Iowa Department of Human Services

Children's Disability Services Workgroup Final Report

November 15, 2013

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Executive Summary

The Iowa Legislature authorized (SF452) the continued work of the Children's Disability Services Workgroup following its 2013 report. The 2013 Children's Disability Services Workgroup was to continue its work in developing a "proposal for publicly funded children's disability services for children and families that ensures children with mental health needs and intellectual disabilities receive the services they need."

Over the course of three meetings, the Workgroup discussed progress on implementing a children's disability service system based upon System of Care principles, and developed a set of five recommendations that it believes will enable Iowa to continue its progress toward developing the system of care. The Workgroup believes that the current implementation of Integrated Health Homes provides a good foundation for the system of care, the opportunity to engage more children, and an ability to monitor outcomes. One of the specific charges to the Workgroup, "considering options for appropriately consolidating or eliminating state councils or bodies that oversee, monitor, or provide input into policy involving publicly funded children's services," is addressed in Recommendation Three in the report. The five recommendations are as follows:

Table 1: 2013 Children's Disability Services Workgroup Recommendations

#	Recommendation	See Page
One	Establish the Iowa Children's Interagency Coordinating Council.	6
Two	Establish the Iowa Children's Advisory Council.	8
Three	Consolidate or eliminate redundant, duplicative, or conflicting children's committees.	9
Four	Establish a minimum set of core services that should be available to all children.	10
Five	Convene an assessment task force to make recommendations about adoption of standardized functional assessment tool(s).	12

This report summarizes the Workgroup activities, including a brief update on progress since last year's report, and elaborates on the five recommendations. Consistent with the legislative suggestion in SF 452 to minimize the potential for duplication, redundancy, conflict and layers of bureaucracy in currently existing committees pertaining to children, the Workgroup also recommends that this committee, the Children's Disability Services Workgroup, be disbanded. All future work involving the planning, design and implementation of Iowa's children's system of care should flow through and be coordinated with the work of the Interagency Coordinating Council and the Children's Advisory Council identified in recommendations one and two.

Introduction and Overview of the 2013 Workgroup Charge and Process

The mission of the 2013 Children's Disability Services Workgroup was to develop a proposal for publicly funded children's disability services for children and families that ensures children with mental health needs and intellectual disabilities receive the services they need. The Workgroup was specifically charged with developing state and local strategies to promote collaboration, coordination, and integration across all existing areas of the publicly funded service system for youth and families. Additionally, the Workgroup was asked to consider options for appropriately consolidating or eliminating state councils or bodies that oversee, monitor, or provide input into policy involving publicly funded youth services. To accomplish its goals the Workgroup was assigned specific tasks which included:

1. Receive reports and updates on implementation efforts from the 2011 and 2012 Children's Disability Services Workgroup recommendations, including placement of children out of state and integrated health homes.

2. Examine current system delivery structure and make recommendations to increase collaboration and decrease fragmentation of services.

3. Determine what a children's mental health system should look like including how it is different from child welfare and juvenile justice.

4. Discuss the roles and responsibility for a children's mental health system and possible integration with the adult system including the role of the regions.

5. Review the list of councils and bodies that interact with the children's mental health system. Develop a strategy to consolidate or eliminate state councils or bodies and a phase-out strategy if appropriate

This report provides an overview of the Workgroup's activities as it relates to the goals and tasks outlined above and offers recommendations for consideration by the Legislature for improving the mental health and disability services (MHDS) system for youth.

Update on Progress since Last Year's Report

Update on the 2011 Workgroup Recommendations

The 2011 Workgroup made several specific recommendations to the Legislature which included:

1. Institute a system of care framework for children's services in Iowa;
2. Develop and roll-out a set of core services across the state:
   a. Intensive care coordination;
   b. Family peer support; and
   c. Crisis services.
3. Allow more flexibility in Psychiatric Medical Institution for Children (PMICs) services as a key resource in keeping children in state and ensuring that out-of-home placements have a purpose.

4. Use the health home model of service delivery.
5. Create a strategy for bringing children back to Iowa from out-of-state.

There has been considerable progress on several of the recommendations from the 2011 Workgroup. First, DHS has adopted three core values and 10 guiding principles that serve as its framework for its development of a mental health and disabilities service system for youth and their families.

Table 2: Guiding Principles of the Systems of Care

CORE VALUES		
Child-centered, family focused, and family driven	Community-based	Culturally competent and responsive
GUIDING PRINCIPLES		
Service coordination or case management	Prevention and early identification and intervention	Smooth transitions among agencies, providers, and to the adult service system
Human rights protection and advocacy	Nondiscrimination in access to services	A broad array of comprehensive services should be made available
Individualized service planning	Services in the least restrictive environment	Family participation in ALL aspects of planning, service delivery, and evaluation
Integrated services with coordinated planning across the child-serving systems.		

These core values and guiding principles have served as a foundation for the work related to the development of **Integrated Health Homes (IHH)** for youth with serious emotional disturbances (SED). In March 2013 DHS submitted its Serious and Persistent Mental Illness (SPMI) Health Homes State Plan Amendment (SPA) to the Centers for Medicare and Medicaid Services (CMS) and received approval of the SPA on June 18th, 2013 with an effective date of July 1, 2013. Iowa's SPMI SPA focuses specifically on serving adults with serious mental illness and youth with SED. The IHHs for youth with SED are charged with providing a set of core services including:

- Comprehensive care management;
- Care coordination;
- Health promotion;
- Comprehensive transitional care from inpatient to other settings, including appropriate follow-up;
- Individual and family support; and
- Referral to community and social support services.

Working with Magellan Health Services, community-based IHH providers utilize teams consisting of a nurse care coordinator, care coordinators, and family peer support specialists to deliver the services described above using the Wraparound model of care coordination. Wraparound is an evidence-based approach to coordinating services for youth with significant emotional and behavioral needs that has been utilized in other states to help reduce the reliance on out of home (and state) care and provide youth and families with the support they need to be successful at home and in the community. As such the IHH can serve as an important part of Iowa's strategy to help prevent youth from being sent out of state and to help youth return to Iowa from out of state placements. With their focus on reducing care fragmentation and providing a "whole-child" approach to facilitating access to an inter-disciplinary array of medical care, behavioral health care and community-based social services, the IHHs provide a firm foundation for Iowa to build its system of care for Medicaid enrolled youth with SED.

At the first Workgroup meeting on October 1, 2013 Jennifer Vermeer, Medicaid Director, provided the group with an update on the IHH program. Since July 1, 2013 approximately 1,937 youth have been actively engaged by the four IHHs in the state. An additional four IHH providers began engaging youth and their families living in Polk, Warren, and Dubuque counties on October 1, 2013. By 2014, it is anticipated that IHHs will be available to youth living in every county in Iowa. An analysis by Magellan showed that as many as 16,000 youth with SED are potentially eligible for enrollment in an IHH. While Ms. Vermeer described some initial challenges with IHH implementation, specifically with regard to locating youth to enroll in IHH services, it is a positive development that Iowa is utilizing the IHH platform to implement two core services first identified by the 2011 Workgroup: intensive care coordination and family peer support.

While the IHHs focus on Medicaid enrolled youth with SED, not all youth in Iowa are eligible or enrolled in Medicaid. In some cases the only way for youth with a SED to gain access to treatment is to get admitted to a Psychiatric Medical Institution for Children (PMIC). Once in a PMIC setting, these youth become eligible for Medicaid, albeit in an extremely costly level of care. Once these youth are discharged to the community, they may lose their Medicaid eligibility and therefore their access to some of the intensive home and community-based services they may need to avoid returning to a hospital or PMIC setting. In State Fiscal Year (SFY) 2013, 1,140 children have been served in a PMIC.

Promoting access to services and supports that can help both Medicaid and non-Medicaid eligible youth remain in their homes, schools, and communities are not only good for youth and families but more cost-effective as well. Several projects funded by State and Federal funds have focused on promoting a system of care for both Medicaid and non-Medicaid eligible youth in Iowa. Many of these activities will be assumed by the IHHs as they are phased in. However, because not all services are eligible for Medicaid, and not all children will have continuous coverage[1] despite the availability of Medicaid, the Children's Health Insurance Program (CHIP) and expansion under the Affordable Care Act (ACA), the Workgroup encourages DHS to continue utilizing these funds to ensure the availability of important, non-Medicaid supports. The current system of care projects in Iowa include:

[1] Kaiser Commission on Medicaid and the Uninsured (2010).
Secrets to Success: An Analysis of Four States at the Forefront of the Nation's Gains in Children's Health Coverage.
http://kaiserfamilyfoundation.files.wordpress.com/2013/01/8273.pdf

- In July 2013, the State of Iowa was awarded a one-year ***System of Care Planning Grant*** by the Substance Abuse and Mental Health Services Administration (SAMHSA). The purpose of the planning grant is to develop a plan to expand system of care practices and principles statewide, building on the implementation of the IHHs for Medicaid-eligible children with an SED. A planning team comprised of state agency representatives, local and statewide stakeholders, family/youth/ and child advocacy organizations, family members of children with an SED, and youth will drive the process of creating a plan. Other grant activities include cultural competency training and development of a wraparound training curriculum to support implementation of SOC principles statewide.

- ***Community Circle of Care (CCC)*** is an existing community-based system of care for children and families in the northeastern counties in Iowa. It began as an initiative sponsored by SAMHSA. Due to the successful child/family and community-centered outcomes of this project, a state appropriation has been devoted to CCC to continue the system of care services in northeast Iowa. In SFY 13 CCC served 1353 youth with a SED.

- The ***Central Iowa System of Care*** (CI-SOC) began serving families living in Polk and Warren Counties in October 2009. In SFY 13, 136 children and youth were served. CI-SOC has helped prevent 47 children who would have been in a PMIC and 13 in comprehensive level group foster care from going to those higher levels of treatment or care. The project served another 33 children who were on a projected path toward residential treatment but were not at imminent risk for that level of treatment during the year.

- In 2012, ***Four Oaks*** was awarded a system of care contract by DHS to help maintain youth in their homes and communities and avoid placement in a PMIC as well as to help youth already in a PMIC return home faster. In SFY 13, Four Oaks served approximately 65 youth in Linn and Cerro Gordo Counties using the wraparound care coordination model consistent with the systems of care approach. Data indicate that Four Oaks has been successful at diverting youth from PMIC placement and reducing average length of stay (ALOS) of youth in PMIC. In Linn County, youth served through this program had an ALOS of 146 days in PMIC compared to 272 days for youth not served in the program. Results were even more impressive for youth in Cerro Gordo County with an ALOS of 115 days for youth served by the program compared to 291 days for youth not participating in the program. Youth served in this program also demonstrated an average 20% improvement in their Global Assessment of Functioning (GAF) scores. As of July 1, 2013, Four Oaks became a pediatric IHH serving Linn County and will continue to work with youth with SED utilizing the IHH model. Four Oaks continues to serve youth in Cerro Gordo County using the existing model but will transition these youth to a pediatric IHH once this service becomes available in Cerro Gordo.

- In addition to the work described above, since January 2011, ***Four Oaks*** has worked closely with Iowa Medicaid Enterprise (IME) and Magellan to serve approximately 26 youth who were originally slated to be placed in out-of-state treatment settings. To accomplish the goal of treating these youth within the state, Four Oaks engaged experts in the field of trauma-informed care to provide consultation on the treatment plans for these youth and to provide training and coaching for staff members in the trauma-informed care model. The additional financial support provided to Four Oaks as part of

this effort also allowed them to hire additional staff to help maintain these youth safely at the Four Oaks PMIC. Of the 26 youth served as part of this program, seven youth have successfully transitioned back to their homes or foster homes, 19 continue to be served by Four Oaks, with only one youth requiring discharge to another setting.

While the projects described above focus on those youth with the most intensive needs, other system oriented projects exist which focus on preventing, identifying, and treating behavioral health issues in young children before they become worse and more difficult and costly to treat. For example, ***Project LAUNCH*** (Linking Actions to Unmet Needs in Child Health) is a SAMHSA funded project that is focused on building strong systems and communities to support the mental and social health of young (0-8 years of age) children. The geographic service area is a designated area of inner Des Moines. Project LAUNCH began in 2009 and its funds are used to provide direct services to families and to build system infrastructure. Since its inception, the project has provided direct services to an unduplicated count of 339 children and 326 families. A comprehensive evaluation of the larger Project LAUNCH model has found that the program has had a measureable impact on policy and practice change at both the state and local level. ***Early Childhood Iowa*** (ECI), a collaborative and comprehensive partnership for the integration of an early care, health, and education system is another example of work going on in the state to support the efforts of local and state-level partners to promote the well-being of young children. ECI has created a comprehensive plan for Iowa's Early Childhood (EC) System which outlines the priorities and strategies for the EC system of care.

Another recommendation of the 2011 Workgroup was to allow more flexibility in PMIC services as a key resource in keeping children in state and ensuring that out-of-home placements have a purpose. As part of that effort, in July 1, 2012 Magellan took over the authorizations of all in-state and out-of-state PMICs. Since taking over management of PMIC, Magellan partnered with DHS and Iowa's children's mental health experts, including PMIC and system of care providers to create a PMIC Clinical Leadership Workgroup. The purpose of the workgroup was to develop viable plans to help keep children closer to home with appropriate services while avoiding out-of-state placements. The group specifically focuses on youth who are currently receiving services in out of state PMIC as well as youth who are at risk of being placed out-of-state. The group reviews clinical information for youth who are currently in out-of-state placements and those at risk of out-of-state placement. They also discuss diagnostic trends, problem solve barriers to returning youth home, and identify successful strategies for preventing youth from being placed out-of-state. Magellan and the participating PMIC providers, through work in their twice monthly calls, were able to divert 66 children (July 1, 2012-October 31, 2013) who would have gone to an out-of-state placement. In addition, since Magellan took over management of PMIC services, the numbers of youth in out-of-state PMIC has fallen from 46 youth in June of 2012 to 34 youth as of June 2013.

Update on the 2012 Workgroup Recommendation

Building off of the 2011 Workgroup recommendations, the 2012 Workgroup recommended that the General Assembly create through legislation a state level Iowa Children's "Cabinet" to provide guidance, oversight, problem solving, long-term strategic thinking, and collaboration among stakeholders. This Children's Cabinet was to be led by Department of Human Services and was to include representatives of state child serving agencies, providers, family members, and other critical stakeholders to support them in the creation of specialized health homes and building out from serving a discrete population to a comprehensive, coordinated system for all youth.

This recommendation was not enacted due to apparent concerns from the Legislature. Among

these included a lack of specificity about the purpose and tasks of the Workgroup, worries about the effectiveness and authority of a large group of public and private stakeholders to realize changes in the system of care for youth, and added layers of bureaucracy on top of multiple existing committees working on children's issues. The Workgroup carefully considered the issues that may have contributed to the failure of this recommendation to make it into law. Believing that a strong governance structure is necessary for a successful children's system of care effort, the Workgroup has renewed and revised its governance recommendations taking these concerns into account.

2013 Children's Disability Services Workgroup Recommendations

The Workgroup developed five main recommendations to continue advancing the development of a children's system of care in Iowa. These recommendations build off of last year's report with a primary focus on establishing formal structures to carry on the planning, design and implementation of the system of care. As mentioned above, it is the Workgroup's belief that a formal governance structure is necessary to ensure that there is coordinated, deliberate attention to the mental health and disability service needs of Iowa's youth who touch the public system. While the Workgroup acknowledged that the focus of this year's effort was limited to the mental health needs of youth, the Workgroup strongly advises that all planning efforts meet the multi-dimensional needs of youth and their families moving forward.

Recommendation One: Establish the Iowa Children's Interagency Coordinating Council

The Workgroup revisited the 2012 recommendation to create a "Children's Cabinet" to *"provide guidance, oversight, problem solving, long-term strategic thinking, and collaboration…"* The Workgroup continues to believe that in order for Iowa's children's system of care to develop and effectively meet the needs of youth and their families, a high level group assigned responsibility for these tasks is essential. Since Iowa's children's system has historically been operated at the state level, Workgroup members felt it was critical for there to be a cross-agency group composed of high level decision makers at the state level who are focused on working across "silos" and ensuring that public funds are utilized prudently and strategically. The establishment of this group is also important to ensure attention to issues facing children and youth given the focus on other important issues (e.g. regionalization of adult disability services). Thus the Workgroup recommends that a formal Interagency Coordinating Council (ICC) be established to continue Iowa's progress on building a system of care for youth. The remaining recommendations from this year's Workgroup flow from this recommendation.

Composition

The Workgroup recommends that Director-level individuals sit on the committee. If this is not possible, at minimum, the departmental representatives assigned must have decision making authority delegated by their Department Director. The Workgroup suggested that the composition of the ICC should include the agencies identified in Table 3 because they are assigned responsibilities directly related to children. The Department of Human Services should chair the committee, and the ICC shall have the discretion to include and invite additional representatives from within their Departments or other state agencies depending on the need to provide information or clarification on issues raised by the Council. The ICC should have sufficient staff support assigned to meet its needs. The recommended state agencies include:

Table 3: Recommended ICC State Agencies

Department/Division Name	
Department of Human Services	Department of Human Rights
Department of Public Health	Department of Management (Early Childhood Iowa)
Department of Education and its Division of Vocational Rehabilitation Services	Iowa Insurance Division
Judicial Branch of Iowa	

Responsibilities

Accordingly, the ICC would be involved in coordinating decision making across state agencies in order to reduce fragmentation and ensure that activities related to youth in Iowa are not performed "in a vacuum." Workgroup members felt that while much of the attention will be on those youth and families served in the public sector, that attention must be paid to the emotional and physical well-being and prevention of behavioral health problems across all domains, public and private. Furthermore, it was felt that the entire ICC must work from the premise that behavioral health is essential for overall health and well-being. The Workgroup recommends that the ICC submit an annual report of activities to the Iowa Legislature and Governor regarding the State's progress on designing, implementing, and operating the system of care.

While the ICC will need to address a host of issues related to the children's system of care, the Workgroup recommends it focus on the following issues in its first year of meeting due to their immediate relevance.

1. Coordination with the Children's Advisory Council: Recommendation Two recommends the creation of a Children's Advisory Council (CAC) charged with advising the ICC on planning and implementation issues, best and emerging practices, and outcomes. A responsibility of the ICC should be to work in partnership with the CAC.

2. Consolidation of Other Children's Committees: Recommendation Three recommends that Iowa evaluate the specific committees, work groups, and task forces that address children with an objective of reducing, consolidating or eliminating groups in order to reduce duplication, redundancy, and conflict of their activities. The ICC should be tasked with the responsibility of conducting the specific analysis and taking the necessary action to achieve this objective. See Recommendation Three for more information.

3. Integrated Health Homes: The ICC should monitor the implementation of the Medicaid state plan amendment, and make recommendations to DHS for improvements as needed.

4. High Risk Youth: The ICC should monitor the progress of efforts to return youth who were sent to out-of-state placements and the State's efforts to improve the ability of providers to serve youth at the highest risk of being admitted to Psychiatric Medical Institutes for Children (PMICs) or sent out-of-state for treatment.

5. Core Services Implementation: Recommendation Four proposes that Iowa adopt a minimum set of core services available to all youth. The ICC should monitor the progress of implementation of core services, and modify and expand core services as necessary within their delegated agency authority and as funding permits. See Recommendation Four for more information.

6. Standardized Assessment Tool: Recommendation Five proposes that an assessment task force be convened to make recommendations about adoption of standardized functional assessment tool(s). See Recommendation Five for more information.

7. Transition-age Youth: The ICC should examine and improve the ability for Iowa agencies to serve youth who are transitioning out of the children's system and into adult services. This may include developing protocols for how to effectively coordinate with the regions to serve youth who require continued supports and services as they transition to adulthood.

Authorization

The Workgroup discussed whether the ICC should be created through the authority of the Governor's office or through legislative action. There was general agreement that the ICC could be created now through Executive Order with a clear charge to the group members. The benefit of this approach is that the ICC could be created in the near future. However, the Workgroup felt that establishing the ICC and its responsibilities through legislation is preferred and would ensure that the ICC has longevity, survives elections and transcends administrative prerogative as governors change.

Recommendation Two: Establish the Iowa Children's Advisory Council

In reflecting on last year's recommendation, the Workgroup revisited the original "Cabinet" recommendation that included state employees and external stakeholders in the decision making process. As a result, there was some question regarding the actual authority that external stakeholders would bring to the table in the original "Cabinet" concept given that the implementation and decision authority is the responsibility of the state agencies; external stakeholder representation may be relatively limited in scope, and that there was no actual or even legal authority that would be delegated to the few external stakeholders that would be on the Cabinet.

The Workgroup felt that in order for stakeholders to have the strongest possible voice, meaningful change to occur, and to fully capture and convey the challenges, barriers, strengths and opportunities for children, youth and families in the system, a formal stakeholder-composed Children's Advisory Council (CAC) should be established.

Composition

The CAC should consist of fifteen members and be composed of a diverse group of stakeholders in order to ensure that a broad range of voices, representative of those who receive or are involved in children's services, help shape Iowa's children's system of care. Representatives should include family members, service recipients or former services recipients, providers of services, academics, juvenile justice, and other members with an interest in ensuring a strong, effective children's disability service system. Council members should be appointed by the ICC.

The Workgroup felt strongly that there should be three year term limits for members in order to ensure fresh thinking and to provide the greatest opportunity to include a diverse range of voices over time. These should be staggered in the beginning to ensure some continuity as Council members turn over.

Responsibilities

The purpose of the CAC is to work in partnership with the ICC for implementing the system of care, but to also enable stakeholders the capacity and voice to hold the ICC and state agencies publicly accountable.

The CAC would be responsible for advising the ICC on planning and implementation issues, best and emerging practices, and outcomes. The CAC would be required to prepare and submit a summary of its activities, progress and recommendations to the ICC for consideration and inclusion into the ICC annual report to the Iowa Legislature. CAC meetings would be open to the public and a forum for stakeholders and advocates to inform its work. The ICC should submit a report of activities to the CAC for each meeting, and conversely, the CAC should submit a regular report to the ICC.

Authorization

Similar to the discussion related to the authorization for the ICC, the Workgroup discussed whether the CAC should be created through the authority of the Governor's office or through legislative action. There was general agreement that the CAC could be created now through Executive Order with a clear charge to the group members. The benefit of this approach is that the CAC could be established quickly. However, the Workgroup felt that establishing the CAC and its responsibilities through legislation is preferred and would ensure that the CAC also has longevity, survives elections and transcends administrative prerogative as governors change.

Recommendation Three: Consolidation of redundant children's advisory committees

One of the tasks assigned to the Workgroup this year by the Legislature was to review the list of councils and bodies that interact with the children's mental health system and make recommendations regarding consolidating or eliminating redundant committees or councils. Workgroup members agreed that there are a number of advisory committees and other groups working on similar issues and sometimes without a clear charge. Concerns were expressed however about the authority of this Workgroup to eliminate these committees, given that some are required as part of Federal grants or Iowa Code. There was general agreement that the work of many of these groups could be assumed by the ICC and/or CAC should they be established by the Legislature.

Given the time necessary to review the specific charge, requirements, and authority of these various groups, Workgroup members recommended that this become a task of the ICC. The ICC should be charged with responsibility for conducting the specific analysis and taking the necessary actions to consolidate or eliminate redundant committees or councils. For example, this could include making a formal recommendation to the legislature to abolish legislatively established committees, or ICC members abolishing or modifying existing committees within their scope of authority. As part of their deliberations on this topic, Workgroup members also considered its own tasks and charge. Over the past several years, this Workgroup has offered policy guidance to Legislators and DHS officials and served as thought leaders on designing approaches for moving Iowa's system of care for youth forward. Workgroup members considered that while there is still much work to do to continue building the system of care for youth, this work should be assumed by the ICC and the CAC going forward.

Recommendation Four: Establish a minimum set of core services that should be available to all youth.

Building off of the work of the Adult Mental Health Redesign Workgroup, the Children's Workgroup undertook an effort to identify a minimum set of core services that should be available to youth across the state. As seen in Table 4, the Workgroup identified four domain areas: 1) Prevention, Early Identification, and Early Intervention; 2) Behavioral Health Treatment; 3) Recovery Supports; and 4) Community-Based Flexible Supports. Recognizing that the needs of youth are different from those of adults, Workgroup members agreed that the domains and core services within those domains would not necessarily align with those adopted for the adult system. For example, childhood presents a critical opportunity to prevent, identify, and treat behavioral health issues before they become worse and more difficult and costly to treat. Thus, the workgroup included prevention, early identification, and early intervention as a core service domain area.

The Workgroup also identified that community-based flexible supports and services as defined in a plan of care for a youth was an important domain area to include given its alignment with the systems of care principle of individualized service planning. Workgroup members agreed that these types of flexible support services which are sometimes not Medicaid reimbursable, could be critical in helping to keep a child safe, assisting a family to maintain their child at home and may prevent a costly out-of-home placement. Determining how these types of funds would be distributed and under what circumstances will need to be outlined in administrative rule.

A sub-group of the larger Children's Workgroup met to review the core services with a particular focus on those youth with an intellectual or developmental disability (IDD). This group wanted to call attention to the fact that for some youth with an IDD access to highly specialized outpatient treatment services such as Applied Behavioral Analysis (ABA) are critical to helping these youth reduce undesirable behaviors such as inappropriate vocalizations or head-banging and improving their ability to function in home and community settings. This group also suggested that within any core service, modifications may be necessary to adapt the service to meet the needs of youth with an IDD and their families, including ensuring access to providers skilled in working with this population of children.

The Workgroup also considered how specific to be when defining the list of core services. For example, there are numerous evidence-based practices (EBP) for youth that have proven success in addressing particular issues such as exposure to trauma, juvenile delinquency, depression, or substance use. Workgroup members expressed that getting into specific detail about which EBPs should be considered "core" could be unnecessarily limiting for providers and/or could place undue burden on the state to ensure statewide access. The same was true with regard to other broad categories of services such as outpatient treatment. By leaving certain service categories more broadly defined the Workgroup believed it would allow for greater flexibility as new treatments or modalities emerge.

Table 4: Youth Core Services

Youth core service domains[2]	Youth core services[3]
Prevention, Early Identification, and Early Intervention	• Behavioral health and substance use education • Medical homes • Behavioral health and disabilities consultation to primary care • Surveillance, screening and referrals for issues related to trauma and family stress, including substance abuse, domestic violence, mental health, child development and behavior concerns in pediatric primary care as part of well-child visit • Assessment and evaluation • Home based health supports • Home visiting (e.g. Nurse Family Partnership or other maternal/child health visiting models)

Behavioral Health Treatment	• Behavioral health and substance use education
	• Assessment and evaluation
	• Medication prescribing & management
	• Mobile crisis intervention and stabilization including 24-hr crisis hotline
	• Acute and sub-acute treatment such as:
	  ○ 23 hour crisis stabilization
	  ○ Crisis residential
	  ○ Inpatient treatment
	  ○ PMIC
	• Behavioral support services through the ID/IDD waiver
	• Integrated Health Homes
	• Care Coordination including transitional services (e.g. from inpatient to outpatient, PMIC to home)
	• Outpatient treatment in home and community-based settings
	• Evidence-based therapies

Recovery Supports	• Transition-age youth services including employment related supports • Behavioral Health Intervention Services • Recovery coaches • Family and peer support • In and out of home respite • Integrated Health Homes • E-health strategies
Community-based flexible supports	Services and supports as identified in a plan of care for youth and family including educational supports

[2] Some service examples may be included in more than one domain.
[3] Contingent on available funding.

The Workgroup acknowledged budgetary constraints when considering core services. Many of the services outlined in Table 4 are already covered by Medicaid as part of its state plan or through a waiver, through Federal grants, state general funds, or some combination, although not all of the identified services are currently available to youth in Iowa. Workgroup members felt it was important to not limit the list of services to what is currently available but to establish a list of minimum core services that the state should implement over the next two to three years as funding permits as part of the ongoing work of building a system of care for youth.

Identifying how to finance the services that do not have an existing funding source, developing provider capacity to deliver these services, including offering training and technical assistance, ensuring access to core services for youth across the state, and establishing a system for monitoring the quality and effectiveness of these services were also viewed as critical tasks necessary to support the implementation of the core services across the state. The work associated with monitoring the ongoing implementation of the core services will be an important aspect of the work of the ICC and the CAC. Additionally, consideration of how to promote access to these core services for youth who may not be Medicaid eligible was viewed by Workgroup members as another key activity of the ICC and the CAC. Finally, the Workgroup did not conduct an analysis of the cost to the state of implementing the identified core services. As mentioned earlier, many, but not all of the identified core services have an existing funding source. Pricing out the cost of implementing the services will be an important activity for the ICC.

Recommendation Five: Convene an assessment task force to make recommendations about adoption of standardized functional assessment tool(s)

In this competitive funding environment where resources are increasingly limited, the Workgroup acknowledged that it is critically important to ensure that youth are receiving the right services to meet their needs and those services are achieving results. More and more, funders are demanding evidence of return on investment and requiring accountability from those receiving public dollars. The Workgroup recognized the need for a more systemic approach to system planning and a strategy for holding providers and policy makers accountable for the results the system is achieving on behalf of some of Iowa's most vulnerable youth.

Behavioral health providers in Iowa currently utilize a variety of instruments to help them assess a youth's level of functioning across life domains. Functional assessment instruments used in Iowa vary from provider to provider. The most frequently utilized tools include the Child and Adolescent Needs and Strengths (CANS) tool, the Child and Adolescent Service Intensity Instrument (CASII), the Child and Adolescent Functional Assessment System (CAFAS), and the Global Appraisal of Individual Needs (GAIN). There is no systematic or "macro level" approach to identifying the service and support needs of a youth and measuring system performance that cuts across providers and levels of care (e.g. outpatient, inpatient, PMIC, IHH, etc.). The current variability with respect to the information collected about the needs of youth makes it difficult to draw an accurate picture of who is being served by the system, determining what level of supports and services a child may require, and how the system is performing.

While Workgroup members expressed concern regarding a "one size fits all" approach to assessing the functioning of a diverse population of youth, they acknowledged that the lack of standardization has limited the ability of the system to use data to help service providers, system designers, and policy makers understand the needs of the youth served by the system and plan appropriately. It has also made it difficult to accurately report to funders how well (or

not) the current system of services and supports is meeting the needs of Iowa's youth with behavioral health needs, information that could be used to help advocate for additional funding or policy changes. Furthermore, the absence of a common framework for informing decisions about the type and intensity of treatment a youth may need has created variability across the system. Workgroup members agreed that a standardized tool can help create a common language among providers and payers and lead to a more uniform process for making placement and treatment decisions.

Workgroup members were clear however that information about a youth's level of functioning is only one piece of information about how well the system of care is working for youth and their families. Other indicators such as family and youth satisfaction, suicide and substance use rates, rates of involvement in the juvenile justice and/or child welfare system, high school graduation rates for students with disabilities, and school readiness are all important markers of how well the system of care is serving youth and their families. The Workgroup felt it was important to build on existing work where possible. For example, the annual Iowa Kids Count report published by the Child and Family Policy Center in collaboration with the Annie E. Casey Foundation looks at some of the broader indicators of child well-being in Iowa. Similarly the Iowa Child and Family Household Health Survey, completed by the University of Iowa Public Policy Center, also offers a wealth of information about the health status, access to health care, and the social environment of Iowa's youth. Identifying several indicators specific to how well youth with behavioral health issues are faring will be important work for Iowa to consider as it moves forward on building its system of care, with change in level of functioning for youth served by the public behavioral health system being one such indicator. Identifying a tool or tools to measure this will be an important to step forward in evaluating Iowa's progress on serving youth with behavioral health needs.

Given the importance of selecting the right tool(s) and designing an approach to evaluating system performance, the Workgroup determined they could not accomplish the task of appraising available tools and making an informed recommendation to the Legislature within the timeframe for submission of this report. There was also a lack of consensus within the Workgroup as to whether to recommend a single tool or to create a defined list of functional tools that providers could select from to measure a youth's change in functioning over time. Therefore the Workgroup recommends that an assessment task force be convened by the ICC. The charge of this group will be to evaluate available tools and make a recommendation to the ICC and DHS regarding the adoption of a specific standardized tool or tools for assessing the service and support needs of youth served by the public behavioral health system. Composition of the task force should include a combination of child and adolescent clinical professionals as well as individuals with administrative experience who can inform discussion about implementation. Once DHS implements a system for measuring changes in youth functioning, it should be responsible for collecting, analyzing and reporting on the information and how it informed decision making regarding the children's system of care.

Conclusion

Over the past three years, the Children's Disability Services Workgroup has engaged in the meaningful and important work of influencing the development of a system of care for youth. As a result of the hard work and dedication of the Workgroup members, many of the recommendations of this body have been implemented. With the development and implementation of Iowa's IHHs, the Workgroup believes that Iowa is moving into the next phase

of its system of care evolution. As such, the Workgroup believes that creating a formal governance structure dedicated to children's issues is critically important to ensuring that Iowa continues to make progress toward developing a public disability service system that meets the needs of its youth. With the establishment of the ICC and the CAC, this Workgroup will be obsolete, but it firmly believes these two entities will be able to move the system forward, building on the solid foundation created by this Workgroup. The Workgroup Chairs wish to express their sincere appreciation and gratitude for the time, effort, and dedication of the Workgroup members and the members of the public who have contributed to the development and formulation of this year's report and recommendations.

References

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