II. LIVING WITH A DISABILITY IN IOWA

This chapter reviews various definitions of disability, summarizes what is known about the prevalence of disability in Iowa, and provides an overview of the supports and services people with disabilities commonly need in order to engage in the activities of daily living, as well as the current capacity of the publicly funded mental health, brain injury and disability service system. More detailed information on the definitions in Iowa Code of specific disabilities can be found in Appendix A.

Definitions of Disability—and Why They Are Important

There is no single definition of disability. It is defined differently depending upon the purpose for which the definition is used. Disability is defined in the Americans with Disabilities Act as: (A) a physical or mental impairment that substantially limits one or more major life activities; (B) a record of such impairment; or (C) being regarded as having such an impairment. Major life activities include, but are not limited to, self-care, seeing, hearing, eating, sleeping, walking, standing, lifting, thinking, concentrating, communicating, major bodily functions, etc. The ADA does not extend protection to people with transitory or minor disabilities (with a duration or expected duration of less than six months), but the disability can be episodic, as long as it substantially limits life activities when it is active.

The purpose of the ADA is to protect individuals with disabilities from discrimination. The Rehabilitation Act of 1973 also contains anti-discrimination provisions, and for those purposes uses essentially the same definition as the ADA, but for purposes of establishing eligibility for vocational rehabilitation services, disability is defined as a physical or mental impairment that results in a substantial impediment to employment. Disability determination as the basis of eligibility for SSI and SSDI relies on more complex factors.

Definitions are important for both anti-discrimination and program eligibility purposes. The ability of Iowans with mental illness, brain injury or other specific disabilities to access the state’s mental health and disability service system depends upon whether they meet the definitions in Iowa Code or in Medicaid regulations. Definitions are generally based on medical diagnoses. Refer to Appendix A for these definitions. Chapter III identifies the disability populations that must be served in Iowa’s county-based system (i.e., that are mandated by Iowa Code), as well as some of the populations with little or no access to the publicly funded system.

Prevalence of Disability in Iowa

Prevalence of All Disabilities. All the information available on the size of disability populations is in the form of estimates of varying degrees of completeness or reliability. It may be tempting to start by looking at statistics on the number of people who get services every year, but the evidence is clear that most people with mental illness or a wide range of other disabilities are not being served by the publicly funded system.
Many people with mental health disorders are either undiagnosed or are unwilling to seek services.¹ Many brain injuries also go undiagnosed. Families are the principal providers of support to most individuals with intellectual disabilities.² Most care giving provided to elders, for example, is by unpaid family members.³

The Centers for Disease Control and Prevention (CDC) has consistently put the number of Americans living with disabilities at 20%, although this is based on a U.S. Census survey, nearly 20 years old, of civilian non-institutionalized citizens.⁴ The U.S. Census Bureau’s American Community Surveys (ACS), conducted between the decennial censuses, also produce important information. Respondents are asked to self-report on whether they have difficulty with various aspects of mobility or cognition. Some of the questions only apply to household members over the age of 16.

The CDC also conducts an annual telephone survey, the Behavioral Risk Factor Surveillance Survey (BRFSS) which collects data on individuals age 18 and older, identifying disability on the basis of two questions—activity limitation due to health problems, and the need to use special equipment such as a cane or a wheelchair. The CDC’s BRFSS data indicates that 396,000 Iowans (18%) have disabilities. The Iowa Prevention of Disabilities Policy Council used a combination of ACS and BRFSS Iowa data from 2003 through 2007 to develop its own analysis: (1) 14.7% of Iowans over the age of five have a disability; (2) Among Iowans with disabilities, 58% have a single disability and 42% have multiple disabilities. Of the 58% with single disabilities, 58% have mobility impairments, 22% have sensory disabilities and 20% have mental disabilities. The prevalence of disability increases with age.⁵

Although the data are incomplete, and gathered with different tools, they are important because they show that this is a very large constituency—and, as Iowans age, one that will get even larger over time.

Prevalence rates for specific populations can be found in Expected Prevalence and Utilization of Mental Health, Developmental Disability and Brain Injury Services in Iowa, in Appendix B at www.iowamhdsplan.org. The analysis focuses primarily on “mandatory populations”—those which Iowa counties are required to serve.

Information on prevalence is summarized briefly below.

Mental Illness. According to the Iowa Consortium for Mental Health (ICMH) at the University of Iowa, the most reliable national data on the prevalence of mental health disorders comes from the National Comorbidity Survey Replication (NCS-R) conducted between 2001 and 2003. Almost 10,000 individuals over age 18 were surveyed face to face in their households. Based on analysis of survey data, researchers concluded that:

- About half of Americans will experience some sort of mental health disorder over their lifetime (including major depressive disorders, alcohol abuse, anxiety disorders, mood disorders, substance use disorders, etc. This estimate is probably conservative because many people are likely to be reluctant to report behavior viewed as stigmatizing.
- Half of all lifetime cases start by the age of 14 and three fourths by the age of 24.
- Over a twelve-month period, 26.2% of the population can be expected to experience a mental health disorder.
- The population represented in the 26.2% can be broken down as follows: Serious – 5.85%; Moderate – 9.77%; Mild – 10.58%.
- About one third of those with mental illness (40% of those with serious mental illness) seek treatment of any kind, publicly or privately funded in a given year.

The ICMH applied the national prevalence rates to Iowa census figures and produced the following estimate of prevalence:

<table>
<thead>
<tr>
<th>Estimated Twelve-Month Prevalence of Mental Illness, by Severity, in Iowa*</th>
</tr>
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<tbody>
<tr>
<td>Serious MI</td>
</tr>
<tr>
<td>Moderate MI</td>
</tr>
<tr>
<td>Mild MI</td>
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<tr>
<td>Any MI</td>
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</tbody>
</table>


These high prevalence estimates reinforce the need for a public health component of mental health policy. It suggests that there are many more people with mental illness than can be helped by currently available resources, but the NCS-R researchers point out that not everyone who has a disorder needs treatment. Even so, the data suggest that Iowa needs to ask whether everyone who does need help is getting it, and if not, why not.

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7 Ibid.
8 Ibid.
The National Comorbidity Survey addressed prevalence only among adults over the age of 18. There are about 725,000 children and youth under the age of 18 in Iowa. According to the National Mental Health Center’s 2004 report on mental health in the United States (at http://mentalhealth.samhsa.gov/publications/), about 20% of children will have symptoms of a diagnosable disorder over the course of a year (or 145,000 children in Iowa), and about 5% (36,250) will have symptoms causing serious functional impairment.

The 2007 National Survey of Children’s Health (conducted by the Centers for Disease Control and Prevention under the direction of the Maternal and Child Health Bureau of the Health Resources and Services Administration) looked at the percentage of children aged 2 to 17 who had one or more emotional, behavioral or developmental disabilities. The seven conditions addressed in the survey were: ADD/ADHD, anxiety, depression, ODD/conduct disorder, autism spectrum disorders, developmental delay, and Tourette Syndrome. 10.6% of Iowa’s children had one or more of these conditions. Interestingly, 40.5% of the children had two or more co-occurring disorders. Prevalence was twice as high in children whose families were below the federal poverty level, but thanks to Iowa’s commitment to children’s health insurance over half of children with these conditions received coordinated care within a medical home.

Intellectual and Developmental Disabilities (ID and DD). A developmental disability is defined (generally) as a severe, chronic disability attributable to mental or physical impairment or a combination of both, which is manifested before the person attains the age of 22, is likely to continue indefinitely, and results in substantial functional limitations. In looking at service needs, it is important to understand that not everyone who has a developmental disability (DD) has an intellectual disability (or ID, formerly referred to as mental retardation or MR). The prevalence of ID can be estimated more accurately than for DD, though there are challenges in estimating both target populations. The definition of intellectual disability in Appendix A is accepted by the major national associations (the American Association on Intellectual and Developmental Disabilities and APA), which have defined practices for developing a diagnosis. On the other hand, although the term “developmental disabilities” has been defined in federal law (notably, the Developmental Disabilities Act of 1978), the term “has not been operationally and procedurally defined by the professional organizations... As a result, prevalence estimates of developmental disabilities have depended on relatively unrefined procedures.”

Estimates of the MR/ID population used to be produced with greater reliability through school-based assessments. However, in recent years there has been a growing reluctance to stigmatize students with a mental retardation label, and school personnel have used the term “learning disability” instead.

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10 The estimate was derived by extrapolating the percentage of children under age 18 in the U.S. Census Bureau’s 2008 estimate (23.8%) to the Bureau’s 2011 general population estimate for Iowa.
11 Data Resource Center for Child and Adolescent Health, found at http://nschdata.org
13 Ibid.
Based upon an in-depth analysis of the National Health Interview Survey – Disability Supplement of non-institutionalized populations, the University of Minnesota Research and Training Center on Community Living/Institute on Community Integration developed the following prevalence estimates: ID/MR (0.78%); DD (1.13%); and ID and/or developmental disabilities (1.49%). These are somewhat lower than other estimates. For example, The Arc of the United States uses estimates of 1% – 3% for ID, and the President’s Commission on Persons with ID cites a 3% estimate. Applied to Iowa’s population of 3,007,856, the RTC/ICI percentages produce the following conservative estimate of disability prevalence:

| Estimated Prevalence of Intellectual and Developmental Disabilities In Iowa (ID, DD, and ID and/or DD*) |
|---|---|
| Iowans with ID | 23,461 (0.78%) |
| Iowans with DD (not ID) | 33,989 (1.13%) |
| Iowans with ID and/or DD | 44,812 (1.49%) |


Despite the problems with estimates produced through school-based assessments alluded to earlier, children with disabilities are almost always identified first through school systems. A respected study in metropolitan Atlanta sought to determine the presence in school populations of ID and three other disabilities. The study used individual school records to develop a prevalence rate for ID of 1.03%. Application of this rate to Iowa’s certified public school enrollment produces an estimate of approximately 6,200 students, or slightly over 10% of the 61,859 students enrolled in special education. Since the Atlanta study only included identification of three other developmental disabilities, comparable estimates cannot be developed for the prevalence of developmental disabilities as a whole.

Individuals with ID but without the most severe impairments have a life-span approximately equal to the general population. Increased longevity of individuals with ID/DD is stimulating demand for services and supports. The aging of individuals with ID in the United States is an important service issue because about 60% of this

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14 Only 28% of the sample members who met the criteria for ID (“mental retardation) or DD met the criteria for both. Those who met criteria for ID but not DD had functional limitations in one or two areas of major life activity, but not the three or more stipulated in the definition of DD in the Developmental Disabilities Assistance and Bill of Rights Act as amended.
population live at home with family caregivers, about one fourth of whom are over 60 years old and facing increasing difficulties in addressing the needs of their family members—the number of Iowans with DD living with caregivers over age 60 was estimated at 7,330 in 2000.\(^\text{18}\) Therefore, there are potentially a large number of families affected by this issue in Iowa who may be under pressure to seek public services.

**Prevalence of Autism.** Autism is a complex developmental disability resulting from a neurological disorder effecting brain function. People with autism have issues with non-verbal communication and social interaction. No two people with autism will have the same symptoms, and the degree of disability may be mild or severe. In February 2007, the Centers for Disease Control and Prevention released findings from the largest summary of prevalence data from multiple U.S. communities participating in an autism spectrum disorder (ASD) surveillance project. The results across 14 states indicated that approximately one in 150 children is affected. Boys are three to five times more likely than girls to be affected. The median age of the earliest diagnosis was age four.

ASD refers to a spectrum of “pervasive developmental disorders” (PDD) including autism, Asperger’s disorder, and PDD NOS (pervasive developmental disorder not otherwise specified). The spectrum may also include Rett’s disorder and Childhood Disintegrative Disorder (CDD). These latter disorders are extremely rare, however. Rett’s has a prevalence rate of 1/20,000 and CDD has a prevalence rate of 1.7/100,000. Application of the most recent CDC prevalence estimate to the estimated 713,032 Iowans between the ages of 0 to 17 produces an estimate of 4,700 children with ASD. Prevalence of the various individual disorders on the spectrum has not been determined with any precision. Prevalence of Asperger’s has been estimated at anywhere from 2/10,000 to 3-4/1000.

**Prevalence of Brain Injury.** Brain damage in some individuals occurs at birth. Acquired brain injuries occur after birth, and can include traumatic brain injuries (TBI) from falls, penetration by a projectile, etc., and non-traumatic brain injuries such as stroke or infection. The Centers for Disease Control and Prevention estimates that approximately 2% of the U.S. population currently has a long-term or lifelong need for help to perform activities of daily living as a result of traumatic brain injury (TBI). Estimates are difficult because many people who experience TBI are not seen in a hospital emergency room and an unknown number never receive care. Applied to Iowa’s population, this produces an estimate of approximately 50,000 people living with brain injury. Males are about 1.5 times as likely as females to sustain a TBI, so it would be expected that of the 50,000 people with TBI, 30,000 would be men.

The Brain Injury Association of America of Iowa (BIA) uses American Heart Association data on the prevalence of stroke in the United States (6.4 million) to develop an estimate of 95,000 for the total number of Iowans with acquired brain injury.\(^\text{19}\)

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\(^{18}\) *Ibid.* State-by-state data were estimated using a prevalence rate of 1.58% for persons with ID or DD, developed in the NHIS –D analysis by Larson *et al.*, cited above, but correcting for estimated institutionalized populations.

\(^{19}\) Found at [http://www.biausa.org/iowa/](http://www.biausa.org/iowa/)
These numbers will certainly increase as a result of injuries experienced by Iowans who have served in combat in Iraq and Afghanistan. Currently about 15,000 people are veterans of these wars, and Iowans continue to be deployed.\textsuperscript{20} Blast exposures account for 60-80\% of all injuries and fatalities, and an estimated 20\% of individuals deployed have had an exposure to some type of brain injury or, in many cases, multiple exposures. This percentage is characteristic of those screened in the Iowa City VA catchment area. Co-occurring TBI and Post Traumatic Stress Disorder is so common as to be the norm.\textsuperscript{21} Many veterans come home with polytrauma (injuries to more than one bodily system). These include TBI, PTSD, depression, pain and physical injuries.

\textit{Prevalence of Other Disabilities.} Thus far this chapter has pointed to the challenge of determining prevalence of mental illness, ID and DD, autism (a type of developmental disability) and brain injury. Prevalence estimates are often based on decades-old surveys, of limited populations, dependent on self reports by people whose disabilities may or may not yet have been diagnosed. Attempts to determine prevalence of the many other disabilities and chronic conditions run into the same problems, and publishers of reports on prevalence are quick to point them out. Below are some statistics on four disabilities and chronic conditions, commonly adult-onset. National prevalence rates were applied to Iowa’s population according to the 2009 U.S. Census.

The statistics make abundantly clear the rationale for emerging federal and state policies to improve care coordination for individuals with chronic conditions. Although only rough estimates are available, the table below shows that the number of Iowans with asthma or diabetes appears to approach a half million. None of these populations are “mandatory populations” which counties are required to serve under Iowa Code, although all individuals with these disabilities, if Medicaid-eligible, can access State Plan services. They may also be eligible for Physical Disability or HIV/AIDS Waiver services.

<table>
<thead>
<tr>
<th>Disability</th>
<th>National Prevalence Rate</th>
<th>Data Source</th>
<th>Estimated No. of Iowans Affected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spinal Cord Injury</td>
<td>.084%</td>
<td>National Spinal Cord Injury Statistical Center, found at \textsuperscript{20} <a href="http://www.fscip.org/facts.htm">http://www.fscip.org/facts.htm</a></td>
<td>2,537</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>.13%</td>
<td>National M.S. Society, found at \textsuperscript{20} <a href="http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/who-gets-ms/index.aspx">http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/who-gets-ms/index.aspx</a></td>
<td>3,919</td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>.36%</td>
<td>Center for Disease Control. HIV Surveillance</td>
<td>10,828</td>
</tr>
</tbody>
</table>

\textsuperscript{20} Michael J. Hall (U.S. Department of Veterans Affairs Medical Center, Iowa City) and Jack Hackett (U.S Department of Veterans Affairs Vocational Rehabilitation and Employment Service). Presentation to Iowa Mental Health and Disability Services Commission (September 16, 2010).

\textsuperscript{21} Ibid.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma</td>
<td>6.5%</td>
<td>Asthma and Allergy Foundation of America, found at <a href="http://www.aafa.org/display.cfm?id=8&amp;sub=42">http://www.aafa.org/display.cfm?id=8&amp;sub=42</a></td>
</tr>
</tbody>
</table>

Supports and Services for People with Mental Illness or Other Disabilities

*Types of Supports and Services Needed.* There is a wide variety and range in intensity of service needs from one person to the next. The ADA defines disability as physical or mental impairment that substantially limits one or more major life activities. These include: caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working. “Major life activities” also includes major bodily functions, such as functions of the immune system, normal cell growth, digestive, neurological, brain, respiratory, circulatory, and other functions.

People may, then, need health services, durable medical equipment, assistive technology, home or vehicle modifications, medications, or personal attendant services to assist with the “Activities of Daily Living” (bathing, dressing, toileting, etc.) They may need assistance with “Instrumental Activities of Daily Living,” through such supports as homemaker or chore services, coaching or training in life skills, or service animals. Mental or behavioral health needs may include inpatient or outpatient psychiatric treatment, substance abuse counseling, peer support, group and family therapy, or drop-in centers/clubhouses. These are just a few examples of services often needed by individuals. Implementation of new state initiatives such as IME’s Money Follows the Person project and IDPH’s involvement with brain injury services sometimes lead to the identification of unmet needs and the development of services to address them.

Designing a system that works for people involves much more, though, than developing a menu of services. The “how” of service delivery is as important as what is delivered. Chapter III summarizes major changes in the design and delivery of services over the past 150 years, especially the trend away from institutional settings to community based services. The system continues to evolve, based on changing attitudes about people with disabilities and changing expectations about what we should be getting for our service dollars. Some important trends at work in Iowa are described below:

- *The increasing focus on outcomes;*
• Promoting consumer empowerment in service planning and delivery;
• Creating more flexible and individualized supports;
• Addressing the high intensity needs of people at risk of institutionalization or out of state placement;
• Recognizing the importance of service coordination and integration;
• The on-going concern for cost-effectiveness.

A Focus on Outcomes. When service plans are developed to address the needs of individuals with mental illness or other disabilities, they include goals for consumers and often for the individuals’ families as well. The plan might include such goals as acquiring life skills, reducing social isolation, keeping the individual at home and at school, or getting a job. There is a growing awareness at both the state and federal level of the need for more accountability for outcomes in the service system.

This can be a major issue when reimbursements are linked to progress towards outcomes, especially if the expected outcome is not crystal clear. Such was the case several years ago, when a number of states, including Iowa, were subject to a federal finding that what had billed to Medicaid as Adult Rehabilitative Option services for people with chronic mental illness was often not consistent with the federally defined purpose of rehabilitation (reducing physical or mental disability and restoring the individual to his or her best functioning level). The audit found that the services were often primarily “habilitative,” which includes more adaptive skills rather than “restorative” services. The finding resulted in hardship for states, providers and consumers. (The situation did lead to positive action in Iowa, however. In 2007, in order to ensure that people with chronic mental illness continued to have access to services, Iowa became the first state in the nation to take advantage of a provision in the federal Deficit Reduction Act of 2005 allowing the inclusion of Waiver-like home and community based service in its Medicaid State Plan. In this case, the Act was used to provide for habilitation services.)

In 2010 a different debate began in earnest in Iowa about what constitutes meaningful outcomes in its employment service system for people with ID/DD and/or mental illness. A report by the Institute for Community Inclusion at the University of Massachusetts, on the states’ employment outcomes, found that in Iowa the percentage of the working age population who were employed was 76.7%, but only 38.7% for people with a mental disability.22 The report cited 2004 data on outcomes for people with ID/DD by employment settings. The number of people served in facility based or non-work settings was over three times that of people served in integrated employment.23 Facility based settings are defined as those where a majority of employees have a disability, such as sheltered workshops. Often employees earn less than a minimum wage. Delivering most services in these settings is inconsistent with Olmstead integration principles.

22 American Community Survey, cited in J. Butterworth et al. StateData: The National Report on Employment Services and Outcomes (Boston: Institute for Community Inclusion – University of Massachusetts, 2009) Mental disability is defined in the ACS as a physical, mental or emotional condition that creates difficulties in learning, remembering or concentrating and lasts six months or more.
Pre-vocational services are intended to prepare a consumer for paid or unpaid employment, and focus on generalized results (compliance, attendance, task completion, problem-solving, and safety), not specific job tasks. As of 2010, if pre-vocational services do not in fact lead to employment, they may not be Medicaid-reimbursable. This, too, has had an impact on community providers.

Changing the focus of Iowa’s employment service system is a complex challenge, and it cannot be accomplished overnight. The State of Iowa has joined the State Employment Leadership Network (SELN), an initiative of the National Association of State Directors of Developmental Disabilities Services (NASDDS). (The Administrator of the Mental Health and Disability Services Division is Iowa’s Director of DD Services.) SELN members are committed to promoting, as the preferred outcome, employment for people with DD which is in integrated settings, consistent with Olmstead. With the assistance of NASDDS consultants and the involvement of a broad group of stakeholders, Iowa has completed the first of many steps towards the kind of transformation contemplated in the SELN process—a thorough readiness assessment. All disability populations, including people with mental illness, are expected to benefit from implementation of the SELN plan to build system capacity. It will require concerted efforts in the area of leadership, redesigned services and supports, definitions of outcomes, and reimbursement policies.

The outcomes issues just described relate to individual services. States also need to focus on systemic outcomes, such as the National Outcome Measures (NOMs) for mental health services. The federal Substance Abuse and Mental Health Services Administration (SAMHSA) provides significant annual funding to States for mental health services through the Mental Health Block Grant. As a condition for funding, states are required to develop a mental health plan, and also to develop data management and reporting systems that will demonstrate progress in the achievement of the NOMs. The NOMs fall into ten domains, such as Employment/Education, Crime and Criminal Justice, and Stability in Housing. DHS is taking steps towards outcomes reporting consistent with Mental Health Block Grant requirements. Progress in achievement of systemic outcomes depends on a number of factors such as whether services are individualized and sufficiently flexible, whether they are evidence-based, best or emerging practices, and whether they are well coordinated.

The corollary to NOMs in the world of developmental disabilities are the National Core Indicators, developed jointly by the NASDDS and the Human Services Research Institute. Since 1997 they have increasingly viewed by states as important to quality management of their services systems. The indicators address domains under both Consumer and System Outcomes. Consumer Outcomes include work, community inclusion, choice and decision-making, etc. System Outcomes include the domains of access, service coordination, consumer and family participation in decision making, etc. Iowa has not yet taken steps towards implementation of the Core Indicators.

*Empowerment.* The philosophy of consumer empowerment is rooted in the historical struggle of people with mental illness, brain injury and other disabilities to free
themselves from marginalization, helplessness and harsh treatment in hospitals, prisons, and other settings where their lives were controlled by others. Disability services have evolved over the centuries from draconian warehousing, to rigid and demeaning service offerings based on low expectations of the individual, to the concept of person-centeredness in the development of service plans, and now finally to actual control over resources available for one’s supports, and the ability to direct one’s own services.

A system which empowers consumers and their families is based on their personal goals, and offers a range of meaningful choices, such as the choice of providers (to which all Medicaid members have a right). IME provides participants in six of the seven Home and Community Based (HCBS) Waivers the option to self direct the portion of their service budget which pays for non-licensed services. Under this Consumer Choices Option, participants can make nontraditional purchases or get services from nontraditional providers (such as family members), if it clearly helps the participant live successfully in the community. While only a relatively small percentage of waiver participants choose to self direct, those who do are vocal about its positive impact on their lives. Self direction may in the future be expanded to other areas of the service system.

Flexible and Individualized Supports. The federal Centers for Medicare and Medicaid Services, the Iowa Legislature and the Department of Human Services, as well as Iowa counties have developed an array of carefully defined services intended to be responsive to people’s needs. Reimbursement is based on provision of services which meet those definitions. Strict accountability for the use of resources is of course essential, but one consequence can be service offerings that don’t fit the needs of individuals. One of the reasons many Waiver participants want to self direct services is that it provides more flexibility than traditional services. Many individuals and families participating in stakeholder input sessions leading to the development of this plan stated that they are offered services that they neither need nor want, and asked for more flexibility.

Flexible and individualized supports are at the heart of another prominent evidence-based practice, known as Wraparound, which has been shown to produce positive outcomes for children and youth with serious emotional disturbance (SED). Wraparound involves formation of an interdisciplinary team chosen by the consumer and family members. The team can include natural supports such as friends and relatives. Based on a family-driven, youth-guided plan, the team identifies resources to provide the full range of supports needed to meet the family’s goals. This can include money to pay rent or buy a tank of gas to get to an appointment, the development of arrangements for natural supports (family, friends or acquaintances) to be available in a crisis, etc. Children’s mental health systems of care (SOCs) employ Wraparound. The Community Circle of Care in northeast Iowa is a SAMHSA-funded system of care serving families, children and youth with SED. Wraparound is also being promoted in other areas of the state by the MHDS Division, with the support of a team of SOC providers from across Iowa.

Flexible and individualized supports still have be justified on the basis of effective outcomes, i.e., that they provide things that people really need in order to live as independently and participate as fully in the community as possible. Service plans should
be based on assessments that are thorough, treat everyone fairly, and focus on what people need in order to live, learn, work and recreate in the community of their choice. DHS is looking at the effectiveness of the Supports Intensity Scale (SIS), a strengths-based tool which has been used effectively in other States not only to improve the quality of assessments and enhance sensitivity to individual needs and choices, but also to improve system planning. Once several hundred assessments have been completed across a state, a picture begins to emerge of the patterns of services that are required for people with varying intensity of needs. This can help states project costs based on service needs (“case rates”), strengthen planning, and allocate resources fairly.

**Addressing High Intensity Needs.** Efforts to contain costs can sometimes keep people from getting the services they need. Providers will be unable to accept, or to continue to serve individuals whose needs exceed any caps on services. Medicaid HCBS Waivers have such caps, and each Waiver program as a whole is bound by the federal requirement that it be cost neutral to the state, i.e., that the waiver services provided not exceed the cost of comparable services to that target population in an institutional setting. Some people with fragile medical conditions or significant behavioral issues require 24/7 services and supports either in a facility or in their own home.

Approximately 200 people with mental illness or other disabilities are currently served out of state, because no Iowa provider can or is willing to serve them. The irony is that caps on reimbursement applied in-state do not apply when DHS is forced to place people in settings out of state. Negative consequences include the impact on Iowa families and the loss of resources which might be better directed to building the capacity of Iowa’s provider network. Many of those served out of state are individuals with brain injury. IME is currently testing a demonstration project with a Brain Injury service provider to serve individuals with intense service needs in a home and community based setting in the Des Moines area.

**Service Coordination and Integration.** This evolving concept is getting increased scrutiny in systems improvement efforts across the country. Traditionally, recipients of public assistance have relied on case managers to help them plan and coordinate their services, but the fact that Medicaid provides reimbursement for coordination only of Medicaid-funded services puts sharp limits on the assistance case managers can provide. Some Iowa disability populations have access to targeted case managers, who have the ability to coordinate important non-Medicaid services needed by individuals. This could include housing subsidies, Food Stamps, or other public and private assistance.

The concepts of service coordination and integration took a leap forward with the adoption of interdisciplinary teams which share responsibilities for service planning, coordination and integration. The teams can include case managers and various providers including clinicians, social workers, and community service providers, and should include the consumer and family members. The Wraparound concept is a further advance—an evidence-based practice that puts children, youth and families at the center, and in charge of the interdisciplinary team. The family makes the decision about the composition of the team, and the planning process is family driven and youth guided.
The family is assisted by a care coordinator, who ensures proper interface among primary care, mental health, child welfare, education and juvenile justice systems. Without a care coordinator, communication among these major systems generally falters. Personnel operate on partial information, waste time and resources, and frustrate families who must shuttle from one siloed system to the next.

In 2005-2006, the Iowa Coalition for Aging and Mental Health (ICMH) reviewed two pilot demonstrations of co-location of mental health services with primary care to assess their impact on the improvement of access to mental health services for older Iowans who would not ordinarily seek them. Primary care physicians are generally the providers first contacted by people with mental health disorders. Often they may be inadequately prepared to diagnose and treat mental illness and serious emotional disorders. Training primary care providers, including physician’s assistants, registered nurse practitioners and other staff can significantly improve coordination of health services. Based on its review of the two demonstrations and of other models throughout the country, ICMH developed a collaborative model for the delivery of mental health services through primary care.

The medical home concept and most recently the “health home” (promoted under the Affordable Care Act) more fully develop the idea of a holistic approach to healthcare. Under the medical home concept, every individual has access to a primary care provider, whose office provides coordination of care across all treatment settings; under the health home concept, coordination of care for people with chronic conditions or mental health disorders can be done by the provider of the services most heavily used by the individual.

Cost-Effectiveness. Controlling costs does not have to equate to cutting services that people really need. Resources can often be redirected to achieve desired outcomes at lower costs. There is little disagreement that cost-effectiveness needs to be a hallmark of the service system regardless of whether or not a state faces a fiscal crisis. The question is how to define and measure cost-effectiveness in a human service system, which can present policy-makers with major challenges.

Cost-effectiveness can be defined as achieving optimum results for the amount expended. Opinions can of course differ on what is optimum. Those who believe that the optimum values for a disability service system are the avoidance of any risk to health and safety, standardization of service offerings, and reliance upon the authority of licensed professionals, are going to look for different results for consumers than those who put the optimum value on consumer-driven service planning, maximum consumer control over resources, flexibility, and full community inclusion.

When four states first began to demonstrate self-direction (the waiver option known in Iowa as the Consumer Choice Option) there was widespread concern that giving people control over some of the resources for their supports would unleash irresponsible

25 Ibid.
decision-making and ballooning costs. In fact, the self direction demonstration has shown that people generally know best what they do and do not need. Similarly, state policies shifting resources from institutionally based care to home and community based options are often met with skepticism from providers who believe that individuals currently residing in facilities which enjoy economies of scale in professional staffing would cost more to serve in more independent settings. Preliminary results from Iowa’s Money Follows the Person grant actually indicate lower average service costs for MFP participants during their “demonstration year” than the service costs per person per year at Resource Center or community based ICFs/MR.

These findings are reinforced by two prominent studies comparing costs of institutionally based long term care with home and community based services (HCBS). The first, in 2006, looked at two target populations (those requiring an ICF/MR level of care and those requiring a nursing home level of care), and attempted to determine the full costs to taxpayers, on average, correcting for the fact that the institutions provide room and board while such costs for HCBS Waiver participants must come from other sources. The study showed significant average cost savings per person. A second study released in 2009 compared the experience of two groups of states—those offering limited non-institutional services and those with large, well-established HCBS systems. The second group experienced an initial short term rise in long term care expenditures, followed by a reduction in institutional spending and a slower rise in long term care costs in ensuing years compared to states relying primarily on institutions.

Cost-effectiveness also has to be measured within a particular time frame. The state budget is planned over a two year horizon, for the most part. The emergence of disability and the intensification of its impact on the individual and the family, on the other hand, are often years in the making. For example, in Fiscal Year 2011 the State of Iowa continued to struggle with a high rate of out-of-home placements of children, especially those with challenging behavior or mental health issues that lead their families into crisis. Research shows that mental health problems exist among the juvenile justice population at rates 3-4 times that of the overall U.S. population under the age of 18. (Unfortunately, comparable statistics are not available for Iowa.) Children with mental health issues are disproportionately represented in the Juvenile Justice system. Today’s teen-ager who drops out of school or develops a criminal record may have been the pre-schooler whose emotional disturbance went untreated. Research has shown that a family’s access to integrated, coordinated and flexible services in a children’s mental health system of care achieves good outcomes for children (keeping them at home, in school and in the


community) through highly cost-effective interventions. Legislators and other policymakers may know this well, but especially in times of fiscal crisis they may find it extremely difficult to invest in a future that is ten years down the road.

It is often said that it is hard to garner support for prevention programs because it is hard to prove that something won’t happen or will happen less often if a particular step is undertaken. Advocates shrug their shoulders and say “Pay now or pay later.” The cost-effectiveness of prevention strategies and early intervention has been documented in every sphere from early childhood development to discharge planning for offenders with mental health issues, to respite services for family caregivers.

One of the purposes of the DHS State Olmstead Plan is to try to lengthen the horizon for investment planning. As the resources available shrink or expand over time, Iowa needs to be able to pick its priorities thoughtfully and direct funding strategically to achieve the vision of a life in the community for everyone.

Capacity of Iowa’s Service System

As with the above discussion of services, this section is not intended to be an exhaustive discussion of system capacity. It will briefly review a few basic and long-standing issues. Chapter III provides additional information on some of them.

Mental Health. Issues related to Iowa’s capacity to address the needs of individuals with mental illness include the need for better outreach, critical service gaps, and severe workforce shortages.

1. Dealing With Mental Health as a Public Health Issue. Like other health conditions, mental illness is generally easier to treat, and the impact on the individual and family can be reduced, if intervention happens early. Left untreated, mental illness can exact significant, sustained costs from the individual and family, schools, employers, the correctional system and taxpayers. Many advocates propose a focus on mental health as a public health issue. The State Plan points to the importance of expanding public education to reduce stigma, familiarize the public with the symptoms of mental illness, and encourage and assist individuals to seek the help they need in a timely manner. Iowa’s natural disasters since 2008, along with at least one highly traumatic incident of school-based violence, heightened awareness of the public health aspects of mental illness, leading to the development of Disaster Behavioral Health Response Teams across the state. The state needs to strengthen its suicide prevention programs for youth; suicide is the second leading cause of death for young Iowans between the ages of 10 and 24.30

29 See, for example, SAMHSA’s Annual Reports to Congress on The Comprehensive Community Mental Health Services for Children and Their Families Program Evaluation Findings at [www.store.samhsa.gov](http://www.store.samhsa.gov)
30 Iowa Department of Public Health and Suicide Prevention Strategy Steering Committee. *Iowa Plan for Suicide Prevention: 2005 to 2009*
2. The Core Services Issue. Community capacity varies significantly across Iowa, partly due to the state’s rural character but also because of the degree of autonomy held by counties in administering the state’s county-based system. A comment frequently heard is that the services that people can access vary from county to county, so that what you get depends on where you live. This is becoming less and less true over time, however. All counties are required to provide a limited set of services to people with mental illness or intellectual disabilities. In addition, in order to qualify for state payments, counties have to develop management plans identifying the populations to be served (which can include other groups besides people with mental illness or ID), describing the service management system as well as the cost-effective, individualized services to be provided to help them be “as independent, productive, and integrated into the community as possible.” Counties have gradually moved towards greater standardization of their plans.

County CPCs point out that any differences in their array of services are due to the decision by some counties to offer more than what is statutorily required. For example, while all counties pay the non-federal match for Medicaid case management for people with chronic mental illness (CMI) receiving Habilitation services, many but not all pay for county funded case management for people with CMI. In addition, 11 counties pay for case management for people with the diagnosis of mental illness (MI) only. There may also be a difference between what county management plans include as coverable services and what services are actually available in a county. An informal MHDS review of county management plans in 2011 seemed to indicate that 36 counties, including the most populous areas in Iowa, provide for funding of Assertive Community Treatment (ACT, discussed below), but there are only five ACT teams in the state serving 250 people. Such disparities in access continue to be seen as both a fairness issue and an issue of equitable resource allocation.

These differences aside, however, CPCs state that a core set of services is identified in Iowa Code (Chapters 220 and 225) and reflected in all management plans. These services include case management; evaluations; outpatient services; inpatient hospitalization and MHI’s; residential care facilities and intermediate care facilities for people with ID and MI; respite; supported community living and various day programming, etc. Advocates see two basic issues with these core service requirements. First, the terminology—and the desired outcomes—are vague. “Outpatient services” is a case in point. A related point is that there is at best no evidence that these core services are linked to the kinds of outcomes states want to track, such as employment, stable housing, avoidance of institutionalization, etc. In fact, in many cases the services specifically do not support those outcomes. Unfortunately, research on evidence-based practices (EBPs) is not well advanced.

Discussions of standardization nevertheless consistently seem to lead policy makers and stakeholders to consider what array of core services should be available statewide to provide a safety net, help maintain people in the community, and avoid use of inappropriate and more expensive service settings. The greatest concern has been for the mental health system. As early as 1998, the Technical Assistance Collaborative’s Report for the Iowa Mental Health Planning Council, entitled *Quick Fixes or Structural Reform:*
An Evaluation of Iowa’s Public Mental Health System, called for numerous reforms, including the development of a set of core services to which all consumers would have access. County CPCs issued a report the following year with similar recommendations, and the core services concept was promoted in 2004 in the MH/MR/DD/BI Commission’s recommendations for redesign of the adult mental health and disability service system, and in 2007 in the Mental Health and Disability Services Division Administrator’s Mental Health Systems Improvement in Iowa: A Report to the Legislature and Governor. The issue continues to be raised in legislation pending in the 2011 Session, on system restructuring.

There is no disagreement that Iowans with mental illness—especially those who do not qualify for Medicaid and are unable to afford private mental health services—need to be assured of a safety net in their communities in times of crisis. Iowa’s network of community mental health centers (CMHCs) could provide the local infrastructure for delivery of safety net services. (A map of CMHC service areas, including providers designated by counties as CMHCs as allowed by Code, appears on the following page.) Chapter 230A of Iowa Code establishes the role of CMHCs and their relationship to counties as the funders of mental health services. The MHDS Commission (formerly the MH/MR/DD/BI Commission) has been reviewing Chapter 230A for two years and striving to develop a legislative proposal to strengthen Iowa’s mental health infrastructure. Currently, the Legislature is broadening that review to consideration of both the structure and financing of the entire mental health and disability services system.

Critical Service Gaps. Service gaps in the mental health system fall into several main categories. The first category was addressed by the Acute Care Task Force over an 18-month period that culminated in their 2009 report, Recommendations for Creating a Statewide Mental Health Acute Care Service System. Commenting that the system of acute care in Iowa exists by default rather than by design, the report points out that the most widely used access point to Iowa’s service system is the hospital emergency room. (Internal research by MHDS indicates that several counties lack any hospital emergency room services, however.) Emergency room services are costly, and all too often do not connect the individual to what he or she needs. Some hospitals operate inpatient psychiatric units, but most do not. Access does vary statewide—there are 23 counties with hospital psych units, which means that three-fourths of counties do not. Although many stakeholders point to what appears to be a shortage of psychiatric beds in Iowa, which puts great pressure on the state’s committal system, other observers, including the Task Force, sharply disagree. In Iowa, the use of emergency rooms and acute care is primarily due to the lack of alternative mental health and substance abuse acute care services, both secure and non-secure, with integrated continuing care options.

There is considerable evidence that prolonged stays in psychiatric units, beyond the point where acute services are needed, are creating excessive costs to taxpayers for want of alternative step-down service options. The Task Force report concludes there is a critical need in Iowa for the development of community-based services as an alternative to the current reliance on institutions for mental health care. MHDS internal data indicate that crisis stabilization services are available in one third (33) of Iowa counties, and seven
counties have 23-hour observation beds. The work of the Task Force led to state initiatives to pilot two crisis stabilization service demonstrations operated through CMHCs in northeast Iowa.

The second major type of service gap is the lack of capacity in the area of evidence based practice (EBP)—service models found to be effective on the basis of rigorous research. As discussed in Chapter III, the number of EBPs adopted by community mental health centers and other mental health providers in Iowa is limited, as is the number of people served. As noted above, there are only five Assertive Community Treatment (ACT) programs in Iowa, serving approximately 250 people. Even though ACT is the most intensive of mental health interventions, using a team of professionals and 24/7 support to individuals, it can be much more cost effective than acute care services. According to research by the Iowa ACT Resource Center at the Consortium for Mental Health, approximately 1200 to 1400 Iowans would be likely to benefit from the services of ACT teams.

The importance of Peer Support as an EBP in person centered recovery is increasingly recognized by mental health professionals and vigorously promoted by the Iowa Advocates for Mental Health Recovery. Peer supporters can work in a variety of settings, from ACT teams to hospital emergency rooms. Formal training is essential in development of qualified specialists, and DHS has used Mental Health Block Grant funds to contract for development of a Peer Support Training Academy.
An important EBP getting increasing attention under the Employment First and State Employment Leadership Network (SELN) is Supported Employment. As is the case in other states, the majority of Iowans with chronic mental illness are unemployed or underemployed, associated with poor outcomes for this population. (Failure to find meaningful daytime activity is also a barrier to community living for individuals with ID.) Other EBPs offered in Iowa include Intensive Psychiatric Rehabilitation Treatment (IPRT), Parent-Child Interactive Therapy for young children with severe conduct disorders and Multi-System Therapy for adolescents at risk of involvement with the criminal justice system, Wraparound services for families and children with SED, and services to individuals with Co-Occurring Disorders. Over the past decade Trauma Informed Care has received increased attention due to new understanding of both acute and complex trauma as factors in the presentation of mental illness and in an individual’s response to treatment. Though not yet defined as an EBP there is growing consensus on the need for trauma informed systems of care. DHS provides financial incentives and assistance in expansion of EBPs, including training and technical assistance through the Iowa Consortium for Mental Health, but most stakeholders would agree that much work remains to be done.

Rural Service Access. The lack of services in rural areas is also discussed in Chapter III. Counties with low population densities provide little opportunity for economies of scale, particularly in the delivery of in-home services requiring a lot of “windshield time” for support staff to reach consumers. This is one reason for the interest in a regionalized service system. Rural isolation is exacerbated by lack of transportation.

Behavioral Workforce Shortage. Behavioral health workforce shortages are a national problem, but a particularly extreme problem in Iowa, both in terms of the low number of practitioners and their maldistribution across a mostly rural state. According to recent statistics developed by the Health Resources and Services Administration of the federal Department of Health and Human Services, 38.4% of Iowans live in areas with a severe shortage of mental health care workers—more than twice the national rate.\(^{31}\) In 2007, 87 Iowa counties were designated in whole or in part as lying within Mental Health Care Health Professional Shortage Area (HPSA) within Mental Health Catchment Areas. (See map on following page.)

The shortage of psychiatrists and psychologists has been a persistent problem in Iowa. In 2005 the state had 231 active psychiatrists and ranked 47\(^{th}\) among states in psychiatrists per capita. In 2008, Iowa Medical Society data ranked the state 44\(^{th}\).\(^{32}\) The most recent data available from the Iowa Consortium for Mental Health shows an increase in the number of licensed psychiatrists, but the data are preliminary and it is not known how many are in active practice. In 2005 Iowa ranked 46\(^{th}\) in psychologists per capita (with a total of 472 in the state), and a more satisfactory 28\(^{th}\) in social workers per capita (with 4,204). The number of Advanced Registered Nurse Practitioners with a specialty in

\(^{31}\) Kaiser Family Foundation (2008). *Iowa: Health Professional Shortage Areas.* Found at [www.state.healthfacts.org](http://www.state.healthfacts.org)

\(^{32}\) Report of the Task force on Iowa’s Health Care Infrastructure (April 2008).
mental health (approximately 68, mostly in private settings) has remained basically unchanged. Iowa’s low ranking in several core mental health professions is likely to be aggravated by the anticipated retirement of large numbers of licensees.

Disability Populations. Service capacity issues for other disability populations have a few similarities to those described above for mental illness, but there are also many differences. Similarities in system capacity issues include a severe shortage of trained direct support professionals and the scarcity of providers in rural areas. On the other hand, while access to adequate health care is tremendously important for people with disabilities, acute care, clinical services and psychotropic meds do not have the same significance as they do for people with mental health issues—unless individuals have co-occurring mental illness. For these individuals the lack of safety net services is just as urgent, and DHS is working hard to build community provider capacity to meet the needs of people in crisis.

Access to Iowa Medicaid and HCBS Waivers. Medicaid is the principal funding source for mental health and disability services. What it will pay for and for whom are thus fundamental factors in system capacity. For example, expenditures on the ID Waiver and ICF/MR services, at nearly $630 million dollars in 2009, accounted for roughly half of Iowa Medicaid long term care expenditures and 21.3% of all Medicaid costs. (There are
about 16,000 people receiving these services—less than 5% of all Medicaid enrollees in Iowa.)

Funding and system capacity are closely linked in both mental health and disability services, but the way services are delivered and paid for is very different. People with a diagnosed mental illness who are eligible for Medicaid are entitled to services under Magellan’s Iowa Plan for Behavioral Health no matter where they live. People who are not Medicaid eligible may or may not get access to services depending upon what their county’s management plan will cover and for whom, and whether the county has the money to pay providers to offer those services. Implementation of expanded Medicaid eligibility in 2014 may be an opportunity to build Iowa’s mental health service system capacity.

The important questions for people with disabilities are not just whether or not they are eligible for Medicaid (a complicated determination process described in Chapter 3) but also whether they are eligible for the HCBS Waiver that best addresses their functional needs. Some disability populations eligible for HCBS Waiver services fare well. Iowans with ID, for example, have access to a large menu of services under the ID Waiver, though their need for such services must be justified in order for them to be included in their individualized plan. A statewide network of providers has thus developed to serve this population.

The Brain Injury (BI) Waiver offers a similar set of services as those under the ID Waiver, and there are both specialized BI providers in Iowa and providers who serve BI along with other populations. As awareness of BI has grown, as well as an understanding of the particular needs of this population, more providers have sought to build their capacity to provide BI services. A small percentage of individuals with BI benefit from behavioral management services, but a more pressing need is neuro rehabilitation. IME is working with a group of providers to define services and develop licensing requirements. The Governor’s Advisory Council on Brain Injury also has a task force examining this service need.

People with developmental but not intellectual disabilities, people with adult onset physical disabilities, and other populations may or may not be eligible for other waivers.

Eligibility is not enough, however. Unlike Medicaid-funded mental health, HCBS Waiver services are not an entitlement. Like other states, Iowa can and does limit the number of “slots” available. Depending on resources available, the Legislature has tried hard to fund sufficient waiver slots to address everyone’s needs, but as demand increases, waiting lists persist—an on-going capacity issue.

A final complication affecting system capacity is the cap on the dollar amount which can be spent on services. Providers will not accept individuals with needs so acute that they cannot be accommodated under waiver service caps. As noted earlier, if no providers can be found, DHS will look for a provider outside the state and has the authority under Medicaid regulations to pay the higher costs associated with their care.
Core Services. Variable access to disability services from one county to the next has stimulated discussion of how to make the system more equitable statewide. However, many disability advocates view the idea of core services differently than do stakeholders concerned with mental health. As described in the section on Supports and Services, above, there is growing recognition of the importance of flexibility and individualized services tailored to the specific needs and personal goals of consumers and family members. In public forums on the State Plan, people frequently commented that the set of services offered to them was not what they wanted or needed. Support was expressed for the Consumer Choices Option available under the HCBS Waivers, which allows people to develop their own budget covering non-traditional supports, from non-traditional providers.

Conclusion. Capacity issues in Iowa’s mental health and disability services system are a tangle of factors—limits in federal, state and local resources, regulatory constraints, economies of scale, the evolution from facility based services to HCBS and its implications for workforce development, poor coordination among the public systems that affect people’s lives, putting them in settings ill-equipped to address their needs, and rising expectations. It is no wonder, then, that the DHS five-year Olmstead Plan is so wide-ranging. Developing and implementing short term Action Agendas will take patience, persistence, occasional opportunism and fidelity to Plan principles.
### Appendix A
Iowa Department of Human Services - Mental Health and Disability Services Division
Definitions of Targeted Population Groups Under Iowa Code

<table>
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<tr>
<th>Definition</th>
<th>Code/Rule</th>
<th>State Agency/Division</th>
<th>Other</th>
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<tr>
<td><strong>“Person with a disability”</strong> (“Mental Illness, Intellectual Disability, Developmental Disabilities, or Brain Injury”) is “a person with mental illness, intellectual or other developmental disability, or brain injury.” (This definition is limited only to disability population groups which Iowa counties are required to serve.)</td>
<td>Iowa Code 225C</td>
<td>DHS-MHDS</td>
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<td><strong>“Persons with a mental illness”</strong> means persons who meet the criteria for a diagnosis of a mental illness as defined in the Diagnostic and Statistical Manual, Third Edition—Revised (DSM III-R). Diagnoses which fall into this category include, but are not limited to, the following: schizophrenia, major depression, manic depressive (bipolar) disorder, adjustment disorder, and personality disorder. Also included are organic disorders such as dementias, substance-induced disorders, and other organic disorders which include physical disorders such as brain tumors. Persons with certain DSM III-R diagnoses as follows are not considered to have a mental illness: 1. Persons with a V Code diagnosis only. This diagnosis includes conditions that are not a mental disorder but are a focus of treatment, such as marital problems, occupational problems, parent-child problems, or other “phase of life” problems. 2. Persons with a psychoactive substance use disorder diagnosis only.</td>
<td>Iowa Administrative Rules 441-22.1</td>
<td>DHS-MHDS</td>
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3. Persons with a developmental disorder diagnosis only. This includes mental retardation, autism, and academic disorders.

"Children with Serious Emotional Disturbance" as defined by the state of Iowa pursuant to Section 1912 (c) of the Public Health Service Act, as amended (58 Federal Register 29422,*29425) are persons who:

- are from birth through age 21
- currently or at any time during the past year
- have had a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within [the current Diagnostic and Statistical Manual] that resulted in functional impairment which substantially interferes with or limits the child’s role or functioning family, school, or community activities.

These disorders include any mental disorder (including those of biological etiology) listed in [the current Diagnostic and Statistical Manual] with the exception of “V” codes, substance use, and developmental disorders, which are excluded, unless they co-occur with another diagnosable serious emotion disturbance. All of these disorders have episodic, recurrent, or persistent features; however, they vary in terms of severity and disabling effects.

Functional impairment is defined as difficulties that substantially interfere with or limit a child or adolescent from achieving or maintaining one or more developmentally appropriate social, behavioral, cognitive, communicative, or adaptive skills. Functional impairments of episodic, recurrent, and continuous duration are included unless they are temporary and expected responses to stressful events in the environment. Children who would have met functional impairment criteria during the referenced year without the benefit of treatment or other support services are included

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<th>DHS-MHDS</th>
<th>Definition used for the Federal Mental Health Services Block Grant.</th>
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<td>Note: This definition will be revised to be consistent with the definition in Iowa code 225C. Code changes occurred after the contracts for block grant were issued.</td>
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“Serious emotional disturbance” means a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within the most current diagnostic and statistical manual of mental disorders published by the American psychiatric association that results in a functional impairment. "Serious emotional disturbance" does not include substance use and developmental disorders unless such disorders co-occur with such a diagnosable mental, behavioral, or emotional disorder.

"Functional impairment" means difficulties that substantially interfere with or limit a person from achieving or maintaining one or more developmentally appropriate social, behavioral, cognitive, communicative, or adaptive skills and that substantially interfere with or limit the person's role or functioning in family, school, or community activities. "Functional impairment" includes difficulties of episodic, recurrent, and continuous duration. "Functional impairment" does not include difficulties resulting from temporary and expected responses to stressful events in a person's environment.

“Adults with serious mental illness” as defined by the state of Iowa pursuant to Section 1912 (c) of the Public Health Services Act are persons who

- are age 18 and over
- currently or at any time during the past year
- have a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within the Diagnostic and Statistical Manual for mental Disorders that has

| Iowa Code 225C.51.5 and 225C.51.3 | DHS-MHDS | 2008 legislative revisions to Chapter 225C | DHS-MHDS | Used for Federal Mental Health Block Grant |
resulted in functional impairment, which substantially interferes with or limits one or more major life activities. These disorders include any mental disorders (including those of biological etiology) listed in DSM-II R or their ICD-9-CM equivalent (and subsequent revisions), with the exception of DSM-II R “V” codes; delirium, dementia, and amnesic disorders category including those related to a general medical condition; substance abuse disorders; and developmental disorders, which are excluded unless they co-occur with other diagnosable serious mental illness. All of these disorders have episodic, recurrent, or persistent features; however, they vary in terms of severity or disabling effects.

**“Persons with chronic mental illness”** means persons 18 and over, with a persistent mental or emotional disorder that seriously impairs their functioning relative to such primary aspects of daily living as personal relations, living arrangements, or employment. Persons with chronic mental illness typically meet at least one of the following criteria:

1. Have undergone psychiatric treatment more intensive than outpatient care more than once in a lifetime (e.g., emergency services, alternative home care, partial hospitalization or inpatient hospitalization).
2. Have experienced at least one episode of continuous, structured supportive residential care other than hospitalization.

In addition, these persons typically meet at least two of the following criteria, on a continuing or intermittent basis for at least two years:

1. Are unemployed, or employed in a sheltered setting, or have markedly limited skills and a poor work history.
2. Require financial assistance for out-of-hospital maintenance and may be unable to procure this assistance without help.

| Iowa Administrative Rules 441-22.1 | DHS-MHDS |
3. Show severe inability to establish or maintain a personal social support system.
4. Require help in basic living skills.
5. Exhibit inappropriate social behavior which results in demand for intervention by the mental health or judicial system.

In atypical instances, a person may vary from the above criteria and could still be considered to be a person with chronic mental illness. (Adapted from the National Institute of Mental Health’s Definition and Guiding Principles for Community Support Systems, revised May 1983).

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<tr>
<th>Persons with developmental disabilities</th>
<th>Iowa Administrative Rules 441-22.1</th>
<th>DHS-MHDS</th>
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<td>“Persons with developmental disabilities” means persons with a severe, chronic disability which:</td>
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<td>1. Is attributable to mental or physical impairment or a combination of mental and physical impairments.</td>
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<td>2. Is manifested before the person attains the age of 22.</td>
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<td>3. Is likely to continue indefinitely.</td>
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<td>4. Results in substantial functional limitations in three or more of the following areas of life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency.</td>
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<td>5. Reflects the person’s need for a combination and sequence of services which are of lifelong or extended duration. (Adapted from Public Law 99-527, Developmental Disabilities Act of 1984)</td>
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<th>Persons with intellectual disabilities (previously termed “mental retardation”)</th>
<th>Iowa Administrative Rules 441-22.1</th>
<th>DHS-MHDS</th>
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<td>means persons who meet the following three conditions:</td>
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<td>1. Significantly sub average intellectual functioning: an intelligence quotient (IQ) of approximately 70 or below on an individually administered IQ test (for infants, a clinical judgment of significantly sub average intellectual functioning) as defined by the Diagnostic and</td>
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2. Concurrent deficits or impairments in present adaptive functioning (i.e., the person’s effectiveness in meeting the standards expected for the person’s age by the person’s cultural group) in at least two of the following areas: communication, self-care, home living, social and interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety.
3. The onset is before the age of 18.
(Criteria from “Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM IV),” 1994 revision, American Psychiatric Association)

**“Brain injury”** (Iowa Code 225C.23 (2)) is “the occurrence of injury to the head not primarily related to a degenerative disease or aging process that is documented in a medical record with one or more of the following conditions attributed to the head injury:
- An observed or self-reported decreased level of consciousness
- Amnesia
- A skull fracture
- An objective neurological or neuropsycho-logical abnormality
- A diagnosed intracranial lesion”
The chapter defines “disability services” as “services or other assistance available to a person with mental illness, mental retardation or other developmental disability, or brain injury”.

**“Brain Injury”** is the clinically evident damage to the brain resulting directly or indirectly from trauma, infection, anoxia, vascular lesions or tumor of the brain, not primarily related to degenerative or aging processes, which temporarily or permanently impairs a person’s physical, cognitive, or behavioral functions. The person must have a diagnosis from the following list:

(Iowa Administrative Code 441-83.81)  
DHS-IME
| Malignant neoplasms of brain, frontal lobe  |
| Malignant neoplasms of brain, cerebrum    |
| Malignant neoplasms of brain, temporal lobe. |
| Malignant neoplasms of brain, parietal lobe. |
| Malignant neoplasms of brain, occipital lobe. |
| Malignant neoplasms of brain, ventricles. |
| Malignant neoplasms of brain, cerebellum. |
| Malignant neoplasms of brain, brain stem. |
| Malignant neoplasms of brain, other part of brain, includes midbrain, peduncle, and Medulla oblongata. |
| Malignant neoplasms of brain, cerebral meninges. |
| Malignant neoplasms of brain, cranial nerves. |
| Secondary malignant neoplasm of brain. |
| Secondary malignant neoplasm of other parts of the nervous system, includes cerebral meninges. |
| Benign neoplasm of brain and other parts of the nervous system, brain. |
| Benign neoplasm of brain and other parts of the nervous system, cranial nerves. |
| Benign neoplasm of brain and other parts of the nervous system, cerebral meninges. |
| Encephalitis, myelitis and encephalomyelitis. |
| Intracranial and intraspinal abscess. |
| Anoxic brain damage. |
| Subarachnoid hemorrhage. |
| Intracerebral hemorrhage. Other and unspecified intracranial hemorrhage. |
| Occlusion and stenosis of precerebral arteries. |
| Occlusion of cerebral arteries. |
| Transient cerebral ischemia. |
| Acute, but ill-defined, cerebrovascular disease. |
| Other and ill-defined cerebrovascular diseases. |
| Fracture of vault of skull.  
| Fracture of base of skull.  
| Other and unqualified skull fractures.  
| Multiple fractures involving skull or face with other bones.  
| Concussion.  
| Cerebral laceration and contusion.  
| Subarachnoid, subdural, and extradural hemorrhage following injury.  
| Other and unspecified intracranial hemorrhage following injury.  
| Intracranial injury of other and unspecified nature.  
| Poisoning by drugs, medicinal and biological substances.  
| Toxic effects of substances.  
| Effects of external causes.  
| Drowning and nonfatal submersion.  
| Asphyxiation and strangulation.  
| Child maltreatment syndrome.  
| Adult maltreatment syndrome. |