

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.