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
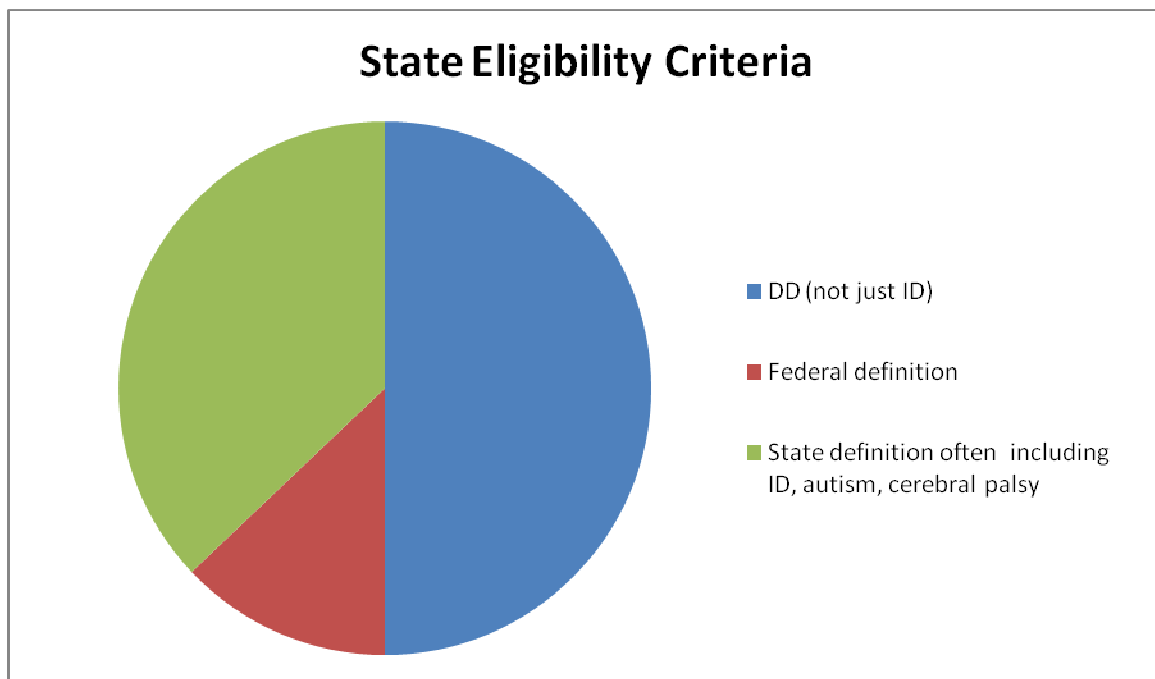
The role of eligibility determination is to provide for a fair and consistent process to allocate scarce resource to those who meet the requirements and to screen out those who do not meet the requirements. How states and the federal government have framed eligibility criteria for individuals with intellectual 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 More recently, the term mental retardation has been replaced by intellectual disability and eligibility standards have moved from reliance on intelligence testing to evaluation of a person's functioning, his/her abilities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.

State Eligibility Criteria

- DD (not just ID)
- Federal definition
- State definition often including ID, autism, cerebral palsy

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 though 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.[1] 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 crisis services be available to people with ID-DD regardless of the type of setting – family home, independent apartment or provider operated home.

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

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.

<u>Workgroup Consensus Recommendations for Core Services</u>

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:[2]

- 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 – 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

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

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.[3] 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 needs[4];

- 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.

3State Balancing Incentive Payments Program Letter, see pages 11-12. https://www.cms.gov/smdl/downloads/Final-BIPP-Application.pdf

4 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 Intervention [5];
- Behavioral Intervention, and Positive Behavior Support Services[6];
- Mental Health Outreach[7];
- 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 housing[8];
- 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.

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

6 IME is drafting regulations on this service as well.

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

8 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.

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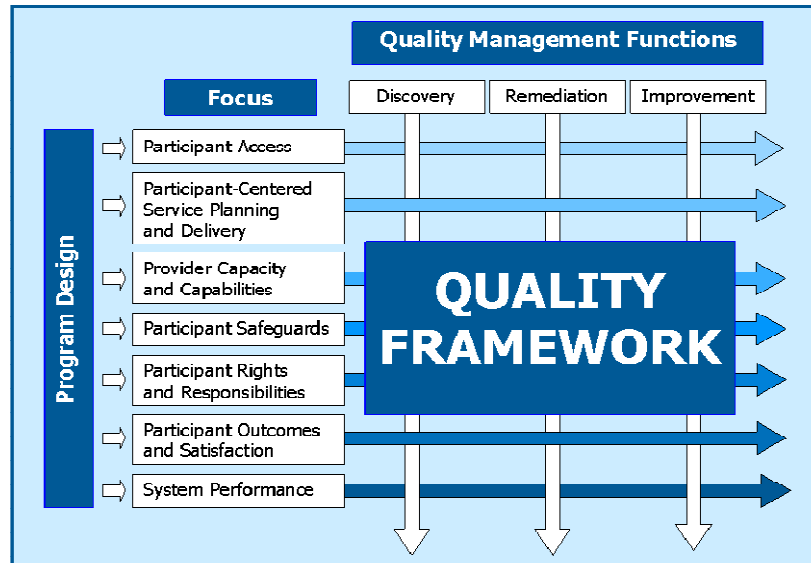
By using the Quality Framework, states can be prompted to consider:

- 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."[9] 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.

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[9] Cornell 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.[10]

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://IowaMHDSPlan.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.

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[10]Statement 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.[11] Current monitoring processes should be reviewed to ensure that what is being measured is consistent with these outcomes.

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11 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 DMRDD[12]. 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 following[13]:

- 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:

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12 http://www.hsri.org/publication/national-accreditation-of-community-service-providers/

13 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.
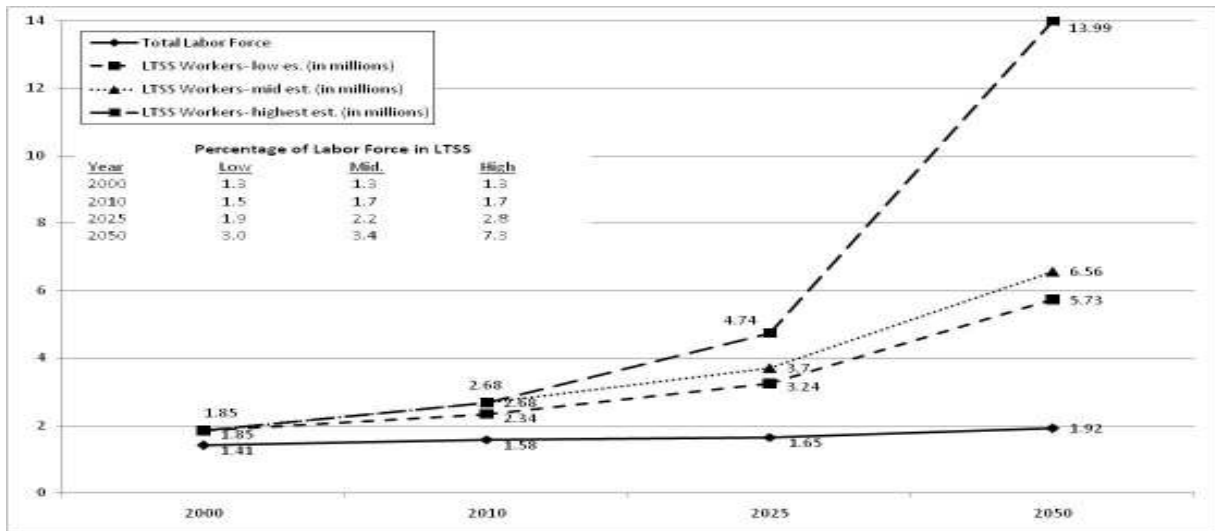
The expectations rise and shortages of sufficient and qualified workers is a national problem. Salary, benefits and career paths for DSPs have not kept abreast of the increased performance expectations. Turnover is high. The statewide average nationally is around 50% and higher in residential and in 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:
• They hear about the job from someone inside the organization.	• They have problems with co-workers.
• They receive a realistic preview of the job and the people who they will be supporting.	• They receive inadequate pay or benefits.
• They feel they are valued and treated fairly by supervisor.	• They have problems with supervisors.
• 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.

Appendix A: 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: 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).*