

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

EXECUTIVE SUMMARY

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

VISION STATEMENT

All Iowa children¹ with serious emotional disorders, mental retardation, developmental disabilities and brain injury² (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.

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

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 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

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

² 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.

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 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 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

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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 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

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

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.

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- 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.

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- 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.