

Iowa MHDS System Redesign

Children's Disability Services Workgroup

Summary of Recommendations

Prepared by the Technical Assistance Collaborative, Inc.

October 25, 2011

I. Introduction

The Children's Disability Services Workgroup has met five times since the enactment of SF 525.¹ The recommendations summarized in this report have been derived from the discussions and consensus-building that occurred during these meetings. For each meeting TAC and DHS prepared: (a) a detailed agenda; (b) a set of reading materials on best practices and examples from Iowa and other states related to the topics on the agenda; and (c) a discussion paper from TAC providing more in-depth explanations of the topics under discussion, best practices from other jurisdictions and considerations for the Workgroup. Workgroup members contributed written materials for review and discussion, provided information from the field, and expertise in promising practices in systems of care, family and peer support, engaging children and families, insight, and information from other child-serving systems (education, child welfare, juvenile justice, primary healthcare, public health (Title V)). Materials were posted on the DHS website before each scheduled meeting, so that participants would have time to become informed about the topics to be discussed.

The timeline for the redesign of the Children's Disability Services Workgroup differs from those of the other workgroups. This initial proposal includes an analysis of gaps in the children/youth system; a review of promising practices in children's/youth's mental health and disability services; initial recommendations for implementing an interim set of care services; a proposal for bringing children and youth home from out-of-state placements; a review of children/youth and family outcomes; and a plan for the next stage of work for the Workgroup². The final proposal is due to the legislature on or before December 10, 2012.

II. Analysis of Gaps in the Children's System

There is no clear, accountable, organizing entity for children's Disability services in Iowa.

- Limited macro-level knowledge.

¹ August 16, August 30, September 13, September 27, and October 11th. An additional meeting will be held on October 25th.

² TO BE DEVELOPED DURING THE WORKGROUP SESSION ON OCTOBER 25, 2011.

- No systemic oversight to assure expertise in serving children, youth and their families through all phases of growth and development (i.e. there are “Agencies on Aging” but no “Agencies on Growing”).

There are no clearly defined, titled, accessible, logical pathways into treatment for children and their families.

- How to access services varies by community and is not easily determined at the user level (the “user” being a parent, child or provider from within the system or in another child-serving system).
- More default than design.

Child-serving systems are disconnected. Care is not coordinated. Services are delivered and outcomes are measured at a program rather than systems level.

- No common values or guiding principles in meeting the health needs of children/youth and families.
- No mechanisms for pulling people/services/systems together.
- No pathways to facilitate cross-service/cross-system care planning for children/youth and families.

There is an over-reliance on Medicaid as the first or sole funder of services.

- Drives children and families to a higher level of care to become Medicaid-eligible.
- Drives access through other funding systems like child welfare and juvenile justice.
- Limits the array of services to those that are Medicaid-eligible.
- Narrows target population.
- Little experimentation with blending/braiding funding from multiple funding streams and/or across systems.

Children/youth get “what we have” rather than “what they need”.

- Not enough service nuance and variety to give children/youth and families, in an individualized way, what they want and need.
- The system is not nimble.
- There is inadequate attention to assuring developmentally and culturally-appropriate services.
- Inadequate attention to building “specialized” competencies.

The unique needs of parents, guardians, caretakers, and family members are not adequately addressed.

- No formalized means for assistance in navigating a very complex system.
- Limited expertise in supporting, partnering with and understanding the journey of parents of children/youth with disabilities.

Residential/PMIC services are not providing optimal impact due to disconnect with community-based services, reimbursement practices and insufficient care/continuity management.

- Lack of appropriate step-down opportunities keeps children/youth at higher levels of care, impacts successful transition and impacts permanency.

Lack of timely access to key individual services delays care, risks harm and contributes to demand for out-of-state care. Examples:

- Waiver – there is an extensive wait list for service that requires child/youth meet criteria for “hospital level of care”.
- PMIC bed/Residential Services – children and youth are housed in shelter and inpatient hospital beds awaiting treatment.
- Waiting lists for children’s inpatient psychiatric beds, especially for children under age 12.

24/7/365 in-community, resolution-focused, crisis intervention, support and brief stabilization for children and families is largely unavailable throughout the state.

- Results in overuse of more restrictive, intensive services (hospital emergency departments, inpatient hospitalization, residential treatment, law-enforcement-involvement, involuntary commitments, or other court orders).
- Increased penetration into Child Welfare and Juvenile Justice system.

Transition planning in and out of institutional settings is insufficient.

- Lack of continuity during the course of care (during admission, course of stay, return to community).
- Insufficient support of and involvement with the family during treatment and at transition.
- Burden falls on parents to manage successful transition.
- Schools often unprepared, unequipped.
- Lack of appropriate step-down services keep children/youth in a higher level of care and impacts successful transition and permanency.

Insufficient focus on health promotion.

- Wellness services
- Healthy Families
- Healthy supported environments and communities—physical, social , and the built environment³
- Social determinants of health

Insufficient focus on prevention and early identification of needs.

- Identification and prevention of adverse childhood experiences
- Trauma informed health care
- Strength based approach
- Building resiliency

Transition-Age Youth⁴ are underserved by both the child/youth and adult systems. There is no mechanism to assure smooth transition into needed adult services and supports when aging out of the children’s/youth’s system.

- Support in completing education

³ Built environment refers to the man-made surroundings that provide the setting for human activity, ranging in scale from how schools are built, where they are located; the proximity of green space, housing and the configuration of neighborhoods and large-scale civic surroundings.

⁴The target age varies by states and programs. Generally, transition-age youth (TAY) are in the range of 14-16 years old up to 22-25 years old.

- Housing supports
- Independent living skills
- Peer supports
- Community connectedness
- Utilizing natural and informal supports in young adulthood

Education supports are inconsistently available and not sufficiently coordinated or tied to the larger treatment services.

- Educational outcomes are key measures of child/youth health and are not being tracked by the mental health provider.
- Insufficient transition services for children/youth going to/returning from placement (credits may not transfer, insufficient planning for support needs, etc.).
- IEP's not readily offered to children/youth with behavioral needs.

Providers need expanded ability to manage needs and behaviors in-state.

- Workforce funding/training needed to achieve competencies across levels of care (out of state placements, juvenile delinquents, etc.).

There is no “repository” that tracks numbers and types of providers for children/youth to assure adequate capacity and competency to match the unique needs of children, youth and families.

III. Promising Practices in Children’s Services

Each session the Children’s Workgroup reviewed a selection of programs and practices from some within and some outside of Iowa. The list of what was reviewed is by no means inclusive of all of the promising practices for children, youth and families either in or out-of-state. For example, promising practices in trauma-informed treatment were not reviewed by the Workgroup during this phase but are considered by the members to be an essential competency of a service system for children and youth.

In-state

Central Iowa Systems of Care

The Central Iowa System of Care serves children and youth who are at risk for out of home treatment. Central Iowa System of Care serves children and youth not only at risk of out of home treatment, but those discharging from out of home treatment. Of those served in FY2011, only 8% required more intensive out of home treatment. The System of Care project helped prevent residential treatment or contributed to an early return home from residential treatment and hospitalization. Ninety-two percent of children/youth stabilized or improved functional status; school suspensions were reduced 71% and 92% of students maintained or improved their attendance. Eighty-three percent had no new juvenile court charges while involved in services.

Community Circle of Care in Northeast Iowa

The Community Circle of Care (CCC) is a regional Systems of Care project located in Northeast Iowa, comprised of a coordinated network of community-based services and supports. The model combines a diagnostic medical model with a wrap around, family team approach, to provide needed services to children and their families with complex mental health and behavioral challenges. CCC is collaboration among the Iowa Department of Human Services, The University of Iowa Child Health Specialty Clinics (Title V agency for Children with Special Health Care Needs), and The University of Iowa Center for Disabilities and Development. CCC is funded through a state/federal cooperative agreement through the Substance Abuse and Mental Health Services Administration (SAMHSA) and is participating in the most comprehensive, national program evaluation to date of a mental health service delivery program for children. Outcomes of the project, collected by various evaluation tools, indicate that of the 1,567 children and youth served by CCC in SFY 2011, 97.70% (1,531 youth) remained in their homes and communities, avoiding more costly and traumatic out of home placements. Of those interviewed, caregivers perceived that their child's functioning in home, school and community domains, improved from 34.3% at baseline to 73.2% at the 1st re-assessment (6 months). Of youth discharged from the program in FFY 10 and FFY 11, 79.7% were reported to be doing well academically in school, and 89.5% were reported to have satisfactory or better attendance. Of those served, 98.4% were satisfied with the care they received from the CCC project. In addition to the standard methodology, a comprehensive chart review of 1,016 CCC children and youth found that in the absence of CCC services, 583 youth (57%) would have received more costly and restrictive services, such as out-of-home placement and involuntary hospital committal. An additional 3,612 children were served through providing community based services and activities including information and referral services (505), training events (1,246), support groups for children, youth and families (641), and events specific to military personnel and their families (1,031). These activities and events were organized by CCC and sponsored by numerous private and public community organizations⁵.

A. Promising practices reviewed by the Workgroup

- Services for Transition-Age Youth (entering adulthood)
- Services for children/youth with/at risk for co-existing mental health and developmental disabilities
- Building Systems of Care
- Family Support Services for Children with Developmental Disabilities
- Health Home Model of Care
- Building Crisis Systems of Care
- Multi-Systemic Therapy
- SAMHSA: Good and Modern Systems
- American Academy of Pediatrics Mental Health Competencies for Primary Care

⁵ ** Awareness Activities include only participants in the Suicide Awareness and Prevention Walk and does not include those impacted by the CCC website or the youth and family newsletters.

*** Numbers are counted as unduplicated at each event. Some families have attended multiple events.

- NAMI: Child and Youth Mental Health Services and Support Array
- National Center for Mental Health and Juvenile Justice: Advances and Innovations

B. Other States

NOTE: The Workgroup was briefed and received materials about the systems of care structures and system redesign activities in a number of other states and some examples are listed in this section. There are advantages and disadvantages to each of the models. This summary section is not intended as an endorsement of any of the models described nor is it an indication that any of them could or should be replicated in Iowa. The information simply served as source material and one stimulant of conversation about what might serve children and families best in Iowa.

Milwaukee, Wisconsin: Wraparound Milwaukee⁶

Initial focus of project was on hard-core delinquents, with the majority of them in the community versus residential settings. Wraparound Milwaukee started small with a narrow population, but they have built capacity to expand the populations they serve. Project is now focusing on pre-juvenile justice and Child Protection youth and has just started a transition-age youth program. “Those served received a flexible, comprehensive array of services designed to ensure better outcomes behaviorally, educationally and socially. The overarching goal of Wraparound is to provide integrated and individualized services in order to provide a strong system of community-based support for the child, youth and family, thereby reducing the need for out-of-home or institutional placement(s).”

Alaska: Bringing the Kids Home (BTKH)⁷

Alaska is in its final two years of its initiative to “reduce the number of Alaska Children who are served in out-of-state psychiatric treatment facilities and to improve outcomes for Alaska children with behavioral health problems.” The state recognized its “increasing reliance” on residential psychiatric treatment centers (RPTC’s) for treatment of youth with severe emotional disturbance. Alaska has reduced the use of out-of-state placements by 88%, reduced placement recidivism from 20% to 8.6% and reduced the unduplicated count of children admitted to RPTC’s from 965 in FY04 to 295 in FY10. Medicaid payments for out-of-state residential psychiatric treatment dropped 62% from \$40 million in FY2006 to \$15.2 million in FY2010. Alaska has employed six strategies:

- Specialized capacity enhancement through reinvestment of funds used for out-of-state placements.
- Care coordination to assure in-state resources are accessible and to coordinate any residential treatment—including paying careful attention to educational transitions.
- Addressing service and funding gaps with particular attention to trauma-informed services, early childhood services, and transition-age services.

⁶ Wraparound Milwaukee, 2009 Annual Report. For more information:

<http://county.milwaukee.gov/WraparoundMilwaukee.htm>

⁷ Bring the Kids Home Update and 2-Year Plan, FY12-13. For more information:

http://hss.state.ak.us/dbh/resources/initiatives/kids_home.htm

- Improving reporting mechanisms to monitor system access, outcomes and service utilization.
- Developing partnerships with communities and in-state providers to organize resources and services.
- Workforce development including strategies to expand expertise through technical assistance, training, startup grants, and contracts.

Minnesota: Children’s Mental Health System Redesign⁸

A number of reforms were enacted in Minnesota under a 2007 Mental Health Initiative that shifted the balance of care away from institutions and into the community through the addition/expansion of services including children’s crisis services, community services and supports, school-based treatment, and respite care.

Kansas: Transition to a Mental Health System of Care⁹

“In Kansas, the HCBS-SED Waiver is an integral and seamless component of the Mental Health System of Care. While there has been a dramatic reduction in State Psychiatric Hospitalization since implementation of the HCBS-SED Waiver, this would not have been achieved if a comprehensive array of community based mental health services were not simultaneously available through General Medicaid.” The average length of stay in residential treatment dropped from 180 to 40 days and institutional expenditures have dropped approximately 60%.

Massachusetts: Children’s Behavioral Health Initiative¹⁰

“The Children’s Behavioral Health Initiative (CBHI) was created by Dr. Judy Ann Bigby, Secretary of the Executive Office of Health and Human Services (EOHHS), to implement the remedy in *Rosie D v Patrick*, a class action law suit filed on behalf of MassHealth-enrolled children under the age of 21 with a serious emotional disturbance (SED). Through CBHI, MassHealth requires primary care providers to offer standardized behavioral health screenings at well child visits, mental health clinicians to use a standardized behavioral health assessment tool, and provides new or enhanced home and community-based behavioral health services. CBHI also includes a larger interagency effort to develop an integrated system of state-funded behavioral health services for children, youth and their families. Six new services (intensive care coordination, mobile crisis intervention, family support, in-home therapy, therapeutic mentoring, and in-home behavioral services) along with extensive statewide training in family/youth-centered and strengths-based treatment, crisis resolution, and wraparound care planning has shifted the location of treatment from institutions to the community.

⁸ Minnesota Children’s Mental Health System, Prepared by the Mental Health Legislative Network. For more information: <http://www.dhs.state.mn.us>

⁹ Kansas’s HCBS-SED Waiver, National Health Policy Forum, 2005.

¹⁰ For more information:

<http://www.mass.gov/?pageID=eohhs2subtopic&L=4&L0=Home&L1=Government&L2=Special+Commissions+and+Initiatives&L3=Children's+Behavioral+Health+Initiative&sid=Eeohhs2>

Missouri

Missouri is the first state to begin implementation of a Health Home model of service delivery for persons with chronic diseases including persons with mental health conditions. Missouri submitted its State Plan Amendment to CMS in July, 2011.

IV. Initial Recommendations

Recommendation 1: Institute a Systems of Care Framework for Children’s Services in Iowa

The recommendation of the Workgroup is that a Systems of Care framework be adopted by the State of Iowa and that the subsequent recommendations in this interim report are developed and implemented in a manner that is consistent with the Iowa Systems of Care’s philosophy and values that are described below:

Systems of Care is often defined as a way to organize and coordinate systems, services and supports for children with a mental health condition who receive multiple services and/or who are involved with multiple child-serving systems. However, systems of care concepts and philosophies can also be applied at a broader level and in that context be inclusive of many more children, youth and families—those experiencing disorders, those at risk of disorders and all others who access child-serving systems. A Systems of Care framework gives an organizing context for working with and delivering services of any kind to children, youth and families. Systems and agencies deliver services or treatment in adherence to Systems of Care principles, values and strategies, but “Systems of Care” in and of itself is neither a program nor a core service. “Fundamentally, a System of Care is a range of treatment services and supports supported by an infrastructure and guided by a philosophy. A system of care incorporates a broad array of services and supports that is organized into a coordinated network, integrates care planning and management across multiple levels, is culturally and linguistically competent, and builds meaningful partnerships with families and youth at service delivery and policy levels.”¹¹

The Workgroup developed the following definition of **Iowa Systems of Care for Children and Youth**:

A child and family-driven, cross-system spectrum of effective, community-based services, supports, policies and processes for children and youth, from birth – young adulthood, with or at risk for physical, emotional, behavioral, developmental and social challenges and their families, that is organized into a flexible and coordinated network of resources, builds meaningful partnerships with families, children, and young adults, and addresses their cultural and linguistic needs, in order for them to optimally live, learn, work, and recreate in their communities, and throughout life.

The cross-systems, whole-health definition is a call not just to the Children and Youth Mental Health and Disability Service system and providers, but to all child-serving systems within our communities to adopt a high-level view and a shared vision for engaging, serving, educating, and supporting children/youth and their families. It requires that we eliminate isolated “silos” of thinking and practice, recognize the

¹¹ Sheila Pires, Building Systems of Care: A Primer, 2002.

interdependence of each system and service on the other, the need to coordinate across funding streams, and that we collectively commit to meaningful partnerships with children and families in every aspect of service delivery in order to optimize care and outcomes.

The vision of the Children’s Disability workgroup is that the Children and Youth Mental Health and Disability Services system is value based and that the state system and providers lead in the delivery of services that are:

Coordinated—at a child/youth and family level, at a community level and at a systems level, mental health and disability services are delivered with attention to integration, fluidity, efficiency, transparency, and child/youth and family outcomes.

Family and Youth-Driven—focused on and adapted to the wishes, needs and strengths of a child/youth and his/her family and delivered through the optimal mix of natural, informal and formal services and supports. Children, youth and families are not asked to fit into prescribed services or processes.

Culturally Competent—able to address the unique cultural and linguistic needs of children/youth and families, eliminating disparities in care, and create equity in outcomes.

Developmentally-driven and evidence-based—to effectively engage and serve children and youth from birth through young adulthood through the use of proven and promising prevention, early intervention and treatment practices, such as trauma informed care.

Flexible, nimble, nuanced, varied, specialized—through collaboration, shared decision-making, use of a blend of formal, informal and natural resources and supports, and through persistence in assuring children/youth and families get what they need to optimally live, learn, work, and recreate in their communities and throughout life.

Delivered “where children/youth are”—home, school and community-based supports designed to help children/youth succeed in their environment in ways that are most natural, normal, comfortable, usable and sustainable.

Accessible—time-sensitive access across a full spectrum of services and supports promotes interventions that are upstream¹², available, welcomed, and least-restrictive.

Attentive to the journey and needs of parents, guardians, caretakers, and families—through support and assistance in navigation, bringing voice and choice to decision-making, engaging with other parents and families.

¹² “Upstream interventions” are delivered early, in anticipation of an event (such as arrest or initiation of involuntary proceedings), or heightened risk, or use of intensive and/or restrictive care. CIT is an “upstream” criminal justice diversion service; mobile crisis intervention is “upstream” of calling 911 for police response to a school or sending a person to an emergency department for treatment. In each example, the opportunity is taken to intervene earlier, engage a person voluntarily and reduce the likelihood of needing a more restrictive or involuntary intervention.

Recommendation 2: Rollout of initial Core Services

The final proposal for the Children’s Disability system redesign is due on or before December 10, 2012 and the new core services that are recommended in this section are viewed as foundational, *but they are not inclusive of all services the committee will recommend in the final report*. They are seen as the preliminary set of essential, flexible, community-based, and child/youth/family-centered services necessary to bring children and youth home from out of state treatment centers and to provide alternative services for the children and youth awaiting placement in or out of state. The Workgroup recommends concurrent implementation (as work continues) of three core services for children and youth and an enhancement of a two additional services in order to set the stage for the full system transformation. Core services delivered to children, youth and families will be delivered in accordance with the Iowa Systems of Care definition and vision described in Recommendation 1.

The three recommended new services are as follows:

- **Intensive Care Coordination:** Intensive Care Coordination is designed to help organize and coordinate the delivery of multi-system, multi- component services. It is recommended as a core service and as a way to carry out Systems of Care principles and practices at the child/youth and family level. This service includes a strengths-based, integrated, coordinated and comprehensive assessment; facilitation of the child/youth and family-centered planning team that is composed of child and family defined team members; service coordination and ongoing service oversight; crisis planning and management; and tracking outcomes. In addition to family-level service delivery, providers of this service play a lead coordinating role in community/regional Systems of Care planning and infrastructure development. It is recommended that this core service fall under the auspices of Specialized Health Homes that are described in Recommendation 3. The Specialized Health Home model shares the same core standards for ‘whole person’, and person-centered planning and coordination, is well-aligned with the Systems of Care principles and offers a way to implement this key core service at a local or regional level. Health Home is a Medicaid option that is new to states and that offers 90% federal match for the first two years of operation.
- **Family Peer Support:** Family peer support is an essential element of most modern Systems of Care for children, youth and families and is a service that is largely unavailable in Iowa today. Results from the *2010 Iowa Child and Family Household Health Survey* showed that 28% of children who needed behavioral and emotional care had parents with “high parenting stress” and 11% have parents who “didn’t have anyone to turn to for parenting support.”¹³ Family Peer Specialists or Family Partners¹⁴ are individuals who have “lived experience” as parent or caregiver of a child with a disability and experience navigating the child-serving system. They

¹³ Children’s Behavioral and Emotional Health in Iowa: Results from the 2010 Iowa Child and Family Household Survey, University of Iowa Public Policy Center, September, 2011.

¹⁴ ¹⁴ “Family Support Specialist” and “Family Partner” are titles used in other jurisdictions to describe care providers who bring to their positions personal experience as parent or caretaker of a child with mental health conditions and experience navigating the child-serving system on the child and family’s behalf.

offer in-house expertise to other team members. Family Peer Specialists bring an authenticity and a knowing to these employment positions based on their personal and family journeys, and through that “shared experience” offer hope and encouragement, facilitate engagement in treatment and help to empower parents. Family Peer Specialists may function as allies or advocates and can assure that family voice and choice are represented and considered by the family-inclusive team. The experience and journey of a parent is very different than the journey of the child or youth who is experiencing the mental health or other condition and supporting parents through their journey helps to keep families intact. It is recommended that this core service fall under the auspices of Specialized Health Homes (Described in Recommendation 3).

- **Crisis Services**, that includes (but is not limited to) the following two key components:
 - Crisis Intervention—An array of crisis services would be provided and/or overseen and coordinated by the Health Home¹⁵ that might include:
 - i. Crisis planning
 - ii. 24/7/365 telephonic support and triage
 - iii. Urgent appointments
 - iv. Site-based crisis intervention
 - v. Mobile crisis intervention (home, school and community-based)
 - vi. Coordination of care across care settings (in the event of admission to an inpatient program or initiation of any in/out of home respite or stabilization service)
 - Crisis Stabilization – Short term (1-7 days) in-home or out-of-home resolution-focused services that provide stabilization and support in a time of crisis. Crisis stabilization services are individualized and person/family-centered (rather than program-centered or milieu-centered), goal oriented, and brief with a thoughtful ‘front and back door’.

In addition, the Workgroup recommends the enhancement of the following two services:

- 1) **Intensive Community-Based Treatment**—This service will be delivered as part of the set of Behavioral Health Intervention Services (BHIS) that as of July 1, 2011 is managed by Magellan under the Iowa Plan.¹⁶ Services will be identified in the individualized care plan and coordinated with/delivered by community partners who would in-turn participate in care planning meetings. The vision for the BHIS services would build upon

¹⁵ The Health Home payment can only cover the care coordination / peer support piece. The Health Home, as a provider entity could provide (deliver the service to the member) crisis and other reimbursable services, but those services would have to be reimbursed separately for Medicaid purposes.

¹⁶ Behavioral Health Intervention Services were previously known as “Remedial Services”.

the work of the Remedial Services Transition Committee that identifies services focused on: conflict resolution, problem-solving, interpersonal skills, communication skills and social skills, and involvement of the family in the treatment process.

- 2) **Psychiatric Medical Institutions for Children (PMIC) Services**—The Workgroup recommends more flexible use of this level of care and sees the service as a key resource in keeping children and youth in the state and in ensuring that periods of out-of-home treatment are purpose-driven and coordinated.

The Workgroup believes this level of care should be:

- Flexible – a child can go back for brief stays when needed
- Accessible – no waiting list for admission
- Used more strategically for the highest need children
- Fully integrated within the array and management of the full system
- Inclusive of family and community involvement in treatment
- Coordinated at both on the front end (goal-directed, timely admission) and back end (carefully coordinated discharge to assure successful transition back to community and reduce need for readmission)

The PMIC Workgroup has begun to work to plan the transition of the PMIC service to managed care effective July 1, 2012.

Recommendation 3: Use of a Health Home Model of Service Delivery

The Children’s Disability Workgroup proposes the development of a Children/Youth “Health Home” model for service delivery. The Health Homes offer a way to deliver key components of a children/youth System of Care: Intensive Care Coordination and Family Peer Support. The Health Home would also play a significant role in crisis management, systems development and systems performance/outcome measures.

As of January, 2011, states have the option to provide health home services to Medicaid beneficiaries with chronic conditions.¹⁷ The CMS standards require that health homes have the capacity for a “whole person” approach to care. To be eligible for health home services, a person must have:

- Two chronic conditions (including asthma, diabetes, heart disease obesity, mental condition, substance use disorder), OR
- One chronic condition and at risk for another, OR
- One serious and persistent mental health condition.

Per Section 1945(h)(5) of the Act, examples of providers that may qualify as a “designated provider” include physicians, clinical practices or clinical group practices, rural health clinics, community mental

¹⁷ Described in section 2703 of the Affordable Care Act, entitled “State Option to Provide Health Homes for Enrollees with Chronic Conditions.

health centers, home health agencies, or other entity or provider that is deemed appropriate by the State and approved by the Secretary.

In concert with the overall mental health and disabilities system redesign, the Workgroup envisions a relationship between the Children/Youth Health Homes, crisis services providers and the envisioned Regional service structure with all entities charged with aspects of systems of care planning, development, efficiency, logistics, capacity management, workforce, oversight, and outcomes tracking.

As described in a November, 2010 letter to state Medical directors from CMS,¹⁸ “The health home provision authorized by the Affordable Care Act provides an opportunity to build a person-centered system of care that achieves improved outcomes for beneficiaries and better services and value for State Medicaid programs. This provision supports CMS’s overarching approach to improving health care through the simultaneous pursuit of three goals: improving the experience of care; improving the health of populations; and reducing per capita costs of health care (without any harm whatsoever to individuals, families, or communities).”

The consideration of a Health Home model for children/youth aligns with many of the attributes of a transformed system that have been identified by Workgroup members. The model could:

- Bring a comprehensive care coordination component to the delivery of services to children/youth that has largely been absent.
- Forward a “whole-health” approach for children.
- Promote services that are individualized, flexible, nimble, and family/youth-centered.
- Aid in achieving the vision of the Olmstead State Plan by assuring families a choice of comprehensive community-based services for children/youth with complex and high-risk healthcare and support needs.
- Focus attention on systemic outcomes that include needs not always well addressed by the treatment system—succeeding in school, preparing for employment, feeling a part of the community, and having meaningful social connections.
- Expands choices for families.

Other considerations:

- States will receive temporary (first eight fiscal quarters) enhanced FMAP at 90% and technical assistance in setting up the plan is provided by CMS.
- Medicaid “comparability” requirement is waived, so the program can offer flexibility in scope, duration and target population and build the service incrementally.
- Planning for implementation can (roughly) coincide with the move of PMICS under managed care and the shift of county-based service system to a regional model.

¹⁸ The CMS guidance to State Medicaid Directors is available in full at <https://www.cms.gov/smdl/downloads/SMD10024.pdf>

How would new (enhanced) core services be delivered under a Health Home model?

The Children’s Workgroup identified new (enhanced) services for treating children/youth and families in their homes, schools and communities. Here is how two of those services (proposed as new core services in Recommendation 2) might be incorporated into a Health Home model:

Intensive Care Coordination—this would be (and is required by CMS) a primary responsibility of a Health Home and includes:

- Individualized Care Plan that coordinates and integrates all clinical and non-clinical services and supports to address the person’s health-related needs (whole-person).
- Coordinating and providing access to mental health, substance use and preventative and health promotion services.
- Comprehensive care management including care coordination, transition across care settings (including offering comprehensive coordination and support to PMICs and other facilities) and chronic disease management.
- Individual and family supports including referrals to community and social supports.
- Establish a continuous quality improvement program focused on both individual and population-level outcomes and to pay attention to key outcomes such as avoidable hospitalization, lower rates of ED use and community tenure.
- The use of Health Information Technology to link services and coordinate care.

In addition, the Health Home could have responsibility for leading in regional systems of care planning processes, workforce development, development of cross-system/cross-service referral pathways, linkages, information exchange, and services collaborations.

Family Peer Support—A member of the Health Home care planning team, a Family Support Specialist or Family Partner would lead in assuring that care is family-centered and culturally appropriate, and offers competency to the team in understanding and considering family journey, voice and choice. In addition, this team member would serve as support, ally, advocate, and navigational coach as identified with and desired by the child/youth and family.

A Tiered-Funding Approach

The way CMS has structured the Health Home option, states may choose to have tiers of eligibility and service intensity. Iowa would work with CMS on structuring Health Homes and would propose performance targets. The Workgroup was asked to consider a three-tiered Health Home model that provides graduated services and care-coordination based on a combination of diagnoses, co-existing conditions and functional impairments.

States are permitted to establish a tiered payment system and have flexibility in proposing payment methodology. Payment could be fee for service or a tiered, per member per month capped rate. But

there would also be a performance-based payment to health homes. Alternative funding methodologies could be considered in the future.

Recommendation 4: Strategy for bringing home children and youth from out-of-state

Several sets of data and other materials were reviewed by the Workgroup to inform planning of a short-term strategy for bring home children and youth receiving treatment out-of-state:

- Demographics
- Financial summary
- Services and specialties of out of state placement
- Results from 2010 Iowa Child and Family Household Health Survey
- Identified how children/youth are getting to out-of-home placement
 - Through systems (MH, DD, JJ, CW, Education)
 - More default than design
 - History of “unsuccessful” in-state placements
 - In-state facilities “declined” admission due to capacity or service needs
- Considered likely treatment and support needs of children/youth returning to Iowa
 - Care coordination for children who most likely have multiple challenges (physical, emotional, behavioral, developmental and/or social)
 - Multiple system and/or multiple service needs
 - Permanency planning, that could include the use of therapeutic foster care
 - Enhanced PMIC/Residential capacity or abilities
 - Flexible in-community supports, resources, and innovations in welcoming, adaptive communities (home, school, neighborhood)
 - Multi-faceted plan for integration back home
 - Specialized support of parents, guardians, caretakers and families
 - Specialized skills in engaging and working with children with multiple challenges (physical, emotional, behavioral, developmental, and social)
 - Redesign community services to fit the needs of the child vs. redesigning the child to fit what the community offers

The Children’s Workgroup recommends a short-term strategy to bring children home from out of state placements that is in alignment with Iowa Systems of Care and will inform the final recommendations for the Children’s Disability Systems redesign. This strategy is designed to be delivered through the managed care plan and is as described below:

- Issue one or more Requests for Proposals (RFP) that will serve children/youth currently out of state and those at risk of out-of-state placement in Iowa.
- The RFP will seek proposals from providers or partnerships of providers to serve these children/youth and develop services necessary to meet their needs with a ‘community first’ focus.

- The proposals would address the development of a health home model for care coordination and peer support, crisis services, intensive in-home services, creation of innovative community based strategies, and sub acute services that meet the goals described above.
- The RFP will consider innovative reimbursement methods, including performance based models.
- The RFP will consider offering therapeutic foster care.
- The RFP will include outcome measures aligned with the Workgroup’s defined outcomes.
- The RFP must address the needs of rural and urban areas of the state.
- Timeline: RFP would be issued by the Iowa Plan shortly after PMIC services transition to the Iowa Plan on July 1, 2012. FY 2013 (7/1/12 – 6/30/13) would include RFP Issuance, development of the proposals and submission and award. Implementation spring of 2013.
- The Children’s Disability Workgroup will continue meeting over this time period. The Workgroup would be continuing to define the requirements of the recommended strategies above. That work would inform the RFP process.

V. Outcomes and Performance Measures

The Workgroup discussed a vision for child/youth and family system outcomes early in the process and held firm to what is important to children, youth and families throughout the sessions. To measure what is meaningful at a child, youth or family-level requires that data not be gathered, held and analyzed solely within a program, an agency or a system, but across child/youth-serving systems and inclusive of whole-health and life domains. Further work will involve a review of what is measured now and how these “outcomes” could be measured in a meaningful way in the redesign. With the Iowa Olmstead goals as a guide, the Workgroup considered outcomes from the “shoes” of children, youth and parents.

Goal I: Welcoming communities that promote the full participation of Iowans with mental illness or disabilities.

- From the perspective of children and youth:
 - I am not broken and recovery is possible.
 - I am safe.
 - I have friends.
 - I can come back (to services) when I need to.
 - I know where to go and what to do when I need help.
 - I have people who understand me.
 - They don’t kick me out when I have a bad day.
 - I don’t have to be cured; I can be proud.
 - People are willing to accept my disability.
 - I have supports to be successful at a job.
 - I know where to enter the system and access it.
- From the perspective of parents, guardians and caretakers:
 - I am not alone.
 - I feel supported rather than blamed.
 - My community is accessible.

Goal II: Increase access to information, services, and supports that individuals need to optimally live, learn, work, and recreate in communities of their choice.

- From the perspective of children and youth:
 - I know that the system is working for me.
 - There are the right kind of services at the right time to help me.
 - I can access information that is easier to find.
 - Technology is working for me to access the services I need.
 - I don't have to go to the hospital/court to get help.
 - People listen to me and I get the services I need vs. the services that are available.
- From the perspective of parents, guardians and caretakers:
 - I can go anywhere and get information, and there is no wrong door.
 - I can identify someone who is knowledgeable.
 - The resources are in formats and language that makes sense to me.
 - I don't have to hear about services from other parents. I can hear about services from the system.

Goal III: A full array of community based services and supports that is practically available to all Iowans.

- From the perspective of children and youth:
 - I can access services with ease. I don't have to drive far and can use telemedicine.
 - I have services in my community/home.
 - I don't have to miss time away from home or friends to get services.
 - I have a school that is part of my team.
 - If there is an emergency, someone is there.
 - I can access services/have medications adjusted 24/7.
 - If I need medicine changes, I know that I can access services.
 - I know that my service providers are competent and talk to each other.
 - I know the services I need are affordable.
 - I help identify and design the array of services.
 - The services are respectful of my culture, values, priorities, and family.
 - I know that I will have a safe place to live.
- From the perspective of parents, guardians and caretakers:
 - There is evidence the system is working.

Goal IV: High quality services and supports

- From the perspective of children and youth:
 - Direct care workers are well-trained.
 - I am part of a community; I belong and am not living a parallel life—I have wholeness of life.
 - I know the services are making a difference.
 - This service being provided to our family has proven to be effective.
 - The services that I need are available to me no matter where I live in the state.
 - The supports and services are simple and easy to access/understand.
- From the perspective of parents, guardians and caretakers:
 - I am seen as an expert regarding my child. This validates that my being there is just as important as a professional's.

- I can make choices, give input and set priorities for my family.
- I am encouraged to give feedback.
- I feel better and have a hopeful future.
- The workers that come to my home are consistent (low turnover) in being there.
- I matter.
- Service providers understand the “lived experience” and respect the “lived experience” of parents who have a child/youth with a disability.

Goal V: Clear accountability for achieving service results for lowans that support individuals to live, learn, work, and recreate in communities of their choice.

- From the perspective of children and youth:
 - At the agency, I am engaged and they demonstrate cultural competence in service delivery.
 - They don’t give up on me.
 - I receive regular communication in writing of my progress and goals.
 - I can find information about the system.
 - I can be maintained in the home.
 - I am making optimum educational progress.
 - I am not picking up criminal charges.
 - I graduate with the skills I need.
 - When I am referred to another specialist or PCP, I don’t have to tell my story over again.
 - My ability to have friends and engage with the community is important.
 - I have peer supports when I need them.
 - If something in the plan isn’t working, there is a commitment to developing a new plan.
- From the perspective of parents, guardians and caretakers:
 - I know that the system providers are looking at data and constantly proving themselves.
 - I have a seat at the table before decisions are made.
 - “Nothing about me (or my child) without me.”
 - I have peer supports when I need them.
 - There is a system for measuring customer satisfaction that matters.

The Workgroup recognizes that more work needs to be done. The next step will be to develop measureable tools that both reflect and achieve the desired outcomes.

VI. Eligibility

The Children’s Workgroup is not immediately prepared to recommend changes in service eligibility. The workgroup recognizes that there are children and youth who have coverage by other third party payors, and we recognize that they may not have access to all of the services proposed by this workgroup. Addressing the issue of service eligibility is a priority for the Workgroup in the coming year. The children and youth who are returning home, who became Medicaid eligible because of their admission to out-of-home treatment will retain Medicaid eligibility for 12 months from the beginning of placement, which may aid in assuring access to the interim set of services outlined in this report to support reintegration into their home, school and community .

VII. Provider Qualifications and Monitoring

Provider qualifications and monitoring were not addressed by the Children's Disability Services Workgroup during this phase of the redesign.

VIII. Workforce Development

Provider qualifications and monitoring were not addressed by the Children's Disability Services Workgroup during this phase of the redesign.