Policy and Systems Development Perspective." In S.J. Meisels and J.P. Shonkoff (Eds.), *Handbook of Early Childhood Intervention* (2nd ed.) (New York: Cambridge University Press, 1997).
- <sup>25</sup> Reynolds A, Temple J, Robertson D, & Mann E. Long-term effects of an early childhood intervention on educational achievement and juvenile arrest: A 15-year follow-up of low-income children in public schools. *JAMA*. 2001 May 9;285(18):2339-46.
- <sup>26</sup> Karoly, L.A., Kilburn, M. R. & Cannon, J.S. (2005). *Early Childhood Interventions: Proven Results, Future Promise*. Santa Monica, CA: The RAND Corporation.
- <sup>27</sup> Stroul, B. (2002) *Issue Brief, Systems of Care: A framework for system reform in children's mental health*. Washington D.C.: Georgetown University Child Development Center, National Technical Assistance Center for Children's Mental Health p3.
- <sup>28</sup> Koyanagi, C., & Feres-Merchant, D. (2000). *For the long haul: Maintaining systems of care beyond the federal investment. Systems of Care: Promising Practices in Children's Mental Health, 2000 Series, Volume III*. Washington, D.C.: Center for Effective Collaboration and Practice, American Institutes for Research.
- <sup>29</sup> *Ibid*
- <sup>30</sup> Research and Training Center for Children's Mental Health 2005. *Effective Systems of Care: A Summary of Implementation Factors*, Louis de la Parte Florida Mental Health Institute, University of South Florida.
- <sup>31</sup> Koyanagi, C., & Feres-Merchant, D. (2000). *For the long haul: Maintaining systems of care beyond the federal investment. Systems of Care: Promising Practices in Children's Mental Health, 2000 Series, Volume III*. Washington, D.C.: Center for Effective Collaboration and Practice, American Institutes for Research.
- <sup>32</sup> *Ibid*
- <sup>33</sup> *Ibid*
- <sup>34</sup> Research and Training Center for Children's Mental Health 2005. *Effective Systems of Care: A Summary of Implementation Factors*, Louis de la Parte Florida Mental Health Institute, University of South Florida.
- <sup>35</sup> New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003, p 2  
<http://www.mentalhealthcommission.gov/reports/Finalreport/FullReport.htm>