



# **Acute Care Transitions Advisory Council Report and Recommendations**

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## Authors and acknowledgments

This report was created by a team of individuals and funded by the Minnesota Department of Human Services. The Acute Care Transitions Advisory Council led the development of this report.

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## **Executive summary**

Delayed discharge from the emergency department (ED) or hospital and difficulties transitioning back home into the community are highly complicated issues impacting Minnesota. These delays happen for many reasons but are most commonly attributed to difficulty finding safe post-discharge care and lengthy administrative or legal processes. While the reasons for discharge delays may vary, the result is that children and/or adults are unable to transition back to their homes in the community after an ED or hospital visit because services are not prepared to support them and/or their families or caregivers effectively.

The purpose of this report is to summarize the findings of the Minnesota Acute Care Transitions Advisory Council (ACTAC) in identifying how discharge delays are related to complex issues associated with barriers to transition into the community. A key assumption of the ACTAC is that all action planning completed by the State of Minnesota must actively work towards eliminating bias, discrimination and health-equity disparities associated with the transition of people from ED or hospitals back into the community. The council recommends the use of systematic strategies for identifying, monitoring and evaluating outcomes for people who represent protected classes as well as other vulnerable and under-represented groups in order work towards dismantling systemic racism in all its forms.

### **Short-term recommendations**

The following recommendations are proposed by the ACTAC. Sources of evidence include council meetings, literature review and public reports, presentations from community partners and focus groups/interviews with community partners. The council met nine times from October 2023 through October 2024 resulting in the following recommendations.

#### ***Recommendation I***

Given the timeline and complexity of the topic, the ACTAC needs to become a standing unit that meets on a regular basis to continue long-term guidance as the action plan is executed. The council recommends that it continues providing this guidance to the DHS while expanding the representation and diversity of the council and retaining individuals representing the major

roles currently present. The goal is to establish a bi-directional communication system between the ACTAC and a team funded via Moving Home Minnesota (MHM) within DHS.

### ***Recommendation II***

Expand regional capacity for existing care navigation by building on the Complex Transitions Team funded via MHM in three regions to support children and adults across the lifespan experiencing barriers to transition from the ED and/or hospital. Activities include establishing a communication pathway between DHS leadership, existing Complex Transitions Teams, counties and the advisory council.

### ***Recommendation III***

Establish a statewide infrastructure that will improve communication systems, provide coordination/support to regions and monitor the development of a unified measurement system. The goal of this infrastructure is to provide a way to collaborate with regional teams and improve coordination and navigation systems for children and adults who may live and receive services in different areas across Minnesota. The goal of this statewide infrastructure is to improve communication and build more effective systems to support children and adults admitted into acute care settings and transitioning back into the community.

### ***Recommendation IV***

Actively integrate measurement systems that monitor and evaluate geographic, racial and ethnic disparities in acute care transitions while coordinating with existing statewide health equity systems change efforts in Minnesota. The council embedded action-planning steps dedicated to health equity within each recommendation. Examples include increasing diversity of council representation should it become a standing unit and designing effective measurement systems for monitoring over-representation of children and adults from Black, Indigenous and people of color (BIPOC) communities experiencing barriers transitioning into the community.

## ***Recommendation V***

Identify the barriers that exist and begin long-term planning, while initiating changes in administrative policy that DHS and other lead agencies can make immediately, to expedite the transition of children and adults out of acute care settings. Examples include, but are not limited to, building short and long-term incentives for direct support staff, providers of existing waiver services and/or organizations that support children and adults while in the hospital to assist with transition planning; expanding on current funding policies for HCBS providers supporting the transition planning process while children and/or adults are in the hospital; assessing practices related to guardianship while addressing the rights of individuals and families; and developing strategies related to expediting MnCHOICES assessments.

### **Acute Care Transitions Advisory Council report**

#### **Introduction**

Delayed discharge from the ED or hospital is a highly complicated issue impacting Minnesota, the United States and other countries across the world (Bhatia et al., 2020; Cadel et al., 2021; Cavallaro et al., 2023; Pellico-Lopez et al., 2019). These delays are most commonly attributed to difficulty finding safe post-discharge care and lengthy administrative or legal processes. Hospitals have become the location of last resort with children and adults arriving with no other options leading to EDs and hospitals becoming “... *a long-term destination rather than... a way station for those who, once their acute care needs are met, are better served in a non-hospital setting.*” (HANYs, 2022, p.1). Today, many children and adults experiencing acute crises are entering hospitals, often via EDs, with increasing frequency (Cushing et al., 2023; Lytle et al., 2018). These individuals, who often have complex discharge needs (e.g., self-injury, suicide, aggression), find themselves unable to transition back to their homes in the community because services are not prepared to support them and/or their families effectively (Stock et al., 2023).

In Minnesota (and other states), communities are ill-equipped to support transitions from acute care settings, because the incentives for organizations to support children and adults requiring tailored and intensive services are not available (Huang et al., 2005). Long waiting lists

for treatment programs and services cause challenges for families and community partners (Levy et al., 2003). Services in settings where more supports can be accessed vary a great deal in both quality and intensity (Lord et al. 2005; Stahmer, 2006). Access to training and mentoring is not available for families, caregivers and staff to effectively implement evidence-based practices (EBPs) when children and adults require more intensive supports (Bruns et al., 2016; Huang et al., 2005; Stock et al., 2023). In some cases, families and caregivers experiencing acute care crises report that they are given the message that they are unfit and/or are responsible for their child or ward's challenging behavior by professionals representing various service systems (Jain et al., 2019). This, in turn, leads to a reluctance to reach out for assistance from providers on the part of family members or caregivers.

The pandemic has led to increased acknowledgment within society of widespread mental-health disparities and the need for equity and advocacy for marginalized youth, including ED visits from Black and Hispanic or Latinx youth (Abrams et al., 2020; Tyson & Ponoose, 2024). Black and Latinx with and without intellectual and developmental disabilities (IDD) are at more risk for hospitalizations and death related to multiple chronic conditions compared to white individuals (Zandam et al., 2024). The use of restraints during ED visits for mental health-related issues are twice as likely to occur with Black young people compared to white youth (Kalb et al., 2019; Nash et al., 2021; SAMHSA, 2023; Wong et al., 2023). Harsher response patterns towards BIPOC populations compared to the white population appears across a number of societal settings including medical systems, education, child welfare and the justice system (West et al., 2023). Structural racism endemic in today's society must be addressed as an integral part of the problems encountered within acute care barriers to transition.

### Purpose

The purpose of this report is to summarize the findings of the Minnesota Acute Care Transitions Advisory Council (ACTAC) in identifying how discharge delays are related to complex multi-faceted issues associated with barriers to transition into the community. Bender and colleagues describe this as: *"...a systems issue that manifests itself in the [emergency departments], which is a common pathway for the problem; but the real problem is about capacity in other parts of the system, adequate funding and being able to move patients to the*

*level of care they need.*” (p. 2, Bender et al., 2009). A scoping review published in 2021 warned that interventions focusing on only one type of system or part of the acute care problem will likely just “move” the problem rather than solve it: “...*adding more intermediate care [inpatient] beds may alleviate pressures in acute care in the short-term but eventually also be at full capacity if community resources are not available.*” (p. 25, Cadel et al., 2021).

Moving the problem rather than solving it is reflected in the history of the deinstitutionalization movement for people with IDD where policy changes focused on decreasing the number of institutional settings where people with IDD were being placed. Advocates fighting for the rights of individuals with IDD made it clear that all people have the right to live in their homes and communities (Lucyshyn, Dunlap, & Freeman, 2015). However, failing to invest in interventions for building effective, well-paid community services for people with more complex systems needs has led to a steady increase in 911 calls when organizations could not provide the services needed. Although this is only one possible explanation for the increased challenges associated with transition, it exemplifies how even interventions that are well intended and necessary can lead to iatrogenic, negative and unintended problems.

### Legislative action

Challenges associated with barriers to transition are varied and complex requiring solutions that address changes in state policies, systems change in healthcare and increases in funding for community services. Such solutions require coordination, collaboration and action by partners including people with lived experience, families and caregivers, hospitals, counties, state champions representing behavioral health, disability services, children and family services, and education. However, the differences in priorities of partners who are working together to effect change can cause challenges. For example, while hospitals are focused on meeting the needs of all patients, running hospital systems efficiently and managing operational costs, community-based organizations may be focused on promoting each person’s self-determination, managing worker’s compensation due to injuries, addressing staff-attrition related issues and dealing with funding deficits (Cadel et al., 2021).

The Minnesota commissioner of human services established the ACTAC to advise and assist in implementing a unified statewide vision and systemic approach to address acute care



transitions in Minnesota. Members of the council are [posted online](#) on the Boards and Commissions website and the [Minnesota ACTAC](#) webpage reports all activities related to the council. The commissioner requested public and community engagement be obtained about the barriers and potential solutions to transitioning patients from acute care settings to more appropriate non-acute care settings and while providing the information through public and community engagement.

The ACTAC was charged with presenting action-plan recommendations by Oct. 31, 2024, to the chairs and ranking minority members of the legislative committees and divisions with jurisdiction over health and human services finance and policy and the commissioner of human services. This action plan is meant to recommend a systemic approach for addressing acute care transitions for Minnesotans. The requested action plan recommendations address (but are not limited to) the following:

1. Improving regional capacity for acute care transitions, including examining the roles and experience of counties and tribes in delivering services and identifying any conflicting and duplicative roles and responsibilities among health and human services agencies, counties and tribes.
2. Creating a measurement and evaluation system within the context of implementation science to analyze regional and statewide data in transitions and make ongoing recommendations for policy and program improvement.
3. Outlining statewide strategies for improving access to transitioning from acute care settings with a focus on addressing geographic, racial and ethnic disparities.

The advisory council contracted with the University of Minnesota Institute on Community Integration (ICI) to facilitate the meetings, gather data, collect partner input and document council recommendations in a written report. Council duties were exempt from state procurement process requirements under [Minnesota Statutes, chapter 16C](#).

In developing the action plan, the ACTAC took into consideration the impact of its recommendations on the existing capacity of state agencies — including staffing needs, technology resources and existing agency responsibilities — and the capacity of county and tribal partners. The ACTAC council did not include any recommendations in the action plan that would result in loss of benefits for the individuals eligible for state health and human services

public programs or exacerbate health disparities and inequities in access to health care and human services.

### Acute care barriers to transition

The literature review used to prepare this report included the following topics relevant for action plan recommendations: a) ED and hospital discharge delays and barriers to transition from acute care settings, b) evidence-based strategies for addressing effective transitions, c) culturally-responsive implementation science to support increased regional and community capacity, d) systems of care strategies for improving coordination across community partners and e) statewide unified measurement systems for addressing acute care barriers. This section of the report outlines national and Minnesota-based contextual issues related to the acute care transitions barriers.

#### *Discharge delays and acute care barriers to transition*

Even before the COVID-19 pandemic, discharge delays were becoming a problem in EDs and hospitals across the world (Ahlin et al., 2022; Bhatia et al., 2020; Cadel et al., 2021; Cushing et al., 2023) with the earliest study on the topic occurring in 1987 (Goncalves et al., 2016; Kennedy et al., 1987). Emergency room delays related to boarding — defined as events where children and adults awaiting inpatient hospitalization are in a holding pattern until inpatient psychiatric admission beds are available — were increasing (Overhage et al., 2023).

Overhage and colleagues reviewed health insurance claims for young people 5-17 years of age from March 2019, to February 2022. Results indicated a 6.7% increase in mental health ED visits and an increase in the ED visits that led to hospitalization (8.4%). The percentage of prolonged boarding episodes increased by 76.4%. A review of data by the CDC reported that from April to October 2020, there was an increased proportion of mental health-related visits to pediatric emergency rooms for children 5 to 11 years when compared to 2019 data (Leeb et al., 2020). A reported 50.6% increase in ED visits occurred related to suspected suicide attempts by girls aged 12 to 17 years with data collected from February through March, 2021 (Yard et al., 2021).

Minnesota faces increasing challenges in supporting children and adults who require more flexibility in services than current local, regional and state systems provide. A number of key reports have noted that discharge delays from ED and/or hospitals in Minnesota are associated with a complex array of challenges across different services and systems, resulting in negative experiences reported by people with lived experience and/or their families (Dillon & Thompson, 2016; Dillon et al., 2024; Engler, 2022; 2022; MHA, 2019; MMA, 2023, see Table 1). People experiencing mental health or wellness crises arrive at local ED and hospitals desperately seeking help, only to find themselves unable to leave EDs and/or hospitals for days, even months, waiting for an inpatient psychiatric bed to open, or for services to be established/available in their homes or communities (Eldred, 2024; Erdahl, 2023). These challenges are associated with varied, unique and complicated conditions associated with systems issues such as funding, the capacity of organizations to tailor services for children and adults and their families or caregivers and the ability of organizations/services/systems to coordinate and communicate effective transition plans (Bender et al., 2009).

Reports by the hospital and healthcare systems highlight challenges in designing transitions to post-discharge settings such as state inpatient psychiatric beds, chemical dependency units and intensive residential treatment facilities (Dillon & Thompson, 2016; Dillon et al., 2019; Engler, 2022). The delays in discharge from ED and hospitals result in negative outcomes associated with patient “flow” issues (ED backlogs, cancelled surgeries, delayed medical care), increases in healthcare costs for patients and negative patient experiences (Rojas-García et al., 2018; Walker, 2011). Many people do not receive needed treatment while in the ED or hospital delaying the opportunity for healing (Cadel et al., 2021; Chen et al., 2012).

Although acute care settings have a role to play in the care continuum, when previous levels of care are unavailable or fragmented and/or when training and clinical support in the community are unavailable, children can remain in these acute care settings for long periods and/or experience frequent readmittance to these systems (AAP, 2019). Children and adults are placed in locations that are not suited for their needs increasing the likelihood of challenging behavior and/or experiencing further traumatizing events. Individuals experience a decrease in their ability to participate in activities of daily living, may become more frail or medically compromised, can experience additional health and wellness issues and/or experience further

cognitive impairment/behavioral challenges (Rojas-García et al., 2018). Chemical and/or physical restraints are used in the hospital to address challenges that arise when individuals are awaiting transition to appropriate services (Nash et al., 2021). While hospital staff generally indicate that all attempts are made to reduce the use of restraints, these physical and chemical interventions are used to address self-injury and aggressive behavior (Bender et al., 2009).

A scoping review assessing the types of interventions studied related to discharge delays reported that while some interventions are promising, none addressed sustainable long-term implementation (Cadel et al., 2021). Scoping reviews have reported a varied number of interventions that have been used to address acute care discharge delays (Abdelhalim et al., 2023; Cadel et al., 2021). The authors of this scoping review advocated for using an evaluation plan to track outcomes related to effective transitions across longer periods of time using developmental evaluation methods that take into account the dynamic and chaotic features involved in acute care transition problem solving (Cadel et al., 2021; Patton, 2008).

**Table 1**

*Summary of Minnesota-based reports on the acute care barriers to transition and improving health equity and disparities*

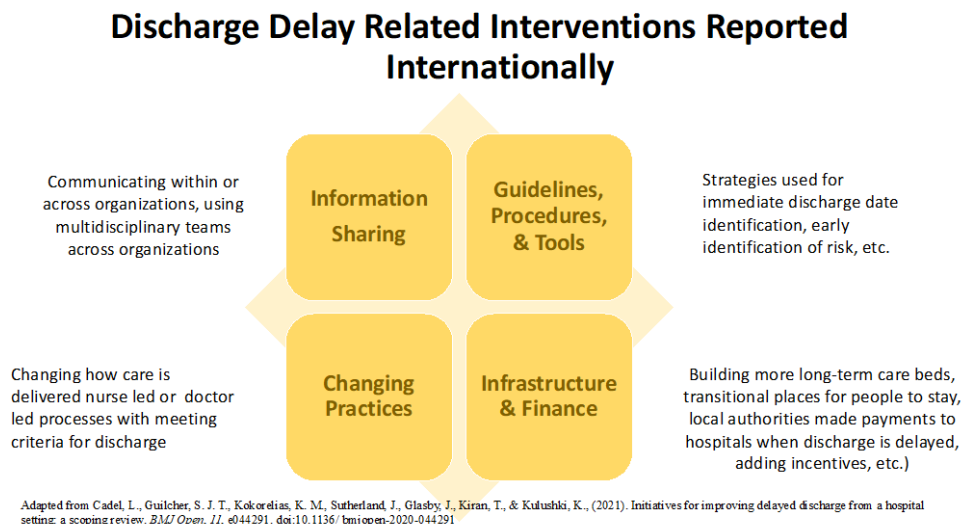
<b>Author</b>	<b>Organization responsible</b>	<b>Report citation</b>
Dillon, Vang, & Hierlmaier	Minnesota Department of Health	Dillon, K., Vang, M., & Hierlmaier, N. (2024). <i>Transfer and discharge delays for behavioral health patients at Minnesota hospitals: Results from the 2023 health behavioral health collection</i> . Saint Paul, Minnesota.
Dillon & Thompson	Minnesota Hospital Association & Wilder	Dillon, K. & Thompson, D. (2016). <a href="#"><i>Reasons for delays in hospital discharges of behavioral health patients</i></a> . Saint Paul, MN: Wilder.
Minnesota Hospital Association	MHA	Schindler, J. (2024). <i>Minnesota Hospital Association’s survey of hospital discharge delays</i> . Acute Care Advisory Council presentation [meeting]. Minnesota Hospital Association.
Pearson et al., (2022)	MN Governor’s Council on Developmental Disabilities & Market Response International	Pearson, T., McCullough, S., Schreifels, L., & Pearson, D. (2022) <a href="#"><i>Impact of the intersection of developmental disabilities and other population profiles on experiences with discrimination</i></a> . The One Minnesota baseline quantitative survey. MarketResponse International.
Pearson et al., (2023)	MN Governor’s Council on Developmental Disabilities & Market Response International	Pearson, T., McCullough, S., Schreifels, L., & Pearson, D. (2023). <a href="#"><i>Phase II intersectionality study, for the Minnesota Governor’s Council on Developmental Disabilities</i></a> . The One Minnesota baseline quantitative survey. MarketResponse International.
Chomilo	Medicaid Medical Director	Chomilo, N. T. (2022). Building racial equity into the walls of Minnesota Medicaid: A focus on U.S.-born Black Minnesotans. <i>Minnesota Department of Human Services Report</i> . <a href="https://edocs.dhs.state.mn.us/lfserver/Public/DHS-8209A-ENG">https://edocs.dhs.state.mn.us/lfserver/Public/DHS-8209A-ENG</a> .

## Community-based acute care barriers

Community-based services and supports for families are not present in many states creating the conditions where discharge delays occur (Bruns et al., 2016; Pires & Stroul, 1996). Temporary flexible funds are often needed to ensure services are in place, prepare adequate training and clinical therapeutic supports in community settings and to assist people in navigating the complex challenges encountered during transitions into the community. Policies and procedures can create barriers making community supports more difficult. For example, Medicaid coverage policies appear to favor institutional settings and nursing home care have resulted in advocates calling for a “rebalancing” of funding allocations toward home and community-based services (Grabowski et al., 2010; Harrington et al., 2009).

### Figure 1

*Types of interventions reported in a Scoping Review by Cadel and colleagues (2021)*



Individuals and their families or caregivers navigating multiple services to meet the person’s emotional and physical health needs often encounter difficulties when transitioning back to their community. Each service requires different paperwork and/or includes duplicative reports or planning documents, while children or adults and their caregivers are expected to attend multiple meetings across multiple services each with similar goals (Freeman et al., 2015). Fragmentation across these different services can contribute to difficult transitions from acute

care back into community settings (Knitzer, 1982). In some cases, repeat visits to the ED and hospital occur because of miscommunication about timing and preparation of services.

### ***Minnesotans experiencing the most frequent barriers to acute care transition***

The need for support in health care transitions, especially for youth and young adults with long-term conditions, has been widely acknowledged for 40 years by professionals across pediatric, adolescent and public health care (Blum et al., 1993; McGrab & Millar, 1989). Individuals experiencing behavioral health, IDD and/or co-occurring conditions are most profoundly impacted by delayed discharge and barriers to transition. (HANYs, 2022; Mirzaian et al., 2024). A common barrier for children with co-occurring mental health and IDD is the lack of experience and knowledge of professionals in addressing both IDD and mental health-related issues using interdisciplinary and multidisciplinary approaches (ASAN, 2024; Mirzaian et al., 2024). These children and their families are often unable to access adequate services. In one qualitative study, professionals participating indicated, “...*Many families have reported that they are unable to secure mental health services for their adult child who has autism, because all of the child’s behaviors are blamed on autism.*” (p. 6, Mirzaian et al., 2024). Rather than treat a mental health related symptom, some professionals consider the diagnosis of Autism itself as an explanation for behavioral challenges that are reported.

The fundamental isolation across disability and mental health services is due, in part, to the way services and funding are structured. In many states, it is not unusual for families or caregivers supporting a person with IDD to be turned away from mental health services with the message that their child should seek guidance from disability services. The family member is then told by disability service professionals that their child needs mental health services and that they cannot provide assistance. This longstanding fragmentation between disability and mental health reflects the ways in which funding streams are organized, how professionals are trained and the lack of interdisciplinary and multidisciplinary collaboration in many parts of Minnesota and across the U.S.

Another structural issue that makes systems change efforts more difficult is related to how professionals are funded by their organizations. For instance, mental health professionals in one state lose all contact with the children and adults they support once an event occurs that

causes placement outside of the home (Freeman et al., 2014). Billing and reimbursement by these mental health professionals must stop until the child or adult has returned to their home and community, during which time billing for services can resume. During transitions, funding is not available for mental health professionals to participate in planning meetings (Matthews et al., 2019).

Communication problems across and between different organizations and agencies are common when transition plans are needed. One mental health professional in a nearby state indicated that “...*but for some of the kids—particularly foster care kids...if they’re coming back to our area, we may not even know that they’re getting discharged ‘til they land on our doorstep.*” (Freeman et al., 2014, p. 54). Transition planning in rural areas often involve planning to bring a child or adult home from a long-distance placement. A Minnesota focus group in 2021 conducted by Freeman, Simacek and her colleagues highlighted this issue with participants recommending that streamlining memoranda of agreement instructions for agencies and systematic state support could help organizations to communicate more effectively when a child or adult is transitioning back home from a metropolitan area.

Minnesota faces extreme shortages of providers across the continuum of care, particularly in geographically dispersed communities (e.g., Greater Minnesota). Focus groups and interviews with Minnesotans representing rural areas of the state report challenges finding and accessing local professionals to provide support, in general, and within medical as well as mental health professional services (Freeman, Simacek et al., 2021). These rural Minnesota participants reported a lack of professional expertise in many areas of the state leading to problems accessing positive supports, psychological and therapeutic practices, medical and/or psychiatric services (Freeman, Simacek, Moore, & Duchelle, 2021; Stock et al., 2023). There are also operating differences across Minnesota counties related to policies, procedural systems, training and other issues that can cause challenges in Minnesota with one qualitative study reporting that the differences across counties can be make it difficult to support people needing services (Kim et al., 2021).

Children and adults, as well as their families and caregivers, who are part of the BIPOC community experience additional barriers in accessing high quality supports and services. Research studies report that complications related to multiple chronic conditions are more severe



and frequent among racial minority groups who are covered by Medicaid or Medicare (Zandam et al., 2024). Nationally, there are clear patterns of inequality present in how BIPOC individuals and families are served. Children of color from low-income families are often under-diagnosed (Tolan & Dodge, 2005) and have the highest unmet needs (Huang et al., 2005).

When BIPOC families seeking support from healthcare professionals raise concerns about developmental challenges their children are experiencing, they are not always believed. This, in turn, decreases the referrals made for mental health services at times when acute care experiences could be prevented. These disparities are a common experience in diverse communities where people tend to avoid accessing mental health and other services because of the negative interactions they experience (Turner et al., 2015).

A high percentage of members of the BIPOC community distrust service systems because of the failure of these systems to actively listen to their concerns and/or serve them appropriately (Edwards et al., 2023; Huang, 2002) resulting in people waiting for longer periods of time before seeking assistance. These families and caregivers are also more likely to drop out of services due to the failure of service providers to attend to specific cultural needs and perspectives. A call to address the barriers related to accessing services in marginalized populations throughout Minnesota is increasing, with attention to the disparities encountered by US-born Black Minnesotans, leading to Governor Walz stating in 2019, *“Disparities in Minnesota, including those based on race, geography (and) economic status keep our entire state from reaching its full potential....As long as these inequities impact Minnesotans’ ability to be successful, we’ve got more work to do”* (Pearson et al., 2023, p. 3).

### *Systems of care and strategies for coordinating services in the community*

Systems of care is an approach that uses flexible strategies to improve organizational relationships across an array of services and systems to coordinate support for children and adults (Hernandez & Hodges, 2003). An effective systems of care effort will include the formation of teams at local, regional and state levels to implement interagency collaboration and service coordination (Kutash et al. 2006). Children and adults who experience barriers to transition are often receiving services across various service systems. Examples of these systems include a) education, b) primary care, c) mental health, d) child welfare, e) juvenile

justice/justice system, f) substance abuse treatment services, g) developmental disabilities services, h) early childhood services, i) recreational services, j) vocational services and k) transition services (Tyson & Punnose, 2024). Effective communication across these systems is essential for a person who is transitioning from the ED or hospitals back to a home in the community (see Appendix A).

Although each of these services are important and play a role in stabilization, maintenance and overall wellness, transitioning from the ED/hospital or other settings can be difficult for people receiving services and their families to manage. These transitions require a complex planning process where communication often breaks down across multiple systems (Matthews et al., 2019).

For instance, the qualitative study conducted by Matthews and her colleagues found that it is not uncommon for a mental health professional to hear about transitions occurring suddenly with no warning, “...a parent will call me and say, so-and-so’s getting out today. And they have no prior warning...” (p. 937). Without planning and preparation, individuals may return to the ED or hospital quickly because adequate supports are not yet in place. Coordinating systems of care using a continuum model for care coordination can address the challenges family or caregivers face navigating services for their loved one.

### *Continuum of care*

Children, youth and adults who need more intensive supports and/or engage in challenging behavior are served across a continuum of care that ranges in intensity, interventionist and setting in which it is delivered (see Figure 2). When defined broadly, care (or interventions, supports and services) can encompass a variety of intervention providers (e.g., therapists, clinicians, special educators) whose roles are to deliver, oversee or direct the care. They are also served by care navigators (e.g., county case management, special education case manager, care coordinators) whose role is to help connect the person with needed support, monitor and follow up as changes to the plan are needed, and the stakeholders, including the person themselves, their family or caregivers and other relevant members of their community, whose roles are to advocate for care, communicate needs, follow through on recommendations, etc.

When care is delivered throughout the continuum, supports can be ‘stepped up’ (increased in a dimension of care) and ‘stepped down’ (decreased in a dimension in care) in a dynamic manner as needed to best meet an individual’s evolving needs. The services and supports are the steps, and the people supporting the movement from one step to the next are the navigators.

As a person prepares to leave an acute care setting and transition back to their community of choice there are several important considerations. First, there needs to be establishment of the supports and services that the person will receive in the community and the community providers need to be ready, with an effective level of knowledge, training and skill in positive supports for the person. To be effective, this support needs to be coordinated and planned so that strategies and interventions that have been effective in one setting translate to the community.

Second, there needs to be on-going monitoring of fidelity to important components of the plan and careful monitoring of the person’s progress so that challenges can quickly be addressed prior to escalation to crisis. Implementing these core components poses many challenges. Considerations during this phase include, (a) a firm understanding of the individual’s specialized needs, (b) a clear list of resources and staff training needs at the site where the individual is transferring, (c) an assessment of service provider experience and capacity that are involved and (d) access to the history of prior implementation plans (e.g., functional behavioral assessment, cognitive behavior therapy, person-centered or wraparound plan, positive behavior support plan, psychological reports).

### *Coordinated specialty care models*

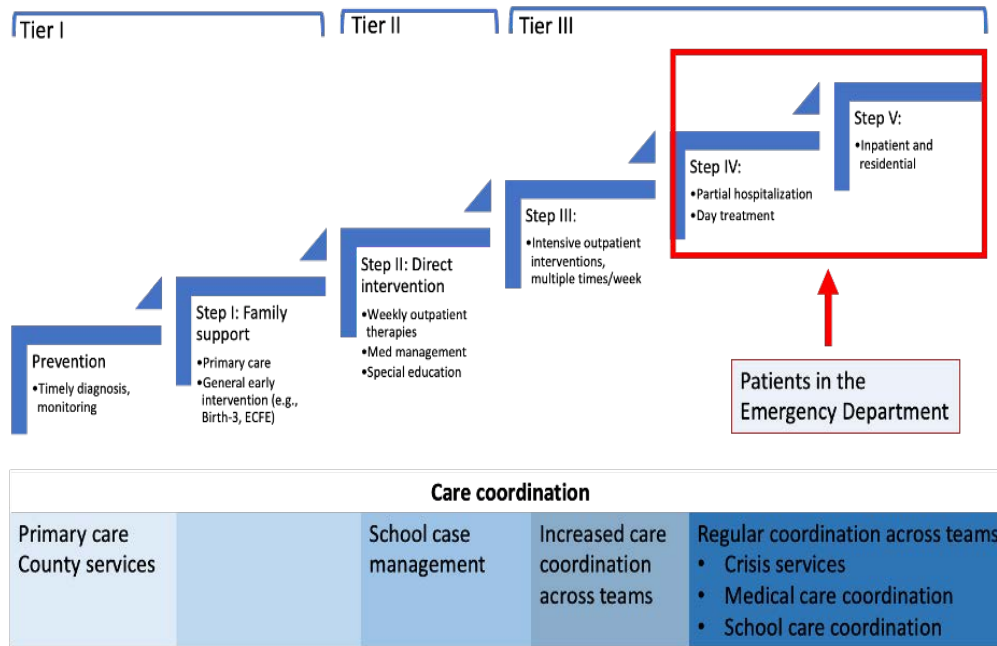
Although fidelity elements will vary across programs and must include individualization, core elements of multi-element coordinated specialty care models that people with more intensive support needs including severe challenging behavior may need include the following: (a) centering/partnership with the individual and their family (and/or care providers), (b) accounting for and promotion of time-sensitive care (e.g., overcoming of care barriers for provision of immediate support), (c) a team approach comprised of multi-disciplinary expertise with proactive and regularly set meetings and coordination and (d) wraparound training of the

team that will be supporting the individual (Addington et al., 2018; Read & Kohrt, 2022; National Academies of Sciences, Engineering, and Medicine, 2023).

For example, the Specialized Treatment Early in Psychosis (STEP) model demonstrated that a Coordinated Specialty Care model included key components related to psychotropic medication management, therapeutic approaches for the individual (e.g., cognitive behavioral therapy) and the family (i.e., family psychoeducation) as well as case management to support the transition and success of the individuals back into the community setting (i.e., school or work) led to lower rates of re-hospitalization and increased success in the community (Srihari et al., 2015).

**Figure 2**

*Serving children, youth and adults via a continuum of care*



Another example is Navigate, which also takes a multidisciplinary and team approach to supporting people in early intervention for psychosis and uses elements of medication management, individual treatment and family psychoeducation, to address support services for transitioning back to the community. The model also specifies the regular and planned transition supports from the multidisciplinary team (Rosenheck et al., 2016). This model was shown to be effective at reducing acute care needs and improving quality of life that resulted in cost savings.

The key elements associated with these specialty care models will likely prove to be useful in supporting transitions from acute care settings for some children and adults.

Assertive Community Treatment (ACT), a team-based approach for supporting people with serious mental illness, is considered an important positive support in Minnesota. The model includes a key contact person who coordinates an array of services offered. [ACT](#) is a practice used to assist people with mental illness as they navigate challenges related to transitioning to their homes and community (Mancini et al., 2009). This intensive outreach-based approach includes a 24/7 on-call system, a multidisciplinary team that includes psychiatrists, nurses, social workers, occupational therapists, substance abuse counsellors and peer support specialists using a low staff-client ratio to ensure support (Bond & Drake, 2015; Deitrich et al., 2017). ACT team members include family members, friends, doctors, mental health professionals and nurses. Supports are put in place based on unique behavioral health needs, team members are available when a person is feeling upset, is experiencing a psychotic episode, needs help related to substance abuse issues or is dealing with work or relationship problems. The goal is to help each person meet their own personal goals and handle the everyday problems associated with daily life (Dixon, 2000). Goals can include making new friends, getting to work on time, taking medication and staying healthy. ACT has been shown to be a practice that assists people with severe mental illness to be successful at home and at work while improving their quality of life (Mueser et al., 1998).

Another practice, wraparound planning, helps to ensure that the services a child or adult requires is coordinated and that collaborative approaches are used amongst the providers involved. Wraparound planning processes are driven by the voice of the person and individuals who are important to that person, involve a team approach and build on the strengths of the person and their community (Bruns, 2004). In addition, individualized wraparound plans are culturally competent and based on the strengths of the child or adult, with a focus on improving social, emotional and quality of life outcomes. Important considerations for people transitioning out of acute care settings should include types of differing challenging situations that may exist in the community, such as the involvement of multiple team members, different settings (e.g., a home setting, a school setting and varied other community locations, such as stores and recreation locations). Since risk factors for youth exist across individual, family, community,

local environment and societal issues can shape mental health outcomes (General US Surgeon, 2021), wraparound efforts require a biobehavioral approach that addresses these social and environmental factors (National Academies of Sciences, Engineering, and Medicine, 2023).

### *Evidence-based strategies for addressing effective transitions*

There are a number of evidence-based practices (EBPs) that assist children and adults in improving quality of life, expanding social growth and learning to regulate and manage strong emotions. The term evidence-based practice refers to the extent to which research has been used to document how well an approach improves outcomes for a child or adult and is based on a scientific method that includes showing that a given approach has been demonstrated to work with a diverse population of people (APA, 2024). Applied behavior analysis, assertive community treatment, cognitive behavior therapies, culture of safety and positive behavior support are just a few examples that are found in Minnesota. Practices that are person-centered, culturally responsive, evidence based or promising, include systems for collecting fidelity and outcome data, and are often implemented with other similar practices are referred to as Positive Supports (Freeman, 2016). The term, positive supports, is used in Minnesota when referring to EBPs.

One of the well-known challenges associated with positive supports is that the research needed to establish a practice as effective is not the same as the type of research needed to demonstrate how it can be implemented in everyday settings by families, providers and other individuals (Fixsen et al., 2019). Translating research to practice has not kept pace with the need states have for effective positive supports in applied settings (Bruns et al., 2016). One of the challenges mentioned in Minnesota, across states reports and in the literature across fields is that children and adults are often encountering barriers related to the lack of effective services for people who need more tailored and intensive positive supports (HANYS, 2022; Stock et al., 2023). Traditionally, organizations addressed new positive supports by sending staff to workshops and hoping this would be sufficient for implementation (Sailor et al., 2000; Smith et al., 1992).

A three-tiered public health model framework is now used in many education, mental health and human service systems to establish and deploy positive supports across a continuum

of increasingly intensive interventions (Gorden, 1983; Walker et al., 1996; WHO, 2004). At Tier 1, all people (staff, managers, family members/caregivers and people receiving supports) in each setting work together to improve their social and emotional skills by building positive relationships, recognizing/celebrating success and encouraging people to improve the quality of their lives. Tier 2 strategies are used to monitor and problem solve when minor challenges occur that have an impact on social interactions and quality of life. Simple strategies are used at Tier 2 to help people who need a little more support. Data is used to identify people needing support as soon as possible before a crisis occurs. Tier 3 interventions are the most costly to implement. There are times when people need more intensive and individualized support at Tier 3. A few people will need more intensive plans at Tier 3 and a more structured plan to address complex challenges during life transitions. At Tier 3, a team forms around a person to help in problem solving. Different types of positive supports are used at Tier 3 based on each person's strengths and needs.

There are three statewide training and technical assistance infrastructures currently in place in Minnesota using a tiered approach (Freeman, Danov et al., 2021; Freeman, Simacek et al., 2021; Johnson, 2017; McIntosh et al., 2010). Early childhood systems, school districts/schools, provider organizations and other systems engage in these long-term sustainable efforts to improve outcomes for children and adults by applying a three-tiered model for implementing positive supports such as positive behavior support, trauma-informed supports and person-centered practices. [School-linked mental health](#) services in Minnesota improve access to positive supports and are linked to tiered implementation efforts in education. Minnesota statewide efforts support implementation of multiple practices that are integrated into schools and organizations, an approach referred to as multi-tiered systems of support (McIntosh & Goodman 2016).

Implementation science (Fixsen et al., 2019) is another important field of study used in Minnesota as the framework for implementing positive supports at a scale of social significance (local, regional and statewide levels). Implementation science is a field that has evolved to address the challenges associated with implementing evidence-based practices in homes and community settings (Fixsen et al., 2005; Fixsen et al., 2013). The leaders of implementation science are interested in the features associated with sustainable and long-term use of EBPs.

These researchers conducted a synthesis of the literature to understand the most important features associated with adoption of positive support practices whether these efforts occurred in education, IDD mental health, juvenile justice or any other human service organization (Fixsen et al., 2005; Fixsen et al., 2009). These core components are called implementation drivers (Metz & Bartley, 2012). Three major drivers are related to staff competency, organizational issues and leadership-level skills.

Actions, mechanisms and resources needed to improve the necessary knowledge and skills of people receiving services, staff, managers/supervisors and administrators implementing tiered support models are all considered “competency drivers” in implementation science (Fixsen et al., 2010). Four elements of competency drivers outlined by Fixsen and his colleagues include performance assessment, selection, training and coaching (see Figure 3). “Organizational drivers” are the systems elements used by teams to establish a training infrastructure needed to support an EBP (Metz & Bartley, 2012). The organizational drivers are used to monitor progress and maintain feedback communication loops that allow teams to share information in a transparent manner (Bertram et al., 2011). The leadership levels skills in implementation science refer to “*technical* challenges” and “*adaptive* challenges. These types of leadership skills explain the different types of problem-solving leaders need throughout implementation (Metz & Bartley, 2012). Technical challenges are associated with basic management and facilitative administrative skills needed to manage and coordinate implementation efforts. Adaptive challenges are more complex, involving more complex social and contextual problems.

In the past, the common approach organizations took was to address cultural responsiveness by hiring a professional with expertise to provide an annual workshop. This approach does little to change the behavior within organizations (Freeman et al., 2023). Researchers have studied whether presenting data without any other culturally responsive interventions in a system would have an impact on equity-related outcomes and found only minimal changes occurred (McIntosh et al., 2020). Organization-wide approaches including interventions such as relationship-building are also needed to encourage active listening and empathy, share stories/experiences of people and facilitate action planning within an organization (Fallon et al., 2023).

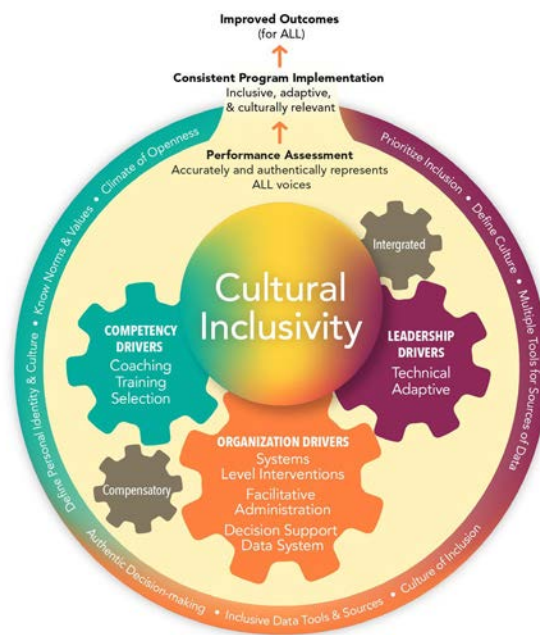


Figure 3 provides a more comprehensive strategy for integrating cultural responsiveness across each of these drivers to ensure organizations, regions and state training systems are improving cultural competence with the context of positive support practices (Freeman et al., 2024). Embedding culturally responsive strategies within competency, organizational and leadership drivers and throughout the implementation of positive supports increases the likelihood that organizations will be able to address implicit bias, identify policies that have a negative impact on marginalized communities and create a climate that welcomes diversity. Researchers and trainers in positive supports have worked hard to build resources that can be used within implementation science including fidelity of implementation and assessment tools, curricula that teaches staff to identify times when implicit bias may be more likely to occur, coaching and training systems to teach self-awareness and empathy and other efforts to embed cultural responsive practices into implementation (Ferro et al., 2023; Gage et al., 2019; Levenson et al., 2021; McIntosh, Barnes, et al., 2014; McIntosh et al., 2020).

Another important way to improve acute care transitions is by using data-based decision making as one of the organizational drivers in implementation science to establish unified statewide measurement, developmental evaluation planning, as well as local, regional and statewide problem-solving teams.

**Figure 3**

*Integrating culturally responsive practices into implementation science drivers*



### *Unified measurements systems*

The literature on barriers to transition from acute care ED and hospital settings call for a focus on better monitoring and evaluation with a focus on sustainability and long-term problem solving (Cadel et al., 2021). This section of the report is organized by (a) the need for data-based decision making and evaluation, (b) the importance of unified and clear operational definitions and measures related to acute care transitions and (c) establishing organizational, regional and statewide systems for sharing data.

### *Data-based decision making and evaluation*

It is challenging to fully understand the scope of the problem in Minnesota related to the multiple and complex needs for improving effective transitions in acute care setting across populations of people experiencing different types of acute care barriers and who represent various ages, ethnicity and race, medical diagnoses and geographic diversity. Important contributions have been made by different sectors including groups such as the Minnesota Hospital Association (MHA), the Minnesota Medical Association (MMA), organizations dedicated to evaluation such as Wilder and the state's work on reporting via the Department of Health. One way to improve communication across the different organizations and systems is to create opportunities to meet and review data that are gathered based on a common language.

Interagency systems change requires a common language across different state divisions, hospital and provider organizations, people with lived experience, their families and caregivers, universities, civic organizations and other community partners (Freeman et al., 2009). Building a common language and common measurement systems allows for information to be shared and discussed. Adding ongoing meetings that form “feedback loops” for reviewing data and making decisions together helps build a common understanding and experience across the different partner groups — e.g., people with lived experience, families/caregivers, hospitals, behavioral health professionals, state leaders, providers, etc. (Freeman et al., 2009).

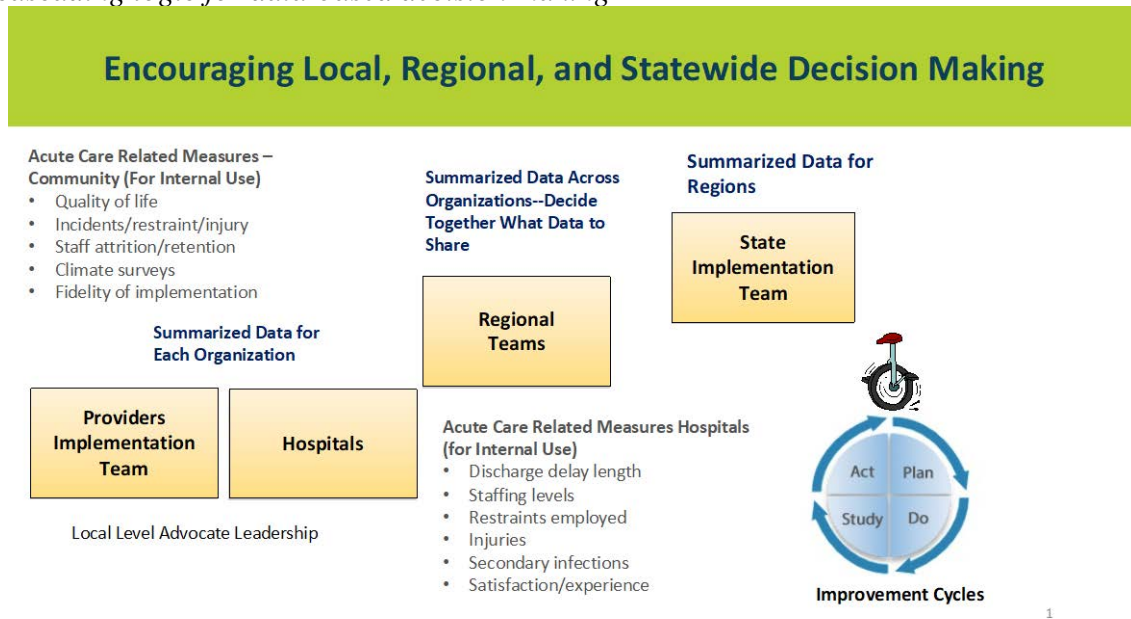
To accomplish this task, an evaluation plan is needed. Evaluation allows the state to establish goals and map out a logic model that will help implement changes in acute care transitions over time. Logic models can be used to show the relationship of acute care interventions to the resources and actions that are taken to address the barriers to transition. They

are described as a road map or pathway to show how the state will reach its intended outcomes. Statewide logic models have been used in a number of states to implement different positive supports using implementation science methods (Freeman et al., 2009; Matthews et al., 2019).

*Unified and clear definitions related to acute care transitions*

Scoping reviews investigating acute care and barriers to transition both within and across countries have highlighted the need for consistent definitions of key terms associated with discharge delays (Abdelhalim et al., 2023; Cadel et al., 2021). The differences in how discharge delays are measured can contribute to confusion and/or difference in interpretation (Glasby et al., 2004). Fortunately, leaders within Minnesota have already conducted research related to this topic and can contribute to operational definitions for the study of discharge delays (Dillon & Thompson, 2016, Dillon et al., 2024; Schindler, 2024).

**Figure 4**  
*Using cascading logic for data-based decision making*



### *Organizational, regional and statewide data collection*

Establishing local, regional and statewide systems for monitoring individuals experiencing discharge delays and/or problems in effective transitioning into the community. Figure 4 is a visual adapted from an EBP related to positive support that is using implementation science to ensure that information for data-based decision making is established in a manner that allows for information to be shared at local, regional and statewide levels. Figure 4 outlines how training and technical assistance, policy and systems change efforts can be used to organize the collection of data. All organizations use data and are required to report information. Agreements across these groups lead to summarized data at the regional level. These summaries help regions to share priorities, action plan and make recommendations to state leaders. Once regional data are shared, the state team engages in the same activities, summarizing data across regions to report an overall state report. Since the individuals experiencing barriers to transition vary, the data systems that are needed must be organized to address different target populations, age ranges, diagnoses and health challenges, and types of organizations providing services.

### *Measures for culturally responsive evaluation planning*

Measures dedicated to monitoring cultural responsiveness and equity in services are important elements of the evaluation of acute care barriers to transition and any future action plan implementation. The Minnesota report written by Chomilo (2022) provides an example of important strategies used when attempting to fully understand the experience of groups of people who may traditionally not have been heard in statewide planning. The report indicates that it “... *aims to continue the evolution of how policy within the Minnesota Department of Human Services (DHS) is designed, proposed and considered by intentionally striving for community co-creation.*” (p. 1). In prior reports funded by DHS, focus groups in Minnesota exploring the implementation of positive supports, professionals have advocated for the following:

- Listening sessions dedicated to specific in rural areas with people representing traditionally marginalized communities.
- Recruitment of people from underrepresented populations to participate in co-creations of new services and systems.
- Intentionally building relationships as a dedicated activity.

- Reaching out to communities rather than expecting them to seek out opportunities to provide feedback (Freeman et al., 2021).

Relationship building and co-equal leadership with people representing the diversity of Minnesota is an important first step to establish “reciprocal trust” that might lead to any effective measurement systems that are created (Fallon et al., 2021). The Minnesota Governor’s Council on Developmental Disabilities (2023) has indicated that *“If progress in reducing discrimination in Minnesota is the goal, then there needs to be a research system put in place for obtaining baseline measures of incidences of discriminatory behaviors and practices and tracking changes over time.”* (p. 2, MN Governor’s Council on Developmental Disabilities, 2023).

### Evaluation methods

Information was gathered and shared with the ACTAC across eight meetings starting in November 2023 through September 2024. This information assisted the council as they considered action-plan recommendations in this report. Professionals from the ICI at the University of Minnesota, conducted focus group and interview sessions, analyzed all data gathered by the council and summarized the results. The methods used to gather and summarize these data are described in this section of the report. The methods section describes participants involved in ACTAC information gathering, procedures for focus group and interview sessions, key public reports summarized and the overall mixed methodological evaluation strategies employed to analyze the results.

The evaluation questions the Acute Care Transitions Advisory Council was asked to explore and subsequently provide action-planning recommendations are outlined in Table 2. Multiple sources of data were used to address these questions including:

- Council related meeting transcripts and public comment.
- Focus groups and interviews with community partners across the state.
- Quantitative and descriptive public reports and/or presentations of data on the topic of discharge delays.
- Public reports on disparities related to geographic, race, ethnicity and other marginalized populations in Minnesota.

The plan for evaluation was submitted to the University of Minnesota Institutional Review Board (IRB). The IRB process is used to ensure that the rights of participants and data collected throughout the study are secure and that individuals are protected from potential harm related to study activities. The IRB confirmed that the study was exempt from full review due to the minimal potential for harm to participants. However, it is important to note that due to the short timelines associated with the council’s activities, focus group and interview data related to people with direct lived experience were not collected. Involving individuals with lived experience, some of whom with various disabilities, required a more rigorous protocol with a longer timeline for completion.

The council strongly recommends that additional steps be taken to gather information from children and adults who have been directly impacted by barriers to transition following an acute care visit to the emergency room and/or hospital. This evaluation is considered incomplete without this essential information.

**Table 2**

*Council evaluation questions outlined by legislature*

Evaluation Questions	Data Sources
1. What are the council’s recommendations for building regional capacity for acute care transitions?	<ul style="list-style-type: none"> <li>• Interviews and focus groups</li> <li>• Past reports on positive supports</li> <li>• Data from state implementation</li> <li>• Council and community public feedback</li> </ul>
2. What measurement and evaluation system should be employed to support an implementation science approach to addressing the barriers to transition for individuals who experience acute care crises?	<ul style="list-style-type: none"> <li>• Quantitative discharge data (public reports &amp; presentations)</li> <li>• Interviews and focus groups</li> <li>• Council and community public feedback</li> </ul>
3. How can the state address geographic, racial, and ethnic disparities in addressing acute care transitions?	<ul style="list-style-type: none"> <li>• Interviews and focus groups</li> <li>• Public reports</li> </ul>

Evaluation took place starting in spring, 2024 beginning with a literature review across the topics outlined in the introduction of this report and an analysis of public reports from

Minnesota and other states. Focus groups and interviews were completed from August 2024 until September 2024. Thematic analysis began immediately in August 2024 and was conducted in an ongoing manner until the recommendations were finalized by the council.

### *ACTAC meetings*

Acute Care Transitions Advisory Council's meetings used a modified Roberts Rules of order to run meetings with business, invited presentations and activities, and discussion occurring across eight meetings. Meetings were streamed live after Nov. 6, 2024 and included open sessions. Quorum was met at every meeting that was scheduled. Table 3 summarized dates of meetings and number of council members in attendance.

### *Participants recruitment*

Participants in the evaluation included community partners across the state of Minnesota with experiences related to barriers to acute care transitions. These participants included people representing family members and/or caregivers, individuals representing Indigenous people/tribal nations, counties, providers and hospital professionals. Flyers were created and distributed, inviting people representing the community partners listed in the purpose section to sign up for either focus group sessions or interview sessions via Zoom. The flyers were distributed via state and local listservs, professionals involved in acute care related work, websites and members of participants representing different community partners. Focus group flyers included a registration site where people registered to participate and subsequently received calendar invitations with a zoom link (the Appendix B contains the flyer used in this evaluation).

There was a total of 64 individuals who contributed to this evaluation via council meetings, focus groups and interviews. Council members (N=36) included the individuals selected as acting members, as well as invited presenters, state representatives, university personnel and staff supporting others on the council. Some council members participated in all meetings while others attended one or more meetings. There were eight focus group participants (five individuals in one session, three in the second focus group) and a total of 20 people recruited for interviews (one person contributed to both council and interviews but was counted

once). One individual with lived experience served as council member. A pseudonym was assigned for each participant and information gathered describing the person’s geographic location, role and type of data source. The list of participants, how they participated, their roles and geographic location are available in Appendix C.

***Procedures for focus group and interviews***

Two, two-hour Zoom-based focus group sessions were held with seven to eight people attending from across the state. One or two university professionals facilitated sessions with one person leading the conversation and another taking notes. Interviews were conducted by Zoom although telephone-based interviews were offered based on participant preference. Interviews were offered for participants who did not want to participate in group discussion or could not make the dates set for the focus group sessions. Interviews were approximately 45 minutes to an hour in length, based on the comfort level of the participant. The interviews, public meetings and focus group transcripts were recorded and zoom chat information from public meetings were used in the analysis.

**Table 3**  
*ACTAC meetings and topics*

<b>Date</b>	<b>Number of Council Members</b>	<b>Topics Addressed in Meeting</b>
Nov. 6, 2023	14	Introduction to ACTAC goals.
Jan. 25, 2024	14	DHS legislative process.
Feb. 29, 2024	13	Complex Transition Team introduction.
April 30, 2024	13	Positive supports and implementation science.
June 4, 2024	13	No invited presentations. Focus group and interview outreach and questions.
July 15, 2024	13	Minnesota Department of Health discharge delay study & Minnesota Hospital Association presentation.
Aug. 14, 2024	14	Data summarized from DHS Complex Transition Team.
Sept. 11, 2024	12	No invited presentations. Council discussion on recommendations.
Sept. 30, 2024	12	No invited presentations. Council discussion and vote on report and recommendations



### *Evaluation questions*

The evaluation questions developed by the council for focus group and interview sessions included the following:

1. What are the most common barriers to acute care transitions that occur in your region of the state?
2. What challenges have you encountered related to this topic personally or in your professional role?
3. What could be done to improve transitions for people who encounter barriers returning home? Are there promising practices or facilitators (i.e., things that have improved transitions home) that you can share?
4. What measures or data sources would help the state in better understanding the challenges associated with transitions from acute care settings?
5. Have you experienced geographic, racial and ethnic disparities personally or in your professional role at work?
6. How can the state address geographic, racial and ethnic disparities in addressing acute care transitions?

All data sources including public meetings were de-identified including names, organizations, towns and references to other people to protect confidentiality. The initial recordings were deleted once transcripts were de-identified and confirmed for accuracy.

### *Summary of key public reports and data presentations*

Facilitators of the ACTAC conducted an informal literature search on the topic related to barriers to transition from the emergency room and/or hospital. Search terms included were used in Google Scholar and other University of Minnesota library search systems including: acute care transitions, alternate level of care, emergency room/hospital discharge delays, bed delay, hospital boarding, transition planning (and related subthemes: Autism, IDD, emotional behavioral disorder, evidence-based practices and acute care discharge, older adults, complex health issues, mental health), systems of care, implementation science, equity and disparities (and related subthemes: across services and supports, health care, BIPOC community), stepped down care, complex health care and acute crises, interventions, evaluation of acute care crises.

All articles were uploaded in folders under varying categories of the search (e.g., Minnesota reports, other state reports, emergency room (ED) boarding and hospital discharge delays, older adults, etc.).

### *Quantitative and qualitative Minnesota data on discharge delays and health equity issues*

Minnesota public reports related to discharge delays were collected for review. Each public report selected for analysis was summarized using a worksheet to capture core information about the type of data reported, rigor of methods, results and recommendations made by the authors. A copy of the worksheet appears in the Appendix D and summarized data are available upon request. The list of reports selected for descriptive analysis is included in Table 1. A total of six public reports or presentations were summarized related to hospital discharge delays/emergency room boarding. Three reports including data related to health equity and disparities in Minnesota were included in Table 1 as well. Other Minnesota reports were used within the report process and informed the literature review and recommendations made by the council.

### *Mixed methods evaluation design*

The council report relied on methodological foundations of mixed methods design to analyze council transcripts, focus group and interviews, and public reports on the topic of acute care barriers to transition (Cresswell, 2014; Cresswell & Clark, 2011). The mixed methods approach merged the results of public reports, council meetings, focus group sessions gathering feedback from the community and interviews with individuals with experience associated with barriers to acute care transitions. Figure 5 provides a visual description of the steps occurring across the evaluation. The methods included an inventory of existing data sources related to acute care barriers to transition as a first step in evaluation. The mixed methods design in Figure 5 shows that the design is convergent with quantitative and qualitative strands collected and analyzed concurrently as separated processes. The major findings were then triangulated across these different data sources (Cresswell, 2009). Data were merged to assess possible convergence or divergence of findings, contradictions occurring across sources of analyzed data or the identification of relationships that appear across the quantitative and qualitative data sources

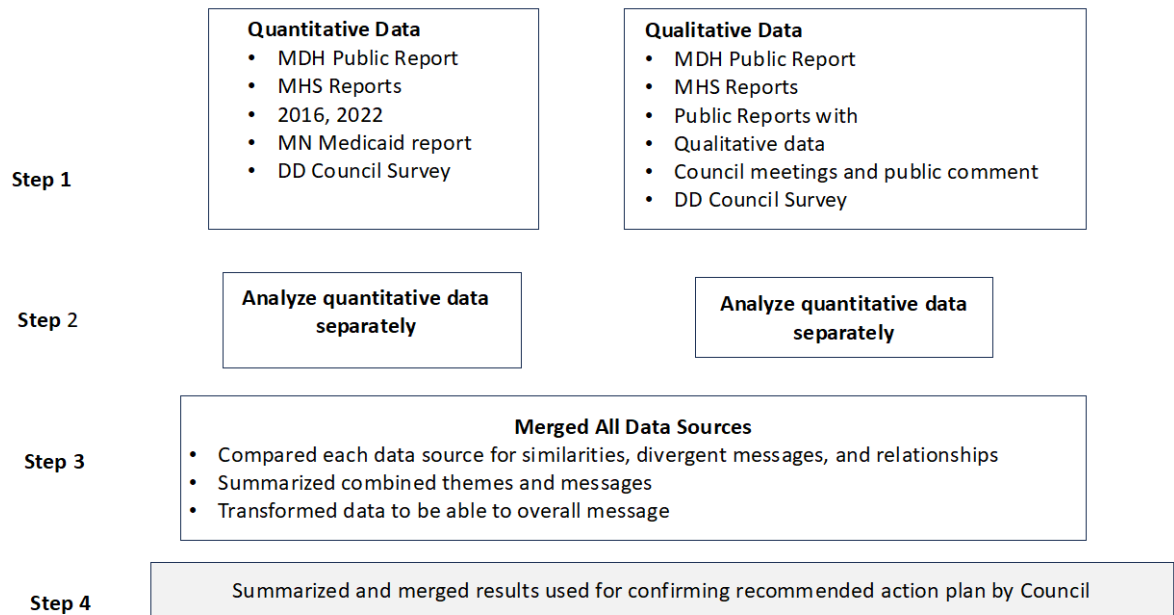
(Cresswell & Clark, 2011). Themes that appeared across multiple sources of data, across the state and by multiple community partners helped the Council better understand the internal validity of information gathered its potential import.

*Qualitative thematic analysis of multiple data sources*

The multiple transcribed data sources (i.e., meetings, focus groups and interviews) were analyzed using qualitative data analysis methods defined by Creswell (2009). An inductive approach was taken to establish codes used and the themes that were identified by the authors of the report (Braun & Clarke, 2006; Patton, 1994). This means that the themes identified were linked to the data itself rather than the authors establishing codes in advance by three major questions posed in Table 2.

**Figure 5**

*Mixed methods design for merging qualitative and descriptive report data*



The transcripts were broken down by themes with codes indicating what data source was used as each code was identified. For each coded section of the transcript, the pseudonym, data source and date, role of the person (i.e., county, hospital, university, etc.) and location in the state (i.e., metropolitan area, northeast, etc.) were noted using a code to represent each category (e.g.,

Lyra-CM-Nov6-University-Metro). This allowed authors analyzing the coded content to quickly identify the main characteristics associated with each coded section of the transcript. As more data was collected, potential categories and themes were discussed, identified, organized, triangulated and prioritized (Merriam, 2009; Creswell, 2009). The codebook used in the evaluation is available in the Appendix E.

## Results and findings

This section of the report summarizes the major findings of the mixed methods evaluation study. Results are organized by each type of data source:

- Council meeting, focus group and interview thematic analysis.
- Descriptive analysis of public reports:
  - a) Emergency room and hospital discharge delays.
  - b) Related to geographic, ethnicity and race disparities in Minnesota.

Each data source is summarized and a merged results section combining the integrated data sources is provided.

### *Council meetings, focus groups and interview thematic analysis*

Since the coding did not change significantly across data sources, the results section has summarized council meetings, focus groups and interviews together. Four primary themes evolved from the data sources related to acute care action planning activities:

- Characteristics and description of people experiencing barriers.
- Barriers encountered, before and after transition.
- Interventions and strategies for addressing barriers.
- Healthcare disparities related to ethnicity, race and geographic areas of the state.

A summary of the major four themes and each of the corresponding subthemes are presented in Appendix E and represent the contributions from community members engaged in this action plan. The barriers described by each of the participants in the council meetings, focus groups and interviews reflected their direct experiences related to barriers to acute care transitions. The subtheme patterns broke down the overall four major themes into smaller more

specific topics and issues. The results section describes these four overall themes introducing some of the subthemes for each section. More details about the overall and subthemes are available upon request.

### *Characteristics of individuals experiencing barriers to transition*

Children and adults across the lifespan were described as experiencing discharge delays from early childhood to older adults over 65 years of age. However, no really young children (ages 1-3) were discussed in this report. Participants discussed the challenges associated with the many diverse characteristics of people (age, race/ethnicity, gender, location in state) experiencing these barriers to transition and the corresponding complexities that result in delays moving back home or into alternative placements (inpatient unit, psychiatric residential treatment facility, foster care, etc.).

The subthemes in Appendix E list the various types of participants who are more likely to face challenges in transition. One participant summarized some of the more common characteristics or defining features “... *people who are in an acute care setting, so a hospital bed or emergency department...[who] no longer have an acute care level of need...or weren't appropriate for hospital admission in the first place and [have] difficulty accessing community supports and discharging to the right level of care, often, because they've been denied by...a high number of providers... They may engage in serious aggression or self-harm. They've often received a service termination notice from their current providers because of some of that aggression...or they need supports...that are very difficult to find in the community, like maybe a two-to-one staffing ratio or something like that.*” (Luca, council participant).

Participants described children under the age of 20 as more commonly experiencing barriers when living in family or foster homes and may later be placed in group residential settings, psychiatric treatment facilities or inpatient settings. Children who are citizens of tribal nations, Black or African-born children were described as over-represented and often had a diagnosis of Autism or IDD and/or other co-occurring diagnoses. Aggression, property destruction and self-harm/suicide attempts or self-injury are often reported as behaviors that are making it more difficult to find placements for children.

Participants also discussed the barriers to transition that adults over 20 years old have experienced. Adults with mental health-related diagnoses and/or substance use disorders (SUD) frequently encounter transition-related challenges. One focus group participant stated that she and her colleagues struggle “*sometimes to find placements for people with kind of an unfortunate combination of physical and mental health and sometimes chemical dependency issues.*” (Val, provider, focus group participant). Val also indicated that “*we have people who, for all practical purposes will discharge...really, they're discharging to homelessness. They're leaving detox to homelessness, and that makes it really hard to...help people get their needs met and just stay safe.*”

The issue of being without a home when transitioning out of acute care was described as particularly true for adults representing tribal nations, “*we have a lot of folks, and the people who end up in the hospital, of course, are the ones who are most vulnerable who are more likely to be houseless.*” (Nora, interview). Nora went on to say that although the number of people representing Native Americans [experiencing acute care delays and not having a home to transition to] are low, however, “*...that's a large portion of our community relative to that of Whites, you know, that might happen to like 20 Whites ...but for us, just a couple is a large portion of our population...*”

Participants discussed the challenges associated with transitions for individuals who are receiving bariatric care and need supports in order to transition from the ED or hospital. Appropriate housing, transportation and other supports were discussed as important considerations related to bariatric service barriers to transition and readmittance to the ED or hospital for this population.

Older adults (over 65+) were also described as experiencing barriers related to transition. Participants described issues that can create barriers for older adults including diagnoses related to dementia, depression or other diagnoses and/or substance use disorder. An older adult who arrives in the ED or hospital may no longer be safe at home without additional supports as part of a transition plan. This places pressure on home health providers to protect individuals.

One provider stated during a council meeting that when older individuals do not have a safe plan for transitioning home, “*... what we experience sometimes is that individuals are being discharged from a hospital setting to home care. And they're really not...If there's not a safe care*

*giving plan in place...they're really not an appropriate referral for home care and then we're stuck in a situation with patients that are medically fragile, complex, and may not have a safe caregiving plan in place in the home...*" (Zoe, council participant). One barrier that came up across focus groups, interviews and within the council was how the lack of time for transition planning increases the likelihood of re-admittance to the ED or hospital.

Discussion in the council meeting focused on how to proceed given the great diversity of challenges, age ranges, systems and characteristics of people involved. This, in turn, led participants to talk about the differences encountered across Minnesota regions *"...Like for some hospital systems...the challenges [may be] guardianship and dementia... related behaviors for seniors...then others it's children with just a mental health diagnosis,...So I would just say that I feel like part of the data question...I think that we have to let the data drive us ..."* (Luca, council participant).

As an example, several participants discussed how closures of SUD-related treatment facilities in one region and hospitals in another area or region impacted barriers to transition. Another participant indicated that availability of nursing home beds was a big problem for the region. A number of participants felt that these regional data patterns are helpful in understanding overall statewide patterns.

Participants indicated that multiple diagnoses and/or complex medical issues complicate transition planning. For instance, one participant described a person experiencing challenges in managing diabetic symptoms while also addressing serious chemical dependency issues. A provider may be well-suited to address one issue while being under-prepared for another complex behavioral or medical issue. A participant provided an example of this by indicating that children or adults with IDD and SUD can create challenges for home and community-based providers, *"... we're learning how to do a lot of the...positive behavioral support stuff to serve people with behavioral complex behavioral needs. But when you add chemical dependency to it, it is one of the things that at least my experience is, we're not very good at it...It is just a challenge for us, and it's hard to partner with people or find people that can help us..."*(Xael, focus group).

Another person representing medical health care for people from tribal nations indicated that individuals from Indigenous backgrounds often reflect higher disparities resulting in

multiple concurrent conditions and that this results in a higher number of complexities required for transition and continued health care treatment. The number of complex healthcare challenges a person may be addressing in their lives has an impact on whether they will experience barriers in transition from acute care.

### *Barriers encountered in acute care transitions*

Numerous barriers were noted by participants who work with and support children and adults across the lifespan. These barriers are listed as four subthemes in Appendix E: a) coordination and communication, b) funding/policy barriers, c) challenges accessing community services and d) discharge delays.

### *Coordination and communication problems*

Many participants described the need for increasing coordination and communication across systems to address the complexity involved in improving transitions for children and adults across the lifespan. Participants acknowledged that state leaders, providers hospitals, counties and any other systems responsible for supporting people in need of transition must work together to solve the complex challenges associated with transition barriers individuals experience. One state leader stated that *“It's going to take the whole community working together across all different sectors to figure out how to help people move from hospitals to appropriate community-based settings”* (Bua, council participant). However, communicating across the numbers of state systems, providers, clinics, hospitals, lead agencies and other sectors was described as very challenging by many participants since each organizational system tends to have its own language, systems and processes. A physician interviewed described how she cannot access her clinic data from the hospital because of the electronic systems involved, describing how she must access *“a certain computer in a certain area”* of the hospital (Nora, interview participant). She went on to say that, *“We have all these systems competing against one another to be the one that each clinic or hospital uses...and then they don't talk to each other...they're competing.”* Even within the state itself (disability services, behavioral health, education, children and family services, etc.), coordination and communication are described by participants as challenging.



According to a number of participants, when many systems are involved, it can be difficult to confirm that there is one person taking a lead role in guiding the transition and failure to make progress is common. Without this leadership role, Aero, a person interviewed said, “*I think we all get stuck without leadership. There's been times that I have facilitated ...kind of the action plan [for a hospital transition team] ...because I just couldn't take it anymore.*”

A participant working in the hospital highlighted the importance of strong partnerships saying, “*... on the hospital side we often see delays because of communication gaps between county placement workers and county services and ... hospital services and hospital case management*” (Byla, council participant). The need to make sure hospital staff have the information they need when discharging an individual was shared by one person while another individual talked about how important it is for case managers and contracted case managers to be updated on important policies related to the acute care barriers to transition such as guardianship.

The need to assess how to navigate across systems and to understand where problems are occurring between services and systems was shared by a person who responded to another council member, “*...But what was the coordination, and what were the variables? That if those things could have been improved...I'm trying to figure out coordination of care and who's responsible for what*” (Cora, council participant). Care coordination during transition periods was highlighted by participants who felt that there was not enough communication across services. One provider expressed her frustration with this issue describing calls she received about someone leaving the hospital:

“*... when I get calls saying the situation [a transition] happened...they're gonna discharge Thursday, and it's Monday, and then I'm expected to get equipment set up...try to find a staff in time to help provide additional coverage for that person...and like you can't move fast enough through that like...okay, they no longer need to be at the hospital ...they're leaving today. Well, [number] 1-They don't have a ride home...[number] 2-They don't have a staff to help support them*” (Yana, focus group participant).

The pressure to move individuals out of the ED or hospital quickly was described as something that added negative pressure impacting relationships with individuals across services. Each participant expressed this frustration in different ways depending upon their roles. Hospital staff expressed the importance that people understand that a child or adult is not in an appropriate

setting when delayed in the hospital and therefore, they need to move on immediately. County professionals expressed their concern that hospital staff sometimes place a great deal of pressure on providers who end up feeling that they, “... *really don't want to work with the hospital anymore because they think they're just not wanting to help them and get someone discharge*” (Mada, focus group participant). Other providers stated *that they feel they are fighting each other all the time*” (Zaci, focus group participant). One person described this situation saying:

*“But it's always that transition piece. And what's the next step? And it seems like it's hard to even say we're bottlenecked at any one place, because it seems like every time you need to do any kind of placement, you're potentially looking at another bottleneck you know... So, we end up with this kind of letting people out of the hospital or discharging them from the hospital early and they end up going right back in...”* (Val, focus group participant).

Many participants representing county and provider roles argue that a statewide approach is needed even when regional problem solving is occurring. These individuals report that many children and adults end up receiving services in multiple different places across the state over time. When there are no memoranda of agreements to allow communication, information cannot be shared by professionals across the state and across organizations. In most cases, participants indicate that there is no information available during each move. The result is that people are starting over each time they are in transition:

*... If you have someone that bebops all over the state they're switching psychiatry every single time... And it's just so detrimental to that case, that there would be a higher support system to ... follow them through the state ... you've followed me for three years, although I went to six placements around the state ... you're starting fresh every single time and for someone to have to tell their traumatic story every single time...”* (Yana, focus group participant).

### *Funding and policy barriers*

Participants discussed a number of funding and policy barriers that make it more difficult to assist children and adults in transition from the ED or hospital. As the case in other states, Minnesota systems for providing funding and policies that impact acute care transitions can introduce iatrogenic barriers (well-intentioned efforts with negative outcomes) making those

transitions more difficult. Problems mentioned by a number of people are delays that occur while individuals are awaiting assessments and/or services. As one participant described it, *“We all have patients in our hospitals right now that are waiting just for those rate adjustments...MnCHOICES [assessment]...and need a way to be able to have those prioritized in the system so that they can be acknowledged and mitigated.”* (Ava, council participant).

Delays that occur in the assessment and application process creates challenges, *“...having a MnCHOICES assessment done while they're in the hospital as opposed to discharging them home...and then we have to refer from the community...and then we get told....they won't be called for five months, you know, just to have the assessment scheduled. That's a huge gap and lag time in getting needed services to help them stay safe and to help stabilize their situation”* (Zoe, council participant).

Several participants pointed out that funding for community services for older adults (65+) is not adequately funded, *“...hospitals get the highest pay and then nursing homes and then home care”* (Mada, focus group participant). Funding and policies are organized to provide more funds to services such as hospitals and nursing homes while inadequate funds are available for care in the home:

*“...because the cost of the services is simply not reimbursed through the State Medicaid system through Medicare Advantage and...they're not even able to pay wages sufficient enough to hire people”* (Mada, focus group participant).

These policies and funding issues are described as problematic for older adults since it makes it difficult for people to transition home safely: *“We're not able to provide 24-hour care to them. We're not able to have a nurse in the home or a home health...in the home for six hours a day. I mean, that's just not how our services are structured it and we know it. But we're trying to help them access additional services to meet that need. But there's a huge gap and a huge delay in being able to get those services in place”* (Zoe, council participant). Another participant described the negative outcomes associated with being placed in more restrictive settings:

*“... We have...quite a few elderly folks that I think sometimes end up in the wrong place. They end up in a memory, a locked memory, care, facility, and they really shouldn't have to be there. They shouldn't have to be so restricted. But we don't have a better, more appropriate place for them that's safe. And so, they end up...probably they're biggest*

*nightmare of their lives being stuck in a...you know, memory care, facility when maybe it doesn't need to be that restrictive” (Val, focus group participant).*

Another policy-related barrier related to adults that was mentioned by participants has to do with capacity building across the state. A number of individuals mentioned the problems associated with reimbursement for positive support services. These reimbursement rates are not high enough to offset the cost of implementation and many individuals across the state have indicated that they do not use the service as a result. Meeting the qualifications for being eligible to bill for positive supports is a challenge, primarily because training and supervision is difficult to find: “...*The qualifications are too strict, especially for analysts. So, you can't find an analyst to work with you, which then really limits your ability to use positive supports. So, when you need those kind of supports to help care for or support a person in the community...It's a challenge to get this, the waiver system funding stream...for those positive support services to work. And so, what happens is a lot of providers don't do it.*” (Xael, focus group participant).

Another participant simply stated that using positive support services was proving to be problematic because “... *we're finding it very, very difficult to make it even break even with the reimbursement rates* (Zaci, focus group participant). The result of these challenges means that participants are reporting that few people can provide positive supports, especially in rural areas.

*“... For this service, I know, the county case managers that I supervise and work with would love to be able to refer to positive support services more frequently. It's just incredibly difficult to access in our area of the state and perhaps, you know, that's not the case, I guess across the board. But I think certainly different regions of the state would really struggle to be able to refer to the service, so we can train you know, about the availability of the service or about the service and what it's supposed to provide. But unless we have people to do that work? I think that will be a challenge”* (Iris, council participant).

Participants described the need for changing qualifications to allow for a competency-based training approach so that in areas of the state where it is difficult to find individuals who have completed college and university degrees, an alternative option is available. In addition, a number of individuals recommended that positive support policies be written that build in incentives for staff by creating a pathway from the specialist services level at the direct support staff, to analyst and all the way to the professional role.

Other participants highlight the need to consider whether the referral to the hospital was necessary in the first place or more likely occurring due to the challenges providers need training in evidence-based practices or positive supports. One person described this by saying people are *“placed into hospitals without fair reason of needing hospital level, of care...because of staff shortages or an incident that you know the staff didn't respond with positive behavioral supports. And there wasn't that appropriate response or support...at the time and then they are...they're just stuck there”* (Aero, interview participant). A number of participants felt the attention on transition is essentially waiting until the crisis has escalated which is too reactive.

### *Difficulties accessing community services*

Most participants discussed the challenges associated with access to staff and was evident when discussing supports for children and adults across the lifespan. The funding available to pay staff salaries is so low it makes it difficult to support children and adults, especially those experiencing barriers to transition. One participant described the challenges she experienced supporting her son: *“...And it's very hard to get support staff, even in the cities...That is part of the reason why my son lives in a group home because we were not able to do the structure and cares he needed in a healthy way, 24/7 as a family...”* (Byla, council participant). Several providers indicated that it is difficult to find people to provide services in the home with one person: *“...right now it is getting harder and harder for people to get home health nurse, physical therapy in home or any other services within the house...”* (Yara, council participant). A provider supporting older adults (65+) indicated that this challenge results in organizations discontinuing services:

*“So that's one of the things. And then home health aides and homemaking, especially homemaking services, and I'm sure those of you from the county and some of the others can speak to that. Those homemaking wages are...so incredibly low. They simply can't hire homemakers. So, a lot of the agencies have discontinued that service and that's actually one of the things that keeps people in their home is, if you can have aids and homemakers that can keep them out of the hospital and in their home”* (Mada, focus group participant).

A number of participants discussed the problems with accessing services that will meet the needs of the child or adult experiencing barriers to transition. This can result in people

feeling that they must settle for services that do not meet their needs. One person who is diagnosed with a bariatric diagnosis described this by saying: “...because the first place they put me wasn't even suitable for me. I mean, they had the equipment and everything. But the staff wasn't there. And now the place I'm in right now. They just sort of look down on you because you're that size... it's just hard to get the help I need and like for rides and stuff...” (River, council participant).

#### *Discharge delays and the need for placements*

Participants reported that discharge delay evaluation data were collected by both the Minnesota Hospital Association (MHA) and the Minnesota Department of Health (MDH). MHA provided a report on discharge delays prior to the pandemic and again in 2022. These evaluation studies were described by participants as being similar in methods and design providing the state with snapshots from multiple hospitals for short periods of time (please review the public report section of this report for more details related to these data): “...And so we are talking about hundreds of patients within this specific two-week period...these delays, regardless of...what the timeframe is are really difficult for patients. They put strain on a hospital system and, given that the majority of the patients in the study are experiencing delays in both inpatient and emergency departments” (Myra, council participant). Council members highlighted the importance of focusing on both emergency room visits and hospital delays, especially since, “We tend to admit people instead of leaving them in the emergency room” (Alma, council member). One individual described how problematic it is for children and adults to remain in the hospital waiting for services saying, “... it's not the right place for kids and for adults to be in...and we've had stories of patients who have been in the hospital for over a year. That means they haven't been outside for over a year. That means they haven't probably seen family in many cases for over years” (Jack, council participant).

The pressures on hospitals to be available to serve the larger community is described as one of the challenges associated with children and adults who are delayed for long periods due to barriers encountered in transition and therefore are using beds that might go to others in need. In addition, hospitals are described as an inappropriate place for children and adults who have complex behavioral, mental health needs or have medically complex needs. As Alma pointed

out, these children and adults who are delayed in ED and hospitals, “... *they live in a place that's not safe for them. I think we're seeing hospitals as safe and they're not. They're low supervision. They don't meet their clinical needs. They don't meet their behavioral needs. And there's a place you can get sick. We know we're not a secure facility. People can walk out and get injured... I mean, those are the kind of things that that put people at risk.*”

One of the major reasons for discharge delays identified in both ED and hospital settings, according to participants who are involved in hospital settings or conduct evaluation research, is the lack of inpatient psychiatric beds or other placement options that are meant to provide a safe place for these individuals. Other top reasons reported by participants included delays related to implementing a plan of care, delays in medical doctor's discharge orders (from ED data patterns) and delays in civil commitment (related to hospital patterns). Additional common reasons for delay both in ED and hospitals according to participants were the lack of chemical dependence SUD facility beds available.

Participants also described the referrals to the state's Complex Transitions Team highlighting the large number of children who are experiencing discharge delays:

*“So, when we talk about children, and for these purposes defining them as 20 and under very often children are engaged that are stuck in hospitals or boarding in the in the emergency departments are engaged somehow with the child welfare system. We see that our Native American children are overrepresented, by a pretty large majority and often kiddos have some type of Autism or IDD may or may not be diagnosed...as I mentioned before, another common feature is some type of aggressive behavior”* (Ivy, council participant).

One person indicated that complexities arise when individuals are also involved in legal adjudication leading to incarceration in prison, “... *that means that people in jails who need to get to the hospital, maybe, then get to an appropriate state facility can't ... move through the system as well*” (Sylas, council participant). Sylas went on to say, “*you also have to support the transitions from jails to appropriate facilities with the ultimate goal if possible...when things stabilize for those people that they can return to home in community as well.*” One participant discussed this as a problem associated with a failure to transition from corrective settings to the hospital, “... *there's like kind of like a lack of transition from those corrective settings to*

*hospitals, even though there might be acute care, needs. So again, I'm seeing it kind of more at that intake side, not the discharge side..." (Fews, interview).*

Discharge planning was discussed by a number of participants as an important issue to consider. One person stated that, "...when we receive that referral...does the person have a discharge plan in place or no...Early information we received was that majority have plans in place. However, now that that's flipped a little bit, you can see about two thirds do not have a discharge plan when we are receiving that referral a lot of times. What we're seeing thus far is...that number is being pushed up because of issues around like MA pending where there's some sort of barrier or challenge and establishing either financial or functional eligibility for medical assistance or Medicaid" (Lily, council participant). Iris, a council participant said that, "I've been ... personally involved in a number of....situations where people are waiting in the...emergency department and just that collaboration...goes a long way you know... everyone kind of pitching in and taking a piece of the pie...maybe there's a medical assistance application that needs to be completed and...the hospital staff are right there and they can assist in getting that."

### ***Interventions and strategies for addressing barriers in acute care transitions***

A number of interventions were identified as both short- and long-term goals that would address barrier to transition from the ED and hospital. These interventions included: a) building regional systems to improve problem solving using effective data systems, coordination and communication, b) care coordination strategies and navigating systems, and c) addressing policy and funding issues that may be contributing to delays. Some of the themes reported in Appendix E are collapsed into the three areas for brevity of reporting purposes.

#### ***Regional systems to improve problem solving, coordination and communication statewide***

Most participants recommended working with the current DHS Complex Transitions Team to expand regional problem solving, coordination, communication and capacity building. This Complex Transition team is described by participants as already starting to work at a regional level. One person said, "*their initial focus is going to be on intake of those...complex transition referrals and helping to navigate through that...but part of their role is also really*



*identifying regional trends. What they need, working with the counties” (Lily, council participant). Many of the council participants described a regional systems approach as the best way to create more flexible solutions to problems associated with transition given the unique aspects of each area or region in the state. Sylas, a council participant stated that, “a whole goal behind some of this, I think, is to keep and transition individuals who need acute care...in closer proximity to their homes.” Another council participant described the need for regional systems to help us in, “thinking about Minnesota as a county administrative system, and ...we're also a very big state, [a] very diverse state, and the resources available in one community or region may not be available in a in a different community or region” (Luca, council participant).*

Another important reason for creating regional systems described by some participants is its potential to improve coordination and communication. Regional systems may assist in how information is shared with families, people with lived experience, hospitals, lead agencies and providers. Sylas, a council participant, described the importance of sharing information saying:

*“...we've evolved to a point in Minnesota, where, if you're in Veterans Court and you successfully complete the programming in Veterans Court, you leave without a conviction...So the whole focus is really on rehabilitation and re-entry, and I'm wondering if we could leverage some of the ideas that have come out of that...getting judges and social workers and public health and counties and county boards to work better together than they have when it's just left to county by county.”*

An important contribution that regional systems can make is to provide a way in which information can be collected systematically and shared to assess statewide patterns in a more systematic manner. Luca, a council participant described this by saying, “...so it's trying to find, I think, some type of a path through that and figuring out, how can we leverage technology to create those sort of communities of practice or create the infrastructure to allow that communication to happen.” Another council member emphasized the need to continue expanding the data-based decision-making systems already being developed by the Complex Transitions Team: “Our data, our ability to collect and analyze data is extremely limited. So, we are looking at building that out and are in process of building that out significantly, but also need we need different systems. We need the ability to do a much more robust data collection

*and analysis system. So that's partially why the information you receive is somewhat limited.”* (Ivy, council participant).

Unified measurement systems and sharing data that already exist were discussed by participants as one way to improve both coordination and communication at regional and state levels. One council participant stated, *“...and then the other piece is for people who are already involved in social services county systems...I found that from our personal experience that often ...your data does not flow between the different systems and so then...everyone within your different spheres of involvement are having to like duplicate their colleagues work because they can't access so I think a good area to look at would be how if you're already involved in services how can each of those departments share that data so they can move on to more meaningful work”* (Byla, council participant). Council members also recommended avoiding developing new measurement systems by assessing what is already available to prevent costly duplication of effort. Lyra, a council participant, emphasized the need for coming together to create statewide operational definitions for key measures: *“I think right now, we have different data sources coming from different places, but they're not harmonized. It's hard to understand how...they all connect together. If things are unique...or we're counting things different ways or defining things different ways...”* A number of participants pointed to already existing definitions and measures that can be considered including the data collected by MHA and MDH. Some participants felt that using the regional process to pilot improving data-based decision making would be helpful:

*“So it's trying to find, I think, some type of a path through that and figuring out, how can we leverage technology to create those sort of communities of practice or create the infrastructure to allow that communication to happen and then capturing, disaggregating, capturing the data in a way that helps us see the problem down the road. So, if we're, let's say, having a some sort of a database or system where we're tracking referrals and we're tracking...we're helping people in real time. Trying to find the right match ... capturing disaggregated data that we can there share publicly ...”* (Luca, council participant).

Many council members are in favor of using technology to improve communication regionally as well as statewide using a dashboard to share information about available beds. Participants described working long hours calling different providers across the state looking for a potential placement. *“...you get pretty ‘gun shy’ making referrals sometimes because you can*

only, you know you can have 25 denials thinking...we're going to like somehow get to the point where we'll have some special something or other that'll magically appear..." (Val, focus group participant). Another person described longer-term supports across time saying about one child with complex transition issues: "...we've contacted 172 placements since she's turned 18." (Yana, focus group participant). Creating a system that will allow transition teams to find possible placements quickly and that was statewide so that individuals who are readmitted across the state can be tracked efficiently was described by many participants as essential. One person indicated that strategy may involve:

*"... creating a central database that is managed by like a specific like role, so that the various community regional people that are trying to do case management and things like that can actually find resources that are available in real time and efficiently"* (June, council participant).

Collecting data on the number of contacts made, number of placements a person has transitioned to, the number of times there are clear housing issues occurring at transition and time between transitions are all examples of helpful data that would inform regional teams and state leaders as part of a unified statewide measurement system.

### *Improving systems for transition planning and care coordination*

A number of participants talked about the need for improving care coordination and establishing clear plans for children and adults experiencing more complex transitions. Nora, a participant interviewed, emphasized the need for a point of contact for someone as they transition, "...like a maybe a discharge case manager who follows people all the way through their first follow up appointment, or whatever the discharging provider can just can discern how many times that how long that that case manager follows them. Should it be two appointments, one appointment whatever." Zaci, a focus group participant, spoke about the need for a carefully planned transition and the challenge without it, "...that has been really difficult, having no way to slowly introduce people into the community before throwing them into some kind of a group home setting and saying, "best of luck." Participants talked about creating ways that would allow time for a transition plan to be created using a step-down approach where the person can safely be supported. Yana, a focus group participant described this challenge saying:

*“I find a placement, I would like that person to be able to stay somewhere for maybe another two weeks, you know, in a hospital setting, so that that new provider can come in and start working with the professionals in the hospital...communicating with them and really getting a behavior plan in place so that once they discharge. It's not a staff, you know, saying, well, I didn't get time to read the plan, and I didn't know that this word was a trigger...allowing for some time would help. You know, I think that's a best-case scenario of allowing time for everybody to kind of review the file and understand what this person actually needs.”*

Another person suggested problem solving how to address the challenges arising before the individual goes into the hospital:

*“So that person isn't going straight to the hospital, maybe to this place for a set transition...so just looking at different programs.” (Atlas, council participant). Lyra, a council participant, indicated that making sure in advance that there are providers who have the skills necessary to support a person in transition was essential: “...[a] plan to make sure that the providers supporting that person in the community, you know, are ready and up to...the ability to implement those back practices...” Lyra went on to say that this planning “is huge... especially in that window ...that six months type window” (Lyra, council participant).*

Care coordination systems for individuals with a history of acute care barriers was described by some participants as an important consideration and that these proactive plans could be created in advance, especially if there were ways to track individuals over time and across the state. One participant indicated that sometimes this requires a plan for providers to proactively expand training in positive supports so that they are better prepared. Other participants discussed being able to access behavioral specialists who could enter the planning process to assist in an immediate transition plan for an individual who may be moving from the ED or hospital and into a new home.

A concern voiced by several people was that the large number of people often involved in complex transition plans can be one of the barriers: *“...what ends up happening is that there's so many people involved...it's hard to navigate the system and know who to go to for what thing. And so, people are spending a lot of time and energy, trying to figure out who to talk to rather than actually getting the substantive issue addressed”* (Luca, council participant). A type of

positive support highlighted by several participants that helps to address this challenge was systems of care and wraparound. Systems of care is an approach for improving communication coordination across different services supports to solve complex planning needs like addressing barriers to transition from the ED or hospital. Systems of care meetings are not meant to address one specific individual. Instead, it is a planning process that can be used at the local community, regional and/or state level to solve policy, coordination and communication issues that impede efforts to provide effective supports for people with complex behavioral challenges.

Wraparound planning, a practice also mentioned by participants, is implemented concurrently as part of systems of care. Wraparound as a planning tool for empowering a child or adult, families and caregivers to lead the team process building on the person's strengths and setting goals for improving quality of life. One participant highlighted how wraparound and systems of care can help address barriers to transition based on each person's unique needs: "...*If ... housing is more of the need ... is it direct support staff... is it residential placements...is it support so that they [a child or adult] can actually just go back to their home... is it behavior specialists, is it therapists that will come in the home, is it...transportation?*" (Isla, council participant). A key element of wraparound planning involved establishing one key care coordinator who works with the child or adult throughout the transition and whose role is to navigate communication with all parties. Systems of care and wraparound, when implemented with a high degree of fidelity has been described by some participants familiar with this positive support as an ideal way to address complex transitions. One person described how important collaboration is across systems: "*All of those teams working together...so the team at either the residential placement or the hospital, the psychiatric treatment facility, the family. If it's an underage person. Their school, like all of those teams working together and having cross-collaborative meetings as we're transitioning out is absolutely critical*" (Uki, interview participant).

#### *Addressing policy and funding issues to improve transition plans*

Many ideas were shared by participants related to changing policies and addressing funding issues that are creating barriers to transition. Some of these strategies have been mentioned earlier while describing other themes. Two of the key issues that participants have

used when speaking of the many possible solutions that connect the various funding and policy ideas include: a) creating flexible ways to address a child's or adult's needs during and after transition and b) building incentives for different partners who are struggling to address the costs associated with complex transitions while also considering ways to establish an understanding that there are obligations to people supported. One person described the way the state was thinking about positive changes, "...we're exploring options where maybe it's not a grant at all maybe it's a payment and an allocation to counties that they can have more flexibility so that when someone is in crisis and does need to transition that they've got that funding available to support them" (June, council participant).

A number of participants mentioned that the funds currently being spent addressing crises could be used in a different manner. June, a council participant, indicated that at, "*the big picture. that's really important information for us as we work together to solve these issues...flexible funds for complex care transitions, landlord mitigation fund that's something that we've heard from the community where...it is challenging to find a landlord for individuals, where there might be the...propensity for property damage...*"(June, council participant). Xael, a focus group participant, suggested, "*we could look at housing, support funding and say, let's use that money to deal with the property issues that are keeping people in hospitals, you know. So, if it's property destruction, or if it's somebody who needs a one-person home and that's going to cost more...use the housing supports to pay for it, so that providers aren't throwing up a big no sign just because they don't want to lose that money on the housing.*"

A number of participants across a number of council meetings, focus groups and interviews advocated for expedited processes to make it easier for children and adults to receive services, "... *if they're above income limits to look at like alternative care services to help get them out more quickly, because I think there's a huge delay in people who aren't already sort of in the ...Home and community-based waiver system that it takes a long time for them to get on, get services set up, get them in place to allow them to be able to go home*" (Yank, interview participant).

Providers participating in meetings, focus groups and interviews were clear that supporting individuals who engage in serious aggression, property destruction, self-injury or other behaviors can often result in providers feeling that they are being blamed when crises

occur. Zaci, a focus group participant described this saying, “*We have a lot of people who are ... [ingesting items] ...So like I had somebody recently swallow a fishhook. You know, and stuff like that...and...those [individuals] tend to come back...staff really do feel like they're having to kind of defend themselves...*” In some cases, these situations are difficult to avoid due to federal and state policies that require investigation of potential abuse:

*“One [barrier] is at least for children –county maltreatment investigations, a lot of times, make staff feel like they're at the sharp end of the stick...like somebody's looking for somebody to blame. And if you're if you're serving some of the most difficult kids in the state, it's going to be tough, and things are not always going to go perfect, and if it feels like your career or job is on the line because of your work...they're just going to say, I don't need that. I'll go work somewhere else where I don't have these challenging needs or behavioral needs”* (Xael, provider).

Several individuals mentioned culture of safety as a positive support that is very helpful in addressing the context in which challenging behavior associated with aggression, property destruction and other self-injurious behaviors occur. Culture of safety is a strategy described by the National Institute on Safety and Health (2024) as an approach that acknowledges the high-risk nature of organizations providing services and assists state, regional and local leaders in creating an environment where people feel responsible for reporting challenges that arise and working together to solve problems. Participants involved in pilot implementation of this positive support in Minnesota are reporting that culture of safety is helpful when organizations are supporting children or adults who engage in challenging behavior.

One participant mentioned the need to address capacity building for positive supports like culture of safety, systems of care and wraparound planning at the regional level and described efforts already starting statewide. Another individual encouraged the state to invest in longer-term efforts that invest in easy-to-access training and incentives for staff and providers to participate in what individuals describe as more intensive and complex supports for people transitioning from the ED or hospital setting. The discussion across multiple participants focused on how to create ways to create incentives for organizations that take on the difficult task of tailoring systems to meet the needs of children and adults who experience barriers in transition from the ED or hospital. An important issue that arose was that, according to participants,

overall, most providers feel there are far more dis-incentives to accept placements when a person has a history of challenging behavior, substance abuse disorder, mental health concerns or are diagnosed as bariatric, medically fragile or have complex medical complications.

Other incentives that were discussed included focusing on ways in which direct support professionals can achieve a career path with corresponding fiscal incentives. One way to accomplish this task is described as adjusting the rates for positive support services and making changes in the policies so it is easier for organizations to meet qualifications for the analyst and professional levels of this service. Establishing a state approved training was described as one potential way in which a person can qualify to provide services and investing in establishing mentors across the state who can provide coaching and supervision in positive supports to integrate positive supports into existing services. One council participant, Akira, emphasized the need to consider how state funded training could be inserted into already existing continuing education or training hours for personal care attendants (PCAs) or direct support professionals (DSPs).

Participants also advocated for community of practice events that the state can use to answer questions providers have related to qualifying for services, share information and roll out changes in policies. Participants indicated that it would be helpful to be able to increase communication about policy and funding issues. One person noted, “...*that's a gap that you need to have information more quickly...I can give you one example... Community First Services and Supports (CFSS), so that's just coming out...it's going to roll out very soon, but I don't think the counties have gotten any training on it*” (Mada, focus group participant). One area that a number of participants advocated for was active involvement by the state in ensuring technology can be used to maximum effect supporting individuals by training by, “...*making sure that the counties understand how technology can be used, how it can be funded, how to use the HCBS system to do all of that*” (Xael, focus group participant). Mada indicated that the focus on using technology strategically is necessary since, “*we simply aren't going to have enough people to provide the needs ... to [support] folks around Minnesota. We're going to have to use technology to supplement and I think we're behind the eight ball on that*” (Mada, focus group participant). Zaci, another focus group participant indicated that as a provider: “*I know that we have had*



*active arguments with multiple counties about approving technology. And the pushback we always get is we're paying you to double staff them.”*

In addition to adding incentives for providers and other systems to take on more complex problem solving associated with people needing support, one of the participants interviewed emphasized the need to build policies that encourage accountability to people receiving support. Some participants urged the state to consider that, in some situations, whether unintentionally, that sending a person to the ER or hospital can become a way for systems that no longer want to work with a child or adult to indicate that they no longer intend to provide services. One participant stated that, “...it's easier to kick someone out of a group home than it is to kick them out of a nursing home or assisted living facility” (Gabe, interview participant). Gabe went on to recommend that the same obligations nursing homes have should be true for group home settings:

*“...once you're into a group home there's obligations. If you want to discharge them, there's obligations of discharge. There should be obligations for discharge planning. There should be obligations to identify a safe discharge location.”*

Another participant, Uki, said something similar, “...and then this idea, that like wherever they're transitioning out from is still on the hook for their transition...because what I've seen happen several times is kind of this...we're at our capacity, not only financially but emotionally...like, we're just exhausted.” These participants were discussed the need to both hold organizations accountable while also assessing ways to decrease the negative systems issues that place stress on organizations until a breaking point is reached.

### ***Health equity and disparities in Minnesota***

A number of participants discussed disparities including an over-representation of children experiencing discharge delays and disparities related to transition planning including “...Native American children and individuals of color very much overrepresented in the data” (Luca, council participant). Data from one discharge delay study points to disproportional representation of BIPOC children and adults experiencing barriers to transition. One individual reported, “...we did find that African American, or African-born patients were experiencing delays disproportionate to...overall...inpatient behavior health patients, and that really stood

*out to us...[it] kind of brings up getting attention to the need to advance health equity” (Jai, council participant). The Complex Transition Team evaluation data also point to health equity-related challenges impacting children who are BIPOC and/or citizens of tribal nations and called for better monitoring: “We need the ability to do a much more robust data collection and analysis system...so far, so we are able to gather some additional information that wasn't gathered previously, and they include...race and ethnicity” (Ivy, council participant).*

Initial discussions that occurred within the first council meetings included the observation that adequate representation by diverse members representing Minnesota communities was necessary for this Council to give everyone a voice in the problem solving. As Cali, one interview participant noted:

*“I just feel in any situation when we're talking about a group of people that none of us who have any firsthand experience and we're just kind of we're part of this bureaucracy that our opinions are maybe secondary to those people who are genuinely being affected.”*

Lyra, a council member, pointed out that it is important to consider people with IDD who may not be able to verbally describe their viewpoint as well as their family members and caregiver, “...making sure that...their story is included...so that might include...caregivers also being able to contribute.” A number of individuals expressed concern that the Council needed to include more people representing the BIPOC community and tribal nations. Strategies discussed included making an initial request to expand the council immediately and/or to do so in the future should the council continue.

One reason for adding focus groups and interviews was described by some council participants as a way in which more information could be gathered from more diverse community partners. Atlas, a council member, talked about reaching out to communities thoughtfully said, “...if we...connect with different people in different communities...it can be ethnicity, you know race, culture...and we get invited in to go into some of those communities and have listening sessions I think that would be very helpful...I guess my question is how do we make sure we're doing it in a way that people feel safe to bring forward their actual thoughts and feelings and not feel guarded because I feel like in a lot of spaces we try to create...certain communities that have experienced you know that distrust or bad experiences or disparities they're afraid to sometimes say exactly what it is because they don't know what the outcome will

be...” Another person mentioned the fact that there is constant pressure on marginalized communities to be involved in these types of activities and that this can impede the professional’s ability to get their everyday work completed.

Representation of people from across the state of Minnesota was also highlighted by participants, “...we're a very big state very diverse state and the resources available in one community or region may not be available in a different community or region and that suggests that there needs to be a way to consider regional aspects needed in the recommendations that are made” (Sylas, council participant). A review of the types of people participating in this evaluation (see Appendix C) suggests given the diversity of council members, focus group participants and interviews from across the state needs to be expanded. Participants stated that it was difficult to establish a council with diverse representation since the decisions for seats were designated by the legislature and the open seat time period was not a very long time period. A number of members stated that the council should continue, and that it will be important to ensure the voices of all Minnesotans are represented.

Children and adults with complex needs and their families are described as more likely to experience disparities in Minnesota by those involved in this evaluation. One medical professional indicated that often people from more vulnerable populations will not engage in follow-up visits after transition from the ED or hospital “...because the long history of lack of faith in the healthcare system...oftentimes I encountered an independence where people didn't necessarily follow [medical recommendations]” (Nora, interview participant”). Nora, as a medical professional went on to say, “I have never met a native person that doesn't dislike the emergency department and in my professional role, absolutely...I mean dismissed or thought to be too emotional about the things that impact our communities.” The feeling for Indigenous patients was described as feeling like they did not belong “....and...they're all white, everybody is white...So you're already ill. You're already not feeling good. And then you start getting stared at the entire time...and then you never, you know, never to ask for pain meds” (Nora, interview participant).

Several participants described family members who were actively engaged in helping their child exit the hospital. These family members were described as actively involved, attending meetings and working hard on their child’s behalf during the transition. Even so,

actions were taken against these families by the hospital to remove the family’s legal decision-making rights and transfer guardianship. One participant hypothesized that, “...*I've heard that there are some providers that don't take folks unless they're under guardianship which I mean, that seems like a whole other...issue*” (Vail, interview). Actions taken to attempt to remove family legal decision-making rights during hospitalization was described as commonly occurring in rural areas of the state but mainly with adoptive parents with BIPOC children who needed support.

### *Quantitative and qualitative public reports*

The most common reports available to the public in Minnesota related to acute care barriers to transition address discharge delays from the ER and/or hospital. Table 1 provides the list of the selected reports that were most closely aligned with acute care barriers to transition. However, it is important to note that these are not the only reports discussing that were helpful to the ACTAC. Additional Minnesota reports are available in the reference section and were used in the literature review. In addition to discharge delays, another type of public report that was selected for review included formal reports addressing race, ethnicity and geographic disparities in Minnesota. A worksheet template was used to summarize each of the public reports in Table 1.

### *Minnesota Hospital Association (MHA) evaluation reports in 2016 and 2023*

Although completed in 2016, the public report by Dillon & Thompson (2016) marks an important contribution to evaluation related to discharge delays. The Dillon & Thompson (2016) report has been used as an evaluation study that other investigators have used as a guide both in Minnesota and other states. The evaluation investigated inpatient hospital 45-day period of data collection with 22 hospitals documenting their data. Twenty of these hospitals had inpatient mental health units, two did not. Data in this ACTAC report only addresses the data based on the 20 hospitals. The investigators were interested in reasons hospital admission was delayed and the number of potential avoidable days patients experienced. Data were collected for 45 days during the pilot period, from March 15, 2016, through April 30, 2016. There were 455 patients during the pilot period with potentially avoidable days in hospitals with inpatient psychiatric units. From

a total of 32,520 possible bed days in the 20 participating hospitals, a total of 6,052 were described as potentially avoidable. The two most common reason for delays included a lack of available space for individuals in psychiatric facilities and delays due to processing.

The MHA conducted an additional evaluation in 2022 and another study in 2023. A presentation given by an MHA representative at the ACTAC council meeting summarized the results of the 2023 evaluation. The study focused on a) patients who are ready for discharge to alternative sites of care but are stuck in hospital beds awaiting discharge to alternative care sites of care, b) ED boarding where residents of alternative care sites are being dropped off, or show up, at the ER. The MHA study occurred from June 2023, through October 2023, and built on a study completed by DHS conducted study earlier from January and May 2023. The presenter indicated that, “...the 10-month summary data was annualized by dividing the discharge delayed days total (January-May from DHS, June - October from MHA) by 10, multiplying by two months and adding that figure to the results for an estimated 2023 total.” The survey hospitals were requested to submit was set up in a spreadsheet with two tabs. One tab was used to complete ER delays and the other tab was used to enter data for inpatient delays. On each tab, hospitals entered patient-level information. Each row contained a patient's MRN, age, gender, as well as the date (and time, if available) of their begin of stay date, their date deemed medically ready for discharge and their end of stay date.

MHA's 2023 study reports data from 101 hospitals. Data indicated that adults represented the higher number of ER and hospital delays and older adults (65+) experienced higher numbers of inpatient delayed days. The survey required that hospitals choose at least one of seven medically complicating reasons why the patient was delayed in their discharge. The seven reasons were obesity, disability, wound care, mental illness, behavior needs, substance use disorder, IV usage and dialysis. A higher number of individuals with reported mental health and behavioral needs experienced frequent delays. Individuals needing wound care and bariatric patients also were reported as higher in both inpatient and ER delays. The study reported that nearly 195,000 patient days of avoidable and unpaid care in occurred in 2023. An estimated \$487 million in direct costs/unreimbursed care were documented in 2023.

*Minnesota Department of Health (MDH) 2024 study*

The study conducted by MDH included 34 Minnesota hospitals from the 128 hospitals who were invited to participate. The data for ER delays included the 34 hospitals with data collected during a 14-day period between Sept. 5, 2023, and Oct. 20, 2023. Data also were collected for 13 inpatient hospital settings with data collected during the same 14-day period and window of time. Approximately 3,064 behavioral health patients were treated in the 14-day study period. Of those, 537 patients (or 18%) experienced a discharge delay, meaning they were still in the emergency department four hours after a disposition decision. These individuals were delayed a total of 560 days (13,442 hours) representing 560 days, with an average of one day delay per patient. The lack of inpatient beds (59%) was responsible for most delays in the ER with (14%) of delays related to waiting on discharge or care plans. Transfers that occurred from the ER the most often were to psychiatric inpatient units while a third of the time, the person was sent home “with or without supports” (pp. 7). A total of 38% of delay days were related to a child or adult’s history of behavioral issues such of dysregulation, resulting in aggression, self-harm and/or sexually inappropriate behavior while twenty percent of patients including 17% of delay days were associated with substance use disorder. Similar patterns occurred with the 13 inpatient hospital data in this study and can be reviewed in the report.

*Minnesota Governor’s Council on Developmental Disabilities qualitative study on discrimination*

The report, entitled, [Impact of the intersection of developmental disabilities and other population profiles on experiences with discrimination](#) was completed in 2022. This report summarized the results of a) a literature review, interviews and focus group sessions with a total of 28 females, 19 males and two individuals who are nonbinary. Of the total 49 participants, 13 were Black, 16 were East African immigrants, four were Latinx, two were Asian, 12 were white and two individuals reported two or more ethnicities. The results of the report describe the types of discrimination people of color with disabilities face in today’s society. Disrespectful behavior, barriers to inclusion, stricter rules and failure to provide accommodations to people were described in housing, education, employment, community businesses and social and public spaces. A recommendation from this report is that, “*If progress in reducing discrimination in*

*Minnesota is the goal, then there needs to be a research system put in place for obtaining benchmark (starting point) measures of incidences of discriminatory behaviors and practices, and tracking changes over time” (pp. 6).*

*Minnesota Governor’s Council on Developmental Disabilities Phase II intersectionality study*

A follow-up study to earlier 2022 study was published in 2023 by the Minnesota Governor’s Council on Developmental Disabilities was designed as a first step in addressing the need for data systems that collect information on the perceptions of Minnesotans on the topic of discrimination. A survey gathered comparative measures of various forms of discrimination that four major populations experience: a) white people with disabilities (n= 187), b) Black, Indigenous and other People of Color (BIPOC, n=185), c) white people without disabilities (n=64) and d) BIPOC individuals without disabilities (n=157). These 591 survey responses were meant to provide a baseline measure for the One Minnesota Council on Diversity, Inclusion and Equity established by Governor Tim Walz in 2019. Results indicate that people with a disability are less likely to feel welcome in their community and more likely to experience barriers to the types of employment and education they deserve. Specific negative impacts varied across white and non-white participants with disabilities indicating differences in the types of discrimination experienced. More respondents came from the metropolitan Twin Cities area, however, all areas of the state included people who responded to the survey.

*Building racial equity: DHS Medicaid report*

The Minnesota Medicaid Director directed the completion of a report entitled [“Building racial equity into the walls of Minnesota Medicaid: A focus on U.S.-born Black Minnesotans.”](#) Although this report does not exclusively focus on the topic of acute care barriers to transition, the information included in this document provides important information about Medicaid funding and the challenges associated with addressing systemic racism within state policies and systems in Minnesota. The report by Chomilo (2022) was designed to encourage co-creation of Medicaid policy change by involving U.S.-born Black community members, leaders of community organizations and those working to advocate for racial equity for Black Minnesotans. An assessment and alignment of community input with policy areas led to discussion about

changes and stewardship in each respective policy area. Four major levers Medicaid has for addressing racial equity were highlighted, including a) eligibility and enrollment, b) access, c) quality and d) early opportunities. Assessment data were gathered across extant data sources such as Minnesota Department of Human Services, U.S. Census Bureau and other important reports both within Minnesota and at the national level. Race, ethnicity and language demographics were described as one way to gain better insight into the impact and need of culturally relevant care. An important emphasis was placed on avoiding pilot projects where funds end and there is a feeling that people are “*checking the box*” versus the need to invest in ongoing “*tangible*” efforts to address disparities and work towards racial equity (p. 37). Chomilo noted that, “*DHS should integrate not just community engagement in general but longitudinal, culturally specific engagement of [Medicaid] enrollees and their families into routine policy, budget and administrative activities.*” (pp. 39).

### ***Summary of major findings merged from mixed methods evaluation***

The combination of different voices in the council, focus groups and interviews and public reports describe a better picture of the complex nature of the barriers to acute care transitions than any single data source can provide. Figure 6 provides shows how the major messages coming from the data encourages the use of multiple interventions and strategies. These strategies require coordination and communication systems across the state of Minnesota including education, disability services, behavioral health, children and family services and a number of other relevant sectors. Placing an emphasis on both short- and long-term planning with the assumption that, “*Failing to invest in interventions that would build effective, well-paid community services for people with more complex needs has led to “moving” the problem to hospital settings*” (Cadel et al., 2021).

Table 4 highlights key findings based on merging data from multiple sources including both qualitative and quantitative analyses. As you can see in Table 4, there are two overarching themes. In the first theme, the results across all data sources point to the need for interventions that address health-equity disparities. The information gathered indicates that Minnesota would benefit from creating measurement systems that provide a way to evaluate progress in addressing



and decreasing disparities that people from marginalized communities experience. Discharge delays are one place where these disparities are evident.

The other overall theme suggests that depending upon the data collected, state-level investments in funding may need to be allocated towards increasing community services or towards the development of inpatient and SUD beds to provide a safe environment for people experiencing barriers to acute care transitions. Again, the development of regional and statewide data-based decision making could help provide more clarity for Minnesota to answer this complicated and vitally important question. The following themes emerged from the multiple data sources.

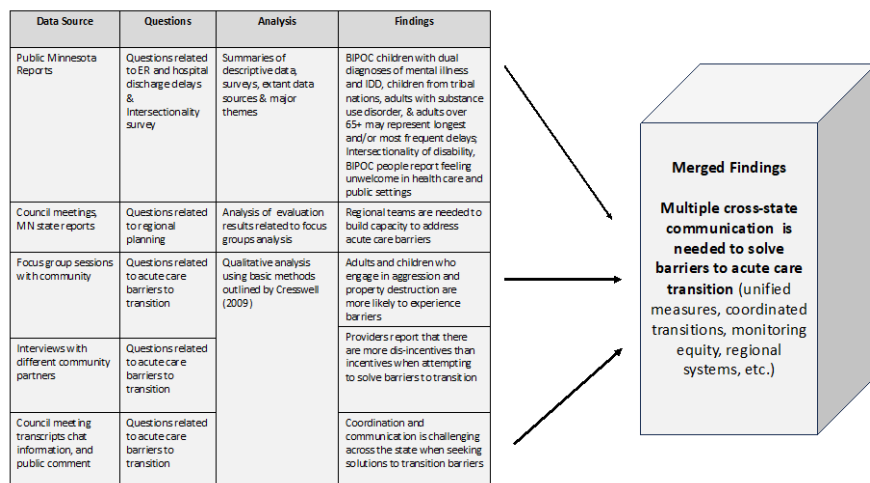
- **Current policy and funding systems are channeling children and adults into more restrictive settings when, in some cases, these individuals could successfully live in their homes and communities with the proper community supports. However, temporary placements are also clearly needed. Data are needed to better understand the different types of people experiencing acute care barriers to transition, especially those requiring inpatient beds, SUD placements, Juvenile Detention Centers, Psychiatric Treatment Facilities and other more restrictive placements. Using data to determine the best choices for policies and funding and improving communication and coordination across systems and services may help address this issue.**

Funding systems and policies currently are organized primarily to fund placements that are intended to provide safe places for individuals on a 24-hour, seven day a week basis. However, these settings are more restrictive in nature and many children and adults may choose to be at home in the community. Unfortunately, the funding for supporting children and adults in their homes is incomplete according to many participants in this evaluation. The ability to fund staff to provide 24-hour, seven-day a week supports at home is described as impossible by participants.

In the absence of home-based services, there is a natural pressure to fund more restrictive placements and with staffing problems related to poor wages for PCAs, DSPs, families and caregivers, home care is often not possible. This, in turn, creates pressures for the state to invest in funds to build more restrictive placements instead of investing in home-

based support funding. One participant suggested that an over-reliance on calling 911 and sending someone to the hospital is a signal that the current support systems are not protecting people: “...throughout history we've been able to provide the support for a lot of our folks and through positive behavioral supports been able to meet their needs in the community...and there's no easy answer with the workforce shortage...but we really have to have some answers and we have to have some protections, and I think some safety, nets for this population” (Aero, interview participant).

**Figure 6**  
Merging ACTAC findings across data sources



- The active involvement of people representing all Minnesotans must start within legislative Councils like the ACTAC. Without the experience of people who are experiencing iatrogenic impacts from current policies.

There is an increasing call by state and community partners to increase the representation of all voices in Minnesota as it relates to processes such as this ACTAC council. In addition to diversity including race, ethnicity, gender orientation and other marginalized groups, the Council needs to be informed by a balance across roles of community partners. ACTAC one council participant, Lara, pointed out that for people in Minnesota, “the point of entry into the mental health system for many is the Emergency Department of the local hospital and the responsibility of providing all-levels of inpatient services has been shifted to the community hospitals. Therefore, it is necessary that any planning for

managing acute care transitions have equal input and representation from community providers as well as state and county entities.”

- Added incentives are needed for systems to maintain the accountability of systems in supporting children and adults experiencing complex transition barriers; a process for establishing community expectations for ensuring the well-being of Minnesota’s children and adults is needed.

The data in this report suggest that a focus on incentives for community service providers is needed to offset the many challenges encountered. Considering ways in which the state can increase accountability of organizations to ensure individuals in transition are treated with dignity and respect while kept safe during acute care crises.

- Investing in prevention-focused efforts is necessary; right now, the systems wait until acute care crises arise and then engage in reactive problem solving with limited success. Focusing on preventing situations where individuals are under pressure to transition immediately from the ER or hospital into new home and placement settings requires a different approach, one that regional systems of care and coordination efforts may help, too.

**Table 4**

*Merged Findings Across Data Sources Strongly Indicate the Need for Multiple Cross-sector interventions for Addressing Barriers to Acute Care Transition.*

<b>Qualitative results</b> (Council meetings, focus groups, interviews)	<b>Qualitative &amp; quantitative public reports</b>	<b>Merged implications for measurement systems</b>
<p><b>Disparities exist in acute care transitions</b></p> <ul style="list-style-type: none"><li>• Over-representation of BIPOC community.</li><li>• Families experience situations where legal decision making &amp; guardianship is threatened during transition.</li></ul>	<p><b>Disparities exist in acute care discharge delays</b></p> <ul style="list-style-type: none"><li>• Over-representation of BIPOC community occurs in discharge delays.</li><li>• Minnesotans are experiencing disparities in Medicaid services.</li></ul>	<p><b>Better measurement systems are needed to</b></p> <ul style="list-style-type: none"><li>• Prevent disparities in acute care transitions.</li><li>• Confirm whether changes selected improve outcomes.</li><li>• Listening sessions with BIPOC communities.</li></ul>
<p><b>There is a need for home-based services as well as temporary placements to keep people safe <i>before and after</i> transitions</b></p> <ul style="list-style-type: none"><li>• Creating strategies to intervene before sending people to the ER or hospital will save money but requires investment.</li><li>• Funding is not allocated to the community services and therefore more restrictive placements are chosen first.</li></ul>	<p><b>There is a great need for placements that will keep people safe</b></p> <ul style="list-style-type: none"><li>• Hospitals are not a safe place for people to be while placement and transition planning is occurring.</li><li>• Data show that the greatest need is for inpatient beds and other placement options.</li></ul>	<p><b>Increasing measurement &amp; data-based decision-making systems could help decide how to invest in funding</b></p> <ul style="list-style-type: none"><li>• More data are needed before allocating funds to home-based services versus more restrictive placements.</li><li>• Interviews with people with lived experience may provide important insights.</li><li>• Gather transition related measures including person-centered goals.</li></ul>

## **ACTAC council action recommendations: Short-term action plan**

It is the shared responsibility of the state of Minnesota, local governments, hospitals and other providers caring for people, to eliminate bias, discrimination and disparities when transitioning people in need of acute care. For the sake of eliminating barriers, the DHS Complex Transitions Teams should identify and track obstacles and outcomes for individuals in identified protected classes and other vulnerable and underrepresented groups.

### **I. Given the timeline and complexity of the topic, one of the recommendations is that this council become a standing unit.**

- A. Continue working with the existing DHS Complex Transitions Team led by DHS leaders from Moving Home Minnesota. Establish a bi-directional communication system between the ACTAC and the Complex Transitions Team with an ongoing system for reviewing progress such as quarterly meetings. The advisory council will provide guidance as new data systems are put in place and as more information is learned.
- B. Use the ongoing council to expand to additional regions, monitor data systems and continue refining action plan, with the purpose of defining an infrastructure for scaling up efforts statewide.
- C. Recruit a diverse range of council members to ensure all Minnesotans have voice in the system (race/ethnicity, gender orientation, geographic diversity, etc.).
- D. Complete long-term recommendations that require more time to accomplish and that may include a future approach that is organized by subgroups reviewing data by types of acute care experiences (such as SUD, children with mental health/ behavioral concerns, older adults 65+, bariatric or medical issues).
- E. Complete focus group and interviews with people with lived experience.

### **II. Expand regional capacity for existing care navigation by building on the Complex Transitions Team in three regions supporting children and adults across the lifespan.**

- A. The ACTAC recommends that DHS and counties in three initial regions work closely together to facilitate effective transitions in local communities for children and adults. Activities needed include establishing a communication pathway between DHS

- leadership, existing Complex Transitions Teams, counties and the ACTAC to document the process for DHS and counties in regions to work closely together to facilitate effective transitions in local communities for children and adults, to support long-term growth.
- B. Support the Complex Transition Team to complete a Plan-Study-Do process to evaluate existing resources and needs of the Complex Transition Team and support current and scale-up efforts. During this process, regional teams continue providing feedback on the processes, tools and systems used by the Complex Transitions Team to assess the effectiveness of transitions across the three regions.
- a. Engage with representatives to help in guiding the system with the following partners:
    - i. Complex Transitions Team regional coordinators from each region
    - ii. Local public health and local social services/county social services
    - iii. Families/People with lived experience
    - iv. Hospitals
      1. Acute care hospitals that provide inpatient and mental health services
    - v. Providers
    - vi. Measurement expertise
    - vii. Court/legal representation
    - viii. Key state divisions (children and family services, behavioral health, disabilities, education)
    - ix. MDH Office of African American Health and Office of American Indian Health.
  - b. Fund and allocate *regional* administrative support and a coordinator role to handle tasks associated in each regional system.
  - c. Ensure regions are collecting the same data using statewide quarterly meeting and annual report:
    - i. Written report based on the results after one year of implementation

- ii. Each region contributes data and group assesses statewide
    - d. Recruit and fund a state personnel as coordinator who will guide the state meetings (funding for FTE...see II for description of role)
    - e. Fund data collection to pilot annual summary of data across three regions
    - f. Authorize the sharing of protected data necessary for effective transitions while maintaining the data's protected classification
    - g. Offset costs for people with lived experience to participate in regional and state team.
    - h. Allocate time of state leaders to review data and make decisions
      - i. MDH
      - ii. DHS overall leaders
      - iii. County leaders
      - iv. MDE
      - v. DCYF
      - vi. Hospitals
      - vii. Providers
      - viii. Other community partners.
- C. Work with the Complex Transitions Team to establish a data-based decision-making system for improving access to information for individuals transitioning from hospitals across the three regional areas of the state. Design the data system so that it can be disaggregated according to race, ethnicity, gender and geographic diversity to address health equity and disparities.
- a. Work with DHS state systems to improve sharing of data across disabilities, behavioral health, older adults, children and families, etc.
  - b. Data systems need to be able to report the following (such as):
    - i. Behavioral events
    - ii. Mental illness (Suicide, psychotic episodes)
    - iii. Systems delays
    - iv. Complex bariatric and other health issues.
  - c. Measures targeted for regional teams, such as

- i. Agree upon unified operational definitions for the following
        - 1. Acute care crisis
        - 2. Discharge delay
        - 3. Populations and experiences contributing to challenges (define behavioral vs. behavioral health/mental health)
        - 4. Days of transition
        - 5. Readmittance
        - 6. Days of stabilization
        - 7. Quality of life
        - 8. Positive supports.
      - ii. How many people are experiencing criteria indicating acute crisis (create unified definition)
      - iii. Geographic, age, ethnicity, race and gender-related data for individuals experience acute care crises
      - iv. Number of positive support trainers, regional team members, etc. representing diversity (geographic, ethnicity/race, etc.)
      - v. Summary of individual transition plans for impact and fidelity in each region.
    - d. Data collection varies by key populations with priorities to biggest problems
      - i. Autism, IDD and challenging behavior
      - ii. Behavioral episodes/mental health events
      - iii. Older adults and complex issues (dementia, medical, etc.)
      - iv. Substance use disorder/housing.
- D. Map out data collection systems collected by regional teams to capture the data needed to assess:
- a. Better understanding of the specific challenges associated with transition-related barriers outside of the hospital related to inpatient beds.
  - b. Different types of individuals experiencing discharge delay and transition barriers back into the community due to:



- i. Behavioral health/mental health Issues (suicide and Self-harm, psychotic episodes, etc.)
  - ii. Behavioral events that occur when individuals with IDD, autism or other disabilities result in self-injury, property destruction, injuries to others
  - iii. Bariatric issues
  - iv. Barriers associated with older adults (65+)
  - v. Issues related to barriers associated with substance abuse.
- E. Capacity building, mentoring and supports for regional teams to use data systems and make changes by regularly reviewing systems. This should include funds necessary to support the data systems, technology, infrastructure and mentoring support needed by the Complex Transition Teams to put data systems in place and analyze the data to identify areas of need to guide data-based decision making.

**III. Establish overall infrastructure and statewide review process to share data and monitor regional teams while also leveraging existing resources dedicated to addressing barriers to acute care transitions.**

- A. Use implementation science strategies to monitor and coordinate regional teams allowing regions freedom to tailor actions while establishing bi-direction information at the statewide level thereby unifying data measurement and reporting systems
  - a. Establish quarterly and annual reviews of data at the regional and state review process
  - b. Use existing data systems and avoid duplication (avoid “re-inventing the wheel”)
  - c. Dedicate a state coordinator linked to regional systems (FTE)
    - i. Make sure monitoring and review of regions occurs
    - ii. Schedule meetings
    - iii. Work with measurement staff to summarize and report across regions
    - iv. Assist with coordination activities such as access for regions to funds

- d. Allocate capacity-building funds in a manner that directly addresses the acute care barriers
    - i. Use funds for positive supports in a manner that directly addresses qualification issues that impact capacity and provides incentives for staff
    - ii. Example: direct funds to establish DSP/PCA accreditation training, work with current PBS facilitators to encourage mentoring in region.
  - e. Engage the MDH Office of African American Health and Office of American Indian Health
  - f. Use recommendations from regional teams and reach out across the state divisions to establish and support completion of data sharing agreements
  - g. Support regions by creating policy that breaks down barriers related to communication (memoranda of agreement templates and guidelines to facilitate children and adults moving into the community).
    - i. Children and adults transitioning from Metro placement to rural home
    - ii. Children and adults transitioning from out of state to home state.
- B. Work with existing groups (regions, MDH, MHA, Complex Transitions) engaged in evaluation to establish a unified measurement system that collects data beyond immediate hospital discharge- use systems already created when possible:
- a. Discharge delays with dedicated attention to systems issues by types of experiences (bariatric, behavioral, mental health diagnosis, substance abuse)
  - b. Transition related measures
  - c. Readmittance patterns
  - d. Diversity (geographic, gender, race ethnicity, etc.)
  - e. Transition satisfaction/quality of life in transition
  - f. Measures of challenges related to types of experiences (suicide, self-injury, property destruction, etc.)

- g. Transition costs (behavioral consultation for transition, crisis respite, making adaptations to physical location at home, hospital related, etc.)
- C. Acquire funds for establishing easy to access statewide training curricula on positive supports directly addressing acute care transitions to the community. Provide examples of how to access these statewide training curricula within existing incentive systems for PCAs/staff.
  - a. Use state team to direct new incentives and efforts to support capacity building
    - i. Training for DSPs and other priorities highlighted by regions
    - ii. Coaching and mentoring to support regions
    - iii. Clinical consultation and tele-outreach to support regions
  - b. Direct support staff, personal care attendant trainings in positive supports directed by regional teams
  - c. Add state approved training to meet qualifications for positive support services (competency-based training, prepare professionals to supervise other professionals).

**IV. Actively integrate measurement and action plans addressing geographic, racial and ethnic disparities in acute care transitions and coordinate with existing state health equity processes.**

- A. Coordinate with existing systems, processes and workgroups to integrate acute care issues into existing efforts to address disparities rather than creating another meeting process. Examples include:
  - a. State Advisory Council on Mental Health and Subcommittee on Children’s Mental Health
  - b. Recommendations by the Medicaid Director (Chomilo, 2022)
  - c. MDH Health Equity Bureau
  - d. Children’s Cabinet on Mental Health.
- B. Actively integrate measurement and action planning into regional systems and measurement related to monitoring disparities (geographic, age, ethnicity, etc.)

- C. Dedicate funds for regions to reach out and recruit diverse members to participate in the regional process
    - a. Allow for stipends used to support the ability of individuals to participate
    - b. Create a way for regions to propose tailored actions for increasing diversity.
  - D. Fund pilot systems for technology-based information sharing and care navigation
  - E. Require regions to report on equity and diversity within region and how the regions are increase active voice and leadership as part of measurement system
    - a. Include data reporting proportion of barriers to transition occurring across the types of populations and population in ED/Hospital discharge delay.
  - F. Work with other areas of state to support efforts to listen and support diverse communities including geographic, gender affirming, ethnicity/race and other individuals with a history of marginalization.
- V. Identify the barriers that exist and begin long-term planning while initiating changes in administrative policy that DHS and other lead agencies can make immediately to expedite the transition of children and adults out of acute care settings. Examples include, but are not limited to, building short and long-term incentives for direct support staff, providers of existing waiver services and/or organizations supporting children and adults while in the hospital to assist with transition planning; expanding on existing funding policies for HCBS providers supporting the transition planning process while children and/or adults are in the hospital; assessment of practices related to guardianship while addressing the rights of individuals and families; and strategies related to expediting MnCHOICES assessment.**
- A. Build incentives for providers within Complex Transition Team regions to support and work with children and adults encountering barriers to acute care transition
    - a. Funds available for providers in three initial regions to access fiscal incentives for supporting complex transitions
    - b. Provide capacity building training and supervision while offsetting fiscal costs
    - c. Allow for funds to address issues related to transition (property damage, tailored home structural changes, etc.).

- B. Use short-term actions to identify additional funding pathways to support effective transition planning between hospital staff, case management and providers and/or caregivers while a person is in an acute care setting
- C. Work with MnCHOICES team to assess strategies for expediting situations involving barriers to transition
- D. Initiate short-term administrative policy changes--Add administrative policy or immediate changes that DHS and other lead agencies can make right now, or very quickly, to expedite the process of transitioning folks out, such as
  - a. service authorization approvals on a temporary interim basis:
    - i. expedited approval for equipment or other needs
    - ii. expedited rate exception process for complex behavioral or high acuity individual folks with bariatric needs.

## References

- Abrams, A. H., Badolato, G. M., Boyle, M. D., McCarter, R., & Goyal, M. K. (2022). Racial and ethnic disparities in pediatric mental health-related emergency department visits. *Pediatric Emergency Care, 38*(1), e214-e218.
- Abdelhalim, A., Zargoush, M., Archer, N., & Roham, M. (2024). Decoding the persistence of delayed hospital discharge: An in-depth scoping review and insights from two decades. *Health Expectations, 27*(2), e14050.
- Addington, D. E., Norman, R., Bond, G. R., Sale, T., Melton, R., McKenzie, E., & Wang, J. (2016). Development and testing of the first-episode psychosis services fidelity scale. *Psychiatric Services, 67*(9), 1023–1025. <https://doi.org/10.1176/appi.ps.20150398>
- Åhlin P., Almström P., & Wänström C. (2022). When patients get stuck: a systematic literature review on throughput barriers in hospital-wide patient processes. *Health Policy, 126*(2):87-98. doi:10.1016/j.healthpol.2021.12.002
- American Academy of Pediatrics. (2024). AAP-AACAP-CHA declaration of a national emergency in child and adolescent mental health: <https://www.aap.org/en/advocacy/child-and-adolescent-healthy-mental-development/aap-aacap-cha-declaration-of-a-national-emergency-in-child-and-adolescent-mental-health/>. Accessed February 19, 2024.
- American Psychological Association, APA (2024). *Policy statement on evidence-based practice in psychology*. <https://www.apa.org/practice/guidelines/evidence-based-statement>
- Autistic Self Advocacy Network, ASAN (2024). Beyond coercion and institutionalization: people with intellectual and developmental disabilities and the need for improved behavior support services. Washington DC.
- Bender, D., Pande, N., & Ludwig, M. (2009). *Psychiatric boarding interview summary*. U.S. Department of Health and Human Services. <https://aspe.hhs.gov/sites/default/files/private/pdf/75756/PsyBdInt.pdf>
- Bertram, R., Blasé, K., Shern, D., Shea, P., & Fixsen, D. (2011). *Policy research brief: Implementation opportunities and challenges for prevention and promotion initiatives*. Alexandria, VA: National Association of State Mental Health Program Directors.

- Bhatia, D., Peckham, A., Abdelhalim, R., King, M., Kurdina, A., Ng, R., Allin, S., & Marchildon, G. (2020). Alternate level of care and delayed discharge: Lessons learned from abroad. *Rapid Review*, 22.
- Blum, R. W., Garell, D., Hodgman, C. H., Jorissen, T. W., Okinow, N. A., Orr, D. P., & Slap, G. B. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions: A position paper of the society for adolescent medicine. *Journal of Adolescent Health*, 14(7), 570–576. [https://doi.org/10.1016/1054-139x\(93\)90143-d](https://doi.org/10.1016/1054-139x(93)90143-d)
- Bond G. R., & Drake R. E. (2015). The critical ingredients of assertive community treatment. *World Psychiatry*, 14(2), 240.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Bruns, E. J., Kerns, S. E., Pullmann, M. D., Hensley, S. W., Lutterman, T., & Hoagwood, K. E. (2016). Research, data, and evidence-based treatment use in state behavioral health systems, 2001–2012. *Psychiatric Services*, 67(5), 496-503.
- Bruns, E. J., Walker, J. S., Bernstein, A., Daleiden, E., Pullmann, M. D., & Chorpita, B. F. (2014). Family voice with informed choice: coordinating wraparound with research-based treatment for children and adolescents. *Journal of Clinical Child & Adolescent Psychology*, 43(2), 256-269.
- Bruns, E. J., Walker, J. S., Adams, J., Miles, P., Osher, T. W., Rast, J., & VanDenBerg, J. (2004). *Ten principles of the wraparound process*. Portland, O.R.: National W.A. Initiative, Research and Training Center on Family Support and Children’s Mental Health, Portland State University. Retrieved February 21, 2023. <https://nwi.pdx.edu/pdf/TenPrincWAProcess.pdf>
- Cadel, L., Guilcher, S. J. T., Kokorelias, K. M., Sutherland, J., Glasby, J., Kiran, T., & Kulushki, K., (2021). Initiatives for improving delayed discharge from a hospital setting: a scoping review. *BMJ Open*, 11, e044291. doi:10.1136/bmjopen-2020-044291
- Cavallaro, S. C., Michelson, K. A., D’Ambrosi, G., Monuteaux, M. C., & Li, J. (2023). Critical revisits among children after emergency department discharge. *Annals of Emergency Medicine*, 82(5), 575-582.

- Chen., A., Zagorski, B., Chan, V., Parsons, D., Vander Laan, R., & Colantonio, A. (2012). Acute care alternate-level-of-care days due to delayed discharge for traumatic and non-traumatic brain injuries. *Healthcare Policy*, 7(4), 41.
- Chomilo, N. T. (2022). Building racial equity into the walls of Minnesota Medicaid: A focus on U.S.-born Black Minnesotans. *Minnesota Department of Human Services Report*. Retrieved April, 2022. <https://edocs.dhs.state.mn.us/lfserver/Public/DHS-8209A-ENG>.
- Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd ed.). Los Angeles: Sage.
- Creswell, J. W., & Clark, V. L. P. (2017). *Designing and conducting mixed methods research*. Sage.
- Cushing, A. M., Liberman, D. B., Pham, P. K., Michelson, K. A., Festekjian, A., Chang, T. P. & Chaudhari, P. P. (2022). Mental health revisits at US pediatric emergency departments. *JAMA Pediatrics*. Doi:10.1001/jamapediatrics.2022.4885
- Dieterich M., Irving, C. B., Bergman. H., Khokhar, M.A., Park, B., & Marshall, M. I. (2017). *Intensive case management for severe mental illness*. Cochrane Database Systematic Review, 1, CD007906. <https://doi.org/10.1002/14651858.CD007906.pub3>
- Dillon, K. & Thompson, D. (2016). *Reasons for delays in hospital discharges of behavioral health patients*. Saint Paul, MN: Wilder. [https://www.wilder.org/sites/default/files/imports/MHA\\_Report\\_7-16.pdf](https://www.wilder.org/sites/default/files/imports/MHA_Report_7-16.pdf)
- Dixon, L. (2000). Assertive community treatment: twenty-five years of gold. *Psychiatric Services*, 51(6), 759-765.
- Dillon, K., Vang, M., & Hierlmaier, N. (2024). *Transfer and discharge delays for behavioral health patients at Minnesota hospitals: Results from the 2023 health behavioral health collection*. Saint Paul, Minnesota.
- Edwards, T., Laylor, A., King, B., & Parada, H. (2023). When home reminds me of jail: The carceral nature of out-of-home care for Black youth in Ontario's child welfare system. *Children and Youth Services Review*, 155, 107309.
- Eldred, S. M., (2024). *Why are kids of color spending days, weeks, months in hospital emergency rooms where they can't treat their problems?* Minneapolis, MN: Sahan Journal. <https://sahanjournal.com/health/minnesota-autism-mental-illness-hospital-boarding/>



- Engler, J. (2022). Boarding mental health patients in Minnesota emergency departments--The unintended consequence of an inadequate mental health system. *Mitchell Hamline Law Review*, 48(4), 893-924. <https://open.mitchellhamline.edu/mhlr/vol48/iss4/3/>
- Erdahl, K. (2023). The 'boarding has got much much worse' mental health task force issues new report on patients stuck in ERs. Minneapolis, MN: KARE. <https://www.kare11.com/article/news/local/breaking-the-news/boarding-has-gotten-much-much-worse-mental-health-taskforce-issues-new-report-on-patients-stuck-in-ers/89-bba76d14-24fd-4b95-8f62-7a6fbc073617>
- Fallon, L. M., Cathcart, S. C., & Johnson, A. H. (2021). Assessing differential item functioning in a teacher self-assessment of cultural responsiveness. *Journal of Psychoeducational Assessment*, 39(7), 816-831.
- Fallon, L. M., Veiga, M., & Sugai, G. (2023) Strengthening MTSS for behavior (MTSS-B) to promote racial equity, *School Psychology Review*, 52(5), 518-533, DOI: 10.1080/2372966X.2021.1972333
- Ferro, J., Fox, L., Binder, D., & von der Embse, M. (2020). *Equity coaching guide*. National Center for Pyramid Model Interventions. University of South Florida.
- Fixsen, D. L., Blase, K. A., Naoom, S. F., & Wallace, F. (2009). Core implementation components. *Research on social work practice*, 19(5), 531-540.
- Fixsen, D., Blase, K., Metz, A., & Van Dyke, M. (2013). Statewide implementation of evidence-based programs. *Exceptional Children*, 79(2), 213-230.
- Fixsen, D., Van Dyke, M., & Blase, K. (2019). *Science and implementation*. Chapel Hill, North Carolina: Active Implementation Research Network.
- Fixsen, D. L., Naoom, S. F., Blasé, K. A., Friedman, R. M., & Wallace, F. (2005). *Implementation research: A synthesis of the literature*. University of South Florida. Tampa, Florida.
- Freeman, R. (2016). Strategies for implementing positive support strategies in agencies and organizations. *Impact*, 29(2), 12-15.
- Freeman, R., Danov, S., Petrie, G., Stansberry-Brusnahan, L., Timothy Moore, T., Simacek, J., & Amado, R. (2021). Minnesota Positive Behavior Support: Networking during a pandemic. *Association for Positive Behavior Support Newsletter*, 19(2), 3-4.

- Freeman, R., Enyart, M., Matthews, K., Quick, S., & Kimbrough, P. (2014). *Kansas Mental Health and Positive Behavior Support project report*. University of Kansas. University of Kansas. Lawrence, KS.
- Freeman, R., Enyart, M., Schmitz, K., Kimbrough, P., Matthews, K., & Newcomer, L. (2015). Integrating and building on best practices in person-centered planning, wraparound, and positive behavior support. In F. Brown, J. Anderson, & R. De Pry, (Eds.), *Individual positive behavior supports: A standards-based guide to practices in school and community-based settings* (pp. 241-257). Baltimore, MD: Brookes.
- Freeman, R. Perrin, N., Irvin, L., Vincent, C., Newcomer, L., Moore, M., Anderson, S., Miller, D., Kimbrough, P., Little, A., Deegan, M., Rennells, K., & Farr Bond, K. (2009). *Positive behavior support across the lifespan: Expanding the concept of statewide planning for large-scale organizational cultural change* (PBS-Kansas Monograph No. 1). Lawrence, KS: University of Kansas, Schiefelbusch Institute for Lifespan Studies.
- Freeman, R., Simacek, J., Jeffrey-Pearsall, J., & Dunphy, D. (2024). *Statewide capacity building to coordinate positive behavior support for families and communities*. Manuscript submitted for publication. Minneapolis, MN: University of Minnesota.
- Freeman, R., Simacek, J., Jeffrey-Pearsall, J., Lee, S., Khalif, M., & Oteman, Q. (2023). Development of the Tiered Onsite Evaluation Tool (TOET) for organization-wide person-centered positive behavior support. *Journal of Positive Behavior Interventions*. DOI: 10.1177/10983007231200540
- Freeman, R., Simacek, J., Moore, T., & Duchelle, N. (2021). *Centers of excellence final report: Focus group results and recommendations*. University of Minnesota, Institute on Community Integration: Minneapolis, MN.
- Gage, N. A., Whitford, D. K., Katsiyannis, A., Adams, S., & Jasper, A. (2019). National analysis of the disciplinary exclusion of black students with and without disabilities. *Journal of Child and Family Studies*, 28, 1754-1764.
- Glasby J., Littlechild R., Pryce K. (2006). All dressed up but nowhere to go? Delayed hospital discharges and older people. *Journal of Health Services Research & Policy*, 11,52-58.

- Gonçalves-Bradley, D. C., Lannin, N. A., Clemson, L., Cameron, I. D., & Shepperd, S. (2022). Discharge planning from hospital. *Cochrane Database Systematic Review*, 2022(2), 1-116. doi:10.1002/14651858. CD000313.pub6
- Gorden, R. S. (1983). An operational classification of disease prevention. *Public Health Reports*, 98, 107-109.
- Grabowski, D. C., Cadigan, R. O., Miller, E. A., Stevenson, D. G., Clark, M., & Mor, V. (2010). Supporting home-and community-based care: views of long-term care specialists. *Medical Care Research and Review*, 67(4), 82S–101S.
- HANYS (2021). *The complex case discharge delay problem*. Healthcare Association of New York State, Inc.
- Harrington, C., Ng, T., Kaye, H. S., Newcomer, R. (2009). *Home and community-based services: public policies to improve access, costs, and quality* [Internet]. San Francisco CA: University of California, San Francisco, Center for Personal Assistance Services. [http://www.pascenter.org/documents/PAS\\_Center\\_HCBS\\_policy\\_brief.php](http://www.pascenter.org/documents/PAS_Center_HCBS_policy_brief.php)
- Hernandez, M., & Hodges, S. (2003). Building upon the theory of change for systems of care. *Journal of Emotional and Behavioral Disorders*, 11(1), 19–26.
- Hoffman, A. K. (2016). Reimagining the risk of long-term care. *Yale Journal of Health Policy and Ethics*, 16, 147.
- Huang, L. (2002, Fall). Reflecting on cultural competence: A need for renewed urgency. *Focal Point*, 16(2), 4–7 [electronic newsletter].
- Huang, L., Stroul, B., Friedman, R., Mrazek, P., Friesen, B., Pires, S., & Mayberg, S. (2005). Transforming mental health care for children and their families. *American Psychologist*, 60(6), 615.
- Jain, S., Reno, R., Cohen, A. K., Bassey, H., & Master, M. (2019). Building a culturally responsive, family-driven early childhood system of care: Understanding the needs and strengths of ethnically diverse families of children with social-emotional and behavioral concerns. *Children and Youth Services Review*, 100, 31-38.
- Johnson, L. A. D. (2017). Scaling the pyramid model across complex systems providing early care for preschoolers: Exploring how models for decision making may enhance

- implementation science. *Early Education and Development*, (7)28, 822-838. DOI: 10.1080/10409289.2017.1286205
- Kalb, L. G., Stapp, E. K., Ballard, E. D., Holiugue, C., Keefer, A., & Riley, A. (2019). Trends in psychiatric emergency department visits among youth and young adults in the U.S. *Pediatrics*, 143(4).
- Kennedy, L., Neidlinger, S., & Scroggins, K. (1987). Effective comprehensive discharge planning. *Gerontologist*, 27(5), 577-80.
- Kim, K. M., Meyer, N., Hall-Lande, J., & Freeman, R. (2021). Supervisory and administrative staff's perspectives of self-directed supports for people with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, 1–8. <https://doi.org/10.1111/jar.12955>
- Knitzer, J. (1982) *Unclaimed children: The failure of public responsibility to children and adolescents in need of mental health services*. Washington, DC: The Children's Defense Fund.
- Kutash, K., Duchnowski, A. J., & Lynn, N. (2006). *School-based mental health: An empirical guide for decision-makers*. Tampa, F. L.: University of South Florida, The Louis de la Parte Florida Mental Health Institute, Department of Child & Family Studies, Research and Training Center for Children's Mental Health.
- Landeiro F., Roberts, K., Gray, A. M., Leal, J. (2019). Delayed hospital discharges of older patients: a systematic review on prevalence and costs. *Gerontologist*, 59(2), e86-e97. doi:10.1093/geront/gnx028
- Leeb, R. T., Bitsko, R. H., Radhakrishnan, L., et al. (2020). Mental health–related emergency department visits among children aged <18 years during the COVID-19 pandemic–United States, January 1–October 17, 2020. *MMWR Morbidity and Mortality Weekly Report*, 69(45), 1675–80.
- Leverson, M., Smith, K., McIntosh, K., Rose, J., & Pinkelman, S. (2021, March). *PBIS cultural responsiveness field guide: Resources for trainers and coaches*. Center on PBIS, University of Oregon.

- Levy, S. E., Mandell, D. S., Merhar, S., Ittenbach, R. F., & Pinto- Martin, J. A. (2003). Use of complementary and alternative medicine among children recently diagnosed with autistic spectrum disorder. *Journal of Developmental and Behavioral Pediatrics*, 24(6), 418–423.
- Lord, C., Wagner, A., Rogers, S., Szatmari, P., Aman, M., Charman, T., et al. (2005). Challenges in evaluating psychosocial interventions for Autistic Spectrum Disorders. *Journal of Autism & Developmental Disorders*, 35(6), 695–708.
- Lucyshyn, J., Dunlap, G., & Freeman, R. (2015). A historical perspective on the evolution of positive behavior support. In F. Brown, J. Anderson & R. De Pry (Eds.), *Individual positive behavior supports: A standards-based guide to practices in school and community-based settings* (pp. 3–25). Baltimore, MD: Brookes.
- Lytle, S., Hunt, A., Moratschek, S., Hall-Mennes, M., & Sajatovic, M. (2018). Youth with autism spectrum disorder in the emergency department. *The Journal of Clinical Psychiatry*, 79(3), 22582.
- Mancini, A. D., Moser, L. L., Whitley, R., McHugo, G. J., Bond, G. R., Finnerty, M. T., & Burns, B. J. (2009). Assertive community treatment: Facilitators and barriers to implementation in routine mental health settings. *Psychiatric Services*, 60(2), 189-195.
- Maryland Hospital Association, MHA (2019). Delays in hospital discharges of behavioral health patients. <https://www.mhaonline.org/docs/default-source/resources/mha-report-jan-2019.pdf>. Jan. 2019.
- Matthews, K., Enyart, M. & Freeman, R. (2019). Putting the pieces together: Perceptions of longitudinal wraparound, systems of care, and positive behavior support implementation. *Community Mental Health Journal*, 55, 932-941 DOI: 10.1007/s10597-019-00379-8
- McGrab, P., & Millar, H. (1989). National Center for Networking Community Based Services, Georgetown University Child Development Center. *Surgeon General's Conference: Growing up and getting medical care: Youth with special health care needs*. A summary of conference proceedings. <https://profiles.nlm.nih.gov/spotlight/nn/catalog.nlm.nlmuid-101584932X870-doc>
- McIntosh, K., Barnes, A., Eliason, B., & Morris, K. (2014). Using discipline data within SWPBIS to identify and address disproportionality: A guide for school teams. *Technical Assistance Center on Positive Behavioral Interventions and Supports*.

- McIntosh, K., & Goodman, S. (2016). *Integrated multi-tiered systems of support: Blending RTI and PBIS*. Guilford Publications.
- McIntosh, K., Filter, K. J., Bennett, J. L., Ryan, C., & Sugai, G. (2010). Principles of sustainable prevention: Designing scale-up of school-wide positive behavior support to promote durable systems. *Psychology in the Schools, 47*(1), 5-21.
- McIntosh, K., Smolkowski, K., Gion, C. M., Witherspoon, L., Bastable, E., & Girvan, E. J. (2020). Awareness is not enough: A double-blind randomized controlled trial of the effects of providing discipline disproportionality data reports to school administrators. *Educational Researcher, 49*(7), 533-537.
- Merriam, S. B. (2009). *Qualitative research: A guide to design and implementation*. San Francisco: Jossey-Bass.
- Metz, A., & Bartley, L. (2012). Active implementation frameworks for program success. *Zero to three, 32*(4), 11-18.
- Minnesota Medical Association (2023). *Emergency department boarding of patients with psychiatric diagnoses (EDBPPD)*. Minnesota.
- Mirzaian, C. B., Deavenport-Saman, A., Hudson, S. M., & Betz, C. L. (2024). Barriers to mental health care transition for youth and young adults with intellectual and developmental disabilities and co-occurring mental health conditions: Stakeholders' perspectives. *Community Mental Health Journal, 1*-13.
- Mueser K. T., Bond G. R., Drake R. E., Resnick S. G. (1998). Models of community care for severe mental illness: A review of research on case management. *Schizophrenia Bulletin, 1998;24*(1): 37–74. [PMID: 9502546]
- Nash, K. A., Tolliver, D. G., Taylor, R. A., Calhoun, A. J., Auerback, M. A., Venkatesh, A. K., & Wong, A. H. (2021). Racial and ethnic disparities in physical restraint use for pediatric patients in the emergency Department. *JAMA Pediatrics, 175*(12):1283.
- National Academies of Sciences, Engineering, and Medicine. (2023). *Early interventions for psychosis: First episodes and high-risk populations: Proceedings of a workshop*. Washington, D.C.: The National Academies Press. <https://doi.org/10.17226/26832>.

- Overhage, L., Hailu, R., Busch, A. B., Mehrotra, A., Michelson, K. A., & Huskamp, H. A. (2023). Trends in acute care use for mental health conditions among youth during the COVID-19 pandemic. *JAMA Psychiatry*, 80(9), 924–32.
- Patton, M. Q. (1994). Developmental evaluation. *Evaluation practice*, 15(3), 311-319.
- Patton, M. Q. (2008). *Utilization-focused evaluation* (4th ed.). Sage.
- Pearson, T., McCullough, S., Schreifels, L., & Pearson, D. (2022) *Impact of the intersection of developmental disabilities and other population profiles on experiences with discrimination. The One Minnesota baseline quantitative survey*. MarketResponse International.
- Pearson, T., McCullough, S., Schreifels, L., & Pearson, D. (2023). *Phase II intersectionality study, for the Minnesota Governor's Council on Developmental Disabilities. The One Minnesota baseline quantitative survey*. MarketResponse International.
- Pellico-López, A., Cantarero, D., Fernández-Feito, A., Parás-Bravo, P., Cayón de Las Cuevas, J., & Paz-Zulueta, M. (2019). Factors associated with bed-blocking at a university hospital (Cantabria, Spain) between 2007 and 2015: A retrospective observational study. *Cantabria, Spain: International Journal of Environmental Research and Public Health*, 18, 3304.
- Pires, S. A., & Stroul, B. A. (1996). *Health Care Reform Tracking Project: Tracking state health care reforms as they affect children and adolescents with emotional disorders and their families*. Proceedings of the Annual Research Conference (9th, Tampa, F.L., February 26-28, 1996); see EC 306 844. Project conducted jointly by Research and Training Center for Children's Mental Health, University of South Florida; Human Service Collaborative, Washington, D.C.; National Technical Assistance Center for Children's Mental Health, Georgetown University.
- Read, H., & Kohrt, B. A. (2021/2022). The history of coordinated specialty care for early intervention in psychosis in the United States: A review of effectiveness, implementation, and fidelity. *Community Mental Health Journal*, 1-12.
- Rojas-García A., Turner S., Pizzo E., Hudson E., Thomas J., & Raine R. (2018). Impact and experiences of delayed discharge: A mixed-studies systematic review. *Health Expectations*, 21(1), 41-56.

- Rosenheck, R., Leslie, D., Sint, K., Lin, H., Robinson, D. G., Schooler, N. R., ... & Kane, J. M. (2016). Cost-effectiveness of comprehensive, integrated care for first episode psychosis in the NIMH RAISE Early Treatment Program. *Schizophrenia Bulletin*, *42*(4), 896-906.
- Sailor, W., Scott, T. M., Nelson, C. M., Freeman, R., Smith, C., Britten, J., & McCart, A. (2000). Using information technology to prepare personnel to implement functional behavioral assessment and positive behavioral support. *Exceptionalities*, *8*(3), 217-230.
- Schindler, J. (2024). *Minnesota Hospital Association's survey of hospital discharge delays*. Acute Care Advisory Council presentation [meeting]. Minnesota Hospital Association.
- Smith, T., Parker, T., Taubman, M., & Lovaas, O. I. (1992). Transfer of staff training from workshops to group homes: A failure to generalize across settings. *Research in Developmental Disabilities*, *13*, 57-71.
- Srihari, V. H., Tek, C., Kucukgoncu, S., Phutane, V. H., Breitborde, N. J., Pollard, J., ... & Woods, S. W. (2015). First-episode services for psychotic disorders in the US public sector: A pragmatic randomized controlled trial. *Psychiatric Services*, *66*(7), 705-712.
- Stahmer, A. (2006). The basic structure of community early intervention programs for children with Autism: Provider descriptions. *Journal of Autism & Developmental Disorders*, *37*, 1344–1354 DOI 10.1007/s10803-006-0284-x
- Stock, C., Zalani, A., Hacker, C., Mercedes, D., Sanchez, J., & Botsford, M. (2023). *Children languish in emergency rooms awaiting mental health care*.  
<https://www.cbsnews.com/news/emergency-rooms-children-mental-health/>
- Substance Abuse and Mental Health Services Administration. (2022). *National guidelines for child and youth behavioral health crisis care*. Publication No. PEP22-01-02- 001 Rockville, MD: substance abuse and mental health services administration.  
<http://hdl.handle.net/10713/20353>
- Tolan, P. H., & Dodge, K. A. (2005). Children's mental health as a primary care and concern: a system for comprehensive support and service. *American Psychologist*, *60*(6), 601.
- Turner, E. A., Jensen-Doss, A., & Heffer, R. W. (2015). Ethnicity as a moderator of how parents' attitudes and perceived stigma influence intentions to seek child mental health services. *Cultural Diversity & Ethnic Minority Psychology*, *21*(4), 613–618.



- Tyson, C., & Punnoose, P. (2024). Coordinated system of care approaches for pediatric emergency and crisis stabilization, mobile treatment, and wraparound services. *Child and Adolescent Psychiatric Clinics*, 33(4):609-626. doi:10.1016/j.chc.2024.03.014. Epub 2024 Apr 30
- Walker, H. M., Horner, R. H., Sugai, G., Bullis, M., Sprague, J. R., Bricker, D., & Kaufman, M. J. (1996). Integrated approaches to preventing antisocial behavior patterns among school-age children and youth. *Journal of Emotional and Behavioral Disorders*, 4(4), 194-209.
- Walker, S. P., Wachs, T. D., Grantham-McGregor, S., Black, M. M., Nelson, C. A., Huffman, S. L., ... & Richter, L. (2011). Inequality in early childhood: risk and protective factors for early child development. *The Lancet*, 378(9799), 1325-1338.
- West, A. E., Conn, B. M., Preston, E. G., & Dews, A. A. (2023). Dismantling structural racism in child and adolescent psychology: a call to action to transform healthcare, education, child welfare, and the psychology workforce to effectively promote BIPOC Youth Health and Development. *Journal of Clinical and Child Adolescent Psychology*, 52(3), 427-46.
- Wong A. H., Whitfill T., Ohuabunwa, E. C., Ray, J., Dziura, J., Bernstein, S. L., & Taylor, R. A. (2021). Association of race/ethnicity and other demographic characteristics with use of physical restraints in the emergency department. *JAMA Network Open*, 4(1), e2035241-e2035241. doi:10.1001/jamanetworkopen.2020.35241
- World Health Organization (2004). Prevention of mental disorders: Effective interventions and policy options. Who, Geneva.
- Yard, E. (2021). Emergency department visits for suspected suicide attempts among persons aged 12-25 years before and during the COVID-19 pandemic — United States, January 2019-May 2021. *MMWR Morbidity and Mortality Weekly Report*, 70(24), 888-94.
- Zandam H., Akobirshoev I., & Mitra M. (2024) Multiple chronic condition emergency department visits among U.S. adults: disparities at the intersection of intellectual and developmental disabilities status and race or ethnicity, *Health Equity* 8(1), 198-205. DOI:10.1089/heq.2023.0228

## **Appendices**

Appendix A:	Participant details
Appendix B:	Qualitative thematic analysis codebook
Appendix C:	Worksheet for public reports analysis
Appendix D:	Dissenting opinions (No submissions prior to public comment)
Appendix E:	Public comment documentation

## Appendix A: Examples of common services and systems for children and adults

### *Children and examples of services and systems*

#### Children with Autism/IDD

Children with Mental Illness and Behavioral Health Episodes

Children with Substance Abuse Disorder

Children with Complex Health Issues

Children Experiencing Systems Issues

Children with Co-morbid Disorders & Multiple Challenges

#### **Potential Coordination, Communication, and Data Sharing Needed for Transition Planning Across the Following for Care Navigation:**

- Families/Caregivers
- Hospitals
- Education
- Independent Clinical (Physicians, BCBA's, etc)
- Residential Providers
- Out of Home Placement (Inpatient, PRTF)
- Legal/Courts, Juvenile Justice
- Counties
- Direct Care and Treatment
- Children and Family Services
- Disability Services
- Behavioral Health Services

### *Adults and examples of services and systems*

#### Adults with Autism/IDD Challenging Behaviors (Property Destruction, Aggression, self-injury)

Adults with Mental Illness and Behavioral Health Episodes

Adults with Substance Abuse Disorder

Adults with Complex Health Issues

Adults Experiencing Systemic Barriers

Adults with Co-morbid Disorders & Multiple Challenges

#### **Potential Coordination, Communication, and Data Sharing Needed for Transition Planning Across the Following for Care Navigation:**

- Families/Caregivers
- Hospitals,
- Nursing Homes, Assisted Living
- Home Health Providers (65+)
- Residential Support Providers
- Employment Services
- Legal/Courts, Prison
- Counties
- Direct Care and Treatment
- Children and Family Services
- Disability Services
- Behavioral Health Services
- Independent Clinical (Physicians, BCBA's, etc.)

## Appendix B: Flyer recruiting focus group and interview participants

### INVITATION TO PROVIDE FEEDBACK

Invitation to provide feedback on barriers to transition from emergency rooms and/or hospitals



#### SHARE YOUR THOUGHTS

The University of Minnesota and the Minnesota Department of Human Services (DHS) is conducting evaluation study research by looking for people who live in Minnesota who can help them better understand the challenges children and adults who are admitted into the emergency room or hospital experience when they have problems transitioning home. There are many reasons why someone might have problems transitioning home after a visit to the emergency room or hospital. Sometimes services are not available to provide support and in other situations there may be paperwork or procedures that are slowing down someone's ability to transition home.

#### YOU MAY BE ABLE TO HELP DHS UNDERSTAND THESE CHALLENGES BETTER IF YOU ARE A....

- Family member or caregiver who has a child, parent, friend, or important person in your life who has experienced barriers to transitioning home from the emergency room or hospital,
- County professional supporting people who are experiencing challenges,
- Hospital or medical personnel involved in supporting someone who is in the emergency room or hospital,
- Professional supporting children and/or adults by providing behavioral health or positive supports,
- Professionals leading or working in provider organizations who support people in residential, employment, or family/caregiver settings, and
- Advocates who are working to improve services and supports to children and adults.

#### HOW YOUR INFORMATION WILL BE USED

You will be asked if it is okay to record and transcribe your thoughts in the focus group and interview sessions. All information gathered will be anonymous. Your name, where you are from, other people mentioned, and other details that might identify you will be removed from notes. You will have an opportunity to choose an interview format that does not involve recording, if you are more comfortable with sharing as a person takes notes. You can choose to leave the focus group or interview session at any time.

#### DIFFERENT WAYS TO SHARE

- Join a 2-hour online zoom focus group with 6-8 other people who are interested in sharing their ideas:  
**August 20th, 12noon - 2:00pm**  
**September 10th, 5:00pm - 7:00pm**
- OR
- Participate in a 45-minute, one-on-one phone or zoom-based webinar

Please share your contact information here if you are interested in signing up for a focus group or interview.

**SIGN UP**

Or, email: [jeffr181@umn.edu](mailto:jeffr181@umn.edu)

## Appendix C: ACTAC evaluation participant list

### *Participants in the Acute Care Transitions Advisory Council*

Participants in council meetings as members, presenters, or individuals assisting others with lived experience, focus group participants and individuals interviewed.

<b>Random pseudonym</b>	<b>Data source</b>	<b>Role or experience</b>	<b>Geographic area of state</b>
	Council participants = CM Focus Group = FG Interview=I	County = Co Family = Fa Lawyer = La State = St Contractor = Con University = Un Provider = Pr Council only lived experience = Le Tribal Nations =TN	East central = EC Metro=M Southeast=SE Southwest=SW Northeast =NE Northwest=NW West central=WC Not in MN =NiMN
1. Mada	FG	Co	NE
2. Nova	CM	St	M
3. Gabe	I	La	M
4. Syllas	CM	La	M
5. Bua	CM	St	M
6. Oak	I	La	M
7. Zaci	FG	Pr	M
8. Cora	CM	Ph	M
9. Mia	CM	Con	NiMN
10. Yara	CM	Pr	M
11. Pace	I	La	M
12. June	CM	St	M
13 Val	FG	Co	NE
14. Cali	I	La	M
15. Vail	I	La	M
16. Ivy	CM	St	M

17. Joan	CM	Con	NiMN
18. Brid	CM	St	M
19. Atlas	CM	Pr	M
20. Byla	CM	Fa/Ho	M
21. Xael	FG	Pr	NE
22. Isla	CM	*	*
23. Ava	CM	Ho	M
24. Yana	FG	Co	NE
25. Leo	CM	Pr	M
26. River	CM	Le	M
27. Jack	CM	Ho	M
28. Ella	CM	Fa/Pr/Co	M
29. Mack	I	La	M
30. Lily	CM	St	M
31. Alma	CM	Ho	M
32. Aim	I	Co	M
33. Akira	CM	Pr	M
34. Luna	CM	TN	NE
35. Rose	CM	*	*
36. Iris	CM	Co	EC
37. Iben	I	La	M
38. Jai	CM	St	M
39. Zoe	CM	Pr	M
40. Uki	I	La	M
41. Otto	CM	Pr	*
42. Fews	I	La	M
43. Hazel	CM	St	M
44. Rae	CM	Un	M
45. Luca	CM	St	M

46. Waru	I	Co	M
47. Kai	CM	Un	NE
48. Caleb	CM	St	M
49. Lyra	CM	Un	M
50. Caia	FG	Fa	*
51. Aero	I	La	M
52. Dale	I	Co	M
53. Ojai	I	Co	M
54. Halle	FG	Co	S
55. Dana	I	Co	M
56. Lara	CM	*	*
57. Okapi	I	Co	M
58. Aj	I	Co	M
59. Wen	I	Co	M
60. Nora	I	Co	M
61. Myra	CM	Con	M
62. Gabi	FG	Pr	*
63. Ivan	CM	St	M
64. Yank	I	La	M

*\* Indicates no information*

## Appendix D: Quantitative worksheet for public reports analysis

### *Public report worksheet and analysis summary*

#### **Citation:**

#### **Initiator of report:**

#### **Data sources**

- Mainly data from literature
- New sources collected
- Multiple data new and from other sources.

#### **Public or informal report**

- Report available
- Presentation of evaluation data collected.

#### **Type of quantitative and qualitative data**

- Survey
- Extant data
- Data collected onsite
- Focus groups
- Interviews
- Other \_\_\_\_\_.

#### **Rigor of evaluation (new) data gathered reported**

##### **Scoring for each element of design**

1=Excellent...2= Good...3=Adequate...4= Poor...5=Unknown logic ...6=Unable to score

- Evaluation questions
- Key definitions for measurement
- Methods
- Analysis.

Comments: Strengths of design



Comments: Weakness of design

**Summary of important data to highlight related to ACTCA evaluation questions**

**Summary of recommendations from report**

**Appendix E: Acute Care Transitions Advisory Council (ACTAC) codebook summary**

Major themes and subthemes from council meetings, focus groups and interviews

<p><b>1. Barriers encountered in acute care transitions</b></p>	<ul style="list-style-type: none"> <li>• Coordination and communication</li> <li>• Funding/policy –barriers</li> <li>• Access to community services and staffing issues</li> <li>• Discharge delays/readmittance.</li> </ul>
<p><b>2. Characteristics of individuals experiencing barriers</b></p>	<ul style="list-style-type: none"> <li>• Bariatric issues</li> <li>• Behavioral health/mental health (Episodes, suicide, psychotic episodes)</li> <li>• Behavioral events (associated with Autism/IDD, self-injury, property destruction, aggression)</li> <li>• Children, adults, older adults 65+</li> <li>• Substance abuse disorder</li> <li>• Systems (Insurance, county response, guardianship).</li> </ul>
<p><b>3. Interventions and strategies for addressing barriers in acute care transitions</b></p>	<ul style="list-style-type: none"> <li>• Assessment &amp; measurement</li> <li>• Communicating across services</li> <li>• Care navigation strategies</li> <li>• Transition planning</li> <li>• Regional and state systems</li> <li>• Capacity building &amp; incentives (DSPs, county, families, etc.)</li> <li>• Positive supports</li> <li>• Funding/policy/legal interventions</li> <li>• Need for beds (inpatient/nursing home/other beds).</li> </ul>
<p><b>4. Health equity disparities (Geographic, ethnicity and race)</b></p>	<ul style="list-style-type: none"> <li>• Diversity of families/homes/culture</li> <li>• Barriers to health equity</li> <li>• Ensuring diverse voices in decision making</li> <li>• Challenges in rural areas.</li> </ul>

### **Appendix F: Dissenting opinions**

The council heard from a broad spectrum of constituents and stakeholders across Minnesota. Efforts were made to incorporate differing perspectives. There were no specific dissenting opinions offered among council members prior to public comment.

## Appendix G: Glossary

**Note: Visit the [CBSM Glossary of Terms](#) for more Minnesota Department of Human Services glossary terms.**

### Glossary of terms\*

#### **Acute care**

Medical care for an episode of injury or an illness.

#### **Assertive community treatment**

Assertive community treatment (ACT) improves outcomes for people with severe mental illness and may be more likely to be at-risk of hospitalization and other negative life outcomes including involvement in the criminal justice system. The practice involves forming a multidisciplinary team including community outreach and action planning.

#### **Boarding**

Refers to the time when patients are in the emergency department waiting for a hospital bed to become available.

#### **Challenging behaviors**

Behavior that are of concern by the people who are living and working with a person. Everyone engages in behaviors that are problematic at some point in life. A behavior becomes challenging if it interferes with quality of life, health and wellness or safety.

#### **Community Access for Disability Inclusion (CADI) Waiver**

Program that provides home and community-based services to children and adults with disabilities who require the level of care provided in a nursing facility. These services are an alternative to institutionalization. They help a person live as independently as possible in community settings and promote optimal health, independence, safety and community integration.

#### **Community Alternative Care (CAC) Waiver**

Program that provides home and community-based services to children and adults who are chronically ill or medically fragile and require the level of care provided in a hospital. These services are an alternative to institutionalization. They help a person live as independently as possible in community settings and promote optimal health, independence, safety and community integration.

#### **Community First Services and Supports (CFSS)**

Refers to the DHS transition from personal care assistance (PCA) to CFSS. The terms PCA and CFSS refer to supports people receive to help them remain independent in the community.

**Competency-based assessment**

A model that is focused on identifying the skills needed for a position, determining a plan to build these skills and designing strategies to evaluate the effectiveness of that plan. The goal is for a person to demonstrate mastery of a skill before moving on to the next competency to be taught. Once they demonstrate the skill, they move to the next skill to acquire. This approach means that time is not wasted on teaching skills a person already knows.

**Competency drivers**

The strategies, systems and resources that are used to improve knowledge and skills within an organization or group is referred to as the competency drivers within an implementation effort. Four major elements of competency drivers include assessing performance, selecting trainers, content taught (curricula) and how coaching and mentoring is provided on an ongoing basis.

**Culture of safety**

Providers who provide a culture of safety acknowledge that the work carries some high risk in the tasks the employee carries out. They also provide a culture that is blame-free, where people can report errors or near misses with our fear of reprimand or punishment. It encourages people across the organization to collaborate and seek solutions together in the spirit of safety for everyone. Organizations who are committed to a culture of safety commit resources to address safety concerns.

**Dementia**

A term used to describe an impairment in a person's ability to remember, make decisions and think that interferes with everyday tasks and activities. Dementia is more common in older adults but it is not a part of the aging process.

**Discharge delays**

Refers to situations where patients in the hospital no longer need medical services and could leave the hospital but are unable to do so for non-medical reasons.

**Evaluation plan**

An approach to organizing the ongoing assessment of practices by explaining what is being evaluated, describing evaluation questions that identify measures and create a plan to collect, summarize and use data to improve HCBS outcomes. The evaluation plan addresses how data are used for decision making in meetings throughout the year and as part of an annual evaluation.

**Feedback loops**

A term used in an organization to 1) gather information, 2) assess the data, 3) make changes based on what has been learned and 4) meeting again to follow progress and make changes.

**Fetal alcohol syndrome (FASD)**

Refers to a condition resulting from alcohol exposure during a mother's pregnancy. Drinking alcohol while pregnant can cause a woman's child to be born with disabilities. These disabilities can impact the child's behavior and physical development, as well as their learning and cognitive processes. Symptoms of fetal alcohol syndrome vary across children and impact the child for their entire life.

**Group residential housing (GRH)**

A state-funded income supplement program that pays for room and board costs for low-income adults who have been placed in a licensed or registered setting with which a county human service agency has negotiated a monthly.

**Home and Community-Based Services (HCBS) Waiver**

Services not normally covered by Medical Assistance that are covered under a 1915(c) federally funded waiver program or through state funds. HCBS waivers allow states flexibility to cover virtually all long-term care services that people with disabilities need to live independently in home and community settings. States may operate several 1915 (c) HCBS waiver programs at once, each offering a distinct package of services and supports to different groups of people.

**Home health agency services**

Services delivered by a home health agency to a person with medical needs due to illness, disability or physical conditions in the person's place of residence or in the community where normal life activities occur.

**Hospital**

An acute care institution licensed under [Minn. Stat. §144.50 to 144.58](#).

**Institutional review board (IRB)**

Refers to a group formally designated to review and monitor research involving human subjects in accordance with U.S. Federal Food and Drug Administration (FDA). An has the authority to approve, require modifications or reject research proposed within an organization or system. The IRB process is meant to protect the rights and welfare of human research participants.

**Juvenile detention center**

A secure facility providing 24-hour treatment, education, housing and transition services for children and youth who are placed in this setting either as a condition of court-ordered probation or as the result of having been committed to the commissioner of corrections.

**Lead agency**

A county, tribal nation or managed care organization (MCO).

**Leadership drivers**

There are two different kinds of leadership skills referred to in implementation science. *Technical* challenges are the types of management-related problems that can be solved easily using basic management and administrative strategies used to coordinate trainings. *Adaptive* challenges are more complex and require more advanced skills such as active listening, empathy and the ability to help groups work through larger and contextual problems. For example, adaptive challenges may arise when there are people feeling unheard or there is a perception that some people are being treated unfairly. Adaptive leaders have the skills to help a group of people navigate these larger social challenges and arrive at potential solutions together.

**Logic model**

Refers to a model used to visually describe the relationship between an organization's resources, activities and the impacts that are sought. A logic model provides a roadmap for a group interested in implementing interventions and/or providing services. The major elements include defining 1) inputs, 2) activities and 3) outcomes.

**Managed care**

Health care delivery system that includes pre-established provider networks and reimbursement arrangements, administration and clinical systems.

**Managed care organization (MCO)**

An organization certified by the Minnesota Department of Health to provide all defined health care benefits to people enrolled in a Minnesota Health Care Program (MHCP) in return for a capitated payment. MCOs are also referred to as health plans or prepaid health plans.

**Medical transportation management (MTM)**

Coordinates non-emergency medical transportation (NEMT) for fee for service Medical Assistance recipients in the Twin Cities metro area through a contract with the Metro County Consortium (MCC).

**Medical Assistance (MA)**

Minnesota's name for the federal Medicaid program that provides medical care for people with low incomes.

**Medicaid**

A jointly funded, federal-state health insurance program for people who have a low income or other needs. It covers children, people who are older, people who have disabilities and others who are eligible to receive federally assisted income maintenance payments. Minnesota's Medicaid program is called Medical Assistance. See also [Medical Assistance](#).

**Medicaid Management Information System (MMIS)**

A mechanized claims-processing and information-retrieval system for Medicaid. The federal government requires all states operate an MMIS to support Medicaid business functions and maintain information in several areas (e.g., provider enrollment, eligibility, benefit package maintenance, managed care enrollment, claims processing, prior authorization).

**MnCHOICES**

A web-based application tool for conducting and creating person-centered assessments and support plans. It helps people with long-term or chronic-care needs make decisions about their care. MnCHOICES includes two electronic tools: assessment and support plan.

**Organizational drivers**

Refers to the way an agency designs the systems that are used in training an evidence-based practice (positive support). Organizational drivers include the way data is collected and summarized to monitor progress, how meetings are structured to encourage feedback and ensure communication is shared across an organization. The problem-solving systems within an organization that helps make sure barriers are removed and solutions to challenges are found quickly are also part of organizational drivers.

**Personal care attendant (PCA)**

A term used to describe a position involving a staff person trained to provide HCBS services to people who are living in homes in the community. PCAs support people with physical, mental health related or intellectual and developmental disabilities with the everyday tasks that help them to live in the community.

**Positive behavior support**

A framework used to improve the quality of a person's life and prevent or decrease challenging social interactions. The tools and strategies used in positive behavior support encourage social and communication skills and involve changing social settings to prevent challenging behaviors. Positive behavior support is based on research from areas including biomedical and behavioral science. Research also guides how positive behavior support is implemented in education and human service settings using a tiered model with interventions that gradually increase based on each person's unique needs. The universal level, or Tier 1, includes interventions for improving the quality of life and social interactions for everyone within a provider setting. The second tier involves monitoring HCBS data to identify problems that a person might have as early as possible and to intervene when challenges are still minor. The third tier is used to create individualized plans for each person who needs more intense supports.

**Positive support practices**

The term positive support refers to practices that are: a) person-centered, family-centered, student-centered and community-centered; b) evidence-based with research studies that show how effective an approach is and who benefits from the practice; c) sensitive and respectful to the unique culture of each person involved; d) adapted and improved over time using data to guide use and e) often implemented with other practices within complex everyday settings.



**Positive support services**

Refers to services that involve developing, implementing and monitoring a person-centered and individually designed plan to improve quality of life while also addressing behaviors that interfere in a person's life. There are three levels of staff involved. A positive support professional develops a plan with the child or adult and their team to enhance a person's quality of life and focusing on emotional and skill development. Analysts provide support to staff implementing the plan and direct support staff provide specialist services by implementing key elements of the plan.

**Private pay**

Paying for long-term care with your personal finances, such as savings and investments, long-term care insurance, home equity, certain life insurance benefits and/or options, certain annuity contracts and trusts.

**Qualitative data**

Information that is used to better understand the perceptions and emotional states of people and that seeks to capture the details of something that is being evaluated. Examples of qualitative measures include interviews with one person or groups, reviewing documents to assess whether changes have occurred, written descriptions of a situation or setting that occur in rich detail or case studies and stories used to assess organize what is being learned by grouping into categories or codes and looking for themes.

**Quality of life**

This is a common term used to describe how a person experiences their standard of health and wellbeing. Quality of life can be broken down into domains: emotional wellness, social interactions, work and employment, financial status, living environment, physical health, intellectual stimulation and spiritual growth.

**Quantitative data**

Information that is measured and results are shown using numbers to assess the amount of quantity of something. Examples of quantitative data include staff attrition numbers in a given year, the frequency of incidents that represent challenging social interactions or how many people report improved quality of life scores using measures that define important quality of life domains (physical health, wellness, finances).

**Scoping review**

Used by groups of people to learn more about a topic of interest by reviewing publications, reports and other communications. A scoping review is often used in situations where a more formal systematic review of the literature is not possible. Scoping reviews are used to identify knowledge gaps, assess the scope of a body of literature, clarify concepts and/or to assess how research is being conducted in an area. Although not as formal as other methods, scoping reviews must employ valid and transparent research methods that can be reproduced by other researchers.

**Social Services Information System (SSIS)**

Case management and data collection application for foster care, out-of-home placement, children's mental health, adoption information and vulnerable adult tracking.

**State Medical Review Team (SMRT)**

Division of the DHS that makes disability determinations using criteria defined by the Social Security Administration.

**Systems of care**

A system of care is a coordinated network of community-based services and supports designed to meet the challenges of children and youth with serious mental health needs and their families. These partnerships of families, youth, public organizations and private service providers address challenging behavior by addressing the mental health services and support needs and building on the strengths of a child, young person or adult. These systems are also developed around the principles of being child-centered, family-driven, strength-based and culturally competent.

**Three-tiered model of positive behavior support**

A framework for implementing universal strategies for all people in a home, work or other setting and by providing a continuum of interventions that increase in intensity based on the unique needs of each person. This framework is applied to positive behavior support and other practices that improve quality of life.

**Tier 1 universal**

Strategies for practicing and learning social and emotional skills that everyone can benefit from learning including people receiving support, staff, supervisors, human resource professionals, leaders, family and community members. Tier 1 also includes recognizing and celebrating positive social interactions, responding in a consistent manner to challenges and using data to assess progress over time.

**Tier 2**

Monitoring for changes in quality of life or challenges that might be occurring in social interactions and intervening as early as possible to prevent an escalation of interfering behavior. Examples of Tier 2 includes simple function-based strategies and group interventions that provide more opportunities to practice skills and receive positive feedback.

**Transitional care unit (TCU)**

A short-term care placement that provides a person recovering from an illness, injury or surgery with a place to recover and regain strength and independence. A TCU is best for patients who need short-term care.

**Trauma-informed support**

Traumatic life experiences such as child or domestic abuse, natural disasters or other negative life events can have a lasting impact on a person's health and emotional wellbeing. Trauma-informed support refers to the core values and messages that describe why it is important for

organizations to be sensitive to the past trauma most people have in their lives. Organizations that are committed to trauma-informed supports change policies and procedures, introduce training to help staff understand how to avoid re-traumatizing people, create ways to monitor the impact of universal training efforts and build expertise within the organization to provide people access to evidence-based practices (e.g. Psychological First Aid, Trauma-focused Cognitive Behavior Therapy, etc.).

### **Wraparound Planning**

A process created to support children, young people and adults with mental health needs and challenging behavior and coordinating the different service systems involved. Each of these services require parents/caregivers to complete forms, attend meetings and respond to requests related to services. Juvenile justice, children and family services, special education, mental health and developmental disabilities are all examples of these different services. The wraparound plan is mean to help youth and their parents by improving service coordination. Wraparound planning is a team-based approach that is child and family driven. Team members include natural supports (friends, family members and people who know the child or young person well). Individuals from formal supports might include a parole officer, counselor, psychiatrist or special education teacher. The goal of wraparound is to assess the child and family strengths to build a plan of support that will improve quality of life.

\* These glossary terms have been taken from existing definitions in different resources including the Minnesota DHS [CBSM Glossary of Terms](#) and the Home and Community-based The [Minnesota Home and Community-Based Services \(HCBS\) Modules for Person-Centered Organizations](#).