Services and Providers Subcommittee Meeting

July 8th, 2025

IOWA Health and Human Services

Agenda

- Review Findings from Statewide Access and Provider Capacity Assessment (SAPCA)
  - Introduction
  - General Findings
  - Challenges in the Overall HCS System
  - Challenges for Youth with SED
  - Conclusions
- Discussion
- Public Comment

Introduction

Motivation

- Two recent legal actions identified shortcomings in Iowa's community-based service (CBS) delivery for two populations:
  - Individuals with IDD
  - Children and youth under age 21 with SED

- Hope and Opportunity in Many Environments (HOME) project is working to ensure that everyone has access to high-quality behavioral health, disability and aging services in their communities.

- Iowa Responsive and Excellent Care for Healthy Youth (REACH) Initiative is working to ensure that Medicaid-eligible children with SED can access intensive home and community-based services.

Objective

- Mathematica, together with the Harkin Institute, designed and carried out a Statewide Access and Provider Capacity Assessment (SAPCA) in 2024 to thoroughly investigate the needs for CBS, by addressing the following questions:

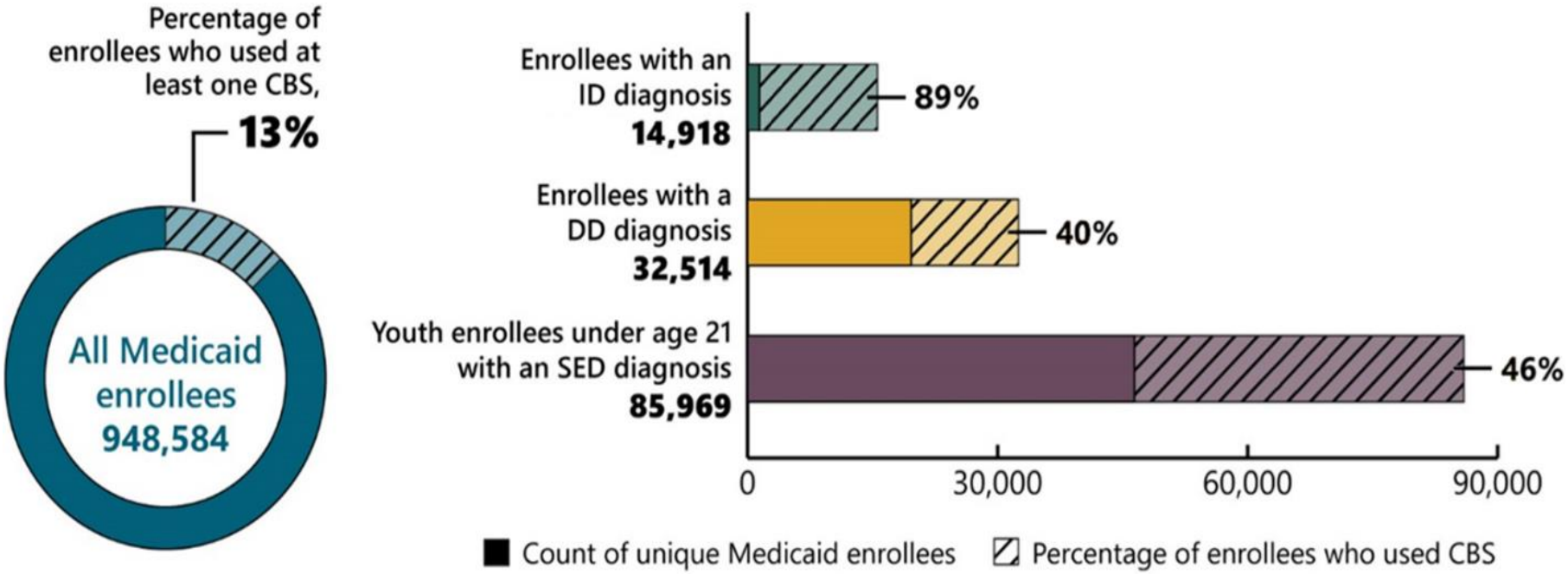
  - What type and number of services and supports are needed and currently available for the specific populations with CBS needs, and how are they funded?
  - What gaps and challenges (for consumers and providers) exist in accessing/providing these services?
  - What strategies might Iowa HHS consider to address these gaps and barriers?

Methodology

- Using mixed methods to gather quantitative and qualitative data from:
  - A literature review
  - An analysis of Medicaid administrative data provided by Iowa HHS and T-MSIS Analytic Files (federal Medicaid data) from peer states
  - Eight focus group discussions among caregivers, advocates and providers
  - An online survey among CBS providers

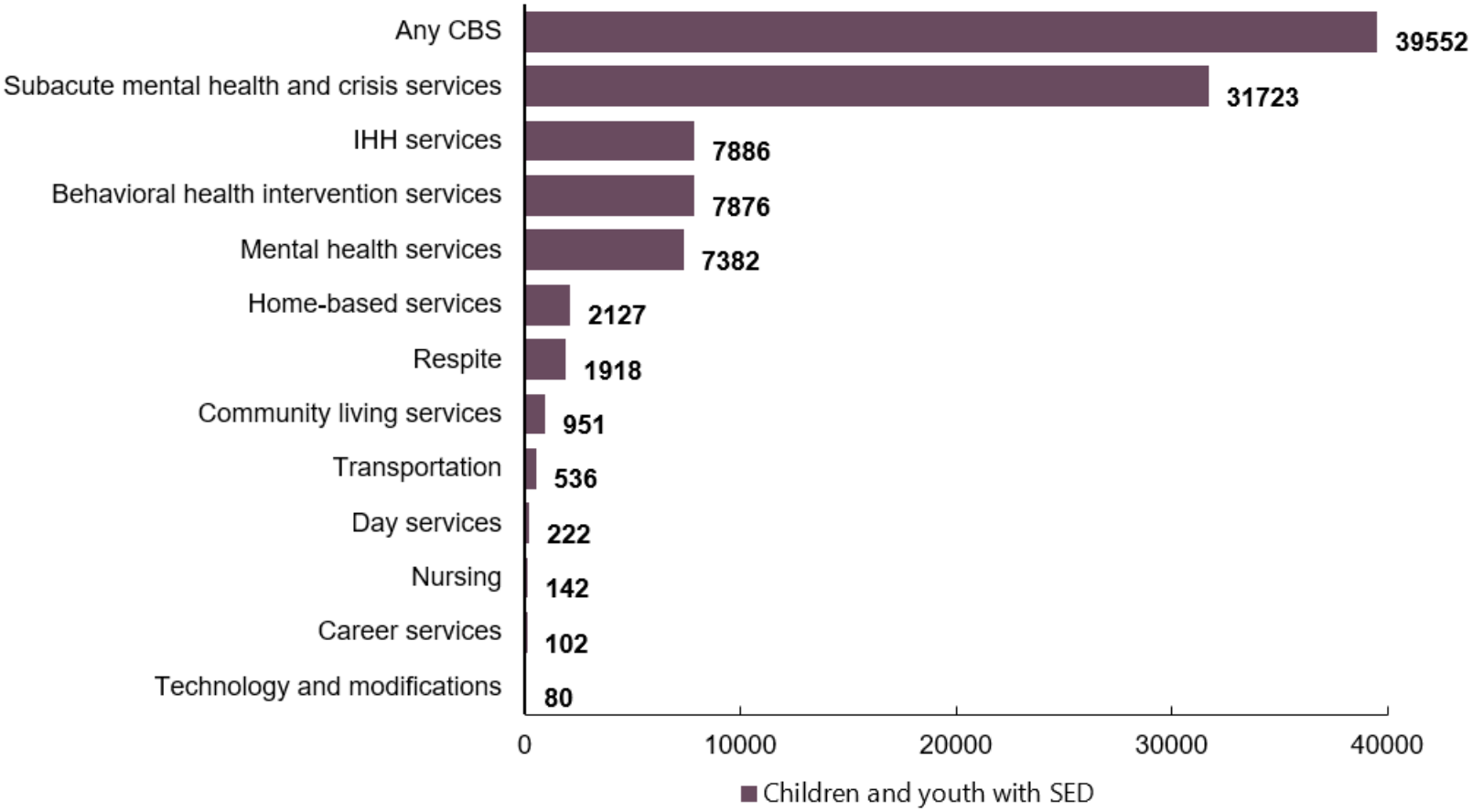
General Findings

CBS use among Medicaid enrollees, by populations of interest, SFY 2023



Source: Mathematica's analysis of Iowa Medicaid claims/encounter data from July 1, 2022, through June 30, 2023.
CBS = community-based services; DD = developmental disability; ID = intellectual disability; SED = serious emotional disturbance; SFY = state fiscal year.

CBS users among children and youth with SED, SFY 2023

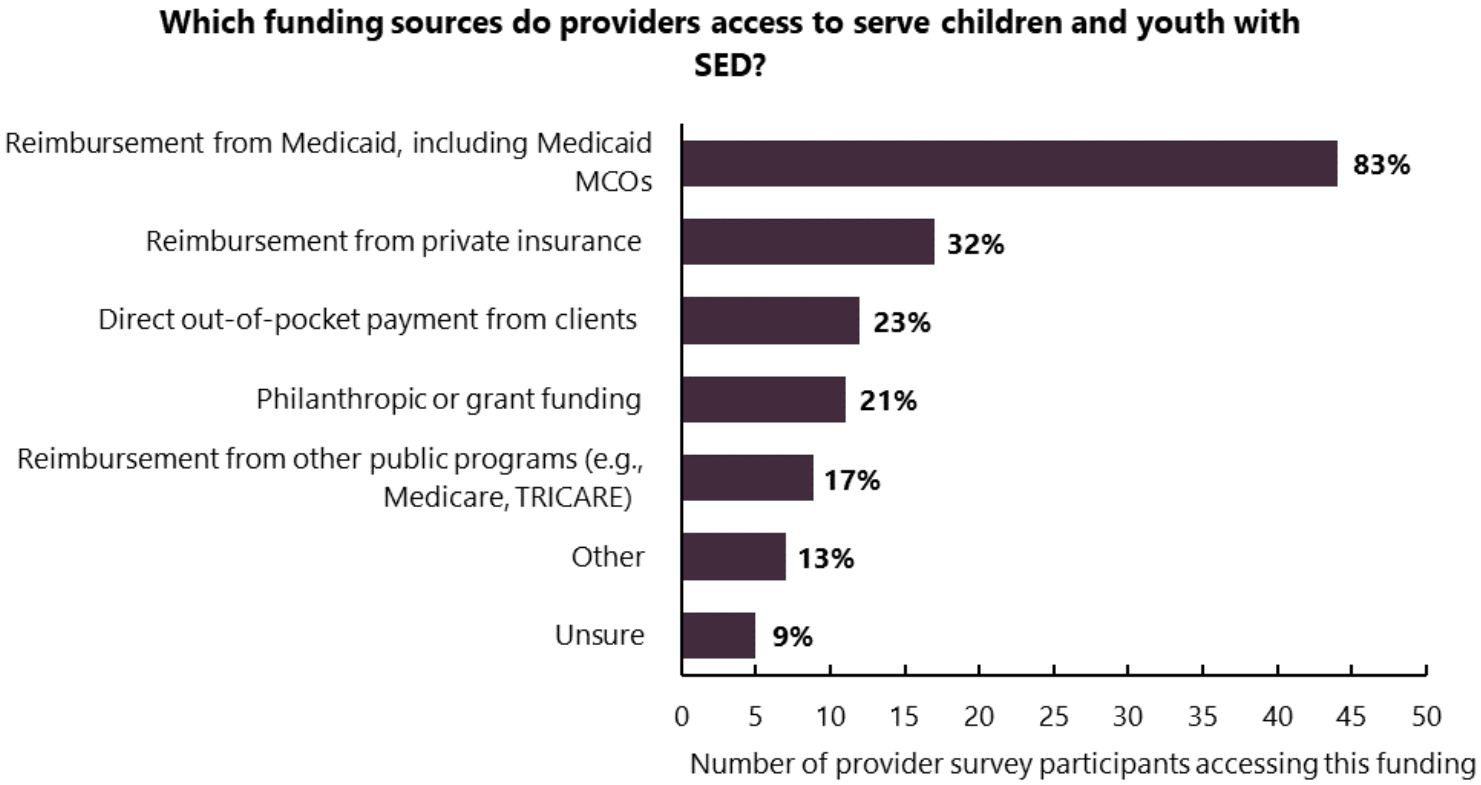


Source: Mathematica's analysis of Iowa Medicaid enrollment and claims/encounter data from July 1, 2022, through June 30, 2023.

Note: Case management is not included here, given that Iowa's contracted managed care plans receive administrative payments for providing community-based case management to all members enrolled in HCBS waivers, which is not captured in the claims/encounter data. In the available claims/encounter data, we only found 306 children/youth with SED using case management service that was billed directly from providers, which is a significant undercount from the number of enrollees eligible for this service.

CBS = community-based services; IHH = integrated health home; SED = serious emotional disturbance; SFY = state fiscal year.

Funding sources for CBS providers serving children and youth with SED



Source: Mathematica's analysis of the 2024 SAPCA Iowa CBS provider survey.
Note: Selections for funding sources were not mutually exclusive; provider survey participants were able to select multiple funding sources, which is reflected in the data above (n=53).
CBS = community-based services; MCO = managed care organizations; SED = serious emotional disturbance; SAPCA = Statewide Access and Provider Capacity Assessment.

Vast majority of children and youth with SED were not enrolled in a HCBS waiver, which increased CBS use

Unique members	Enrolled in a waiver		Not enrolled in a waiver	
	Total enrollees	Percentage who used CBS	Total enrollees	Percentage who used CBS
85,969	3,274	84	84,483	44

Among enrollees who participate in the CMH waiver, regardless of diagnosis, the most commonly authorized waiver services are respite services, family counseling and training as well as in-home family therapy.

Source: Mathematica's analysis of Iowa Medicaid claims/encounter data and service authorization data from July 1, 2022, through June 30, 2023.

CBS = community-based services; CMH = children's mental health; SED = serious emotional disturbance; SFY = state fiscal year.

Challenges in the Overall HCS System

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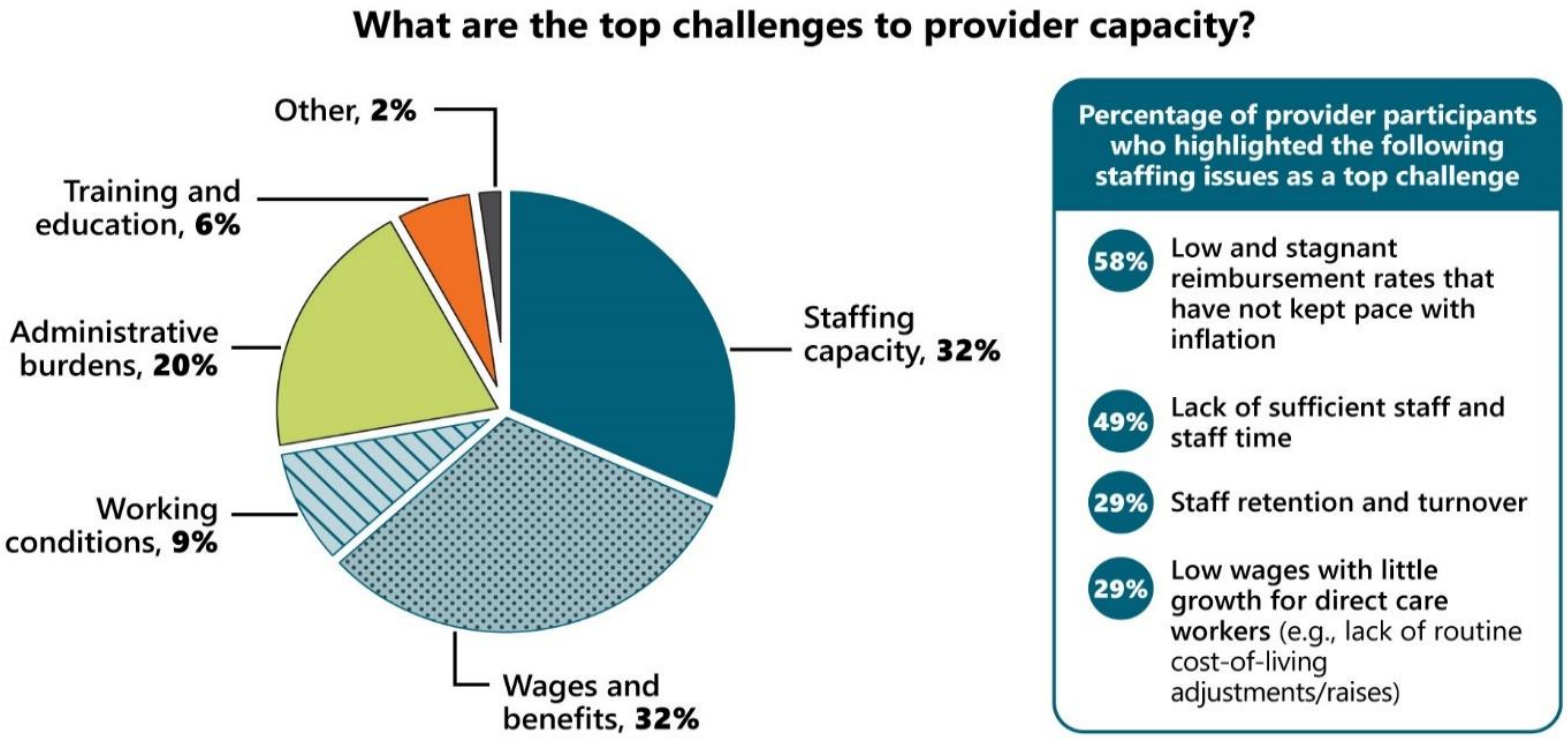
Top challenges to provider capacity, according to provider survey respondents



Source: Mathematica's analysis of 2024 SAPCA Iowa CBS provider survey.
Note: Provider survey respondents were asked to rank the top three challenges they encounter from a list of challenges (n=191). Challenges were grouped by theme and responses were tallied under their respective themes, shown in the pie chart above. The four challenges pulled out on the left are the challenges that were most commonly selected.

General Challenges to CBS

Provider Capacity

System Navigation and Coordination

Rural Issues

Provider Capacity Challenges

- The provider shortage in Iowa significantly impacts the ability of individuals to access CBS.
  - Low reimbursement for CBS makes it difficult to earn a living wage and compounds provider shortage issues.
- Enrollment and reporting documentation can be frequent, duplicative, and time-consuming.
- Complex rules and exclusions for accessing HCBS waiver services cause frustration to providers and caregivers alike.

Provider Capacity Challenges p.2

- Although providers are often interested in training and career advancement, many felt that they lacked the resources and incentives to adequately train staff.
  - The lack of access to and incentives for training is directly tied to availability and quality of providers, especially for more complex cases.
- The lack of advancement opportunities combined with low pay creates broad difficulty recruiting and retaining the workforce.

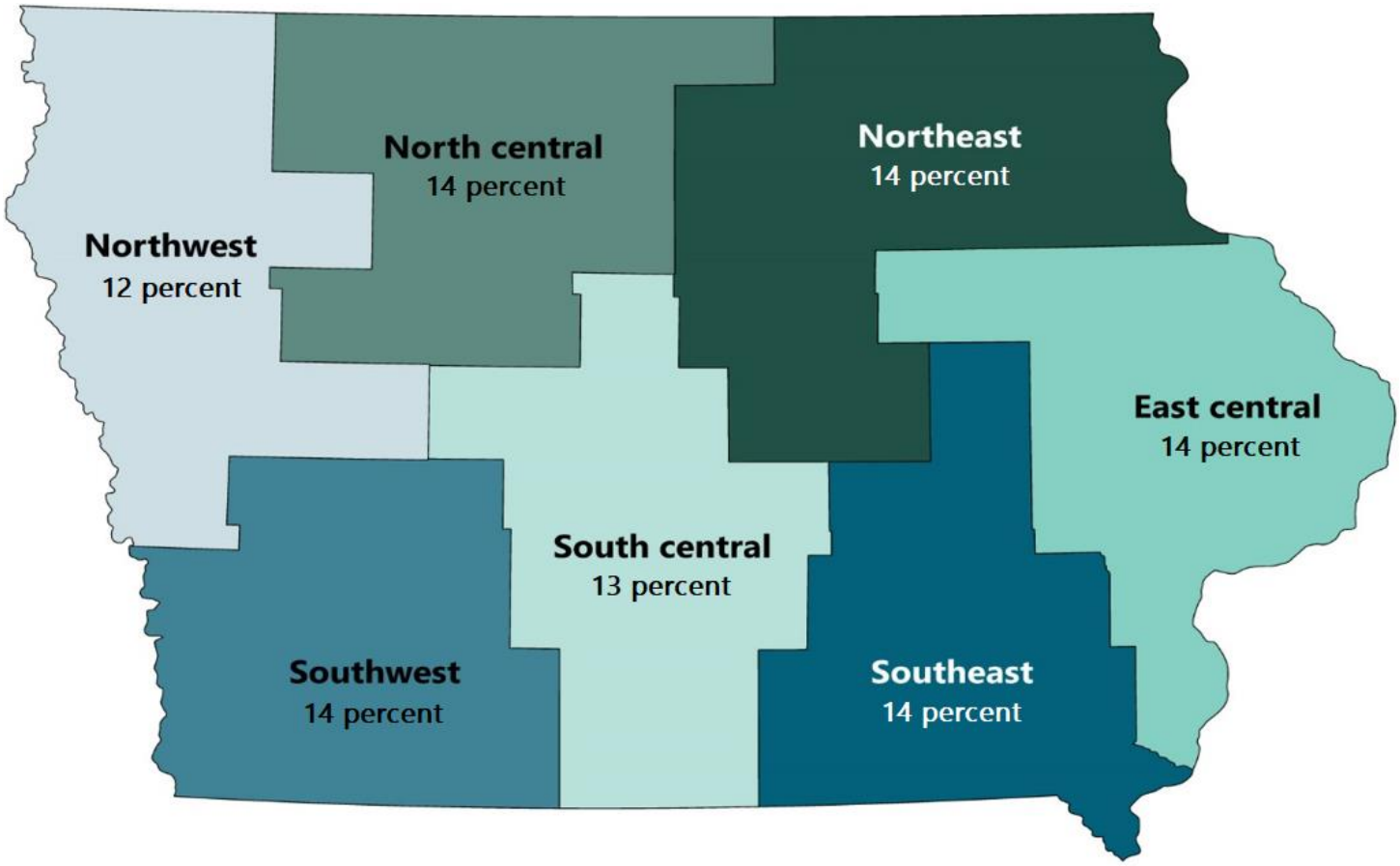
System navigation and coordination challenges

- Lack of communication between CBS providers and other providers in the health system due to siloed systems of care is a barrier to efficient care coordination.
- Many providers reported that MCO case managers are vital to effective care coordination and system navigation, but often lack the necessary training and knowledge to effectively guide members through the system, causing some CBS providers to fill gaps in availability and expertise.
- Some participants attribute gaps in continuity of care and high-quality care navigation to incentives under the MCO model.

Challenges to serving rural residents

- We compared CBS utilization rates among Medicaid enrollees, and found that rates are between 12 and 14 percent, with rural residents experiencing lower CBS utilization than their counterparts elsewhere.
- Providers shared that staff shortages, including a lack of quality staff, in rural areas are major barriers to CBS provision.
- Transportation is a major barrier to care in rural communities for both clients and providers.

CBS utilization rates among Medicaid enrollees by region, SFY 2023



Source: Mathematica's analysis of Iowa Medicaid claims/encounter data from July 1, 2022, through June 30, 2023.

Challenges for Youth with SED

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Top service gaps among clients with SED, according to provider survey respondents

Caregiver and family support and strengthening

For example, respite, family peer supports, parent skill building, parent leadership trainings, caregiver counseling and family and community support services

Crisis response and support services

For example, crisis evaluation and stabilization, crisis planning and support and mobile crisis response

Autism spectrum evaluation and treatment services

Source: Mathematica's analysis of the 2024 SAPCA Iowa CBS provider survey.

Note: Provider survey respondents were given a list of services and asked to rank the top three services that Medicaid-enrolled children and youth with SED need, but face challenges accessing, either within their organization or elsewhere. The percentages shown above represent the proportion of all survey respondents (n=53) who selected the service as one of the top three service gaps they perceive their clients to face.

Challenges specific to children and youth with SED

- Children and youth with SED face several barriers to accessing care in an outpatient setting.
- Study participants noted that there is lack of **training and provider availability** for the most complex cases, including those involving children who exhibit violent behaviors.
- **Inadequate SBS** is a particularly pressing issue for children and youth with SED.
- The lack of services and confusing processes are exacerbated for transition-age youth who need to **navigate new approvals and systems** while maintaining current services.
- There are **difficulties accessing** BHIS, psychiatric medical institutions for children (PMIC), habilitation, and other mental health services, particularly in rural areas.

Challenges to serving rural residents p.2

"Outside of the fact that there's a dearth of providers in a lot of rural areas, transportation is a huge issue. We see lots of families who could (be) reimbursed (for) transportation but aren't even aware that they can do that or that it's available to them. A lot of providers are unwilling to go into rural areas, and I guess that makes sense, given the costs associated with it."

Children/youth with SED provider focus group participant

Addressing unique needs among special populations

In accordance with Section B.8.e.ii. of the class action Interim Settlement Agreement, we conducted focus groups and dedicated a portion of the provider survey to study how CBS could be improved for special populations within children and youth with SED, including BIPOC and LGBTQIA+ populations.

Study participants were aware of specific barriers that children/youth with SED who are BIPOC or LGBTQIA+ face. However, providers opted to have a broader need-based model of care rather than specific internal policies governing care for BIPOC or LGBTQIA+ individuals.

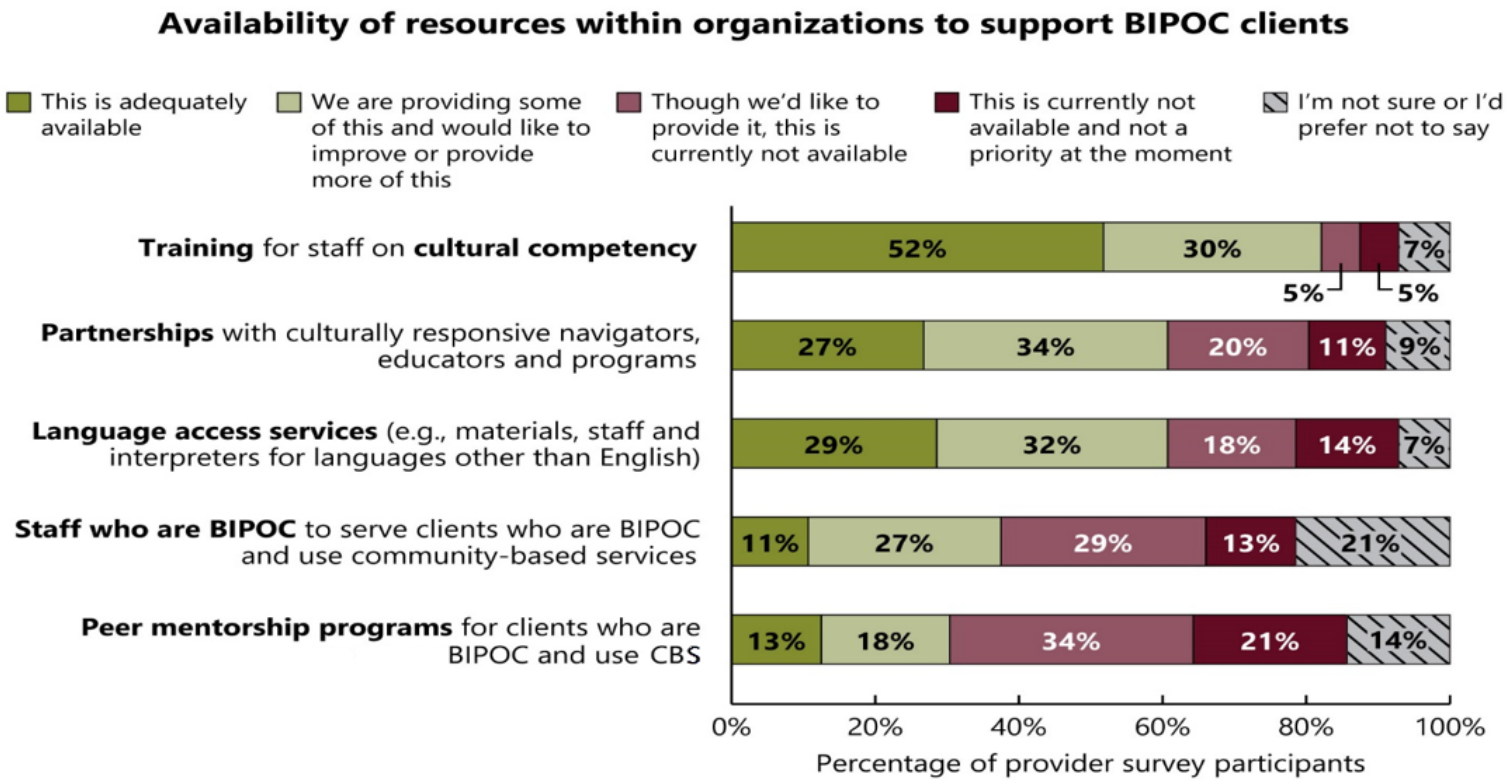
Training in providing and identifying services for unique needs could be beneficial in helping providers give more person-centered care to individuals.

Findings specific to BIPOC children and youth with SED

- One in five children and youth with SED in Iowa is BIPOC. This is likely an underestimate, as 28 percent of children and youth with SED had missing or unknown race/ethnicity in Iowa Medicaid enrollment data.
- Pacific Islanders had the lowest CBS utilization rate (36 percent), whereas Black and American Indians had the highest CBS utilization rate (51 percent and 50 percent, respectively), compared with white children and youth with SED (46%).
- Provider survey respondents and focus group respondents had potentially conflicting views* on
  - Availability of culturally responsive services for BIPOC children/youth
  - Importance of tailoring care based on the race or ethnicity of a client.

* This divergence in views could be driven by the fact that one of our focus groups specifically targeted providers and advocates currently serving children and youth with these unique needs, who may have deeper knowledge about the related issues; whereas respondents to the survey are more general CBS providers.
BIPOC = Black, Indigenous, and people of color

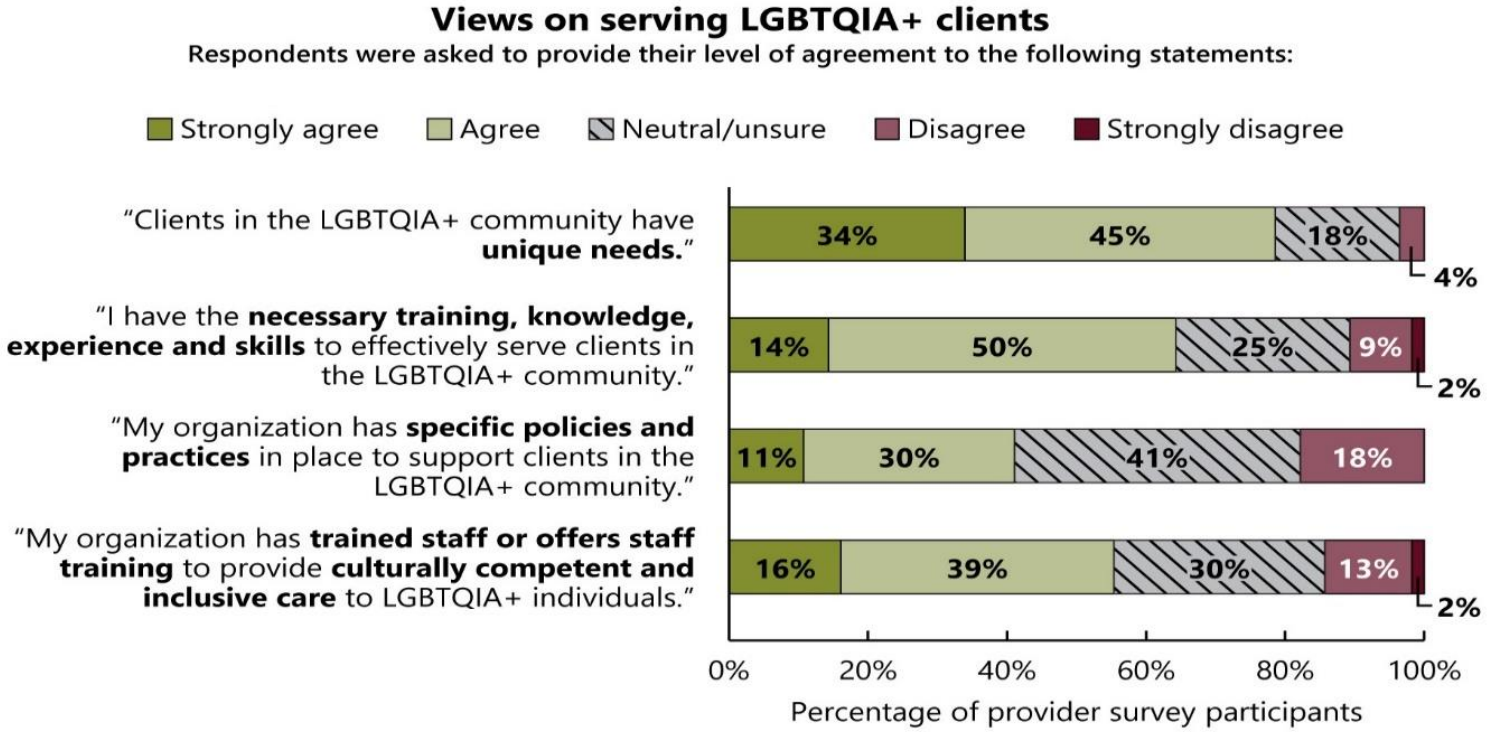
Availability of resources to support BIPOC clients, according to provider survey respondents



Source: Mathematica's analysis of the 2024 SAPCA Iowa CBS provider survey.
Note: Only survey respondents who noted they served children and youth with SED were asked to indicate whether the resources above were available in their organization (n=56).
BIPOC = Black, Indigenous, and people of color; CBS = community-based services; SED = serious emotional disturbance; SAPCA = Statewide Access and Provider Capacity Assessment.

Findings specific to LGBTQIA+ children and youth with SED

- Study participants noted that LGBTQIA+ youth's experience accessing care is affected by a lack of acceptance of LGBTQIA+ communities in Iowa.
- Providers feel adequately equipped to meet the needs of clients in the LGBTQIA+ community, but did not report having organizational policies and practices to support this population.



CBS use among children and youth with SED enrolled in Medicaid: Iowa compared with peer states

CBS category	Iowa	Illinois	Kansas	Minnesota	Nebraska	Washington
Caregiver support	**27**	DS	13	5	DS	18
Case management	**45***	10	42	40	0	2
Community transition services	**<1**	0	1	<1	0	DS
Day services	**3**	1	<1	1	DS	0
Equipment, technology, and modifications	**11**	1	41	4	15	<1
Home-based services	**29**	31	31	26	79	26
Home-delivered meals	**8**	DS	<1	2	DS	0
Non-medical transportation	**18**	DS	13	1	7	7
Nursing	**6**	0	5	5	DS	12
Participant training	**<1**	DS	4	33	DS	19
Round-the-clock services	**8**	69	2	40	12	40
Services supporting self-direction	**10**	0	2	22	0	0
Supported employment	**1**	0	DS	1	0	6

Source: Mathematica's analysis of TAF RIFs data from July 1, 2018, through June 30, 2022. CBS service categories based on the national criteria from: "Identifying and Classifying Medicaid Home and Community-Based Services Claims in the Transformed Medicaid Statistical Information System, 2016-2020."

Note: Shaded cells indicate the state with the highest utilization rate of specific type of CBS among CBS users. Cells with associated counts smaller than 11 are suppressed to protect enrollee confidentiality (DS = data suppressed)..

* Iowa's contracted managed care plans receive administrative payments for providing community-based case management to all members enrolled in HCBS waivers, which is not captured in the claims/encounter data. As a result, this figure only reflects case management services separately billed by providers in claims data and is likely an undercount of the total number of enrollees who received case management services in Iowa.

Recommendations to HHS for improving CBS among children and youth with SED

1. Increase training on serving children and youth with SED
2. Develop tailored resources for transition-age youth and their families.
3. Explore options for expanding telehealth as a supplemental measure for services such as outpatient therapy and peer support.
4. Increase access to peer mentoring and advocates for children and youth with SED who identify as BIPOC or LGBTQIA+.
5. Develop standards and guidance for working and communicating with children and youth from BIPOC and LGBTQIA+ communities.

Recommendations to providers for improving CBS among children and youth with SED

1. Provide training in culturally appropriate and respectful care

2. Recruit and retain staff with lived experience

3. Use telehealth to connect children and youth with culturally appropriate care

4. Improve outreach to BIPOC youth and families by building partnership and tailoring communications and educational materials.

Conclusions

Key Pressure Points

- Many children and youth with SED (54 percent) did not use any CBS.
- Low Medicaid reimbursement rate (and the resulting low wage) is a leading constraint on the entire CBS system, compounded by complex and sometimes repetitive administrative processes.
- Providers, caregivers, and members struggle to navigate the complex system of accessing CBS in Iowa.

Recommendations to HHS for consideration

Near term

1. Re-consider “use it or lose it” policy for services, especially for cases where lack of use is due to provider capacity issue.
2. **Streamline administrative requirements** for testing, assessment, and background checks to reduce redundancies and increase efficiency.
3. Provide guidance for proper use of **telehealth for CBS**, with providers’ input.
4. Identify gaps, improve the training platform or **require MCO-provided trainings** to cover topics in demand, such as how to handle seizure (for people with IDD) or **de-escalation training** (for youth with complex SED-related needs).
5. Help publicize and facilitate application to other funding opportunities among CBS providers to diversify their funding sources.
6. [Specific to children/youth with SED] **Add resources for transition age youth** and their families, such as adult services and employment services to minimize the experience of a service cliff.

Long term

1. **Review rate setting** and consider increasing reimbursement rates for CBS in general, with additional incentives for providers caring for more complex cases and rural communities.
2. Create a centralized user-friendly portal or **information hub where both consumers and providers can track coverage, service usage, and availability**.
3. Consider gaps in service use in comparison to peer states and explore ways to increase use of specific CBS categories that may be underutilized (for example, through additional spending, and policy modifications).
4. Strengthen oversight of MCOs’ accountability and improve quality monitoring.
5. [Specific to children/youth with SED] **Strengthen communication across care settings** including, but not limited to, clinics, ERs, the court system, schools, families, and community agencies.

Recommendations to providers, advocates or MCOs for consideration

Near term

1. Improve communication with service users by adopting culturally appropriate plain language in outreach materials.
2. Recruit staff with lived experience (including, but not limited to, BIPOC and LGBTQIA+ service providers).
3. Consider implementing policies or providing training on cultural humility and addressing stigma.

Long term

1. Provide economic incentives for strengthening the workforce (with increased reimbursement rate from Medicaid) (for example, increase wages and benefits to staff, provide overtime pay, provide incentives for additional training and credentialing, and offer hiring and retention bonuses).
2. Improve career advancement opportunities (for example, training, peer mentorship, and portability of skills).
3. Strengthen IT and data systems as well as quality improvement processes to ensure available services match client needs.

Conclusions

- Many of the unmet needs (for both providers and service users) we identified are long standing issues and will take time and careful deliberation from all partners in the system to address.
- Study participants strongly support the shared goal of delivering services that promote health, well-being, and independence.
- Through the HOME project, Iowa HHS and Mathematica are already working to address many of the issues identified in this SAPCA.
  - Efforts include, but are not limited to, ongoing work on a broad waiver redesign, developing a uniform assessment, improving and simplifying the waitlist process, and training community-based MCO case managers.
- More can be done to enhance the capacity of providers in general and to serve the people with unique needs, as mentioned previously.

Discussion

What do you see as the primary barriers to HCS services for youth with SED?

This study identified the following barriers:

Overall system barriers		
Provider capacity	System navigation and coordination	Rural access

Barriers for youth with SED			
Provider availability	Inadequate school-based services	Transition support for older youth	Lack of services, especially in rural areas

Gaps in available services		
Family supports	Crisis management	Autism spectrum evaluation and treatment

How can we address current barriers?

- In an ideal world, what would school-based services look like for youth with SED?

- Did any of the recommendations shared today seem useful? Are there any other recommendations we should consider?

Public Comment

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