

Consumer Steering Committee Meeting

July 10, 2025



Health and
Human Services



Agenda

- ▶ Review Findings from Statewide Access and Provider Capacity Assessment (SAPCA)
 - Introduction
 - General Findings
 - Challenges for Youth with SED
- ▶ 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:

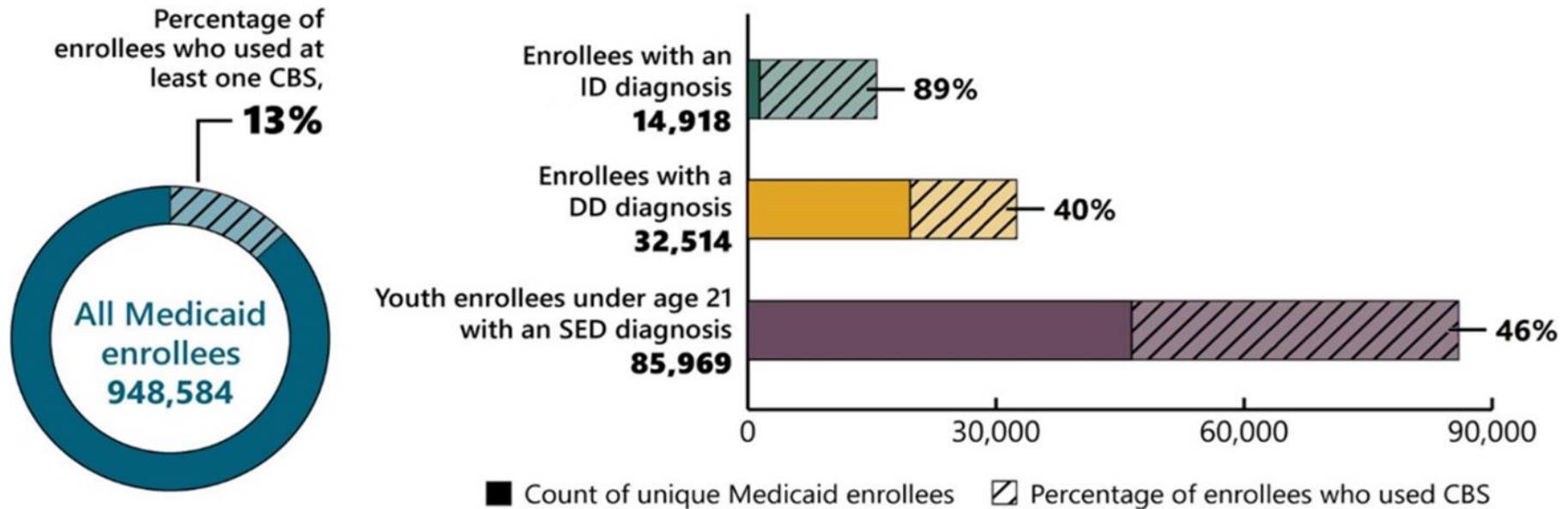
- What type and number of services and supports are needed and currently available for the specific populations with CBS needs, and how are they funded?
- What gaps and challenges (for consumers and providers) exist in accessing/providing these services?
- What strategies might Iowa HHS consider to address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

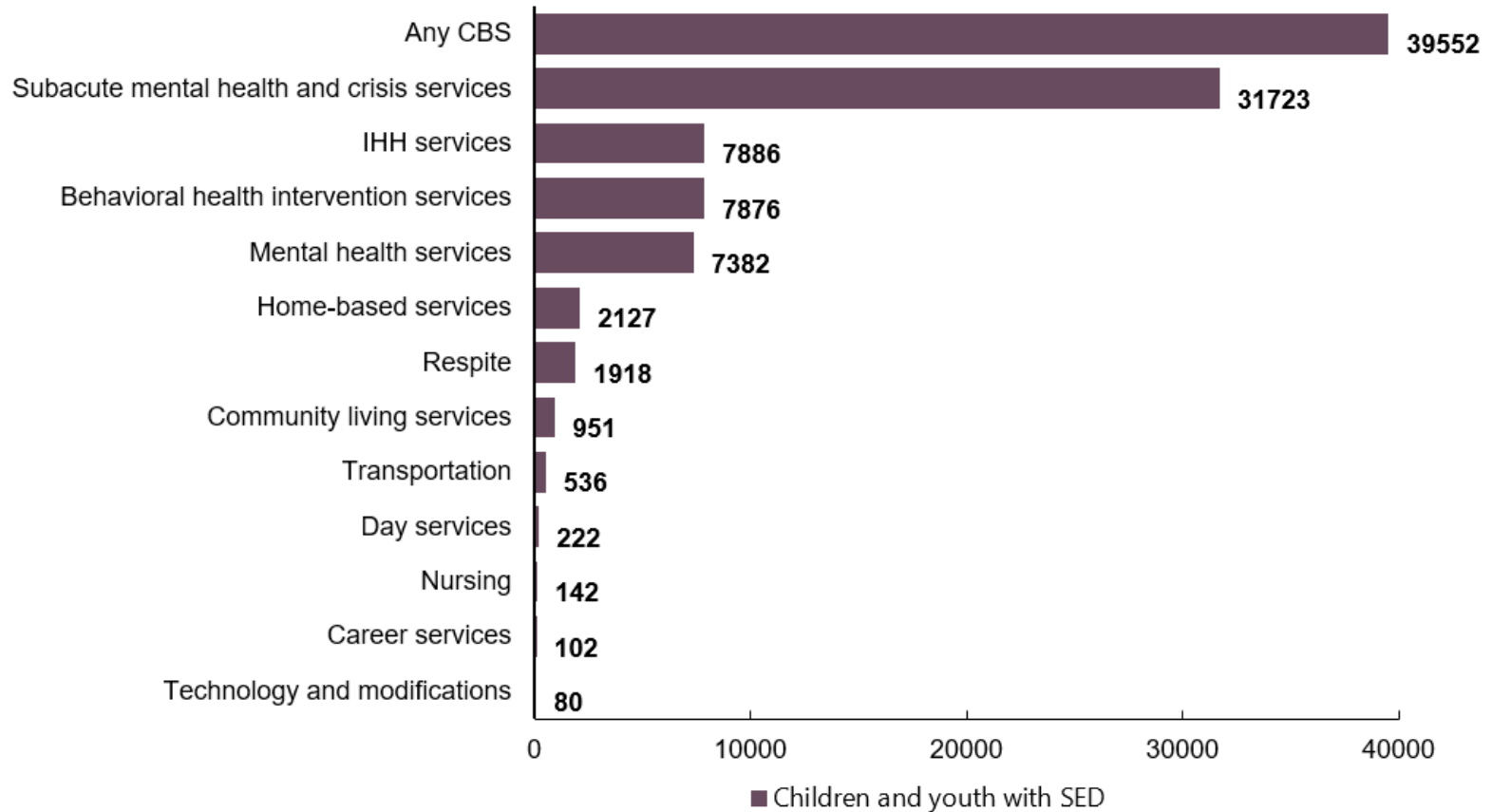
General Findings

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



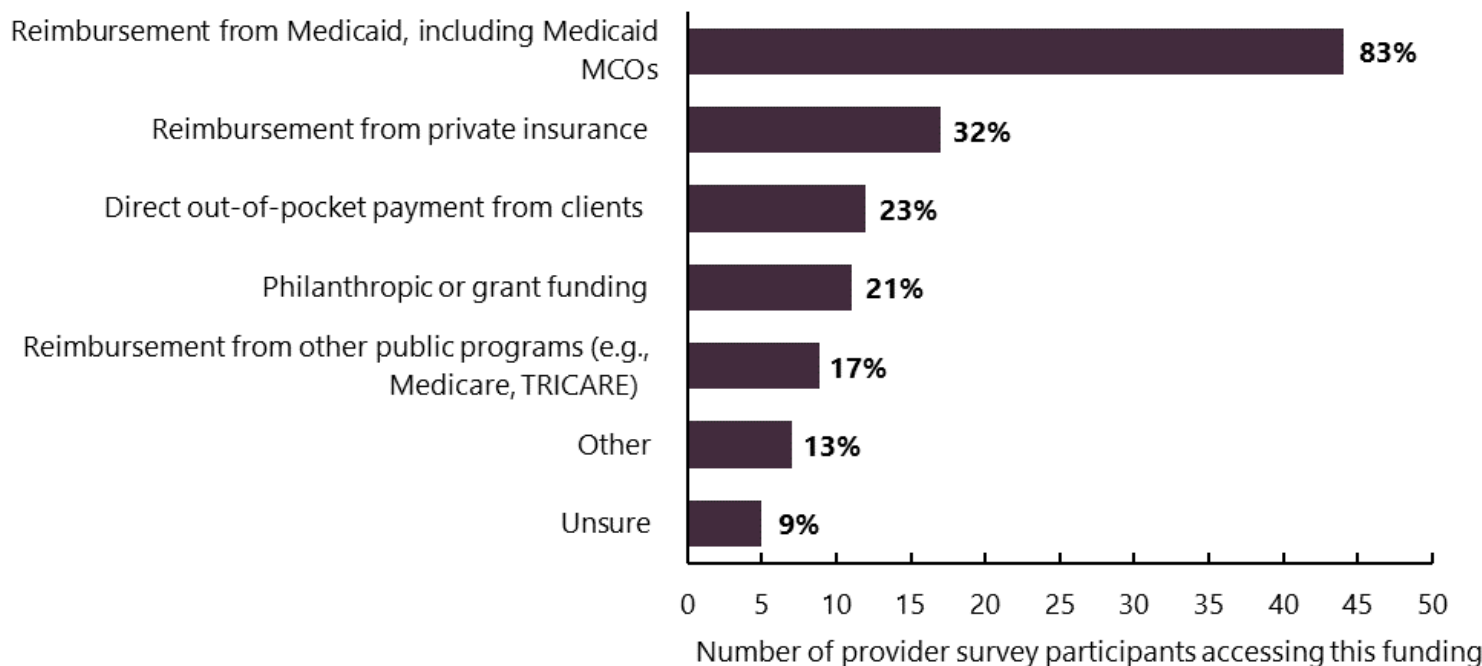
Source: Mathematica's analysis of Iowa Medicaid enrollment and claims/encounter data from July 1, 2022, through June 30, 2023.

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

Which funding sources do providers access to serve 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 authorized waiver services are respite services, family counseling and training as well as in-home family therapy.

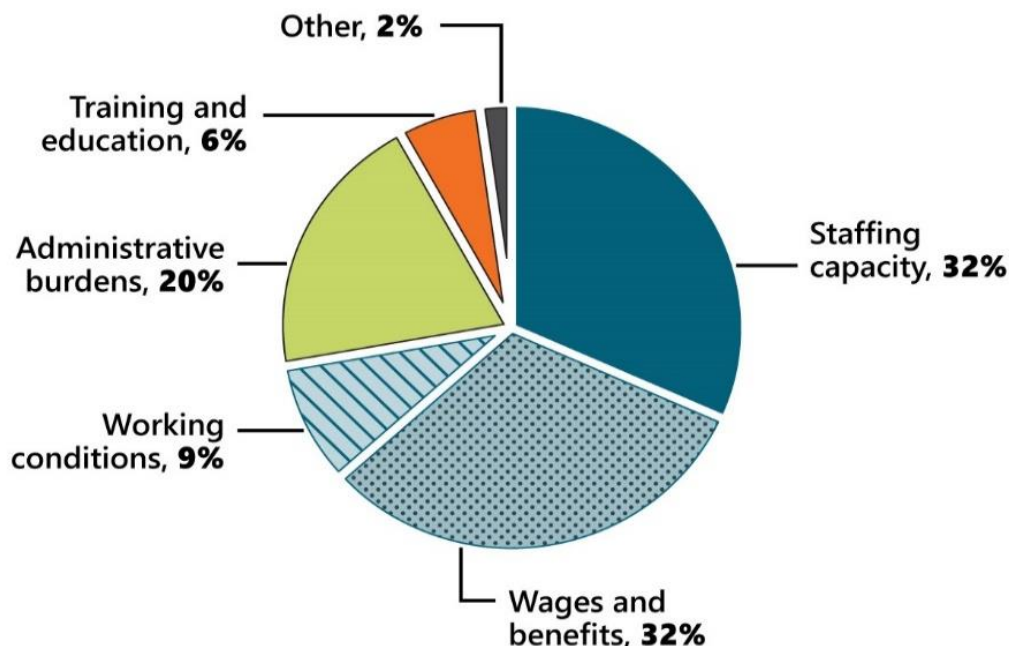
Source: Mathematica's analysis of Iowa Medicaid claims/encounter data and service authorization data from July 1, 2022, through June 30, 2023.

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

Challenges in the Overall HCS System

Top challenges to provider capacity, according to provider survey respondents

What are the top challenges to provider capacity?



Percentage of provider participants who highlighted the following staffing issues as a top challenge

- 58%** Low and stagnant reimbursement rates that have not kept pace with inflation
- 49%** Lack of sufficient staff and staff time
- 29%** Staff retention and turnover
- 29%** Low wages with little growth for direct care workers (e.g., lack of routine cost-of-living adjustments/raises)

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**

Challenges for Youth with SED

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

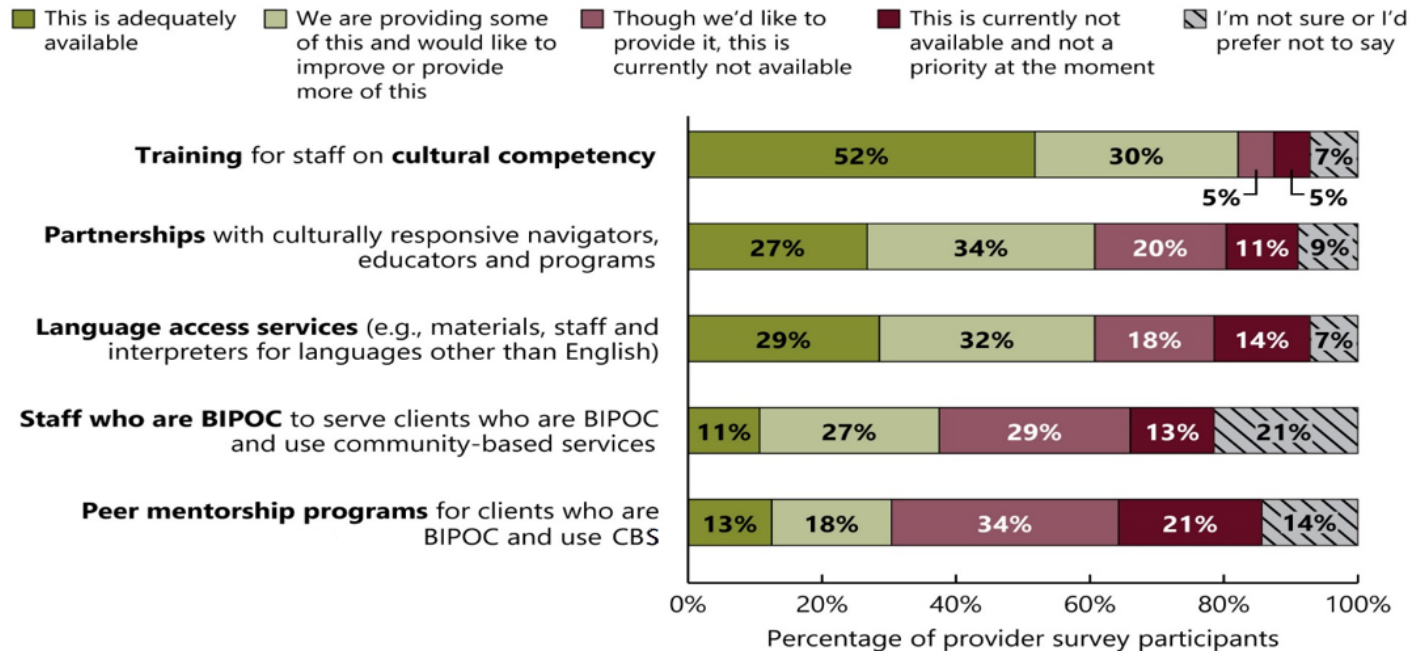
In accordance with Section B.8.e.ii. of the class action Interim Settlement Agreement, we conducted focus groups and dedicated a portion of the provider survey to study how CBS could be improved for special populations within children and youth with SED, including BIPOC and LGBTQIA+ populations.

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.

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

Availability of resources within organizations to support BIPOC clients



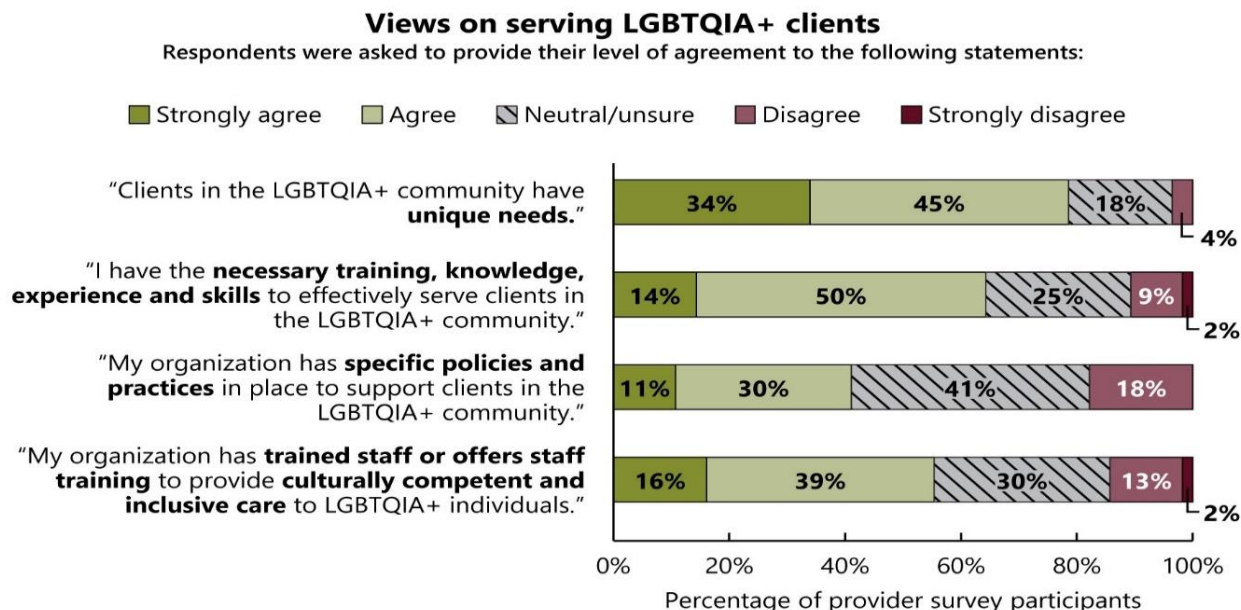
Source: Mathematica's analysis of the 2024 SAPCA Iowa CBS provider survey.

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.





Discussion



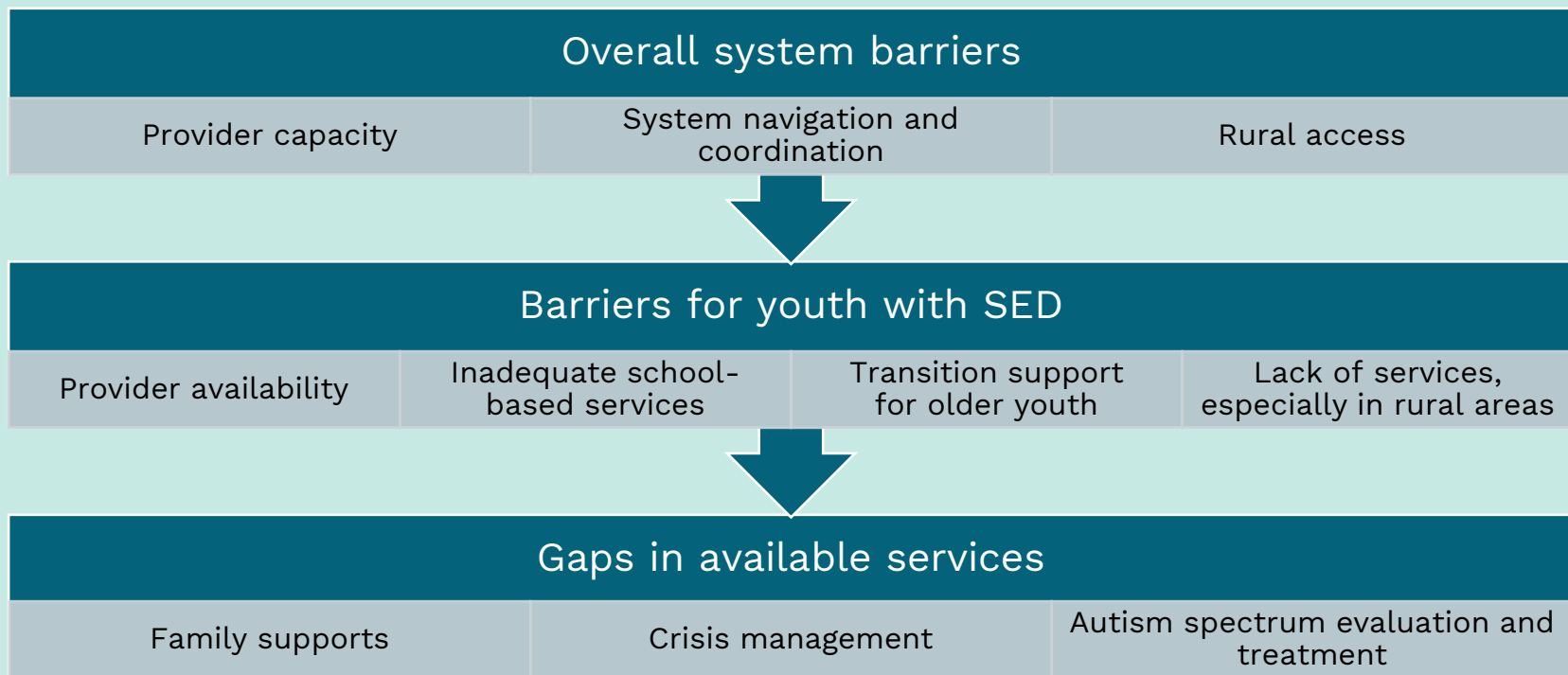
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Key Pressure Points

- ▶ A large number of 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.

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

This study identified the following barriers:





Public Comment



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