IOWA DEVELOPMENTAL DISABILITIES COUNCIL'S 5 YEAR PLAN (2017-2021)

Comprehensive Review and Analysis Introduction:

The Council's Comprehensive Review and Analysis included a variety of activities by Council Members, staff, contractors and partners. Council members who represent other federally funded programs provided information to all Council Members about their programs, barriers identified, gaps in services and need areas. Council members participate in annual and periodic review of surveys of participants in Council sponsored programs and activities to glean both formative and summative evaluation information that members used to consider future priorities. Through contractors, public input was solicited from Iowans with disabilities, family members and other advocates related to the barriers and gaps to full community inclusion.

Annually, the Council surveys ID Action registrants (9500,) infoNET recipients (3700), participants in trainings and those attending Advocating Change Day to gather formative and summative feedback for the Council and its contractors. Through those surveys we learn more about how well we're doing but also what individuals affected by DD are doing as a result of Council activities and what they view they need to be better advocates. ID Action Registrants were asked to rate their effectiveness as an advocate, what they need to live independently, what would help them be better advocates, how to better communicate their needs to decision-makers, where they receive news and what they feel are the most important needs related to: Accessibility, Communications. Education, Emergency Management, Health, Housing, Recreation and the Arts, Transportation, Employment. (499 surveys were completed.)

51% said they think they are somewhat effective advocates, 35% thought they were very effective and 14% reported they did not feel they were effective. When asked what would help them be better advocates respondents identified information and training about issues and effective advocacy, information and training to assist with the development and communication of an effective message to decision-makers and how to organize others in my community. Of the areas important to them for community living, the most important was health care (managed care), transportation, and employment.

The Council was a partner on the Iowa Coalition for Integrated Employment during which surveys were conducted with family members, case managers, employment providers, state agency staffs, and educators to determine progress made during the project and continued needs. Need identified included for family engagement, staff training and educating decision-makers.

The Council hosted focus groups in communities to ask how well the community was doing in engaging, integrating and including Iowans with developmental disabilities and their families. Conversations revealed the continued need for information about resources, best practices and funding.

The Council members and staff have engaged in conversations about un-served and underserved groups in Iowa, including ethnic minorities, refugees, and immigrants with members of those groups sharing their perceptions of communities they represent. In addition state reports were reviewed to determine any findings reported specifically for such groups of people with disabilities. Staff has reached out to the Office of Asian and Pacific Islanders, representatives from the Latino community and groups representing African Americans and are developing partnerships to address the disparity in civic participation noted by leaders in those communities.

Information was gathered through reports such as those distributed by the Iowa Department of Inspection & Appeals following reviews of facilities, reports from the Department of Human Services/Medicaid and partnering in other information gathering efforts such as the State Employment Leadership Network, the Iowa Coalition for Integrated Employment, the Olmstead Consumer Task Force, Iowa Statewide Independent Living Council survey, WIOA Implementation and community forums on Managed Care. In addition Council staff and members serve on committees and task forces related to Medicaid, Mental Health and Disability Services redesign, Medical Home Advisory Council, Prevention of Disability Policy Council, Transportation Coordination Council, the Aging and Disability Resource Center and the Money Follows the Person Grant to name a few. It is through these the Council is able to stay abreast of the strengths, gaps and need areas related to services for Iowans with developmental disabilities.

The Council's public policy manager monitors legislation during the legislative session and other policy related activities by departments and the legislature the rest of the year. This monitoring allows the Council to stay abreast of the trends, themes, and budget priorities for plan development as well as advocacy targets.

Racial and Ethnic Diversity of the State Population

Race/Ethnicity	Percentage Of Population
White, alone*	86 %
Black or African American alone*	3.5 %
Asian alone*	2.4 %
American Indian and Alaska Native alone*	0.5 %
Hispanic or Latino (of any race)*	5.7 %
Native Hawaiian & Other Pacific Islander alone*	0.1 %
Race unknown*	0 %
Two or more races *	1.8 %
Some other race*	0 %
Do not wish to answer*	0 %
Total	%

Poverty Rate 12.2%

State Disability Characteristics

Prevalence of Developmental Disabilities in the State* 49358
Explanation* Based on 1.58% prevalence rate for DD in each State/Territory. According to AIDD staff during the discussion on the Council's funding formula, the National Health Interview Survey on Disability (NHIS-D) is the most reliable measure of the incidence of developmental disabilities. Iowa's current total population is 3,123,899 X 1.58%.

Demographic Information about People with Disabilities

People in the State with a disability	Percentage

People in the State with a disability	Percentage
Population 5 to 17 years	5%
Population 18 – 64 years	9.3%
Population 65 years and over	32.5%

Race and Ethnicity	Percentage
White alone	11.8%
Black or African American alone	11.7%
American Indian and Alaska Native alone	18.5%
Asian alone	4.9%
Native Hawaiian and Other Pacific Islander alone	3.3%
Some other race alone	6.7%
Hispanic or Latino (of any race)	6.8%
Two or more races	11%
Do not wish to answer	0%

Educational Attainment Population Age 25 and Over	Percentage with a disability	Percentage without a disability
Less than high school graduate	14.9%	6.4%
High school graduate, GED, or alternative	40.9%	28.9%
Some college or associate's degree	30.5%	33.3%
Bachelor's degree or higher	13.8%	30.5%

Employment Status Population Age 16 and Over	Percentage with a disability	Percentage without a disability
Employed	45.6%	82.2%
Not in labor force	20.6%	69%

Earnings in Past 12 months Population Age 16 and Over with Earnings	Percentage with a disability	Percentage without a disability
Earning $1 to $4,999 or less	22.6%	11.9%
Earning $5,000 to $14,999	21.4%	14.5%
Earning $15,000 to $24,999	15.3%	13.7%
Earning $25,000 to $34,999	10.6%	14.3%

Poverty Status Population Age 16 and Over	Percentage with a disability	Percentage without a disability
Below 100 percent of the poverty level	18.7%	10.2%
100 to 149 percent of the poverty level	14.3%	7.2%
At or above 150 percent of the poverty level	67%	82.5%

Portrait of the State Services

Health/Healthcare

Access to health care and long term support services for low income Iowans and those with disabilities comes from a variety of state and federally funded programs, including:

Medical Assistance:

The Iowa Medicaid program, managed by the Iowa Department of Human Services (DHS) provides health coverage to more than 680,000 Iowans through a variety of different programs. Services are covered only if they are medically necessary. Medicaid members have free choice of a doctor, dentist, pharmacy, and other providers of services.

Eligibility criteria – There are 11 general coverage groups (and more subgroups within each of those groups), those that are most pertinent to persons with developmental disabilities include:

1) Beneficiaries of cash assistance under the Supplemental Security Income (SSI) program for low-income persons who are aged, blind, or disabled.

2) People who reside in a medical institution (a hospital, nursing facility, psychiatric institution, or intermediate care facility for the mentally retarded) and the Medically Needy Program which provides coverage to people pregnant women under 21, caretaker relatives, aged, blind, or disabled, and who slightly too much income or resources to qualify for Medicaid or have higher incomes but have unusually high medical expenses.

Iowa Medicaid also delivers Home and Community Based Services (HCBS) through seven 1915(c) waivers that are targeted to specific populations including persons who are elderly, have intellectual or physical disabilities, are children with a serious emotional disturbance, have a brain injury or are living with HIV/AIDS

In 2014, Iowa implemented the Iowa Health and Wellness Plan (HAWP), an expansion of the state's Medicaid program enacted to provide comprehensive health care coverage to low income adults. The plan has two components, the Iowa Wellness Plan which covers adults ages 19 to 64 with an income at or below 100 percent of the Federal Poverty Level (FPL) and the Iowa Marketplace Choice Plan which covers adults with an income from 101 percent through 133 percent of the FPL. The Marketplace Choice Plan allows members to get health care coverage through select insurers with plans on the Health Insurance Marketplace. Medicaid pays the premiums of the health plan for the member and they get care from providers approved by the health plan. During SFY 15 the Plan served an average of 122, 759 individuals previously not covered by a full benefit Medicaid plan. Eligible individuals, who are identified as Medically Exempt, may opt to instead receive services through the Medicaid state plan benefit. Medically Exempt Individuals include those with disabling mental disorders, chronic substance use disorders, serious and complex medical conditions, physical, intellectual or developmental disabilities that significantly impair their ability to perform 1 or more activities of daily living, or a disability determination. Approximately 16,000 individuals have been enrolled in Medicaid as medically exempt.

In 2014 Iowa also completed the yearlong roll out the Integrated Health Home program designed to help adults and children with serious mental illness get the services they need to live healthy lives by focusing on physical health, mental health, and social supports. The program:

- Provides a point of coordination for an individual's health care
- Ensures individuals and their families have access to appropriate services and supports.

• Builds alliances with professionals that serve and support the individual and their family.

• Provides different levels of care coordination to meet the needs of individuals and their families.

• Involves agencies and other partners to provide needed services and supports.

• Provides whole-person care coordination across medical, behavioral and social services and supports.

• Offers quality improvement to improve effectiveness of services based on established outcomes.

Currently, 629 Medicaid members using the Children's Mental Health waiver and 7,401 members accessing Habilitation services are receiving care coordination through an IHH. On April 1, 2016, 98% of all Iowa Medicaid recipients were transitioned into the IA Health Link which brings physical, behavioral and long term care together under one program across Iowa which is covered by three managed care organizations (MCOs) from which the member chooses the one best suited for his/her needs.

Most new members who become eligible after April 1, 2016, will also be enrolled in IA Health Link. Those excluded include Program for All Inclusive Care for the Elderly (member option), Health Insurance Premium Payment Program (HIPP) where Medicaid already pays premiums and undocumented persons eligible for short-term emergency services only. Those groups continue in the traditional fee for service Medicaid program. Members in the managed care program receive their services directly from one of three MCOs and their MCO's care teams. Benefits members previously received from Iowa Medicaid will continue after a member enrolls with an MCO, including, but not limited to; inpatient and outpatient, behavioral health care, transportation (for members who are eligible for services), facility-based services, and HCBS waiver services. Service plans for members enrolled in an MCO and receiving Home- and Community-Based waiver Services will be developed by the member's MCO care team.

Hawk-i Insurance for Children:
Hawk-I, short for Healthy and Well Kids in Iowa, is Iowa's version of the federal SCHIP program. It covers some 60,000 children whose household income is too high for Medicaid (also known as Title 19). In Iowa, the hawk-i program covers children whose household gross income is less than 302% of the FPL. In order to be eligible for hawk-i, a child must not be covered by other insurance. If a child is covered by health insurance, but not dental insurance, they may still receive dental insurance through hawk-i. On April 16, 2016, the hawk-I program was transitioned into the IA Health Link managed care program.

Maternal and Child Health Care:
In addition to regular Medicaid services such as physicians, clinics, hospital care, etc., Medicaid also covers:

- Maternal Health Center services - including prenatal risk assessment, prenatal and postpartum medical care, health education services for patients who are not determined high-risk, and "enhanced" (more intense) prenatal services for patients determined high-risk.
- Screening Center services - health, vision, and hearing screening for members who are under 21 years of age; nutritional counseling; care coordination; and transportation to necessary medical care, dental care, and mental health care.

- Infant and Toddler Program – for children under 36 months old, covers necessary audiology, developmental services, health and nursing services, medical transportation services, nutrition services, occupational therapy services, physical therapy services, psychological evaluation and counseling, social work, speech-language services, vision services, and service coordination or case management services.

Services for children with special health care needs:

- School-based services – includes audiology, behavioral, medical transportation, nursing, nutrition, occupational therapy, personal assistance, physical therapy, psychologist, school based visit, service coordinator, speech-language, social work, and vision services provided by an local education agency. Also includes audiological, nursing, occupational therapy, physical therapy, psychological, speech-language, social work, and vision services provided by an area education agency.
- Health and Disability Waiver - provides services to maintain people with special health care needs in their own homes or communities who would otherwise require care in medical institutions.
- Intellectual Disability Waiver - provides services to maintain people with mental retardation in their own homes or communities who would otherwise require care in an Intermediate Care Facility for Persons with Mental Retardation (ICF/MR).

Children's mental health services:

- Children's Mental Health Waiver - services to meet the needs of children under 18 years old with serious emotional disturbance (SED). The parents of eligible children "waive" using services in an institution and choose instead to use services and individual supports to keep their children in their own home.
- Remedial Services - Remedial services are skill-building interventions that ameliorate behaviors and symptoms associated with a psychological disorder that has been assessed and diagnosed by a licensed practitioner of the healing arts.
- Habilitation Services - Habilitation Services provide Home and Community Based Services (HCBS) for Iowans with the functional impairments typically associated with chronic mental illnesses. Habilitation Services are designed to assist participants in acquiring, retaining and improving the self-help, socialization and adaptive skills necessary to reside successfully in home and community-based settings. Remedial and Habilitation Services are available to both children and adults. Younger children may not meet the needs-based criteria for Habilitation, but often transitional-age youth will meet criteria.

In 2016, the Iowa Legislature appropriated $300,000 for the development of children's mental health crisis services and the establishment of "learning labs" to review emerging collaborative efforts to improve the well-being of children with complex needs and their families. The action, based on recommendations from a work group created by the legislature in earlier years, also created a Children's Health and Well-Being Advisory Council within the DHS to continue their work.

Institutional Care Options:

- Intermediate Care Facility for Persons with Intellectual Disabilities (ICF/ID) – A licensed residential facility providing treatment and services for persons with mental retardation. Residents receive a continuous active treatment program, which is defined as the aggressive, consistent implementation of a program of specialized and generic training, treatment, health services and related services. Active treatment is directed toward the

acquisition of the behaviors necessary for the resident to function with as much self-determination and independence as possible; and the prevention or deceleration of regression or loss of current optimal functional status. This category also includes the two state-run ICF/ID facilities at Glenwood and Woodward which have decreased in size to 231 and 146 residents respectively.

- Psychiatric Medical Institutions for Children (PMIC) – A licensed residential facility providing psychiatric treatment for children less than 21 years of age. Inpatient psychiatric services must include active treatment. "Active treatment" means implementation of a professionally developed and supervised individual plan of care that is developed and implemented by an interdisciplinary team.

Other institutional care options covered by Medicaid include Acute Care Hospitalization (including the State MHIs), Nursing Facilities, and Skilled Nursing Facilities.
The state does not collect or report information on heal/health care or health care disparities for individuals with developmental disabilities from culturally and linguistically diverse backgrounds.

Employment

The state of Employment in Iowa is much different than it was 5 years ago. Much of that is the result of ongoing work of stakeholders numbering more than 250 supported with federal funding from the Office of Employment Policy (DOL) and the Administration on Intellectual and Developmental Disabilities (AIDD). The following information about services and supports is largely a result of the work by these stakeholders.

The federal vocational rehabilitation basic support state grant in Iowa is divided between the Iowa Department for the Blind and the Iowa Department of Education - Iowa Vocational Rehabilitation Services (IVRS) in the ratio of 19 percent to 81 percent. This is a historical agreement and has been in place for in excess of 40 years.

IVRS estimates that 242 individuals will be supported in employment during Fiscal year 2016. Currently there are 44 Community Rehabilitation Programs (CRPs) available to provider services under a contract with IVRS, in addition to more than 20 that accept standardized payments derived from prior agreements. IVRS has made some modifications to the way it does business as a result of work through federally funded projects: ODEP's Employment First State Mentor Leadership Project and the AIDD Iowa Coalition for Integrated Employment. Some of the adjustments include 1) shifting to a menu of services from a package of services so that services can be purchased to meet an individual's job needs rather than purchasing a package of services, 2) adding services that include Discover and Customized Employment, Alignment with Medicaid waiver funding for system consistency. In 2015, 333 job candidates earned an average of $8.39/hr, working 19 hours per week; up from 252 job candidates who earned $8.12 in 2014.

Self-employment is a vocational option that may be considered as part of an individual's informed choice. In 2015 there were 46 successful closures in the self-employment program with an average hourly wage of $13.74 and an average of 29 hours worked per week.
In FY15, IVRS coordinated service delivery support to seven Project Search Programs, six of which were funded as part of an Occupational Skills training program. Iowans with intellectual and developmental disabilities are benefitting from these programs located in health care facilities and other industries such as Hy-Vee food stores.

IVRS has not supported segregated employment for more than 16 years. However, schools have still transitioned students with the most severe disabilities into segregated settings without the assistance of IVRS. IVRS local area office supervisors are working with the local school districts to develop plans that identify how IVRS and DE will work collaboratively so these students may try competitive employment first.

IVRS and the Iowa Department of Education are currently working on a shared data dashboard that will assist both IVRS and local high school districts to better understand the level of collaboration occurring between the two. This dashboard will outline the number of potentially eligible students on an Individual Employment Plan and compare that to the number of students who have been referred to IVRS. It will also outline outcome data such as students participating in post-secondary training, employment outcomes, hours worked, and hourly wages for students connected to IVRS. Also outlined on the dashboard will be Indicator 14 data collected by the Department of Education so that a comparison can be made between the outcomes of IVRS participants and those not connected to IVRS. This dashboard will help identify schools that are succeeding and schools that need improvement in their collaboration with IVRS. This will allow the two programs to target these schools for development of practices that will assist in successful outcomes for students with disabilities.

The Transition Alliance Program (TAP) is jointly funded by a school district and IVRS. Each TAP provides enhanced transitional services to eligible IVRS clients who require year-round support up to age 25. All TAP contracts include information related to Order of Selection/IVRS Wait List, and outline non-federal provisions and match dollars accordingly.

Youth Leadership Forum, College Leadership Forum – Along with several other state agencies IVRS has participated in efforts to provide Summer leadership development opportunities for 40 high school or college students with disabilities since 1999.

The Employer Disability Resource Network (EDRN was designed to increase the employment of persons with disabilities by pooling agency resources and providing technical expertise to employers throughout Iowa. Members of this group include staff from IVRS, the Department for the Blind, Veteran's Administration, Small Business Administration, Division of Persons with Disabilities, Workforce Development, Community Rehabilitation Providers and Iowa Medicaid Enterprise.

In the spring of 2015 data was requested from 20 Employment Service Providers representing all of the Mental Health and Disability Services (MHDS Regions as a pilot to collect individual employment outcomes data. Nineteen providers with 27 locations located in 12 regions provided the data. This was a pilot project undertaken to lay a foundation for employment data and individual outcome data collection statewide. This is in line with best practices from states that do well in employment of people with disabilities and is consistent with the MHDS mandate to collect individual and system outcomes and with one of the objectives of the Iowa Coalition for Integrated Employment (ICIE). The goal of the pilot was to test a collections method and data points for gathering individual level information on the outcomes of employment related services provided with public funds. A secondary goal was to obtain some baseline data useful to gauge the impact of the employment systems change work underway. The completion of this pilot and the results demonstrate how the goals of several data collection efforts can be united. The providers surveyed reported serving an unduplicated total of 2104 individuals. Of those 686 were in individual jobs in the community working an average of 25 hours over 2 weeks and earning $8.67 per hour.

The work begun through the federal projects has shifted the momentum in Iowa toward integrated community employment.

Informal and formal services and supports
There are a variety of services and supports, both within and outside the traditional "disability services system", available to individuals with disabilities and their families but data, when it is collected, is inconsistent and insufficient to identify recipients with DD. The state's seven Medicaid waivers (Aids/HIV, BI, Children's MH, Elderly, Ill and Handicapped, ID, and Physical Disability) for instance include several common service elements; offer enrollees access to a Consumer Choices Option (CCO) and all consistently report numbers of individuals served (24,259 in July, 2016).

Though each waiver may be serving individuals with DD, only the ID Waiver, by the categorical nature of its eligibility criteria can identify specific recipients with DD (12,019 in July, 2016). Iowa's Money Follows the Person (MFP) grant, launched in September 2008, was focused solely on transitioning Iowans with ID/DD from ICF/MR to community-based settings. In January 2014 CMS approved an expansion of MFP to include transitioning individuals from nursing facilities if they qualify or the ID or BI waiver. To date, 532 individuals have transitioned to qualified living arrangements in the community. Other Medicaid state plan services including managed mental health and substance abuse treatment, and PACE, a program that provides managed long-term care services to assist Medicaid members 55 or older to remain in their own homes, are available to all eligible enrollees. Absent from Iowa's plan though, are Personal Assistance Services, thought to be too expensive by policy-makers. Medicaid for Employed People with Disabilities (MEPD) is an optional Medicaid coverage group that allows individuals with disabilities to work and keep their access to medical assistance. A recent report shows16,665 individuals enrolled in the program.

The Family Support Subsidy (FSS) program provides families with children who have serious emotional disturbance, ID, DD or BI with a monthly payment of $265.63 if their net income is below $40,000. In 2010, the Iowa Legislature voted to sunset the program and DHS stopped enrolling new children from the waiting list and accepting new applications. The Children-At-Home program provides assistance similar to the FSS, except that the assistance is provided on an "as needed" basis and is time-limited, often one-time-only. Under this program, families receive an average of $350 per year. In addition to helping family's purchase needed services and resources; the program also provides service coordination that may involve helping them access services through other community resources.

The Autism Support Program (ASP) was created by the Iowa Legislature in 2013 to provide funding for applied behavioral analysis (ABA) services for children under the age of 9 who meet certain diagnostic and financial eligibility criteria. The legislature appropriated $2 million for SFY 14 and $3 million in SFY 15 as well as allowing carryover of any unspent funds. In 2015 the legislature appropriated an additional $2 million to fund the program for SFY16. 30 applications were received in SFY15 and 16 were approved for ABA services totaling $120,875. Concerns cited for the underutilization of the program included a limited provider network, uneven access to services across the state and the age and income limitations of the program. The legislature in 2016 addresses several of those concerns by expanding eligibility from age 9 to 14 and income eligibility from 400% to 500% of the FPL (they also increased the required cost sharing from 10% to 15%). They also designated $250,000 of the SFY17 appropriation to be used to fund a board certified behavioral analyst and certified assistant behavioral analyst grants program administered by the Iowa Department of Public Health. To date, 21 children have received ABA services since the program began in January 2014.

The redesign of the state's outdated county model of service delivery was completed in July 2014 when 15 MH/DS regions began delivering a standardized set of non-Medicaid core services to "targeted populations" that include adults with intellectual disabilities and those with mental illness. The redesign also permitted regions to serve individuals with DD or BI as their funding allows. In SFY15, the state's regions reported serving 17,227 individuals with mental illness, 2,538 with intellectual disabilities, 732 with other DD and 53 with BI. Long term funding for the regional system remains uncertain after the Legislature in both 2015 and 2016 failed to appropriate the per-capita equalization funds (state dollars) that were a part of the transition to the new system. That left two regions with shortfalls that would have resulted in cuts in services had the legislature not appropriated $2 million in targeted relief prior to ending their 2016 session.

Lifelong Links is Iowa's network of Aging and Disability Resource Centers, whose purpose is to expand and enhance the state's information and referral resources for older adults, adults with disabilities, veterans and caregivers as they begin to think about and plan for long-term independent living. Administered by the Iowa Department on Aging and in partnership with Iowa's six Area Agencies on Aging, Lifelong Links is modeled on the "no wrong door" approach, meaning it is available to any Iowan in need of home-based and community services and is accessible through physical locations across Iowa, a toll-free call center and a website. With a mission to help Iowans achieve their personal goals for independence and full participation in their community, Lifelong Links provides information about topics and services and connects individuals to local service providers in an effort to support the philosophy of self-directed care.

Iowa's six Centers for Independent Living (CIL's) are independent, consumer-driven, cross disability, community-based non-profits committed to the principles of Independent Living. Centers, which must provide core services including information and referral, peer support, independent living skills development and individual and systems advocacy, are currently serving individuals in 32 of Iowa's 99 counties.

Outside the public sector, Iowa Able provides Iowans with disabilities with access to loans with flexible terms to help them increase their independence at home, work, and in the community. The statewide, nonprofit program loans funds for any item, equipment or product used to improve a person's quality of life. In FY13-FY15, the Iowa Able foundation approved 136 loans for $587,615. In 201 they have approved 39 loans for $137,668, most for home and vehicle modifications.

Other informal services and supports are common in Iowa's rural communities, many the product of community action programs, ministries or small non-profits like Passageway, a central Iowa "clubhouse model" that provides work and transitional employment opportunities for people with mental illness. Still others spring from disability service providers or service organizations like the Kiwanis that sponsor local Aktion Clubs, service clubs for adults with disabilities that exist across the state.

Interagency Initiatives

Members of the Special Education Advisory Panel represent public and private sectors that by virtue of their position, interest, or training can contribute information in regard to the education of students with disabilities. Fifty-one percent of the members must be parents of a child with a disability (ages birth through 26) or individuals with disabilities. The Iowa Special Education Advisory Panel (SEAP) advises and assists the Iowa Department of Education with the provision of free and appropriate public education for individuals with disabilities. It exists by

authority of the Individuals with Disabilities Education Act (IDEA2004) to provide guidance on special education programs and services.

The Medical Assistance Advisory Council (MAAC) advises and provides recommendations to the Director for consideration regarding the budget, policy, and administration of the medical assistance program. The MAAC meets quarterly. The following make up the MAAC membership: Business/professional entities, public representatives, the Department of Public Health, the Department of Elder Affairs, Des Moines University, the University of Iowa College Of Medicine, the House of Representatives, and the Senate.

Workforce Investment Boards: The boards work closely with Iowa Workforce Development and the Iowa Workforce Development Board to create a system to help Iowans respond to the rapid changes occurring in today's workplace. The boards' responsibilities include identifying local workforce development needs, assisting in the award of local service provider contracts and monitoring their performance, and providing an annual report and recommendations to the Iowa Workforce Development Board. Each board consists of a total of 14 members including representatives from the following groups: five-business, five-labor, one-city official, one-county elected official, one-school district representative, and one-community college representative.

The role of the State Rehabilitation Council is to bring a consumer voice to Rehabilitation services, advocate for Vocational Rehabilitation to others in the state and maximize the opportunities for independent living in the state.

The mission of the Iowa Statewide Independent Living Council is to strengthen the voice of Iowans with disabilities on issues affecting their lives, to build a statewide network of centers for independent living, and to collaborate with our partners in advancing the independence, productivity, and full inclusion of Iowans with disabilities.

Aging and Disability Resource Center (ADRC) Planning Committee members provide comment for the Iowa Department of Aging to consider as it develops Iowa's state plan including areas of prioritization, opportunities to streamline and recommendations.

The Commission on Mental Health & Disability is the state policy-making body for the provision of services to persons with mental illness and disabilities. Commission members are appointed on the basis of interest and experience in the fields of mental health, intellectual disabilities, or other developmental disabilities, and brain injury, to ensure adequate representation from persons with disabilities and individuals who have knowledge concerning disability services. OImstead Consumer Task Force: In early 2000, the Governor designated the Iowa Department of Human Services (DHS) as Iowa's lead agency to respond to Olmstead by reporting on Iowa's current service system and developing an "effectively working plan. DHS convened a statewide steering committee to gather input that shaped the 2001 Iowa Plan for Community Development. Task force members include people with disabilities, family members, advocates, representatives of key state agencies, and other stakeholders.

The Iowa Coalition for Integrated Employment grew out of a grant project 5 years ago and has plans to continue beyond the life of the grant. Members include state agency representatives from the Iowa Departments of Human Services, on Aging, Workforce Development and Human Rights, Iowa Vocational Rehabilitation Services. Members also include staff from Disability Rights Iowa, the Center for Disabilities and Development, and stakeholders such as individuals with disabilities, family members, community rehabilitation providers, and Managed Care

Organizations and case managers/care coordinators. The purpose of the Coalition is to address funding, policy and capacity barriers to Integrated Community Employment.

The Iowa Transportation Coordination Council (ITCC), established by the Iowa Legislature, discusses transportation issues affecting Iowa. The Iowa DOT chairs and staffs the meetings. Members include representatives from Iowa Department on Aging (IDA), Iowa Developmental Disabilities Council, Iowa Department of Human Services – Iowa Medicaid Enterprise (IME), Iowa Department of Public Health, Iowa Vocational Rehabilitation Services, Iowa Workforce Development (IWD), Iowa Commission on Volunteer Service (ICVS), American Cancer Society, United Ways of Iowa, Iowa Public Transit Association, Iowa's Metropolitan Planning Organizations (MPOs) and Regional Planning Affiliations (RPAs), AARP, TMS Management Group, Iowa League of Cities, Iowa Mobility Managers Network, and the Federal Transit Administration (FTA). The ITCC serves as the statewide coordination advisory group, identifying gaps in transportation needs, identifying barriers to coordination, and developing recommendations for solutions and transportation options.

Though it's not counted or reported, the Council is aware of representation by people with developmental disabilities and families from culturally and linguistically diverse backgrounds on some of the taskforces, coalitions and councils described above.

Quality Assurance

Four Iowa agencies assume primary responsibility for the monitoring of services and supports and assistance to prevent abuse and exploitation of individuals with disabilities.
The Health Facilities Division of the Department of Inspections and Appeals (DIA) conducts regulatory oversight of all licensed and/or certified facilities during surveys, revisits and investigations of complaints. Those facilities serve Iowans with developmental and intellectual disabilities and mental health needs. Efforts are made to ensure protection of residents' rights, including considerate and respectful care and freedom from abuse, neglect or mistreatment. DIA also works to determine that residents receive individualized services, based on their specific needs that consider their existing abilities and possible skill enhancement to increase independence and self-determination.

Disability Rights Iowa (DRI), the state's protection and advocacy agency, serves individuals with Developmental Disabilities. DRI conducts primary and secondary (records review) abuse and neglect investigations where death, prone restraint, or serious harm has resulted and when incidents are reported to the agency, reports and coordinates investigation with the appropriate authorities.

The state's dependent Adult Abuse program is housed within the Iowa Department of Human Services and provides evaluations and assessments of alleged abuse to dependent adults. The program attempts to provide services and makes referrals to assist abused dependent adults acquire safe living arrangements. Protective Service Units are available in DHS county offices statewide.

The mission of the Office of the State Long-Term Care Ombudsman is to protect the health, safety, welfare and rights of individuals residing in long-term care by investigating complaints, seeking resolutions to problems and providing advocacy with the goal of enhancing quality of life and care. Iowa's Long-Term Care Ombudsman program is responsible, through federal and state law, for advocating for residents and tenants of long-term care facilities, including nursing facilities, residential care facilities, assisted living programs and elder group homes. The Office strives to fulfill this responsibility every day by working to resolve complaints that impact the

health, safety and welfare of residents and tenants, as well as by informing residents and tenants of their rights.

The Managed Care Ombudsman Program is the division of the Office of the State Long-Term Care Ombudsman (OSLTCO) that advocates for the rights and needs of Medicaid managed care members who receive care in health care facilities, assisted living programs and elder group homes in Iowa, as well as members who are enrolled in one of the following seven Medicaid home and community-based services (HCBS) waiver programs:
AIDS/HIV
Brain Injury
Children's Mental Health
Elderly
Health and Disability
Intellectual Disability
Physical Disability
Approximately 57,000 Medicaid managed care members in Iowa are included within this scope.

Transportation

Iowa has 35 public transit systems covering all 99 counties. Public transit is funded through local funds, passenger fares, State Transit Assistance, and the Federal Transit Administration. During Fiscal Year 2015, 28.7 Million rides were provided by Iowa's 35 public transit systems. Of those rides, approximately 3.3 Million were individuals with disabilities.

Iowa has 3 types of public transit service:

1. Demand Response provided by the 16 regional transit agencies. Ride reservations are made in advance, normally 24 hours, with the bus picking up passengers at their location and taking them to their destination. Service is available to the general public, including persons with disabilities.

2. Fixed Route provided by the 19 urban transit agencies. This type of transit is provided with set routes, stops, and time points. No advance reservations are necessary. Service is available to the general public, including persons with disabilities. (One unique type of fixed route service, used by several Iowa communities, is the flag stop system. The buses still operate on fixed routes, but rather than having specific marked stops, persons wishing to ride simply need to be at an intersection along the route and wave to the driver to stop. Likewise, the passenger may be let off at any intersection along the route.)

3. ADA Complementary Paratransit provided by the 19 urban transit agencies in, at a minimum, ¾ mile around a fixed route. Passengers must apply, meeting ADA-qualifications to ride. Ride reservations are mad the day prior to the desired trip, with the bus picking up the passengers at their location and taking them to their destination. Fares for this origin-destination service may be no more than double the regular fixed route fare.

Other Passenger Transportation Services:

1. Taxis provide on-demand, personal transportation, from the passenger's location direction to the destination. Taxi services are available in communities of all sizes across Iowa. However, the majority are not ADA accessible.

2. Intercity Bus provides cross-country passenger transportation option for those who don't want or are unable to afford flying or driving. Intercity bus service also connects more small communities than flying, making it more accessible for some.
   Volunteer Transportation-Many volunteer organizations exist around the state, providing a range of services from home repairs to food pantries to transportation. Volunteer transportation programs can be formalized through an established non-profit organization, or simply through a smaller network of neighbors. Volunteer organizations may only serve specific segments of the population such as low-income or those aged 60+ or only provide transportation for specific purposes. These programs fill a niche in the community, responding to a recognized need often faster and at a lower cost than a public or private transportation provider could. Services are generally provided at low or no cost to the rider. Funding can come from a variety of sources: free will donations, community foundations or even state and federal grants.
3. Human service agencies transport clients in agency or personal vehicles or work with public transit agencies to ensure clients' transportation needs are met. While not the core of their business, transportation is an essential function to ensure clients receive the care and services they require Because the transporting of clients is often an afterthought or an "other duty as assigned" in a job description, human service agencies may not know the actual cost of providing this service when staff time, insurance, fuel and maintenance costs are all tabulated.
4. Veterans Transportation-a survey of the county Veterans Affairs offices, found that 69 of Iowa's 99 counties have transportation available to veterans; generally, to medical appointments only.
5. Private Providers-Passenger transportation can also be a profitable business venture. In addition, to the taxicab and intercity bus services already discussed, private, for-profit companies provide: Non-emergency medical transportation (NEMT) (Medicaid, Waiver) and Charter Services.

Coordination and navigation of services:

Under Iowa Code, any agency receiving public money for passenger transportation is to first coordinate with the local public transit agency to provide those services. Coordination isn't just codified, it's a good idea. No matter the partnership - public/private, private/private, or public/public, coordinating transportation services can save money and time and create efficiencies.

With all the options presented, it can be a very overwhelming to know how to best get from point A to point Z. Several communities and regions throughout the state have hired mobility coordinators in the past couple years to help with just that issue. An important component in navigating the passenger transportation services in Iowa over the past several years has been the availability of Mobility Managers or Coordinators in a few regions and urban areas. Mobility management is an innovative approach for managing and delivering coordinated transportation services to customers, including low-income individuals, older adults, and persons with disabilities. Mobility management is person-centered, assisting with the whole trip, using as many modes of transportation necessary, not just public transit.

1. Transportation Advisory Groups (TAG) are in place for the Regional Planning Organizations (18) and for the Metropolitan Planning Organizations (9). These groups discuss gaps in service or coordinated transportation needs with metropolitan and

regional planning agencies. Variety of passenger transportation providers and human service agencies typically attend.

2. Transportation is a covered service through some of Iowa's Medicaid Waivers. For example through the ID Waiver: Vehicle lifts, driver specific adaptations, remote start systems, including such modifications already installed in a vehicle. Transportation between work or between activities related to employment. Other forms of transportation must be attempted first. Transportation services may be reimbursable for members to conduct business errands, essential shopping, to receive medical services, to travel to and from work or day programs, and to reduce social isolation. However, there are a lot of caveats to eligibility. Having coverage for services does not guarantee access to the service.
3. The NEMT Program is designed to reimburse medical transportation expenses for eligible Medicaid members, including mileage reimbursement, meals and lodging. If the member is unable to drive themselves or find someone to transport them the broker will make arrangements for a transportation provider to pick-up the member and transport them to and from their medical appointment. Urgent care trips can also be scheduled in less time for members who become ill and need to see their doctor immediately or if they experience an unexpected medical situation. Urgent care trips are not emergency trips which would require an ambulance and lifesaving attention.

The complexity is now compounded by the advent of the Managed Care System with three organizations using difference providers for services.

Despite what some might consider adequate resources, when asked and/surveyed, people with disabilities identify transportation as the number one barrier to participation in health care, socialization, employment and civic participation. The hours rides are available do not coincide with individuals work schedules, interests in hobbies, socialization and general community inclusion.

Analysis of the State Issues and Challenges

Criteria for eligibility for services:
Most Iowans with developmental disabilities access services through either the state's Medicaid plan or the Regional MH/DS system. Medicaid provides services to children and adults with disabilities through the state plan, the Medicaid expansion known as the Iowa Health and Wellness Plan (which covers adults age 19-64 with an income up to 133 percent of the FPL) and five Medicaid waivers that serve: individuals who have intellectual disabilities, individuals who have physical disabilities (two waivers), individuals who have a brain injury and children with a serious emotional disturbance. While eligibility is the same across the waivers, the service menus and the total costs allowed on each vary widely from a low of $672/month (Physical Disability) to a high of $2,812 (BI). What is notable about eligibility for these waiver services is that it is largely driven by diagnosis as opposed to functional need which results in gaps, most notably for individuals with developmental disabilities such as autism, who do not have an intellectual disability. The April 2016 launch of the state's Medicaid privatization initiative shifted most Medicaid services, including HCBS waiver services, to a managed care model. While eligibility criteria for all services remained unchanged the resulting confusion did result in disruptions and gaps in service provision as individuals with disabilities and their families attempted to navigate the new system The state created an Autism Support program in 2014 that provides access to applied behavioral analysis (ABA) services for children under the age of 14. Eligibility for the program was increased in 2016 to allow children in families earning

up to 500% of the FPL to have access to services. Beyond state funded programs and such as the Autism Support program and services available through the educational system there are few additional resources available to many children with developmental disabilities. There are fewer yet, available to many adults with developmental disabilities (who do not have an intellectual disability). The Regional MH/DS system consists of 15 regions that provide services to targeted populations defined as individuals with intellectual disabilities and those with mental illness. Regions may serve individuals with DD and many do but the availability of funding has limited their capacity to do so, with only 3% of those served identified as having a DD without an ID diagnosis. The MH/DS redesign of 2012 also established new financial eligibility criteria for services, designated as individuals earning less than 150% of the FPL.

Analysis of the barriers to full participation of unserved and underserved groups of individuals with developmental disabilities and their families:
Unserved and underserved ethnic groups in Iowa include Asians, African Americans, Hispanics/Latinos, and Native Americans. There is little data available to document the extent to which these individuals with disabilities go unserved or underserved and representatives of each ethnicity in the Iowa Department of Human Rights are often unaware of the prevalence of disability or the extent of need. The most common barriers to the receipt of services and supports identified by those representatives remain language and cultural. The absence of culturally competent information, written in one's native language, is believed to result in diminished access to accommodations and services. The culture and values of a given population also effect decisions that individuals and families make about accessing public support and services and other assistance beyond their family or cultural community.
Other unserved and underserved groups include children and adults with developmental disabilities other than an intellectual disability (i.e. autism) and persons with brain injury. The regional MH/DS system in Iowa provides funding and administration of a set of core non-Medicaid services to a target population of adult residents with intellectual disabilities and mental illness. While regions may provide services to individuals with other developmental disabilities or to persons with brain injury, access for those populations is limited by funding. Currently, individuals with DD and BI make up only 12% of the numbers served by the state's 15 regions. The state is responsible for providing services to children and despite modest increases in access to mental health services, children, most notably those with autism that do not have an intellectual disability, may have limited access to any services outside of the educational system. The Autism Support Program created in 2013 provides funding for applied behavioral analysis (ABA) services for children under the age of 14 who meet diagnostic and financial eligibility criteria but for older children and adults with autism there are few services available outside the state's Medicaid ID waiver which again, is accessible only to those with an ID diagnosis. This gap has been noted by autism advocates and others, including the Iowa Autism Council which has made recommendations to the Iowa Legislature for policy improvements that create access to both public and private services for adults with autism.
Also often identified as underserved are the approximately 800 Iowans with developmental disabilities living in nursing facilities throughout the state. Many of these individuals have identified a desire to move to other least restrictive and more appropriate settings but until CMS, in 2014, approved a change that allowed Iowa's Money Follows the Person grant to begin transitioning individuals living in a nursing care facility to community living with support from the ID or BI waiver, often provided the only remaining, albeit often less than appropriate, point of access for needed services.

Language and cultural barriers aside, the greatest barriers to full participation for all Iowans with developmental disabilities and their families remains the absence of funding sufficient to build the community capacity to provide services and supports that promote self-determination and

independence, and offer Iowans affected by disabilities with choices about where they live and work. The recent move to reduce Medicaid costs (by as much as $100 million/yr) by privatizing the majority of the state's Medicaid program has created confusion for members and service providers alike. Issues related to billing and provider reimbursement are taking a financial toll on many providers and threatening their ability to continue to provide needed services and supports.

The Availability of Assistive Technology:

The Iowa Program for Assistive Technology (IPAT) is funded under the Assistive Technology Act of 1998, as amended by the U.S. Department of Health and Human Services Administration for Community Living. IPAT, the statewide assistive technology program for Iowans, is a program of the Center for Disabilities and Development at the University of Iowa Children's Hospital. Services and programs available as a result of IPAT include the following for Iowa residents.

- Alternative Financial Loan Program has reduced interest loans available for purchase of assistive technology (AT) devices or services, including home modifications adapted vehicles
- Device Recycle and Reuse Services make used assistive technology devices available for free or at a lower cost.
- Device Demonstration Services allows individuals and families to try a device before purchase. This can be in person or with a "virtual" demonstration.
- Device Short Term Loan Programs allows individuals to borrow an AT device for a short period of time before purchase to help make a decision, to use instead of purchase, or to use while a device is repaired.
- Information and Assistance Services provide free information to individuals with disabilities, older persons, family members and service providers about available AT devices, services and funding resources.
- Public Awareness Activities provide information about AT devices and services: publications, newsletters, conference exhibits and presentations, and articles.
- Training Activities are provided to consumers, family members, care providers and service providers on a wide range of AT topics.
- Technical assistance provided to organizations and agencies to increase access to AT devices and services through collaboration and policy changes.
- Protection and Advocacy for Assistive Technology (PAAT) provides free legal advocacy to individuals with disabilities to help them acquire they AT devices that they need and to which they are entitled.

Easter Seals of Iowa also provides opportunities for individuals to learn about, sample and use assistive technology. Some of the functions of IPAT are being assumed by Easter Seals. Opportunities include the following:

- Equipment Loan: Easter Seals loans durable medical equipment such as electric hospital beds, electric and manual wheelchairs, and adaptive bathroom devices to those in need. Equipment is provided at a nominal fee and can be used for an unlimited length of time. Easter Seals seeks donations of used medical equipment for use in this program.

- Demonstration Center: The Demonstration Center showcases different types of assistive technologies, such as tub lifts, kitchen and bathroom features, and other items individuals may use to make their home more accessible. The Demonstration Center is a valuable resource in allowing clients to try equipment before it is brought into the home.
- Lending Library: Equipment and resources are available for families, individuals, counselors and schools. Up to 5 pieces of equipment can be checked out for 30 days to find out if it will work for them before deciding to purchase from vendors.
- UERS (Used Equipment Referral Service): Will Now Be Accessed Through Easter Seals Iowa! UERS, a "classified ads" feature connects people with available Assistive Technology.

Iowa Center for Assistive Technology Education and Research (ICATER) - An assistive technology resource center located within the University of Iowa College Of Education that serves the university, as well as communities throughout the state. The Center provides students with disabilities, parents, College of Education students, and education professionals hands-on assistive technology training, information, and materials. ICATER also conducts and collaborates on research projects, resulting in innovative methods and best practices of assistive technology usage. Through these training programs and research projects, ICATER impacts all students with disabilities by providing access to a variety of assistive technology devices, helping them accomplish their educational goals.

The Iowa Department of Education provides information on the following on the Department's website: Federal Regulations, State Rules, Quality Indicators for Assistive Technology (QIAT) Services, State AT Liaisons, AEA AT Contacts, Assistive Technology Consideration, Areas of Assistive Technology, Funding Sources, Frequently Asked Questions, and Resources
The State Assistive Technology Liaisons Team is a group of Assistive Technology professionals representing each of the state's 9 Area Education Agencies, large Local Education Agencies, the Iowa Program for Assistive Technology, and several of the state's colleges and universities across the state. This team collaborates to address and advise the Department of Education on systemic assistive technology issues and initiatives in Iowa's K-12 schools.

LifeLong Links is Iowa's network of Aging and Disability Resource Centers to expand the state's information and referral resources for older adults, adults with disabilities, veterans and caregivers as they begin to think about and plan for long-term independent living. A number of resource links are available through LifeLong Links related to education, vocational rehabilitation, post-secondary education and providers and other sources of AT services.

Iowa Vocational Rehabilitation Services has an agreement with the University of Iowa Program for Assistive Technology and Easter Seals Iowa Assistive Technology Center. This outlines responsibilities for personnel providing rehabilitation and independent living services to persons with disabilities with the support of assistive technology and assistive technology services. It establishes parameters for how we provide assistive technology devices and services authorized with a minimum of expense or duplication of effort.

Iowa Vocational Rehabilitation Services also provides information about devices, software and programs related to AT for employment. Resource tools include ADA accessibility guidelines, Accommodation Apps, Resources for Iowans, vendor lists, computer adaptations, technology consideration checklist, AT assessment Business Information as well as Job Candidate information, film clips of AT devices and information about resources listed above.

Waiting Lists

Numbers on Waiting Lists in the State

Year	State Pop (100,000)	Total Served	Number Served per 100,000 state pop	National Average served per 100,000	Total persons waiting for residential services needed in the next year as reported by the State, per 100,000	Total persons waiting for other services as reported by the State, per 100,000
2016	31.24	3344	107.52	148.9	Not furnished	Not furnished

Attempts to establish prioritization of waiting list applicants has been discussed but never implemented.

Description of the state's wait-list definition: The disability service delivery consists primarily of the state's Medicaid and Medicaid waiver program and the locally funded non-Medicaid Regional MH/DS system that was created in 2014. Waiting lists are maintained for all seven of the state's Medicaid waivers, though only five have current waiting lists. Individuals are pre-screened for Medicaid eligibility when they apply for waiver services but no further assessment takes place until a slot becomes available and a case manager is assigned. Iowa DHS estimates that as many as 40% of those on the waiting lists for waiver services are found to be ineligible when a slot becomes available, in many cases 2-3 years after application. Applicants for waiver services are placed on the waiting list in the order in which their application is received and slots, when they become available, are awarded in a similar fashion.

The state funds all Medicaid services while the Regional MH/DS system funds a set of defined core non-Medicaid services to a target population defined as individuals with intellectual disabilities and those with mental illness. Core services include inpatient and outpatient mental health treatment, basic crisis services, supported community living, family and peer support and health homes. Regions may also, as funds permit, serve individuals with other developmental disabilities and brain injury. The county waiting lists that existed prior to the 2014 implementation of the MH/DS redesign were resolved with a 2014 appropriation of equalization funds as well as savings realized from the expansion of Medicaid in Iowa.

While no regions have waiting lists at the present time, this is unlikely to continue unless the long term sustainability of adequate funding is addressed by the General Assembly. Waiting lists will be established by regions when their financial resources are fully encumbered and they are expected to be managed, as within the waiver program, on a first come first served basis.

Applications for waiver services are "pre-screened" for Medicaid eligibility by DHS but no further assessment takes place until a waiver slot becomes available, often two years or more for Medicaid waivers such as the ID, BI, children's mental health and physical disability.

While there may be some structured activities available to assist waiting individuals and families understand their options and to plan for the future, they may not be available to all applicants. For example, individuals who receive Targeted Case Management services may receive those

services from the case manager but those without access to a case manager may have no assistance or support. Many Area Education Agencies also provide assistance as children transition to adulthood, while others outside the educational system are less likely to have access to similar services.

Summary of Waiting List Issues and Challenges:

The availability of resources, especially financial resources, remains the greatest challenge to addressing waiting lists. Demand for Medicaid waiver services has outpaced state funding for Medicaid and forced the implementation of cost containment measures that include rate, dollar and unit caps and, most recently the establishment of an ID waiver waiting list before 2015 did not exist. The state legislature has attempted to overturn several of those measures but consistent vetoes by the Governor have kept those cost containment strategies in place.

The 2016 Legislature did appropriate and additional $2 million to reduce waiver waiting lists but that falls far short of the estimated $10 million or more needed to serve all who are waiting. In 2015, the state suspended $32 million in per capita equalization payments to the state's 15 MH/DS regions, which serve largely individuals with intellectual disabilities and mental illness, requiring them to spend down existing fund balances. The 2016 Legislature did the same while awarding $2 million in emergency funding to two regions that were facing reductions in services to individuals they serve. While none of the state's regions currently have waiting lists for services, the continued absence of a sustainable funding stream, i.e. state funding or increased property taxes, will mean this is likely to occur in the SFY2018.

Analysis of the adequacy of current resources and projected availability of future resources to fund services:

The availability of financial resources to fund essential services and supports for Iowans with disabilities remains a significant challenge. While state revenues have slightly exceeded projections, the Governor and Republican controlled House of Representatives continue to fight for cost containment and, more recently cost savings in Medicaid, while obligating current and future state funds to pay for a substantial reduction in commercial property taxes that was passed in the 2013 legislative session. In addition, the federal match rate for Medicaid has declined in recent years, leaving the state with a $56 million hole to fill in the SFY16. An additional $36 million was necessary to fund increases in costs and the numbers served, so in January 2015, the Governor unveiled a plan for "cost containment' initiatives intended to save Medicaid $70 million. Included in that plan was a projected $50 million in savings from moving most of the state's Medicaid program, including all LTSS services, to managed care, a move that was completed when CMS authorized the implementation on April 1, 2016. The result has left both Medicaid members and service providers struggling to navigate the new system. In a recent survey, more than 400 doctors, hospitals, local clinics and non-profit health care providers say they are seeing higher costs in running their businesses. For example:

- 90 percent say privatization has increased their administrative expenses.
- 79 percent are not getting paid on time by the for-profit corporations now running Iowa Medicaid.
- 28 percent have had to borrow money to pay their bills while waiting to be reimbursed by out-of- state Managed Care Organizations.
- 66 percent say when they do get reimbursed, it's at lower rates than agreed upon.

Survey respondents also say services for Iowans on Medicaid will suffer because of privatization:

- 46 percent of providers are planning to reduce services.
- 61 percent say privatization has reduced the quality of services they can provide.
- 38 percent say Medicaid patients can no longer see their out-of-network specialty providers.

In 2015 Iowa Governor Terry Branstad also announced his plan close two of Iowa's mental health institutes (MHI) in Clarinda and Mt. Pleasant. Despite the objections of a number of legislators as well as from family members of individuals served at the facilities the closures proceeded after the Governor vetoed a bipartisan compromise plan that would have reversed his closure of the mental institution at Mount Pleasant and temporarily kept open a similar facility at Clarinda. Much of the resistance to the closures came from family members and legislators who argued that the institutions were providing specialized services to individuals with high levels of need and that those services were not available elsewhere. Since the closures, Iowa's has fallen to the worst in the nation in its ability to provide inpatient mental health treatment. According to the nonpartisan Treatment Advocacy Center, Iowa has only 64 state beds (down from 149 in 2010) for mental health patients and 731 total mental health beds (public and private), which appears insufficient to meet the needs of Iowa children and adults with mental illnesses. The situation has been exacerbated by the shift to managed care, and which was the focus of a recent rally at the Statehouse attended by 500 individuals with disabilities and advocates.

The Iowa Legislature and the Governor also failed to fund, in SFY16 and SFY17, $30.6 million dollars in per capita equalization funds that were a part of the 2011- 2014 redesign that ended the county based service system and created a new, standardized Regional MH/DS system that pays for non-Medicaid services. The loss of equalization funds has required regions to spend down existing fund balances and emergency appropriations have been required by 2 regions that would have been forced to cut services without the $2 million in relief provided in SFY17. Reductions in regional funding have been exacerbated by a 1996 cap on property tax levies that fund services in these regions and no plan for a sustainable funding stream for the future, a subject that legislators pledge to revisit in the 2016 legislative session.

Analysis of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are in facilities receive:

Iowa has been slow to develop a long-term care system that supports choice and full inclusion for people with disabilities. Despite efforts to expand home and community-based services, the state's Medicaid program retains a bias that frequently serves seniors and individuals with disabilities in higher-cost, more restrictive institutions, instead of in lower cost and more desirable home and community settings. Specific numbers of people in placements are difficult to find due to the State's not supplying national data sources with figures. (DNF) or did not furnish appears too often in the tables to be able to draw accurate conclusions. The implementation of Managed Care will eventually result in better data but right now there's some confusion at the state level about who has what data to share. What we do know is that as of May 2016, 13,567 Medicaid members who are enrolled in a Managed Care Organization were receiving facility based services which includes skilled nursing facilities and ICF/IDs including the State's two Resource Centers (353). Both the nursing home and ICF/ID provide 24/7 access to professional health services and the ICF/ID requires provision of "active treatment" that entails a program of training, treatment, health and related services to assist the individual

to learn behaviors and skills needed to function with as self-determined and independent as possible. While the services provided are generally regarded as being adequate and of good quality, independent reviews by the state's Department of Inspections and Appeals (DIA) and Disability Rights Iowa (DRI), the state's protection and advocacy agency suggest there is room for improvement.

DIA has found infractions in reviews of ICF/IDs with emerging "themes" including deficiencies related to the absence of written policies for emergency medical care in case of sudden illness or accident; inconsistencies in incident reporting; failure to provide services in accordance with an individual's needs; failure to meet infection control standards; service and individual program plans (IPP) that are not completed as required; failure to implement doctor's orders by qualified personnel; and non-compliance with drug administration standards that require an assurance that clients are taught to self-administer medications if identified as an appropriate objective by the interdisciplinary team and the physician. Staffing issues continue to plague both facility based providers and related DIA findings frequently cite inadequate staffing ratios and the inadequacy of staff training to perform essential functions such as implementation of the resident's IPP. Providers are required to provide DIA with a plan of correction to respond to each deficiency cited in the review or investigation and most are satisfactorily resolved.

Also controversial was the Governor's proposal to close the doors at two of Iowa's mental health institutes (MHI) in Clarinda and Mt. Pleasant. The Department of Human Services called the closures an "Institutional Realignment" noting that some beds would be added to the remaining two MHIs (Independence and Cherokee) and others would be sent to community-based residential programs if and where appropriate. Despite the objections of a number of legislators as well as from family members of individuals served at the facilities the closures preceded after Governor Branstad, in July, vetoed a bipartisan compromise plan that would have reversed his closure of the mental institution at Mount Pleasant and temporarily kept open a similar facility at Clarinda. Much of the resistance to the closures came from family members and legislators who argued that the institutions were providing specialized services to individuals with high levels of need and that those services were not available elsewhere. The primary state workers' union and 25 Democratic legislators also sued the Governor, contending his veto of more than $6 million in spending broke a law requiring the state to operate four mental hospitals, including the two he closed.

To the extent that information is available, the adequacy of home and community-based waivers services:

The disability service system in Iowa has continued to evolve from a largely institutional one to one that is less reliant on traditional residential services and more focused on the development of a broad range of services that support Iowans with disabilities to live independently in the communities of their choice. Iowa began participation in the Balancing Incentive Program (BIP) program in 2012 with an anticipated $61 million in enhanced Federal Medical Assistance Percentages (FMAP) available to enhance access to home and community based services (HCBS) and reduce unnecessary reliance on institutional services.

In March 2013 the DHS reported that 47.98% of the state's total LTSS was spent on community based services. By 9/30/15, the state had drawn down $58.3 million of the allowed $61.8 million. Using the funds to operate the state's ID waiver without a wait list, increase provider rates by 2% and expand the number of individuals served through the 1915 (i) waiver resulted in a slight increase in the percentage of total LTSS dollars spent on community services to 52.51%.

Despite the enhanced funding from the BIP, DHS did, on January 1, 2015, establish a waiting list for the ID waiver. That waiver, the most robust of Iowa's 7 waivers, serves approximately 12,700 Iowans with DD. The waiting list has since grown to 2,484 with wait times that are approaching two years. That wait list was necessary, according to the DHS, because there is no age limit for the waiver and the average cost per individual served had grown to $38,732 annually or $3,228 monthly in FY14. Two hundred of the 12,912 ID Waiver slots are reserved for individuals transitioning from ICF/ID or through the state's MFP program, which has transitioned 493 individuals to the community since September 2008. The program, formerly available only to individuals moving from an ICF/ID was expanded in January 2014 when CMS approved the transition of individuals living in nursing facilities who qualify for either the ID or BI waivers. 103 referrals have been made as a part of that expansion but only 39 individuals have successfully transitioned to the community. This is due in part to reluctance on the part of family members and guardians as well as more systemic challenges such as the availability of prevocational or employment opportunities and providers, the unavailability of rent subsidies and crisis intervention services in some communities and workforce issues that affect the capacity of providers to serve those who are transitioning.

In addition to the ID waiver, Iowa operates six additional waivers with distinct service menus, target populations, case management processes, payment limits and other policies. The categorical nature of eligibility for each of the waivers often excludes many who could benefit from access to services. Expanding the ID waiver, for instance, into a DD waiver would accommodate individuals with developmental disabilities such as autism who currently have little access to those services. And while it is appropriate to tailor the service menu to the target group served, there are service gaps in some waivers and services that go unused in others. Greater consideration of expanding the supports and services available under each of the waivers would permit greater flexibility and better facilitate the design of individualized services. Expansion though would likely come at a cost and the greatest threat to the adequacy of existing waivers is the availability of funding that is sufficient to meet the needs. Waiting lists have continued to grow, as have the lengths of time that people wait. Funding has failed to meet the increased demand and state is turning to other means, including rate, dollar and unit caps and prior authorization of some services, to attempt to balance the needs of individuals with available resources.

Rationale for Goal Selection

There are two goal areas in which the Council has invested that have resulted in outcomes for Iowans with Developmental Disabilities. As a result, the Council voted early on to keep those goals in this 5 year plan. The focus areas identified as priority needs through the review and input process for developing this plan seemed to fall logically into two goal areas, Advocacy and Systems Change. These broad goal areas have allowed the Iowa Council to be responsive to the shifts and changes in policy, opportunities and funding Iowa has experienced for political and economic reasons.

The Iowa Council has adopted the principle that the best advocates are those who live daily with developmental disabilities. Advocates continue to tell us through conversations and annual surveys what they need so that they can more meaningfully engage in decision-making and advocacy for the change they want to see in their lives. Though others might be experts in systems, theoretical constructs, programs and "best practices", it's those who live with DD daily who get the attention of members of the public and decision-makers when they tell their stories

and ask for what it is they need to live independently in the community. To that end the Council has developed goals to continue its work to increase the knowledge, skills, confidence and competence of those living with DD and others to articulate the demand for and participate in the design of services and supports they require to live independently. The Council, through its ID Action project, will continue to prepare advocates with disabilities as leaders for needed change at the federal, state and local levels and who lead coalitions and train others. Our experience in this area has taught us that this is also a need for the families of Iowans with DD. The Council's and AIDD's investment in the Iowa Coalition for Integrated Employment (ICIE) has resulted in changes in the way that employment providers prepare, place and support individuals with disabilities and in the state support and funding for those services. More employment providers are changing their model of service delivery from facility based to community based. The Council decided to keep this momentum going by engaging family members to continue to articulate the demand for services that lead to community integration and to assist the continued convening and work of the Coalition for ongoing training and technical assistance to employment providers and their staffs.

Through the ICIE meetings and a survey of providers about barriers to employment, transportation emerged as a barrier. This is not surprising as most Iowans with DD identify it as the #1 barrier to access to a variety of opportunities. Transportation is also identified by the Department of Aging and Iowa Vocational Rehabilitation Services as a barrier to their clients' participation in growth opportunities.

While Iowa has a number of challenges, there are also opportunities created through state legislation, federal initiatives, national trends and research that afford the Council opportunities to actively engage Iowans with DD and family members in systems design and redesign efforts. Iowans with disabilities and their families and advocates identify health care, housing, employment and education as the most important components of community living and these will be the initial areas of investment for the Council. The goal for systems design/redesign was made broadly enough that the Council can continue to be responsive to critical needs identified by those living with DD as well as opportunities and threats over the next five-year period.

In summary, the Iowa Council intends to conduct and support advocacy, capacity building, and systemic change activities. Specific goals describe the strategies to be used rather than the emphasis area targeted. This approach seems to more accurately reflect the role of the Council over the next five years and positions the Council to be more responsive to the environment and to the input from individuals affected by DD. The Council's approach to systems change will: 1) prepare and engage Iowans with DD as advocates and as leaders who build coalitions, organize others and facilitate leadership growth 2) develop stakeholders and community allies who can help to increase the capacity of communities to welcome people with DD as fully participating citizens 3) actively engage Iowans with disabilities in the design and/or redesign of the services and supports they use and 4) educate and inform policymakers.

Collaboration

The Iowa DD Network comprised of Disability Rights Iowa (DRI), the Center for Disabilities and Development (CDD) and the Iowa Developmental Disabilities Council (IDDC) have engaged in specific conversations about the Council's Plan since last winter. Those involved an inventory of what each entity was currently working toward individually, with one other entity and all three together. In addition we engaged in discussions about the current environment in Iowa with the

majority of conversations about the implementation of Managed Care for most Medicaid services, including long term services and supports. The Council provided some approaches to goals and objectives for the 5 year plan and the other two entities listed activities in which they were already engaged. Consensus was reached on collaboration for employment, self-advocacy and monitoring and advocating for community inclusion. DRI and the CDD work with the Council to support an annual conference designed for Iowans with developmental disabilities. Staff from each agency serves on a conference planning team which determines session topics and speakers, identifies exhibitors and sponsors, provide support to conference participants and assist with evaluation. This is planned to continue. Other entities engaged in this event and it's planning include the Iowa DHS, Mental Health and Disability Services Bureau, the Iowa Caregivers Association, the Iowa Association of Community Providers, individuals with disabilities, managed care organizations and a marketing & events planning company.

Staffs from all three entities are also engaged with the Iowa Coalition for Integrated Community Employment (ICIE). Engagement has included attending and presenting at Coalition meetings, conducting research related to relevant topics and advocacy for Administrative Rules to shift State resources toward integrated community employment (ICE). Network Partners plan to continue this important work even without the grant funds. Specific roles and outcomes are pending funding to continue the work of ICIE to further shift public resources in accordance with the HCBS Settings Rules. Other entities to be included in this work include: Iowa Medicaid Enterprise, MHDS, Iowa Vocational Rehabilitation, Iowa Department of Education, Iowa Workforce Development, Iowa Association of Community Providers, Case Managers, Managed Care Organizations, Community Rehabilitation Providers, Family Members, individuals with disabilities. As members of the coalition these entities will be engaged in community conversations about employment, training sessions for Iowans with disabilities and family members, outreach to providers and employers.

The Iowa DD Council has no specific activities to work with each of the Partners individually though we maintain a relationship that allows us to call on one another for unplanned opportunities to be responsive. For example when there are questions about guardianship and an individual's right to vote, we will engage DRI in the conversation or make a referral if that is appropriate. There are other issues related to guardianship for which our response may be to ask DRI to conduct training, answer questions or take on a case if they deem it worthy and consistent with their plan. The Council also will use the CWICs to answer questions related to benefits planning, engage them in training for families and individuals and refer individuals and families to them for services. The Council also counts on DRI for data related to the issues they get calls on and cases they take.

The CDD is a possible partner in the IDDC objective for people with Autism. However, there are still conversations we need to have before specific plans are in place for year 2. Similar to our relationship with DRI, we count on the CDD for training, answers to questions and a referral for services as we respond to Iowans with DD and family members. CDD has a staff person assigned to MHDS on whom we rely for information and conversations about Medicaid spending. Another who is similarly assigned to work on data collections and reporting has been a good resource for us to discuss the state's need for data on which to base reviews of progress and program and funding planning.

IOWA DEVELOPMENTAL DISABILITIES COUNCIL'S 5 YEAR PLAN (2017-2021)

5 Year Goals

Goal #1: Advocacy

Description:

Strengthen the capacity of the Iowans with Disabilities (ID Action) network to connect individuals with developmental disabilities and their families with resources that grow their advocacy and leadership skills and build their capacity to lead others in coalitions and grassroots systems change.

Expected Goal Outcome:

People with developmental disabilities and family members lead the change they want in services and supports through advocacy, training and leading others, building coalitions and change agendas.

Objectives:

1. Build the capacity of ID Action to become a self-sustaining, cross-disability advocacy network led by people with disabilities and less reliant on funding from the Iowa Developmental Disabilities Council. (baseline: currently 100% DDC funding)
2. Increase the number of Iowans with disabilities and family members who are aware of and use information, skill building resources and opportunities to engage in civic and political decision-making processes on issues important to them. (50% of those participating in Council/ID Action Activities)
3. With support from ID Action, increase the number of people with developmental disabilities and family members who train and lead community groups to identify local needs, develop solutions, and plan for projects that increase the integration and inclusion of people with disabilities in community living, working and learning.
4. Develop and employ alternate formats, languages, leadership engagement and other culturally appropriate strategies to increase the use of ID Action resources that assist Asians, Latino and African Americans with disabilities to effectively advocate for change.

Goal #2: Systems Change

Description:

Advocate for, engage others and monitor development, improvement and implementation of policies and practices that assure increased access to services and supports that provide opportunity for Iowans with developmental disabilities to be productive, included and integrated members of community living, learning and working.

Expected Goal Outcome:

Supports and services increase employment, transportation, and community living options.

Objectives:

1. With DD Network and other partners, advocate for improvements to community infrastructure, services and supports (including natural supports), and funding that supports individuals with developmental and other disabilities to live productive lives in the community.
2. With DD Network and other partners, increase community employment of individuals with developmental disabilities by improving public policies, budget actions and practices that shift public resources toward services that result in integrated community based preparation, job placement and ongoing supports.

3. Advocate for and support initiatives that improve local, regional and other transportation efforts that address transportation needs for Iowans with developmental disabilities particularly those in rural areas.
4. Increase the number of adults living with autism who have access to services that support them to live and work in communities of their choice.

Evaluation Plan

The Council will use both formative and summative evaluation approaches to assess both the processes and satisfaction with its activities and events as well as information about the outcomes of the activities and events. Following trainings sessions, activities and events, participants will be asked questions related to their satisfaction with the event and logistics and asked specific questions about what they learned from the experience, behaviors they expect to change (or not), and/or what they plan to do with the information or skills covered during the training. Results of these will be discussed during the Council's monthly meetings held between all contractors and staff to determine necessary changes to the components of the activity for future use. A result of these discussions may also be the development of further training or other resources.

Annually, registrants in the ID Action project, those who receive InfoNET, participants in mini-grants, and the community coalitions will be asked to respond to questions related to their overall satisfaction with their participation in these, the resources made available, how they use resources, the activities in which they've engaged, the issues for which they've advocated a position, what form of advocacy they used and their perception of their success and changes they feel they've made. Registrants and participants will be asked what further resources would help them to be more active and engaged.

The attached working draft of the ID Action logic model provides some of the activities that will be measured, the outputs that result, the outcomes and the impact. This draft will continue to evolve as contractors are procured during the first quarter of 2012 and work plans developed during contract negotiations. The following are some examples:

- Number of Iowans affected by developmental disability advocate for services and supports in Child Care, Education, early intervention, Employment, Housing, Health Care, Informal & Formal Community Supports, Quality Assurance, Recreation, &Transportation
- Number of Iowans affected by DD who are knowledgeable about their issues and who report they use that knowledge and their personal experiences to advocate for themselves and others
- Number who vote in local, state and national elections Number who lobby their elected officials and hold them accountable for their public policy.
- Number who lead by building coalitions and consensus around priority issues
- Number who influence policy as members of national, state and local governing and advisory bodies.
- Number who report that their advocacy resulted in change in one of the emphasis areas
- Number who report that DD Council resources were helpful to them in their advocacy efforts (by emphasis area) (inclusion)

One strategy through which we will learn about the status of the needs is through the annual surveys of ID Action Registrants and subscribers of InfoNET when they are asked annually to report on the issue areas in which they target their advocacy. People will stand up and take action on those issues or concerns that have the most meaning for them so this seems to be an appropriate measure of the areas in which people affected see the most need and sometimes the most opportunity.

The Council's Public Policy Manager will monitor policy including legislation, policy discussions in agencies as well as participate on a number of workgroups that allow the Council to have access to good information about policy issues and changes. Council staff, through participation on a number of task forces, work groups and committees, gathers information and data about trends in services and supports for Iowans with DD. And, finally Council members will provide information which serves to allow the Council to be current with other federally funded programs providing supports and services as well as the perception of family members and individuals with DD of their effectiveness.

The Council will continue to monitor data and trends identified in the development of this plan and use that information to inform decision-makers and advocates, e.g. Census Data, State Data Info, Residential Information System, State of the States. These methods will be used to gather information, data and systems that indicate trends related to supports and services for individuals to live in communities according to the on which the Council has chosen to focus. Some examples of that data include the following:

Number of policies created or improved.

- Amount of funds leveraged to improve the quality of life for Iowans living with a disability.
- Number of Iowans who have services as a result of policy and/or funding leveraged.
- Number of other groups that include disability agenda items in their policy agendas.
- Number who influence policy as decision maker.
- Amount of funding leveraged to improve community quality of life, services and supports for Iowans living with a developmental disability.
- Public funding for facility based employment vs. community based employment.
- Number of Iowans with DD served in facility based vs. community based employment.
- Employment status of Iowans with disability vs. those without.
- Educational Attainment of Iowans with disabilities vs. those without.
- Earnings of Iowans with disabilities vs. those without.
- Public funding for 6+ bed living arrangements vs. <6 bed.
- Number of Iowans with DD served in 6 bed or less, 7 or more bed settings, family settings, homes of their own, HCBS, Nursing Homes.
- # of programs changed, created, improved as a result of advocacy.
- Poverty rate for Iowans with disabilities.
- Number of people with DD waiting for services.
- Number on waivers.
- Infants & toddlers who reactive early intervention services within 30 days of the consent for services
- The percent of infants and toddlers with IFSPs who primarily receive early intervention services in the home or community based setting.

- Percent of youth with IEPs graduating from high school with a regular diploma.
- Percent of youth with IEPs dropping out of high school.
- Percent of youth who are no longer in secondary school, had IEPs in effect at the time they left school, and were: Enrolled in higher education within one year of leaving high school, enrolled in higher education or competitively employed within one year of leaving high school, enrolled in higher education or in some other postsecondary education or training program; or competitively employed or in some other employment within one year of leaving high school.

Council members receive all evaluation information described in the previous section. In the past, the Council has had in-person annual reports from contractors and staff related to progress in following work plans developed for implementation of goals. The goal of the Council with this 5 year plan is to engage Council members in the review and focused discussion on these evaluation reports and on the quarterly reports from contractors as well as reports from staff on their activities.

A team of Council members has agreed to review the evaluation measures to develop more specific timelines, consistent methods and investigate the use of random sampling in some areas to be able to extrapolate better information about the activities and status of registrants in ID Action and InfoNET. This group will also investigate methods to make the information gathered more meaningful for all Council members through the possible use of consistent reporting formats using graphs, charts or other visual aids.

Council members are invited and encouraged to read and comment on publication of the Council as well as websites and social marketing sites. Some of this is done independently and some during meetings with staff and/or contractors providing navigation hints and tips. It's through this interaction that Council members often have evaluative comments that lead to better accessibility for all members.

Finally, the Council has a role in determining the areas of systems change on which to focus. This is reflected in the measures the Council identified and presented in the first item in this section. This data will be gathered and be the focus of discussion during the year so that all members have an opportunity to learn more about systems, trends and issues.

The annual review of goals and objectives, data for the measures identified, results of legislation, opportunities created by the federal government, information disseminated related to research findings, priorities of other programs and agencies, and environmental shifts, all contribute to the Council's review and analysis and decisions about strategies. The goals have been written in broad enough terms to allow the Council to shift its emphasis based on the information gathered and needs identified by those affected.

As described above, one operational goal for the Council is to develop consistent trend data presented in a meaningful way so that members can use more data driven approaches to decision-making. Data gathered in the course of preparing for the plan identified areas in which the Council needs to pay more attention to better articulate the state of the state related to developmental disabilities in terms of data and trends.

The annual surveys of ID Action registrants, the majority being individuals with disabilities and family members, provides good information about the issues, needs, gaps important to Iowans. The Council will use this input along with descriptive data to determine priority areas of

emphasis in which to target its training and advocacy and update the review and analysis. The Council will also continue to use the information provided by these registrants to determine the resources we need to develop for them to advocate for the change they need in their lives. All of the data, information, policy and environmental issues will be used in an annual review of goals, objectives and strategies to determine whether the Council believes it is on the right course and/or whether course corrections are needed. These will be based on progress made (or nor and why) and lessons learned to further inform the revision on the current plan. This plan was developed with the intent that it would allow for course corrections based on annual feedback and assessment without changing the priority goals which reflect the role and purpose of Councils.