COMMUNITY INTEGRATION STRATEGIC PLAN
YEAR 1

October 2021

Iowa Department of HUMAN SERVICES

COMMUNITY INTEGRATION STRATEGIC PLAN: YEAR 1

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In 2020, the Iowa Department of Human Services (DHS) actively renewed and reinvigorated Iowa's commitment to serving individuals with disabilities in their homes and communities. *Building the Community 2020: Community Integration Strategic Plan* reflects actions intended to honor this commitment. The plan provides a vision for re-evaluating existing strategies and building new practices to ensure individuals with intellectual and developmental disability have access to the least restrictive setting to support high quality of life. DHS engaged in multiple conversations with stakeholders focused on presenting the vision and listening to the experiences of members, families and caregivers followed by integration of their feedback into planning and practice. DHS also engaged multiple stakeholders to develop and execute discrete action items identified in the Plan.

I. OVERALL PLAN PROGRESS

Throughout the planning process, stakeholders identified 108 actions necessary to implement meaningful Community Integration (CI). As of August 2021, just five of those actions were delayed. Of the 103 remaining items, 39% were complete, 48% were in progress, and 8% were being planned. The tasks were managed by key stakeholders who provided status updates during regular meetings.

DHS developed benchmarks for activities within the Plan and assigned a six- or 12-month timeline for completion. Progress on these benchmarks was impacted by the COVID-19 public health emergency and the need to develop the foundational structures within the system necessary to ensure forward progress.

All six-month benchmarks identified in 2020 were completed with either sustained or continued progress. These benchmarks represent procedural and process changes. As a result, six of 12 individuals identified will have been discharged by the end of October 2021.

Six Month Benchmarks	Current Status
Individual assessments remain on track.	Complete and Sustained
Individual meetings ongoing.	Complete and Sustained
Waves reconciled.	Complete and Sustained
First wave in active transition.	In Process
Key providers identified.	Complete and Continued
Reluctant guardian materials developed.	Complete
Admissions and discharge policies revised.	Complete
Listening sessions completed.	Complete and Continued
Iowa Association of Community Providers (IACP) meetings held.	Complete

Six Month Benchmarks	Current Status
American Federation of State, County & Municipal Employees (AFSCME) listening sessions held.	Complete
Quality assurance work plan complete with measurable objectives and deadlines.	Complete and Continued

The twelve-month benchmarks established in 2020 represented medium-term objectives related to systems change and were completed with either sustained or continued progress. Delays experienced in establishing new waiver homes and identification of legislative initiatives will result in those items being addressed during year two of the Plan.

Twelve Month Benchmarks	Current Status
Actively working on member transitions, new waiver homes established.	Planned and Delayed
All initial meetings related to transitions are complete.	Complete
Report of community gaps completed and distributed.	In Process
Legal structure in place for faculty positions and expansion of the Iowa's University Center for Excellence in Developmental Disabilities (UCEDD) role in supporting the community either through legislation or memorandum of understanding.	Complete
Project work plan for enhancing each activity identified in "Building the Community" section complete with measurable objectives and deadlines.	Complete and Sustained
Legislative initiatives identified and drafted for presentation.	Planned and Delayed

II. ACTIVE TRANSITIONS

The Active Transitions component of the plan outlined activities intended to support individual transitions to community-based settings.

Results After One Year

The work to improve Iowa's system for CI was tracked monthly throughout the year. There were 17 unique action steps identified with 18 stakeholder workgroups dedicating time and resources toward completing those actions. Of those, 82% were complete or in process.

Active Transitions Benchmarks	Current Status
Ensuring clinical and case management practices at the SRCs are promoting resident skill development and promoting community transitions to fidelity.	In Process
Partnering with MCOs and community stakeholders to collect information on strong community providers with a track record of successful transitions.	In Process
Approaching identified providers to assess what they need to successfully serve an individual.	In Process

Active Transitions Benchmarks	Current Status
Developing transitional or step-down programs.	Planned
Developing additional state-staffed waiver homes. Current direct support staff would have hiring preference and would bring needed skills and knowledge.	Delayed
Assessing common needs identified in the waves and collaborating with MCOs and community providers to develop new needed supports.	In Process

Progress has been made in promoting skill development for SRC residents. Individual and population-wide gaps have been identified and more work is needed to prepare individuals for independence when they move to the community. Wrap-around services and step-down programs have been discussed and supplemental funding has been secured by the Money Follows the Person (MFP) program to expand Systemic, Therapeutic, Assessment, Resources, and Treatment (START) programs. Collaborative Weekly Resource Center Rounds were established with each MCO to resolve barriers to transition on a case-by-case basis. While the establishment of new waiver homes has been delayed, the activity remains a focus of the group to be continued in 2022.

Stakeholders engaged in a targeted effort to reduce or remove barriers to provider enrollment in Medicaid. The group identified eight providers as having the capacity to promote community transitions. A universal application form was discussed along with options for collecting information about providers' specialization and ability to serve residents who are ready to transition. Assessing quality among providers is a next step.

III. BUILDING THE COMMUNITY

The Building the Community section of the Plan highlighted several activities aimed at increasing the development of robust community supports and equivalent services needed in the community.

Results After One Year

Stakeholder workgroups dedicated time and resources to address the action steps and the 10 activities articulated in the Building the Community 2020 plan with employment opportunities, meaningful day habilitation activities, building clinical expertise, implementation of evidence-based models, and stakeholder engagement at the center of the discussions.

There has been some progress in the areas of employment opportunities and day habilitation. Finding jobs for individuals has been a challenge given the impact of the COVID-19 pandemic and shortages experienced by community providers. However, stakeholders have identified success with the Individual Placement Support (IPS) model. In 2020, Medicaid and Vocational Rehabilitation developed a structure for equal funding of IPS services. In 2021-2022, the focus will be on building infrastructure and increasing access to IPS services.

The day habilitation rules were amended to clarify these services as a pathway to employment; add in provider training requirements; and clarification of the activities that may be provided to assist members to participate in the community, develop social roles and relationships, and increase independence. Day programming at SRCs was revamped and collaborative efforts were directed toward building supported employment opportunities and meaningful day activities.

Work related to expanding Iowa's Technical Assistance and Behavioral Supports (I-TABS) and START models has produced additional improvement. The I-TABS program resources have been

identified but the expansion is on hold in lieu of the need for additional psychology services for individuals living in SRCs. The MFP application submitted to the Centers for Medicare and Medicaid Services (CMS) on June 30, 2021, focused on having grant opportunities for providers to expand Iowa's START program in sites throughout the state. Funds will be awarded in the spring of 2022.

DHS executed an MOU with the Iowa's University Center for Excellence in Developmental Disabilities (UCEDD). Through this MOU SRCs have access to expanded consultation and peer review. A one-year planning grant was awarded for Transition Resources for Adult Care for Health. In addition, In August 2020, Director Garcia signed an agreement to establish a residency program with Broadlawns Medical Center. As of March 2021, four psychiatry residents have been engaged and increased community provider-physician relationships have been a positive outcome. There has been limited progress to engage clinical specialty providers for consultation in the SRCs and the development of faculty relationships at the UCEDD.

Twelve stakeholder engagement sessions have been held and will continue to be held into the future. The investment of ARPA funds during FY2022 will focus on building the workforce and provider capacity. Alternatives such as remote monitoring and increasing assistive technology utilization will also be explored.

Building the Community Activities	Current Status
Expanding supported employment initiatives.	In Process
Developing additional regular or customized employment opportunities in the general workforce.	In Process
Developing meaningful day activities for persons for whom supported employment is not suitable.	In Process
Expanding the I-TABS program for providing behavioral consultation.	Planned and Delayed
Expanding START crisis prevention and intervention services statewide.	In Process
Exploring consulting relationships for other clinical specialties within the SRCs.	Planned
Developing faculty positions at UCEDD.	Planned
Entering into an MOU with UCEDD to expand the State's access to content experts and specialized services.	Complete
Creating a training agreement or rotation at Broadlawns Medical Center to train more specialists.	Complete
Continue to partner with AFSCME to understand the needs of the direct support workforce	In Process

IV. SUMMARY OF STAKEHOLDER FEEDBACK

The DHS team participated in conversations throughout 2020 and 2021 focused on outlining Iowa's renewed commitment to serving individuals with disabilities in their homes and communities. DHS presented the Plan overview in public meetings and actively engaged with stakeholder questions and comments. In that process, DHS also received feedback from individuals and families who shared their experience stories and suggestions for improvement. DHS takes stakeholder feedback seriously and believes in addressing problems or concerns by working collaboratively and openly.

DHS is committed to working with and lifting up experiences of individuals and families to continue to guide our efforts. Many of the comments were candid, but they are vital in helping DHS better understand both the perceptions and realities for our stakeholders throughout Iowa.

WORKFORCE

- Workforce shortages are at a crisis point limiting the ability of providers to meet the needs of Iowans presenting for care and support.
- Many Behavioral Health (BH) and Long-Term Services and Supports (LTSS) providers report they are unable to offer competitive wages and benefits to recruit or retain employees.
- There are not enough available workers to meet current demand.
- Demand for workers is expected to increase as more Baby Boomers age into LTSS.

> “My brother has lived in the community with very negative outcomes. When he was in the community, he did not have trained staff that knew how to redirect his attention or even recognize his irritation. He was arrested twice for disorderly conduct.”

TRAINING

- Training resources are both limited and fractured with no required curriculum for LTSS providers.
  - LTSS providers note high quality training is a significant expense.
- Current provider registry information is not easy to use, especially for those seeking individual service providers (such as CDAC or CCO).
- Information about LTSS provider training, quality, and outcome data is not easy to find or understand.
- Many reported relying on friends, family, and neighbors, as well as social media and message boards to find well-trained providers.

PROVIDER CAPACITY

- Workforce and training limitations are seen as factors limiting LTSS provider capacity.
- Some stakeholders expressed a lack of confidence that community-based providers can meet high levels of need.
- Home and Community Based Service (HCBS) options to support Iowans with high intensity, specialty care needs, such as co-occurring Intellectual and Developmental Disability (I/DD) and BH needs, are limited.

A lack of options for children was noted across levels of care.

No residential service option under the Children’s Mental Health (CMH) waiver.

There are no providers for CMH waiver services in some areas of the State.

There are few Intellectual Disability (ID) waiver providers for children’s residential services.

Psychiatric Medical Institutes for Children (PMIC) have waiting lists and rarely accept children with lower IQ’s (co-occurring Serious Emotional Disturbance (SED) and I/DD).

Children with high intensity needs are living in shelter care for months waiting services.

Inpatient acute psychiatric care for children is limited. At times, there are no beds available in Iowa.

Providers focused on treating substance use, misuse, and addiction in youth are limited; experts who focus on treatment services for youth have restricted access to funding through Iowa's Substance Abuse Prevention and Treatment Block Grant.

- Care continuum gaps for adults are also described as significant.
  - Iowa lacks step-up / step-down services and long-term, clinically supervised residential options for those diagnosed with Serious Mental Illnesses (SMI) and / or multi-occurring disorders.
  - Gaps in the care continuum result in long stays at Mental Health Institutes (MHI) or other hospital inpatient psychiatric units waiting for community-based care.
  - LTSS and BH providers equipped to address BH needs for individuals with I/DD are rare.
  - There are limited options for those with BH and/or I/DD related needs who also have a history of aggressive, self-injurious, or sexualized behaviors, or those on the sex offender registry.

    Options are more limited if individual is also an older, frail adult in need of nursing facility care, leaving Department of Corrections, or a court-involved juvenile.
- Providers supporting older adults often lack training and capacity to support those with BH needs, especially if those needs are related to SMI diagnoses. Providers able to support older adults with BH needs are rare.
- Employment for individuals with BH, aging and / or disability related needs is limited.
- Effective diversion activities identifying and targeting interventions for individuals at risk of becoming incarcerated, hospitalized, or institutionalized are limited. Intervention too often comes too late at great expense.
- Prevention and early intervention services are lacking, increasing pressure and expense in crisis intervention and LTSS. Stakeholders expressed a desire to devote resources to "go upstream" or "build fences" to prevent crisis and divert long term care needs.

> "Where do we go for assistance? The psychiatrists in our area do not want to work with people with the ID diagnosis. They say they are not amenable to treatment."

DATA-DRIVEN DECISION MAKING

- Transparency and public accountability could be improved by making data more accessible.
- Use of data in meaningful ways to drive decisions was cited by many as an opportunity.
  - There is concern among some stakeholders about the validity and reliability of self-reported data.
- Concern about a lack of transparency, accountability, and results in LTSS left some stakeholders feeling defeated by a complicated system that didn't deliver what they expected.
- Access to meaningful, outcome-focused data was seen as an opportunity to support informed decision making.
- Increased transparency about LTSS provider performance, such as involuntary discharge from residential services or members who report an improved quality of life, was also seen as an opportunity to improve informed decision making.

> "Why aren't these providers being held accountable? My son's case may not be severe, but it still is heartbreaking that all he does is sit in his room when they are supposed to be helping him with life skills. I have a year and 4 months' worth of Therapy and nothing is documented that comes close to his ISP."

COMPLICATED SYSTEMS and RELUCTANT DECISION-MAKERS

- Iowa's HCBS waivers offer different service options, rates, and limits based on diagnosis.
  - Oversight falls under multiple state departments, divisions and bureaus resulting in different regulatory interpretations, complicating navigation, and requiring significant effort to comply with different rules and guidance.
- There has been no meaningful reduction of census at Iowa's State Resource Centers in years.
  - Reluctant decision-makers are the most cited barrier to returning individuals to community-based services.
- Layered LTSS systems feel confusing to individuals, families, and decision-makers which contributes to uncertainty and reluctance in decision making.
- Negative provider and member experiences with denials and service reductions, as well as a lingering sense of unpredictability, have led to a lack of trust amongst some prominent voices in Iowa's LTSS communities fueling decision-maker reluctance.

> "We have continued to experience families reaching out in a crisis with their child who is diagnosed with an intellectual disability, (meaning an IQ under 70) and/or a developmental disability such as Autism Spectrum Disorder. These families are often seeking immediate help and support, whether that be in the form of out of home placement or community-based services. Unfortunately, these services are difficult to access, families often hit barriers with funding the services, and these programs often have extremely long waiting lists."

- Family caregiving is not well supported. Some care givers worried they are viewed as "free labor".
  - LTSS Case Management lacks consistent definition and oversight.
- Stakeholders continue to express concern about the loss of Targeted Case Management (TCM) and a view that case management within MCOs creates a conflict.
  - Some LTSS service recipients and their families report they're "resigned" to MCO case management, but not satisfied; though, many also report they like their assigned case manager.
- Policy and procedure guiding the coordination of transitions and multiple systems is limited.
  - The roles between multiple parts of DHS, MCOs, and providers are unclear.

    At times, the lack of clear roles and responsibilities slows action.
  - Support to access and maintain non-Medicaid funded support is limited.

    Some expressed concern that MCO case managers are not trained to connect to resources and funding other than Medicaid.
  - Having multiple "case managers" is confusing to service recipients, families, and decision-makers.
- LTSS and BH funding decisions are unpredictable, unequal, and / or unfair.
- Inconsistency between Iowa Medicaid and MCO payers contributes to uncertainty for providers, service recipients and decision-makers.
- Perverse incentives contribute to the view held by some that LTSS case management within MCOs lacks the urgency or ability to secure services by design.
- Uncertainty about reliable funding and a lack of accountability delays access to care.

> "I'm very worried for her safety. My pleas might be heard but don't get acted upon. We haven't even been successful on getting a sound alarm on her window to at least notify staff if her window is opened in the middle of the night. I feel helpless."

    - There is no clear expectation of case managers or payers when there is a denial of a residential service but, no alternative secured.
    - Hospitals express concern that they are not paid for care while a patient is waiting other residential options; delays cause capacity to be stretched and limits overall availability.
- The role of the Mental Health and Disability Services (MHDS) Regions and how the Regions fit into the overall BH and LTSS system has changed over time and feels uncertain to some stakeholders.
    - MHDS Regional funding decisions vary and are, at times, unpredictable.
    - There are concerns that eligibility requirements and available services change from one Region to the next.
    - Funding decisions about optional services are made on a Region-by-Region basis.
    - Some stakeholders are concerned that Core and Mandatory services don't reflect the true needs of the MHDS system today.

V. SUMMARY AND NEXT STEPS

DHS is committed the work outlined in the Plan, which includes public facing progress updates, analysis of data to better understand gaps and drive decisions, and continued engagement with stakeholders to discuss successes and challenges. The addition of Town Hall Meetings beginning in October 2021 will how outline investments made from American Rescue Plan Act will enhance and strengthen Iowa's systems of community-based services and supports to meet our needs today and to be prepared to meet the needs of our future.

Substantial progress was made in year one. In year two this progress will be expanded and maintained. We've identified five key areas of focus: *Workforce, Training, Community provider capacity for specialty supports, Data, and Guardian reluctance.* Moving forward we will progress from transactional to transformational work. We will focus on outcomes that align to our vision, discreet identification of short-term, mid-term and long-term solutions in each of the identified focus areas, ongoing engagement with stakeholders, and leverage the significant opportunities to invest in community-based services via strategic use of ARPA funds. The goal will continue to be sustainable transformation; and collaboration that centers the experiences of Iowans living with disability related challenges will remain a pillar of this work.