

# FIVE-YEAR STATE PLAN

2022-2026

Iowa Developmental Disabilities Council

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## **Council Membership Rotation Plan**

The Iowa Developmental Disabilities (DD) Council is comprised of 24 members. Each Council Member is appointed by the Governor for a three-year term. Members may be appointed by the Governor for an additional three-year term at the discretion of the Governor. Members are only allowed to serve two consecutive three-year terms. To ensure continuity, appointments have been staggered so that few members rotate off the DD Council and are replaced each year. The DD Council works closely with the Governor's office to appoint new members whenever there are resignations and/or when terms end. It does take a few months to get new appointments and the DD Council has frequent openings. As of August 2021, the DD council currently has one opening, a Protection and Advocacy representative. We have twelve female members and eleven male members. We have ten members from a rural area and thirteen members from an urban area.

## **Council Staff**

The Iowa DD Council has three full-time staff persons. An Executive Director, a Public Policy Manager and an Administrative Assistant.

## **The Designated State Agency**

The Iowa Developmental Disabilities (DD) Council's Designated State Agency is the Iowa Department of Human Services (DHS). DHS does provide direct services. The state of Iowa has two state operated Intermediate Care Facilities that has oversight by DHS. DHS also provides limited case management services.

DHS provides significant administrative support to the Iowa DD Council. This includes receiving and accounting for funds, contract management, information technology support and equipment, human resources support, payroll and other personnel related support, travel support and reimbursement and legal support. In addition, the DSA provides a small appropriation to the DD Council.

The DD Council does have a Memorandum of Understanding with the DHS. DHS was designated as the DSA in 1970.

## **Comprehensive Review and Analysis**

### **Introduction**

The Iowa Developmental Disabilities Council's Comprehensive Review and Analysis included a variety of activities by Council members, staff and partners. During council meetings, federally mandated members from state agencies presented information about their agencies, the barriers and gaps identified from their perspective and areas of need. Council members also participated in a survey developed specifically for their input and then participated in a facilitated discussion about the needs of Iowans with disabilities and priorities that the Council should focus on in the new state plan. Council members identified Employment, Community Living, Self-Advocacy and Transportation as the top areas of priority. Council members also indicated that we should put a special focus on individuals with

disabilities living in rural areas and have this as a targeted disparity goal. Council members agreed that we should continue some of the same activities from the previous plan such as leadership and training and strengthening community living and employment. In addition, Council members would like to strengthen the brand and awareness of the Councils' projects and activities.

The Council members also had a meeting with the Director of the Department of Human Services (the council's Designated State Agency) to discuss mutual priorities. The Director indicated two priority areas for the Council to consider: community capacity building in relation to workforce development and supporting people with disabilities with telling their story to legislators.

The Council also disseminated a survey statewide to self and family advocates, providers and disability advocates. We received 273 responses. Survey results indicated employment, health, housing and community living as top priorities or areas of focus for the Council. General themes that came from the comments in relation to these priorities included: offering leadership and mentoring opportunities, transportation barriers with all aspects of community living, support in rural areas, support with transitioning to adulthood, aging in place with developmental disabilities, increasing direct support wages, political engagement and providing informational resources.

Iowa's with Disabilities in Action, an advocacy project of the Council, conducts an annual survey of advocacy registrants to gauge the satisfaction of the project as well as determine additional issues and priorities we can address. Responses were received from 301 registrants with most of the respondents being people with disabilities. Forty-one percent of respondents said that Iowa's with Disabilities has helped them become a more effective leader. When asked how Iowa's with Disabilities in Action could continue to help people become a better and more effective leaders, more training and resources and communication and more outreach to rural areas were the top responses.

Council staff and Council members also participated in two events called "community Conversations". Additional "Community Conversations" scheduled for spring 2020 were cancelled due to the Pandemic. Take-a-ways from these conversations were more training and outreach at the local and rural areas is needed as well helping students transition into adult services and supports.

Council staff also serve and participate on various committees and taskforces to obtain and provide input. These include the Medical Assistance Advisory Committee, the Mental Health and Disabilities Services Commission, the Autism Council, the Employment First network, the Iowa Coalition for Integrated Employment, the Transportation Coordination Council, the Olmstead Task Force, and Brain Injury Council.

The Council continues to have a strong partnership with the Department of Human Rights (DHR). In 2018, the Council collaborated with DHR to complete a Data/Status Report to determine the changing needs and opportunities of the underserved and underrepresented populations in Iowa. The underserved and underrepresented populations included African Americans, Asian and Pacific Islanders, Deaf and hard of hearing, Latinos, Native Americans, Persons with Disabilities, and women. The Council was particularly interested in the needs of people with disabilities within each population. Unfortunately, even with extensive outreach and interviews, that information was not as accessible. Civic engagement was identified as a need across the populations. A lack of mentors with disabilities was also identified as a need but also an opportunity. The Council will continue to work with DHR to address the needs of the underserved and underrepresented especially in rural areas.

*Iowa's current population as of July 2019 is 3,155,070.*

**Racial and Ethnic Diversity**

White alone	85%
Black or African American Alone	4%
Asian Alone	2.7
American Indian and Alaskan Native alone	.5%
Hispanic or Latino alone.	6.2%
Native Hawaiian or other Pacific Islander alone	.1%
Two or more Races	1.8%
Some other Race	0%

**POVERTY RATE 11.2%**

**State Disabilities Characteristics**

Based on 1.58% prevalence rate for DD in each State/Territory from the HHS. 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 3,155,070 X 1.58%. Prevalence of Developmental Disabilities in the state: 49,850.

**Residential Settings**

Year	Total Served	A. Number Served in Setting of <6 (per 100,000)	B. Number Served in Setting of >7 (per 100,000)	C. Number Served in Family Setting (per 100,000)	D. Number Served in Home of Their Own (per 100,000)
2015	11,741	2	1921	Not reported	Not reported
2016	11,623	2	1843	Not reported	Not reported
2017	14,424	139	1796	Not reported	Not reported

**Demographic Information about People with Disabilities**

People in the State with a disability	Percentage
Population 5 to 17 years	5%
Population 18 – 64 years	18%
Population 65 years and over	66 %

Race and Ethnicity	Percentage
White alone	11.8%
Black or African American alone	10.7%
American Indian and Alaska Native alone	24%
Asian alone	5.8%
Native Hawaiian and Other Pacific Islander alone	NA
Some other race alone	6.1%
Hispanic or Latino (of any race)	6.6%
Two or more races	8.7%

Educational Attainment Population Age 25 and Over	Percentage with a disability	Percentage without a disability
Less than high school graduate	19.5%	9.6%
High school graduate, GED, or alternative	33.8%	25.3%
Some college or associate degree	28.5%	28.6%
Bachelor's degree or higher	18.2%	36.5%

Employment Status Population Age 16 and Over	Percentage with a disability	Percentage without a disability
Employed	28.4%	71.4%
Not in labor force	68.6%	26.1%

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	15%	8.1%
Earning \$5,000 to \$14,999	19.4%	12.5%
Earning \$15,000 to \$24,999	15.1%	12.9%
Earning \$25,000 to \$34,999	12.6%	13.1%
Earning \$35,000 to \$49,999	13%	15.5%
Earning \$50,000 to \$74,999	12.6%	17.1%

Earnings in Past 12 months Population Age 16 and Over with Earnings	Percentage with a disability	Percentage without a disability
\$75,000 or more	12.3%	20.7%

Poverty Status Population Age 16 and Over	Percentage with a disability	Percentage without a disability
Below 100 percent of the poverty level	19.5%	9.7%
100 to 149 percent of the poverty level	11.8%	6.4%
At or above 150 percent of the poverty level	68.7%	83.8%

## Portrait of the State Services

### Transportation

Iowa has 35 public transit systems covering all 99 counties, served by 19 urban systems in cities and 16 regional systems that are multi-county in nature. These public transition systems provided 23,828,108 rides in Fiscal year 2019 with 2,915,724 rides for people identifying as having a disability.

Iowa has three types of public transit service:

1. Demand response: provided by the 16 regional systems, with curbside service for passengers scheduling in advance.
2. Fixed Routes: provided by the 19 urban transit agencies with set routes, stop and time points. In some communities, people can flag the bus down along the route
3. ADA complimentary paratransit: available in the 19 urban transit areas in zones around fixed routes to those who meet certain disability qualifications under the Americans with Disabilities Act. Ride reservations are made the day prior to the trip with passengers being picked up at their home or other site and delivering them to their desired location.

Iowa does have one of the oldest transit fleets in the nation. Iowa continues to locate a reliable funding stream for purpose of repairing and replacing at both federal, state and local level.

### Other Transportation services:

**Non-emergency Medical Transportation (NEMT):** The NEMT services are for individuals with full Medicaid benefits, who need travel reimbursement or a ride to get to their medical appointments. Since April 2016, Iowa's Medicaid system has been contracted to Managed Care Organizations (MCO). There are currently only two MCOs in Iowa. The MCOs are each responsible for providing non-emergency medical transportation to their Medicaid clients. Each MCO has a separate transportation broker. There is a small Medicaid population who still uses Fee for Service for Medicaid and the Iowa Department of Human Services also has a transportation broker. Each transit agency must contract with the transportation brokers for reimbursement by Medicaid. Each broker has their own policies and billing process that can make it complicated.

**HCBS waiver services:** Transportation and home and vehicle modifications are available under the Intellectual Disability waiver as well as other waivers. Transportation is available for grocery shopping running errands, and going to, and from work. In December 2017, a rule change limited transportation funding for people on the Intellectual Disability waiver who were receiving 24 hours of supported community living support. The supported community living support provider would be responsible for providing transportation as part of their current rate of service. This has caused a burden for service providers with some providers not able to provide full transportation to the people they support.

**Mobility Management:** Mobility management has become a major player in assisting and educating the community about employment options. Mobility coordinators assist individuals in navigating from point A to Point B no matter the modes of transportation required. They may also provide travel training showing persons how to ride the bus and read bus maps. Mobility coordinators also meet with human services agencies, businesses and other organizations to educate them on the public transit services and to inspire more collaboration. There are currently nine mobility coordinators around the state and one statewide coordinator.

**Ride Share:** Iowa has a ride share program that has a statewide matching software so that the public can locate others with similar origins and destinations in order to share transportation costs. In the past two years, 1,852 have become registered users and there are 119 total vanpools in the system. In 2019, no disability rides were provided on vanpools and most vanpool vans are not accessible, but if a person in a mobility device requests to participate in a vanpool the transit system would need to find an accessible vehicle so that person could be accommodated in a vanpool.

## **Interagency Initiatives**

Iowa Program for Assistive Technology (IPAT). IPAT is Iowa's state assistive technology program under the Assistive Technology Act of 1998. The Program's goal is to improve access for individuals with disabilities and aging Iowans to assistive technology that promotes independence at home, work, school, and in the community. The University of Iowa's Center for Excellence in Developmental Disabilities (UCEDD) contracts with Easter Seals Iowa Assistive Technology program to implement the program that includes a low-income loan program, device recycling, device demonstration, device loans for trial use, and training and technical assistance. Council staff, the UCEDD, Easter Seals and Disability Rights Iowa meet quarterly to discuss assistive technology barriers, needs and ways to collaborate.

Advisory Council on Brain Injury and the Traumatic Brain Injury State Implementation Partnership grant: The council consists of members who are survivors of brain injury, family members of individuals who have experienced a brain injury, and/or professionals working in a field related to brain injury services. In addition to appointed members, representation from various state agencies also comprise the council as non-voting members. In June 2018, the Iowa Department of Public Health received federal funding from the U.S. Administration for Community Living.

Through this 2018-2021 project, Iowa's goal is to increase access to appropriate services and supports by individuals with brain injury and their families. The objectives are:

- increase implementation of evidence-based return-to-learn protocols
- increase awareness of brain injury and concussion
- increase outreach to, and services for, underserved and inappropriately served individuals with TBI
- increase effectiveness of the Iowa Department of Public Health and the Advisory Council on Brain Injuries
- improve national impact of the TBI program.

Council Staff regularly attend their meetings and programs and continue to offer training opportunities together.

Special Education Advisory Panel (SEAP): represent public and private sectors that by virtue of their position, interest, or training can contribute information regarding 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. 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 to provide guidance on special education programs and services.

The Medical Assistance Advisory Council (MAAC): The Purpose of the MAAC is to advise the Director about health and medical care services under the Medical Assistance Program. MAAC is mandated by federal law and further established in Iowa Code. Membership includes five public representatives, one who must be a recipient of medical assistance, the Department of Public Health, the Department of Aging, the office of the long ombudsman, Des Moines University, and the University of Iowa College of Medicine. State Senate and House of Representatives are also included. Partner agencies such as the DD Council serve as nonvoting members.

Mental Health and Disabilities Services Commission(MHDS): The Iowa Mental Health and Disability Services (MHDS) Commission is the state policy-making body for the provision of services to persons with mental illness, intellectual disabilities or other developmental disabilities, or brain injury. It is authorized by the Code of Iowa. The Commission currently consists of eighteen voting members appointed by the Governor and confirmed by a two-thirds vote of the Senate. Commission members are appointed based on interest and experience in the fields of mental health, intellectual disabilities or other developmental disabilities, and brain injury, and to ensure adequate representation from persons with disabilities and individuals who have knowledge concerning disability services. Council staff regularly attends the MHDS meetings as a member of the public and provides comments as necessary.

State Rehabilitation Council (SRC): SRC works in partnership with Iowa Vocational Rehabilitation to provide feedback and recommendations for effective services. A majority of the membership consists of people with disabilities.

Iowa Statewide Independent Living Council: The Iowa Statewide Independent Living Council (SILC) is a council where the majority of members are persons with disabilities. The role of the Council is to plan for the coordination and expansion of independent living services in Iowa.

Work Force 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 14 members including representatives from the following groups: five-business, five-labor, one-city official, one-county elected official and one-school district representative and one-community college representative. The Region 8 Board has 28 members.

Disability Access Committee: Developed in 2019, this is a standing committee of the state workforce board. Each workforce one-stop shop in each Iowa region has a local Disability Access Committee. These are chaired by Iowa Vocational Rehabilitation Staff and the Iowa Department of the blind and include representation from required partners in the local area. These committees are tasked with identifying physical accessibility issues, program accessibility issues and ways to collaborate and partner together to increase employment outcomes through the one-stop shops Centers for people with disabilities

The Olmstead Consumer Task Force: The Olmstead Consumer Taskforce is a statewide advocacy group charged by Executive Order to monitor Iowa's response to the 1999 Supreme Court's Olmstead Decision. Activities support the full inclusion of people with disabilities in housing, employment, transportation, healthcare, and other areas. Members include people with disabilities and family members, state agencies, providers, and others to ensure that legislation, changes in administrative rule, and other public policies and programs promote the full inclusion of individuals with disabilities in all aspects of life in the community. Council staff regularly attend meetings as a member of the public and provides presentations and public comment when necessary.

The Iowa Coalition for Integrated Employment (ICIE): The purpose of this coalition is to address funding, policy and capacity barriers to integrated and community employment. Members include state agency representatives from the Iowa Department of Human Services, Department of Aging, Workforce Development, Iowa Vocational Rehabilitation services, the UCED, Disabilities Rights Iowa, Community providers and people with disabilities and family members. The DD Council is a founding member of this coalition

## **Quality Assurance**

Four 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 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. To assist the dependent abuse program, in 1996, the Dependent Adult Protective Advisory Council was established. It has the responsibility to:

1. Advise the director of human services, the director of the department on aging, the director of inspections and appeals, the director of public health, the director of the department of corrections, and the director of human rights regarding dependent adult abuse.
2. Evaluate state law and rules and make recommendations to the general assembly and to executive branch departments regarding laws and rules concerning dependent adults.
3. Receive and review recommendations and complaints from the public, health care facilities, and health care programs concerning the dependent adult abuse services program.

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). This program 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. Approximately 49,000 Medicaid managed care members in Iowa are included within this scope.

## **Health Care/Health**

Medical Assistance: provides medically necessary health care coverage for financially needy adults, children, and parents with children, people with disabilities, elderly people and pregnant women.

The Department of Human Services implemented the IA Health Link managed care program for the 95% of the Medicaid population on April 1, 2016. Most Medicaid members are now being served by two managed care organizations (MCOs); AmeriGroup and Iowa Total Care. The Iowa Medicaid Enterprise (IME) continues to operate a limited Fee-For-Service (FSS) program for the Medicaid members not enrolled in managed care.

Medicaid is projected 792,000 (unduplicated) or 25.2 percent of Iowa's population by SFY21. Generally, Medicaid covers low-income members who are aged (over age 65), blind, disabled, pregnant women, children (under 21 years of age) or members of a family with children. Twelve percent of those enrolled are people with disabilities, although they account for 53% of the expenditures.

Medicaid covers a comprehensive range of health care services for Iowans who meet the program's eligibility criteria:

- Physical Health Care Services include physician care, hospital services, labs, prescription drugs, home health care, rural health clinic (RHC) services, Federally Qualified Health Centers (FQHCs) services, chiropractic care, physical therapy, and dental care.
- Behavioral Care Services include community mental health services, hospital services, physician care, psychiatric medical institution care, outpatient treatment and therapy, rehabilitative mental health services (known as Behavioral Health Intervention Services), as well as non-traditional services such as peer support and Assertive Community Treatment, and substance abuse treatment that can only be delivered through managed care.
- Care for Kids: Early and Periodic Screening Diagnosis and Treatment provide prevented health care services for children ages 0-20.
- Medicaid for Kids with Special Needs assists with paying for medical bills for children with special needs due to a disability
- Long Term Care Services include Nursing Facilities (NF), Skilled Nursing Facilities (SNF), Nursing Facilities for Individuals with Mental Illness (NF/MI), Intermediate Care Facilities for the Medically Complex (ICF/MC), Intermediate Care Facilities for Persons with Intellectual Disabilities (ICF/ID), and Home and Community Based Services (HCBS) that allows individuals to remain in their homes. Currently there are two state operated ICF/ID facilities that serve 334 individuals as with disabilities (four children under 17 and 330 adults). There are 1,778 people served in private ICF/IDs
- Home- and Community-Based Services (HCBS) are for people with disabilities and older Iowans who need services to allow them to stay in their home and community with services. The programs include HCBS Waivers Habilitation Services, PACE, Home Health, *Hospice*, *Targeted Case Management (TCM)*, and *Money Follows the Person (MFP)*. These programs include services such as employment, residential, home health, assistance with personal care, homemaking, transportation and respite care that are intended to assist members with remaining in their homes and communities.
- HCBS Services are delivered through seven 1915(c) waivers that are targeted to specific populations including persons who:
  - Are Elderly (8093 currently served and currently no one on the waiting list)
  - Have an Intellectual Disability (12, 302 currently served and 4,014 on a waiting list)
  - Have a physical disability (1,177 currently served and 1,373 on a waiting list)
  - Have a health care/medical disability (2384 currently served, 5213 on a waiting list)

- Are Children with Serious Emotional Disturbance (1,281 currently served and 812 on a waiting list)
- Are Living with HIV/AIDS (29 currently served and currently no one on a waiting list)
- Have a Brain Injury (1509 current served and 1,898 on a waiting list)
- Care for Kids: Early and Periodic Screening Diagnosis and Treatment provide prevented health care services for children ages 0-20.
- State Plan HCBS Services are delivered through the 1915(i) state plan amendment. The HCBS Habilitation program provides service funding and individualized supports to maintain eligible members in their own homes or communities who require assistance due to the functional limitations typically associated with chronic mental illness. Services include case management, home based habilitation, day habilitation, and employment. (7544 are currently served under this program)

In 2014, Iowa implemented the Iowa Health and Wellness Plan (IHWP), an expansion of the state's Medicaid program enacted to provide comprehensive health care coverage to low income adults. IHWP covers adults ages 19-64 who are not otherwise eligible for Medicaid or Medicare

- Persons with incomes 0-100 percent of FPL (up to \$12,490 for a family of one and up to \$16,910 for a family of two).
- Persons with incomes between 101 percent and 133 percent of FPL (\$12,491-\$16,612 for a family of one and \$16,911-\$22,491 for a family of two).
- During SFY19, the Iowa Health and Wellness Plan served an average of 154,972 individuals that were not previously covered by a full benefit Medicaid plan.

Healthy and Well Kids in Iowa (HAWKI): This is Iowa's plan for Children's Health Insurance Program (CHIP) that provides health care coverage for children and families whose family income is too high to qualify for Medicaid but too low to afford individual or work provided health care. CHIP members receive services through an MCO.

CHIP has three parts: a Medicaid expansion, a separate program called Hawki, and a dental-only plan.

- Medicaid expansion provides coverage to children ages 6-18 whose family income is between 122 and 167 percent of the Federal Poverty Level (FPL), and infants whose family income is between 240 and 375 percent of the FPL.
- The Hawki program provides coverage to children under age 19 in families whose family income is between 168 percent and 302 percent of the FPL based on Modified Adjusted Gross Income (MAGI) methodology.
- Total CHIP enrollment increased by 8 percent (5,494 enrollees) in SFY19. Enrollment is projected to increase by 2.4 percent (1,772 enrollees) in SFY20 and 1.3 percent (959 enrollees) in SFY21. Projected increases are based on historical enrollment.
- Iowa is one of only a limited number of states with CMS-approved dental plans, which include basic dental coverage and medically necessary orthodontic coverage.
- Children covered by the Medicaid expansion receive full Medicaid coverage through MCOs
- Hawki coverage is similar to commercial health care coverage and includes, but is not limited to, doctor visits, inpatient and outpatient hospital, well-child visits, immunizations, emergency care, prescription medicines, eye glasses and vision exams, dental care and exams, speech, occupational, and physical therapy, ambulance, and mental health and substance abuse care covered through managed care

State Supplemental Assistance: Helps low-income older Iowans and Iowans with disabilities meet basic needs and reduces state spending for Medicaid. State Supplementary payments provide cash payments to help meet basic needs. Individuals receiving In-Home Health-Related Care, Residential Care Facility, and Family Life Home services help pay for the cost of their care through an assessed client participation amount. SSA pays the difference between the actual cost of care and the client participation amount. Forty-two percent of the expenditures for this program are spent on dependent older Iowans or Iowans with Disabilities who have a financially independent relative living in the home. Thirty-three percent of expenditures are spent on older Iowans or people with Iowans with Disabilities who required personal in-home related care.

Maternal and Child Health Services Block Grant: The federally funded program through Title V of the Social Security Act devoted to improving the health of women children and family. There are four programs available in Iowa to improve the health of Iowa's families:

*Child and Adolescent Health:* Twenty-two local child health agencies provided child health direct and enabling services to 175,249 children, ages 0-22 years across the state. The child health programs help families access physical examinations, vision and hearing screening, dental education and referral. Services are a collaboration with the Iowa Medicaid Agency

*Maternal Health:* Twenty-three local maternal health agencies provide maternal health services to 8275 low-income pregnant women. Services include health education, risk assessment, psychosocial screening, oral health screening, delivery planning and presumptive eligibility.

*Oral Health:* In fiscal year 15 over 48 percent of Medicaid eligible children in Iowa ages 0-5 received dental or oral health services.

*Children and Youth with Special Health Care Needs:* This program is administered through the Child Health Specialty Clinics (CHSC) with the University of Iowa Steady Family Department of Pediatrics. CHSC's mission is to assure a system-oriented approach to care for Iowa's children and families. Through a network of 13 community based regional centers and four satellite centers, CHSC services enhance access to care through family support and engagement, care coordination and gap-filling clinical services including telehealth.

Mental Health and Disability Services (MHDS): MHDS is responsible for planning, coordinating, monitoring, improving and partially funding mental health and disabilities for Iowa. MHDS is a division of the Iowa Department of Human Services that works closely with the Medicaid Department. MHDS is the designated State Mental Health Authority and distributes federal funds received through the Community Mental Health Block grant. MHDS oversees the statewide local regions that are responsible for providing core services to people with disabilities who are not eligible for Medicaid or on a waiting list. In state fiscal year 2020, the MDHS regions combined provided services to 1,709 people who had an intellectual disability and 745 individuals who had a developmental disability. Core services include: Case Management, home health, personal emergency response, respite, home and vehicle modification, supported community living, family and peer support, Assertive Community Treatment, inpatient treatment, crisis response, and employment supports.

## Employment

Iowa Vocational Rehabilitation Services (IVRS), the largest division within the Iowa Department of Education, is responsible for majority of the Federal Vocational Rehabilitation funding for people with disabilities. The Iowa Department for the Blind is responsible for employment services for people who are blind. The ratio of the federal funding is 81% to 19%. Over the past few year IVRS, with various employment grants and the passing in 2014 of the Workforce Innovation and Opportunities Act (WIOA) have opportunities to expand employment options for both students and adults with disabilities.

Since 2012, Iowa has received technical and financial assistance dollars directed to community provider transformation to help people with the most significant disabilities access community, competitive, integrated employment. IVRS was the lead agency for federal funds received from the Department of Labor's Office of disability and Employment policy for the last eight years and partnered with our Council to continue transformation efforts.

IVRS served more than 9,000 potential eligible students with the change in federal legislation with the workforce investment act in 2019. Twenty-nine percent of IVRS referrals came from the Iowa school district in 2019 and 827 students were successfully employed working 30 hours a week at \$12.89. In 2019, IVRS placed 1,930 Iowans with disabilities in competitive employment. IVRS also assisted 26 entrepreneurs with disabilities with starting their own business. As of June 30, 2020, there were 183 individuals on a waiting list. IVRS reports that individuals with significant disabilities are entering services almost immediately and not placed on the waiting list.

IVRS also collaborates with local education agencies, community rehabilitation providers and other community partners to provide pre-employment transition services to Iowa students. These projects include:

*Transition Alliance Program (TAP):* developed with the school districts. TAP services are provided through a collaborative service coordination model with includes pre-employment transition services with the goal of competitive employment. In 2019 3044 students were served in TAP

*Project Search:* The goal of each student participant is competitive employment. The program provides real-life work-based learning experiences combined with workplace readiness training. Project Search through IVRS served 68 students in 2019

*Intermediary Networks:* This program through delivery of pre-employment transition services prepares students with disabilities for the workforce by connecting students, the educational system, businesses and the community through relevant work-based learning activities across the careers emphasizing science, technology, math and engineering. This program served 3,044 students in 2019.

Employment services are also available under the Intellectual Disability and Brain Injury HCBS waivers and Habilitation program. Since 2012, IVRS and the Department of Human Services have been working together with other community partners including the ICIE program mentioned earlier to redesign employment services. With the passing of WIOA Act, IVRS and DHS have an established "resource sharing agreement". By establishing Resource Sharing agreement, IVRS and DHS have outlined their respective funding obligations when paying for Supported Employment Services for a mutual client served by both agencies. For job candidates under the age of 24, IVRS implemented a Memorandum of Agreement with DHS to establish IVRS as the payer of first resort for individualized services necessary to

obtain and stabilize in competitive integrated employment. This has eliminated some confusion on which services and funding stream a person may be eligible.

The DD Council and IVRS have also collaborated the last three years to provide customized employment training to community rehabilitation providers and Vocational Rehabilitation Counselors across the state to increase employment outcomes for people disabilities.

## **Informal and Formal Services and Supports**

There are a variety of formal and informal supports available to people with disabilities and their families although how many access these services with a developmental disability is not easily available

Ask Resource Center: Provides parent training, information, and advocacy for families of children with special needs. Ask serves as the Iowa family-to-family health information center. It also provides early hearing detections and intervention screening to newborns.

Autism Support Program: provides funding for Applied Behavior Analysis services to children under the age of 14 who are not eligible to receive services through Medicaid or private health insurance and who meet certain diagnostic and financial eligibility criteria. Fifteen people with autism were served under this program last year.

Centers for Independent Living: Iowa has six independent living centers that serve 32 of Iowa's 99 counties. They provide five core services: information and Referral, independent living skills training, peer support counseling, individual and systems advocacy and transition services.

Children at home program: designed to assist families with services and supports that help children remain at home. Financial assistance is intended to obtain services and supports not met by other. Programs. The family's net income cannot be over \$60,000 Services typically provided are equipment, therapy, family training and personal care.

Home and Community Based Services (HCBS) Rent Subsidy: Provides HCBS members who are 18 and older with a monthly rent assistance payment. They must be ineligible for or on a waiting list for Department of Housing and Urban Development rental assistance. This program helps an average of 330 Iowans each month to stay in their home.

Iowa Compass: Provides information and referral information to Iowans with disabilities. It has a website database people can access to find information, as well as toll free number, email and live chat option.

## **Analysis of the State Issues and Challenges:**

### ***Criteria for eligibility of services:***

Most Iowans with developmental disabilities access services through either the state's Medicaid plan or the regional Mental Health and Disability services system. Medicaid provides services to children and

adults with disabilities through the state plan, the Medicaid expansion plan known as the Iowa Health and Wellness Plan (covers adults 19-64 with an income not to exceed 133% poverty level) and five (out of seven) Medicaid Home and Community Based Services. The waivers include an intellectual disability waiver, a physical disability waiver, a health and disability waiver, a brain injury waiver, and a children's mental health waiver. Income eligibility remains the same for all waivers, but level of care determination, diagnosis, services available and total costs allowed vary by waiver. Individuals do not need to determine eligibility or provide a needs assessment or diagnosis prior to applying for a waiver. Individuals with disabilities are encouraged to apply for all waivers at the time of application and are then placed on the waiting list for all waivers. People with disabilities then may have an available "Waiver slot" available for them that they are not eligible for. It causes unnecessary confusion and additional paperwork.

Most of Iowa's Medicaid members including the long-term care population are enrolled in a managed care program called Iowa Health Link. Currently, there are only two managed care companies in Iowa. Since the implementation in 2016, there has been turnover in managed care companies providing services in Iowa. Case management services for individuals eligible for waiver services are provided through the managed care program. With the turnover of companies managing the services for individuals with disabilities, there has been turnover in who is providing case manager services. Many individuals on the waiver programs cannot tell you who their case manager is. This can make navigating the service system difficult.

Services are also available for people with disabilities through the regional Mental Health and Disability Service system. There are 14 regions that levy property taxes to pay for services that are mandated that they provide. Based on the population of the region, the funding will vary. Only about 2% of the persons served across the regions are people with Intellectual Disabilities or developmental disabilities

***Analysis of barriers to full participation of unserved and underserved groups of individuals with developmental disabilities and their families:***

Iowa's unserved and underserved populations include Asians, African Americans, Latinos and American Indians. Our Council has historically struggled to find substantial data on barriers faced by unserved and underserved populations. To this end, the Council collaborated with the Department of Human Rights (DHR) to develop a Data/Status Report to identify needs and opportunities among underserved populations including people with developmental disabilities within those groups. As mentioned previously, even though DHR conducted extensive outreach and interviews it was still difficult to bring to light specific needs and opportunities of people with disabilities within those communities. Although through the Data Report and then confirmed through our needs assessment survey and focus groups it was determined that there is a need to do outreach in rural areas with Asians African, Americans, Latinos and American Indians and those with disabilities within those populations.

Other general themes that came to surface:

- Knowledge of available public services.
- Lack of community connections
- Opportunities for civic engagement
- Higher education opportunities
- Lack of ADA compliance in rural communities

### ***The Availability of Assistant Technology***

The Iowa Program for Assistive Technology (IPAT) is Iowa's state assistive technology program under the Assistive Technology Act of 1998. The program's goal is to improve access for individuals with disabilities and aging Iowans to assistive technology that promotes their independence at home, work, school and in the community. The Center for Disabilities and Development contracts with the Easter Seals Iowa Assistive Technology Program to implement these services:

- *Alternative Financial Loan Program* has reduced interest loans available for purchase of assistive technology (AT) devices or services, including home modifications and adapted vehicles.
- *Device Recycle and Reuse Services* make used assistive technology devices available for free or at a lower cost.
- *Device Demonstration Services* allow you to try a device before purchase. This can be in person or with a "virtual" demonstration using your computer.
- *Device Short Term Loan Programs* allow you 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 your 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* is provided to organizations and agencies to increase access to AT devices and services through collaboration and policy changes.

Easter Seals also provides an Assistive Technology Exchange Program, a free on-line listing of used devices that people are selling and looking to buy.

Disability Rights Iowa manages the Iowa Protection and Advocacy for Assistive Technology program. Through this DRI provides legal assistance and advocacy to help individuals with disabilities to obtain the assistive technology equipment and services to improve their quality of life. This includes assistance with appealing denials for adapted equipment from your insurance company. DRI worked with 15 individuals this last year.

Iowa Area Education Agencies Assistive Technology Services work as educational partners with every public and accredited, nonpublic school in Iowa to improve the learning outcomes and wellbeing of all students. Each of the nine AEA designates one or more professionals to specialize in assistive technology support for schools and families in their region. These specialists support systemic implementation of assistive technology special education services for children and students from birth to 21 years of age.

## Waiting Lists

Year	State Population (100,00)	Total Served	Number served per 100,000	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 person waiting for other services as reported by the state per 100,000
2020	31.55	15684	497	454	Unreported	Unreported

State waitlist definition: The number of persons receiving HCBS intellectual disability waiver services in the state shall be limited to the number of payment slots provided in the HCBS intellectual disability waiver approved by the Centers for Medicare and Medicaid Services (CMS). The department shall make a request to CMS to adjust the program limit as deemed necessary. Currently there are 4,148 individuals on the intellectual disability waiver waitlist, 5,423 on the Health and Disability waitlist and 1,503 on the Physical Disability waitlist.

The state maintains the waiting list for the HCBS waivers. Five of the waivers have waiting lists including the ID/DD waiver. It takes approximately two years for a person to come off the waiting list. Besides the HCBS waiver waiting list there is not another statewide standardized data collection in place. Out of the 14 MHDS regions, only one currently has a waiting list for services. Individuals on an HCBS waiting list can receive services through the MHDS regions.

The ID waiver does allow for prioritization for the wait list. Waiver applicants that meet any of the emergency criteria are placed on the statewide wait list based on the total number of criteria met. Applicants with an equal number of criteria are placed on the wait list based on application and the age of the applicant. Applicants meeting the emergency criteria shall receive the first available funding slot. Examples of emergency criteria include death of a caregiver and homelessness. Applicants who meet any of the urgent criteria shall be placed at the statewide list after those meeting emergency criteria and based on the total number of criteria met.

Examples of urgent criteria include a caregiver not being able to provide care in the next 60 days and the potential for losing permanent housing within 31-120 days. Applicants who do not meet either emergency or urgent criteria are placed on the wait list based on the date of application and the age of the applicant. In addition, applicants who currently reside in a community-based neurobehavioral rehabilitation residential setting, an intermediate care facility for persons with an intellectual disability (ICF/ID), a skilled nursing facility, or an ICF and have resided in that setting for six or more months may request a reserved capacity slot. Currently the state has 125 reserved capacity slots available yearly.

Waiver applicants are screened for Medicaid eligibility by the state, but no further assessment of need or level of care determination is made until a waiver slot becomes available. As mentioned earlier, there are some services available for people through the MHDS regions, but with the implementation of managed care, local option counseling services are not as available while people wait for services.

***Summary of Waiting list issues and challenges:***

Each year Iowa's Medicaid population increases to approximately 1% more of the population. Over 50% of the Medicaid costs are on long-term care services, which includes HCBS services. Iowa first implemented a waiting list for the Intellectual disability waiver in 2015. At the time of implementation there were 369 placed on waitlist with 12,600 served. Currently there are 4,148 on the waitlist with a similar number served. People with ID/DD receive waiver services for many years and thus waiver slots do not open up as frequently as they do for older adults. As more individuals with ID/DD live longer and maintain community placements, this results in longer wait times for waivers serving individuals with ID/DD. People are currently waiting three years for a waiver slot.

In 2016, legislature did appropriate \$2 million to reduce waiting lists but at the time, it was estimated that it would take an estimated \$10 million to serve all individuals on all waiver wait lists. There has been no money appropriated for reducing the Intellectual disability waiting list since 2016. In 2019, 1.2 million was appropriated to reduce the children's mental health waiver waiting list. The challenge is to continue serve the current population on all waivers without initiating additional cost containment measures such as reducing rate caps and service caps.

***Analysis of the Adequacy of Current Resources and Project availability of Future Resources to Fund Services***

The Current state budget total for SFY21 is 1.55 billion, 24.8% comes from state general funding, 3.80 billion is federal funding or 60.9% 893.1 million is other funding such as rebates and other recoveries. Iowa's FMAP, federal share has been increasing since 2017.

As with most States, Iowa does estimate a slight decline of revenues for the current fiscal year. The true impact to the state revenue due to COVID 19 is not entirely known yet. We do know that the state saved \$288.1 million from the 6.2% enhanced federal match for COVID Relief. Medicaid will end FY 2021 with an extra \$234.6 million balance that will carry into FY 2022. Medicaid will end FY 2022 with \$81.3 million surplus balance at end of the year. This means additional state dollars are not needed in FY 2022 to keep Medicaid services at current levels.

People with Disabilities account for 51% of the Medicaid expenses but are only 18 % of the Medicaid population. In 2019, 47% of the HCBS waiver population were people on the Intellectual Disability Waiver. The average cost for ID waiver services per person was \$60,738. In contrast, the average cost for individuals receiving Intermediate care Facility services was \$175,630. Iowa in recent years has spent more money on HCBS then facility services. Currently 66% of the Long-Term Care population is in HCBS services

A mentioned earlier, MHDS local regions are responsible for providing core services to people with disabilities who are not eligible for Medicaid. The local regions, established in 2014 with the redesign of the mental health and disability system, are mandated to provide core services. An adequate, equitable and sustainable funding source for these services has not been established. It has solely relied on property tax with an outdated levy capitation. Changes to how the MHDS system will be funded in the future was the debated topic of the 2021 Legislative session. At the end of session, a bill passed that made significant changes in Iowa's tax laws. It contains more than \$400 million in tax relief, including the elimination of the property tax that pays for regional mental health and disability service replacing it

instead with an automatic state appropriation. The automatic state appropriation does have some advocates and a few of the regions concerned. The appropriation could be subject to future budgetcuts if the economy does not fare well.

Iowa Implemented managed care in 2016 for all long-term care services and medical and behavior health services. It was felt by many stakeholders and advocates that implementation was rushed and the state was not prepared for this transition. Services were cut, providers closed, and care coordination failed. Iowa continues to struggle to meet the needs of people with disabilities in a Managed Care system. As mentioned earlier there has been constant turnover in the companies managing care with only one company remaining since implementation. This has led to constant turnover with who is coordinating services for individuals with disabilities.

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

Iowa has two state operated ICF/ID facilities that serve 334 individuals with disabilities (four children under 17 and 330 adults). There are 1,778 people served in private ICF/IDs. The Department of Inspection and Appeals has oversight of the private ICF/IDs. Surveyors from DIA conduct routine, unannounced on-site survey visits to assess the quality of care and services provided to clients. If any problems are discovered, DIA will work with the facility to ensure compliance with State and federal rules; department staff may also issue disciplinary action, if merited.

DIA staff also investigate complaints received regarding improper care or treatment of patients or clients in licensed health facilities. If specific complaints or concerns are received, DIA staff may complete on-site inspections in addition to routine compliance inspections. All findings, complaints and reviews are public information located on the DIA website. All information is searchable by the provider.

DIA completes recertification surveys at least every 15.9 months, with an average survey cycle of 12.9 months. Prior to the Covid-19 pandemic and national emergency, the survey cycle average was less than the required 12.9 months. Frequently cited deficiencies included: failure to provide active treatment according to individuals' program plans (IPP), inadequate supervision of individuals receiving services, and inadequate staff training. In many cases, lack of adequate and appropriate active treatment and failure to provide the appropriate level of supervision stemmed from lack of sufficient staffing levels and inadequate staff training. Since the pandemic began, these issues have been exacerbated. Many ICF/ID facilities were stricken with staff and individuals receiving services testing positive for Covid-19. DIA conducted and continues to conduct focused infection control surveys in all facilities. Facilities are required to submit plans of correction for deficient practices and revisits are conducted by DIA to ensure return to compliance with the ICF/ID federal regulations and state rules.

The Department of Justice (DOJ) concluded an investigation in December 2020 into conditions at Glenwood Resource Center, one of the state operated ICF/ID facilities. It determined that there is reasonable cause to believe the conditions at Glenwood violate the Fourteenth Amendment of the U.S. Constitution and that these violations are pursuant to a pattern or practice of resistance to the full enjoyment of rights protected by the Fourteenth Amendment.

The department found reasonable cause to believe that Iowa subjects Glenwood residents to unreasonable harm and risk of harm by subjecting residents to uncontrolled and unsupervised

experimentation, inadequate physical and behavioral healthcare, and inadequate protection from harm, including deficient safety and oversight mechanisms. Specifically, the department concluded that the state violated Glenwood residents' constitutional rights by conducting experiments on them without their consent. The department found that one experiment, which involved overhydrating residents, caused physical harm. In addition, the department concluded that Glenwood residents receive constitutionally inadequate physical health care. The department found that residents fail to receive timely or clinically appropriate medical assessments or treatment, at times resulting in severe physical harm. The department also concluded that Glenwood's behavioral health care, including its use of restraints, violates residents' due process rights. The department found that, from 2017 to 2019, Glenwood's use of restraints increased by more than 300 percent. Finally, the department found severe deficiencies in the oversight and quality management at both Glenwood and the Iowa Department of Human Services and that these deficiencies fostered an environment in which the constitutional violations could and did routinely occur. The Department of Human Services has oversight of the state operated ICF/ID facilities and now must respond to the remedial measures required by the DOJ. The DD Council has been part of an advisory group formed by DHS to address some of the findings.

### ***The Adequacy of Home and Community based waiver services***

Iowa currently serves 66% of the long-term care population in HCBS services. The percentage gradually increases each year. However, Iowa had a relatively large decline in the LTSS rebalancing ratio from FY2017 to 2018. Iowa declined from 54.45 of LTSS expenditures for HCBS to 41.5 percent. This increase was due to increases in nursing facility per diem rates and increases in the number of beneficiaries receiving nursing facility services between FY 2017 and 2018. Iowa continues to be one of the few states running a Money Follows the Person program and still received federal funding and an enhanced match to transition individuals from facilities. To date, Iowa has transitioned 680 people out of ICF/IDs and 165 from nursing facilities.

The Intellectual Disability has a fairly comprehensive service package although does not include individuals who have a developmental disability diagnosis such as autism. Iowa does have six other waivers that a person with developmental disability may qualify for but the case management process, payments limits, services and other policies vary. Iowa has researched combining waivers into a more comprehensive overall waiver, but this effort has lost momentum over the years.

The following services are available under the Intellectual Disability waiver.

- Adult Day Care
- Consumer-Directed Attendant Care (CDAC)
- Day Habilitation • Home and Vehicle Modifications
- Home Health Aide
- Interim Medical Monitoring and Treatment
- Nursing
- Personal Emergency Response System
- Prevocational
- Respite
- Supported Community Living
- Supported Community Living – Residential Based
- Supported Employment
- Transportation

- Consumer Choices Option- self direction option

As mentioned previously, there are currently over 15,000 people on waiting lists for the seven HCBS waivers. People can wait over two years to obtain waiver services.

## **Rationale for Goal Selection**

Our Council voted to retain and expand upon our investments with our Advocacy goal, objectives and activities. Through our needs assessment survey, leadership skill building, advocacy training, mentoring opportunities and preparing individuals with disabilities to serve on boards and commissions rose as top priorities for the Advocacy goal. Health as a priority also rose to the top for self and family advocates, community providers and other community members. Health has not historically been a focus area that our Council has addressed. The Council chose to add this as priority under Advocacy and to assist people with advocating for their own health care needs.

Our Council also voted to retain and expand upon our investments with System Change with a focus on improving policy and practice. It was clear through our needs assessment survey and through our facilitated discussion with Council members that we should continue to offer public policy publications and resources such as infoNet and assist advocates with proposing new legislation and /or policy changes. During our facilitated discussion with Council members, it was discovered that there was a desire for our Council to take a stronger position with educating policy makers about specific policies and practices that have an impact on people with disabilities. As shared in the Comprehensive Review and Analysis, waiting lists for community services continue to grow. Educating policy makers on how the large waiting lists effect the lives of people with disabilities and their families is a priority for our council members and other stakeholders. Therefore, a new objective addressing this priority was developed.

The Council also chose to add a third goal area focusing on Capacity Building. The Council members believed that we were already investing in capacity building activities and there continues to be a need to provide training and technical assistance to promote inclusion in community living. Employment continued to be a top priority for the Council to address for Council Members, self and family advocates. The Council chose to continue the partnership with Vocational Rehabilitation and DD network to improve competitive outcomes. The Council also chose to partner and invest in other demonstration projects to be determined later that address other priority areas, transportation housing, assistive technology, health, education and emergency preparation.

Through our facilitated discussion and our needs assessment survey, it was also discovered that there are rural areas of our state that are not familiar with the Council and/or our resources. This is especially more evident with the underserved populations in our rural areas. The Council does not have a strong relationship currently with these populations. The Council chose to address this as our targeted disparity goal, with a focus to first develop relationships then see what advocacy needs they may have.

## **Collaboration**

The Iowa DD Network which includes the DD Council, The Center for Disabilities and Development (CDD) Iowa's Center for Excellence in Developmental Disabilities) and Disabilities Rights Iowa (DRI), Iowa's Protection and Advocacy) have historically collaborated in many arenas and mutual goal areas which include voting rights, accessibility and education, employment, community integration, youth and adult leadership trainings and mentoring programs. The DD Council currently has three formal projects with CDD that focus on retaining direct support professionals, providing mentoring and leadership opportunities, and hosting a youth leadership academy. Work on these projects will continue as goals for the next five years.

The DD Network have also worked together to be responsive to the needs of people with disabilities during the COVID-19 Pandemic. We provided education and outreach on safety precautions and the importance of being vaccinated, connected to do social check-ins, provided small grant opportunities to cope with social isolation and provided Personal Protection Equipment. If one DD network partner was taking the lead in an initiative, the other two partners would help communicate and market what was happening. The DD Network continues to meet frequently to discuss future options of collaboration for emergency responses such as this.

Both CDD and DRI provided input into the plan development. Both provided presentations to the Council on areas they suggested the Council prioritize. As mentioned, the DD Council will continue to collaborate with CDD on our leadership and mentoring projects. In addition, we are collaborating with CDD on the health advocacy objective. The DD Council, CDD and DRI will also be collaborating with educating people with disabilities to serve and be an active participant on boards and commissions. We also will be working assisting boards and commissions with being more inclusive. Department of Human Rights is also partnering with us on this effort.

DRI and the DD council will continue to partner on voting education, rights and accessibility. The DD Network will also continue to be part of the Employment First network along with Vocational Rehabilitation. The Youth Leadership Academy, an activity of our Advocacy Goal is a partnership between CDD, the DD Council, and Department of Human Rights, a local Center for Independent Living Center and Iowa's Parent Training and Information Center. The DD Council is more effective when we collaborate with other Iowa Disability network agencies.

## **Five-Year Goals and Objectives**

### **Goal One Advocacy: Develop Strong Advocates and Leaders Who Create the Change They want**

OBJECTIVE 1: Annually increase the number of Iowans with disabilities and family members who engage in the civic and political decision-making process.

OBJECTIVE 2: Annually increase the number of Iowans with disabilities— including young adults and their family members—who lead and mentor others and take on leadership roles in projects, coalitions, councils and boards that increase the inclusion of people with disabilities in community living.

OBJECTIVE 3: By 2026, increase the number of Iowans with disabilities who successfully advocate for their own health care needs

### **Goal Two Systems Change: Improve Policy and Practice that Positively Impacts People with Disabilities**

OBJECTIVE 1: Annually, target at least three key policy proposals (e.g. legislation, executive orders, or regulations being announced) to identify opportunities to educate policymakers about the impact of specific policies and make recommendations to ensure policies align with the principles of the Developmental Disabilities Act and the legislative priorities of the DD Council.

OBJECTIVE 2: With the use of DD Council resources, people with disabilities and/or their family members will annually propose new legislation and/or policy changes or about an issue important to them.

OBJECTIVE 3 (TARGETED DISPARITY GOAL): In collaboration with our DD network partners the DD Council will establish relationships with underserved populations of people with disabilities living in rural communities to increase those that use our DD Council tools and resources to advocate for priorities that address the needs in their communities.

### **Goal Three Capacity Building: Strengthen Communities to Support People with Disabilities**

OBJECTIVE 1: Through annual training, technical assistance, and resources, the DD Council will collaborate with the DD network, state agencies, and community programs to improve competitive employment outcomes for people with disabilities.

OBJECTIVE 2: By September 30, 2026, the DD Council will partner with the DD network, state agencies, and/or other community programs to invest in at least two projects to demonstrate new approaches to direct services, enhance systems, respond to emergent issues, or eliminate barriers to access and use of community services (such as transportation, housing, assistive technology, health, education, and emergency preparation).

## **Evaluation**

Over the next five years, the council will implement a multi-method approach to evaluate the plan and make changes as needed. Results of the methods used will inform the Council members as to which activities have been conducted, progress made on objectives, objectives that have been achieved, factors that have impeded achievement and results obtained.

Electronic surveys, hard copies surveys, focus groups and when appropriate face-to-face interviews will be conducted with attendees and participants of all Council supported (either DD Council staff supported, or grant supported) events trainings and conferences. In addition, all of the Iowans with Disabilities in Action network, our advocacy network as well as subscribers to our policy publication, InfoNet will be annually surveyed to determine their satisfaction with their participation in events, the resources made available to them, how they used the resources and if they resources helped them become a better advocates and/or leaders. We will also ask what further resources are needed to help

advocates stay engaged and be part of a greater system change and capacity building efforts. We will share all information obtained from these methods with Council members.

The council will also incorporate “qualitative” methods of evaluation of our activities. By using face-to-face interviews and focus groups we will collect the stories of people putting our training and/or using our resources and tools to practice and having advocating successfully for what matters to them. We will share success stories with Council members, other advocates, state and local leaders and legislators. We will also use this method to listen to what is not working and share this information with Council members and make changes to our activities as needed.

The Council’s Public Policy Manager will monitor policy, legislation and policy discussions in agencies and in other disability related councils, boards and advocacy groups to allow the Council to have access to issues and needed policy changes. Council staff through participation in various work groups and committees gathers information and data about trends in services and supports for lowans with Disabilities. Council members will also be a source of information about trends in services and needs in their local community and across the state. Information gathered will also assist the Council with updating the Comprehensive Review and Analysis.

The attached Logic Model will serve as our guide for evaluating the five-year plan and provides activities that will be measured the outputs as a result and the outcomes. Below are some examples of what has been identified:

*Goal: Self-Advocacy*

- Number of people engaged with our network of advocates, lowans with Disabilities in Action, and InfoNet-*Statewide Self-Advocacy element*
- Number of people who report (through surveys, face to face interviews, focus groups) that the DD Council resources and tools helped them to advocate for what they want and/or directly contact legislators
- Number of people who report that they helped others advocate on issues of importance as a result of Council support or training. *Leadership element*
- Number of people who report that they feel they are better leaders in their community as a result of Council training and/or or resources. *Leadership element*
- Number who reported voting in local, state and national elections as a result of training supported by the Council
- Number of people supported by the Council who trained others to vote. –*Leadership element*
- Number of people who reported being a member of disability coalitions, boards and commissions as a result of training or resources offered by the Council. –*Self-advocacy participation in cross disability and diverse coalitions*
- Number of people engaged in grassroots advocacy efforts as a result of Council support.
- Number of people who report advocating for their health care needs as a result of support from the support offered by the Council

*Goal: Systems Change*

- Number of policy changes or policies developed that are advocate driven as a result of Council support
- Number of legislative priorities developed, policy changes or policies developed with underserved populations in rural areas-*Targeted Disparity Objective*

- Number of educational and awareness documents developed for legislators by Council Staff, Council members, and those supported by the Council.
- Number of policy changes or polices developed that are Council staff driven and/or supported
- Number of decision maker and/or legislators that report that they were informed or knowledgeable about disability issues as a result of Councils work.
- Number of policy changes, or policies developed

Goal: Capacity Building

- Number of Community Rehabilitation Providers trained through Council support
- Number of employment success stories started with businesses, legislators and other stakeholders
- Number of people with disabilities who report learning more about employment options through events sponsored by the Council.
- Number of people that report positive outcomes by community inclusion demonstration projects supported by the Council.
- Number of lessons learned through community inclusion demonstration projects supported by the Council that lead to sustainable efforts for capacity building.

Our Council has not been actively engaged in evaluating progress on the state plan in a consistent basis. Going forward, Council staff, with the assistance from the Executive committee, will develop a plain language quarterly report containing all mentioned evaluation methods. We will share the quarterly progress report at each council meeting with the hopes of engaging Council members in robust discussion on amendments to the state plan needed and other areas that the Council should address.

## **Public Input and Review**

The DD Council approved the draft state plan Goals, Objectives and a few key activities at the March 2021 meeting for release for public comment. Public comment began March 12, 2021, and ended July 8, 2021 when the Council voted on the final version of the State Plan.

Notice of the public comment period was given through a variety of methods and resources. The draft State Plan was posted on the Council's website, along with a statement that it would be available in other formats upon request. People viewing the website were given an option to complete a survey about their thoughts on the plan or send comments via a dedicated email box. A link to the plan was also emailed and mailed on post card to everyone registered in our Iowans with Disabilities in Action Network. A link to the plan was also shared in our Iowa Advocacy Connection newsletter, three issues of our public policy publication InfoNet and the Department of Human Services Newsletter. Our DD network partners also shared via email and newsletters including the Autism Society, Iowa Coalition of Integrated Employment, Vocational Rehabilitation, Disability Rights Iowa and the University Center for Excellence in Developmental Disability. The link to the plan was also shared on social media 23 times. A press release was also released.

In addition, our Council hosted three listening sessions through webinars to receive public comment. One session specially reached out to the deaf and hard of hearing community. All three sessions provided an American Sign Language interpreter. Thirty-three people attended the sessions.

Overall, a majority of the comments received were positive and in agreement with the plan. A few comments asked for more clarification and detail. The Council Members reviewed the comments received during the May meeting. A few minor changes were made to the activities of the plan and to the Targeted Disparity Objective.

### Projected Council Budget

<b>GOAL</b>	<b>SUBTITLE B\$</b>	<b>OTHER</b>	<b>TOTAL</b>
<b>ADVOCACY</b>	<b>\$398,446</b>	<b>0</b>	<b>\$398,446</b>
<b>SYSTEMS CHANGE</b>	<b>\$123,446</b>	<b>0</b>	<b>\$123,446</b>
<b>CAPCITY BUILDING</b>	<b>\$63,869</b>	<b>0</b>	<b>463,869</b>
<b>GENERAL MANGEMENT</b>	<b>\$188,415</b>	<b>\$35,000</b>	<b>\$223,415</b>
<b>TOTAL</b>	<b>\$774,176</b>	<b>35,000</b>	<b>\$809,176</b>

### Assurances

Written and signed assurances have been submitted to the Administration on Intellectual Disabilities, Administration on Community Living, United States Department of Health and Human Services, regarding compliance with all requirements specified in Section 124 (C) (5) (A) in the Developmental Disabilities Assurance and Bill of Rights Act

Approving officials for Assurances: Council Chair Al Fagerlund

A copy of the State Plan has been provided to the Designated State Agency, Department of Human Services.