

Iowa Mental Health and Disability Services System Redesign

Interim Report To the Department of Human Services

Prepared by the Technical Assistance Collaborative, Inc.

October 31, 2011

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EXECUTIVE SUMMARY

Values and Principles

Recommendations from each of the Workgroups were based upon a foundation of values and principles and intended to guide the development of services that lead to meaningful outcomes for consumers and their families. The values and principles utilized by the Workgroups came primarily from two sources. The first source is the principles of the Iowa *Olmstead* Plan. *Olmstead* is a 1999 United States Supreme Court decision that further interpreted the Americans with Disabilities Act with an integration mandate – that states had an affirmative obligation to ensure the civil right of people with disabilities to live in the least restrictive, most integrated settings possible. Iowa’s plan clearly states the vision of “***A Life in the Community for Everyone***” and adheres to the following principles:

1. **Public awareness and inclusion**...Iowans increasingly recognize, value, and respect individuals with mental illness or disabilities as active members of their communities.
2. **Access to services and supports**...Each adult and child has timely access to the full spectrum of supports and services needed.
3. **Individualized and person-centered**...Communities offer a comprehensive, integrated and consistent array of services and supports that are individualized and flexible.
4. **Collaboration and partnership in building community capacity**...State and local policies and programs align to support the legislative vision of resiliency and recovery for Iowans with mental illness, and the ability of Iowans with disabilities to live, learn, work, and recreate in communities of their choice.
5. **Workforce and Organizational Effectiveness**...Investing in people through appropriate training, salary and benefits improves workforce and organizational effectiveness.
6. **Empowerment**...Communities recognize and respect the ability of people (1) to make informed choices about their personal goals, about the activities that will make their lives meaningful, and about the amounts and types of services to be received; and (2) to understand the consequences and accept responsibility for those choices.
7. **Active Participation**...Individuals and families actively participate in service planning; in evaluating effectiveness of providers, supports and services; and in policy development.
8. **Accountability and results for providers**...Innovative thinking, progressive strategies and ongoing measurement of outcomes lead to better results for people.
9. **Responsibility and accountability for government**...Adequate funding and effective management of supports and services promote positive outcomes for Iowans.

The second source of principles is the integrated list of consumer-focused outcomes and system performance domains developed by the Intellectual and Developmental Disability (ID-DD), Mental Health and Children’s Workgroups. As a first priority, each of the service population Workgroups (ID-DD, Mental Health, Children’s Disability Services, and Brain Injury) worked to develop consensus on a uniform set of outcome and performance domains that could form the basis for system monitoring, quality improvement and accountability throughout the state. These recommended domains address System, Consumer and Family outcomes.

Taken all together, the Iowa *Olmstead* principles and the recommended domains for outcome and performance measurement provide a comprehensive template that was used by the Workgroups to guide their deliberations and consensus-building. Virtually all of the consensus recommendations of the workgroups discussed in this interim report can be aligned with and shown to be consistent with these principles and measures.

Olmstead

Consistent with *Olmstead*, each of the Workgroup reports contains recommendations intended to serve people in the least restrictive, most integrated settings possible. Paramount is the need to keep civil rights and fact based dialogue regarding the prudent use of taxpayer dollars at the forefront of all discussions. It is increasingly accepted that smaller, more integrated community-based settings over large congregate settings, both inpatient and community-based, are more preferable to consumers, produce better outcomes and are more economical to states. The report acknowledges that rebalancing systems is complex and requires changes in thinking, commitment to ensure civil rights of consumers, and creative funding strategies. Several areas in the report grapple with the role larger facilities (e.g. Mental Health Institutes, Intermediate Care Facilities, Residential Care Facilities) should play and how funding should be allocated toward services.

Multi-occurring Conditions

Each of the Workgroups also recognized that people regularly present with two or more disabilities. Recommendations in the report consider that people with multi-occurring conditions are the expectation in the system, not the exception, and that the system should plan and develop services that are capable of serving or coordinating services for people with multiple needs. Accordingly, all of the component parts of this report addressed by the Workgroups, such as core services, outcomes and performance measures, provider standards, and workforce development, are premised on the need to thoroughly consider the needs of people with multi-occurring conditions.

Intellectual and Developmental Disabilities Workgroup

The report of the Intellectual and Developmental Disabilities (ID-DD) Workgroup describes the current state of services and supports in Iowa and asserts the desired shape and content of the system going forward. The report furthers the work of the *Olmstead* planning group by exploring specific system

components that will be necessary to see the goals of *Olmstead* realized. Best practices around the country in eligibility determination, outcome measurement, core services, workforce, and provider capabilities are highlighted.

The report discusses the evolution of eligibility for services in the field to be more inclusive of developmental disabilities, and that the majority of states are now using a developmental disability definition to determine eligibility. The report details several recommendations involving eligibility, among these: 1) the need for a standardized assessment tool, such as the Supports Intensity Scale (SIS), developed by the American Association on Intellectual and Developmental Disabilities (AAIDD), for the measurement of the support needs of people with intellectual/developmental disabilities services for planning purposes as well as for resource allocation; 2) exploring and planning for the expansion within the intellectual disability waiver of current eligibility requirements to include individuals with a developmental disability; and 3) consideration for consolidating waivers with overlapping target groups including the Ill and Handicapped waiver, the Brain Injury waiver, Physical Disability, and the Intellectual Disability waiver.

Regarding Core Services, the report describes how expectations for services now focus on being individualized, person centered and aimed at achieving and maintaining integrated lives in the community, and refers to the Iowa *Olmstead* Plan as a tool to guide the development of services. Recommendations include the development and enhancement of services in the following key areas: 1) service coordination; 2) family support; 3) community living; 4) employment services; 5) health and primary care; and 6) crisis intervention and prevention. The group further agreed that the current array of residential, day and vocational, and other ancillary services – including those supported through waivers, and offered on a statewide basis through either county or state funding should be considered “core”.

The report makes specific recommendations for Iowa to explore a transition to a case management system that is conflict-free. Specifically, conflict free case management means that the function is divorced from the direct provision of service in order to ensure that individuals and families are given adequate choice among a range of available providers.

The report goes on to describe the need for the system to identify and evaluate meaningful outcomes, and associates the strong influence on performance measurement in the past 10 years in the ID-DD service system coming from a change in expectations of the federal Centers for Medicare and Medicaid Services (CMS) regarding 1915(c) Waivers. Parallel trends include demand for accountability for results for the investment of public funds and increased transparency. Examples of in state and out of state best practices in performance and outcome measurement are provided, including a systemic approach to performance and outcome measurement known as National Core Indicators (NCI).

The report suggests that measurement and monitoring of the performance of services and supports should be premised to a significant degree on the achievement of positive outcomes for individuals and families. DHS should also be allocated staff resources to review and analyze data across systems, identify trends, and develop quality improvement strategies. Several recommendations are provided in

order to standardize approaches, recognize cost implications for providers and make quality monitoring information easily available and understandable to all citizens.

The report discusses workforce issues as a national crisis confronting Iowa and discusses best practice strategies, including credentialing from the National Alliance for Direct Support Professionals (NADSP) and online training through The College of Direct Support (CDS). Included as a recommendation is the expanded use of the College of Direct Supports and the use of minimum competencies expected from direct support professionals in the field.

Adult Mental Health Workgroup

The report of the Adult Mental Health Workgroup identifies the need to establish a continuum of mental health services that is recovery-oriented; accessible and easy to navigate; ensures the availability of safety net, crisis intervention and diversion services; and supports the rights of people to live in integrated settings.

The Workgroup recommended that moving toward more inclusive eligibility criteria that recognizes the prevalence of mental illness in the general population, and the fact that people are affected uniquely by their mental illness and should be encouraged to seek treatment if they experience signs and symptoms of mental illness that are impacting their life. The report further details recommendations for eligibility including specific recommendations on age, residency, financial, diagnostic and/or functional impairment criteria.

The Workgroup spent considerable time on financial eligibility. The Workgroup agreed there should be consistent application of 150% of the Federal Poverty Level (FPL) for financial eligibility, and strongly recommended that beginning July 1, 2014, savings resulting from the Affordable Care Act's expansion of Medicaid and private insurance to currently uninsured individuals shall be reinvested to expand eligibility to 200% of the FPL. The Workgroup agreed that a copayment for services is acceptable, but that sufficient waiver requirements be established to ensure that the use of copayment and sliding fees, for those both below and above 150% of FPL, do not become a barrier for those seeking services.

Discussions regarding the availability of core services centered on the need for the system to be able to deliver and pay for evidence-based and other effective services depending on individuals unique needs developed through a person-centered planning approach. The Workgroup spent considerable time discussing the current availability of services, inconsistency across the State, access issues, particularly in rural areas, the need to develop a stronger continuum of crisis prevention and intervention services, and rebalancing the service delivery system. The Workgroup approached core services by recommending that minimum Core Service Domains, consistent with those identified as outcomes to be measured, should be mandated throughout the State.

In addition, the Workgroup identified several services that should be developed or expanded throughout the State due to their effectiveness. These include: 1) peer run self-help centers; 2) crisis services (including a 24/7/365 crisis hotline, mobile response, 23-hour crisis observation, evaluation,

holding and stabilization services, and crisis residential); 3) sub-acute services; 4) jail diversion services; 5) Assertive Community Treatment (ACT); 6) Community Support Services/Supportive Community Living/Case Management; 7) Health Homes; 8) Supported Employment and Supported Education; and, 9) Family Support Services.

The Workgroup agreed that the Vision and Principles identified earlier in this report provide a sound foundation for the specific development of outcomes and performance measures. Therefore, the Workgroup further recommends that an Outcomes and Performance Measures Committee be established to continue and finalize this work beyond the Redesign process. The report details the tasks to be conducted and membership of the committee.

The workgroup recommended that outcomes should be clear and understandable to a wide variety of audiences. DHS, the Iowa Plan contractor and regional entities should be required to monitor and evaluate similar outcomes and performance indicators. In order to ensure that outcomes are evaluated throughout the continuum of services, the Workgroup suggested that outcomes be measured in at least the following core service domains: 1) Acute Care and Crisis Intervention Services; 2) Mental Health Treatment; 3) Mental Health Prevention; 4) Community Living; 5) Employment; 6) Recovery Supports; 7) Family Supports; 8) Health and Primary Care Services; 9) Justice Involved Services; and 10) Workforce Development.

The challenge of having a sufficient workforce is not unique to the Intellectual Disability community. Insufficient numbers of mental health staff combined with existing staff whose knowledge and experience are inadequate to meet the needs of service recipients has created a national workforce crisis in behavioral health. Given the broad range of topics within workforce development, the Workgroup recommends that the legislature direct DHS to convene a standing Workforce Development group comprised of multiple stakeholders to address this multi-faceted issue.

The Workgroup also discussed encouraging the development of a greater peer workforce. The use of Peer-delivered services is considered a best practice approach, and the Workforce Development group that is convened should recommend ways to expand Iowa's peer workforce. Iowa does use Certified Peer Specialists and should continue to encourage the use of peers in the delivery of nearly all services.

Provider accreditation, certification and licensure issues are presented in the report. One theme that emerged was the sense that there is too much fragmentation between multiple agencies as it relates to this process, particularly in the areas of mental health and substance use provider oversight and monitoring. The group acknowledged the important role the State plays in ensuring that providers deliver safe and quality services to service recipients, but encouraged a process to streamline accreditation, certification and licensing standards and the inspection process in order to minimize unnecessary burdens on providers, reduce redundancy and align the delivery of services.

Children’s Disability Services Workgroup

The Children’s Disability Services Workgroup report 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 Workgroup.

The leading recommendation from the Workgroup is that a Systems of Care framework be adopted by the State of Iowa. 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. 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.

The Workgroup developed and recommends the following definition be adopted as a foundation for the development 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 Workgroup focused on youth placed out of state both as an issue to be addressed now and as a potential driver of system-wide solutions for the children’s systems of care in Iowa. A short-term strategy to bring children home from out of state placements is presented, and includes the issue of 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 Workgroup report identifies 15 gaps in the current children’s system that should be addressed as part of the development of a system of care. These include lack of accountability for children services; limited access to services; lack of coordination among providers; inadequate support for parents, guardians, caretakers, and family members; reimbursement issues for providers; lack of an organized crisis response system; and transition-age issues for youth aging out of the children’s system.

The Workgroup considered a number of evidence based and promising practices in children’s services inside and outside of Iowa and examples are provided in the report.

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: 1) coordinated; 2) family and youth-driven; 3) culturally competent; 4) developmentally-driven and evidence-based; 5) flexible, nimble, nuanced, varied, and specialized; 6) delivered “where children/youth are”; 7) accessible; and 8) attentive to the journey and needs of parents, guardians, caretakers, and families.

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 the preliminary report are intended to be foundational and as an initial 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 two additional services in order to set the stage for the full system transformation. These are Intensive Care Coordination, Family Peer Support and Crisis Services. In addition, the Workgroup recommends the enhancement of two services: Intensive Community-Based Treatment and Psychiatric Medical Institutions for Children (PMIC) Services.

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 report points out that the Health Home would also play a significant role in crisis management, systems development and systems performance/outcome measures.

Regional Workgroup

The Regional Workgroup had extensive discussion of the benefits that could be derived from regions and the possible risks or downsides of forming regions. Taken all together, the recommendations of the regional Workgroup create a vision for a regional structure that incorporates the following features:

- Establishment of a single point of clinical and financial accountability for non-Medicaid services for all citizens of Iowa;
- Establishment of a regional entity that can build on the best elements of current county systems while at the same time improving access to core services and attaining consistency of service access and delivery;
- Maintenance of the strength of local interagency and multi-systems arrangements and relationships while also attaining economies of scale; and
- Creation of regional entities that can function as the unified managers of systems of care and different service modalities for consumers with different disabilities and service needs and choices, while at the same time fostering integration, coordination and reduced duplication between these various systems of care and service modalities.

The Workgroup strived to attain a reasonable balance between the benefit of “organic,” voluntary formation of regions versus the recognition that DHS would have to have some authority to act if such voluntary regions were not formed or if one or more counties were to be left out of contiguous regional groupings. The Workgroup developed criteria for the formation of regions that strikes a reasonable balance between the benefits of local knowledge, relationships and personal contact with consumers and other stakeholders with the need to attain equity, consistency and economies of scale. Among the recommended criteria for the formation of regions include: 1) there should be total of five to 15 MHDD regions in Iowa; 2) the target population for regions should be in the range of 200,000 to 700,000 total people; 3) there must be a psychiatric inpatient facility and a state-certified CMHC or a FQHC that provides behavioral health services within each region; and, 4) regions must be comprised of contiguous counties.

The Regional Workgroup recognized that governance and financial management are critical to the successful formation, sustainability and accountability of regions. Recommendations for regional governance, regional financial management and topics to be included in 28E agreements are included in the report.

The Workgroup identified essential core functions necessary for a region to be held accountable and to meet performance standards. The Workgroup understood that regions will be operating with fixed global budgets and thus will need to have financial management and analytic capacities to manage effectively within their fixed budgets. The Workgroup recommends that the contents of regional management and strategic plans be established by DHS rulemaking and that the statute provide DHS the authority for such rulemaking but not spell out the contents of the plans. An outline for the required regional management and strategic plans is included.

Judicial Workgroup

The Judicial Workgroup was established between the judicial branch of government and Department of Human Services pursuant to 2010 Iowa Acts, chapter 1192, section 24, subsection 2, to improve the processes for involuntary commitment for chronic substance abuse under chapter 125 and for mental illness under chapter 229, and to coordinate its efforts with the legislative interim committee as part of this redesign process. Specifically, the Workgroup addressed the following issues:

1. The current provision of transportation by the county sheriff. There is a serious issue with the amount of time and manpower it takes to transport a respondent in the commitment process. Recommendations include designating transportation as a core service and having each region designate a transportation coordinator.
2. Civil Commitment Pre-screens: Recommendations include the recognition of pre-commitment screening services for involuntary commitments as a core service, and pre-commitment screening services should be the role of Community Mental Health Centers or a designated facility contracted by the region.
3. Court authorization to order an involuntary hold under Chapter 229.10 for not more than 23 hours for a person who was not initially taken into custody, but declined to be examined

pursuant to a previous order. The Workgroup recommended a change in Chapter 229.22 to allow for the 48-hour hold to be available 24 hours a day. This would necessitate a change in section 602.6405, subsection 1 concerning limitations on non-lawyer magistrates.

4. Revision requirements for Mental Health professionals involved in the court committal process. Recommendations include that only a physician should examine the patient and provide a report to the court during the committal process, and that a Psychiatric Advanced Registered Nurse Practitioner may provide the annual report to the court for an outpatient committal.
5. The role, supervision and funding of mental health and substance-related disorder advocates.
6. Implementation of jail diversion programs.
7. Comprehensive training of law enforcement in dealing with persons in crisis.
8. Recommendations on residential care facilities, enhancing the consistency of services for individuals who are court ordered to a residential care facility and addressing issues related to the appropriate placement for an individual with criminal involvement.
9. Mental Health Courts and Identification of promising reforms related to mental health and the criminal justice system.

Brain Injury Workgroup

Senate File 525 charged the MHDS Brain Injury (BI) workgroup with reviewing best practices and programs utilized by other states in identifying new approaches for addressing the needs for publicly funded services for persons with brain injury. The recommendations reflect both a short and long term implementation timeline in recognition of the need to further develop the brain injury service system.

According to the Centers for Disease Control and Prevention (CDC), nearly 1.7% of people in Iowa or approximately 50,000 Iowans are living with long-term disabilities caused by a traumatic brain injury (CDC 2008). Brain injury is the most debilitating outcome of injury characterized by the irreversibility of its damages, long-term effects on quality of life, and healthcare costs. Brain injury can be acquired, e.g., stroke, or traumatic in nature and Iowa's aging population and increasing numbers of military service veterans will drive up the rates of incidence.

The Workgroup identified and defined Best Practices. Recommendations are designed to create a continuum of care that is affordable, accessible, available, appropriate, and acceptable to all individuals with brain injury in all regions. The Workgroup felt that all services currently offered to people with brain injuries should continue to be offered as core services. A number of these services are included in the Brain Injury Services Program at the Iowa Department of Public Health (IDPH), and Medicaid State Plan Brain Injury Services and Home and Community Based Brain Injury Waiver Services at the Iowa Department of Human Service (DHS). The recommendations are prioritized based on the degree of impact on improving the existing system, Optimized Core Services, Expanded Core Services and New Core Services.

Psychiatric Medical Institutions for Children (PMIC) Transition Committee

The PMIC Workgroup was charged with making recommendations to facilitate the successful transitioning of the administration of PMIC services from a fee for service program administered by the Iowa Medicaid Enterprise (IME) to the Iowa Plan, through which the IME provides managed behavioral health care to its Medicaid enrollees. This process is expected to continue in coordination with the work of the Children's Workgroup, and the preliminary report provides a course of action for the Workgroup that includes: 1) identifying admission and continued stay criteria for PMIC providers (4b3); 2) evaluating changes in licensing standards for PMICs, as necessary (4b4); and 3) evaluating and defining the standards for existing and new PMIC and other treatment levels (4b9).

In addition, the Transition Committee will discuss reimbursement rates for current PMIC services, and will utilize a sub-committee to discuss payment for ancillary services by PMICs beginning July 2012, as required by the Centers for Medicare and Medicaid Services.

Integration and Transition Planning

Finally, Section X of the report synthesizes each of the Workgroup reports in order to demonstrate what an integrated system will look like, and to offer considerations for transitioning to a redesigned system. This Section further highlights that an important feature of the integrated and unified systems contained in the consensus recommendations is that the system is organized to assure people a "no wrong door" experience regardless of where they present in the system and regardless of their disability or disabilities. Facilitated access; consistency of service delivery across systems, and equity of service resource deployment are hallmarks of the recommended new system. The importance of the unified single point of accountability is to facilitate movement between disability and funding stream silos for people with multiple needs. The report discusses the need for integration across multiple systems in recognition people's unique, and frequently multi-occurring needs, and other types of integration and coordination necessary.

As noted throughout the recommendations in this report, there will be a need to transition from the current system to the desired new system. This transition process must first and foremost be respectful of consumers and families, some of whom have been living or participating in their programs for long periods of time, and who are comfortable with their existing provider(s) of services. The transition must also be respectful of providers, many of whom have been doing what the system has asked of them for years, and who may have substantial capital investments in their program facilities. Finally, the transition will be an iterative process, and must be cognizant of the available resources, both resources already in the system, and in any new resources that may become available. Clear choices will have to be made on the amount of transition progress that can be made in the context of available resources.

I. INTRODUCTION

This is the Interim Report of the Technical Assistance Collaborative TAC and the Human Services Research Institute (HSRI) to the Iowa Department of Human Services (DHS) related to the redesign of Iowa's Mental Health (MH), Intellectual and Developmental Disability (ID-DD) and Brain Injury (BI) system. The report, and all the activities leading up to the report, is based on the recently enacted Senate File 525. It is the intent of TAC and DHS to share this report with the Legislative Interim Committee established under SF 525 as a prelude to the formal report to be produced for the Interim Committee by December 9, 2011.

SF 525 provides guidance for both the structure and the process of reforming the Iowa MH/ID-DD system. SF 525 envisions a uniform statewide system of core services accessed and managed through a set of regional entities that would assure service access and care coordination for non-Medicaid services. Based on the Legislative history and the contents of SF 525, and on the statements of Legislative leaders associated with the Legislation, we understand the overall goals of SF 525 are to:

- In the context of available resources, assure timely, consistent and equitable access of the citizens of Iowa to a uniform set of core services designed to produce positive outcomes for consumers and their families and for the communities in which they live;
- In the context of available resources, and being respectful of the strengths and traditional practices of the existing MH and ID-DD service systems, begin to transition towards integrated community services modalities: (a) that are consistent with Iowa's *Olmstead* plan; and (b) for which there is sufficient evidence that the services modalities will produce positive outcomes for consumers and their families;
- Assure the quality and cost effectiveness of the MH and ID-DD service systems through implementation of best practice services, strengthened overall state and regional monitoring and quality improvement, and consistent and timely data submission and analysis;
- Make best use and maintain effective stewardship of scarce public services resources through reduction of duplicative administrative functions and costs; and
- Implement a MH/ID-DD system that is simple, clear, transparent, easy to access, and understandable to all consumers, families, providers, and other stakeholders.

The primary purpose of this Interim Report is to synthesize and communicate the consensus recommendations of the Workgroups as required by SF 525. Seven Workgroups have been meeting over the past three months to consider the organizational and operational challenges outlined in SF 525, and to come to consensus recommendations for reform of the MH and ID-DD systems. In addition to the requirements of SF 525, the Workgroups were guided in their deliberations by two major sets of principles: (a) the Iowa *Olmstead* Plan; and (b) the uniform set of consumer outcome and system

performance measures developed by the ID-DD, Mental Health and Children Services Workgroups. These are listed in Chapter III below.

DHS and TAC made an effort to have the deliberations of the service system-oriented work groups (MH, ID-DD, Children's Services, and BI) as consistent as possible. These workgroups, with the exception of BI, each addressed: (a) outcome and performance measures; (b) eligibility; (c) core services; (d) services for people with dual or multi-occurring disabilities; (e) workforce development; and (f) provider qualifications and monitoring. The other work groups, Regionalization, Judicial, and Psychiatric Medical Institutions for Children (PMIC) had more individualized agendas, and also expected to rely on the recommendations developed by the services Workgroups. The recommendations of each of the seven Workgroups are summarized in chapters IV through X below.

It is important to emphasize that this is an interim report.¹ DHS will think through the implementation tasks and costs associated with the recommendations, and will present a logically consistent set of recommendations to the Interim Committee once this interim report is digested.

More importantly, this report is just the beginning of a process that will ultimately result in better and more cost effective services for the citizens of Iowa. Any change process, including the redesign and reform of the Iowa MH and ID-DD service systems, must start from and be respectful of a baseline of existing services, providers, system relationships, funding approaches, etc. And, no change process can take place in a vacuum. Consumer and family needs and choices are constantly changing. Science and practice based knowledge of what services work best for people continues to improve. National Health Reform and the Affordable Care Act are already presenting new challenges and opportunities for state governments. The redesign and reform process in Iowa must take place in the context of these constant, on-going changes.

TAC and HSRI have attempted to inform the process by providing background information on: (a) best and promising practices reflected in the literature; and (b) experiences of other states with regard to implementing preferred practices. Because of our national policy work, we have also been able to keep workgroup participants informed about new policy directions and potential financial resources emanating from the federal government. These include new Medicaid standards and requirements (Centers for Medicare and Medicaid Services - CMS); new mental health best practices and initiatives (SAMHSA); new activities related to the Americans with Disabilities Act and the integration mandate of the *Olmstead* decision (Department of Justice and CMS); and new housing resources for people with disabilities (HUD).

As will be described below, the three months of activities leading up to the production of this interim report have been intensive and complicated. TAC and HSRI would like to express our deepest gratitude

¹ Note: SF 525 intended the Children's and BI Workgroups to have a two-year life span. The other Workgroups were intended to finish their recommendations within the three-month timeframe reflected in this report.

to all the DHS staff who dedicated time and effort to the Workgroup process. DHS made sure all the logistics of meetings, conference calls, document review, etc. worked smoothly and in a timely manner.

In addition, the participants of the Workgroups volunteered many hours, not only to participate in Workgroup meetings, but also to read materials and to bring new information to share with other Workgroup participants, both in an effort to make the maximum amount of contribution to the process. Equally important, Workgroup members came to the meetings ready to listen, to learn and to attempt to forge consensus about the best direction forward for Iowa. This made the Workgroup process more effective, and contributed to the generation of many excellent recommendations.

II. METHODOLOGY

Senate File 525 calls for the formation of several workgroups through which DHS and the Legislative Interim Committee could derive input and advice related to the redesign and reform of the MH/ID-DD and children's services systems in Iowa. In response to the SF 525 mandate, DHS formed seven Workgroups:

1. Intellectual Disabilities and Developmental Disabilities (ID-DD)
2. Adult Mental Health (MH)
3. Children's Disability Services
4. Regionalization
5. Judicial– DHS (i.e. to address Court/Legal issues)
6. Services for people with Brain Injury (BI)
7. Psychiatric Medical Institutions for Children (PMIC)

Initially, DHS widely disseminated information about SF 525 and the workgroup process, and requested volunteers to serve on the workgroups. More than 150 individuals representing the geographic diversity of Iowa as well as all the various stakeholder groups initially volunteered to participate. DHS then selected more than 100 workgroup participants from this group of volunteers. In some cases DHS reached out to additional individuals, to achieve balance and adequate representation of certain perspectives on each workgroup. DHS made a special effort to assure consumer and family participation in each workgroup as well.

DHS, along with Judiciary and the Department of Public Health, established a schedule for regular workgroup meetings beginning on August 16, 2011 and ending on October 25, 2011. Each workgroup met at least five times during that time frame. DHS established a section of the main DHS website (<http://www.dhs.state.ia.us/Partners/MHDSRedesign.html>) where workgroup participants and the general public could readily access information generated by and for the workgroups.² DHS established a sequential process whereby the agendas and reading materials for each workgroup were published on DHS's website by the Thursday or Friday prior to each meeting. The reading materials included (a) a discussion paper developed by TAC/HSRI³ germane to the topics to be discussed at the up-coming meeting; (b) reference materials identified by TAC/HSRI and DHS related to best practices and examples from other jurisdictions that could inform participant recommendation formulation; and (c) materials submitted by participants in the workgroups also designed to inform participants in their deliberations and consensus building.

² Detailed information about the membership, schedule, agendas, discussion papers, and related materials are available at the DHS website.

³ The TAC HSRI discussion papers were for the Mental Health, ID-DD, Children's and Regionalization Workgroups.

DHS assigned staff to assist with meeting preparation and logistics, and to take detailed notes during each meeting. These notes were reviewed by DHS and the workgroup facilitators, and once complete were published on the DHS website within five business days of the workgroup meetings. This allowed participants to review the proceedings of each meeting, to make sure their positions were accurately represented and to assure that reports of consensus recommendations were properly stated. These minutes of meetings also gave stakeholders and the public real time information on how the work groups were progressing and what types of consensus recommendations were being developed by the groups.

The workgroup meetings were open to the public and two periods of public comment took place during each workgroup meeting: one at the end of the morning session and one at the end of the afternoon session. This gave members of the audience the ability to reflect on the discussion they heard during the day and/or add their own perspective. The minutes of each meeting include brief summaries of the public comment provided. In addition, Legislators were active participants in the discussions of the workgroups and provided useful guidance related to the Legislative intent of SF 525.

In addition to the workgroup process, DHS collaborated with advocacy groups on nine regional stakeholder forums to give consumers, families, providers, County officials and staff, and other interested stakeholders an opportunity to (a) learn about the system redesign and reform process; and (b) to provide meaningful input into the deliberations. A DHS summary of the input from those meeting is posted on the DHS website.

As described above, the process for discussing and reaching consensus recommendations for DHS and the Legislative Interim Committee related to SF 525 was both comprehensive and exhaustive. More than thirty workgroup sessions including over 100 participants and many more audience-based stakeholders took place over a time span of 11 weeks. Massive amounts of written materials were developed, collected, reviewed, and discussed. In fact, the materials now available on the DHS website constitutes an excellent library of state-of-the-art materials on best practices related to ID-DD, adult mental health, children's disability services, brain injury and the judicial systems as well as materials on the organization and financing of services in other states.

The workgroup and community forum processes were as inclusive and comprehensive as possible given the very brief time frame available. Some will say that the process was too quick: that not enough stakeholders were able to be involved and not enough time was allowed for deliberations. While that could be said about any system redesign and reform effort, it is also true that too much time can be the enemy of making decisions and moving forward. To the extent there are funding and operational problems in the current system that impede timely and responsive delivery of best practice services to consumers and their families, there is an obligation to remedy those issues as quickly as possible. The process established by the Iowa Legislature and DHS strikes a reasonable balance between the need for careful deliberation and input from stakeholders on one hand, and the need for all deliberate speed on the other hand.

III. VISION AND PRINCIPLES FOR THE REDESIGNED MENTAL HEALTH AND INTELLECTUAL AND DEVELOPMENTAL DISABILITIES SYSTEM

Prior to beginning the workgroup process, TAC, HSRI and DHS discussed the basic values and principles that should drive the process for formulating consensus recommendations to the Legislative Interim Committee. It was decided that there would be two sources of these values and principles. The first is the principles of the Iowa *Olmstead* Plan, which reinforces the community integration mandate of the Americans with Disabilities Act, which was enacted by Congress in 1991. The second would be the integrated list of consumer-focused outcomes and system performance domains developed by the ID-DD, MH and Children's Workgroups.

Iowa DHS has published a comprehensive *Olmstead* Plan in conformance with federal requirements and guidelines under the American's With Disabilities Act. This plan clearly states the vision of "a life in the community for everyone." This vision is supported by a number of key principles related to a life in the community for everyone. These are briefly summarized below.

Iowa *Olmstead* Principles: A life in the Community for Everyone

1. **Public awareness and inclusion**...Iowans increasingly recognize, value, and respect individuals with mental illness or disabilities as active members of their communities.
2. **Access to services and supports**....Each adult and child has timely access to the full spectrum of supports and services needed.
3. **Individualized and person-centered**....Communities offer a comprehensive, integrated, and consistent array of services and supports that are individualized and flexible.
4. **Collaboration and partnership in building community capacity**....State and local policies and programs align to support the legislative vision of resiliency and recovery for Iowans with mental illness, and the ability of Iowans with disabilities to live, learn, work, and recreate in communities of their choice.
5. **Workforce and Organizational Effectiveness**....Investing in people through appropriate training, salary and benefits improves workforce and organizational effectiveness.
6. **Empowerment**....Communities recognize and respect the ability of people (1) to make informed choices about their personal goals, about the activities that will make their lives meaningful, and about the amounts and types of services to be received; and (2) to understand the consequences and accept responsibility for those choices.
7. **Active Participation**....Individuals and families actively participate in service planning; in evaluating effectiveness of providers, supports and services; and in policy development.

8. **Accountability and results for providers**....Innovative thinking, progressive strategies and ongoing measurement of outcomes lead to better results for people.
9. **Responsibility and accountability for government**....Adequate funding and effective management of supports and services promote positive outcomes for Iowans.

SF 525 specifies that DHS should develop consumer outcomes and performance measure for application in a consistent manner throughout the public MH/ID-DD system. As a first priority, the ID-DD, Mental Health and Children's Disability Services workgroups worked together to develop consensus on a uniform set of outcome and performance domains that could form the basis for system monitoring, quality improvement and accountability throughout the state. These recommended domains address system outcomes, consumer outcomes and family outcomes. The recommended domains are listed below.

Consolidated Workgroup Recommendations on Global Outcomes

System Outcomes

- Help Iowans increasingly recognize, value, and respect individuals with mental illness and/or disabilities as active members of their communities.
- Provide each adult and child with timely access to the full spectrum of supports and services needed, including for those who have co-occurring disabilities.
- Offer a comprehensive, integrated and consistent array of services and supports that are individualized, person-centered, flexible, and culturally informed.
- Ensure that state and local policies and programs align to support the legislative vision of resiliency and recovery for Iowans with mental illness, and the ability of Iowans with disabilities to live, learn, work, and recreate in communities of their choice, thereby reducing Iowa's current reliance on high-cost institutional settings.
- Invest in people through appropriate training, salary and benefits to improve workforce and organizational effectiveness.
- Recognize and respect the ability of people (1) to make informed choices about their personal goals, about the activities that will make their lives meaningful and about the amounts and types of services to be received; and (2) to understand the consequences of, and accept responsibility for, those choices.
- Ensure that individuals and families actively participate in service planning, in evaluating effectiveness of providers, supports and services and in policy development.
- Encourage the use of innovative thinking and progressive strategies that lead to better results for people.
- Provide adequate and flexible funding and cost effective management of supports and services that promote positive outcomes for Iowans.
- Ensure that children and adults receive the necessary services and supports to achieve their optimal educational potential.

Individual Outcomes

- People make choices about their lives including with whom and where they live.
- People have support to participate in their communities.
- People have friends and relationships.
- People have support to find and maintain meaningful, competitive, community integrated employment.
- People have transportation to get them where they need to go.
- People are safe from abuse, neglect, restraint, seclusion, injury, and coercive interventions.
- People receive the same respect and protections as others in the community.
- People secure needed health services and are supported to maintain healthy habits.
- People's treatment, including medications, is managed effectively and appropriately.
- People receive information about their disability and the services and supports they need in easily understood language.
- People are actively engaged in planning their services and supports.
- People are supported to be self-determining and to manage and direct their own services.
- People are supported to advocate for themselves.
- People have timely access to services and supports in the community that aid in preventing and resolving crises in a least restrictive, person/family-centered and minimally disruptive manner.
- People receive the necessary services and supports to achieve their optimal educational potential.

Family Outcomes

- Families have equal access to needed services and supports, including crisis intervention and respite, regardless of where they live and the nature of their family member's disability.
- Families receive accurate and accessible information and counseling regarding the nature of their family member's disability and relevant services and community resources.
- Family voice is sought and choices are respected and considered by the family-inclusive service team.
- Families have the information and support necessary to assist in the development of a plan for their family member.
- Families that choose to self-direct flexible budgets can do so (for families with children).
- Families receive supports necessary to keep the family together.
- Families get the services and supports they need to make a positive difference in their lives and the life of their family member with a disability.
- Families use integrated community services and participate in everyday community activities.
- Families are supported to maintain connections with and participate in the treatment of family members with disabilities not living at home.
- Families have a primary decision-making role in the care of their (dependent) children, as well as the policies and procedures governing care for all children.
- Families are given accurate, understandable and complete information necessary to set goals and to make informed decisions and choices about the right services and supports for (dependent) children and their families.

Taken all together, the Iowa *Olmstead* principles and the recommended domains for outcome and performance measurement provide a comprehensive template that was used by the Workgroups to guide their deliberations and consensus-building. Virtually all of the consensus recommendations of the workgroups discussed in Chapters IV through IX of this report can be aligned with and shown to be consistent with these principles and measures. And, in cases where consensus was not reached on certain topics, the Workgroups typically asserted that whatever solution is ultimately adopted by the Legislature and DHS should adhere to *Olmstead* principles.

IV. REPORT OF THE INTELLECTUAL AND DEVELOPMENTAL DISABILITIES WORKGROUP

A. Overview of Redesign Recommendations for Services for People with Intellectual Disabilities

Continuous quality improvement in any field requires that stakeholders periodically conduct a purposeful and thoughtful reflection on the performance of a given system and the areas in need of reform. The passage of Senate File 525 made it possible for the Workgroup on Intellectual and Developmental Disabilities to take the time to participate in a conversation about the current state of services and supports in Iowa and to reflect on the desired shape and content of the system going forward. It has also provided an opportunity to continue the work of the Olmstead planning group by exploring specific system components that will be necessary to see the goals of Olmstead realized. Further, the discussion has illuminated best practices around the country in eligibility determination, outcome measurement, core services, workforce, and provider capabilities. It has made it possible for Iowa stakeholders to learn about and evaluate where Iowa stands in relation to other states and to consider use of resources on more productive and person centered program models, and explore new service models.

B. Eligibility Assessment

Trends and Best Practice in Eligibility Determination and Standards

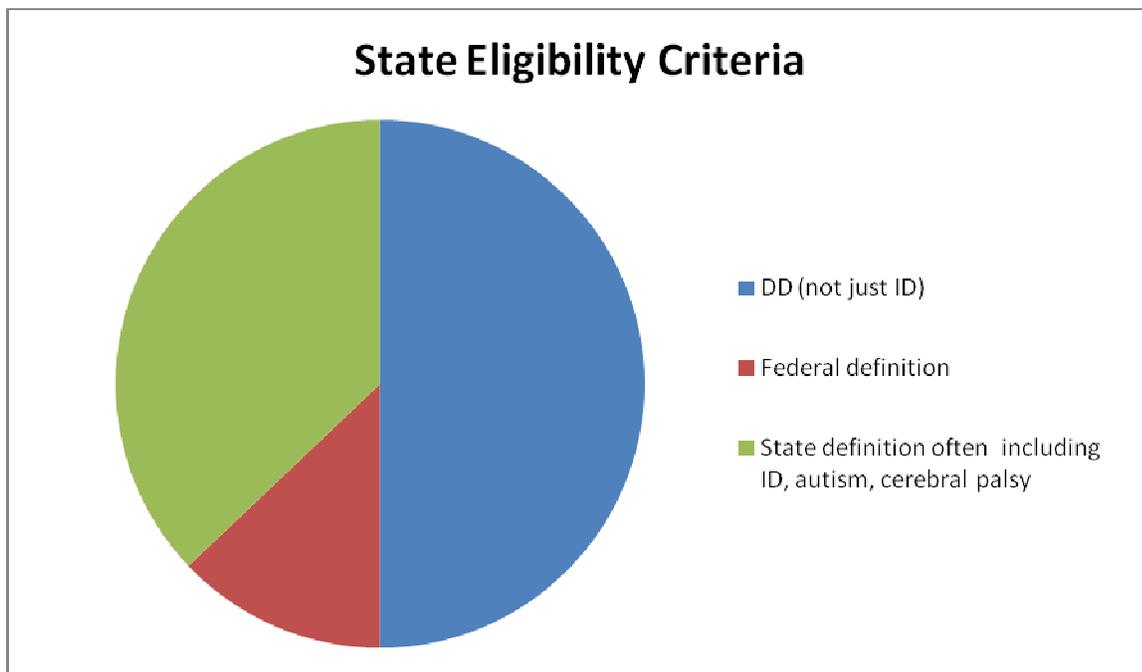
The role of eligibility determination is to provide for a fair and consistent process to allocate scarce resource to those who meet the requirements and to screen out those who do not meet the requirements. How states and the federal government have framed eligibility criteria for individuals with intellectual disability has changed substantially over time. In the past, eligibility for publicly funded services was limited to a narrow definition of mental retardation assessed using an IQ testing. More recently, the term mental retardation has been replaced by intellectual disability and eligibility standards have moved from reliance on intelligence testing to evaluation of a person's functioning, his/her abilities and need for support. The American Association on Intellectual and Developmental Disabilities (AAIDD) definition of intellectual disabilities includes both intellectual functioning and adaptive behavior including conceptual skills, social skills and practical skills.

Since the 1970s, the federal statute expanded the notion of intellectual disabilities to include other related disabilities including cerebral palsy, epilepsy and autism. This expanded term is "developmental disabilities". The definition of the term is found in the Developmental Disabilities (DD) Act and is based on the following functional criteria:

- Severe, chronic disability of person 5 years of age or older
- Occurring before age 22

- Likely to continue indefinitely
- Substantial functional limitations in three or more areas of major life activity: Self-care, Receptive and expressive language, Learning, Mobility, Self-direction, Capacity for independent living, or Economic self-sufficiency

State approaches to determining eligibility have changed with the evolving definition. At this time 47 states use some combination of categorical and functional assessment processes. The majority of states are using a developmental disability definition to determine eligibility. The chart below illustrates the criteria states use to define eligibility.



In addition to the way in which states define eligibility for ID-DD services, they also stipulate eligibility criteria for Home and Community Based Waiver Services:

- 34% based on MR definition
- 66% based on broader definition

States have some latitude regarding the target population for waiver services. Level of care criteria are based on whether individuals require the services and supports provided in an Intermediate Care Facility for People with Mental Retardation (ICF/MR).

In Iowa, the eligibility for ID waiver is based on the following criteria:

- Financial – Medicaid eligible
- Functional assessment – must meet ICF/MR level of care
- Categorical – have a diagnosis of ID or IQ of 70 or less

Iowa also provides services to individuals with intellectual and developmental disabilities with a mixture of state and county funding to a range of individuals with intellectual and developmental disabilities who don't meet waiver criteria or who may be waiting for services. There are advantages to state/county funded services since they can be made available to a broader group of participants, can cover services not funded by Medicaid (e.g. housing and rental assistance), and can be more flexibly administered. However, the level of discretion in the availability of such services and supports potentially creates a lack of standardization of eligibility determination protocols across the many county jurisdictions.

Workgroup consensus Recommendations for Eligibility determination

1. There should be a standardized assessment tool for the measurement of the support needs of people with intellectual/developmental disabilities services for planning purposes as well as for resource allocation. One tool that should be explored is the Supports Intensity Scale (SIS), which is a valid, reliable and normed instrument that assesses an individual's strengths as well as his/her needs for supports. Developed by the American Association on Intellectual and Developmental Disabilities (AAIDD), this tool is being used in several states around the country to determine appropriate funding levels and/or individualized budgets. At the direction of the Legislature, DHS should explore the implementation of this assessment and its use for resource allocation. Given the need for a group of trained interviewers to conduct the SIS, the Legislature should consider vesting the administration of the SIS with the newly created regions.
2. Standardize the eligibility process so that tools and processes for determining eligibility are streamlined (free of redundancy and simplified) and consistently implemented across the state.
3. Over the next year, the State should explore and plan for the expansion within the Intellectual Disability waiver of current eligibility requirements to include individuals with a developmental disability.
4. The State should also consider consolidating waivers with overlapping target groups including the Ill and Handicapped waiver, the Brain Injury waiver, Physical Disability waiver, and the Intellectual Disability waiver. In order to accomplish this, it will be necessary for DHS to determine: how many of the individuals with developmental disabilities being served with county funds would meet waiver level of care; what services and supports they would require; what the potential cost would be; and what services are being provided by the county that are not included in waivers. The Legislature should ensure that DHS staff has the information they need (i.e., an accurate count of individuals with developmental disabilities currently served at the county level).
5. With respect to the consolidation of waivers, it will be necessary for DHS at the direction of the Legislature, to analyze the current service arrays in the four aforementioned waivers, the

utilization and costs associated with each waiver, and the level of care requirements in order to determine the feasibility of combining two or more of the waivers. Iowa currently has waivers that mix populations and eligibility thresholds. It should be noted that the Centers for Medicare and Medicaid Services (CMS) is currently receiving comments on a new rule that would allow states to develop cross population waivers.

6. In order to determine who would meet the “developmental disabilities” eligibility requirement, the State should develop criteria that include clinical/diagnostic as well as functional status. With respect to clinical/diagnostic requirements, at a minimum, they should include cerebral palsy, epilepsy and autism spectrum disorders. Functional characteristics can be derived from the current federal definition or could be aligned with a standardized functional/support needs tool.
7. In order to continue the progress made as part of Money Follows the Person in moving individuals out of the resource centers as well as out of private ICFs/MR, it will be necessary to examine what has worked and what has not worked to ensure the sustainability of community placements. Specifically, there needs to be increased concentration on the expansion of crisis services for individuals with multi-occurring conditions, medical issues and behavior challenges. This should include early prevention of behavioral crises through the use of applied behavior analysis and positive behavior supports. In addition to availability of crisis services, the State should consider ways to increase provider capacity and competency and develop outcome measures/incentives that promote community placement and retention.

C. Core Services

Trends and Best Practice in Core Services

Core services are those considered most essential and effective to improving the lives of individuals with ID-DD and their families. Over time, what constitutes best practice in core services has changed, just as measuring performance has changed, and how and where we deliver services has changed. Expectations for services now focus on being individualized, person centered and aimed at achieving and maintaining integrated lives in the community.

The Olmstead Principles and Iowa’s Olmstead Plan offer guidance for system redesign pertinent to the introduction of best practice services not currently available in Iowa to individuals with ID-DD, as well as the spread of best practices not yet available on a statewide basis. The Plan also describes the need for a long-term plan to move to high priority, best practice services while minimizing dislocation of the current system in the short run. In keeping with the Olmstead Plan, best practice core services should include the following:

1. Service Coordination

Service Coordination, also known as case management, is typically the interface with the service system for the person receiving services. It is the service coordinator that meets with the person and helps him/her make informed decisions about services and supports. In the ID-DD system, the service coordinator acts as an independent advocate for the individual. In order to be independent, service coordinators should be free of conflicts of interest and where any bias may exist, to fully disclose that to the individual. In order to advocate for the person, the service coordinator has to have knowledge of disabilities, of the service system, and of state and local resources. In addition, the effective service coordinator assists with selection of qualified service providers and has the ability to navigate the system on behalf of the individual.

Service coordinators in most states are also responsible for facilitating the service planning process. Best practice dictates that this be a person-centered process resulting in a service plan that represents the individual's preferences and goals. Periodic monitoring of service delivery and the fit of services to needs is another role of the service coordinator.

With the advent of participant directed services, the service coordinator may need to assist the person as they direct their services. In some states this entails assisting the person to hire, train or even fire staff, or checking that financial responsibilities are fulfilled. And as people move from institutional placements to community settings, the experienced service coordinator fulfills a critical role, ensuring the transition is planned and implemented well.

2. Family Support

Family Support refers to services provided to help families keep a member with a disability at home. Often these services are viewed as "whatever it takes" to prevent a person from being placed outside the natural home. Services should allow families to make informed decisions, be sensitive to the needs of the entire family and be flexible enough to satisfy the unique needs of different families (Bradley, 1990).

Characteristics of family support include the following:

- Family driven: *Each family leads the decision-making process concerning the type and amount of support they receive.*
- Easy to use: *Families are not overwhelmed by paperwork and red tape.*
- Flexible: *Families can choose supports and services based on their individual needs and preferences.*

Family support services usually center on the types of services below:

- Respite – Respite is the short-term, temporary relief to those who are caring for family members. It is the service most often requested by family caregivers. Respite can be provided in the family home or in another location.
- Family to Family mentoring – Matches knowledgeable and more experienced families with those in need of assistance to offer guidance and support.
- Crisis prevention and support – Includes evaluation of possible risks and puts in place deterrents to prevent and ameliorate potential crisis situations. Should a crisis occur, on-site evaluation, intervention and training would be available in the community on 24-hour basis.
- Counseling services – Includes individual therapy, family therapy, support groups, coaching, and other therapeutic interventions to assist a family with understanding, coping and working through difficult situations and times.

3. Community Living

Community living for people with developmental disabilities is not only best practice, but a decade after the *Olmstead* decision, it is expected practice. Community living should be outcome driven, focused on ensuring the services provided result in progress and achievement of the goals for the person served. Community living services support the integration of people with developmental disabilities in their local communities. People with intellectual and developmental disabilities should be able to live, work and play in their local neighborhoods and communities. These services should emphasize the unique characteristics of each individual and include options for self-direction.

4. Employment Services

The vision for employment services should be well articulated and focused on a Work First policy that expects that people with developmental disabilities will earn wages at or above minimum wage and will include benefits commensurate with employees without disabilities. Employment services focused on this goal should include the following services:

- Job Development that identifies steps to assist the person to achieve integrated employment.
- Prevocational services that are time-limited and not an end point in themselves. The service is focused on activities that lead to competitive employment and include volunteer and other unpaid activities.
- Supported Employment to assist the person with a developmental disability once they have a job. The service can be provided in both an individual and group setting.

5. Health and Primary Care

People with developmental disabilities experience more difficulty accessing basic health and primary care services than the general population. This occurs even with coverage through the Medicaid program available to most adults with intellectual and developmental disabilities. In 2011, a University of New Hampshire report found that 40% of people with disabilities report their health as fair or poor compared to 23% general population.

Best practice health and primary care services should be available in local communities and provide the following basic services:

- Effective diagnostic and clinical evaluation services
- Access to general health screenings and primary care
- Care Coordination
- Behavior Support services
- Psychiatric and Counseling services
- Therapies – Occupational Therapy, Physical Therapy, Speech-Language Pathology
- Medication management and self-administration training programs
- Dental services

Access to health and primary care services is especially important considering that the highest proportion of sedentary people is those with disabilities (37%). Inactivity is strongly linked to obesity and 38% of people with disabilities are obese.⁴ National data collected through the National Core Indicators (NCI) project further shows a link between level of ID and obesity. NCI national data also shows high use of psychotropic medication. Fifty-one point three percent of people take medications for mood disorders, anxiety, behavior problems, or psychotic disorders. The use of psychotropic medications is strongly linked to obesity and health problems when used long term. Access to health and primary care practitioners can help address these challenges for people with intellectual and developmental disabilities.

6. Crisis Intervention and Prevention

Effective crisis intervention and prevention services ensure that people with intellectual and developmental disabilities are fully supported in their communities. This is especially important for people with ID and mental health or substance abuse issues. Best practice dictates that crisis intervention and prevention services be provided in the community, where the person lives. They must be responsive and available for family and community agencies on a 24-hour basis. With the number of adults with ID-DD who live with their families increasing, it is important that

⁴ *Health Disparities Chart Book on Disability and Racial and Ethnic Status in the United States*. Institute on Disability, University of New Hampshire. August 2011.

crisis services be available to people with ID-DD regardless of the type of setting – family home, independent apartment or provider operated home.

The most important aspect of crisis services is prevention. Crisis service models that include training for direct support staff, family care givers and provider agencies effectively increase the capacity of communities to meet the needs of people with dual diagnosis. When crisis intervention is needed, it is important that the service model be based on Positive Behavioral Supports and only remove the person from their current living environment if they present a risk of harm to themselves or others.

Workgroup Consensus Recommendations for Core Services

Participants in the core services discussion acknowledged the importance of the *Olmstead* principles that were developed by stakeholders all over Iowa as a guide to the future development of services and supports for people with intellectual and developmental disabilities in the state. While understanding that these principles were not fully realized in the current service system, there was support for continuing to press the system to meet those aspirations related to service provision, including:⁵

- Each adult and child has timely access to the full spectrum of supports and services needed.
- Communities offer a comprehensive, integrated and consistent array of services and supports that are individualized and flexible.
- State and local policies and programs align to support the legislative vision of resiliency and recovery for Iowans with mental illness, and the ability of Iowans with disabilities to live, learn, work, and recreate in communities of their choice.
- Communities recognize and respect the ability of people (1) to make informed choices about their personal goals, about the activities that will make their lives meaningful and about the amounts and types of services to be received; and (2) to understand the consequences and accept responsibility for those choices.

The steps necessary to move the system to a place where the services and supports offered to people with intellectual and developmental disabilities meet these goals will take time, creativity and the collaboration of all stakeholders. Movement toward these ends should be thoughtful and deliberate keeping the interests of people with intellectual and developmental disabilities at the forefront. No one benefits from precipitous change.

For that reason, the group agreed that the current array of residential, day and vocational, and other ancillary services – including those supported through waivers, and offered on a statewide basis through either county or state funding –should be considered “core”. There were earnest concerns that if a particular service was not included (e.g., sheltered workshops, residential treatment facilities, etc.) that

⁵ These are principles excerpted from the *Olmstead State Plan Framework*, <http://iowamhdsplan.org/>

– in these difficult budget times – those services might be discontinued leading to disruption in the lives of the clients as well as challenges for providers. A list of services currently available in the State of Iowa through Home and Community Based Waivers as well those currently supported with county and state funding is included as Appendix A to this report.

Therefore, with the above caveats, the group agreed that further expansion of core services should be premised on the principle of “community first” with a priority placed on the goals and outcomes established in Iowa’s Olmstead Plan. It is recommended that services that expand and support community integration should be encouraged and enhanced (i.e., supported community living, self-direction, transition services, supported employment, etc.). Further, the state should explore, identify and eliminate the barriers currently experienced in Iowa that prevent achievement of *Olmstead*.

Additional recommendations are noted below.

Case Management Recommendations

Iowa should explore a transition to a case management system that is conflict-free. Specifically, conflict free case management means that the function is divorced from the direct provision of service in order to ensure that individuals and families are given adequate choice among a range of available providers. Conflict-free has recently been defined at the federal level as meeting criteria laid out in the CMS State Balancing Incentive Payments Program Letter to Medicaid Directors and Application. Appendix B contains an excerpt from the Application of criteria for conflict-free case management.⁶ The Workgroup discussed the importance of reasonable capacity requirements for case managers. There was a consensus on the functions that case management entails:

- Assisting persons in gathering information and applying for eligibility determination and annual level of care redetermination;
- Independent assessment of a persons’ support needs⁷;
- Identification of risk and planning to mitigate risk;
- Consumer directed service planning;
- Ongoing monitoring of service delivery; and
- Assistance in navigating access to both local and state supports and resources, including referrals to service providers.

⁶State Balancing Incentive Payments Program Letter, see pages 11-12. <https://www.cms.gov/smdl/downloads/Final-BIPP-Application.pdf>

⁷ Assessment will need to be fully independent from other case management functions if the state moves to a resource allocation model (i.e. if the assessment is connected to the funding amount a person receives).

Additional Core Services Recommendations

The workgroup also discussed adding new services and supports – many of which reflect a growing concern to address the needs of people with co-occurring ID/Mental Illness diagnoses. Therefore the group recommended exploring the inclusion of the following services on a statewide basis to individuals with intellectual and developmental disabilities. Exploration should include an analysis of resources and funding, as well as the potential impact of the expansion of Medicaid eligibility once the federal Patient Protection and Affordable Care Act becomes fully operational. Adequate funding must be made available for the addition of any new services, including:

- Crisis Prevention and Intervention⁸;
- Behavioral Intervention, and Positive Behavior Support Services⁹;
- Mental Health Outreach¹⁰;
- Services focused on treatment of co-occurring disabilities, both mental illness and substance abuse;
- Speech, Occupational and Physical Therapies needed for habilitation and therefore beyond the scope of rehabilitative criteria in the State Plan;
- Housing supports – people with intellectual and developmental disabilities need safe, decent, affordable, and accessible housing and the state should expand supports to help people find housing¹¹;
- Tele-health resources;
- Peer to Peer support for self advocates; and
- Guardianship services provided through a public guardian or similar entity with due process protections for individual.

Expansion of Services Available through Home and Community Based Waiver Services

Other services, not included in the current ID waiver, are available through the other six HCBS waivers. The Workgroup discussed that with the expansion of the ID waiver to DD, some of the services from other waivers may be appropriate for inclusion as services for people with intellectual and developmental disabilities as well, for example, assistive technology.

8 IME is drafting regulations to add this as a service to the waiver based on the IPART model.

9 IME is drafting regulations on this service as well.

10 IME is drafting regulations to add it to the current waiver.

11 Models for expanding housing exist in the state. For example, Polk County owns and leases out housing using county dollars; Iowa Finance Authority program offers housing support.

D. Outcome Assessment and Performance Measures

Trends and Best Practices in Outcome Assessment and Performance Measurement

All stakeholders care about the quality of services. What changes over time is what constitutes the minimum standards for a quality service and how we measure whether these standards are being achieved. In the past, ID-DD service systems valued and measured the quality of services using prescriptive licensing and treatment standards. We focused on process rather than outcomes. Thus criteria by which quality was evaluated were more concerned with fire and safety code compliance, and less about whether a person was supported in the most integrated service setting. DHS does conduct consumer surveys on a regular basis. However, these consumer surveys and interviews are not currently used as a specific component of the provider approval process. People receiving services were not extensively engaged in evaluating quality, and outcomes desired by people with disabilities were not given the priority that their expectations are afforded evaluating quality today.

Pressure for change in the way we measure quality has come from many directions. We have an increasingly complex service system. No longer are services delivered in one or two locations; now services to people with ID-DD are more individualized. A person receiving services may be married and living independently with support staff that come to the apartment, with transportation that carries the individual to a part-time job, then to the YMCA for exercise, to a dentist appointment, then to a Human Rights Committee meeting on which the person serves as a client representative. This degree of individualization requires sophistication to evaluate how it is working. Fortunately, more useful technology is also evolving and can offer aid to public service managers and service providers with collecting and analyzing data about the quality of services.

A parallel trend is demand for accountability for results for the investment of public funds. Accountability has also been paired with an increasing demand for transparency. Performance information is now posted online in many states, for example Massachusetts and Tennessee report on their websites the results of service providers' quality reviews. The federal government posts for the public information about the quality of care of nursing homes funded through Medicare (<http://www.medicare.gov/NHCompare>). The State of Iowa too has demonstrated transparency in some areas. On the State's home page is an invitation to review the results of quality reviews for restaurants. People are invited to "View your favorite restaurant's inspection report," (<http://www.iowa.gov/>) but this transparency is not yet in place for people making choices about providers of ID-DD services.

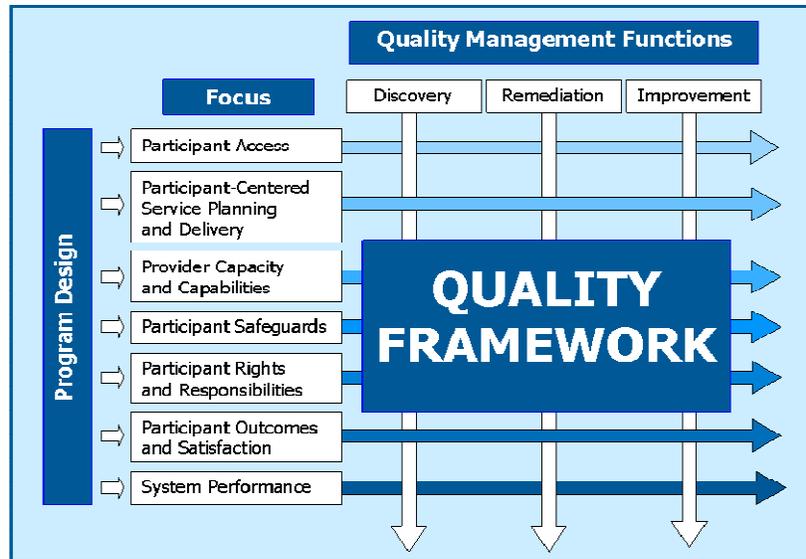
It is a cliché that "what gets measured gets done". What we measure should be what we value. The ID-DD field has traditionally measured processes and the outputs related to quality (e.g., whether a background check policy is in place for new hires, whether a person has an annual service plan review). What is more challenging is measuring the outcomes of providing a service or support, the impact of assistance in a person's life. How we measure performance should mirror our values:

- Person-centered, individually crafted
- Self-direction and self-determination
- Freedom from harm and abuse – health, welfare and safety issues
- Independence and productivity – working, earning money
- Inclusion and community participation
- Family support

A strong influence on performance measurement in the past 10 years in the ID-DD service system was the change in expectations of the federal Centers for Medicare and Medicaid Services (CMS) regarding 1915(c) Waivers. The changes in federal oversight were a consequence of a report by the GAO (U.S. Government Accountability Office) in 2003. The GAO report was highly critical of the level and consistency of CMS monitoring and recommended a more comprehensive approach. As a result, CMS revised its oversight of waiver programs and shifted away from a point in time site visit evaluating the waiver program to requiring states submit periodic reports with evidence of performance. The evidence required is based on six Assurances, i.e., guarantees that states make for use of public funds to operate HCBS waiver programs. The six Assurances and their component sub-Assurances are the measurement of achievement of outcomes of provision of waiver services. Although the Assurances and sub-Assurances are set by CMS, states determine exactly how they will measure and report their performance to CMS. The Assurances are:

- Eligibility (level of care) is determined in a valid, reliable, and equitable manner;
- Individual plans include services and supports that align with the individual’s goals, strengths, and needs;
- Provider qualifications are regularly checked and monitored;
- Individual health and well being is maintained;
- Financial accountability is maintained; and
- The Medicaid agency maintains administrative authority.

A parallel initiative of CMS to offer states additional guidance on measuring quality is CMS’ HCBS Quality Framework. For over a decade, this Framework has been a mechanism for states to think about and organize their quality assurance processes.



By using the Quality Framework, states can be prompted to consider:

- Do people have access?
- Is service planning and delivery person-centered?
- Do providers have the capacity and capabilities to meet the need?
- Are safeguards in place to protect people?
- Do people know their rights and responsibilities?
- Are people achieving the outcomes they desire?
- Are they satisfied with the services and supports they receive?
- Is the system performing as it should?

Pressure for change that focuses on outcomes has also come from the U.S. Department of Justice's (DOJ) renewed activity to enforce state compliance with the Supreme Court's decision in *Olmstead v. L.C.*, the 1999 legal decision upholding the Americans with Disabilities Act integration mandate. The *Olmstead* decision affirms that under Title II of the Americans with Disabilities Act, "States are required to place persons with mental disabilities in community settings rather than in institutions when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities."¹² Because of many states' lackluster efforts to provide individuals with disabilities opportunities to live their lives as individuals without disabilities live, in 2009, the 10th anniversary year of the *Olmstead* decision, President Obama launched "The Year of Community Living" and directed federal agencies to vigorously enforce the civil rights of Americans with disabilities.

¹²Cornell University Law School posting of *Olmstead v L.C.* Supreme Court decision. <http://www.law.cornell.edu/supct/html/98-536.ZS.html>

In response, the DOJ increased its oversight of state activity to achieve integrated services and published, in June 2011, a Technical Guide for states on how to demonstrate progress.¹³

Iowa responded to this call for heightened compliance with *Olmstead* and committed to a comprehensive process of crafting a five year compliance plan, the DHS *Olmstead* Plan for Mental Health and Disability Services (<http://lowaMHDSPlan.org>). Iowa's *Olmstead* Plan is the result of hard work from hundreds of stakeholders representing diverse constituencies.

Best Practice in Outcome Measurement

Once the desired and targeted outcomes of services are established, the next step is determining the methods for evaluating whether, and to what extent, the outcomes are present for individuals and families served. States collect, aggregate and analyze quantitative/qualitative data from a variety of data sources to identify areas of strong performance and areas for improvement. Evidence is analyzed and information is used to remediate and improve services and supports. Typical sources of performance information for states, many of which are in place in Iowa, include the following:

- Service coordination monitoring – Some Targeted Case Managers in Iowa conduct monitoring reviews and collect outcome data
- Record reviews – Present in Iowa
- Risk assessment results - Present in Iowa
- Satisfaction surveys - Iowa Participant Experience Survey (IPES/DD) for individuals living in the community; Iowa does not collect consumer survey information from those residing in ICFs/MR
- Provider certification reviews – Iowa utilizes a quality review of provider services
- Waiver audits – Present in Iowa
- Incident management data – Present in Iowa
- Complaint data – Present in Iowa
- Paid claims and financial audits - Present in Iowa
- Mortality review- Present in Iowa

All of these data sources can be robust sources of evidence of performance. With data, states can conduct useful analyses. Comparative analyses can be useful to focus attention on differences, identify areas needing further review and analysis, or target analysis to region, type of provider or service, living arrangement, population, etc. Data can be evaluated to identify trends, both positive and negative, and for benchmarking progress from quality improvement efforts. With the right data, training needs can be identified. Data can also provide information to state managers making decisions on how to allocate resources. HSRI prepared a comparison table of the Workgroup's recommended Outcomes and potential data sources that could be useful for evaluating performance and presenting evidence of performance to CMS.

¹³Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.*, June 2011. http://www.ada.gov/olmstead/q&a_olmstead.htm

The table below illustrates how typical data sources for ID-DD state managers can be used to present evidence of performance.

Methods of Discovery	Evidence
Incident reporting system	Analysis of serious incidents by type of residential arrangement, age, level of disability, etc.
Service coordination monitoring	Percent of individuals receiving all services and supports in their service plan.
Consumer Satisfaction Survey	Proportion of people reporting that they feel safe in their communities.
Complaint reports	Numbers of complaints by specific issue (e.g., privacy concerns, transportation constraints, etc.).

A systemic approach to performance and outcome measurement created for state directors of ID-DD service systems is National Core Indicators (known as NCI). NCI was developed and is managed by the National Association of State Directors of Developmental Disability Services (NASDDDS) and the Human Services Research Institute (HSRI). Participating states pool their resources and knowledge to create and refine performance monitoring systems, identify common performance indicators, work out comparable data collection strategies, and share results. Many state agencies use NCI as a key component within their quality management systems to benchmark their state’s performance and to compare their state performance to that of other participating states. Other states, like Iowa, use the Participant Experience Survey (PES) to measure outcomes. The PES was developed with funding from the Centers for Medicare and Medicaid Services.

A challenge for state managers is standardizing, aggregating, analyzing, and reporting data. Those state ID-DD agencies that have overcome these challenges are able to use data to track incidents, causes of death, quality of individual plans and accomplishment of outcomes – and are able to apply these findings to system improvement initiatives. Finally, states have opened up avenues for the interpretation of performance data by including self advocates and family members in the conversation.

WORKGROUP CONSENSUS RECOMMENDATIONS FOR OUTCOME MEASUREMENT

1. Measurement and monitoring of the performance of services and supports should be premised to a significant degree on the achievement of positive outcomes for individuals and families.¹⁴ Current monitoring processes should be reviewed to ensure that what is being measured is consistent with these outcomes.

¹⁴ These are included in the list of global outcomes included in Chapter III of this report.

2. Data regarding the performance of providers, regions as well as the state ID-DD system should be aggregated and reported and made public to stakeholders across the state. This should include information from the Iowa Participant Experience Survey, case management profiles, provider reviews, and incident management systems. This recommendation recognizes that the discovery processes noted do not necessarily cover all individuals with ID-DD in all settings but DHS should begin to work with the data that it currently has and plan for the expansion of performance data over the next few years. This work should be done in conjunction with the development of regional quality assurance functions. DHS should be allocated staff resources to build and maintain this capability.
3. DHS should also be allocated staff resources to review and analyze data across systems (Department of Inspections and Appeals, county, school, and DHS), identify trends and develop quality improvement strategies. DHS should develop a quality improvement committee that looks at data across discovery processes to develop a holistic view of the performance of the system. This same capacity should be developed at the regional level.
4. In collaboration with the provider association, DHS should work to develop more standardized and consistent family and individual satisfaction surveys that are based on those surveys currently being circulated by individual providers. A standardized satisfaction survey should be based on the consolidated quality of life measures developed by the redesign workgroups.

E. Provider Qualifications and Monitoring

Trends and Best Practice in Provider Qualification and Monitoring

Over the past few decades, the approaches to monitoring the quality of services have shifted. Until recently, monitoring was conducted with a primary focus on a physical facility and health and safety code compliance. Today, focus has expanded to include individual outcomes, the presence of individualized services, and satisfaction with services.

- Monitoring requirements are also driven by a range of factors that have influenced the way that services and supports are provided. Enhanced accountability is commensurate with significant public investment in ID-DD services.
- The *Olmstead* decision and subsequent pressure on states to move individuals to least restrictive more person centered settings in the community.
- Attention to recruitment and training of direct support professionals.
- Expansion of supports to individuals on a waiting list and waiting list lawsuits.
- Emergence of individualized services that may be directed by the individual and/or family, e.g., participant-directed services.
- Involvement of stakeholders to monitor services, formally and informally.
- Increased reliance on the generation of data regarding performance.
- Increased importance of case management.
- Pressures for accountability and transparency.

- Increased requirements by the Centers for Medicare and Medicaid Services (CMS) for quality improvement strategies in waiver management.
- With respect to Home and Community Based Services (HCBS), CMS has set higher expectations for monitoring and the use of information for quality improvement. States now must analyze information, identify trends and put in place quality improvement strategies for areas of weaker performance. States have the primary responsibility for monitoring, responsibility that lies with the Medicaid agency, and evidence of the state’s monitoring for HCBS is meeting waiver Assurances. CMS ensures the state is sufficiently monitoring the program and is in compliance with Assurances. HCBS Assurances are organized into six domains (noted below), each with sub-Assurances: Eligibility (level of care) is determined in a valid, reliable, and equitable manner.
- Individual plans include services and supports that align with the individual’s goals, strengths, and needs.
- Provider qualifications are regularly checked and monitored.
- Individual health and well being is maintained.
- Financial accountability is maintained.
- The Medicaid agency maintains administrative authority.

The CMS approach to oversight, reflected in these Assurances, is to move away from a monitoring visit at a point in time to review of the state’s evidence (data) on how it is meeting the Assurances over time. CMS’ review of periodic reports from the state assesses how effectively the state is monitoring its own performance and addressing the issues identified. The DHS *Olmstead* plan system principles include shared responsibility—accountability and results for providers and responsibility and accountability for government.

Provider Qualification

Provider qualifications are requirements for providers of service that help the state perform its important role of “gate keeper”. As gatekeeper, the State opens the door for willing and qualified providers and holds those providers that do not yet meet the requirements from providing services until requirements are met. States play a balancing act as gatekeeper. If requirements are set too low, then providers that do not have wherewithal to sustain services can be approved and fail, which negatively impacts individuals and families. Moreover the state may have expended significant resources providing technical assistance and monitoring of the new provider prior to failure. On the other hand, if requirements are too high, then desired new providers, such as those proposing to serve an unserved area or provide a specialized or culturally competent service, may be inhibited from going into business.

In order to pass through the initial screen, states typically require a provider to show a business license, a qualified CEO and leadership staff, financial capacity to operate for a given amount of time, a Medicaid provider number, and policies and procedures in place that meet state and federal requirements. States can set different qualifications for different services. Core qualifications can be set for all providers, enhanced by specific qualifications for each service type. Additionally, Medicaid and the operating agency can have different expectations, though expectations should work in tandem.

CMS has not promulgated minimum provider qualifications for waiver services so states have latitude in establishing qualifications. What CMS does specify is that states describe their method for establishing qualifications and ensuring compliance. Provider Qualification sub-Assurances are found in the CMS HCBS Waiver Application and noted below:

- The State verifies that providers initially and continually meet required licensure and/or certification standards and adhere to other standards prior to their furnishing waiver services.
- The State monitors non-licensed/non-certified providers to assure adherence to waiver requirements.
- The State implements its policies and procedures for verifying that provider training is conducted in accordance with state requirements and the approved waiver.
- For each type of individual or agency provider identified the state must specify the provider qualifications.
- The waiver application provides for three types of provider qualifications:
 - A license issued under the authority of state law.
 - A certificate issued by a state agency or other recognized body, i.e., a recognized accreditation organization.
 - Other standards specified by the state; may be in addition to a required license or certificate and must be specified.
- Like other Medicaid services, waiver services are subject to any relevant requirements contained in state law. Provider qualifications must be reasonable and appropriate in light of the nature of the service. They must reflect sufficient training, experience and education to ensure that individuals will receive services from qualified persons in a safe and effective manner.

Provider Monitoring / Quality Assurance

Provider monitoring is a review process or processes used to determine the extent to which a provider meets federal and state requirements and contract provisions. The bottom line is that a provider is as good as the expectation to which it is held. State statute, regulation and policies form the foundation by which a provider's performance is measured. Monitoring activities are the best way of determining which providers demonstrate excellence, which demonstrate uneven performance and could benefit from technical assistance and those that need sanctioning (e.g., fine, increase oversight or remove). States need clear authority (free of political influence) to monitor and sanction poor providers.

Monitoring can take many forms including review of financial records and billing, maintaining staffing ratios, review of staff training compliance, observation of a service site, interviewing people receiving services and their families, interviewing staff, reviewing provider records, and reviewing critical incident and complaint data. It is considered best practice for states to use more than one form of provider monitoring. In the past, states relied primarily on only one or two monitoring processes, such as licensing and reviews of Medicaid expenditures. Now states utilize multiple data sources to track performance: licensing, state QA monitoring, national accreditation, provider reporting of QI initiatives, incident management, financial oversight, complaints, satisfaction surveys, etc. With multiple sources

of performance data, it is important to ensure that the oversight entity is reviewing data across the data sources to evaluate provider performance and identify systemic problems.

Monitoring information is vital for presenting evidence to CMS of compliance with waivers. States collect data for evidence reports on the following outcomes and all evidence derives from some level of oversight/monitoring activity:

- Assessments are accurate, complete and timely
- Health and safety risks are identified and mitigated
- Individuals participate in service planning
- The Plan of Care (service plan) has strategies to meet participant needs and preferences
- Plans of Care and services are up to date and timely
- Participants are protected in the event of an emergency
- Participants have choice
- Participants' needs are met
- Participants are safe and free of abuse, neglect and exploitation
- Provider agencies have qualified and competent staff
- Management structures support effective and efficient operations
- Data management systems produce timely and useful information
- Services and outcomes are continually improved

National accreditation is another source of information about the quality of a provider's service and is a qualification requirement for some providers in Iowa. In 2008, the Human Services Research Institute (HSRI) conducted a survey of state practices regarding national accreditation of community service providers for Missouri's DMRDD¹⁵. Of the 46 states that responded, 32 states neither encourage nor require providers have national accreditation. The main finding from the review was that state managers view accreditation as an adjunct quality assurance process that complements, but does not replace, state quality monitoring. Reasons cited included national accreditation surveys are infrequent, do not (without explicit contracting between state and accreditation agency) provide for communication with state on provider performance, nor measure state-specific requirements.

As CMS strongly encourages states to make participant direction a central feature of all waivers, monitoring the services of an independent provider is now an important consideration. National Quality Enterprise staff prepared a monograph for state managers on monitoring independent providers. Recommendations include the following¹⁶:

- Individual providers should meet universal, essential basic qualifications.
- Individual providers should have the training to effectively support the person including person-specific knowledge (i.e., service plan).
- Mechanisms should be in place to track at individual and system levels:

¹⁵ <http://www.hsri.org/publication/national-accreditation-of-community-service-providers/>

¹⁶ http://www2.ancor.org/issues/medicaid/04-15-08_Guide_to_Employing_Individual_Providers_Under_Participant_Direction.pdf

- services are delivered according to plan (can use billing data);
- back up plans are in place for when scheduled staff are unavailable; and
- person receives services free of abuse, neglect, or exploitation.
- Information about individual providers is readily to individuals and families in order to make informed choices in providers.

Another benefit of monitoring is for system wide evaluation of performance such as the quality of providers of crisis services statewide, or compliance with up to date plans of care by case managers. CMS HCBS Assurances require states have mechanisms in place, and provide evidence of, ongoing system performance evaluation and improvement.

Workgroup Consensus Recommendations for Provider Qualifications and Monitoring

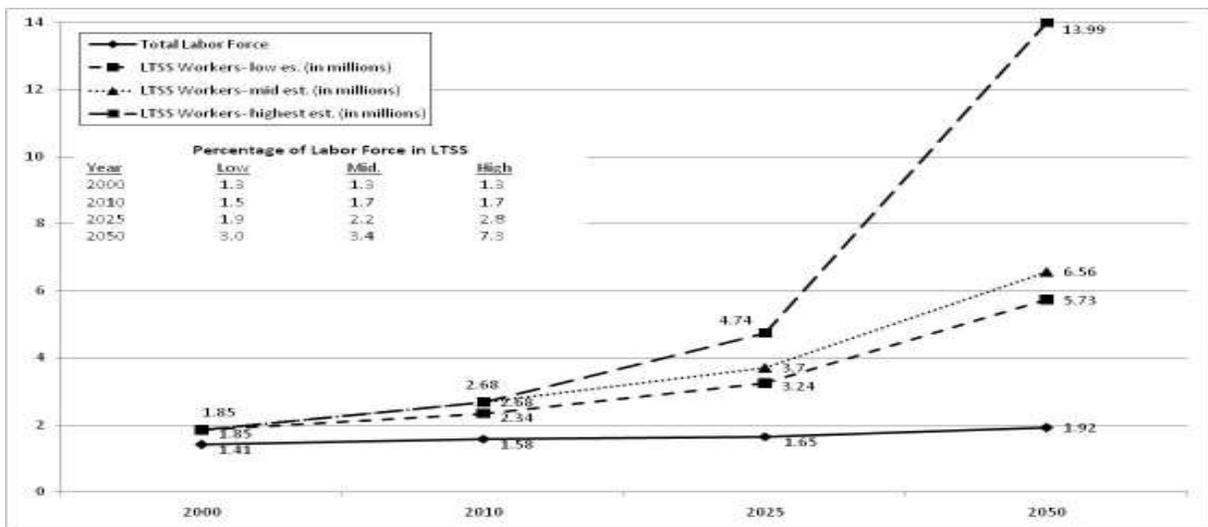
1. In the development of quality monitoring efforts, consider the costs to providers in responding to such efforts.
2. Develop uniform, streamlined and statewide cost reporting standards and instruments, inclusive of current cost reporting tools.
3. Make quality monitoring information easily available and understandable to all citizens. Information should be posted to a website in people first language. Information about providers should include who is providing which service in which geographic areas, and the quality of services.
4. Establish regulations that are clearly understood and are accompanied by interpretive guidelines to support consistent understanding by those responsible for applying the regulation.
5. Develop a partnership with providers in order to improve the quality of services. Develop mechanisms for the provision of technical assistance (TA). TA mechanisms can include peer to peer provider support and provider mentoring and/or state staff or contracted quality assurance entities. Discussion of enhancing the state's technical assistance capacity is underway now with IME. To further expand technical assistance, the state should look for funding sources and opportunities for technical assistance in general and technical assistance as part of quality improvement strategies.
6. The state should develop consistent data collection efforts based on statewide standards and should ensure that feedback regarding the analysis of data submitted is made available to providers. Providers are interested in a report card with which to compare their performance, at a point in time as well as over time, among providers providing the same service. Consistent information technology (IT) requirements would be useful for uniform data collection. Sufficient resources should be available at the state and regional levels to collect, analyze and share data so that it can be used for quality improvement efforts and for identifying areas for technical assistance.
7. The state should evaluate current provider qualification and monitoring efforts to:
 - a. Identify duplication;
 - b. Identify gaps; and
 - c. Align with valued outcomes.
8. Based on this analysis, current standards should be streamlined and enhanced.

9. Given the current inclusion of accreditation as a foundation for provider approval, the state should consider where this aspect of performance measurement fits in the certification of provider qualifications. An overview should assess the role of accreditation in:
 - a. Assuring minimum provider characteristics as a gate keeping function;
 - b. Ongoing quality management; and
 - c. Additional data point regarding quality of services.

F. Supporting and Maintaining a Competent and Committed Workforce

Best Practices in Supporting and Maintaining a Competent and Committed Workforce

As more and more people with ID-DD are supported in community settings, the roles of Direct Support Professionals (DSP) are changing. The DSP supporting individuals in a community setting needs to provide supports individualized to each person, rather than the same thing for everyone that was the practice in institutional care. Community settings also mean that DSPs are more isolated from a more formal chain of command and must rely more on their own knowledge and skills to problem solve various situations. And with provision of care and support, the DSPs of today must also provide skilled support (e.g., crisis management, behavior intervention, etc.). They must help people they support integrate into their communities, and while they are providing care, DSPs must also document the support they provide and a person's response.



The expectations rise and shortages of sufficient and qualified workers is a national problem. Salary, benefits and career paths for DSPs have not kept abreast of the increased performance expectations. Turnover is high. The statewide average nationally is around 50% and higher in residential and in home positions than in day services. And turnover is expensive. The average cost of a new hire is about \$2,800 - \$3,500. DSP supervisors spend an average of 18% of their time with new or “exiting” employees when turnover is 50% (Larson, 2007).

Staff are more likely to stay if:	Staff are more likely to leave if:
<ul style="list-style-type: none"> • They hear about the job from someone inside the organization. 	<ul style="list-style-type: none"> • They have problems with co-workers.
<ul style="list-style-type: none"> • They receive a realistic preview of the job and the people who they will be supporting. 	<ul style="list-style-type: none"> • They receive inadequate pay or benefits.
<ul style="list-style-type: none"> • They feel they are valued and treated fairly by supervisor. 	<ul style="list-style-type: none"> • They have problems with supervisors.
<ul style="list-style-type: none"> • They are involved in care plan meetings. 	

Larson, Lakin, Bruininks, 1998

Best practice entails implementing practices known to retaining caring support workers. Nationally, lobbying continues to raise the floor of wages and benefits for DSPs. As the Wyoming 2002 study showed, wages do matter in retention of DSPs. Initiatives to promote a professional identity for the skill set of DSPs via voluntary credentialing also have been shown to improve retention and DSP satisfaction. Voluntary credentialing initiatives have been launched by states (Illinois, Kansas and Ohio) and nationally, since 1996, through the National Association of Direct Support Professionals (NADSP).

The National Alliance for Direct Support Professionals (NADSP) offers DSPs the opportunity to earn a national credential as part of a nationally recognized career path. Voluntary credentialing through NADSP is based on nationally validated competencies (knowledge, skills and attitudes) called the Community Support Skill Standards, the NADSP Code of Ethics and DSP Professionalism. Credentialing is affordable, flexible, portable, and nationally recognized (<http://www.nadsp.org>).

The College of Direct Support (CDS) offers online training for DSPs and supervisors. CDS is a web-based learning management system available 24 hours a day, seven days a week for learners to improve their skills in providing supports for people with disabilities. Over 30 states have utilized CDS and Iowa has a pilot underway. CDS competency-based coursework includes: community inclusion, person-centered planning, positive behavioral supports, civil rights & advocacy, cultural competence, direct support professionalism (ethics), employment supports, functional assessment, medication support, person centered planning, safety, healthy lives, and other essential topics. The learning management system

allows supervisors to track a DSP's progress through their assigned course of study and record the successful application of knowledge and skills on the job (<http://info.collegeofdirectsupport.com>).

Workgroup Consensus Recommendations for a Competent and Committed Workforce

1. As part of Money Follows the Person, Iowa has made the College of Direct Support available to any provider planning on serving people coming out of the Resource Centers or other ICFs/MR. Currently, 44 providers are participating. Based on the positive outcomes, the state should make the College of Direct Support available for free to all ID-DD providers in the state. In order to implement the statewide curriculum, there would need to be three types of administrators: the state administrator as primary point of contact for learning management system issues; regional administrators who would likely want to monitor local providers' utilization; as well as administrators at the individual provider level who would assign modules to staff members and review their progress.
2. The State should require that every direct support professional (DSP) demonstrate a level of competency in the core curricula (e.g., 80%). Additional modules should be made available for supervisors and DSPs responsible for specialized support (e.g., medical support, behavioral support, etc.).
3. The State should provide financial incentives for those providers that support staff to secure a voluntary certification from the National Alliance of Direct Support.
4. In order to support the costs involved in training staff, the current rate reimbursement formula should be changed to allow providers to bill such costs as a direct expense rather than an indirect cost.
5. Each region should have staff available to provide positive behavior supports training and to mount crisis intervention and prevention response modeled on the IPART initiative.
6. Technical assistance – including peer to peer consultation – should be available to providers for such issues as crisis intervention, workshop conversion, etc.
7. There needs to be cross training for mental health professionals regarding the needs of people with co-occurring disabilities. There should also be training for primary care practitioners regarding the appropriate response to behavioral issues among people with ID-DD.

V. REPORT OF THE ADULT MENTAL HEALTH WORKGROUP

A. Introduction

The Mental Health Workgroup met five times between August and October. A sub-committee met one time to discuss standardized level of functioning assessments and reported back to the full Workgroup at the October 4 meeting.

As required by Senate File 525, the Workgroup discussed a range of topics including eligibility, outcomes and performance measures, Core Services, and workforce development issues necessary to deliver a system of comprehensive, evidence-based services to lowans. Added consideration was given to additional content areas such as multi-occurring conditions, older adults, cultural diversity and competence, and the need for Iowa to serve people in the most integrated settings possible (*Olmstead*).

This report summarizes the recommendations from the Mental Health Workgroup. Recommendations in this report were informed by comments made in the public comments session following each meeting. The Workgroup generally agreed on most issues, and the report notes areas where there was lack of consensus.

Within the context of these recommendations, the Workgroup offers two overarching issues critical to the success of the redesign process. First, mental illness is a leading cause of disability in this country. Upwards of 761,588 lowans (25% of the population) will have a diagnosable mental illness over the course of a year, and 182,781 (6% of the population) has a serious mental illness¹⁷. In addition, on average, people with mental illness die 25 years sooner than the general population largely attributed to co-morbid diabetes, hypertension and other medical conditions¹⁸. The prevalence of mental illness throughout the population and its significant socio-economic impact to individuals, government and private industry across sectors (e.g. healthcare, criminal justice, lost productivity) make it a key public health issue that this country faces. According to Iowa's 2010 National Outcomes Measures (NOMS) 2010 report, 96,430 individuals were served in Iowa's public adult and children's mental health system¹⁹.

While not all people with a mental illness need or will seek treatment, access to services is most typically reliant on the availability of services. Accordingly, the Workgroup premises its recommendations on the need to maintain, and, when possible, expand funding in order to ensure the success of this redesign process.

¹⁷ Based upon 2010 Census data and generally accepted prevalence rates.

¹⁸ National Association of State Mental Health Program Directors. (2006). *Morbidity and mortality in people with serious mental illness*.
http://www.nasmhpd.org/general_files/publications/med_directors_pubs/Mortality%20and%20Morbidity%20Final%20Report%208.18.08.pdf

¹⁹ <http://www.samhsa.gov/dataoutcomes/urs/2010/iowa.pdf>

Furthermore, this redesign process as conceptualized will only be partially complete until such time that there is alignment across all systems, including primary healthcare, so that people with mental illness can have access to coordinated mental health, substance use and primary care necessary to promote whole health, and that the private insurance industry is held accountable for ensuring access to a range of effective mental health services.

B. Multi-Occurring Conditions²⁰

The Workgroup discussed multi-occurring conditions in the context of Iowa's system and how best to build a multi-occurring capable system. The Workgroup presumes that multi-occurring conditions are part of each of the recommendations in this report, and encourages any action on these recommendations by the legislature, DHS or any other agency consider the effect on individuals with multi-occurring conditions.

In its discussion, the Workgroup utilized a position statement submitted by Drs. Kenneth Minkoff and Christie Cline²¹, nationally recognized experts in the field of multi-occurring conditions. The position statement defined multi-occurring disorders as:

“An individual with multi-occurring conditions is defined as any person of any age with ANY combination of any MH condition (including trauma) and/or developmental or cognitive disability (including Brain Injury) and/or any Substance abuse condition, including gambling and nicotine dependence, whether or not they have already been diagnosed.”

There was consensus that there must be active consideration of co-occurring and multi-occurring conditions across all functions of the system and within all services provided within core service domains. Accordingly, the Workgroup supported the following statement excerpted from the position paper:

“For individuals and families seeking services in Iowa, multi-occurring issues should be the expectation, not the exception. We need to design a system in the State in which all services are organized to welcome, inspire and provide integrated services to individuals and families

²⁰ The terms “co-occurring” and “dual diagnosis” often refer to individuals with two diagnoses such as a mental illness and substance use disorder or an intellectual disability and mental illness. The use of “multi-occurring” expands on this concept that a person may have two or more co-existing conditions that need to be addressed simultaneously, and that systems must develop the capability to serve and/or coordinate care for those with multi-occurring conditions.

²¹ Minkoff, Kenneth & Cline, Christie. (2011). *Assuring a system of care designed to serve individuals and families with multi-occurring conditions and disabilities, and other complex needs; A guide for universal implementation*. Prepared for the Iowa Mental Health and Disability Redesign. http://www.dhs.iowa.gov/docs/Co-occurringPositionStatementandGuidanceDocument_10-13-2011.pdf

with multi-occurring conditions and disabilities, and other complex needs. Therefore, we recommend that as part of addressing the elements of each workgroup's charge (e.g. eligibility, core services, workforce, accreditation, performance measurement/quality management), Iowans should expect all agencies and programs in the State that provide mental health, intellectual/developmental disabilities, brain injury and substance abuse services to commit to work as partners, both statewide and in regional systems, to develop "multi-occurring capability" within their existing resources and according to their stated missions, by continuously improving their ability to address the needs of individuals and families with multi-occurring issues and disabilities."

This includes, but is not limited to, state agencies working together on regulatory standards and financing, eligibility for services, service delivery models, workforce development initiatives, and outcomes measurement and evaluation. Like many other issues discussed in the redesign process, working with individuals with multi-occurring conditions requires the involvement of multiple stakeholders at various levels.

The Workgroup particularly encouraged DHS and the Iowa Department of Public Health (IDPH) to continue to work collaboratively together. The Iowa Department of Human Services (DHS) and the Iowa Department of Public Health (IDPH) are committed to a statewide system of care for Iowans with complex concerns, including but not limited to, disabilities, mental health issues, and substance use disorders. Related efforts over the past several years have involved consumers, clients, family members, providers, policy-makers, consultants, county and state staff, and other stakeholders in varied venues ranging from public forums and listening posts to planning groups and trainings. As a result, Iowa has a strong base of educated and committed individuals who are contributing in ways specific to their individual or organizational mission to a comprehensive system of care that supports people working toward personal recovery. The following joint statement from DHS and IDPH is consistent with the intent of addressing multi-occurring conditions:

"Over time, all Iowa disability, mental health, and substance use disorder services – and all State processes that support such services – will become recovery-oriented and capable of meeting the complex needs of individuals and families."

The Workgroup generally agreed that no new organized structure should be created to address co-occurring/multi-occurring conditions, but rather all component parts of the system must commit to addressing multi-occurring conditions within their scope of work. The group was clear that multi-occurring conditions are the expectation, not the exception, and silos that perpetuate barriers to a welcoming, holistic approach should continue to be broken down.

C. Eligibility - Adults

The Workgroup concluded that having two definitions in the Iowa code – Mental Illness and Chronic Mental Illness – were unnecessary. The definition of mental illness, as described below in “Diagnosis,” and level of impairment should determine general eligibility, and clinical assessment and consumer choice should factor into eligibility for specific services rather than meeting a definition of “chronic mental illness”.

Regarding Financial Eligibility, there was consensus in support of a co-payment and sliding fee scale as long as there is the ability at the provider level to waive the co-pay and adjust the sliding fee depending on individual circumstances. It was noted that the use of co-pays and sliding fee scales should not become a barrier to individuals who may be seeking treatment. Some members also suggested that if an individual’s income increased that there should be a mechanism to ease them off of assistance rather than dropping them off immediately.

The Workgroup further recommends that DHS conduct an impact analysis on the number of people who could be served at 150% of the Federal Poverty Level (FPL) versus 200% of FPL. While it understands the limitations of available funding, the Workgroup felt that this analysis would support a more informed decision-making approach to the threshold that is ultimately applied.

It was noted that this eligibility criteria is for general eligibility for services in Iowa. Other insurance coverage (e.g. Medicaid, Medicare, other third party) will have unique eligibility criteria. In addition, people will receive specific services depending on certain criteria including level of functioning, severity of symptoms and other needs and by funding source (i.e. federal block grant). In any case, however, a person experiencing a crisis should receive appropriate services regardless of their situation.

Age: An individual must be 18 years or older.

Residency: An individual must be a Resident of the State of Iowa.

Financial Eligibility: An individual must have an income equal to or less than one 150% of the Federal Poverty Level, as defined by the most recently revised poverty income guidelines published by the United States Department of Health and Human services. A contracted provider shall apply a copayment requirement for a particular disability service to a person with an income equal to or less than 150% of FPL. The copayment amount shall be established with rules adopted by the commission applying uniform standards with respect to copayment requirements, including a waiver provision. A person with an income above 150% of FPL shall be eligible subject to a copayment or other cost-sharing arrangement subject to limitations adopted in rule by the commission. A person who is eligible for services must apply for and utilize other potential sources of insurance or financial coverage for services prior to using public funds. The Workgroup recommended that beginning July 1, 2014, savings resulting from the Affordable Care Act’s

expansion of Medicaid and private insurance to currently uninsured individuals shall be reinvested to expand eligibility to 200% of the FPL.

Diagnosis: An individual must have or have had at any time during the past year a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within the DSM-IV or their ICD-9-CM equivalent (and subsequent revisions) with the exception of DSM-IV "V" codes, substance use disorders, and developmental disorders, which are excluded, unless they co-occur with another diagnosable mental illness²². An individual will also be eligible for services in situations where criteria for a specific diagnosis have not yet been met, but the individual is experiencing functional impairment and psychological duress which substantially interferes with or limits one or more major life activities. An assessment of functioning must be documented in the clinical record.

Continuity of Services: It is expected that individuals will progress through treatment and services. Consumer preference and clinical assessment shall be considered in determining the appropriate programs and services available to an individual so as not to jeopardize the recovery of a consumer through premature discharge or termination.

Functional Assessment: Following the Workgroup meeting on September 9, 2011, a subcommittee met to discuss functional assessments and reported to the full Workgroup on October 10, 2011. The Workgroup recommends that a standardized functional assessment tool, such as the LOCUS, be used by all contracted providers who receive Medicaid and non-Medicaid, public funds for individuals needing an intensity of services beyond Outpatient treatment. Data from the functional assessment shall be available to DHS, IME and/or the regional entity responsible for managing service provision and payment for services as applicable. The tool should be administered at set intervals consistently across the regions, and more frequently as needed to support clinical decision making for levels of care.

The purpose of the standardized assessment includes the following:

- The tool can be used as an authorization for services to support the recommendation for a particular service. The Regional entity can verify that an assessment has been done and that the service a consumer is receiving or assigned to is consistent with the level of care identified in the assessment. For example, the tool may indicate a level of service equivalent to Outpatient Counseling. Thus, placement into Assertive Community Treatment (ACT) would be inappropriate and better utilized by a person in need of that level of service, unless a more detailed clinical assessment justifies the need for the more intensive level of care. The Workgroup felt strongly that an individual who is benefitting from a particular program or

²² The exclusion of substance use and developmental disorders is as a result of existing statutory requirements for the use of funding. The Workgroup recognized the limitations perpetuated by this criteria, and recommends that the legislature, DHS and IDPH work together to ensure that existing or potential statutes and regulations and restrictions on the use of resources do not create barriers to accessing services for those with mental illness, substance use disorders, developmental disorders and multi-occurring conditions.

service should be considered for continued stay in the program or service, despite the tool’s recommendation, if consumer preference and clinical assessment justify continued stay.

- Aggregate data collected from the report can be used in a Dashboard Report by DHS, regional entities and the Iowa Plan to support outcomes. For example, progress or regression can be identified over time on an individual, regional and a statewide systems level.
- At a state level, aggregate functional assessment data would allow for analyses of levels of service across regions vs. expected need.
- Aggregate data can be used to inform policy makers and payers regarding the general need for particular levels of services. For example, if a region didn’t have access to an ACT team, it would be expected that there would be more discrepancies between the functional assessment recommended and actual levels of care, with more patients being in residential settings. This would help support the development adequate array of services to match the needs in each region.

D. Outcome Assessment and Performance Measures

The workgroup felt strongly that outcomes should be clear and understandable to a wide variety of audiences. DHS, the Iowa Plan contractor and regional entities should be required to monitor and evaluate similar outcomes and performance indicators.

Recommendation: The group suggested that outcomes be measured in at least the following core service domains:

CORE SERVICE DOMAINS	
Acute Care and Crisis Intervention Services	Recovery Supports
Mental Health Treatment	Family Supports
Mental Health Prevention	Health and Primary Care Services
Community Living	Justice Involved Service
Employment	Workforce Development ²³

Recommendation: Outcomes and Performance Measures Committee: Due to the limited time available, the Workgroup was unable to recommend detail regarding the specific outcomes and performance measures the system should work on. The Workgroup did agree that the Vision and Principles identified earlier in this report (Section III) provide a sound foundation for the specific development of outcomes and performance measures.

²³ Workforce Development was added to the Outcomes list because of the serious workforce issues confronting Iowa.

Therefore, the Workgroup further recommends that an Outcomes and Performance Measures Committee be established to continue and finalize this work beyond the Redesign process. The first responsibility of the committee should be to recommend specific outcomes and performance measures to be measured consistently across the system. To the extent possible, there should also be consistency across disability groups. This Committee should also include an evaluation of current data collection requirements that should be eliminated because they may be administratively burdensome or have little relevance to outcomes or other reporting requirements (e.g. legislature, federal block grants). A summary of the various data elements that are currently captured by DHS or other entities is attached.

The committee should be composed of DHS employees and stakeholders with expertise in quality improvement, including representatives from the Iowa Plan, the *Olmstead* workgroup, regional entities, University of Iowa, consumers and family members, and the provider community.

Once the outcome and performance measures are established, the MHDS Commission and Department should monitor, evaluate and report the progress toward system outcomes on at least an annual basis as well as any recommendations for improvement or modification.

Recommendation: Data collection must be tied to outcomes. Data must also have relevance to each of the players in the system, including the Department, the Medicaid contractor, the Regional Entities, and providers. Data with little or no relevance to the system should be phased out. The Workgroup noted that much data is collected in the system, but the general consensus is that it is not used to guide decision making.

Recommendation: Contributing to this is the lack of capacity at DHS due to relatively small numbers of staff. DHS is in need of additional staff resources if it is to be able to perform a satisfactory role in monitoring outcomes and the overall effectiveness of the system. Sufficient staffing for this function must also be considered in the development of the regional entities.

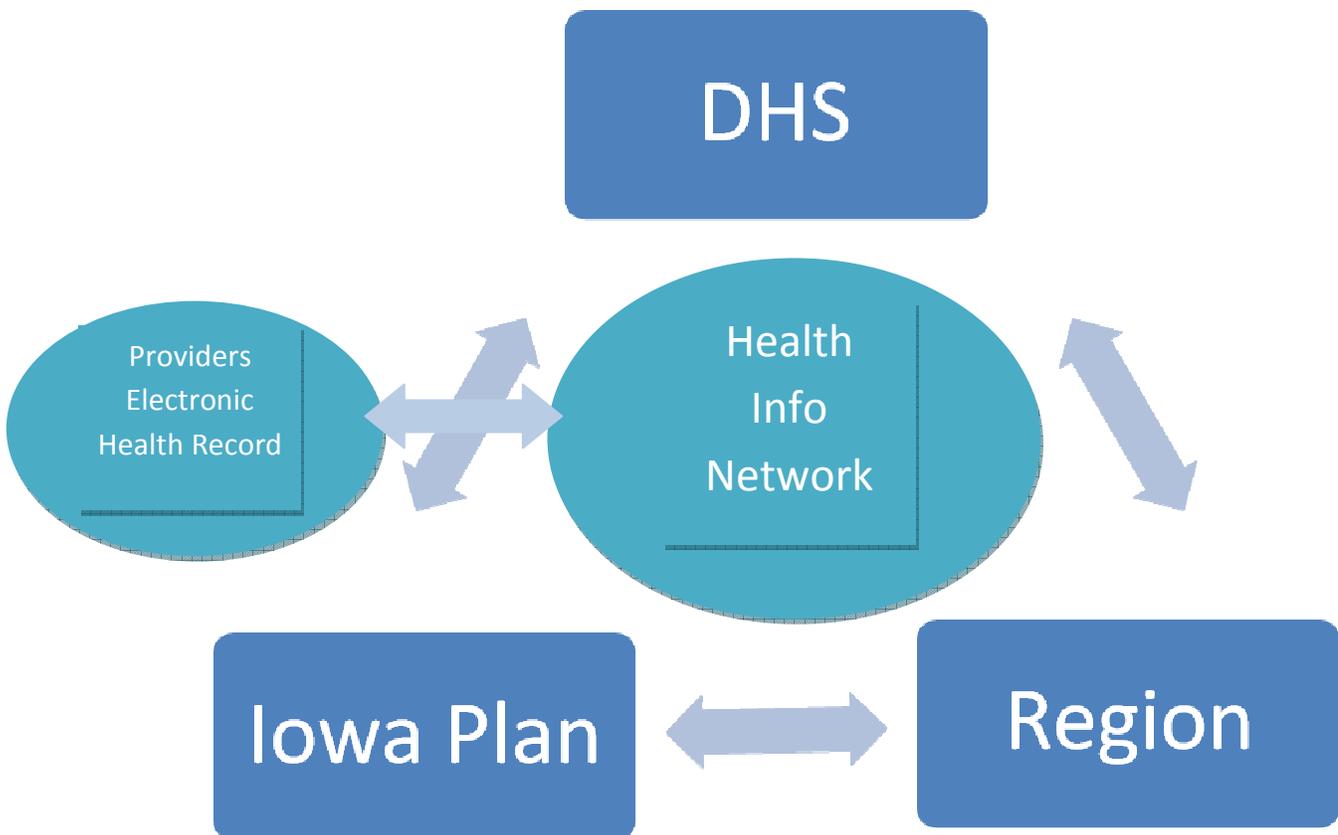
Recommendation: There was discussion regarding whether data for performance indicators should be handled by DHS or by the Iowa Plan contractor and regions. The Workgroup felt that a singular repository at the State level is desirable though much of the data will flow through the regions and the Iowa Plan contractor as a first step in the process. DHS currently is able to access data about Medicaid recipients. Ability to access similar data on a timely basis about non-Medicaid services, including but not limited to dashboard reports, is also necessary to provide clarity of services delivered in the state as a whole.

Recommendation: An Iowa Health Information Network (IHIN) is currently under development state wide and will serve as Iowa's Health Information Exchange. While Electronic Health Records (EHR) are currently being adopted across health care systems, full implementation is still several years away. However, EHR's alone are not enough without the ability to aggregate and analyze the data. Therefore, EHR's should connect to the IHIN.

Any current or future state or regional IT systems (for example the current ISAC CNS system) should also connect to the IHIN. It was strongly recommended that mental health and disability services providers must be considered active partners throughout the development in the process as this has not been the case thus far.

A web-based system at the regional and provider level should also be developed that can support the seamless input and output of data through the IHIN. Data planning efforts need to incorporate HIPAA transaction standards and ICD-10 coding. This will ensure that data collection and coding are consistent and thus provide the ability to extract meaningful information.

A basic diagram for an integrated data delivery system is provided below and demonstrates that when an integrated electronic IHIN is developed with other electronic data feeding into that system, each of the component parts of a system can extract and utilize the data for its purposes.



E. Core Services

Recommendation: Core Service Domains: The Workgroup discussed “core services” over several meetings. The Workgroup generally felt that the continuum of services identified in the SAMHSA paper, *Description of a Good and Modern Addictions and Mental Health Service System*²⁴, is ideal, and considered its components during this process. While there is a need to fund evidence-based practices and other effective services within the system, the Workgroup was hesitant to develop an exhaustive list of core services that should be mandated.

The reasoning for this stems from the idea that, from a person-centered planning approach, different services may benefit consumers depending on their unique circumstances. Therefore, the Workgroup identified minimum Core Service Domains that should be mandated throughout the State. Within each Domain, a range of services can be provided depending on individual needs. There will likely be some variability in what services are funded and how they are delivered due to certain variables, such as rural versus suburban or urban communities. Nonetheless, each region, as well as the Iowa Plan, must ensure that a cadre of known effective services and evidence-based programs are available within each of the following Core Service Domains:

CORE SERVICE DOMAINS	
Acute Care and Crisis Intervention Services	Recovery Supports
Mental Health Treatment	Family Supports
Mental Health Prevention	Health and Primary Care Services
Community Living	Justice Involved Service
Employment	

Recommendation: As part of the discussions on core services, specific services were discussed. In addition to the development of a continuum of available, flexible services in each Domain in each region, the Workgroup does recommend the following services be created in each region. Each service should be capable of working with individuals who present with multi-occurring disabilities and those with more specialized needs (e.g. older adults). It is also recommended that services have adequate reimbursement to ensure financial viability necessary to achieve intended outcomes and fidelity to accepted models.

²⁴ http://www.dhs.iowa.gov/docs/SAMHSA_ModernAddictions_8-22-11.pdf

1. Peer Run Self-help Centers: The use of peers in delivering services is recognized as an evidence-based practice in producing positive outcomes for consumers, and has a secondary gain of expanding the workforce necessary to meet the demand. Each region should establish one or more self-help centers. The self-help centers should be managed by a Consumer Program Manager at a gainful salary. The self-help center should consist of a governance structure that is composed of more than 50% consumers. The self-help center should also build in wellness and supported employment functions to the extent possible.

2. Crisis Services: Each region should have Psychiatric Emergency Services (PES) services that contain a range of crisis intervention and diversion services. PES services can be organized and administered by a single provider within a region or through a coordinated network of crisis response services as long as the core functions exist. When diversion is not possible, the PES will be responsible for facilitating inpatient hospitalization when necessary. The Acute Care Task Force Report (February 2010)²⁵ contains models that should be referenced for program development.
 - 24/7/365 crisis hotline. The hotline should be answered locally within a region. However, for ease of access to the general public, a single hotline number can be established that automatically bumps to the local area code that the individual in crisis is calling from so that it is answered by PES in close proximity to the caller.
 - Mobile Response: The PES must have 24/7/365 mobile response with the goals of, first, mitigating the crisis and diverting from inpatient hospitalization; second, facilitating inpatient hospitalization when civil commitment is necessary; and, third, ensuring linkage with the appropriate follow-up services. Mobile Response may be initiated by PES when a person calls, or may be requested by local police. In situations where Mobile Response is unavailable, a person may go to or be brought to the PES program for evaluation. The PES program should have capacity and/or access in the local emergency room, as well as, in non-hospital based settings.
 - 23-Hour Crisis Observation, Evaluation, Holding and Stabilization: These beds are used to provide assessment, extended observation, acute intervention, and continuity of care services under medical supervision and continuing nursing evaluation for up to one day to individuals in crisis and exhibiting acute psychiatric symptoms/impairments. Time spent in the bed is used to further evaluate the patient for the most appropriate level of care.
 - Crisis Residential: Each region should have short-term (0-7 days) crisis residential capacity in an unlocked setting. The purpose of this voluntary program is to help a person stabilize a psychiatric crisis and to avoid an unnecessary inpatient stay. Crisis residential programs may be staffed with consumers. Crisis Residential is for people

²⁵ Iowa Acute Care Task Force Report (February 2010).

http://www.dhs.iowa.gov/docs/AcuteCareTaskForceRecommendations_FINAL_10-14-2011.pdf

who are experiencing an acute episode such that if this intervention is not in place, they would otherwise meet inpatient criteria. Crisis Residential services may be provided in a person's place of residence with intensive on-site, wraparound support or in a residence designed for this purpose. The residence should serve less than six people at any given point in time. If not directly managed by the PES program, it should work closely with the Crisis Residential program to ensure the efficient use of the beds. DHS should establish standards for Crisis Residential to ensure consistency across the State.

3. Sub-acute Services: The Workgroup felt that a range of sub-acute residential services should be available in each region as both a step-down and inpatient diversionary service. Sub-acute services should be defined as a residentially based service, either a) in the person's home; or b) in another residential setting. Sub-acute services have the ability to provide up to 24 hour on-site support with a range of psychiatric, substance use and medical treatment and support services. Eligible consumers should not require inpatient care, but their level of functioning is such that they require more intensive supports to remain in the community. Sub-acute services are intended to be temporary in nature with average length of stays up to 30 days with longer lengths of stay requiring authorization from the region. Sub-acute services are ideally in settings with fewer than six people. The Acute Care Task Force Report (February 2010) contains models that should be referenced for program development. However, the Workgroup did not reach consensus as to whether sub-acute facilities should have the ability to be locked or unlocked facilities. This issue should be explored further because it could have potential *Olmstead* and Medicaid reimbursement consequences. DHS should establish standards for Sub-acute Services to ensure consistency across the State.
4. Jail Diversion: Each county within a region should have access to a Jail Diversion program, such as a Crisis Intervention Team (CIT) based upon the principles in the Memphis, Tennessee CIT model. Several programs were studied for best practices including the jail diversion program in Bexar County, Texas as well as the program in Blackhawk County, Iowa. DHS should lead development of jail diversion in coordination with the Department of Corrections, local law enforcement and other stakeholders (e.g. Judiciary, consumer, NAMI). Using the Sequential Intercept Model, which is currently being used in Polk County, Iowa, jail diversion services should assist along the various points of intersection with the criminal justice system.
5. Assertive Community Treatment (ACT): Each region should have at least one ACT team that can serve Medicaid and non-Medicaid eligible individuals. Regulations that define the scope of ACT services should be established by DHS to ensure consistency throughout the state and fidelity to the ACT model. Some states, such as Texas, apply different standards to ACT teams depending on whether they are in rural or more urban

areas. ACT teams in rural areas can be expected to have smaller caseloads and spend more time traveling to see consumers.

6. Community Support Services/Supportive Community Living/Case Management: DHS should blend and consolidate these services into a single service that provides an array of flexible, recovery-oriented support and care/case management services delivered by a team of professionals, paraprofessionals and consumers, building off of a supportive housing model. By consolidating these services, duplicative, fragmented and competing services can be eliminated in lieu of a more coordinated approach to delivering services. Supporting an individual in their own residence, whether it is with family, a small shared living residence or their own home/apartment is cost effective, consistent with *Olmstead*, and desired by consumers. In this program, housing is not contingent upon receipt or compliance with services. This model often meets the needs of consumers who are very independent and those who are often difficult to serve in group settings, but can succeed in community living arrangements with intensive wraparound supports. DHS should establish standards for a Community Support Service/Supportive Housing service to ensure a level of consistency throughout Iowa. Any future modifications to the Targeted Case Management program should be considered in this consolidation.
7. Health Homes: Section 2703 of the Affordable Care Act (ACA) gives states the ability to submit a State Plan Amendment (SPA) to create Health Homes. CMS will pay for 90% of the costs of care management for the first two years. The Iowa Medicaid Enterprise (IME) should submit a SPA to develop Health Homes in each region of the state. Health Homes should be available to Medicaid and non-Medicaid individuals who fall into this category. Magellan currently has an integrated health home pilot underway. Health Homes are more a way of organizing service delivery rather than a new service.
8. Supported Employment and Supported Education: Obtaining gainful, meaningful employment is critical to a person's recovery and enables individuals to contribute to the system. Each region should establish these programs, and mechanisms to coordinate with the Iowa Departments of Labor and Education, and at the local level with employers, colleges and universities, should be established. The Workgroup did not recognize sheltered workshops as Supported Employment.
9. Family Support Services: Family psycho-education is considered a best practice. Regions should create mechanisms for families to receive support, skill building training and other supports to help cope with the illness of their loved one and to assist in their recovery.

Recommendation: Reimbursing evidence-based practices and services identified through a person-centered planning approach: The Workgroup recommends moving toward the availability of statewide evidence-based practices within each Domain and away from services that do not have an

evidence base. In addition to the Core Service Domains and specific services identified above, there are other services that are as important to an individual's recovery. These may include, for example, more traditional services like outpatient counseling as well as things like rental assistance, transportation, or homemaker services. The critical concept is that a successful system ensures that there is a foundation of core, evidence-based services and programs that deliver a cadre of flexible, individualized services.

Some services that may be important to an individual, based on a person-centered planning process, are not currently covered by Medicaid because of federal requirements or are not currently in the Medicaid state plan, but are important nevertheless. For instance, in a Community Support Services model, a service or function such as rental assistance or paying for food on an emergency basis may not be covered by Medicaid, but are worthy of reimbursement as compared with costly alternatives (e.g., homelessness). Therefore, Regions should have the flexibility to pay non-mandatory, yet essential, "services" as needed. Rather than include or exclude specific services that should be considered as reimbursable, the workgroup suggests that the following criteria be considered by regions when reimbursing for services:

1. A person-centered planning process should be utilized to justify the need for particular services.
2. The services should be recognized as having an evidence-base to support them.
3. Conversely, agencies should move away from providing those services for which the evidence base demonstrates that they do not yield the desired outcomes, i.e., move away from those services that appear to be ineffective.

The third recommendation is to examine the support provided to services that do not appear to be effective or supportive of Olmstead principles. A good example is the continued wide use of sheltered workshop for adults with mental illness versus supported employment. Accordingly, the Workgroup recommends that as regions are developed, they demonstrate a business plan for how they will implement evidence-based and best practices within each of the Domains over a five year period and reimburse services identified in individual service plans. The Workgroup felt this should be developed at a regional level due to the variability in regional makeup. Regional phase-in schedules should demonstrate how services that will yield the greatest return on investment will be phased in earlier in the process. The Workgroup also recommends that any expansion of new services should not be at the expense of current, effectively working programs.

F. *Olmstead* and System Rebalancing

Trends

Mental health systems across the country have historically been built upon an institutional, “get sick first” foundation. In the 19th century, many large state psychiatric hospitals were built and housed thousands of patients and employed thousands of individuals. At times, institutions played various roles including taking care of war veterans with “shell shock,” family members from wealthy families who paid to have their loved ones taken care of, and the severely disabled. “Scientific” treatments evolved from hydrotherapy, lobotomies, dental and electric shock to the use of psychotropic medications, cognitive therapies, and other best practices known today aimed at recovery and preventing the need for inpatient treatment. Whereas the population of state institutions in the early to mid-20th century ranged in the hundred thousands, the census today is roughly 50,000 individuals nationally.

Note: Data in the following section is mostly excerpted and adapted from SAMHSA’s *Funding and Characteristics of State Mental Health Agencies*, 2009 and 2007 editions^{26/27}.

In 2008, Iowa had approximately 150 adult residents in the state psychiatric hospitals at the start of the fiscal year. Patients per population (100k) were 6.8, as compared with a national average of 18. Average length of stay for adults was 53 days as compared with a national average of 170. Thus, the Mental Health Institute’s in Iowa play more of an acute care role than in many other states. In addition, 80.7% of children and adolescents were involuntarily admitted in FY 11 while those categorized as Adult Psych was 87.6%, and 70.4% for the Adult Dual program.

Most states use their state psychiatric hospitals to serve adults, elderly consumers, and forensic patients (e.g. those determined Not Guilty By Reason of Insanity, needing competency evaluation/restoration, or on detainer status). Patient demographics are increasingly toward treating those with forensic involvement or who require a longer inpatient stay and serving individuals without forensic status in community settings or local acute care inpatient settings as needed. Nationally, nearly one-third of all consumers in state hospitals were involuntarily criminally committed. Since 1993, state psychiatric hospital expenditures have increasingly been applied to forensic services. In 2006, 2% of Iowa’s MHI population had a forensic status whereas the average across the country was 32%. Voluntary admissions into state hospital level settings are in decline, though Iowa has a relatively high number of voluntary admissions (21%) as compared with some states with fewer than 5% of admissions being voluntary (e.g. New Jersey, Mississippi, Montana, Nebraska, Nevada, New Hampshire, Tennessee, Utah,

²⁶ Lutterman, T., Berhane, A., Phelan, B., Shaw, R., & Rana, V. (2009). *Funding and characteristics of state mental health agencies, 2007*. HHS Pub. No. (SMA) 09-4424. Rockville, Md: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration.

²⁷ Substance Abuse and Mental Health Services Administration, *Funding and Characteristics of State Mental Health Agencies, 2009*. HHS Publication No. (SMA) 11-4655. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2011.

and others). Several factors may contribute to this including geography in rural states and lack of funding for community-based alternatives.

As State Mental Health Authorities (SMHA) continue to reduce the size and presence of state psychiatric hospital beds and more frequently treat consumers in community-based treatment settings, funding for psychiatric hospitals continues to decline. In FY 2001, 63% of SMHA funds were devoted to community mental health systems. In FY 2007, SMHAs expended over 71% of their funds on community mental health services, whereas state psychiatric hospital inpatient services represented 27% of SMHA resources.

Nonetheless, the cost of operating state hospitals is mostly paid for by states and counties, and is expensive. The federal government, through CMS, continues to refrain from financial participation in large inpatient and community-based congregate care settings, known as Institutions for Mental Diseases (IMD). In 2008, the average expenditures, nationally, per patient day for civil status adults were \$566.80, or roughly \$207,000 annually. This number may actually be higher since many SMHAs do not account for fringe benefits in their cost estimates since these are often the responsibility of state Treasury departments.

In 2008, 26 SMHAs indicated that they either have closed, or are planning to reorganize, downsize, or close, a total of 44 state hospitals. Four states have closed a total of seven facilities in the past 2 years, and five states are currently planning to close one or more state psychiatric hospitals. Rather than eliminate state-operated inpatient psychiatric services altogether, many states are opting to reorganize their systems. Of the 26 SMHAs with plans to reorganize, the most frequently cited activities include closing hospital wards (58 percent), significantly reorganizing within one or more state hospitals (46 percent), downsizing one or more hospitals (42 percent), and consolidating two or more hospitals (23 percent). Eleven SMHAs are replacing old state psychiatric hospitals with new hospitals.

Olmstead

Several challenges emerge as states seek to redefine the roles of state psychiatric hospitals and other service providers, and rebalance the use of resources. There are many public opinions about what's best for consumers and where they should be served and economic and employment concerns for local communities. Paramount is the need to keep civil rights and fact based dialogue regarding the prudent use of taxpayer dollars at the forefront of all discussions. States, and in many instances, counties, will also continue to play a role in ensuring the availability of safety net services.

While the availability of inpatient treatment, both longer and shorter term, will be necessary in the foreseeable future, it is increasingly accepted that smaller, more integrated community-based settings over large congregate settings, both inpatient and community-based, are more preferable to consumers, produce better outcomes and are more economical to states. However, rebalancing systems is complex and requires changes in thinking, commitment to ensure civil rights of consumers, and creative funding strategies. Iowa will need to grapple with the design of its residential/housing

continuum, how it should be funded, and what role larger facilities should play in the mental health system.

What is clear is that states are increasingly facing litigation from the US Department of Justice and/or statewide protection and advocacy organizations, using the US Supreme Court *Olmstead* decision, to force development of smaller, more integrated housing and services options for people with mental illness and other disabilities. Though the Supreme Court decision was rendered in 1999, *Olmstead* efforts appear to have accelerated in the past few years. For example, New York lost a case last year for having too many people living in “adult homes,”²⁸ large board and care facilities that provided little treatment and community integration. New York also recently settled a lawsuit aimed at overutilization of nursing homes for people with mental illness, and is geared toward facilitating the movement of people into more integrated housing options²⁹. Illinois recently settled a case where it was asserted by the Illinois ACLU and other advocacy organizations that they had too many people living in nursing homes³⁰.

As stated above, CMS continues to refrain from financial participation in large inpatient and community-based congregate care settings, known as Institutions for Mental Diseases (IMD), and is focusing its efforts on providing Medicaid reimbursement opportunities in smaller settings. Thus, states and counties remain the primary payer for larger settings whereas the federal government will participate financially in smaller settings enabling many states to serve more people at a fraction of the costs. CMS has developed various funding strategies to support community integration. Among these include the use of optional services such as the 1915(i) (Note: Iowa has a 1915(i) state plan option), rehabilitation option services, and Money Follows the Person. More recently, the care coordination features in the Health Homes option are likely to lead to positive outcomes. CMS will not reimburse for services provided in residential programs with more than 16 beds.³¹

While Iowa tends to have fewer patients per 100,000 residents in its Mental Health Institutes, its percentage of civilly committed and voluntary patients is higher than many other states, and its percentage of those with forensic involvement is lower than the national average. It should be anticipated that as those collectively involved in the mental health system (i.e. providers, courts and police) engage and divert people away from the criminal justice system to the mental health system, there could be added pressure for inpatient settings in lieu of corrections. This may ultimately present an issue of whether to add additional beds or redefine the target population served in the continuum of inpatient settings in Iowa.

²⁸ This case is under appeal.

²⁹ *Joseph S. et al. v. Hogan*

³⁰ *Williams v. Quinn*

³¹ There are some exceptions. CMS will pay for services for those under 21 or over 65 years of age. CMS may also pay for services if the facility has more than 16 beds, but less than 50% of the residents have a mental illness or substance use disorder.

Workgroup Discussion and Recommendations:

The Workgroup discussed *Olmstead* principles in several meetings and agrees that people should be served in the least restrictive, most integrated settings possible. By investing in services consistent with *Olmstead* principles, the system will be working to ensure that the civil rights of individuals with disabilities are protected, will have a greater return on its investments, and enable the State to rebalance or reallocate funds to fill gaps in services. This includes the recognition of serving people in smaller, non-congregate care settings and leveraging Medicaid to the extent possible. Examples of smaller settings include independent apartments and small shared living residences. This process will take time, and, ultimately, financial incentives should be built into rates or contracts to support this transition.

Within the continuum of inpatient care, the Workgroup discussed the role of the Mental Health Institutes, local inpatient treatment at acute care hospitals and non-inpatient, sub-acute settings. The Workgroup recommends that the legislature direct DHS to continually evaluate the inpatient continuum of services as the community system develops. The Workgroup agreed that there is a need for additional forensic inpatient capacity within the Mental Health Institutes and that as the need for long-term, civil commitment inpatient beds decreases as the community system strengthens, some beds can be re-purposed for individuals with mental illness and forensic circumstances. The Workgroup decided that the current construct of a forensic psychiatric hospital being located within the prison system should be transitioned to one that is located within the control of the mental health system.

The group agreed that, when needed, inpatient care should be delivered in local, acute care settings to the extent possible and that the Mental Health Institutes are more appropriate for patients who require longer term treatment. Local, acute care inpatient units are largely non-existent in Iowa for several reasons, mostly due to geographic and reimbursement issues for acute care hospitals. The Workgroup suggests that the legislature direct DHS to explore the expansion of local acute care, inpatient capacity, including a call for beds through a Certificate of Need process and suitable reimbursement for beds. The current number of operational beds at the Mental Health Institutes is needed and should not be decreased further without a corresponding increase in the number of psychiatric inpatient beds within local, acute care hospitals.

It was suggested that more beds are not necessarily needed in the system, but rather existing beds be used more efficiently. However, most members agreed there is a shortage of acute psychiatric inpatient beds and that consideration should be given to expanding beds now to meet immediate demand, even if on a transitional basis. This does not necessarily mean that new beds become permanent, and the system should be flexible enough to reallocate resources as the system evolves. As community-based alternatives become operational and demand for acute inpatient decreases, beds can be closed and funds reallocated to community services.

The Workgroup also recommends that DHS continue to evaluate the need for sub-acute services consistent with the recommendations in this report and the previous Acute Care Task Force Report. Within this discussion, there was discussion about the role of Residential Care Facilities (RCF) in the state. There is a wide variation in RCFs, including numbers served and services provided. Most RCFs are large (i.e. over 16 beds) and do not receive any Medicaid funding for services. The Workgroup recommends that DHS engage the Department of Inspections and Appeals and other stakeholders on defining the role of RCFs in the system and modifying licensing and inspection standards accordingly. The use of substance abuse residential services should also be considered for use as sub-acute care.

G. Supporting and Maintaining a Competent and Committed Workforce

The challenge of having a sufficient workforce is not unique to Iowa. Insufficient numbers of staff combined with existing staff whose knowledge and experience are inadequate to meet the needs of service recipients has created a national workforce crisis in behavioral health. For most mental health positions, there are severe workforce shortages, and nearly all of Iowa's counties are designated as shortage areas in Mental Health Care Health Professional Shortage Areas (HPSA)³². Iowa consistently ranks toward the bottom in terms of the availability of psychiatrists and psychologists. In 2000, Iowa ranked 47th among states in the number of psychiatrists per 100,000 people and 46th among states in the number of psychologists per 100,000 people³³. The workforce crisis is especially profound in rural areas³⁴, and with children, youth and older adults, and on issues pertaining to co-occurring disorders, trauma-informed care, and cultural competence. The frequency of turnover in the workforce, often due low salaries and burnout, negatively impacts continuity and quality of care, and results in an added cost burden to providers who continually need to train new employees.

The Workgroup reviewed the Annapolis Coalition (2008) report, *Iowa Mental Health and Disability Services Workforce Review*³⁵, and the Department of Public Health's report (2006), *Iowa's Mental Health Workforce*, that addressed Iowa's workforce challenges. The reports highlight the need to develop recruitment and retention strategies (e.g. loan repayment programs, career ladders), work with higher

32 Center for Health Workforce Planning, Bureau of Health Care Access, Iowa Department of Public Health 2006 Report, Iowa's Mental Health Workforce.

33 U.S. Department of Health and Human Services Bureau of Health Professions, 2000. The Iowa Health Workforce: Highlights from the Health Workforce Profile. Available at URL <http://bhpr.hrsa.gov/healthworkforce/reports/statesummaries/iowa.htm>.

34 More than 85% of the 1,669 federally designated mental health professional shortage areas are rural (Bird, Dempsey, & Hartley, 2001), and they typically lack even a single professional working in the mental health disciplines.

35 Annapolis Coalition on the Behavioral Workforce and the Western Interstate Commission for Higher Education. (2008). *Iowa Mental Health and Disability Services Workforce Review*.

education to shape curricula, develop rural training opportunities, and work with primary care providers.

While the Workgroup did not specifically recommend any of the initiatives in the reports due to time constraints, it generally agreed with the content and makes the following two recommendations in order for there to be meaningful efforts in strengthening the capacity and capability of Iowa's mental health workforce. While more efficient use of staff, local training collaboratives, and the use of technology may serve to enhance the workforce, the Workgroup believes that sufficient progress cannot be made without an investment of resources to address the workforce crisis.

Recommendation: Creation of a standing Mental Health and Disability Workforce Development Group:

Given the broad range of topics within workforce development, the Workgroup recommends that the legislature direct DHS to convene a standing Workforce Development group comprised of multiple stakeholders to address this multi-faceted issues. The group may consist of state agencies such as DHS, IDPH, Education, and Corrections, as well as regional entities, the Iowa Plan contractor, academia, providers, consumers, and families. The Workgroup was clear that unless this issue is given sufficient attention from both the legislative and executive branch of government, Iowa will continue to face a workforce crisis, and it could cripple system redesign efforts.

Recommendation: Development of a Peer Workforce: The Workgroup also discussed encouraging the development of a greater peer workforce. The use of peer-delivered services is considered a best practice approach, and the Workforce Development group that is convened should recommend ways to expand Iowa's peer workforce. Iowa does use Certified Peer Specialists and should continue to encourage the use of peers in the delivery of nearly all services. In Iowa, as in other states, peers remain a largely untapped resource. Consideration should be given to how to fund this workforce, as well as training, certificate and credentialing programs for peers that can be recognized by DHS, Medicaid and the Iowa Plan for allowing peer positions in programs. Training for peers, as well as supervisors and non-peer co-workers, should be funded to aid in the acceptance of the peer workforce and to help reduce burnout. The intent is not to replace professional or other paraprofessional staff, but to utilize the unique skills of peers as additional services.

Peers can be encouraged to enroll in traditional majors such as social work or psychology, and consideration should be given to the development of specialized certificate and degree programs. The University of Medicine and Dentistry in New Jersey, for example, offers certificates and an Associate's degree through PhD in Psychiatric Rehabilitation, and has many consumers enrolled. The State can also create its own or adopt national certificate curriculums/programs that can be used as recognized credentials to work in various programs. Some programs tailor the curriculum so that students, including peers, can become credentialed as Certified Psychiatric Rehabilitation Practitioners (CPRP), a rigorous, recovery-oriented credential.

H. Provider Qualifications and Monitoring

The Workgroup discussed accreditation, certification and licensure issues in the final meeting. Provider members felt that there is too much fragmentation between multiple agencies as it relates to this process, particularly in the areas of mental health and substance use provider oversight and monitoring. The group acknowledged the important role the State plays here in terms of ensuring that providers deliver safe and quality services to service recipients.

Recommendation: The Department of Human Services, the Department of Public Health and the Department of Inspections and Appeals should establish a process to streamline accreditation, certification and licensing standards and the inspection process in order to minimize unnecessary burdens on providers, reduce redundancy, and align the delivery of services. The use of deemed status by national accrediting bodies should be encouraged, but not required.

Recommendation: DHS and IDPH should continue their efforts to minimize the licensure and inspection burden to dually accredited/licensed providers that provide both mental health and substance abuse services.

Recommendation: The Department of Human Services and the Department of Inspections and Appeals should jointly review the standards and inspection process for Residential Care Facilities in order to more clearly delineate the roles, functions, available services, and client eligibility in these facilities. *Olmstead* implications should be considered in this process.

Recommendation: Consideration should be given to increasing the number of staff dedicated to provider oversight. The intent is not to increase the amount of work for providers, but to 1) have staff to work together on streamlining the accreditation, certification and licensure process across state departments; and 2) to ensure that the quality of monitoring is sufficient to ensure the availability of safe and quality services.

I. Transition Planning

The best approach is to incrementally implement portions of services within each service domain simultaneously in order to ensure greater access in more desirable services as the system rebalances. While a heavier investment in Acute Care and Crisis Services may be necessary early on, the expansion of non-crisis services, such as peer-delivered services, must quickly follow to ensure access for those who otherwise may have been admitted to an inpatient setting. Similarly, expanding jail diversion services requires that there be services accessible to those who are diverted. While it is critical to implement acute and crisis services to ensure a sound safety net, DHS should remain cognizant that people should have access to more recovery-oriented services in order to avoid the need for accessing the safety net in the first place.

In addition, the Workgroup felt that implementation of services must consider two issues. First, several desirable services do exist in Iowa but are not statewide. DHS should ensure that regions take current evidence-based practices to scale. Second, some services do not currently exist in Iowa at all, and DHS will need to work with regions to ensure these are operationalized. In both instances, DHS should ensure that there is consistency across the State in the development of regional systems, and that effectively working existing services are not sacrificed in order to implement new services as a result of the redesign process.

J. Community Mental Health Center Statutory Changes

In regards to Community Mental Health Centers, recommendations were made to amend Senate File 525.

Specifically, these include:

Section 230A.106, subsection 2, paragraph c, as enacted by 2011 Iowa Acts, Senate File 525, section 16, is amended to read as follows:

1. Page 17, c. Add the sentence: "An Assertive Community Treatment program may be offered as an alternative to the above services in section c."

Section 230A.110, subsection 1, as enacted by 2011 Iowa Acts, Senate File 525, section 20, is amended to read as follows:

2. Page 19: Section 20, 1: Strike "and" and add "or" to the following sentence: "The standards adopted shall conform with federal standards applicable to community mental health centers and shall be in substantial conformity with the applicable behavioral health standards adopted by the joint commission, formerly known as the joint commission on accreditation of health care organizations, "or" other recognized national standards for evaluation of psychiatric facilities unless in the judgment of the division, with approval of the commission, there are sound reasons for departing from the standards."

VI. REPORT OF THE CHILDREN'S SERVICES WORKGROUP

A. Introduction

The Children's Disability Services Workgroup has met six times since the enactment of SF 525³⁶. As part of the process, 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]). The recommendations summarized in this report have been derived from the discussions and consensus-building that occurred during these meetings.

The timeline for the redesign of the Children's Disability Services Workgroup differs from those of the other workgroups. SF 525 established a two-year time frame for the activities of this Workgroup. Thus, the Workgroup did not attempt to form consensus recommendations on topics such as provider quality monitoring and workforce development. Rather, these topics are included in the work plan described in Section G of this Chapter.

This Chapter 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 Workgroup. Finally, this Chapter contains a summary of commentary from the Workgroup members.

B. Analysis of Gaps in the Children's System

One charge to the Workgroup was to identify strategies for bringing home those children with disabilities who are currently placed out of state. As a corollary, the Workgroup considered the service and systems issues associated with preventing out of state placement if at all possible. As a first step in this analysis, the Workgroup identified a number of important gaps in the current children's system. These include:

There are no clear points of accountability or organizing entities for children's Disability services in Iowa.

- Limited macro-level knowledge.
- 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").

³⁶ August 16, August 30, September 13, September 27, and October 11th and October 25th.

There are no clearly defined, 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.

There is insufficient focus on health promotion.

- Wellness services
- Healthy Families
- Healthy supported environments and communities—physical, social , and the built environment³⁷
- Social determinants of health

There is 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 Youth³⁸ 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
- Housing supports
- Independent living skills

³⁷ 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 neighbourhoods and large-scale civic surroundings.

³⁸The 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.

- 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 and settings (out of state placements, schools, 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.

C. Promising Practices in Children’s Services

Having identified current needs and gaps in the children’s service system, the Workgroup then considered a number of evidence based and promising practices in children’s services. These would form the basis for developing recommendations for service and system improvements both for youth who are currently placed out of state and for the larger number of in-state youth at risk for out of home placement. The list of what was reviewed is by no means inclusive of all of the promising practices for children, youth and families. 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. The practices reviewed by the Workgroup included:

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

- Learning Supports for Students
- Iowa graduation rates for children entitled to special education

In addition, each session the Children's Workgroup reviewed a selection of programs and practices from within and outside of Iowa.

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 11% 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 a 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 organizations³⁹.

Iowa Department of Education: Interagency Initiatives

The Iowa Department of Education is engaged in a number of initiatives to promote social-emotional skills and positive culture; address challenging behaviors and enhance a continuum of integrated supports for learning in order to promote student learning in the Iowa Core Curriculum; healthy development; and success in school and in life. The Department is developing “a continuum of school and program-wide Positive Behavior Interventions and Supports (PBIS)” that is inclusive of all children “birth to 21” (Program-wide is implemented in early childhood settings, B to 5 years). PBIS is a process for creating environments that are predictable and effective for achieving learning and social goals. A key strategy of the PBIS process is prevention. Three tiers of children/students and strategies are identified: Primary, Secondary and Tertiary. There is an emphasis on school/program-wide system of support that include proactive strategies for defining, teaching and supporting appropriate individual behaviors to create positive school/program environments.

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 Milwaukee⁴⁰

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

³⁹ **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.

⁴⁰ Wraparound Milwaukee, 2009 Annual Report. For more information:

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

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)⁴¹

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.
- 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 Redesign⁴²

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.

⁴¹ 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

⁴² Minnesota Children’s Mental Health System, Prepared by the Mental Health Legislative Network. For more information:

<http://www.dhs.state.mn.us>

Kansas: Transition to a Mental Health System of Care⁴³

“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 Initiative⁴⁴

“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.

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.

⁴³ Kansas’s HCBS-SED Waiver, National Health Policy Forum, 2005.

⁴⁴ 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>

D. Initial Recommendations

Recommendation One: 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.”⁴⁵

The Workgroup developed and recommends the following definition be adopted as a foundation for the development 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 interdependence of each system and service on the other, the need to coordinate across funding

⁴⁵ Sheila Pires, Building Systems of Care: A Primer, 2002.

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 upstream⁴⁶, 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.

⁴⁶ “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 Two: 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 two additional services in order to set the stage for the full system transformation.

The Workgroup emphasized that core services delivered to children, youth and families should be delivered in accordance with the Iowa Systems of Care definition and vision described in Recommendation One.

The three recommended new services are as follows:

1. **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 Intensive Care Coordination fall under the auspices of Specialized Health Homes that are described in Recommendation Three. 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 Intensive Care Coordination 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.
2. **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.”⁴⁷ Family Peer

⁴⁷ 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.

Specialists or Family Partners⁴⁸ are individuals who have “lived experience” as parent or caregiver of a child with a disability and experience navigating the child-serving system. They 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 Three).

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 Home⁴⁹ that might include:
 - a. Crisis planning
 - b. 24/7/365 telephonic support and triage
 - c. Urgent appointments
 - d. Site-based crisis intervention
 - e. Mobile crisis intervention (home, school and community-based)
 - f. 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

⁴⁸ “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.

⁴⁹ 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.

under the Iowa Plan⁵⁰. 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 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 children’s System of Care
 - 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 Three: 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.⁵¹ 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

⁵⁰ Behavioral Health Intervention Services were previously known as “Remedial Services”.

⁵¹ Described in section 2703 of the Affordable Care Act, entitled “State Option to Provide Health Homes for Enrollees with Chronic Conditions.

- 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 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,⁵² “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.

⁵² The CMS guidance to State Medicaid Directors is available in full at <https://www.cms.gov/smdl/downloads/SMD10024.pdf>.

- 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.

Example of how enhanced core services could be incorporated into and delivered under a Health Home model.

The Children’s Workgroup identified new services for treating children/youth and families in their homes, schools and communities. Two of the services can and should be incorporated into the recommended Health Home model. For example:

- Intensive Care Coordination: is required by CMS to be a primary responsibility of a Health Homes, 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, Health Homes should lead or participate actively 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 and could include performance-based payments. Alternative funding methodologies could be considered in the future.

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

The Workgroup focused on youth placed out of state both as an issue to be addressed now and as a potential driver of system-wide solutions for the children's systems of care in Iowa.

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, including:
 - 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

Review of this information led the Workgroup to recommend a short-term strategy to bring children home from out of state placements. The recommendation aligns with the Iowa Systems of Care vision 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 use of resources such as 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.

E. Outcome Assessment 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. There will also be additional work to assure that standard uniform measured of outcomes and performance are tailored to the specific needs and interests of children and their families.

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 lowans 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 is 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 lowans.

- 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 measurable tools that both reflect and achieve the desired child, youth and family-centric outcomes outlined above.

F. 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 payers, and 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 and 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 .

During the last meeting, the Workgroup developed a comprehensive Planning Agenda for 2012 that can be found in full in Appendix C.

G. Comments on the Recommendations and Redesign

In consideration of the Workgroup's report and recommendations and the preliminary work plan for CY2012, the members of the Children's Disability Workgroup offered comments to summarize the product along with broader considerations on system redesign:

I'm concerned that to have a truly good system of care we will need multiple funding sources that are new and not tied to core standards. Legislature is tied to having core standards and it might not work for kids as it does in an adult system of care. We are not about just having specific services in order to bring the kids back home.

The real key is the funding for the System of Care, and how it will meet the needs of the children and families. The funding has to be a primary focus.

The disjointed systems between education, Juvenile Justice, mental health, etc. need to be working together across systems. We need to do this with the not-so-obvious partners. We have to do this with the community, not to the community.

This is as thorough a process as it could be in a short period of time. But, there are not enough families around the table.

I am confident in this product. It represents a document to hold decisions to. We will need a commitment from each entity. It is a foundational document that was achieved in a multi-disciplinary way. All of the primary elements are in the document, and we need to push forward.

It is a great start. I am always concerned about families in areas of the state where they do not have anything. It will be important to get their buy-in to make it work. Another concern is that will there be enough buy-in for people to do what is needed to get services they need.

We get lots of kids from southern Iowa (in our program). Parents do not visit, and they cannot bring kids to hospital-based step-down programs. Therefore, kids are in the hospital longer because there are no services in the areas in which they live.

We need to assure that we do a good crosswalk with kids and mental health and intellectual disability. No child should have to be an Exception to Policy in the system. We also need to be assured that there will be capacity in the community to serve these kids; it is not present now.

It is a good start. We got to first base. I hope we get to 'second base' this time with the ideas. I've been involved before in these initiatives.

I like the philosophy. I have problems with Recommendation #4 (RFP). We are not in a position now to make this recommendation a reality. Somebody -- DHS or someone else -- has to put time into the RFP process and the details.

If we missed anything, we will need the opportunity to clarify, communicate, and refine what is needed.

We are charged to design something that does not really exist. We are a little different than the other workgroups. I want to be clear that we have to develop an infrastructure and have the funding to build the infrastructure for coordination and quality to achieve the outcomes we want. The funding is often available at the end but we have to build the components and the infrastructure to that end.

Having an organized infrastructure and evaluating how the system evolves over time will be very important. We will have to focus on early brain development, epigenetics, adverse childhood experiences and transitions.

We have to have innovative funding. This is not just a mental health redesign; we will have to have constant improvement as we move forward with the plan. We will need an infrastructure to keep things growing.

My worry is more along the lines of ~ 'we've been here before.' From a family perspective, the organizing entity is so viable to the system. In the past, there have been turf wars and we do not move beyond that point to system change. There has not been (historically) a clear message from the system to the legislature, and they (legislature) end up doing nothing because we are on different pages.

It is important that if we are going to team with families that we need to bring our resources together as a team—to look at common pieces across systems and professions, and bring them all together without duplication.

First, I believe it was unfortunate that we did not have a youth voice on the workgroup. Having youth in the decision-making process is important. Secondly, I want us to be cautious about combining this with other services. This (children's system) has to be built differently. The structure has to be different than the adult system.

VII. REPORT OF THE REGIONALIZATION WORKGROUP

A. Introduction

The purpose of this chapter is to summarize the recommendations of the Regional Workgroup formed as part of the MHDD redesign effort to provide input and recommendations to the Legislative Interim Committee pursuant to SF 525.

Based on discussions of the Workgroup, including Legislators and state officials, the goals of the regionalization redesign effort include:

- Improve and clarify the methods and entry points by which consumers and families can request and access services.
- In the context of available resources, assure equity of access to core services for all citizens of the state of Iowa.
- Assure consistency of service access and provision throughout Iowa, while also maintaining the value of locally designed and operated systems of care for people across the lifespan with MH, ID-DD service needs.
- Assure high quality and continuous quality improvement of services within the systems of care for people with disabilities.
- In the context of available resources, foster the implementation of evidence based and promising best practices known to produce the most positive outcomes for consumers and their families.
- Assure accountability, efficiency, and proper stewardship of public resources in the system.

The Regional Workgroup has met five times since the enactment of SF 525⁵³. The recommendations summarized below have been derived directly from the discussions and consensus-building that occurred during these meetings. Much of the material presented below originated in the materials and discussion papers prepared for the Workgroup, and the consensus recommendations are already reflected in the minutes of the meetings.

B. Why Regions?

The first meeting opened with an overview of SF 525 and a summary of expectations for the Workgroup from DHS and Legislators. This triggered an extensive discussion of the benefits that could be derived from regions and the possible risks or downsides of forming regions. The consensus of the Workgroup with respect to pros and cons of regions is summarized in Table One below.

⁵³ August 16, August 30, September 27, October 11th and October 25th

Table One: Summary of the Potential Pros and Cons of Regions

Why Regions: Pros	Why Not Regions: Cons
<ul style="list-style-type: none"> • Create economies of scale so that scarce resources can be better used for things that consumers and their families really want. • Assure easy and equitable access to an array of core services. • Simplify navigation of the system for both consumers and providers – no wrong door. • Provide a clear locus of responsibility and accountability for the quality and effectiveness of services. • Reduce complexity and inefficiency in the system. • Reduce the duplication of administrative systems and resources. • Increase the degree of consistency in service access, delivery and funding throughout Iowa. • Maintain the value and effectiveness of local connections and relationships with other systems of importance to consumers and families. • Be respectful and responsive to geographic differences within the state. • Improve data collection and reporting. 	<ul style="list-style-type: none"> • Create another layer of bureaucracy. • Create further distance between primary consumers (and their families) and the service system that is supposed to be responsive to their needs and choices. • Create geographic or transportation barriers to accessing services. • Overlook or overpower the tradition of home rule and local county commitment to services. • Create regional barriers or differences in service access and delivery that are similar to those that now exists with the county-based system.

The Workgroup agreed that this list of the potential benefits and risks of forming MHDD regions could be used as a template for assessing recommendations from the group. That is, for each topic discussed and each consensus recommendation reached, the Workgroup would assess the degree to which the potential benefits of regions could be enhanced, while the potential downsides could be mitigated.

C. Criteria for formation of Regions

SF 525, and the Legislative history leading up to SF 525, provides substantial guidance related to criteria for the potential formation of regions. The criteria for regions summarized below are a synthesis of criteria already included in SF 525 plus additional criteria determined by the group to (a) be consistent with Legislative intent; and (b) strike a reasonable balance between the benefits of local knowledge, relationships, and personal contact with consumers and other stakeholders with the need to attain equity, consistency and economies of scale.

Recommended Criteria for the formation of regions:

1. The target population for regions should be in the range of 200,000 to 700,000 total people.
2. Per SF 525, there must be the presence of or assured access to inpatient psychiatric bed capacity for the citizens of each region.
3. Per SF 525, there must be a state-certified CMHC or a FQHC that provides behavioral health services within each region.
4. Per SF 525, regions must be comprised of contiguous counties.
5. There must be no fewer than three counties per region. (There will be no single county regions.)
6. There is no upper limit on the number of counties that can be included in a region.
7. There will be no specific criteria for minimum travel times or distances to administrative offices within a region (although such factors will have to be addressed in a region's management plan).

The Workgroup assumed that the application of these criteria would result in a total of five to 15 MHDD regions in Iowa. This is believed to be consistent with the intent of SF 525.

D. Governance and Financial Management

The Regional Workgroup recognized that governance and financial management are critical to the successful formation, sustainability and accountability of regions. The Workgroup also understood that changes in the financing of the MHDD system could alter the types of governance and funds management options appropriate for regions. For the purposes of the Workgroup discussion, it was assumed that (a) the authority for county levy funding for MHDD would be continued; and (b) county elected officials (Supervisors) or their designees would form and have majority control of the governing boards of regions.

The following is a brief summary of consensus recommendations reached after extensive discussions over the course of two meetings of the Workgroup:

Regional Governance

- There was consensus, as noted above, that the governing boards of counties would be comprised of Supervisors (or their designees) from each of the counties included in a region. Each participating county would have one Supervisor (or designee) identified to serve on the board of the region.
- There was consensus to support the "one county-one vote" principle for the regional governing boards, and to not attempt to have proportional or weighted voting among the counties participating in regions. This was done in recognition that all counties, regardless of size, have an equal stake in the success of regions while continuing to represent the interests and priorities of their local citizens.
- There was consensus that the governing body for each region should have at least three consumer/family members on the board. The method of selection/appointment could be spelled out in each region's 28E agreement. The Workgroup emphasized that the regional board and 28E agreement should emphasize balanced representation of consumers and

families from among the different disability groups receiving services under the auspices of the regions.

- There was discussion of whether DHS or another representative of the state should have a seat on the governing boards of the regions. The consensus is that because the state will enter into and enforce performance contracts with the regions, it should not also have a seat on the governing boards.
- There was consensus that providers should have an active role in advising Regions in service system planning, implementation and quality improvement, but that providers should not be included in the governing boards. It should be noted that one Workgroup member made cogent arguments for including at least one provider on the governing board. The basis for that position is (a) that providers are increasingly important partners with the MH/ID-DD system as a whole and the Counties/Regions in particular; and (b) that national health reform models of provider-sponsored accountable care organizations and health homes provide models for the roles of providers in the leadership and governance of systems of care. It was suggested that the provider council established by each region could nominate a provider to serve on the governing board. However, the majority of Workgroup members maintain the position that providers should not be included as voting members of the governing boards.
- There was consensus that 28E agreements governing regions could either support creation of a new organizational entity or could cement a regional consortium of participating counties. The suggested topic areas to be covered by 28E agreements are listed below.

Regional financial management

- There was consensus that the regions should utilize a single “checking account” into which county levy funds⁵⁴ would be deposited and from which county levy funds would be spent. It was agreed that maintaining separate accounts for county levy funds within each county was inefficient and could increase “transactional friction”. This consensus was reached after much discussion of various options, and is based on the ability of regions to use information technology to report expenditures by consumer, service and provider at the county level. This transparency of reporting will allow each participating county to maintain stewardship of locally-levied funds for MHDD services.

Topics for 28E agreements

This list of topics is derived from (a) a review of the current Iowa statute governing 28E agreements; (b) the 28E agreement now in force for the one fully-functional multi-county MHDD region in Iowa (County Social Services); and (c) examples of similar inter-local agreements from other multi-county jurisdictions in other states.

- Purpose: the goals and objectives of entering into the interlocal agreement.

⁵⁴ Plus state funds allocated to the regions and any other sources of revenues.

- Identification of the single point of accountability for the region: the governing board and its executive.
- Parties to the agreement: list of counties participating in this particular 28E agreement.
- Term: how long is the agreement to be in force, and on what time frames will it need to be renewed? (For example, if there are sunset provisions in the statute, will the interlocal agreement sunset at the same time?)
- Methods for adding new participants: on what basis and under what circumstances will the initial partners admit one or more addition counties to the agreement?
- Governing Board: membership, terms, methods of appointment, voting procedures, etc.⁵⁵
- Formation and use of consumer/family and provider advisory councils.
- Executive function: role of the Governing Board in appointing and evaluating the performance of the chief executive of the region, specification of functions and responsibilities of the executive.
- Specification of functions: (a) to be carried out by each of the partners in the agreement; and (b) to be carried out via sub-contract with external parties (does not include provider network contracts).
- Methods for funds pooling, management and expenditure.
- Methods for allocating administrative funds and resources.
- Contributions and uses of any start-up funds or related contributions made to the region by the participating counties.
- Methods for acquiring and/or disposing of property.
- Process for deciding on the use of savings for reinvestment.
- Process for annual independent audit.
- Method(s) for dispute resolution and mediation.
- Method(s) for termination of the inter-local agreement and /or for termination of the membership of one or more counties in the agreement.

E. Process and Timeframes for the Formation of Regions

The Regional Workgroup had considerable discussion of the process for formation of regions and the elapsed time necessary to form regions that can be successful, have the buy-in of county supervisors and have support of consumers, families and other stakeholders. The workgroup also recognized that there will need to be a transition period of at least a year after formation of regions during which they will draft county management plans, create provider networks, formalize the designation of access points and targeted case management, and put into place all necessary information technology and business systems to (a) be successful as regions; and (b) meet DHS criteria for performance contracting with regions (see Section H below).

SF 525 specifies a target date of July 1, 2013 for “full implementation” of the redesign plan. To the extent regions are critical to the implementation of the overall redesign plan, they will have to be ready

⁵⁵ It is assumed that the 28E agreement will form the basis and framework for by-laws to be created by each regional board. These by-laws will spell out in greater detail the structure and operations of the governing board and the formally established advisory groups (consumers and families; providers).

to begin operations and transition activities on the same date. However, it should be noted that some members of the Workgroup advocated for a longer process, with implementation to begin on or about July 1, 2014. The basis for extending the timeframe was a concern that county supervisors will need more time to understand the redesign process and to make informed decisions about the best way to collaborate with other counties in the formation of regions. A countervailing position among Workgroup members was that there is momentum for change now, and that delay could result in dissonance about the redesign objectives and process.

There was considerable consensus among Workgroup members related to the process for formation of regions. The discussion focused on attaining a reasonable balance between the benefit of “organic,” voluntary formation of regions versus the recognition that DHS would have to have some authority to act if such voluntary regions were not formed or if one or more counties were to be left out of contiguous regional groupings.

The following is a brief summary of the points of consensus reached by the Workgroup:

- There was consensus that the basic standards and criteria for regions should be established by statute as opposed to by regulation.
- In this context, there was consensus that the population ranges for regions (200,000 to 700,000) should be stated as “targets” as opposed to absolutes, to allow for some discretion on the part of DHS to approve/contract with regions not exactly meeting the population criteria.
- There was consensus that the statute should give DHS authority to:
 - Assign or re-assign counties to regions if they have not joined a region by a date certain as established by the legislature or if a region is re-structuring membership for some reason.
 - Intervene to assure continuity of services and payment for providers if a region is “breaking up” or fails to meet performance standards.
- There was agreement that if a region is ready to go at any time after enactment of the legislation,⁵⁶ it could start functioning as a region and could be eligible to receive TA from DHS.
- There was no consensus on the criteria for “when a Region is ready to start”. Criteria discussed included:
 - Identification of the member counties.
 - Meeting all regionalization criteria to be included in the statute.
 - Approval by County boards of commissioners of “letters of intent” to form a region.
 - Approval of a 28E agreement by each of the participating counties (Boards of Supervisors, it is assumed).
 - Draft of the first regional management and strategic plan (it was noted that this would be a “transition plan,” not a complete management and strategic plan).

⁵⁶ Assumed to be April 2012 or so.

These latter criteria for “readiness to begin” could be set by DHS and guidelines and/or as performance contract criteria. Given that early-adopting regions will be eligible for technical assistance from DHS, it is likely that such criteria will emphasize the commitment to form a viable region, rather than full operational readiness.

The Workgroup held further discussions of these issues at the October 25th meeting. It was decided to conceive of the establishment of regions as having two stages: “formation” and “implementation”.

For the “formation” phase, the Workgroup recommended the following criteria:

- The counties to comprise a region have been identified.
- The County Supervisors have signified their intent to join a certain region through a written letter of intent.
- The regional formation proposed by the participating counties meets all the statutory criteria included in the enabling statute enacted (hopefully) by next spring.
- DHS agrees in writing to the participating County Boards of Supervisors that the counties forming the region are in compliance with statutory requirements.

Once the following criteria have been met, a regional group can begin receiving technical assistance and support from DHS. There is no necessity for regions to wait until the end of the process to indicate their intent to form a region and to receive DHS approval.

For the “implementation” phase, the Workgroup recommended that the following criteria constitute a “readiness review” for a region to begin full operations:

- A 28E agreement has been signed by the parties.
- The County Supervisors in each participating county have voted to approve the 28E agreement.
- The County Supervisors of designees to constitute the governing board have been appointed/identified.
- An executive has been identified/engaged for the regional group.
- A “transition” regional management/strategic plan is been drafted which identifies the steps to be taken to (a) designate access points; (b) designate TCM; (c) identify the provider network; (d) define the service access/service authorization process; (e) identify the IT/data management capacity to be employed to support regional functions; and (f) establish business functions, funds accounting, etc.
- DHS has approved the 28ER agreement and the initial draft “transition” plan.

A. *Timeline for regional formation and implementation*

As noted in earlier discussions, SF 525 specifies an implementation date of July 1, 2013.

The Workgroup recommends a time line based on the criteria listed above, as described in Table Two below:

Table Two: Timeframe for Regional Formation and Implementation

Date	Activity	Comments
April 2012 or thereabouts	Enactment of the enabling statute for the MHDD system redesign.	Criteria for regions, requirements for 28E agreements, etc. are expected to be included in this statute.
January 2012 through June 30, 2013	Regions voluntarily forming and meeting statutory criteria will be eligible for TA from DHS.	
January 2012 through 2013	DHS will work with counties and nascent regions to assist with regional formation. By April, 2012, if regions have not formed, or if there are “orphan” counties, DHS may step in to negotiate and/or assign membership.	
July 1, 2013	All regions meet the “formation” criteria listed above.	Between 7/1/13 and 6/30/13 the regions could potentially be operating under “one plan” and a unified financial management system, but they could also be operating as “virtual regions as they work to meet the “implementation” criteria by 7/1/14.
July 1, 2014	All regions meet the “implementation” criteria listed above.	

F. Functions of Regions

Table Three below summarizes the planned functions of regions as determined by the Regional Workgroup.

Table Three: Functions of Regions: Consensus Recommendations

Function	Yes	No	Comments
Regional Management and Strategic Planning	X		
Designation of Access Points	X		

Function	Yes	No	Comments
Designation of TCM	X		Modalities and providers of TCM to be defined by DHS, not the regions
Designation of service management for non-Medicaid people/services	X		
Plan for Core Services	X		
Plan for Systems of Care	X		
Assure effective crisis prevention, response and resolution	X		
Provider network formation and management	X		
Provider reimbursement approaches for non fee-for-service modalities and for non-traditional systems of care providers	X		Must use standard state uniform cost report as applicable
Provider certification	X	X	Not for state licensed or certified providers, but yes for non-traditional and non-licensed providers
Grievances	X		Regional discretion within guidelines for the grievance process
Appeals	X		Must be consistent statewide
Quality Management/Quality Improvement	X		
Assurance of payment of providers	X		Invoice adjudication and direct provider payments do not necessarily have to be done within each region. However, each region needs to be accountable for timely and accurate provider payments.
Funds accounting	X		
Financial forecasting	X		

Function	Yes	No	Comments
Data collection and reporting	X		As with provider payments, certain data collection and reporting functions could be shared among regions and/or centralized, as long as each region can use its data for provider accountability, consumer access and outcomes, funds accounting, etc.
Interagency and multi-systems collaboration and care coordination	X		

The functions outlined above were determined by the Workgroup to be the essential core functions necessary for a region to be held accountable and to meet performance standards. It will be noted that the functions listed above do not rise to the level of the regions becoming “managed care companies” or functioning in a full risk environment. However, the Workgroup understood that regions will be operating with fixed global budgets,⁵⁷ and thus will need to have financial management and analytic capacities to manage effectively within their fixed budgets.

The Workgroup discussed some additional potential functions of Regions that could be considered for the future. These include:

- Management of the provision of Interim Assistance Reimbursement;
- Have regions hire and manage the Mental Health Advocates;⁵⁸
- Make Regional designated TCM entities access points to apply for the Home and Community Based Waiver programs;⁵⁹
- Give regions authority to contract with MHIs and Resource Centers for beds;
- Give Regions the ability to manage some detoxification services, shelter care and the Toledo Center; and
- Assign Money Follows the Person case managers to each region.

The Workgroup agreed that Regional management of what has traditionally been a county function, such as Interim Assistance, would logically fit within the responsibilities of the regions. With regard to the other suggested functions, the Workgroup recommended that these be initially considered as issues

⁵⁷ Comprised of county levy funds, state allocated funds, and any other recurring sources of funding.

⁵⁸ Note: the Judicial Workgroup has recommended that the Mental Health Advocates become a state function.

⁵⁹ The ID-DD workgroup has recommended that TCM entities assist with HCBS waiver applications, etc., but has noted that only DHS/IME can actually approve eligibility for the waivers.

for coordination and inter-systems collaboration. For example, access to Home and Community Based waivers will also be facilitated through the Aging and Disability Resource Centers being established by the department on Aging. The workgroup did not recommend further action on these potential functions at this time.

The Workgroup also discussed the degree to which regions should have discretion with regard to the implementation of certain regional functions. Table Four below summarizes the consensus recommendation of the Workgroup with regard to regional discretion.

Table Four: Regional Discretion to Implement Essential regional Functions

Function	Regional discretion within state standards	No discretion – must be consistent statewide	Comments
Regional Planning	X		Must follow DHS guidelines/topic areas
Designation of Access Points	X		Must be able to meet access standards established by DHS
Designation of TCM	X		Only can designate DHS/IME approved providers
Plan for Core Services		X	Core services will be defined by DHS and all regions will have to assure that core services are consistently and equitably available within each region
Plan for Systems of Care ⁶⁰	X		
Assure effective crisis prevention, response and resolution	X		
Provider network formation and	X		Must abide by state licensure/certification

⁶⁰ In this context systems of care includes non-traditional services and providers, including employment, housing assistance, informal care-giving, self direction, and other activities that are essential to maintain people in systems of care but are not defined as core services.

Function	Regional discretion within state standards	No discretion – must be consistent statewide	Comments
management			process and decisions
Provider reimbursement approaches for non-fee for services or non-traditional systems of care providers	X		Must use standard state uniform cost report
Provider certification	X	X	Yes for for non-traditional, non Medicaid services and providers that comprise systems of care; but no for providers licensed/certified by the state
Grievances	X		
Appeals		X	
Quality Management/Quality Improvement	X		
Payment of providers		X	Regional accountability but function can be shared/contracted out
Funds accounting		X	Regional accountability but function can be shared/contracted out
Financial forecasting	X		
Data collection and reporting		X	
Interagency and multi-system collaboration and care coordination	X		

G. Regional Management and Strategic Plans

The Workgroup recognized that a key function of the regions will be to develop regional management and strategic plans. The Workgroup reviewed current DHS standards for county management and strategic plans, and found these to meet most of what should be included in the Regional Plans. The Workgroup recommends that the contents of regional management and strategic plans be established by DHS rulemaking, and that the statute provide DHS the authority for such rule making but spell out the contents of the plans.

Consensus was reached on the following outline for the required regional management and strategic plans:

1. The Regional Management Plan

- Basic information on the geographic area covered by the region
 - Communities served
 - Socio-demographics of the citizens
 - Locations of major service centers, hospitals, etc.
 - Identification of the central administrative entity for the region (the single point of accountability)
 - Description of the governance board of the regional administrative entity
- Description of the roles of consumers and families (and other stakeholders if applicable) in the design, operations and evaluation of regional functions
- Specification of people to be served
 - IDD (Adults and Children/Youth)
 - Clinical/level of care criteria for service access
 - MH (Adults and Children/Youth)
 - Clinical/level of care criteria for service access
 - Children's Systems of Care
 - Other disability populations (e.g., people with BI) as provided by the Legislature/DHS
 - Financial eligibility requirements for each service population – sliding scale (if applicable)
- Specification of services to be provided
 - Core services - Transition plan during first year of operations
 - System of Care services (in addition to core services which may be included as resources on a case-by-case basis for people in systems of care)
- Specification of clinical/level of care criteria for accessing each core service and systems of care for each sub-component of the service population
- Customer relations
 - Information dissemination
 - Information and referral
 - Outreach and engagement
 - Process for consumer and family grievances (not appeals – these are included under service authorizations)

- Designation of access points
 - Locations, contact information
- Description of how services are accessed
 - Roles of access points
 - Roles of the regional administration with regard to service authorization and re-authorization (previously considered to be CPC functions)
 - Description of the service application process
 - Description of methods to assure consumers informed choice of services and providers
 - Description of how, when, why, and by whom clinical assessments are conducted
 - Description of how, when, for whom, and by whom a person centered plan is developed
 - Process and criteria for issuing notices of decision (or service authorization process) and continued stay authorization
 - Plan and protocols for coordination with Medicaid managed behavioral health care and Medicaid Home and Community Based Services
 - Process for appeals of service authorizations/decisions
 - Description of how conflict of interest and self-dealing is avoided in the service access, service planning and service authorization processes (note: this is not just an issue for TCM)
- Designation of targeted case management
 - Specify source(s) of TCM for each sub-population
 - Identify specific roles and functions of TCMs with regard to person centered planning, care coordination and service authorization for each sub-population
 - Identify how TCM-like service planning, coordination, linkage and monitoring functions may be carried out by other service modalities (e.g., Assertive Community Treatment teams, community support teams, children’s Specialty Health Homes, etc.)
 - Define the responsibilities of TCM with regard to clinical homes and multi system care coordination
 - Define the responsibilities of TCM with regard to care coordination between Medicaid and non-Medicaid services
- Designation of service management for non-Medicaid eligible consumers
- Specification of the provider network
 - Name the providers of each core service and systems of care for each sub-population
 - Specify the methods and criteria for selecting providers for the network
 - Use of state certification/credentialing processes and criteria
 - Use of national accreditation status
 - Use of statewide uniform cost reports and rate setting mechanisms
 - Provider data submission requirements
 - Assurance of provider network sufficiency
 - Choice of provider for core services
 - Cultural linguistic competence
 - Geographic access
 - Methods of provider billing and reimbursement

- Specification of the regional crisis prevention, response and resolution system
 - Crisis planning with consumers, families and providers
 - Early warning systems
 - 24/7/365 call center
 - Mobile services
 - Crisis respite capacity
 - Response to crises in ED's, jails, shelters, etc.
 - Methods for reducing arrests and incarcerations
 - Process for acute psychiatric admission if necessary
 - Specialty crisis capacities for IDD, children and youth, etc.
 - Relationships with first responders, hospital emergency departments, magistrates, advocates, etc.
- Outcome and Performance measurement
 - State domains and indicators: annual performance targets (benchmarks)
 - Regional performance objectives and indicators and benchmarks
 - Use of performance data for management of the quality and effectiveness of the region
- Regional business functions
 - Information technology and data reporting
 - Service authorization and expenditure tracking
 - Provider contracting and performance monitoring
 - Funds accounting and financial forecasting
- Description of inter-organizational relationships and functions within the region
 - County officials
 - Justice system
 - Judges/magistrates/advocates
 - Sheriff/police
 - Jail
 - Juvenile justice
 - Probation and parole
 - Education
 - Specific transition planning relationships, points of contact, etc.
 - Housing
 - Employment
 - Substance abuse services
 - Health Care
 - First responders
 - Emergency departments
 - Health centers/FQHCs
 - Description of interagency care coordination process where applicable
- Quality Management/Quality Improvement Plan (summary)⁶¹
 - Quality issues to be addressed and objectives for improvement
 - Data aggregation⁶² and analysis plan related to each issue

⁶¹ Each region is likely to have a more detailed annual QM/QI plan.

⁶² Primarily from existing and regularly collected data sources.

- Process to be used and resources to be committed to each quality objective
- Time frame for completion

2. The Regional Strategic Plan

Note: for the first year(s) of regional operation, the strategic plan will focus on transition issues and activities such as meeting core services requirements, establishing regional care coordination functions, developing regional business systems and capacities, etc.

- Needs assessment
 - How many of each defined need population (IDD, MH, Children and Youth, etc.) are estimated to need the types of services offered under the aegis of the region?
 - Description of special needs for services (e.g., health disparities, cultural or linguistic competence, etc.).
- Gaps analysis
 - What are the numeric gaps between the number of people served in each sub group and the estimated need for services for each sub-group?
 - What required or desired services are currently not as accessible or specialized as needed in the region (e.g., there is insufficient IDD supported employment capacity; there is insufficient child crisis response capacity; there are insufficient bi-lingual MH clinicians)?
 - What operational functions or systems need improvement to be more efficient and/or to provide more responsive services to constituents (e.g., improved service linkage and consumer choice; improved grievance and appeals process; more accurate data reporting)?
- Strategic objectives and action steps
 - What measurable action steps will be taken over a three year period to address identified needs and fill identified gaps in the service system?
 - What steps will be taken to improve the quality and effectiveness of the service delivery system?
 - What steps will be taken to assist providers and their direct service staff to learn new skill and provide better practice services?
- Indicators of progress towards and attainment of strategic plan objectives and action steps
 - Milestones for strategic action steps.
 - Indicators of outcomes for consumers/families and communities. (What will have actually changed for people and how will it improve their lives?)⁶³
 - Specification of incentives/rewards for attainment of or contribution to strategic plan objectives.
- Consumer and family Involvement in Plan development
- Other stakeholder involvement on strategic plan development

⁶³ These most likely will be drawn from the standard set of outcome and performance measures adopted on a statewide basis.

H. Performance Indicators for Regions

A key feature of SF 525 is the expectation that performance based contracts will be established between the state (DHS) and the regional entities. The Regional Workgroup recognized that for performance contracts to be established, there must be a clear and objective set of performance indicators to be applied on a consistent and transparent basis to assess and profile regional attainment of performance standards. The Workgroup did not attempt to define specific performance indicators or benchmarks, or to identify the sources of data for these indicators. These will be developed later in the implementation process. However, the Workgroup did identify the major domains for regional performance measurement. These are summarized in Table Five below.

Table Five: Performance Domains and Examples of Performance Indicators for Regions

Performance Domain	Examples from other States ⁶⁴	Comments
Attainment of consumer and family outcomes	Employment; community living; children in families; children successful in school; quality of life	State-defined outcome domains and indicators reported and profiled at the regional level
Attainment of system performance outcomes	Reduced inpatient bed day utilization; reduced congregate care bed day utilization; family stability & re-unification; penetration rates; children served near their family	State-defined system performance measures reported and profiled at the regional level
Attainment of defined quality standards	Accreditation; credentialing; appeal and grievance frequencies and resolutions; critical incidents; workforce development; consumer/family satisfaction	Relate to CMS quality framework for waiver services
Ease of access to core services	Elapsed time from intake to first service; timely service connections following facility discharge; no gap in services for transition age youth	
Effective and consistent operations of TCM	Attainment of consumer outcomes; consumer choice and	Must be monitored by DHS/IME, too

⁶⁴ The other Workgroups are developing recommended outcome and performance measures for Iowa. These are included just to provide examples of what types of performance indicators are typically included in these domains.

Performance Domain	Examples from other States ⁶⁴	Comments
	satisfaction with case manager	
Provider network sufficiency	Adequate provider choice; cultural and linguistic competence; attainment of consumer outcomes	
Successful crisis prevention and diversion	Reduced crisis presentations at acute care sites; reduced inpatient hospitalization; reduced arrests; maintenance of community living (family and/or independent)	
Evidence of continuous quality improvement of all regional functions, including provider quality and effectiveness and workforce development	QM/QI reports documenting progress and results of QM/QI initiatives	
Timely and accurate payment of providers ⁶⁵	90 percent of clean claims paid within 30 days of submission; provision of accurate explanations of benefits to consumers (if requested) and providers	
Accurate funds management	Clean annual audit; less than 5% variation from annual budget; attainment of administrative cost limitations	
Compliance with applicable state regulations and the performance contract between the state and the regions	Results of state monitoring and reporting of compliance with contract terms	

⁶⁵ Including this domain does not assume that each region will physically adjudicate and pay claims – it only means that regions will be responsible to see that claims are paid in a timely manner and to correct problems if they exist.

Performance Domain	Examples from other States ⁶⁴	Comments
Timely and effective resolution of grievances and appeals	Meeting all timelines for appeals and grievances; low frequency of reversal of service authorization decisions on appeal; documented use of grievance and appeal data in QM/QI activities	

The Workgroup emphasized that while each region should be held accountable for and profiled on a standard set of performance indicators, each region should also establish “aspirational” goals and attendant performance measures related to their own strategic and QM/QI plans.

I. Residency

The Workgroup considered the definition and application of “residency” as it applies to regional administration of funds. The objective of the discussion was to assure that the concept of residency would become another form of “county of legal settlement”. The Workgroup agreed that the definition of residency as adopted by the MHDD Commission should be implemented. This definition is included as Appendix D of this report. The Workgroup also recommends that core services operated under the aegis of regions be considered as statewide services, and that regional residency not be used as a criterion for denial of service if other eligibility and clinical criteria are met. The Workgroup recognizes that there may occasionally be disputes about legal responsibility to pay for a person’s services, and that there is already a resolution mechanisms available in statute which can be triggered when necessary. The Workgroup agrees that services should be continued pending the outcome of that review mechanism. Finally, the Workgroup recognized that uniform data about service access and utilization will be more readily available under the reformed system, and therefore, cross regional migrations for service access can be tracked and documented. If a disproportionate impact can be documented from the data, DHS could use state funds to remedy the imbalance.

J. Conclusion

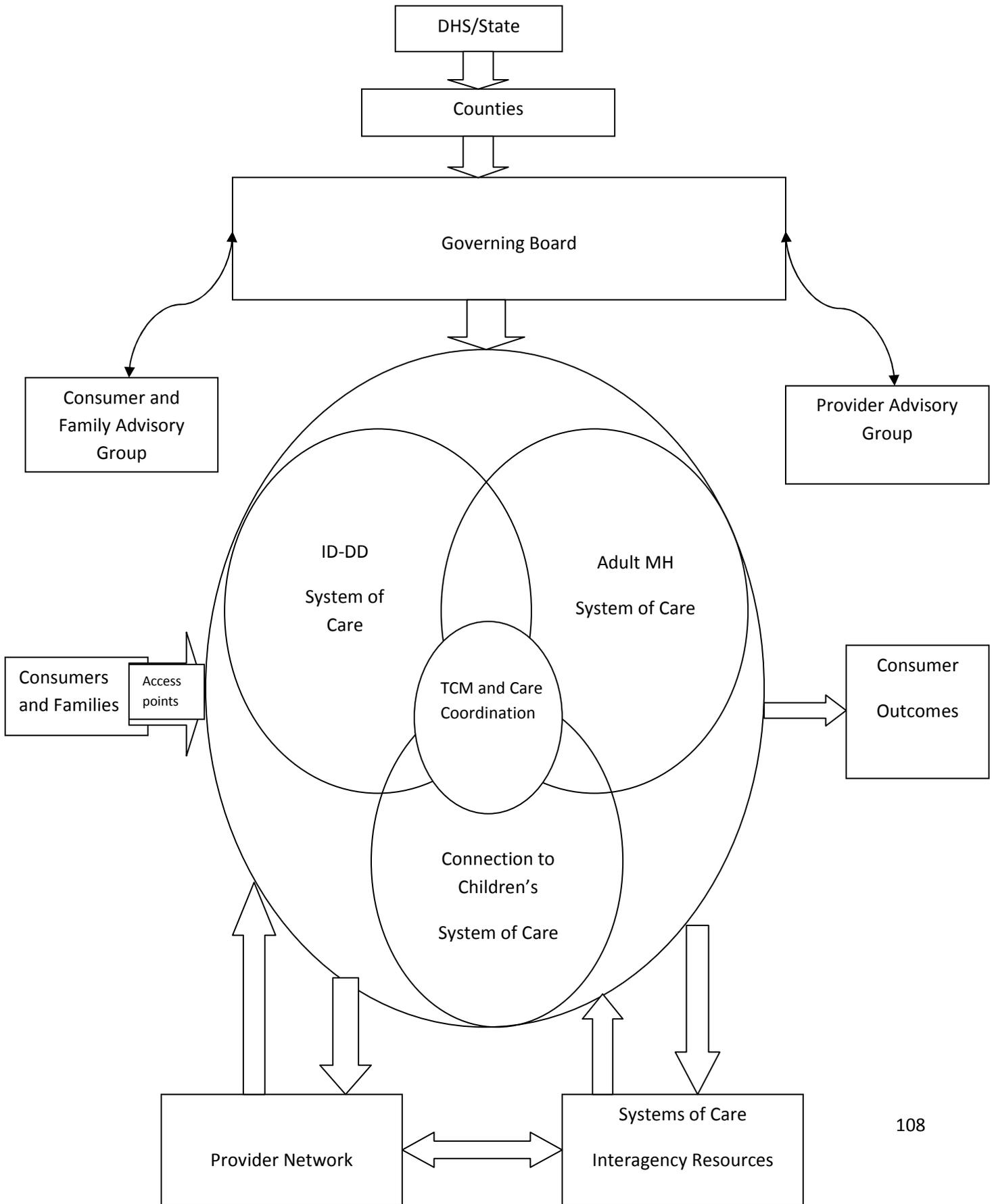
Taken all together, the recommendations of the regional Workgroup create a vision for a regional structure that incorporates the following features:

- Establishment of a single point of clinical and financial accountability for non-Medicaid services for all citizens of Iowa.
- Establishment of a regional entity that can build on the best elements of current county systems while at the same time improving access to core services and attaining consistency of service access and delivery.

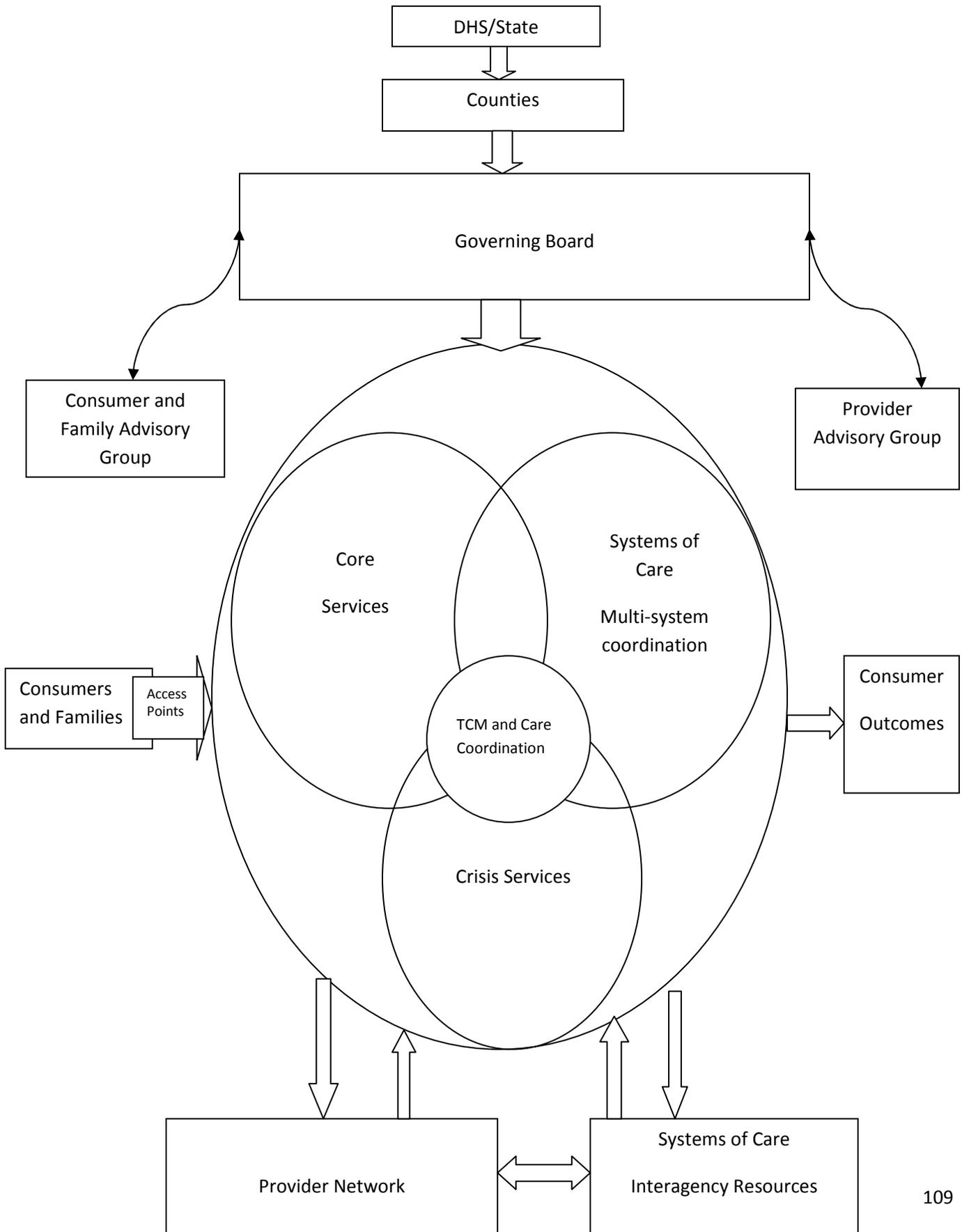
- Maintenance of the strength of local interagency and multi-systems arrangements and relationships while also attaining some economies of scale.
- Creation of regional entities that can function as the unified managers of systems of care and different service modalities for consumers with different disabilities and service needs and choices, while at the same time fostering integration, coordination and reduced duplication between these various systems of care and service modalities.

The two charts on the following pages display these integrative functions of regions: first for the different disability populations, and second for core and system of care service modalities. The charts reflect the vision communicated in the above recommendations of the regions as the local “face” of MH, ID-DD and children/youth services. They also reflect the regions’ responsibilities to facilitate access to and coordination of care across multiple systems.

System of Care Coordination at the Regional Level



Service Integration and Coordination at the Regional Level



VIII. REPORT OF THE JUDICIAL WORKGROUP (DHS)

The Judicial-DHS workgroup consisted of 24 members representing Judges, District Court Administration, Clerks of Court, Private Agencies, the Ombudsman's office, Department of Human Services' Mental Health Institutions, Department of Corrections, Iowa Hospital Association, Community Mental Health Centers, County Central Point of Coordination Coordinators, Chief Jailer, Attorney General's office, Olmstead Consumer Task Force, and Mental Health Advocates. David Boyd, State Court Administrator for the Judicial Branch and Karalyn Kuhns, former Interim Administrator for the Division of Mental Health and Disability Services with the Department of Human Services, were the co-chairs of the workgroup and Donna Richard-Langer facilitated the workgroup.

Senate File 525 charged the judicial branch and department of human services to continue the workgroup implemented pursuant to 2010 Iowa Acts, chapter 1192, section 24, subsection 2, to improve the processes for involuntary commitment for chronic substance abuse under chapter 125 and for serious mental illness under chapter 229. Nine separate tasks were identified for the workgroup to address.

The workgroup members read best-practice materials and case studies and heard subject matter experts that fostered interactive dialogue among the workgroup members and public resulting in solid recommendations to address the issues.

Workgroup Tasks, Summaries and Recommendations

I. The current provision of transportation by the county sheriff

Discussion points

- There is a serious issue with the amount of time and manpower it takes to transport a respondent in the commitment process.
- Transportation is the biggest issue for many counties in the committal process.
- County data indicates that \$697,520 was spent by Sheriffs for transportation for 6,950 people to be transported (12/1/10 data provided by DHS). Story County spends \$60,000 on transportation each year.
- Transportation issues need to be addressed while focusing on safety, efficiency and the needs of the consumer.
- The Southeast Iowa Crime Commission has a program that does transportation for several counties and this has worked well for many years.

Workgroup Recommendations:

- A. Transportation for Court Committal process should be a core service. This includes transportation to a Community Mental Health Center (CMHC) or other designated facility for a mental health evaluation, to a hospital for admission and to a court hearing if the patient is attending.

- B. Regions designate a transportation coordinator. The transportation coordinator where the patient is located/presented is to assign a sheriff or other appropriate transportation based on safety and the patient's best interest.
- C. Consideration should be given for actual costs to be paid, as the current system does not reimburse at full cost.

2. Civil Commitment Prescreens

Discussion Points

- Larry Hejtmanek from Eyerly Ball Community Mental Health Center presented on the Court prescreen service in Warren County in 2007-2011.
- Pre-commitment screenings grew out of a frustration to find a hospital bed for commitments.
- When someone comes into the clerk's office to file commitment papers, they need to be offered an opportunity to speak to a mental health professional.
- Data presented from Warren County indicates that with pre-commitment screenings, 60% were identified as not appropriate for involuntary commitment. The respondent was more appropriately referred to their primary care physician, substance abuse treatment, outpatient treatment and other services in the community.
- Warren County pre-committal screenings were discontinued following a complaint to the court, noting there is no provision in Chapter 229 that allows for a pre-commitment screening when someone is referred for involuntary commitment.
- The screenings need to occur in a timely manner and currently some Community Mental Health Centers cannot serve someone for 4-6 weeks.
- Data submitted by Dan Royer, Iowa Hospital Association: From 2nd Quarter 2010 - average length of stay for an inpatient behavioral health patient was nearly 6 days and cost nearly \$9,000.

Transfers: 2010 (full year) - approx. 2,600 patients were discharged to or transferred to an inpatient psych unit from an Emergency Room (ER) - at an average cost of \$1,700 for the transfer. That's nearly \$5 million for ER transfers alone. This does not include the cost of care received in the ER if needed. Also does not include patients transferred from acute inpatient to inpatient psych (at another hospital). It's from the ER only, but again, illustrates a point that the ER is not an appropriate access point to the behavioral health (BH) system.

The key point from a diversion perspective is to try and keep people out of the ER and to provide an alternative, more appropriate "entry point" into the BH system. This will save money and get people the right level of care at the right time.

Workgroup Recommendations:

- A. Provide a provision in Chapter 229 that allows for a pre-commitment screening process prior to the initial filing.
 - B. Pre-commitment screening service for involuntary commitments needs to be a core service.
 - C. The pre-commitment screening services would be the role of the CMHC or a designated facility contracted by the region.
3. **Court authorization to order an involuntary hold of a patient under Chapter 229.10 for not more than 23 hours who was not initially taken into custody, but declined to be examined pursuant to a previous order.**

Discussion Points

- Clarification of prescreen/assessment/observations. Pre-commitment screening for appropriate services is what is needed.
- Maybe a 23-hour hold for a screening could take place in a hospital emergency room. Maybe at a hospital without a psychiatric bed.
- A pre-commitment screening is for a person who does not need to be in immediate custody.
- Story County has Crisis Beds available in a location separate from the hospital staffed 24 hours with access to psychiatric staff. It is less expensive than a hospital bed. It is funded by Magellan and the county.
- The Acute Care Task Force recommended in 2009 that crisis stabilization services be available 24 hours.
- Currently an emergency commitment cannot be ordered between 8:00am and 4:30pm. It needs to be available anytime.

Workgroup Recommendation:

- A. Make a change in Chapter 229.22 to allow for the 48-hour hold to be available 24 hours a day. This would necessitate a change in section 602.6405, subsection 1, concerning limitations on non-lawyer magistrates.
4. **Revising requirements for Mental Health Professionals involved in the court committal process.**

Discussion Points

- There are two definitions of mental health professionals in Iowa Code, chapter 228.1 (Mental Health Professional) and Chapter 229.1 (Qualified Mental Health Professional).
- A two-tiered system makes sense but this occurs in 228, not 229.

- Inclusion of Physician Assistants makes sense, not just Advanced Registered Nurse Practitioners (ARNP). However, Physician Assistants must work under the supervision of a physician and an ARNP does not.
- Regarding the issue of who makes the report to the court, the physician must evaluate the patient and he/she generally testifies by telephone. The physician incorporates the observations of those working with the patient, which may include professionals other than those designated in 229.1. Therefore, there is no need to include a definition of a qualified mental health professional in chapter 229. The physician will utilize the information from those working most closely with the patient, and those that have observed the patient. Therefore a qualified mental health professional does not need to be defined.

Workgroup Recommendations:

- A. Remove from Chapter 229 the title and definition of Qualified Mental Health Professional and any reference to it.
- B. Support the provisions in Chapter 229 that only a physician is to examine the patient and provide a report to the court during the committal process.
- C. Support the provisions in Chapter 229 that a Psychiatric Advanced Registered Nurse Practitioner may provide the annual report to the court for an outpatient committal.

5. The role, supervision and funding of mental health and substance-related disorder advocates.

Discussion Points

- Mental Health Advocates are appointed by the Chief Judge and paid for by the county.
- There is no consistency in the compensation and benefits of mental health advocates, nor what is funded.
- Presentation by Rose McVay, Mental Health Advocate for 7th Judicial District. Additional information provided by Beth Baldwin, Court Administrator and Kelly Yeggy, Mental Health Advocate.
- A mental health advocate job description has been developed and approved by the Judicial Council, but it has not been consistently utilized.
- Section 229.19 of the Code implies that the state supervises the mental health advocate position; however, there is not a state entity designated for this responsibility and the position is handled differently depending on the county. The position needs consistent training, policy, procedure, audits, and oversight across the state.
- What about mental health advocates for children, those with substance abuse and those committed with other disabilities? Currently most advocates are assigned to adults with mental health issues.
- Children that are committed have either their parents, and if they are not available, then DHS is generally involved. In substance abuse commitments, they are short term, and after detox they are generally better able to advocate for themselves. For those with co-occurring substance abuse and mental health, a mental health advocate would be beneficial.

Workgroup Recommendations:

- A. Amend section 229.19 to change legal settlement to residency.
- B. Statewide implementation of the mental health advocates job description adopted by the Judicial Council.
- C. The mental health advocates need a single point of accountability that is independent and autonomous.
- D. This one entity needs to oversee policy, training, supervision, and audits of the advocate. The majority of the workgroup recommends that this not be the judicial system, but rather an administratively attached specialize unit such as the Child Advocacy Board, the public defenders office or the Court Appointed Special Advocate Structure.
- E. Advocates should be appointed to individual cases based on where the individual resides or at the discretion of the state authority overseeing mental health advocates.
- F. The funding should be moved from the county to the state. Consistent reimbursement standards need to be developed.
- G. An advocate may be assigned in cases of dual commitment (chapter 125 and 229).

6. Implementation of jail diversion programs

Discussion Points

- Karen Herkelman presented on the Black Hawk County program that offers assessment and treatment services for mentally ill offenders.
- In Black Hawk County the CPC funded a full time Community Treatment Coordinator with the Department of Corrections in Waterloo. This position identified mentally ill offenders in the Black Hawk County Jail and completed an assessment to identify offenders who may be appropriate for services in the community.
- The treatment coordinator initiated contact with various agencies to determine resource options available for the offender and presented this to the court, attorneys and probation/parole officers regarding possible alternatives to jail and prison.
- Community collaboration is the key for this position to be successful.
- In SFY 11, Black Hawk County screened 174 inmates in jail and 88% were released. Dubuque County screened 43 inmates in jail and 93% were released.
- Three years into the program 74% of those served have integrated successfully back into their community. Twenty-six percent had a re-arrest.
- Mentally ill offenders are housed longer and they have burned many bridges, especially with family.
- If the mentally ill offender can manage his/her mental health issues he/she can be released and do well.
- We need community education for law enforcement, corrections staff, county attorneys, and defense attorneys.
- David Higden presented on the Polk County jail diversion program. The mobile crisis team helps approximately 2,000 individuals a year and only 3% of the 2,000 actually ends up in jail. Of those not going to jail, 65% of the people present mental health or substance abuse problems

and were resolved by the team in the field. This reduces the hours that police spend during a crisis.

- David Higden also reviewed the Bexar County, Texas program. The center works with homeless issues, substance abuse and mental health, conducts medical triage assessments and mental health evaluations, medical screening, lab and radiology, jail and detention medical consultation and clearance, operates a sobering and detoxification unit, and a drug court is on site.
- The center provides comprehensive services for most in need, provides increased availability of comprehensive substance abuse services, reduces barriers to service access and increases motivation with treatment compliance, employs evidence based practices known to be effective, and utilizes system tracking and outcome based effective treatment.
- During the first year of operation in Bexar County, 1,720 people were diverted from jail; the booking costs were \$2,295 for a total savings of \$3,947,400.
- The Sequential Intercept model was presented.

Workgroup Recommendations:

Justice related/involved services needs to be a core service. This includes:

- A. Specialty training for Law Enforcement and Department of Corrections personnel similar to that provided in Crisis Intervention Training (CIT) or Mental Health First Aid.
- B. Mental Health Court including both Diversion and Condition of Sentencing models.
- C. Jail Diversion program

Suggested elements of jail diversion would be:

- ❖ Intensive Case Management.
- ❖ Screening and Assessment.
- ❖ Pre-Arrest: The goal prior to arrest is to keep the individual out of the system.
- ❖ Single point of contact for pre-arrest, post-arrest and pre-release.
- ❖ Assess level of assault utilizing mental health criteria for alternate placement.
- ❖ Discharge Planning: Assistance with housing, medicine and employment.
- ❖ Sub-Acute level of care: 23 hour type of model that directs people to the right level of care.
- ❖ Cost Avoidance: Must assist the population on the front end.

7. Comprehensive training of law enforcement in dealing with persons in crisis

Discussion Points

- Presentation by Cyndee Davis and Kim Wadding, Iowa Law Enforcement Academy.
- The academy has incorporated training on special needs, stress management and mental health education.
- Four hours of mental health is offered during field training. Mental health training is offered post academy as an in-service training option, but it is not mandatory. Twelve hours of

Mental Health First Aid is offered once a cadet becomes an officer; however, it is not mandated.

- There are programs other than those offered by the Iowa Law Enforcement Academy through which law enforcement may receive training, so there is not a core mental health curriculum requirement across the state.
- The Law Enforcement Academy would like to have more instructors trained as trainers for Mental Health First Aid.

Workgroup Recommendations:

- A. Strongly recommend that officers receive additional training in mental health each three year period similar to that provided in CIT and Mental Health First Aid.
 - B. Strongly recommend that consumers are part of officer training.
- 8. Residential care facilities: educating judicial magistrates and advocates on ways to enhance the consistency of services for individuals who are court ordered to a residential care facility and address issues involved with identifying facilities with the capacity to provide an appropriate placement for an individual who has been arrested, charged or convicted of assault, a forcible felony, arson or an offense that requires registration as a sex offender under Chapter 692A.**

Discussion Points

- The traditional populations served in Residential Care Facilities (RCF's) are individuals with chronic and persistent mental illness. The current populations served are with higher and more acute needs than when the RCF rules were first written.
- RCF's are treatment oriented, including stabilizing individuals, teaching living skills and developing support for when they live independently.
- There is no consistency to how RCF's are funded. There are non-profits, for profits and one in Story County that is county funded.
- A RCF's determines its own admission criteria and protocols. An application includes a physical report, TB status, funding information, and a social history.
- The 12/15/10 Governor's Developmental Disabilities Council Report to the Governor was reviewed.

Workgroup Recommendation:

- A. Placement to a residential care facility should occur only after notification and acceptance by the facility.

9. Mental Health Courts and Identification of promising reforms related to mental health and the criminal justice system.

Discussion Points

- Chief Judge Bower presented the Equinox Program in Blackhawk County, which is a jail diversion program completing its second year.
- Mental Health courts have diverted people from jail, prison and inpatient hospitalization (data to be sent by Judge Bower).
- There must be a team approach with the judge, attorneys, mental health providers, probation/parole staff, consumers, and family. Staff needs to be consistent, and attend mental health court meetings regularly.
- Trust and respect is essential, as well as training for professionals involved. Defuse and De-escalate are two important skills.
- Judge Rickers also added information from Idaho and Seattle regarding mental health courts that have been successful.
- There are two known mental health courts in Iowa - Woodbury County and Blackhawk County – and both started with grant funding.

Workgroup Recommendations

(Recommendation is included with the recommendation under (F) Jail Diversion.)

IX. REPORT OF THE BRAIN INJURY WORKGROUP (DHS)

Introduction

Senate File (SF) 525 charged the MHDS Brain Injury (BI) workgroup with: “Reviewing best practices and programs utilized by other states in identifying new approaches for addressing the needs for publicly funded services for persons with brain injury.” Although the timeframe for the BI work product was established as December 2012, the workgroup felt strongly that their work should be considered in conjunction with the entire redesign project. The workgroup translated the identified best practices into specific recommendations as necessary actions for improving Iowa’s system for serving people with brain injuries. The recommendations reflect both a short and long term implementation timeline in recognition of the need to further develop the brain injury service system.

According to the Centers for Disease Control and Prevention (CDC), nearly 1.7% of people in Iowa or approximately 50,000 Iowans are living with long-term disabilities caused by a traumatic brain injury (CDC 2008). Brain injury is the most debilitating outcome of injury characterized by the irreversibility of its damages, long-term effects on quality of life, and healthcare costs. Brain injury can be acquired, e.g., stroke, or traumatic in nature and Iowa’s aging population and increasing numbers of military service veterans will drive up the rates of incidence.

Prompt and comprehensive continuity of care for people with brain injury decreases expensive and untoward medical outcomes and associated secondary conditions. Secondary conditions can include multi-occurring disorders, defined as “any person of any age with ANY combination of any MH condition (including trauma) and/or developmental or cognitive disability (including Brain Injury) and/or any Substance abuse condition, including gambling and nicotine dependence, whether or not they have already been diagnosed.” (See Section V. B) Continuity of care is the process by which the patient and the physician are cooperatively involved in ongoing health care management toward the goal of high quality, cost-effective medical care (American Academy of Family Physicians).

The vision of Olmstead is, “A life in the community for everyone.” The Brain Injury workgroup developed recommendations whose outcomes will help people with brain injury and other disabilities, of any age, receive supports in the most integrated setting consistent with their needs in concert with Iowa’s Olmstead Plan.

Recommendations

The Brain Injury Workgroup recommendations, based on best practices in Iowa and around the country, are designed to create a continuum of care that is affordable, accessible, available, appropriate and acceptable to all individuals with brain injury in all regions. The recommendations are prioritized based on the degree of impact on improving the existing system (high) and the degree of deployment difficulty (low). Optimized core services, expanded core services, and new core services, are ranked separately.

See Appendix F for details of each ranking, including best practice citation, short and long-term implementation, the impact/difficulty score and necessary policy action.

Core Services

All services currently offered to people with brain injuries should continue to be offered as core services. Current core services are all programs included in the Brain Injury Services Program at the Iowa Department of Public Health (IDPH), and Medicaid State Plan Brain Injury Services, and Home and Community Based Brain Injury Waiver Services at the Iowa Department of Human Service (DHS), as listed below.

- Neuro- Resource Facilitation (NRF). (IDPH)
- Iowa Brain Injury Resource Network (IBIRN). (IDPH)
- Community Based Neurobehavioral Rehabilitation services funded through state Medicaid dollars. (DHS)
- Medicaid Home and Community Based Services (HCBS) Brain Injury Waiver program and services. (DHS)
- Post-Acute inpatient skilled nursing level of care and outpatient neurorehabilitation. (DHS)
- Medicaid-funded intensive neurobehavioral services at the hospital, nursing facilities (including SNF and ICFMR), and community based services, currently unavailable in Iowa to children and adults (PMIC). (DHS)
- Other Medicaid Plan Services applicable to Brain Injury, e.g., acute care, NF, etc. (DHS)
- Brain Injury Registry Outreach letter. (IDPH)

See Appendix E for definitions of Neuro-Resource Facilitation, the Iowa Brain Injury Resource Network, Neurobehavioral and Neurorehabilitation services.

Optimized Core Services

Optimized core services are modest to relatively low cost, high impact adjustments to current core brain injury services.

Prioritized Ranking for Optimized Core Services	Recommendation
A-1	Determine eligibility <u>at the time of application</u> for Medicaid Waiver funding based on fiscal, functional and diagnostic criteria, immediate referral to NRF and other services regardless of eligibility.
A-2	Implement uniform brain injury assessment process and tool across regions.
A-3	Prescreen individuals for brain injury at all access points (i.e., MHDD, ID, Substance Abuse, county veterans offices, waiver application, etc.).
A-4	Replace current assessment tools for the Brain Injury Waiver with a more sensitive, standardized tool to assess cognitive, psychosocial and functional abilities and needs, to determine initial and ongoing eligibility for state brain injury services.

A-5	Provide funding to eliminate any waiting period for eligible individuals within the HCBS BI Waiver, to decrease expensive and untoward medical outcomes and associated secondary conditions.
A-6	Increase availability of acute to home neurobehavioral services across the service continuum to reduce need for out-of-state placement and increase ability to bring people back to Iowa.
A-7	Increase availability of post-acute neurorehabilitation services across the service continuum to reduce need for out-of-state placement and increase ability to bring people back to Iowa.

Expanded Core Services

Prioritized expanded core services refer to moderate to mid costs, high impact adjustments to current core brain injury services.

Prioritized Ranking for Expanded Core Services	Recommendations
B-1	Require regional administrative hubs to participate as IBIRN sites with adequate funding for regional resource materials (i.e., Brain Injury Tote Bags).
B-2	Amend Iowa Code Chapter 135.22 Brain Injury Registry to align with the brain injury definition in IAC 441-83.81(249A) and require the BI Registry notification in administrative rule.
B-3	Reduce the lag time for receipt of outreach letters generated from the Brain Injury Registry regarding brain injury services in order to increase timely access to services and supports.
B-4	Expand the scope of the Residential Care Facilities specialized licensure (IAC 481-63.47(135C)) to include Brain Injury.
B-5	Expand the current NRF services to accommodate the significant increase in utilization of this service to allow NRF caseloads to align with national averages and to develop veteran-specific NRF services.
B-6	Optimize conflict-free case management for brain injury services by developing specialized brain injury case management within the case management structure.
B-7	Increase and provide adequate funding for the unfunded Brain Injury Service Program cost-share component at the IDPH.
B-8	Elevate the Governor's Advisory Council on Brain Injuries to the Brain Injury Services Commission to expand the current scope to identify it as the state policy-making body for the provision of services to Iowans with brain injury.

New Core Services

Prioritized new core services are moderate to mid costs, moderate to high impact new services, which are absent from the current service system.

Prioritized Ranking for New Core Services	Recommendations
C-1	Implement a standardized brain injury screening tool identified in collaboration with the Brain Injury Services Commission (see item B-8) to be implemented at all access points to include, but not limited to: all agencies as required by 225C.23, domestic violence shelters, mental health centers, substance abuse treatment centers, emergency rooms, crisis intervention, homeless shelters, senior centers, schools, correctional facilities, and non-profit or community based organizations providing human services, etc.
C-2	Form and support a state of Iowa interagency, intergovernmental Brain Injury Coordinating Committee to meet quarterly to continue deploying best practices for brain injury services.
C-3	Review and revise funding mechanisms, rate structures, service definitions, and reimbursement methodologies, to emphasize and incentivize person-centered, community-based employment and interagency collaboration.
C-4	Deploy brain injury competency training and education in existing and new crisis intervention programs.
C-5	Deploy and expand tele-health services for Iowans with brain injury and multi-occurring disorders.
C-6	Develop a statewide, interdisciplinary brain injury consultation team to serve the regions.
C-7	Deploy brain injury competency training and education in existing and new jail diversion programs.
C-8	Deploy and expand services to engage survivors of brain injury and their families in on-going education, peer support, mentoring, and advocacy.
C-9	Develop and deploy a web-based, searchable, comprehensive brain injury resource information and services database/directory.
C-10	Provide specialized brain injury training for direct service providers across the service array to include but not limited to human services, rehabilitation, nursing, home health agencies, assisted living, community and facility based providers, correctional, jail diversion, crisis intervention, and judicial agencies.
C-11	Provide access to flexible and reliable transportation services for brain injury rehabilitative, medically necessary care and community integration.
C-12	Deploy phone follow up service to individuals receiving brain injury registry outreach letter.

C-13	Develop acute inpatient hospital-based neurobehavioral treatment programs to prevent out of state placements for lowans with brain injury and multi-occurring disorders.
C-14	Develop and deploy a follow-up outreach service for individuals served by the Iowa Brain Injury Resource Network (tote bag).

IX. REPORT OF THE PSYCHIATRIC MEDICAL INSTITUTIONS FOR CHILDREN (PMIC) WORKGROUP (DHS)

Introduction

The Iowa General Assembly directed the Department of Human Services (DHS), through SF 525 to establish a Psychiatric Medical Institutions for Children (PMIC) transition committee ("Transition Committee). Section 525 directs the Transition Committee to develop a plan for the transitioning of the administration of PMIC services from a fee for service program administered by the Iowa Medicaid Enterprise (IME) to the Iowa Plan, through which the IME provides managed behavioral health care to its Medicaid enrollees. The work of this Transition Committee is happening at the same time that DHS has convened a two-year effort to overhaul its mental health system for children. Section 525 required specific representation on the Transition Committee. The Administration developed this preliminary report to detail the planned work of the Transition Committee to review the current PMIC program and propose how the program should be modified as it moves to the Iowa Plan.

Interaction with the Children's Mental Health Initiative

DHS is engaged in a statewide stakeholder effort to improve the children's/youth's mental health system in Iowa. The PMICs play an important role in the system today, and will continue to do so in the future. Because the improvements to the children's/youths' mental health system will occur in phases and will not be completed by the planned transition of PMIC services to the Iowa Plan in July 2012, there are a number of issues identified in SF 525 that will be addressed instead through the larger effort. The following issues will be considered mainly in the larger effort, but will also be vetted with the PMIC Transition Committee, where appropriate:

- Development of specialized programs to address the needs of children in need of more intensive treatment that are underserved (4a);
- Navigation, access and care coordination for children in need of services from the children's/youth's mental health system (4b1);
- Integrating children's/youth's mental health waiver services to ensure availability of choices for community placement (4b2);
- Evaluating alternative reimbursement and service models that are innovative and could support overall system goals (4b5);
- Evaluating the adequacy of reimbursement at all levels of the children's/youth's mental health system. (4b6) (Note: the PMIC Transition Committee will be specifically discussing PMIC reimbursement rates and inclusion of ancillary services within those rates.);
- Developing profiles of the conditions and behaviors that result in a child's/youth's involuntary discharge or out of state placement (4b7); and,
- Evaluating and defining the appropriate array of less intensive services for a child/youth leaving a hospital or PMIC placement (4b8).

As Jennifer Vermeer, the Director of the Medicaid enterprise of the DHS chairs both groups, she will ensure that the groups appropriately collaborate.

Process for Developing a Transition Plan and Issues for Discussion

The Transition Committee held its first meeting on October 4, 2011. At this meeting, the Transition Committee discussed the process for developing the transition plan for moving coverage of PMICs from fee-for-service into the Iowa Plan. Many Transition Committee members participated in the Remedial Services Transition Committee effort last fall and agreed to follow a similar process for this effort.

The Transition Committee agreed to hold two working committee meetings.⁶⁶ At those meetings, the Transition Committee will discuss overall goals for the transition of PMICs to the Iowa Plan and discuss specific issues raised in the SF 525 including:

- Identifying admission and continued stay criteria for PMIC providers (4b3);
- Evaluating changes in licensing standards for PMICs, as necessary (4b4); and,
- Evaluating and defining the standards for existing and new PMIC and other treatment levels (4b9).

In addition, the Transition Committee will discuss reimbursement rates for current PMIC services, and will utilize a sub-committee to discuss payment for ancillary services by PMICs beginning July 2012, as required by the Centers for Medicare and Medicaid Services.

Next Steps

The Transition Committee will work diligently over the next six weeks to develop a draft final transition plan to be submitted to the legislative interim committee by December 9, 2011 as required by SF 525 and will address any concerns made by the legislative interim committee into a final plan to be developed by December 31, 2011. This final plan will be submitted to the general assembly by January 16, 2012.

⁶⁶ The meetings are scheduled for November 4, 2011 and December 7, 2011.

X. INTEGRATION AND TRANSITION PLANNING

The previous chapters of this report have provided considerable detail about consensus recommendations related to the specific objectives and topics covered by each Workgroup as defined by SF 525. Each chapter, standing alone, provides a road map for redesigning and reforming services for specific populations, and for addressing the structure, management and operations of desired systems of care for each priority population. Each chapter also points to issues and opportunities for cross-over and coordination among the recommendations. For example, each Workgroup has addressed people with dual or multiple conditions that will necessitate collaboration across services, providers and funding streams. However, by themselves the recommendations do not communicate a picture of a fully integrated and logically consistent system.

In Chapter VII, **Regionalization**, a core concept of the recommendations is to establish a platform which can effectively manage coordination and collaboration among various systems of care and between these systems of care and other essential services such as housing and employment. This platform is specifically designed to provide a unified home base and single point of accountability for the integration of services around people's needs and choices. Uniform system management and accountability across systems is integral to attainment of the primary benefits of regional structures as outlined in Chapter VIII.⁶⁷

An important feature of the integrated and unified systems contained in the consensus recommendations is that the system is driven by people in need of services. The system is not compartmentalized by age, by disability, by eligibility or by funding stream. Rather, it is organized to assure people a "no wrong door" experience regardless of where they present in the system. Facilitated access, consistency of service delivery and equity of service resource deployment are hallmarks of the recommended new system.

Uniform system management and integration of services does not mean that all consumers receive the same types of services, or that there's a one-size-fits-all model for service access, planning, delivery, and monitoring. Rather, the recommendations of the workgroups make it clear that there are needs for specialization and disability-specific expertise across all elements of the system. The importance of the unified single point of accountability is to facilitate movement between disability and funding stream silos for people with multiple needs. It is not intended to blur or mitigate the specific clinical expertise needed for each priority population.

⁶⁷ The features and functions of the uniform and integrated platform for service management would be necessary to develop even if there were no local funds and no local governing boards. To our knowledge, no states operate systems of care without the benefit of regional/local intermediaries.

Integration across multiple systems

Adults and children in need of mental health, BI, or ID-DD systems interventions rarely just need one single service. Frequently, their conditions are multiple and complex, and their needs and choices change over time. In addition, consumers and their families age, their eligibility for various benefits changes and their living situations can evolve. For all these reasons, the redesigned system must have a clear and operational obligation to its consumers and constituents to assist them to manage transitions and cross system service planning. This is why all the recommendations include a focus on systems of care as well as on specific core services.

In addition to coordination and collaboration within the ID-DD, BI, mental health and children's systems of care, there are three other types of integration and coordination necessary. These are:

- **Access to, joint service planning with, and service coordination among all the other delivery systems affecting a person's ability to have a life in the community.** These include education, employment, housing, transportation, law enforcement, adult and juvenile corrections, and substance use services. Each of these systems has its own eligibility rules, service modalities and resource limitations. Barriers to access to these various systems is known to be one of the major reasons people get into crises, need hospitalization, lose their program or home setting, or become institutionalized.
- **Access to and coordination with physical health care.** People with ID-DD or MH disabilities are known to have poor access to primary healthcare, dental services, and specialty and long term healthcare services. All people with disabilities have a high potential to have chronic health conditions in addition their primary disability. In most states, children with multi-system involvement (Youth Services, Mental Health, Juvenile Justice), have no primary care physician and/or infrequent contact with physical health care. For all these reasons, a critical component of the recommended systems of care in this report is facilitated access to and coordination with physical and specialty health services. In several places the report includes recommendations to implement Health Homes. This is an allowable activity for Medicaid under the ACA, and could provide viable and flexible models for attaining good coordination between the disability services systems and the physical health systems. However, there are other current and promising models for achieving integration, and different approaches can work for different people.
- **Integration between Medicaid and Non-Medicaid consumers and services.** There are many ways in which the Medicaid and non-Medicaid services systems need to collaborate and interact in Iowa. In some cases, people move back and forth between Medicaid eligibility and non-eligibility. In other cases people need both Medicaid funded and non-Medicaid funded services. Currently, the state behavioral health managed care contractor (Magellan) collaborates with the County-based CPCs to coordinate care for people who receive both Medicaid reimbursable services and non-Medicaid services. There are many other examples of coordination, including cross system activities related to Targeted Case Management and Home and Community Based Services Waivers. The existing degree of communication and collaboration between Medicaid and non-Medicaid people and services needs to be strengthened and expanded in the reformed system. In addition, as more individuals and families become

eligible for Medicaid after 2014, there will be a need to manage and facilitate the movement of people (service participants), services, and providers into the Medicaid funding stream.

Transition plan and phasing from current services to new recommended core services

As noted throughout the recommendations in this report, there will be a need to transition from the current system to the desired new system. This transition process must first and foremost be respectful of consumers and families, some of whom have been living or participating in their programs for long periods of time, and who are comfortable with their existing provider(s) of services. The transition must also be respectful of providers, many of whom have been doing what the system has asked of them for years, and who may have substantial capital investments in their program facilities. Finally, the transition must be cognizant of the available resources, both resources already in the system, and in any new resources that may become available. Clear choices will have to be made on the amount of transition progress that can be made in the context of available resources.

Transition planning and the implementation of system reforms are not linear processes. Rather, they are iterative, taking small steps and a prelude to being able to implement bigger changes later on. Early steps in the transition process are designed to: (a) provide learning and motivation to people in the system by producing quick and positive results; and (b) generate additional resources to support implementation of the next steps in the reform process. This is particularly true in an environment with constrained resources in which some system reforms must be put into place before larger scale reinvestments of existing resources can be accomplished.

Several of the recommendations emanating from the ID-DD, Mental Health, BI, and Children's Workgroups point to incremental resource development as a strategy for implementation of desired core services and other system reforms. They are also based on the realization that changes in one part of the system cannot be effectively be implemented unless other parts of the system are already in place. For example, the system will not be able to substantially reduce emergency department presentations and hospitalizations until crisis response services are in place. At the same time, currently there are insufficient resources available to invest in brand new crisis response systems throughout the state. Thus, the Workgroups recognized that sequential steps would have to be taken to begin implementation of crisis system components, so that resources can begin to be freed up to invest in later stages of implementation.

Across the Workgroups, there was an emerging sense of priorities with regard to early investments in system transformation and enhancements to core services. For example, expansion and enhancement of crisis services were mentioned by all Workgroups as being critical to the first stages of implementation. Jail Diversion programs were also identified as a priority, particularly in the Judicial Workgroup. Several Workgroups identified Positive Behavioral Supports or Neurobehavioral supports as critical both to sustain integrated community living and to prevent or reduce crises. For adults in the

ID-DD system and the mental health system, Supported Employment⁶⁸ was identified as a key component of reformed systems of services. For Children, the most important priority, which fits integrally with crisis services, is to expand comprehensive systems of care.

Throughout this transition, the system should strive to ensure a continuum of accessible, cost effective, high quality service modalities that help people achieve their fullest potential and live in the most integrated settings possible. This sense of priorities for transition could form the basis for new funding strategies for both the Medicaid and non-Medicaid programs that can further advance the redesign objectives. If there are to be any service expansion efforts in the next few years, in addition to current efforts to reinvest savings in the system, the funding could be directed towards these implementation priorities.

⁶⁸ A SAMHSA-recognized evidence based practice.

XI. CONCLUSION

This report presents a substantial number of recommendations to redesign and reform the system of services for adults and children with mental health disabilities, intellectual and developmental disabilities, and brain injury in Iowa. All of the issue analyses and formation of consensus recommendations were carried out in the context of SF 525. While the report may not address every issue in SF 525, it does provide a clear and concrete set of recommendations and implementation guideposts that can be used by the Iowa Legislature to meet its own goal of reforming these systems of services for people with disabilities. It also provides a set of principles and consumer-focused outcomes that can guide the Legislature in its decision making.

The report represents the contribution and collaborations of many different stakeholders who came together over a brief period of time and engage in intensive discussions of very difficult and complex issues. The degree of consensus reached is a testament to both the hard work of these stakeholders and their willingness to put special interests aside in order to develop recommended reforms for the common good. The quality of this work, and the degree of consensus reached, should give the Legislature a high degree of confidence that, if the recommendations are accepted, there will be considerable support for implementation.

All participants in the process recognized that resources are limited. Participants also realized that “the perfect can be the enemy of the good”. Thus, the consensus recommendations included in this report are considered by the Workgroup participants to be feasible to implement in a multi-year sequential process in the context of Iowa priorities, resources, and traditions.

Appendix A

ID-DD List of Current Services

Services Currently Provided to Adults with Intellectual Disabilities

The following services are currently offered to adults with intellectual disabilities as part of the ID Waiver and should be included statewide as core services for adults with intellectual and developmental disabilities.

Medicaid-Funded ID Waiver Core Services:

- Adult Day Care
- Consumer Choices Option (CCO)
- Consumer Directed Attendant Care (CDAC)
- Day Habilitation
- Personal Emergency Response System (PERS)
- Home Health Aide
- Home/Vehicle Modifications
- Interim Medical Monitoring & Treatment (IMMT)
- Nursing
- Prevocational Services
- Respite: Basic Individual
- Respite: Group
- Respite: Specialized
- Supported Community Living (SCL)
- Supported Employment (SE)
- Targeted Case Management
- Transportation

Facility-Based Services

- ICF/MR – Intermediate Care Facility for Individuals with Mental Retardation - Medicaid does pay for this service but it is not a waiver service.
- RCF – Residential Care Facility – currently funded by the county. Medicaid does not pay for the residential component of RCF's but does pay for some services offered.

Vocational Programs

- Job Development
- Supported Employment
- Sheltered workshops
- Prevocational

Appendix B

Federal Requirements for Conflict Free Case Management

CMS State Balancing Incentive Payments Program

Patient Protection and Affordable Care Act, Section 10202 Letter to Medicaid Directors and Application Template

Excerpt from pages 11-12:

B. Conflict-Free Case Management Services

States that participate in the Balancing Incentive Program will develop, as part of their NWD/SEP system, conflict-free case management services to develop a service plan, arrange for services and supports, support the beneficiary (and, if appropriate, the beneficiary's caregivers) in directing the provision of services and supports for the beneficiary, and conduct ongoing monitoring to assure that services and supports are delivered to meet the beneficiary's needs and achieve intended outcomes.

For purposes of Balancing Incentive Program, States will establish conflict of interest standards for the independent evaluation and independent assessment. In this section, we refer to persons or entities responsible for the independent evaluation, independent assessment, and the plan of care as —agents□ to distinguish them from —providers□ of home and community-based services.

The design of services, rate establishment, payment methodologies, and methods of administration by the State Medicaid agency may all contribute to potential conflicts of interest.

These contributing factors can include obvious conflicts such as incentives for either over- or under-utilization of services; subtle problems such as interest in retaining the individual as a client rather than promoting independence; or issues that focus on the convenience of the agent or service provider rather than being person-centered. Many of these conflicts of interest may not be deliberate decisions on the part of individuals or entities responsible for the provisions service; rather, in many cases they are outgrowths of inherent incentives or disincentives built into the system that may or may not promote the interests of the individual receiving services. To mitigate any explicit or implicit conflicts of interest, the independent agent should not be influenced by variations in available funding, either locally or from the State. The plan of care must offer each individual all of the LTSS that are covered by the State that the individual qualifies for, and that are demonstrated to be necessary through the evaluation and assessment process. The plan of care must be based only on medical necessity (for example, needs-based criteria), not on available funding. Conflict-free case management prohibits certain types of referrals for services when there is a financial relationship between the referring entity and the provider of services. Payment to the independent agent for evaluation and assessment, or qualifications to be an independent agent, cannot be based on the cost of the resulting care plans.

We are aware that in certain areas there may only be one provider available to serve as both the agent performing independent assessments and developing plans of care, and the provider of one or more of the LTSS. To address this potential problem, the State may permit providers in some cases to serve as both agent and provider of services, but with guarantees of independence of function within the provider entity. In certain circumstances, CMS may require that States develop "firewall" policies, for example, separating staff that perform assessments and develop plans of care from those that provide any of the services in the plan (and ensuring that the evaluations of that staff are not based on the cost of the care plan); and meaningful and accessible procedures for individuals and representatives to

appeal to the State. States should not implement policies to circumvent these requirements by suppressing enrollment of any qualified and willing provider.

CMS recognizes that the development of appropriate plans of care often requires the inclusion of individuals with expertise in the provision of long-term services and supports or the delivery of acute care medical services. As discussed previously, this is not intended to prevent providers from participating in these functions, but to ensure that an independent agent retains the final responsibility for the evaluation, assessment, and plan of care functions.

The State must ensure the independence of persons performing evaluations, assessments, and plans of care. Written conflict-free case management ensures, at a minimum, that persons performing these functions are not:

- related by blood or marriage to the individual,
- related by blood or marriage to any paid caregiver of the individual,
- financially responsible for the individual
- empowered to make financial or health-related decisions on behalf of the individual,
- providers of State plan LTSS for the individual, or those who have interest in or are employed by a provider of State plan LTSS; except, at the option of the State, when providers are given responsibility to perform assessments and plans of care because such individuals are the only willing and qualified provider in a geographic area, and the State devises conflict of interest protections. *(If the State chooses this option, specify the conflict of interest protections the State will implement).*

Appendix C

Children's Disability 2012 Planning Agenda

Children's Disability Planning Agenda for 2012

In its final session, the Children's Disability Workgroup engaged in planning for CY 2012 that will lead to the submission of a full set of recommendations in December, 2012. What follows is an initial draft of key tasks and considerations.

I. Development of Health Home option

- Architecture/framework within System of Care
- Certify providers ~ what qualities/practices make a health home?
 - Provider qualifications and certification
 - Eligibility required assessment of need
- Implementation planning/funding
 - Performance measurement/outcome measures
 - Reimbursement model
 - Fee for service/managed care crossover and primary care/other system crossover
- CMS approval ~ State Plan Amendment
- EHR (Electronic Health Record) ~ Data Support needs
 - Cross-system engagement modeling
 - Accessibility of providers
 - Financing/capacity for non-Title 19 eligible
- Improvement methodology
 - Investment/support for practice change
 - Plan for 2 year funding transition
 - Sustainability/scalability model
 - Support for all to participate in the team
 - Health team roles/convening of the team

II. Systems of Care

- Points of accountability and organization
 - Family
 - a. Family Peer to Peer
 - b. Family Driven
 - Community
 - State
 - Cross Matrix
- Catalyzing change
 - Vision
 - Environmental
 - Holistic Perspective
 - Innovative
 - Consensus
 - EBD ~ Evidenced Based Design
 - Value ~ quality/care
 - Advocacy

- Roles
- Data
- Communication
- Community readiness
- Strategies for partnering with other child-serving systems/agencies/provider
 - Multi-system Inclusions ~ loose silos
 - Identify priorities

III. Engaging Parents, children and youth in system redesign

- Identify current strategies in place across the state
 - Family finding
 - Community forums ~ day and evening
- Analyze what works/what doesn't work ~ providers/families/community
- Providing access points for families to receive information or connect to resources
 - Use survey monkey
 - Office of Consumer Affairs & other email distribution lists
 - Facebook page
 - Website with information to access
- Plans are developed within specific communities that incorporate families/providers/
 - Provider work with families
 - Parent training and education
 - Parents may need services
 - Support parents with family-driven practices ~ choice/empowerment/after 'business hour' availability

IV. Crisis system development including interface with all-population crisis system development

- What is in place?
- What are Evidence Based models?
- What are core components?
- Interface with the adult system
- Finance
- Reimbursement method/financing
- Strength-based
- Recognizes that Emergency Room is often the access point
- Must include shelter care
- Bed capacity in hospitals and shelters
- Capacity for crisis response statewide
- Capacity of staffing
- Community awareness and buy in

V. Children's Disability System--Interface with Regional redesign activities

- Review Regional recommendations
- Regional role in system outcomes and system organizations

- Understand funding differences between children and adults
- Funding contributors ~ Local/State/Federal/Non-government
- Regionalized inventory of services
- Include capacity to serve
- Determine gaps in each region
- Specialized TA available to communities in the region
- Determine opportunities for shared services and cost reductions
- Workforce development especially in rural regions
- Assure children do not get lost due to numbers
- Care coordination for entire family
- Seamlessness for families within and between regions
- Develop regional process improvement methodology

VI. Core Services for children and youth

- Service eligibility
- ID/DD
 - HCBS Waiver
 - Include Brain Injury population and workgroup
 - Child Care Specialized
 - Positive Behavioral Supports
 - Crisis Support
 - IQ Evaluation
 - Systems of Care & Targeted Case Management
 - Short term out of home respite ~ enhanced
 - ICF based on defined level of care assessment
 - Family – Peer Support
 - Integrated Plans ~ IPP/ISP/ISFP/IEP
 - Recognize ‘progress differences’ with child with ID
 - Waiting list priority for waiver
 - Life skills transition to adult
 - Pre-Vocational
- Mental Health
 - Family centered
 - a. Whole Child Health perspective
 - b. Primary care
 - c. Research supported interventions ~evidence based practices
 - Coordination of care
 - a. Seamless
 - b. Managed across the continuum
 - c. Family navigators or Peer-to-Peer
 - d. Family support and respite
 - Sub acute care
 - Medication management
 - Tele-medicine and use of ARNPs
 - Must include Addiction as a specialty
 - Services available in all counties

- Crisis teams
- Immediate access to waiver, if eligible
- Flexibility to move up/down continuum
- Meaningful access to all levels of care
- Early Childhood
 - Learn about Early Childhood Iowa (birth – 5 system); it is multi-systems and child/family in multiple settings and eligibility
 - Learn evidenced based practices for early childhood
 - a. Early childhood mental health consultation
 - b. Share issues/strategies and needs with other providers and school as child grows ~ transition supports from one setting to another
 - Learn current Iowa initiatives ~ infant/child mental health association (IAAP)/Project Launch/PBIS/Early Access and ARRA reports/Early Childhood Iowa's Mental Health group/Help Me Grow (CHCS)
 - Identify ways to spread adoption of best practices
- Transition-Age Youth
 - Keep 'family' engaged
 - Catalogue all of the initiatives across education/health/child welfare/Juvenile Justice, etc.
 - Coordinate definitions, services, etc to identify what's available; eligibility, etc.
 - Engage needed community partners
 - Look at funding opportunities/barrier/gaps
 - Funding to meet needs
 - Funding to cover services past age 18; no drop off cliff on birthday
 - Services for support needs
 - Strong encouragement to have Transition Plan in place prior to age 17
 - Interagency collaboration – how does it happen/how is it coordinated
 - Vocational support
 - Half-way houses
 - Other housing options, like waiver home idea
 - Transitional living programs

VII. Assessment tools

- Gather assessment tools currently in use in different systems and determine how/when they are used
- Analyze commonalities of tools being used
- Assess current tools for gaps re: needs of this population
 - a. Family Assessments
- Strategize about whether a single assessment is at all viable OR whether common items can carry from system to system
- Utilize appropriate assessment tool – Not one
Utilize one assessment so we can compare and contrast
- Develop core System of Care assessment process
- Family and child based outcomes

VIII. Provider qualifications

- Assure all regulations/rules are applied and consistent
- Eliminate IAC Chapter 24 ~ other state licensing standards require National accreditation as standard (CARF/COS/JCAHO)
- Review certificates and licenses of other professionals ~ IBC/CTA/Nursing
- Explore opportunities to collaborate/align credentials in adult systems and schools, ie. Behavior analysis specials and Child behavior specials/consultants
- Partner with universities to evaluate workforce needs and programs offered in state
- Reimbursement rates for qualifications requested
- Evidenced based
- Remove barriers to funding
- Expand opportunities based on training and outcomes
- Funding should incentivize evidence based practices, i.e. FFT specially trained workforce
- Across your systems knowledge when system is implemented
- Trainings should be required with ongoing re-certifications
- Offer training opportunities for people to increase qualifications
- Cultural competency
- Competent in trauma-based care
- Do not excessively quality practitioners

IX. Performance and Outcome measures

- Tracking system to report on aggregate measures
 - Data repository
 - Centralized data collection
 - Data systems
 - Safe environment to report errors and failures
- Common set of measures to track performance
 - Develop agreed upon standards for Social-Emotional skills across the age-span; need consistency; explore what other states have developed
 - Meaningful
- Continuous improvement system
 - Quality improvement
- Track long term 'successful' adults

X. Workforce development

- Recruiting and developing profession
- System training
 - Education to train teachers in managing aggressive behavior
 - Cross-system funding for training
 - Cross training
- Curriculum and competency based
- Dual diagnosis and positive behavior competencies

- State plan for college/university preparation programs (speciality vs. access, distance learning)
- Increased reimbursement rates for adequate staffing
- Incentives
- Psychology Prescribing
- Stability
- Technology
- Outside the 'box' innovations such as Microboards; human service coops; and ideas are 'refreshed' continuously
- Willing to work outside M-F, 8:00 am – 5:00 pm
- Child & Youth psychiatric consult program for Iowa
- CYC – I

XI. System financing

- Identify current funders
 - Options in Medicaid funding
 - Buy in from insurance/3rd party
 - Buy in at local level financially
 - Other county funding partners, ie United Way, Foundations
 - Braided resources
- Flexible Funding System ~ what does this child/family need
 - Non-categorical funding options (wraparound) ~ legislature won't know what they are specifically buying
 - Funding system services ~ care coordination, possibly crisis
- Performance-based contracting

XII. Community Readiness

- Non-system investment ~ religious and other informal communities
- Ownership of constituents ~ 'a village'
- Collaboration attempts/successes
- Culture of family based decision-making
- Assessment of barriers
- Service availability
- Assessment of readiness
- Education opportunities and awareness
- Description of process ~ easy to understand so can 'buy in'
- System of care champion
- Community champion
- No wrong door concept
- Organizing entities
- Focus on maintenance of success

XIII. Request for Proposal (RFP)

- Identify return to state and the risks
 - Define how to fund from start to finish

- State owned responsibility, not solely provider responsibility
 - How to use to build System of Care infrastructure
- How to prevent financial cut, i.e. shifts resulting in service gaps
 - Evaluate why kid is out of state
 - Potential return directly home
 - Strong family supports before kid comes home
 - Focus on use of existing resources first
 - Individual case vs. community system development
 - What the family/child need ~ non category funding
- Link to outcome to be achieved
 - Pay for performance
 - Multiple systems collaboration
 - Consider 'asking' partners to apply with consideration to develop their capacity
 - Develop potential service array

Appendix D
Recommended Definition of Residency

Definition of Residency

The new definition of residency as approved by the MHDD Commission is quoted below:

“County of residence” means the county in Iowa where, at the time an adult applies for or receives services, the adult is living and has established an ongoing presence with the declared, good faith intention of living permanently or for an indefinite period. The “county where a person is living” does not mean the county where a person is present for the purpose of receiving services in a hospital, a correctional facility, a halfway house for community corrections or substance abuse treatment, a nursing facility, an intermediate care facility for persons with mental retardation, or a residential care facility, nor for the purpose of attending a college or university. For an adult who is an Iowa resident but falls within the exclusion for “county where a person is living” as described in this rule, the county where the adult is physically present and receiving services shall be the county of residence. The county of residence of an adult who is a homeless person is the county where the adult usually sleeps.

Appendix E
Brain Injury Definitions

Brain Injury Definitions:

Neuro- Resource Facilitation (NRF):

NRF is an evidence-based, national best practice in the field of brain injury. NRF is a statewide and regional service that responds to the unique medical, disability and multi-occurring (multi-occurring disorders to include mental health, substance abuse, intellectual disability, and brain injury in any mix) needs of lowans with brain injury and their families. This service supports individuals with brain injury, their families, caregivers and providers to choose, get and keep needed services and supports reducing the risk of segregation as well as the risk of secondary conditions, leading to an increased ability to live, learn, work and recreate in communities of choice. This service is contracted through the Iowa Department of Public Health (IDPH).

Iowa Brain Injury Resource Network (IBIRN):

The Iowa Brain Injury Resource Network (IBIRN) is a Statewide and regional system providing communication, education and resource sharing (i.e. BI Tote Bags) with identified primary points of contact for individuals and families living with brain injury (i.e., medical, mental health, disability, substance abuse, corrections and educational sites, etc). This service is contracted through the Iowa Department of Public Health.

Neurorehabilitation:

A complex, multi-disciplinary process, specifically and individually designed to facilitate and accelerate recovery from an acquired brain injury, to minimize and/or compensate for any resulting functional alterations, and to support adaptation and accommodation to such alterations.

Neurobehavioral rehabilitation:

A specialized category of neurorehabilitation provided by a multi-disciplinary team of allied health and support staff that have been trained in, and deliver, services individually designed to address cognitive, medical, behavioral and psychosocial challenges, as well as the physical manifestations of acquired brain injury. Services work concurrently to optimize functioning at personal, family, and community levels, by supporting the increase of adaptive behaviors, the decrease of maladaptive behaviors, and the adaptation and accommodation to challenging behaviors to support an individual to maximize his/her independence in activities of daily living and the ability to live in their own home and community.

Appendix F

Brain Injury Workgroup Recommendations Grid

Brain Injury Workgroup Recommendations Grid

<i>Corresponding # to narrative recommendations</i>	<i>Recommendation</i>	<i>Best Practice Citation</i>	<i>Impact/Difficulty Score</i>	<i>Policy</i>	<i>Funding</i>	<i>Timeline for ROI (short, mid, long-range)</i>
A-1	Determine eligibility <u>at the time of application</u> for Medicaid Waiver funding based on fiscal, functional and diagnostic criteria, immediate referral to NRF and other services regardless of eligibility.	Wisconsin LTC FS—pre-screening Reid-Arndt, S.A, Schopp, L., Brenneke, L., Johnstone, B., & Poole, A.D. (2007). Evaluation of the Traumatic Brain Injury Early Referral Program in Missouri. <i>Brain Injury</i> , 21(12), 1295-1302.	Impact=10 Difficulty=3	Administrative rule change at DHS	Increased funding for NRF for capacity to divert wait list	Short
A-2	Implement uniform brain injury assessment process and tool across regions.		Impact=10 Difficulty=1	Administrative Rule change at DHS.	Minimal or no cost to identify tool	Short
A-3	Prescreen individuals for brain injury at all access points (i.e., MHDD, ID, Substance Abuse, county veterans offices, waiver	Minnesota Alabama Kentucky	Impact=10 Difficulty=2	Policy in Place	Funding needed to comply with the law	Short

<i>Corresponding # to narrative recommendations</i>	<i>Recommendation</i>	<i>Best Practice Citation</i>	<i>Impact/Difficulty Score</i>	<i>Policy</i>	<i>Funding</i>	<i>Timeline for ROI (short, mid, long-range)</i>
	application, etc.).					
A-4	Replace current assessment tools for the Brain Injury Waiver with a more sensitive, standardized tool to assess cognitive, psychosocial and functional abilities and needs, to determine initial and ongoing eligibility for state brain injury waiver services.	Minnesota BI Waiver tool Kansas Vermont	Impact=10 Difficulty=6	Administrative Rule change at DHS	Minimal cost to identify tool and provide training for implementation	Short
A-5	Provide funding to eliminate any waiting period for eligible individuals within the HCBS BI Waiver, to decrease expensive and untoward medical outcomes and associated secondary conditions.	Kansas Wisconsin Kentucky	Impact=10 Difficulty=6	Legislative and DHS Policy	Dependent upon current waiting list	Short

<i>Corresponding # to narrative recommendations</i>	<i>Recommendation</i>	<i>Best Practice Citation</i>	<i>Impact/Difficulty Score</i>	<i>Policy</i>	<i>Funding</i>	<i>Timeline for ROI (short, mid, long-range)</i>
A-6	Increase availability of acute to home neurobehavioral services across the service continuum to reduce need for out-of-state placement and increase ability to bring people back to Iowa.	Massachusetts Minnesota Texas	Impact=10 Difficulty=7	Legislative	Potential to save money in the long run due to expense of out of state placement	Short
A-7	Increase availability of post-acute neurorehabilitation services across the service continuum to reduce need for out-of-state placement and increase ability to bring people back to Iowa.		Impact=9 Difficulty=9	Legislative	Potential to save money in the long run due to expense of out of state placement	Mid to long range
B-1	Require regional administrative hubs to participate as IBIRN sites with adequate funding for regional resource materials	Tennessee DPH BIA-OH	Impact=9 Difficulty=3	Legislative		Mid

<i>Corresponding # to narrative recommendations</i>	<i>Recommendation</i>	<i>Best Practice Citation</i>	<i>Impact/Difficulty Score</i>	<i>Policy</i>	<i>Funding</i>	<i>Timeline for ROI (short, mid, long-range)</i>
	(i.e., Brain Injury Tote Bags).					
B-2	Amend Iowa Code Chapter 135.22 Brain Injury Registry to align with the brain injury definition in IAC 441-83.81(249A) and require the BI Registry notification in administrative rule.	<i>Recommendation developed at final meeting.</i>				
B-3	Reduce the lag time for receipt of outreach letters generated from the Brain Injury Registry regarding brain injury services in order to increase timely access to services and supports.	Florida	Impact=8 Difficulty=2	Policy (IDPH)	Minimal cost	Short
B-4	Expand the scope of the Residential Care Facilities (3-5 beds) specialized			Legislative		Short

<i>Corresponding # to narrative recommendations</i>	<i>Recommendation</i>	<i>Best Practice Citation</i>	<i>Impact/Difficulty Score</i>	<i>Policy</i>	<i>Funding</i>	<i>Timeline for ROI (short, mid, long-range)</i>
	licensure (IAC 481-63.47(135C)) to include Brain Injury.					
B-5	Expand the current NRF services to accommodate the significant increase in utilization of this service to allow NRF caseloads to align with national averages and to develop veteran-specific NRF services.	New Hampshire Vermont	Impact=9 Difficulty=7	Legislative	Needs additional funding based on utilization	Short
B-6	Optimize conflict-free case management for brain injury services by developing specialized brain injury case management within the case management structure.	Virginia Minnesota Illinois Tennessee	Impact=8 Difficulty=8	Legislative	Funding needed for training and a new or shift of money.	Short

<i>Corresponding # to narrative recommendations</i>	<i>Recommendation</i>	<i>Best Practice Citation</i>	<i>Impact/Difficulty Score</i>	<i>Policy</i>	<i>Funding</i>	<i>Timeline for ROI (short, mid, long-range)</i>
B-7	Increase and provide adequate funding for the unfunded Brain Injury Service Program cost-share component at the IDPH.	Many States	Impact=6 Difficulty=6	Existing code	Additional funding needed to support existing code	Short
B-8	Elevate the Governor's Advisory Council on Brain Injuries to the Brain Injury Services Commission to expand the current scope to identify it as the state policy-making body for the provision of services to lowans with brain injury.		Impact=5 Difficulty=5	Legislative	Additional funding need based on charge of Commission	Short
C-1	Implement a standardized brain injury screening tool identified in collaboration with the Brain Injury Services	Minnesota Alabama Kentucky	Impact=10 Difficulty=2	Legislative	Funds needed to identify tool and provide training for implementation	short

<i>Corresponding # to narrative recommendations</i>	<i>Recommendation</i>	<i>Best Practice Citation</i>	<i>Impact/Difficulty Score</i>	<i>Policy</i>	<i>Funding</i>	<i>Timeline for ROI (short, mid, long-range)</i>
	Commission (see item B-8) to be implemented at all access points to include, but not limited to: all agencies as required by 225C.23, domestic violence shelters, mental health centers, substance abuse treatment centers, emergency rooms, crisis intervention, homeless shelters, senior centers, schools, correctional facilities and non-profit or community based organizations providing human services, etc.					
C-2	Form and support a state of Iowa interagency,	Minnesota	Impact=9 Difficulty=3	Policy (IDPH)	Could be supported by federal HRSA	Short

<i>Corresponding # to narrative recommendations</i>	<i>Recommendation</i>	<i>Best Practice Citation</i>	<i>Impact/Difficulty Score</i>	<i>Policy</i>	<i>Funding</i>	<i>Timeline for ROI (short, mid, long-range)</i>
	intergovernmental Brain Injury Coordinating Committee to meet quarterly to continue deploying best practices for brain injury services.				TBI Implementation grant	
C-3	Review and revise funding mechanisms, rate structures, service definitions, and reimbursement methodologies, to emphasize and incentivize person-centered, community-based employment and interagency collaboration.	<i>Recommendation developed at final meeting.</i>				
C-4	Deploy brain injury competency training and education in existing and new crisis intervention	North Carolina	Impact=10 Difficulty=3	Legislative		Short

<i>Corresponding # to narrative recommendations</i>	<i>Recommendation</i>	<i>Best Practice Citation</i>	<i>Impact/Difficulty Score</i>	<i>Policy</i>	<i>Funding</i>	<i>Timeline for ROI (short, mid, long-range)</i>
	programs.					
C-5	Deploy and expand tele-health services for lowans with brain injury and multi-occurring disorders.	Idaho-HRSA project	Impact=10 Difficulty=3	Legislative		Short
C-6	Develop a statewide, interdisciplinary brain injury consultation team to serve the regions.	Brain Injury Resource teams are currently in the Area Education Agency system in Iowa. The team would need to be expanded to include other disciplines.	Impact=10 Difficulty=6	Legislative	Need funding for training and administrative support	Mid
C-7	Deploy brain injury competency training and education in existing and new jail diversion programs.	Maryland	Impact=10 Difficulty=6	Legislative	Funds needed to develop and deploy training program.	Short
C-8	Deploy and expand services to engage survivors of brain injury and their families in on-going education, peer	Olmstead Minnesota Wisconsin	Impact=6 Difficulty=4	Agency level policies to collaborate with advocacy groups		Short term and ongoing

<i>Corresponding # to narrative recommendations</i>	<i>Recommendation</i>	<i>Best Practice Citation</i>	<i>Impact/Difficulty Score</i>	<i>Policy</i>	<i>Funding</i>	<i>Timeline for ROI (short, mid, long-range)</i>
	support, mentoring and advocacy.					
C-9	Develop and deploy a web-based, searchable, comprehensive brain injury resource information and services database/directory .	Arizona Colorado New Hampshire New Mexico Oklahoma	Impact=7 Difficulty=7	Legislative	New funding	Mid
C-10	Provide specialized brain injury training for direct service providers across the service array to include but not limited to human services, rehabilitation, nursing, home health agencies, assisted living, community and facility based providers, correctional, jail	Massachusetts Michigan New Hampshire New York Wisconsin	Impact=8 Difficulty=8	Legislative (could use the DHS model training)	Low	Mid

<i>Corresponding # to narrative recommendations</i>	<i>Recommendation</i>	<i>Best Practice Citation</i>	<i>Impact/Difficulty Score</i>	<i>Policy</i>	<i>Funding</i>	<i>Timeline for ROI (short, mid, long-range)</i>
	diversion, crisis intervention and judicial agencies.					
C-11	Provide access to flexible and reliable transportation services for brain injury rehabilitative, medically necessary care and community integration.	Minnesota New Jersey	Impact=9 Difficulty=9	Legislative	High cost	Long
C-12	Deploy phone follow up service to individuals receiving brain injury registry outreach letter.		Impact=9 Difficulty=9	Policy (IDPH)	Moderate	Mid
C-13	Develop acute inpatient hospital-based neurobehavioral treatment programs to prevent out of	Massachusetts Minnesota	Impact=10 Difficulty=10	Legislative	Potential to save money in the long run due to expense of out of state placement	Mid

<i>Corresponding # to narrative recommendations</i>	<i>Recommendation</i>	<i>Best Practice Citation</i>	<i>Impact/Difficulty Score</i>	<i>Policy</i>	<i>Funding</i>	<i>Timeline for ROI (short, mid, long-range)</i>
	state placements for lowans with brain injury and multi-occurring disorders.					
C-14	Develop and deploy a follow-up outreach service for individuals served by the Iowa Brain Injury Resource Network (tote bag).		Impact=10 Difficulty=10	Administrative rule change	Additional funding needed	Mid

Appendix G
Workgroup Member List

Adult Intellectual and Developmental Disabilities Workgroup

Name	Agency	Job Title
Chair - Kuhns, Karalyn	Department of Human Services: Division of Division of Mental Health and Disability Services	Interim Division Administrator
Co-Chair - Bacon, Robert	University of Iowa Center for Excellence on Disabilities, Center for Disability & Development	Director
Aberg, Jim	Opportunity Village	Services Director
Askland, Ron	Horizons Unlimited	Chief Executive Officer
Dubert, Mary	Community	Community Volunteer
Edgington-Bott, Marsha	Woodward Resource Center	Superintendent
Francis, Dawn	Iowa Statewide Independent Living Council	Executive Director
Gehlhaar, Stephanie	Mosaic	Executive Director
Heidemann, Jan	Bremer County	Central Point of Coordination
Johnson, Terry	Genesis Development	CEO
Kaestner, Cindy	Abbe Center for Community Mental Health	VP/Executive Director / Service Provider
Lusala, Roger	Mayor's Youth Empowerment Program	Executive Director
Peterson, Mia	Consumer	Consumer & Advocate
Seehase, Susan	Exceptional Persons	Services Director
Todd, Dale	Mental Health Commission	Family Member

Adult Mental Health Workgroup

Name	Agency	Job Title
Chair - Palmer, Charles M	Department of Human Services (DHS)	DHS Director
Co-Chair - Atchison, Christopher	University of Iowa (U of IA) College of Public Health Department of Health Management and Policy	Director, University of Iowa Hygienic Lab; Associate Dean for Public Health Practice; Clinical Professor
Albrecht, Deb	Berryhill Center for Mental Health	Executive Director
Baltzer, Lynne	Consumer	Consumer
Bartruff, Jerry	Department of Corrections (DOC) Offender Services	Statewide Reentry Coordinator
Bomhoff, Teresa	MH Planning Council NAMI Greater DM AMOS	Chair Vice President Work Group member
Cervený, Gilbert	Alegent Health Systems: Gergen Mental Health Center	Manager
Cleveland, Becky	Gunderson Lutheran	Senior Consultant for Behavioral Health
Dave, Dr. Bhasker	Independence Mental Health Institute	Superintendent
Ferrell, Lynn	Polk County Health Services	Executive Director
Flaum, Dr. Michael	University of Iowa Consortium for Mental Health	Professor of Clinical Psychiatry
Hoffman, Chris	Pathways	Executive Director
Schmitz, Patrick	Plains Area Mental Health Center	Executive Director
Stone, Kathy	Iowa Department of Public Health (IDPH): Division of Behavioral Health	Division Administrator

Brain Injury Workgroup

Name	Agency	Job Title
Chair - Hartwig, Megan	Iowa Department of Public Health (IDPH) Iowa Brain Injury Program	Manager
Co-Chair- Hackett, Jack	Iowa Health: Employee and Student Assistance Program	Senior Therapist
Block, Mark	Survivor of Brain Injury	
Brown, Tom	Community NeuroRehab	Executive Director
Carter-Larson, Katrina	Department of Corrections (DOC) Offender Services	PSE 4
Fidler Dixon, Julie	On With Life	Executive Director
Graber, Kay E.	Family Member of a Survivor of Brain Injury	
Hall, Michael	Veterans Affairs Medical Center at Iowa City	Neuropsychologist
Johnson, Dave	Survivor of Brain Injury	
Jordal, Rhonda	Family Member of a Survivor of Brain Injury	
Langlitz, Lisa	Cherokee County	Central Point of Coordination
Lauer, Geoffrey	Brain Injury Association of Iowa (BIA-IA)	BIA-IA Executive Director
Moskowitz, LeAnn	Department of Human Services, Iowa Medicaid Enterprise	Program Manager
Woodworth, Ben	Iowa Association of Community Providers	Brain Injury Training Director

Children's Disability Workgroup

Name	Agency	Job Title
Chair - Vermeer, Jennifer	Department of Human Services: Iowa Medicaid Enterprise	Division Administrator
Co-Chair - Peltan, Mark Ph.D.	Mercy Behavioral Services: Mercy Medical Center-North Iowa	Clinical Psychologist
Althoff, Marilyn	Hills & Dales	Executive Director
Barber, Gail	Judicial Branch of Iowa	Director, Children's Justice
Beaman, Nicole	United Way	Health Director
Connolly, Paula	Ask Resource Center	Family Support Coordinator
Curry, Julie	Department of Education (DE): Early ACCESS Project	State Coordinator
Ernst, Jim	Four Oaks	Executive Director
Foxhoven, Jerry	Drake Neal & Bea Smith Legal Clinic	Executive Director
Haglund, Jason	Youth & Shelter Services, Inc.	Treatment Services Director
Heikes, Jan	Allamakee/Winneshiek Counties	Central Point of Coordination
Lane, Janice	Children & Families of Iowa	Assistant Director
Lantz, Marilyn	Judicial Department (JD): Juvenile Court Services	Chief
Murphy, Samantha	Iowa Health Des Moines (Blank Children's Hospital)	Director, Children's Behavioral Health Services, RN, B.S.N.
Rickman, Wendy	Department of Human Services: Division of Adult, Children & Family Services	Division Administrator
Shouse, Rhonda	Iowa Mental Health Planning Council	Parent Representative
Smith, Jason Psy.D.	Cherokee Mental Health Institute	Superintendent
Stout, David	Orchard Place	Vice President
Waldron, Dr. Debra	University of Iowa	Clinical Associate Professor of Pediatrics

Judicial-DHS Workgroup

Name	Agency	Job Title
Co-Chair - Boyd, David	State Court Administrator	
Co-Chair - Kuhns, Karalyn	Department of Human Services: Division of Division of Mental Health and Disability Services	Interim Division Administrator
Baldwin, Beth	District Court Administrator	
Baldwin, John	DOC Director	
Berg, Ron	MECCA Services	CEO
Brecht, Diane	Penn, Inc.	Executive Director
Brundies, Linda	Assistant Ombudsman	
Butler, Kathy	Partners for Progress	CEO/Administrator
Dave, Dr. Bhasker	Independence Mental Health Institute	Superintendent
Eachus, Tom		Executive Director
Fagan, Neil		Director
Gibson, Mary Ann		Executive Director
Gooding, Virgil	Key to Awareness	Director
Hoffman, Steve		Chief Jailer
Hornback, Jesse	Keokuk County	Central Point of Coordination
Kraemer, Gretchen		Assistant Attorney General
Littlejohn, Deb		Clerk of Court
Mayes, Jerry	Olmstead Task Force	Chair
Rickers, Terry		District Court Judge
Royer, Dan		Directory of Advocacy
Schildroth, Deb		
Stein, L. Jay		Magistrate
Wilson, Kimberly		
Yeggy, Kelly	Polk County	Judicial Mental Health Advocate

Legislative Interim Committee

Name	Agency	Job Title
Co-Chair - Hatch, Jack	Iowa Senate	Democrat, District 33
Co-Chair - Schulte, Renee	Iowa House of Representatives	Republican, District 37
Bolcom, Joe	Iowa Senate	Democrat, District 39
Ernst, Joni	Iowa Senate	Republican, District 48
Heaton, David E	Iowa House of Representatives	Republican, District 91
Heddens, Lisa	Iowa House of Representatives	Democrat, District 46
Johnson, David	Iowa Senate	Republican, District 3
Miller, Linda J	Iowa House of Representatives	Republican, District 82
Ragan, Amanda	Iowa Senate	Democrat, District 7
Smith, Mark	Iowa House of Representatives	Democrat, District 43
Ward, Pat	Iowa Senate	Republican, District 30
Wolfe, Mary	Iowa House of Representatives	Democrat, District 26

PMIC Transition Workgroup

Name	Agency	Job Title
Armstrong, Vern	DHS Field Operations	Division Administrator
Barker, Mike	Children's Square	CEO
Dahlen, Kermit	Jackson Recovery Center / Jackson Adolescent Center	CEO
Freeman, Dan	Independence MHI	Director
Discher, Joan	The Iowa Plan	Director
Ernst, Jim	Four Oaks	CEO
Estle, George	Tanager Place	CEO
Gansemer, Gary	Hillcrest	CEO
Gookin, Don	IME, Bureau of Long Term Care	Executive Officer 2
Gray, Gloria	Children and Families of Iowa	Executive Director
Halverson, Scott	Alegent Health Mercy Hospital Southwest Iowa	Program Manager
Janssen, Dennis	Iowa Medicaid Enterprise	Clinical Director
Juliano, Nick	Care coordination and integration of PMIC and community based services	Expert
Lantz, Marilyn	Iowa Juvenile Court	Officer
Meis, Belinda	Lutheran Services in Iowa	Director of Beloit Residential Services
Moskowitz, LeAnn	Dept. of Inspections and Appeals	Management Analyst 3
Oliver, Kristie	The Coalition of Family and Children's Services in Iowa	Executive Director
Rickman, Wendy	DHS Adult, Children & Family Services	Division Administrator

Name	Agency	Job Title
Shults, Rick	DHS Mental Health & Disability Services	Division Administrator
Silva, Art	Boys and Girls Home	
Vermeer, Jennifer	Iowa Medicaid Enterprise	Division Administrator
Wolff, Brock	Orchard Place	CEO
TBD		Consumer / Advocate
TBD		Consumer / Advocate

Regionalization Workgroup

Name	Agency	Job Title
Chair - Palmer, Charles M	Department of Human Services	DHS Director
Co-Chair Vavroch, Mary	Retired	Assistant Attorney General - Retired
Arnold, Jane	St. Luke's Health System	Director Rehabilitation, Behavioral Health & Discharge Planning, MA, OTR/L
Brownell, Robert	Polk County Board of Supervisors	County Supervisor
Chavez, Mary	Consumer	Consumer
Eachus, Tom	Black Hawk-Grundy Community Mental Health Center	Executive Director
Elam, Lori	Scott County	Central Point of Coordination
Guenthner, Jack	Plymouth County, Iowa Supervisor	County Supervisor
Harvey, Donna	Iowa Department on Aging	Director
Hudson, David	Advocate: Brain Injury	
Kaufman, Sarah	Henry County	Central Point of Coordination
Langston, Linda	Linn County Board of Supervisors	County Supervisor
Lincoln, Bob	County Social Services Region: Black Hawk, Butler, Cerro Gerdo, Floyd, Mitchell and Wright Counties	Central Point of Coordination
Stutsman, Sally	Johnson County Board of Supervisors	County Supervisor
Watson, Suzanne	Pottawattamie County	Central Point of Coordination
Willey, Jack	Jackson County	County Supervisor