JB Pritzker, *Governor*

Grace B. Hou, *Secretary*

Developmental Disabilities
600 East Ash • Building 400 • Springfield, IL 62703

July 14, 2023

Dr. Kari M. Wolf
SIU School of Medicine Professor and Chair, Department of Psychiatry,
CEO of the Behavioral Health Workforce Center

RE: SIU School of Medicine's (SIU SOM) Choate Transformation Report, Phase One

Dear Dr. Wolf,

I would first like to thank you and your team for being a partner in the Illinois Department of Human Services' (IDHS) efforts to transform the Choate Mental Health & Developmental Center (CMHDC) and IDHS's other State-Operated Developmental Centers (SODCs). Your work, analysis, and report serve as important input and strategies for us to knit into the fabric of the comprehensive activities already underway. We appreciate the recommendations submitted by SIU SOM and will be reviewing them closely. Part of that review will be continuing discussions with both SIU SOM—as they continue their important, expert advisory work on the transformation—and with other stakeholders in this vitally important area.

Throughout my career working with individuals with intellectual and developmental disabilities, I've seen firsthand how complex the system of care is. This report recognizes that complexity and helps us to continue our work of transforming the system to better serve and support each and every individual. As the new Director of the Division, I am also visiting facilities and meeting with both leaders and frontline workers to continue to learn more.

I know that we will continue to have more conversation, but I wanted to take the opportunity to provide you with an update on some of IDHS's work, to date, many of which align with SIU SOM's recommendations:

Clinical Operations
Eleven Choate residents have transitioned out of the facility, and significant investments are being made to ensure that, over a 3-year period, over 100 more can successfully transition to the living arrangement of their choice, including waiver-funded settings such as Community Integrated Living Arrangements (CILAs), Home Based Support Services (HBS), and Community Living Facilities (CLFs), as well as long-term care facilities such as Intermediate Care Facilities (ICF-DDs) and other SODCs. Several residents are also participating in pre-transition stays outside of Choate before they decide where to live more permanently.
Unprecedented investment in Home and Community Based Service Capacity has been made. Additional beds serving individuals of all abilities are being made available in Southern Illinois and across the state, thanks to the highest-ever State investments in

CILA (group home) settings and wage reimbursements for front-line workers in the community-based DD service ecosystem.

Culture of Safety
Enhancing the culture of safety, accountability, and quality care is our top priority. In March, IDHS hired a Chief Resident Safety Officer to outline a new, robust Safety Plan to improve and ensure long-term quality and safety infrastructure in all SODCs. IDHS is in the time-intensive (and, as SIU SOM notes, incredibly important) process of procuring an Electronic Health Record that will enable us to better serve individuals in our care. IDHS is also installing indoor and outdoor video cameras in common areas across the CMHDC to further enhance security and safety for residents and staff and to better achieve high quality policies, practices, and environments. With the goal of having them at all SODCs.

PA 103-76 (Fine/LaPointe), a bill signed by the Governor, championed by the IDHS Office of the Inspector General, and supported by IDHS, removes employees who materially obstruct investigations into abuse or neglect from the being able to work at our SODCs or in any other healthcare setting. We believe that this measure will deter additional misconduct and encourage full and appropriate cooperation in reviews into abuse or neglect at State facilities.

Workforce Development
Sufficient permanent State staff is key to providing quality services to individuals at Choate and to ensuring that everyone is safe and supported. While we are contending with a nationwide shortage of healthcare staff, the department has been filling existing vacancies through continuous postings of jobs, broadly advertising available jobs, hosting on-campus job fairs to allow potential employees to apply in real time, working with the State's Department of Central Management Services to speed up the hiring process to onboard employees as quickly as possible, and increasing the starting wages for new employees.

The ongoing care, health, and welfare of individuals with developmental disabilities remains our top priority, and we will continue to work diligently to provide the highest quality care, supports, and programming. We very much thank the Southern Illinois University School of Medicine for their assistance in helping us to transform the system of care for individuals with developmental disabilities in Illinois and look forward to continuing to partner in that process.

Sincerely,

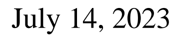
Tonya Piephoff
Director
Division of Developmental Disabilities

Choate Transformation Report
Phase One

Submitted by
SIU School of Medicine
Kari M. Wolf, MD

July 14, 2023

SIU SCHOOL *of* MEDICINE



July 14, 2023

Via Email

Secretary Grace Hou
401 S. Clinton, 7th Floor
Chicago, IL 60607
Grace.hou@illinois.gov

Dear Secretary Hou:

In March 2023, Southern Illinois University School of Medicine (SIU SOM) and the Illinois Department of Human Services agreed to partner on transformation efforts at Choate Mental Health and Developmental Center (CMHDC). SIU SOM agreed to review programs and services offered at CMHDC and make recommendations to address safety concerns, repurpose the CMHDC campus, improve access to services in the community and region for people with developmental disabilities and those with mental illness.

Over the past four months, SIU SOM has met with community leaders, staff, advocates, and state and community-based organizations to gather input on potential areas of improvement on the campus. SIU SOM has reviewed current operating practices, workforce needs, needed campus upgrades, and safety measures. Please find attached a series of recommendations for your consideration. SIU SOM commends DHS for their leadership in transforming services at CMHDC and hopes this report will assist in your efforts.

Sincerely,

Kari M. Wolf, MD
Chair, Department of Psychiatry
Co-Executive Director, SIU Neuroscience Institute
CEO, Illinois Behavioral Health Workforce Center

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Executive Summary

The Choate Mental Health and Developmental Center (CMHDC) in Anna, Illinois, has been serving individuals in need of mental health and intellectual and developmental disability (DD) services since it was opened in 1873. Over the past two decades, CMHDC has experienced a number of allegations of abuse and neglect which have been investigated by the Office of the Inspector General (OIG) for the Illinois Department of Human Services (DHS).

On March 8, 2023, at the request of DHS Secretary Grace Hou, Southern Illinois University School of Medicine (SIU SOM) Department of Psychiatry partnered with the Illinois Department of Human Services (DHS) to support the transformation of Choate Mental Health and Developmental Center as part of a critical DD system transformation initiative that will take place over the next three years. This report does not address DHS's decision to close existing DD units at Choate.

The role of SIU SOM in the CMHDC Transformation Program is defined in three phases.

- Phase One involves making recommendations (this report) regarding the repurposing of the Choate campus and is to be submitted to DHS by July 14, 2023.
- Phase Two involves making recommendations to address individuals receiving care and staff safety on the Choate campus and is to be submitted to DHS by December 31, 2023.
- Phase Three, to be developed over the next 2-3 years, involves making recommendations regarding the statewide systems of care needed to support individuals with intellectual and developmental disabilities as well as those with serious mental illness.

The methodology for this Phase One report included SIU SOM conducting interviews with individuals and organizations (see appendix A), reviewing reports, touring facilities on campus, and identifying best practices from scientific literature and other states to address the transformation of CMHDC. SIU SOM conducted interviews with employees, community leaders, legislators, CMHDC administration, DHS leaders, OIG, Equip for Equality, and various community-based organizations in the region. SIU SOM met with leaders from other State Operated Development Centers (SODCs) in Illinois to gain an understanding of effective processes and procedures being implemented in other SODCs.

As a result of interviews, recent reports, and a best practice search, SIU SOM has identified the following key recommendations to improve CMHDC's clinical operations, culture and safety, workforce needs, and campus redevelopment.

Key Recommendations for Clinical Operations

Build out a comprehensive continuum of care to reduce reliance on institutionalization. Maintain certified, specialized, and limited DD units in the short term; maintain forensic DD units; expand step-down and civil mental health units; and add forensic mental health units.

- DHS and CMHDC should strive to partner with other state agencies and community providers to build a system of care that reduces reliance on institutionalization for individuals with DD and/or mental illness.
- Create a continuum of DD and mental health services (including short-term and permanent supportive housing programs in collaboration with a third party) on CMHDC campus so more individuals can successfully transition to less restrictive settings.
- The current Dual Diagnosis units should continue to exist in the short term, but with closer alignment to other SODCs with competencies to treat dually diagnosed individuals under existing DD structure.
- In the long-term, DHS should explore the feasibility of making the CMHDC campus *the* exemplary campus for transitioning individuals to community-based care.
- The existing forensic DD unit and step-down unit should remain on CMHDC campus. Step-down services should be expanded to a less restrictive setting on campus such as the cottages or other supportive housing arrangements.
- CMHDC should consider expanding inpatient forensic and civil mental health services on the campus.
- DHS should strive to have all units at SODCs and SOPHs certified.
- Increase specialized services (assistive technology, trauma-informed care, substance misuse treatment, behavior analysts, psychotherapy) to individuals at remaining CMHDC units.
- Relocate non-clinical programs/offices out of the cottages such that they can be utilized for step-down care for individuals receiving services at CMHDC.
- Separate the budget, leadership, and oversight role for SODC and SOPH services on CMHDC campus and allow for more DHS Division of Mental Health (DMH) involvement in the delivery of psychiatric services.
- DHS should conduct a review of Choate’s admission and discharge processes to ensure alignment with state requirements and incorporate best practices learned from other SODCs.

Preliminary Recommendations for a Culture of Safety

Assess safety protocols for individuals remaining on campus and establish a culture of safety as part of a comprehensive safety program.

- DHS must expedite the implemention of an Electronic Health Record for all SODCs and SOPHs.
- CMHDC should create a systematic culture of safety and implement a comprehensive safety program.
- CMHDC should streamline the process for implementing medication changes more quickly once the order has been written.
- CMHDC needs a continuous, consistent, evidence-based training program for its staff, individuals receiving care, and administration.
- CMHDC should improve communications processes regarding individual status updates and behavior changes with families and guardians.

Key Recommendations for Workforce Needs

Preserve and retrain the existing workforce and establish pathways and professional development programs to grow the clinical workforce in the area.

- With the planned closure of the DD units at CMHDC, the existing workforce from those units can be maintained and retrained to work on remaining units at CMHDC. This should decrease the need for temporary/travel workers and mandatory overtime.
- CMHDC should review staff assignments to ensure people are working at the top of their licenses.
- In partnership with Central Management Services (CMS), DHS should investigate the option for on-site workers' compensation process to evaluate, treat, and return healthy workers to the workforce more quickly.
- In partnership with OIG and Illinois State Police (ISP), CMHDC should expediently and thoroughly investigate staff accused of abuse and neglect such that staff can return to their assigned duties more quickly when allegations are unsubstantiated or do not warrant action.
- CMHDC should establish workforce development programs that bring learners to campus for some or all of their clinical rotations; up-train, retrain, and build career ladders for current CMHDC employees; and create pathways for high school, community college, university, professional, and technical school students to easily move into positions at CMHDC upon graduation.
- Explore development of post-graduate, clinical training programs for professionals (psychiatrists, psychologists, licensed social workers, etc.) to gain significant portions of their clinical experience on CMHDC campus. These programs can be developed in partnership with accredited training programs in the region/state.

- DHS should explore developing partnerships with rural residency and fellowship programs across the state to enhance not only the current workforce but also aid in the development of its long-term workforce.
- Develop a partnership between CMHDC leadership, people of Anna, IL, and the Illinois Commission on Discrimination and Hate Crimes to address and discuss any potential underlying issues surrounding race in the community. Such improvements may bring larger candidate pools within the CMHDC workforce.
- In partnership with CMS, DHS should advocate for more streamlined processes for hiring with emphasis on timeliness, local input into candidate selection, and identifying applicants with a passion for working with individuals served at SODCs.

Key Recommendations for Campus Redevelopment

Redevelop spaces to accommodate community-based services, crisis stabilization centers, regional offices for state agencies, and services to support individuals living in the community.

- DHS should build upon the success of the Division of Family and Community Services' eligibility call center to develop a comprehensive Community and Family Resource Center on CMHDC campus.
- DHS should continue to explore the feasibility and development of creating a state-wide training program for Mental Health Technicians.
- CMHDC should explore partnerships with organizations to bring safe and affordable childcare to CMHDC campus.
- Explore partnerships with state and federal programs to bring safe, affordable housing to CMHDC campus.
- CMHDC should partner with community members, community leaders, and leadership from CMHDC to rebuild connections and programs on CMHDC campus that draw people from the region to the campus and provide community benefit for people from Anna and the region.

Background

CMHDC serves people with mild to profound intellectual disabilities and people with mental illness. CMHDC offers a variety of treatment programs/services including but not limited to: psychiatric/psychological, medical/physical, social, educational, vocational/rehabilitation, recreational, speech, language and hearing, pharmacy, dental, and dietary services, and referrals and special consultations. Staff at CMHDC include Nurses, Social Workers, Dietary Staff, Mental Health Technicians, Activity Therapists, Psychiatrists, General Physicians, Psychologists, Buildings and Grounds, and Security staff.

CMHDC was chartered in 1869 and opened in 1873. The majority of the buildings currently occupied by individuals and patients were constructed between 1950-1965. The center is located on the northeastern edge of Anna, Illinois, in Union County. CMHDC has six buildings for individual care, treatment, and habilitation. Additionally, the campus maintains a hospital for the acute psychiatric treatment of patients. The campus also includes Family and Community Services (FCS) office, which provides eligibility services for both on-site and call center requests and is currently in the process of expanding as well as spaces for the OIG, and Office of Rehabilitative Services (ORS).

Clinical Operations Recommendations

Developmental Disability Services

Continuum of Care

CMHDC has a long history of partnering with the Anna, Illinois, community to better the lives of individuals with developmental disabilities. The current workforce programs in Anna and in the surrounding areas could be expanded to benefit individuals receiving care at CMHDC. The CMHDC campus has historically hosted work-based programming and entertainment that benefits both the individuals with DD being served as well as the community. Examples include the greenhouse plant sales and the café.

As a long-term plan, SIU SOM recommends DHS explore the feasibility of making the CMHDC campus *the* exemplary campus for transitioning individuals to community-based care by developing a plan to move away from residential units towards short-term crisis stabilization units with expanded community-based resources such as CILAs, permanent supportive housing, day programming, assisted work programs, etc. with the help of third party. Such a recommendation will take several years to effectuate but this would reduce the reliance on institutionalization for those individuals who could successfully live in community-based settings. Current individuals with developmental disabilities who reside at CMHDC would be evaluated to determine in partnership with families and guardians whether they can and choose to successfully transition to the community-based programming being developed in the area or

whether they continue to require a SODC level of care and would need to transition to another SODC.

Interviews with several community providers indicate difficulties in accessing DD services for individuals who need the higher level of care currently provided at CMHDC. The lack of community-based services in the region contributes to the reluctance of agencies to accept people from CMHDC into community-based settings. SIU SOM recommends that DHS work collaboratively with mission-aligned community providers to develop a full continuum of care for individuals in need of DD services on the campus of CMHDC and in the region. Providing a continuum of services would allow more individuals to successfully transition into the community as there would be ready access to the services necessary for that successful transition. Furthermore, it would help ease the transition into and out of the higher level of care provided by the current services on the CMHDC campus. In addition, CMHDC should develop a more transparent and streamlined intake process that engages families in the development of an individualized care plan for the individual receiving care. Assessment services need to be more readily available in the region to properly place individuals in the right care setting.

To prevent potential admissions at SODCs, DHS should invest in a care coordination program that incentivizes both SODCs and Community Integrated Living Arrangements (CILAs) to work together with families in need of MI and DD services in Southern Illinois to identify options for families to care for their family member in a community setting. DHS would need to provide financial incentives to support these prevention services. Workforce development programs in the region would help to expand access to services for individuals and their families.

Transition planning

Development of crisis stabilization services at CMHDC and in the region to support individuals in distress would prevent readmissions to CMHDC and allow them to return to a community-based setting. Expanding habilitative services, day programs, and vocational services at CMHDC would support individual care plans and movement toward the goal of residing in the least restrictive setting.

CMHDC needs to prioritize short-term stays and develop a transition program that is implemented from day one of admission. Transition planning and support services at CMHDC need to focus more sharply on the individual's goals and status to create a transition plan that meets their needs from pre-admission to discharge. Another Illinois SODC has an exemplary transition program with a <1% recidivism rate for individuals receiving care who move to community-based settings. While all SODCs are required to have a transition director, one facility in particular has a transition director who actively engages the individuals, family members, and community-based agencies in the transition planning. Leadership attributes their success to "a transition director who is constantly out talking with individuals receiving care and their guardians, to understand their goals and what they want out of life." Their process is to work with the unit social worker and guardians about goals and talk with staff in CILAs pre-,

during, and post-transition. Transitions are very slow starting with a lunch visit and gradually introduces the individual receiving care through an overnight visit, a 7-day visit, and a 14-day visit before fully transitioning to their new home. The transition director provides ongoing follow-up visits post-transition.

To successfully transition the individual receiving care, SODCs and community-based agencies need to prepare the new home to be as similar as possible to the one they are leaving and make sure it is ready for when they arrive. To ease the stress of relocation, the new room should be set up similarly to their former room, a roommate with similar interests should be chosen, and favorite foods, activities, and routines should be set up similar to those at their former home.

Improvements to the transition process at CMHDC should include regular and consistent visits by the individual receiving care and their families to introduce them to their new environments and ensure their new room, daily schedules, food and roommate preferences, day and vocational service options, and other support services are as similar as their previous environments as possible. CMHDC staff should be trained to perform follow-up visits to community-based settings and to other SODCs that receive individuals from CMHDC. Another Illinois SODC also provides extensive follow-up to community-based agencies to support the needs of the new staff working with a transfer. SIU SOM recommends that DHS create an ECHO web-based training and skill-building program on transition processes and goals for all SODCs that allow SODC transition directors to meet regularly and share best practices and lessons learned in an all-teach, all-learn environment. Evaluation criteria and benchmarks for transition programs within all SODCs should be created and assessed regularly.

SIU SOM also recommends that CMHDC and local community-based agencies that receive referrals from CMHDC develop and participate in a 12-month discharge monitoring program for individuals receiving care that includes weekly monitoring for the first month and monthly monitoring for the following 11 months. While this is already required, SIU SOM recommends that the monitoring be in person or via videoconference if in-person is not possible. The state should require documentation of the frequency and outcomes of the monitoring sessions.

Currently, staff have close bonds with many of the individuals receiving care at CMHDC and their guardians and families. Although working closely with individuals, their families, and guardians is important for staff, those close personal bonds may impact the individual's length of stay and create barriers to discharge. CMHDC should build upon the existing DD Code to ensure clear discharge criteria, processes, and procedures are consistently applied across all individuals receiving care at CMHDC. Furthermore, DHS should consider an external Utilization Review process or oversight to improve the discharge/transition process. CMHDC should set a culture from the time of admission that the goal is to transition individuals receiving care to the community with as much independence as possible and ensure that the staff, individual, and guardian understand and work toward that goal. CMHDC may want to consider not calling people who receive 24/7 services "residents" as that subliminally sends the message to everyone (individual receiving care, guardian, staff) that the person will be there forever. The goal should be a successful transition to community settings for as many people as possible.

Training Programs/Professional Development

SODCs currently develop their own training programs to meet identified gaps in the state-required training programs. This supplemental, site-specific training is piecemeal and varies in quality. DHS should create a central repository of these supplemental trainings that are not necessarily pertinent to every facility but to ensure that all facilities who need training in a particular area are receiving the same, high-quality training to provide the foundation of information and skill-building needed for staff serving SODCs in Illinois. Furthermore, the required trainings should be reviewed to ensure they are meeting the new and emerging needs that are consistent across all facilities. For individuals with intellectual and developmental disabilities at CMHDC, there is an additional need for DD staff to be trained on mental illness and trauma. Training programs at CMHDC should also include training for direct-line staff to appropriately document any behavior changes in the record of the individual receiving care and communicate those changes to their guardian. DHS should monitor and ensure consistent utilization and documentation of the behavior monitoring and tracking program for individuals receiving care at CMHDC.

SIU SOM recognizes that individuals who work in SODCs are in the job classification of mental health technicians (MHT). For purposes of this report, those individuals are referred to as Disability Support Professionals (DSPs). DSPs are a nationally recognized group of professionals who bring certain skills and responsibilities to the work they perform. As such, SIU SOM believes those trainings, skills, responsibilities, and opportunities for career progression should be provided within the SODC setting.

There is a need for more training and increased salary for DSPs who serve as the front-line staff providing direct care to individuals with disabilities. Improving the level of training, reimbursement, setting accountability standards, and benchmarking performance measures for DSPs will have a direct impact on the quality of care provided at CMHDC. It is also important for DSPs to have a career path that allows for promotion opportunities to become trainers, mentors, or supervisors of DSP services at CMHDC. This could address employees who may feel "stuck" in their current position and decide to leave CMHDC for other professional opportunities.

In addition to behavior monitoring and documentation, there is also a need for additional programming by behavior analysts on the DD units to improve behavior so that individuals receiving care are able to transition to a less restrictive environment.

In order to make these transitions to community settings possible, there will need to be an expansion of community-based agencies, such as Community Integrated Living Arrangements, that are prepared to provide care for individuals transitioning out of CMHDC. That may require the recruitment of new providers in the region and the expansion of existing providers to ensure access and capacity for the individuals. Providers will need increased reimbursement rates for individuals transitioning from an SODC to offset the additional labor costs, training, and quality

improvement processes to support individuals that may require a higher level of care. Staff supporting individuals in community-based settings will need training to manage individuals with special needs such as mental illness, trauma, and grief from the loss of their friends and staff at the SODC. SIU SOM recommends that DHS review and assess existing training programs for CILAs to ensure high-quality care delivery and build the workforce for the region.

For individuals transitioning to another SODC or community provider, DHS should develop a trauma-informed protocol for addressing potential mental health needs associated with fear, anxiety, and panic.

The CMHDC administration should ensure assistive technology is available to people receiving services within CMHDC (Southern Illinois Centers for Independent Living [SICIL] may be able to assist with evaluations and access to technology).

SIU SOM agrees with several interviewees that recommended the creation of transitional homes on the CMHDC campus to prepare individuals for their transition to a smaller group home environment. These homes can be state-operated or a public-private partnership with state oversight. There are several organizations that create and monitor short-term stabilization programs (90 days) that could support the development of such programs on the CMHDC campus as an alternative to SODC placement.

Other Initiatives

DHS should explore the creation of CILAs for "hard to place" individuals, such as sex offenders, to ensure transitions for all. Specialized CILAs would receive specialized training, funding, and staff supports.

SIU SOM recommends the expansion of respite programs for caregivers of individuals with DD who are maintaining the individual in their homes.

There is also a need to increase Substance Use Disorder (SUD) services in the DD unit to support the increasing numbers of individuals admitted to SODCs across the state with co-occurring substance use and misuse disorders. This population of predominantly younger adults with intellectual disabilities in the mild range presents with vulnerabilities and treatment needs above and in addition to those seen in the general population.

Mental Health Services

Dual Diagnosis Units

In the short-term, SIU SOM recommends the discontinuation and conversion of the Dual Diagnosis Units on the CMHDC campus for several reasons. First, there is no evidence that the patient population on these units is markedly different from new admissions coming into other SODCs around the state. In interviews with leaders at other SODCs, SIU SOM was told that ~60% of the individuals receiving care at some facilities are dual diagnosis, primarily younger patients with mild or borderline DD or Autism Spectrum Disorder who have MI as their primary clinical condition. Studies have indicated that mental illness occurs in 40-60% of individuals with DD, which is 2-3 times more common than in the general population[1]-[2]. Individuals with Autism Spectrum Disorder have a co-occurring mental illness at rates of 54-70%.[3] Second, these units account for the majority of Office of Inspector General (OIG) substantiated reports of abuse (50%) and neglect (74%) at CMHDC[4]. Third, the lack of oversight by the Illinois Department of Public Health (IDPH) may be a contributing factor to the high rates of substantiated reports.

SIU SOM recommends that DHS consider converting these units to IDPH-licensed DD units (recognizing that all SODCs regularly admit individuals with significant mental health symptoms and trauma). There are community-based programs to support these individuals already in place in Anna and the surrounding region; CMHDC has specialized equipment to be utilized by them (such as food prep machines in the cafeteria); and a presence of higher functioning individuals with DD on the CMHDC campus enhances some of the community resources recommendations to follow. Eventually, as more community-based resources are developed on and around the CMHDC campus, these DD residential units can be discontinued and transitioned to shorter term stabilization units.

Forensic Units

SIU SOM recommends that CMHDC expand forensic psychiatry services, including both inpatient and outpatient competency restoration services. To be successful in providing this service, SIU SOM recommends that DHS develop a process for on-site fitness to stand trial evaluations. Likewise, a process needs to be developed (potentially requiring a change in the Mental Health Code) to expand videoconferencing for court hearings—both civil and forensic—

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[1] Kalb, L. G., Beasley, J. B., Caoili, A., McLaren, J. L., & Barnill, J. (2021). Predictors of Mental Health Crises Among Individuals With Intellectual and Developmental Disabilities Enrolled in the START Program. *Psychiatric Services*, *72*(3), 273–280. https://doi.org/https://doi.org/10.1176/appi.ps.202000301

[2] Pinals, D. A., Hovermale, L., Mauch, D., & Anacker, L. (2022). Persons with intellectual and developmental disabilities in the mental health system: part 1. clinical considerations. *Psychiatric Services*, *73*(3), 321–328.

[3] Romero M, Aguilar JM, Del-Rey-Mejías Á, et al. Psychiatric comorbidities in autism spectrum disorder: A comparative study between DSM-IV-TR and DSM-5 diagnosis. International Journal of Clinical and Health Psychology. 2016;16(3):266-275. doi:10.1016/j.ijchp.2016.03.001

[4] OIG report to DHS, June 7, 2023.

such that patients are no longer being transported to the county in which the court proceedings were initiated. The state of Michigan has implemented this program[5]. The current practice of providing individuals the option to attend court hearings face-to-face utilizes a lot of resources that could be better directed to improving the health outcomes of individuals receiving services on the CMHDC campus.

SIU SOM recommends an expansion of the forensic DD program utilizing the seven cottages as a CILA-type service for individuals stepping down from the forensic DD program. Cottages currently occupied by non-clinical services should be moved to administrative office space in other buildings on campus.

In regards to mental health clinical services, SIU SOM recommends that DHS consider adding MISA services for inpatient and outpatient settings and consider developing a mental health forensic unit to build upon CMHDC's very successful forensic DD unit. SIU SOM recommends keeping the current civil units at CMHDC and potentially expanding civil capacity to accommodate forensic step-down units. Upgrading and retrofitting the two vacant units in the building with two mental health units could accommodate forensic step-down services. SIU SOM recommends that CMHDC expand community-based resources to support people without family ties in the state to transition successfully to a community setting in the CMHDC region.

Expanded Psychiatry

SIU SOM recommends an enhanced use of telepsychiatry to provide 24/7 coverage for CMHDC individuals receiving care and confirm with the court system and providers at CMHDC that telepsychiatrists can complete certificates for involuntary civil commitments. SIU SOM recommends that DHS expand Psychiatry Hospital capacity at CMHDC.

As with the DD population, SIU SOM recommends that CMHDC consider an external utilization review process, develop clear discharge criteria, and prioritize the goal of transition to the community from the time of admission. While this process is driven by the state's mental health code, there is variability in how discharge planning is conducted across SOPHs. SIU SOM recommends that DHS evaluate the processes at CMHDC to identify opportunities to make the processes more efficient and consistent.

SIU SOM recommends the addition of psychiatry services at CMHDC to include a 25-bed forensic unit and an extended care, non-acute setting for longer-term care for "difficult to place" civil individuals who no longer need SOPH level of care. These extended care services could be located in the cottages or accommodations similar to that.

To expand planning and program development, SIU SOM recommends that DMH provide operational and budgetary oversight for care of individuals with mental illness at CMHDC.

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[5] National Center for State Courts, Guidance from Michigan Virtual Courtroom standards, guidelines, and best practices, April 2020.

Other Clinical Services

SIU SOM recommends the creation of a comprehensive cadre of clinical services that can be accessed by people receiving services at CMHDC as well as individuals in the community setting who receive mental health or DD services. DHS should consider partnering with health care providers/systems in the region who are mission-aligned to develop stabilization of dentistry services as poor dentition contributes to poor overall health and poor behavioral outcomes in individuals with difficulty expressing their needs[6]; include vision and audiology services to help optimize functioning and level of independence for individuals receiving care; and include mental health services (medication management, psychotherapy, case management, and partial hospitalization programs). Services should also include primary care with providers who understand these populations, as well as specialty care for individuals with complex medical needs. These needs have been identified by many stakeholders in the region. Some of these services would not need 5-day a week presence and some may be able to be performed in a mobile vehicle that travels throughout the region .

SIU SOM recommends establishment of a process for regular meetings facilitated by established leaders amongst behavioral health providers in the region to coordinate care, identify gaps, and develop solutions to gaps or barriers identified within the system. This system would also allow the development of community-wide care plans for high utilizers of services to ensure optimal, coordinated services resulting in better outcomes—and often cost savings. Given the significant role CMHDC plays in this process, DHS should ensure representation from CMHDC. DHS should consider including local elected officials and law enforcement as individuals with MI often interact with city/county officials and services. City and county officials also have access to resources to help solve identified problems/gaps in care.

SIU SOM recommends utilizing land at CMHDC to build permanent supportive housing to help people maintain their independence, particularly those individuals with mental illness, substance use disorders, and DD.

SIU SOM also recommends that apartment buildings be built on campus for people in the community. DHS could consider IHDA partnership with DHS to create housing for specialty populations on campus including the staff working at CMHDC, students who are receiving training at CMHDC, individuals receiving clinical care at CMHDC, step-down services for people preparing to transition out of CMHDC, and integrative living models for people who live on the campus.

The state may need to evaluate the funding stream for care for the DD population placed in community settings as many individuals with co-morbid mental illness (especially cluster B

[6] Association Between Mental Health and Oral Health Status and Care Utilization, Front Oral Health, 2021;2: 732882, published online 2022 February 7.

personality disorders) need to be able to access evidence-based psychotherapies for treatment. But when funded through the DD system, the types of therapies that are reimbursed often do not appropriately address these psychiatric conditions.

SIU SOM recommends that DHS consider adding pet therapy services on the CMHDC campus and consider having residential pets on some units and/or cottages.[7]

SIU SOM recommends the development of geriatric psychiatry and dementia-related services on the CMHDC campus that can meet the needs of aging individuals receiving care at CMHDC, in the Anna Veterans Home, and for residents in the region.

The CMHDC campus could provide individual and group counseling services that can address the needs of CMHDC, the Anna Veteran's Home, and residents in the community. DHS should assess the need for partial hospitalization and/or intensive outpatient programs to enhance psychiatry services in the region, and expand access to specialty services including trauma care, separation anxiety, and foster care transitions.

These programs would need to be geographically placed on campus adhering to requirements regarding distance from programs and services for minors on campus.

Culture of Safety Recommendations

DHS has already begun the process of assessing current safety protocols for individuals remaining on the CMHDC campus. The following recommendations will enhance this work as further analysis and recommendations are made in Phase Two.

Health Monitoring

DHS should expedite the transition to an Electronic Health Record (EHR) for all SODCs and SOPHs to document, track, and make individual records available to providers serving the CMHDC campus on-site and via telemedicine. Paper records, manually recorded, allows for a higher error rate in diagnosing and treating patients at CMHDC. Electronic health records would also include a patient portal such that family members and guardians would have transparency about the care individuals receive at CMHDC.

SIU SOM recommends that DHS ensure consistent utilization of IntellectAbility, an online 360-degree Health Risk Screening Tool that can be used to collect data on changes to the health status of individuals receiving state services. The CIRAS (Critical Incident Reporting and

[7] Dogs Supporting Human Health and Well-Being: A Biopsychosocial Approach, Vet Science, 2021; 8: 630465, Published online 2021 March 30.

Analysis System) data collects reports from Independent Service Coordination (ISC) agencies to track participants involved in a critical incident and includes follow-up activities and reports.

Thorough Root Cause Analyses (RCAs) should be conducted for safety issues as outlined in the Program Directive Requirements. The RCAs should be systematic, following all core steps of an RCA, and a centralized RCA team process should be deployed from DHS or IDPH to perform RCAs across the systems. Given the current safety culture at CMHDC, SIU SOM recommends expanding the role of DHS staff and adding staff members from outside CMHDC who have expertise in quality improvement and conducting RCAs to lead the process—ensuring a comprehensive, systematic approach to RCAs—and can help teach CMHDC staff how to conduct RCAs so that eventually the process may be conducted under the oversight of CMHDC.

SIU SOM supports the recommendations of the OIG and efforts of DHS to install cameras in common areas of the CMHDC facilities and all other permissible areas in an effort to prevent abuse and neglect of individuals living at CMHDC.

Quality Improvement

SIU SOM recommends that DHS explore the use of a national accreditation program for CMHDC and other SODCs to evaluate and benchmark the quality of care provided at state facilities.

In an effort to increase the capacity of individuals receiving care to report safety and other concerns, CMHDC should designate and train at least one individual on each unit who can communicate safety (and other) concerns. Many have their own cell phones on non-mental health units. CMHDC administrators should post signs on each floor and in all common areas to inform individuals receiving care how to bring forth concerns. SIU SOM recommends the use of a third-party vendor to staff an anonymous hotline for complaints.

DHS should create a quality improvement program for CMHDC based upon an ongoing, systematic evaluation of the quality of providers and programs at CMHDC. DHS may consider tying reimbursement for services to quality outcomes which should include process measures such as the quantity of activities for individuals that engages them in their community. The CMHDC quality improvement plan should focus on future improvements for individualized service plans versus previous allegations and investigations.

Guardian Communication

To increase transparency at CMHDC, the administration should alter their visitation policy to welcome guardians and visitors any time they want to visit their friends and family members. Proper visitor sign-in policies to ensure the safety of individuals receiving care should be part of the new policy.

DHS may consider an SODC Bill of Rights for individuals receiving care and staff that should be posted in common areas. To support people residing at CMHDC without family in the area, CMHDC may want to pair them with a community advocate that can check in with them while they are in the area.

CMHDC should systematically implement technology to allow families and guardians to utilize commercially-available audiovisual equipment to connect with individuals receiving care from a distance. In addition, CMHDC should enhance communication with guardians by creating a protocol for communication flow: better documentation of behaviors and notify guardians about problems prior to them escalating.

CMHDC should ensure individuals receiving care and guardians are aware of the provision of basic individual services (bathing, meals, etc). CMHDC should monitor, verify, and ensure proper education and adequate level of understanding are in place when "consumer choice" or similar verbiage is documented as the reason for an individual's refusal of services. Guardians or family members should be notified when resident choice alters the provision of basic services for the individual receiving care.

Training and Evaluation

The CMHDC Administration should create training programs to meet the needs of people being served at CMHDC, especially enhanced mental health training for staff working with the DD population, enhanced training on trauma, and de-escalation.

CMHDC should evaluate competency of existing staff and provide ongoing, skill-based training and assessments to improve care delivery.

All CMHDC employees should have a state email address to access communication from state and regional offices on a regular basis. For direct service staff members who may not utilize a computer in their daily work, CMHDC should make available state computers on campus so that employees can access email and other resources to assist them in performing their job duties.

DHS should create and require a supervision policies and procedures training, followed by required skills verification for SODC employees to reduce incidence of neglect. Compliance policies and procedures should also be required training for all SODC staff. Completion of the trainings should include the signature of the employee agreeing that they have participated in the training and will comply with items covered during the training program.

Annual safety surveys should be provided across all SODCs with benchmarks and goals documented for each facility. CMHDC should conduct regular, recurring facility safety walk-throughs on units. Walk-throughs should be both announced and unannounced and periodically include leaders from DHS.

Safety surveys at CMHDC should be unannounced to accurately assess the use of proper processes and procedures by staff and the administration.

CMHDC should create or review the role of a designated Patient Safety Officer and appoint a Safety Champion for every unit. CMHDC can create and appropriately train Adverse Event Response Teams (AVRTs) to promptly respond to adverse events to keep the atmosphere calm, mitigate harm and prevent further harm, curtail any undue punitive actions, ensure complete reporting of the event into the safety tracking system, review what occurred, and support family and staff. The AVRTs could potentially re-enact or simulate adverse events to better understand the organizational or procedural processes that failed.

When appropriate, CMHDC should involve individuals receiving care and their families in safety initiatives as an added layer of information gathering and reporting given the documented difficulties of individuals having access to telephones or other means of reporting potential issues. DHS should develop, standardize, and simplify reliable care and safety processes; train staff on how to use them; and monitor for accountability.

Medication Management

Currently, inconsistent processes, procedures, and timelines related to medication management and changes exist that could impact the health and wellness of the individuals at all of the SODCs. At CMHDC, on average it can take up to one month from the time a medication change is ordered by the physician to the time the individual receives their new medicines, which could be harmful to the individual receiving care. Evidence-based practice includes input from a Behavioral Intervention Committee (BIC) and Human Rights Committee (HRC), review by a licensed physician or psychiatrist, and in discussions with the individual and family member or guardian when possible. Depending on the urgency of the individual's status, the process should allow for flexibility to implement medication changes in a short amount of time if needed. Other SODCs have a process that allows for same or next-day medication changes after a team meeting with the psychiatrist. They have established a process to obtain verbal consent (preferably by having guardians participate in the team meeting where medication changes are decided) to be followed by written consent. SIU SOM recommends that CMHDC leaders review their policies and procedures and develop a more timely and inclusive medication change process. DHS should develop a BIC guidebook and provide consistent training for all SODCs on processes and procedures.

Staff Management

With the planned closure of the DD units at CMHDC, the existing workforce from those units can be maintained and retrained to work on remaining units at CMHDC. This should decrease the need for temporary/travel workers and mandatory overtime.

CMHDC should create or review staffing plans to ensure staffing goals remain in alignment with organizational changes at CMHDC. Staffing plans should include, but not be limited to, determining staffing goals, analyzing staffing patterns and changes, updating job descriptions,

skills assessment and skills gap analysis, and relief staffing given the obstacles in hiring, employee absences, and length of time required for investigatory processes.

SIU SOM acknowledges the impacts of the current workforce shortage on CMHDC and other SODCs. Some temporary staff members do not always have the training or capacity to provide difficult or complex services which leaves the most difficult services to be provided by staff who are working overtime shifts, are often times exhausted, and are being put at greater risk of injury, resignations, and early retirements. In order to decrease reliance on temporary staffing, CMHDC should explore offering bonuses to permanent staff for extra work, creating workforce development programs, streamlining the worker's compensation evaluations and programs to get people back to work quickly, and speeding up the investigation of allegations of abuse and neglect so that employees can return to their regular job duties more quickly reducing stress on employees covering for those sidelined during investigations. Most importantly, the CMHDC administration should create an "Employer of Choice" campaign in the region to attract and retain a highly skilled workforce for the future.

CMHDC should lead an effort within the community to address real and perceived systemic racial barriers that prevent people of color from working at CMHDC.

CMHDC should establish a systematic way to communicate with staff as currently exists at other SODCs. This communication system should include center-wide email, print and post notices in every work area, ongoing communication with leaders of each area, and face-to-face communications in each area. Important notices should be delivered by supervisors to employees with documentation that communication occurred and what employees were told during those conversations. To improve communications related to the daily status of individuals served at CMHDC, huddles should be implemented during shift changes to provide continuity of care from one shift to another. A process needs to be in place to communicate high-risk situations at the start of each shift (shift change safety information handoffs) to assist in reducing the potential of errors and adverse events. Safety huddles[8] improve safety for both the individual receiving care and the employee and only require 10-15 minutes a day for leaders across the campus who carry that information back to their units to share daily safety priorities and shift-to-shift handoffs.

SIU SOM recommends that DHS place an external monitor at CMHDC to specifically oversee the transition of individuals who are moving from the units that DHS has decided to close to other SODCs and community-based settings. The goal is to ensure safety for the transitioning individual through a well-defined transition plan with proper preparation at both the current home and the future home for the individual and their families. SODCs and community-based organizations need to be fully prepared and have all of the equipment, therapies, programs, and

[8] Impact of multi-disciplinary team huddles on patient safety: a systematic review and proposed taxonomy, Brian J Franklin, Tejal K Gandhi, David W Bates, Nadia Huancahuri, Charles A Morris, Madelyn Pearson, Michelle Beth Bass, Eric Goralnick, BMJ Quality Safety, 2020 Oct. 29 (10): 1-2.doi: 10.1136/bmjqs-2019-009911. Epub 2020, April 7.

services in place prior to the transition of the individual and communicate the plan to individuals, their family members and guardians.

Workforce Development Recommendations

Pipeline Programs

CMHDC should partner with schools in the region to recruit more trainees (*e.g.,* psychology externs and social work interns from SIUC; students from nursing schools such as Shawnee). CMHDC should recruit Certified Recovery Support Specialists (CRSS) currently being trained throughout the state by DHS and their partners. CRSSs are people with lived experience in the behavioral health system who are trained to utilize their experience and knowledge to support others in the behavioral health system. They could serve as advocates for individuals living at CMHDC and those transitioning to community-based settings.

DHS should partner with local high schools in the region to pilot a pathway program to train students for jobs needed at CMHDC. Students can apply for a position at CMHDC while in high school, work in a trainee position, complete testing (if needed), and be ready to start working at CMHDC upon graduation. The 6-9 month hiring process can be completed during the senior year of high school. One example of such a program would be a pathway for high schools to train as Mental Health Technicians for CMHDC. Another example could be for Public Aid Eligibility Assistants who could become case workers for the state. DHS divisions should explore additional entry-level titles that could receive coursework at local high schools and job training at CMHDC (See Appendix D).

CMHDC should partner with post-secondary schools in the region to train professional students (nursing, psychology, social work, psychiatrists) on the CMHDC campus. Such partnerships bring expanded clinical providers utilizing the trainees as well as serving as a recruitment tool for CMHDC and other organizations that provide services to individuals with DD and/or mental illness.

Residencies and Fellowships

DHS should explore partnerships with hospitals and health systems in the region to develop a rural residency track for psychiatry in Southern Illinois. The rural residency track would include inpatient and outpatient services at regional hospitals and would perform rotations at SODCs in Southern Illinois. Such a program not only expands the immediate workforce by having physicians in the psychiatry residency providing direct patient care (under the supervision of their psychiatry faculty) but also serves as a strong recruitment tool to expand the permanent

workforce as studies have shown that individuals are likely to stay to work within a 30-mile radius of their residency program experiences[9].

DHS should examine its partnership with psychiatry residency training programs across the state to enhance not only the current workforce but to also aid in the development of its long-term workforce. SOPHs and SODCs that are near existing psychiatry residency programs should partner with those programs to fund residency slots and faculty time to provide direct patient care to DHS-funded services. Residents who rotate in these locations are more likely to choose to work in those settings upon graduation and then transition to independent practice. The availability of such partnerships may lead DHS to redistribute forensic and civil units throughout the SOPHs as there will likely be more psychiatric services available at facilities that have partnered with psychiatry residency programs.

DHS should also consider funding a Developmental Disabilities Fellowship Program within one of the state's existing psychiatry residency programs. Indiana University has such a fellowship and it serves as a pipeline to a psychiatric workforce with both the expertise and interest in working with people with DD. Given that such a fellowship is not ACGME-accredited, consideration could be given to allow physicians from multiple specialties (psychiatry, pediatrics, family medicine, internal medicine) to enter the fellowship training.

Staff Development

CMHDC should review current staff assignments to ensure people are working at the top of their license. In many cases, LCSWs are processing paperwork instead of providing clinical work. Having administrative support for these functions or utilizing BSWs would allow the LCSWs to work at the top of their license. CMHDC could utilize MSWs and Masters in Psychology to provide therapy services which would expand access to therapy for people receiving services at CMHDC.

DHS should partner with experts such as the National Alliance for DSP and the Council on Quality Leadership to implement a statewide training program for DSPs. The Illinois Student Assistance Commission (ISAC) could expand its health care loan repayment program to include DSPs who want to be certified in Illinois (40 hours in the classroom plus 80 hours on the job training). The Behavioral Health Workforce Center could work with CMS to create a pathway for DSPs who are looking for opportunities to become DSP supervisors, mentors, and coaches at SODCs, DHS could explore the development of statewide DSP and QIDP training programs to ensure a high-quality workforce for front-line service needs and staff for SODCs in the future.

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[9] Baum N., King, J (2020) The Behavioral Health Workforce in Rural America: Developing a National Recruitment Strategy, (February 2022), https://behavioralhealthworkforce.org/wp-content/uploads/2020/02/Recruitment-and-retention-of-BH-Provers-Full-Report-2.2020.pdf

Worker's Compensation

In partnership with CMS, DHS should consider on-site worker's compensation evaluation clinics (conducted by a neutral 3rd party) to speed the process of evaluation and return-to-work processes for individuals with worker's compensation claims.

The state should conduct a comprehensive multi-year analysis of workers' compensation reports to identify preventable injuries by reducing workplace risk. This analysis is not to include employee identifiers but should include date, time, type of injury, location of occurrence, etc. Reporting of incidents and data from same is managed through CMS' third-party administrator.

Equity, Diversity, and Inclusion

CMHDC should facilitate a partnership between the leadership and people of Anna, IL, and the Illinois Commission on Discrimination and Hate Crimes to address and discuss any potential underlying issues surrounding race in this community. Whether real or perceived, implicit or explicit, this commonly discussed cloud of divisiveness must be addressed in order to heal the community and provide for greater feelings of safety, diversity, and inclusion, larger candidate pools within the CMHDC workforce, and organizational recruiting efforts. Conversations of understanding and crucial conversations moderated by trained professionals could provide the foundation for identifying and uprooting any potential sources of discrimination or bias that may be lingering from the past and, as a result, preventing the community from moving forward.

State Hiring Processes

DHS needs to address barriers to service delivery due to an inefficient and ineffective hiring process. SIU SOM heard repeatedly that the state hiring process at CMS takes too long and people who apply cannot wait months (up to six months) to hear the status of their application. The state also needs to improve the screening of applicants to ensure required skills are included in the hiring process. Special attention should be paid to hiring a workforce with a passion to serve people with disabilities and compassion for individuals served at CMHDC.

Campus Redevelopment Recommendations

State Agency Presence

The State of Illinois could develop a comprehensive Community and Family Resource Center on the CMHDC campus to include: SNAP enrollment, connections to other services (cases of eviction, domestic violence, etc.), register customers, handle address changes, etc. A comprehensive approach like the approach being implemented with the DHS Division of

Community and Family Services eligibility call center is a model that can be replicated with other services needed statewide.

The State of Illinois could develop a one-stop-shop for unemployment services, workforce development, SNAP, childcare, wrap-around services for at-risk youth, etc. Currently, the regional Workforce Innovation and Opportunities Agency (WIOA) serving Anna is located in Carmi, Illinois, which is a 90-minute drive for anyone seeking employment services.

Community Resources

Most of the people interviewed in and around Anna spoke of opportunities to connect the CMHDC campus to the ongoing activities in the community and in the region. They recommended utilizing CMHDC for annual community events, festivals, and sporting events. SIU SOM recommends creating a group of community members, community leaders, and staff at CMHDC to brainstorm ways to integrate the community activities and residents onto the CMHDC campus, understand what community initiatives could occur on campus (e.g., the baseball field is always reserved), and identify what services would benefit the community that could be located on CMHDC.

As part of these community conversations and examining the feasibility for redevelopment, CMHDC should explore the options and safety parameters to develop a daycare center (in collaboration with other companies or organizations such as the YMCA) on campus to provide service to the community and enhance the ability to hire staff. There is currently only one daycare in the community with an exceptionally long wait list. This lack of access to daycare serves as a barrier to individuals returning to the workforce. If a daycare center is developed, consider giving preference to children of CMHDC employees.

As mentioned in the recommendations for clinical operations, SIU SOM recommends that housing be built on campus for use by multiple different groups of individuals. These housing units could be constructed through partnership between DHS and IDHA or other state and federal agencies. Housing could include safe, affordable apartments for employees at Choate and other community members; temporary housing for students or other individuals receiving training at CMHDC; permanent supportive housing for individuals with mental illness and/or developmental disabilities to enhance community placements; and transitional or other integrative living models for people receiving services at CMHDC.

Finally, CMHDC should establish a continuum of clinical services to include, in addition to what was previously recommended, home health services on the campus to support the needs of CMHDC, the Anna Veteran’s Home, and the surrounding communities.

Other Recommendations

Mental Health Code Changes

DHS should explore changes to the mental health code to expand the use of secure videoconferencing for civil court hearings (commitment and involuntary treatment) and clarify which providers can complete first and second certificates. Forensic court hearings should also be completed utilizing secure videoconferencing systems.

Facility Upgrades and Improvements

The CMHDC campus has many historic and usable facilities for purposes that would benefit both CMHDC and the surrounding community. A tour of the facilities demonstrates facility upgrades needed to repurpose the buildings, however, this investment would benefit the state, local educational organizations, and community-based providers. A facility plan should be developed to make necessary improvements to buildings on the campus. (See appendix E for list of buildings and potential uses for the space). DHS should partner with the Illinois Housing Development Authority, Capital Development Board, U.S. Housing and Urban Development Agency, USDA Rural Development, and others to fund building renovations at CMHDC.

Enhanced Image of CMHDC

The CMHDC administration and staff have an opportunity to capitalize on the 150+ year presence of CMHDC from the historically significant bat wing architecture to the 230 acres of beautiful landscape to providing workforce and revenue opportunities and enhancements to the citizens and community in which the facility resides. The buildings were built with Southern Illinois resources and staffed and maintained by generations of Southern Illinoisans. The artifacts from days gone by could be properly curated and displayed with the goal being to show the public the advancements in care.

System Enhancements

Transition Processes and Procedures

The foundation of a statewide continuum of care for persons with intellectual or developmental disabilities is to establish SODC transition processes and procedures that enhance individualized transition plans to be supported through a special Medicaid rate for individuals moving into community-based settings.

DHS should create a training curriculum for CILA and other community-based providers serving people with I/DD to improve access to high-quality care in the least restrictive environment.

Protocols should be established for all SODCs to integrate family engagement from the time of admission to post-discharge and stabilization centers will provide an alternative to readmissions at SODCs and support the goals of persons with disabilities to live in the community.

The State of Illinois should explore programs operating in other states that provide for a continuum of care such as the START program in New Hampshire and others.

Medication Regimen

DHS should develop a process whereby individuals who are stabilized on a given medication regimen within an SODC or SOPH have those medications automatically approved by Medicaid to improve success with transitions to the community. All too frequently, individuals who are stabilized in a state-operated facility are transitioned to a community setting where Medicaid refuses to pay for one or more of the medications that helped lead to stability in the inpatient/residential setting. Upon abrupt discontinuation of the medication by lack of coverage through Medicaid, the individual destabilizes and ends up re-institutionalized, potentially through the criminal justice system.

DHS should increase community-based outpatient restoration programs to minimize need for inpatient forensic services for people who could instead receive community-based forensic services.

Community Integrated Living Arrangements

DHS will need to expand the number and quality of group homes and CILAs in the state to accommodate the number of people who are transitioned out of SODCs and diverted from unnecessary admissions. DHS should ensure some are equipped for special populations—people who use sign language to communicate, vision-impaired, insulin pumps, and those that are difficult to place.

With a goal of moving individuals to more community-based settings, DHS should review the status of CILAs, their ongoing training for staff, activities for individuals receiving care (day programs, socialization, etc.), and unannounced surveys to ensure programming, services, and safety standards are being met.

DHS should provide a systematic training program with resources for CILA employees to ensure quality and breadth of training are adequate for individuals being served. DHS should ensure disability awareness training (provided by SILCIL) is part of the training programs for all services funded through the state.

More people could participate in area day and work programs operated by local businesses for people with DD if more CILA beds or supportive housing were available in the community.

Reimbursement for Community Support Services

The state should work with Medicaid Managed Care Organizations to provide reimbursement for community support services which will help individuals transition to community-based living arrangements. Those services would include the following:

- Case management and care coordination
- Services identified in individualized treatment plans, i.e., evidence-based psychotherapy for trauma; evidence-based psychotherapy for individuals with co-occurring developmental disabilities and mental illness
- Applied Behavior Analysis (ABA) and other evidence-based treatments for individuals with autism
- Screening, Brief Intervention, and Referral to Treatment (SBIRT) for substance use disorders
- Integrated and collaborative care for mental health services
- Preventive services such as those that have proven efficacy at preventing the development of mental illness (currently can only bill for service if the individual gets diagnosed with a mental illness): programs that decrease risk of developing post-partum depression; programs to decrease risk of developing anxiety disorder for pediatric cancer patients; programs to mitigate trauma before development of ACES sequelae; violence prevention programs; parent training programs, etc.
- Peer support programs
- Consider paying for a bundle of services or pay for outcomes rather than the transactional fee for services
- Dentistry for individuals who have transitioned into community
- Insulin (including insulin pumps) for individuals who have transitioned into CILAs

The state may need to redefine how costs are calculated. Several state agencies are spending money on some subsets of patients. Each is trying to keep their own costs down but that may be forcing other state agencies to provide more expensive care leading to a greater overall cost. For high-needs individuals, there should be a way for state agencies systematically across the state agencies to calculate the total cost of care, streamline the funding and services to the most efficacious services, and allocate those costs across agencies or through a centralized fund for the complex patients. For example, one agency may not pay for a particular service or array of services because they are not covered benefits so other agencies end up incurring the costs of institutionalization. Some individuals receiving care through the DD system need access to specific, evidence-based psychotherapies to address their individual mental health and trauma

needs. However, the therapies available through the DD system are limited and do not include those specialized treatments that may allow individuals to transition to less restrictive settings. Likewise, until recently, Medicaid did not cover Applied Behavior Analysis (ABA) at all and it continues to limit the service to Certified Behavior Analysts with required sign-off/oversight by a psychologist or clinical social worker. As a result, many people with Autism Spectrum Disorders and Illinois Medicaid still cannot receive ABA services and end up being institutionalized in SODCs. It would be better for the system and the individual if the various agencies came together to ensure the appropriate community-based services were available and reimbursed to prevent institutionalization. For these types of situations, looking at the aggregate costs across all agencies and developing plans of care may help move people successfully towards greater independence while decreasing the overall cost of care. DHS should convene an interagency task force to evaluate this situation and propose a collaborative, aligned process for ensuring efficient, high quality care is delivered across the agencies and systems involved.

Areas for Further Exploration

DHS should work with commercial insurance carriers and Medicare to pay for crisis services provided by Community Mental Health Centers (CMHCs).

DHS should expand upon its Peer Support Specialist programs to include the use of parents/families who are caregivers and guardians to help other families keep their loved ones in community-based settings.

DHS should develop/expand its in-home respite services so families/caregivers can keep their loved ones at home but get a much-needed break.

DHS needs to explore an expansion of transition services in the community. Currently, civil mental health beds are used as forensic step-down beds and state psychiatric hospitals have difficulty finding appropriate placement which leads to long lengths of stay for civil beds (preventing access).

DHS should assess the landscape of current size, scope, and geographic distribution of services across MI and DD continuum to determine if there are enough services, the right services, services are that geographically distributed, and whether those in need have access.

DHS should also work to eliminate silos based upon diagnosis (DD vs mental health vs substance use disorder), recognizing many people have overlapping diagnoses.

Appendices

A. **Interview and Visit List**
B. **Supporting Documentation for Recommendations**
C. **Additional Resources**
D. **Facility Overview**
E. **Glossary**

Appendix A
List of Choate Interviews and Visits

Organization
Equip for Equality
Illinois Psychiatric Society
Illinois Nurses Association
Centerstone
AFSCME
IARF
Anna Community Leaders
Legislators meeting
Friends of Choate Meeting
DHS Division Leaders
Department of Veterans Affairs
Harrisburg Mulberry Center
Southern Illinois Center for Independent Living
Illinois Guardianship & Advocacy
Children's Behavioral Health Transformation Initiative
OIG meeting
DFCS
DHS Choate Mental Health and Developmental Center
DHS Murry Developmental Center
DHS Shapiro Developmental Center
DHS Ludeman Developmental Center
DHS Mabley Developmental Center
DHS Fox Developmental Center
IABH Resident Experience Meeting
ILADD

Appendix B
Supporting Documentation for Recommendations

1. Start Program (University of New Hampshire)

The National Center for START Services™ aims to improve the lives of persons with DD and mental health needs and their families through fidelity to the START model with exemplary services and supports that emphasize local, person-centered, positive, multidisciplinary, cost-effective and evidence-informed practices.

START is an evidence-based, community crisis prevention and intervention service model for individuals aged 6 and older with intellectual and developmental disabilities (DD) and mental health needs (DD-MH). The START model is person-centered and solutions-focused, employing positive psychology approaches and other evidence-based practices.
Training & Professional Development

The National Center for START Services™ Training Department oversees the development, coordination, and delivery of all training and professional development offered to the national START Network and Network stakeholders. The goals of the Training Department are:

1. Prepare leaders in the field of DD-MH through innovative learning experiences, interdisciplinary teaching models, and programs of study that incorporate universal design principles, include the perspective and voice of people with lived experience of DD-MH, and employ varied instructional methods and formats.
2. Offer professional development that is evidence-based, progressive, and culturally relevant.
3. Expand issues related to DD-MH, community engagement, and research into coursework and learning opportunities beyond the traditional schools of education and health and human services at UNH and the curriculum programs offered by our UCEDD partners.

START is a support to the person *and* the system (the team), so in some instances an enrollee may call the START crisis line directly, but this is rare. The START crisis line is different from traditional mental health hotline supports in that the primary support is offered to the *system*. It is the goal of START to support the system in helping the person through challenging and stressful times. Only then will capacity be built and sustained. The START Emergency Assessment is an in-person assessment conducted following a crisis call using START sanctioned tools. The purpose is to quickly determine the factors that contribute to the presenting problem and identify interventions that may be employed to intervene quickly and effectively.

2021 Annual Report: https://centerforstartservices.org/annual-report

START Resources: https://centerforstartservices.org/resources

2. Envision Unlimited

For more than 70 years, Envision Unlimited has served people with disabilities across all ages, abilities, and backgrounds. Today, they provide a wide array of home and community-based programs benefitting over 2,000 individuals across the State of Illinois. Envision provides day programs, community living services, employment services, a foster care program, and mental health services.

Envision, invites regular independent evaluation to ensure that they successfully address clients' and families' unique needs. Across the 14 consecutive surveys offered since 1978, they received the highest possible scores from the Commission on the Accreditation of Rehabilitation Facilities (CARF). They measure their success by program participants' progress, as they help children and adults realize self-identified goals and objectives. Above all, Envision is an advocate for the disability community. They believe all individuals, given the right opportunities, are capable of achieving great breakthroughs and leading lives of choice, independence, and inclusion.

Individual Advocacy Group Programs

IAG provides a variety of programs and supports to assist individuals with disabilities and their families.

3. IAG Community Integrated Living Arrangement (CILA)

Illinois Advocacy and Guardianship's (IAG) CILA Program began in 1999 and has grown to provide 24-hour supports to more than 80 CILA sites. The individuals in IAG's CILAs have an Intellectual Disability; most also have a secondary disability such as autism or a mental health or an emotional-behavioral diagnosis, which has limited other CILA provider's willingness and ability to provide services.

Individuals in IAG's CILAs are provided supports based on their personal needs and interests and are encouraged to participate within their communities. IAG's CILA program is unique in that the individuals' residences are independently controlled and each person has their own bedroom. This means that the individuals or their guardians rent their own homes, are responsible for the lease and are responsible for all associated living expenses. IAG provides the supports for these individuals so they can live meaningfully within the community

4. ECHO Program

The ECHO model was created at the University of New Mexico 25 years ago to bring academic information and knowledge to rural and remote health care providers, teams of experts at an academic medical center train teams of rural providers remotely using a case-based, interactive, all teach-all learn model. Inspired by the way clinicians learn from medical rounds during

residencies, the ECHO Model® has evolved into a learning framework that applies across disciplines for sustainable and profound change.

ECHO participants engage in a virtual community with their peers where they share support, guidance and feedback. As a result, of the collective understanding of how to disseminate and implement best practices across diverse disciplines continuously improves and expands.

During an ECHO session, participants present real (anonymized) cases to the specialists—and each other—for discussion and recommendations. Participants learn from one another, as knowledge is tested and refined through a local lens.

This continuous loop of learning, mentoring and peer support is what makes ECHO unique, with a long-lasting impact far beyond that of a webinar, e-learning course or telemedicine care. Each participant receives an ECHO box that houses all ECHO presentations, resources, and best practices.

This knowledge-sharing model brings together specialists from multiple focus areas for a robust, holistic approach.

Appendix C
Additional Resources and Materials

Potential state trainee titles for workforce development

- Mental Health Administrator Trainee
- Mental Health Specialist Trainee
- Mental Health Technician Trainee
- Mental Health Administrator Trainee
- Social Service Aide Trainee
- Social Services Career Trainee

Appendix D
Facility Overview

Building	Current Use	Future Use	Need of Repairs	Notes
Magnolia	Residence Hall	Residence Hall		
Dogwood	Residence Hall	Residence Hall		
RedBud	Residence Hall	Residence Hall		
Cedar	Residence Hall	Residence Hall		
Cypress	Residence Hall	Residence Hall		
Sycamore	Residence Hall	Residence Hall		
Dewey Cottage	Alternative school	Training center	Needs new HVAC, tuck-pointing, new paint	Does not meet fire code for schools, no elevator
Chapel	Minimal use, funerals	Maintain current use		
Car wash	Functional	Maintain current use		
Pool	Functional and used	Maintain current use		
Willow Hall	DORS, OIG, FCRC offices	Maintain current use	Needs new paint, upgrade air handlers	Nicest building on campus, moving to Oak Hall -- kitchen, offices, FCRC Now, old dental clinic (3 rooms + lab), has elevator, OIG not moving
Administration	Offices, conference rooms	Maintain current use	Needs paint, ceiling repairs, updates to interior	
Clinical Building	Offices of state guardian (OSG, ASH), employee credit union, offices upstairs + apartment	Maintain current use	Interior updates, paint, ceiling repairs	Shawnee Div. Corp services, food pantry in basement for community
Goodner	Theatre, gymnasium, stage	Community events/dances, sports leagues/summer camps, special Olympics events, job fairs, basement = café + UC center	Wall and ceiling updates	
Cottage #1	Southernmost Tourism office	Current use or Transitional housing	Interior remodel needed	Tourism Bureau, 2 bedrooms
Cottage #2	Union office for AFSCME Local 141	Current use or Transitional housing	Interior remodel needed	2 bedrooms
Cottage #3	Vacant	Transitional housing	Interior remodel needed	2 bedrooms

Building	Current Use	Future Use	Need of Repairs	Notes
Cottage #4	Vacant	Transitional housing	Interior remodel needed	Has basement, 5 bedrooms
Cottage #5	Vacant Covid housing	Transitional housing	Interior remodel needed	2 bedrooms
Cottage #6	Vacant	Transitional housing	Interior remodel needed	Not brick, 7 bedrooms
Cottage #7	Vacant	Transitional housing	Interior remodel needed	Same as Cottage #6
Main Building	Post office, offices, upstairs theatre and stage	Maintain current use	Needs major interior upgrade (paneling walls, paint chipping, old windows) Top floor is really bad (unoccupied, needs new HVAC)	
Food Storage	Large food prep area	Maintain current use		
Dietary	Food prep, functional	Maintain current use		Recycling, general mechanical stores, community residents employed
Greenhouse		Upgrade and expand work opportunities for individuals at Choate	Only 2 of 3 greenhouses in use now due to needed repairs	Residents employed, annual flower sales,
Manual Skills building	Storage	Maintain current use		
Life Skills building	Crafts and food prep	Could house 24/7 occupants Possible forensic step-down facility	New HVAC, fence for forensic patients	
Athon	Previously dorms	Could be remodeled to serve as a group home	No power or water, needs interior renovations	Has good bones
Lence	Previously dorms	Current renovations to be processing center, DHS long-term care determinations	Renovations in process	
Oak Hall	Previously served as office and learning facility; state agency call center.	Office space and learning center	Needs renovations	
Barnes	Previously used as a daycare center, head start	Could serve as offices or training center	Repairs to car entrance and parking lot, concrete updates for ADA compliance, needs central HVAC, new windows	

Building	Current Use	Future Use	Need of Repairs	Notes
Butler	Storage for trucks and maintenance shop	Maintain current use		
Engineering office	Small office used by B+G	Maintain current use		
230 surrounding acres	Rented to farmers	Keep ball field. Create community gardens on the grounds, Create supportive housing on campus		
Water tower		Maintain current use		
Power plant & lawn shed	In use	Maintain current use		
Café	Rec area – pool table, Ping pong, cafe	Maintain current use		Provides work opportunities, popular game room

Appendix E
Glossary

AVRT – Adverse Event Response Team
Behavioral Health – mental health, DD, and substance use disorder services
BIC – Behavioral Intervention Committee
CART – Clinical and Administrative Review Team
CILA – Community Independent Living Arrangement
CMHDC – Choate Mental Health and Developmental Center
DCFS – DHS Division of Community and Family Services
DD – Intellectual and/or Developmental Disabilities
DHS – Department of Human Services
DMH – DHS Division of Mental Health
Developmental Disability – Individuals with an Intellectual and/or Developmental Disability or a related condition.
DSP – Disability Specialist Provider
Dual Diagnosis – Co-occurring DD and mental illness
ECHO – Extending Community Health Outcomes Training Model
EHR – Electronic Health Record
HRC – Human Resource Committee
ICS – Independence Coordination Service Agency
IDPH – Illinois Department of Public Health
Intellectual Disability – significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested before the age of 18 years.
Non-certified unit – not inspected by IDPH
OIG – Office of Inspector General at DHS
Related Condition means an individual who has a severe, chronic disability that meets all of the following conditions and is attributable to: Cerebral palsy, autism or epilepsy; or any other condition, other than mental illness, found to be closely related to intellectual disabilities because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of persons with intellectual disabilities and requires treatment or services similar to those required for these persons; it is manifested before the person reaches age 22; likely to continue indefinitely; and results in substantial functional limitations in three or more of the areas following of major life activity: self-care; understanding and use of language; learning; mobility; self-direction; capacity for independent living.
Significantly sub-average is defined as an intelligence quotient (IQ) of 70 or below on standardized measures of intelligence. This upper limit could be extended upward depending on the reliability of the intelligence test used.
SODC – State Operated Development Center are specialized Intermediate Care Facilities/Developmental Disabilities (ICFs/DD) for persons with developmental disabilities who are unable to be served in a community setting due to intense behavioral and/or medical difficulties. only serves individuals with a developmental disability.
SODC Eligibility Requirements**:** individual must have a developmental disability and require intensive supports/supervision not available in a community setting. Persons must be screened by an ISC agency, receive technical assistance through the DD Network Clinical and Administrative Review Team (CART), and be approved for admission by an SODC representative.
SOPH – State Operated Psychiatry Hospital
Utilization Review – Process to control unnecessary utilization of services by evaluating patient needs and the appropriateness, quality and timeliness of service delivery.