



MENTAL HEALTH DATA SURVEY REPORT

Report of Stakeholders' Survey for the Proposed
System of Care Integrated Data System for Children's
Mental Health

System of Care Team, Behavioral Health Div.,
Minnesota Department of Human Services
For more information contact sam.olukiran@state.mn.us

Table of Contents

Executive Summary.....	2
Background	3
Survey Recipients	4
Types of Data	5
Service utilization.....	5
Accessibility.....	5
Outcome measures.....	5
Youth with mental health needs and their families	6
Concerns	7
Findings	9
Recommendations	9
Example of How Stakeholders might use the Proposed System	9
Conceptual Diagram.....	10
Next Step.....	10
Conclusion.....	10
Appendix	11
Some Qualitative Responses to Survey Questions	11

Executive Summary

As part of the process for developing an Integrated Data System for Children's Mental Health, we administered a survey to gain insight into how stakeholders are using mental health data across the state. The survey was distributed to a broad range of stakeholders including youth with mental health needs and their families.

The survey helped us understand how stakeholders can utilize the proposed system to achieve better outcomes for children's mental health in their communities. The system will also provide children's mental health data useful for decision making and overall awareness of how children's mental health services are working in the state.

The survey contained multiple open-ended questions, which allow respondents to answer in details. A total of 114 individuals representing their organizations responded to the survey. The majority of respondents (88%) were key stakeholders (providers, health partners, government agencies, counties/tribes health services providers, advocacy groups, practitioners, collaboratives, and other policymakers) while the remaining 12% were youth with mental health needs and their families.

The survey focused on identifying types of data that are important to stakeholders to achieve better outcomes for children's mental health programs and services.

Themes from the responses show survey participants would like to have access to data that relates to:

- How children access mental health services
- What mental health services and supports are utilized
- What resources are available to children and youth with mental health needs

Access to the above data will help stakeholders identify gaps, monitor progress and design strategies for service improvement. Stakeholders would similarly use summary data for program reports to support funding.

We plan to incorporate feedback from all stakeholders into the design of the proposed System of Care Integrated Data System for Children's Mental Health. The survey responses reinforced and validated our work for the development of an Integrated Data System for Children's Mental Health. The plan for our proposed system is to use existing data sources from our System of Care state agency partners (Health, Education, Human Services and Corrections) to tell stories of how children's mental health services are working in the state.

We learned from the survey results and meetings with stakeholders of related concerns to the development of the integrated data system. Concerns expressed by survey respondents include the following;

- Protecting children and youth privacy
- Misuse or misinterpretation of data
- Adequate oversight to the proposed system

This report will provide potential strategies to resolve concerns expressed by survey respondents to ensure data safeguards and other protections.

Background

In 2017, the Minnesota Department of Human Services was one of eight states to be awarded a System of Care Expansion and Sustainability grant from the U.S. Department of Health and Human Services Substance Abuse and Mental Health Services Administration (SAMHSA). The overall goal of the System of Care Expansion Project is to improve the behavioral health outcomes for children and youth with serious mental health needs and their families.

Minnesota's grant proposal includes the development of an integrated data system for children's mental health in partnership with State Departments of Corrections, Education, Health and Human Services which includes behavioral health and child welfare. In developing our grant proposal, creating an infrastructure for data exchange across state agencies will allow families and professionals to have information for decision making, provide policymakers and key stakeholders with children mental health data and information to steer policy decisions, and children's mental health information for the general public.

In addition, a key objective in developing an integrated data system is to use existing data from government agencies to tell the stories of how children mental health is working in the state. The integrated data system will not include individual identifiable data. We hope the proposed system will help key stakeholders understand better how children's mental health services are working in the communities.

Minnesota's grant proposal also includes the creation and expansion of community based services and interventions to reduce the number of children being placed out of their homes for treatment. Department of Human Services—System of Care Team is partnering and working with counties and Fond du Lac who submitted letter of commitment to develop and expand children's mental health community based services and supports to children and youth with mental health needs.

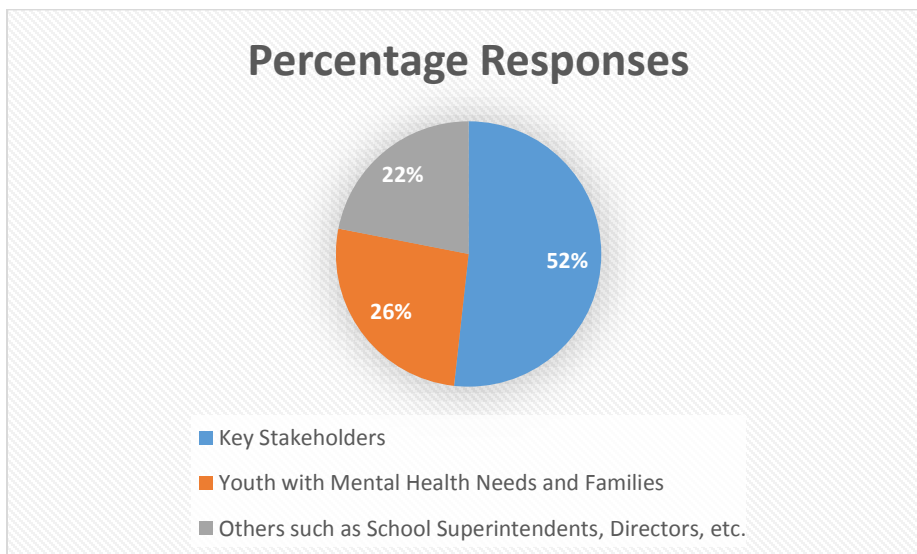
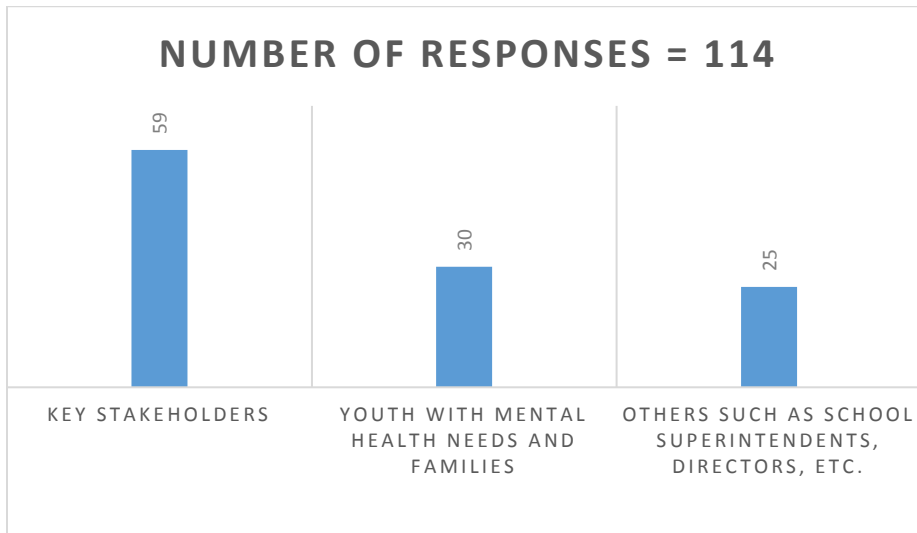
System of care work is anchored in key core values and principles to improve outcomes for children with serious mental illness and their families. These core values include cultural and linguistic competence, family driven and youth guided service and supports. The DHS team and contracted vendors are providing these training in working with our counties, Fond du Lac and their communities.

As we are developing the data system, we will continually gather input from stakeholders on how the proposed system could help improve mental health services in their communities. The overall goal of the System of Care Expansion Project is to improve outcomes for children and youth with mental health needs and their families.

Survey Recipients

The System of Care Team designed a survey to understand how key stakeholders will use the proposed system. The survey was administered to diverse groups of stakeholders that provide or support children’s mental health services in the state. The group that participated in the survey included mental health providers, health plans, local collaboratives, counties’ and tribes’ health workers, policymakers, researchers, and youth with mental health needs and families.

The survey was divided into three sections. The first section was designed for youth with mental health needs and their families, while the second section was meant for key stakeholders (Providers, Health Plans, Collaboratives, Government Agencies, Counties/Tribes Health Services Providers, Advocacy Groups, Practitioners, and other Policymakers). The second section contained questions related to how key stakeholders measure, report and evaluate children’s mental health services. The third section was intended for participants that did not fit into the first two groups. The survey was distributed through established mental health organizations throughout the state. A total of 114 responses was received at the end of the survey.



Types of Data

The survey asked questions about how stakeholders use data to measure and evaluate mental health services. It is important to get participants' feedback to understand what type of data to include in a proposed system. The responses highlight different ways practitioners and policymakers use data to measure program effectiveness. Some participants use summary data for reporting to funding sources, while others use data to monitor service trends.

Currently, stakeholders have to reach out to different organizations and/or government agencies in order to get such data. They sometimes have to jump through many hoops in order to get needed data. Some participants mentioned the lack of a one-stop-shop where they could get access to summary data on a timely basis.

These are few data points that stakeholders use to evaluate youth and children's mental health in their communities:

Service utilization

- Children/youth receiving services, demographics, success stories
- Out of home placement, prevalence and hospitalization, parents' participation
- Diagnosis, school performance, suspension and expulsion, outpatient and inpatient, waiting lists, placements
- Case management, caseload numbers and intake, backlogs, intake, ER trips, housing, parents' participation

Accessibility

- Screening, referrals, needs assessment, waitlist
- Transportation to service location
- Age of first access, professionals and practitioners providing services, insurance coverage

Outcome measures

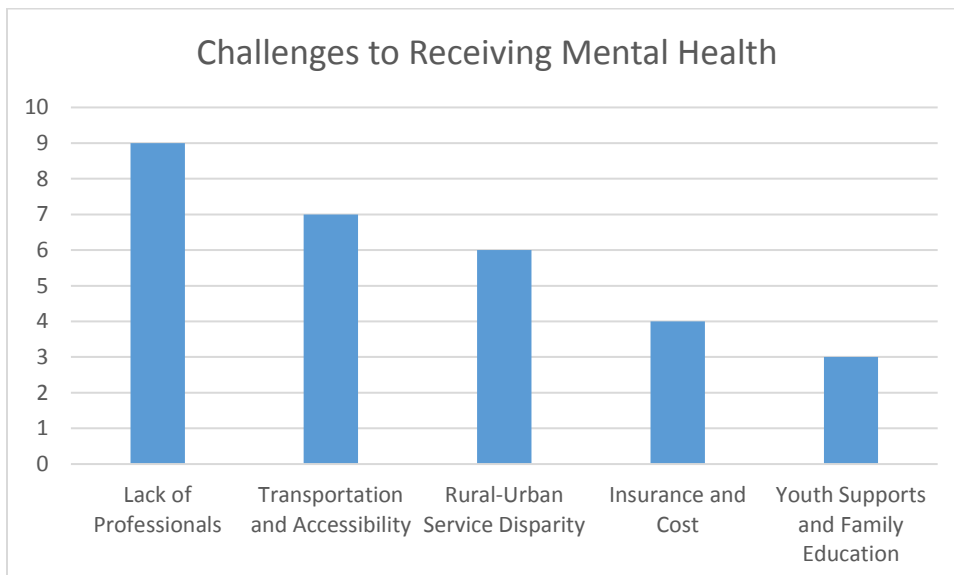
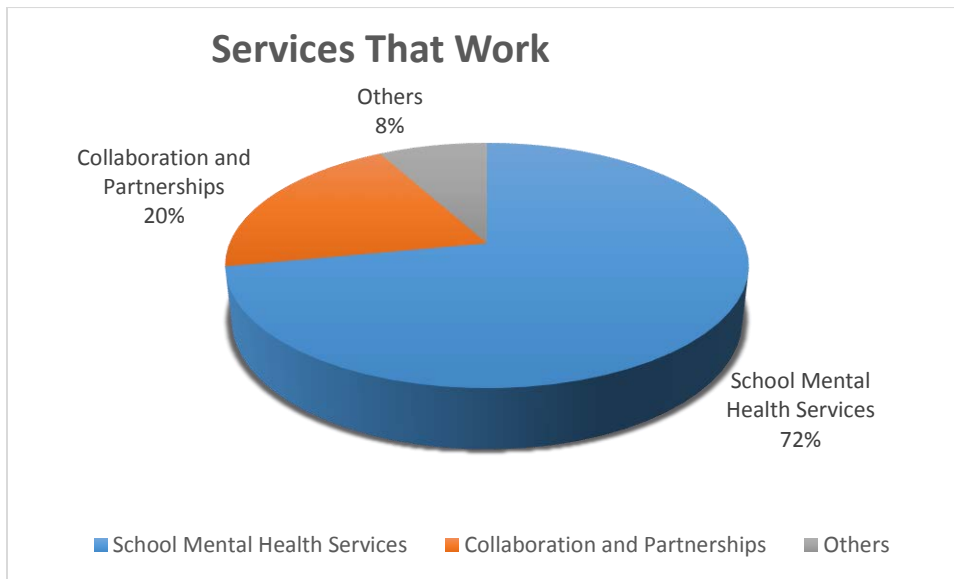
- Client satisfaction survey, risk and protective factors
- Progress reports, goals completion
- Mental Health Assessment instruments

The proposed system will comprises data from public-funded programs. These include mental health services that are provided through government agencies.

Youth with mental health needs and their families

We asked youth and families about what mental health services worked better for them and what challenges they encountered while receiving services. Many respondents mentioned school mental health as most beneficial to children and youth with mental health needs. Others mentioned collaborations and partnerships among agencies and providers as being helpful to children and youth receiving services.

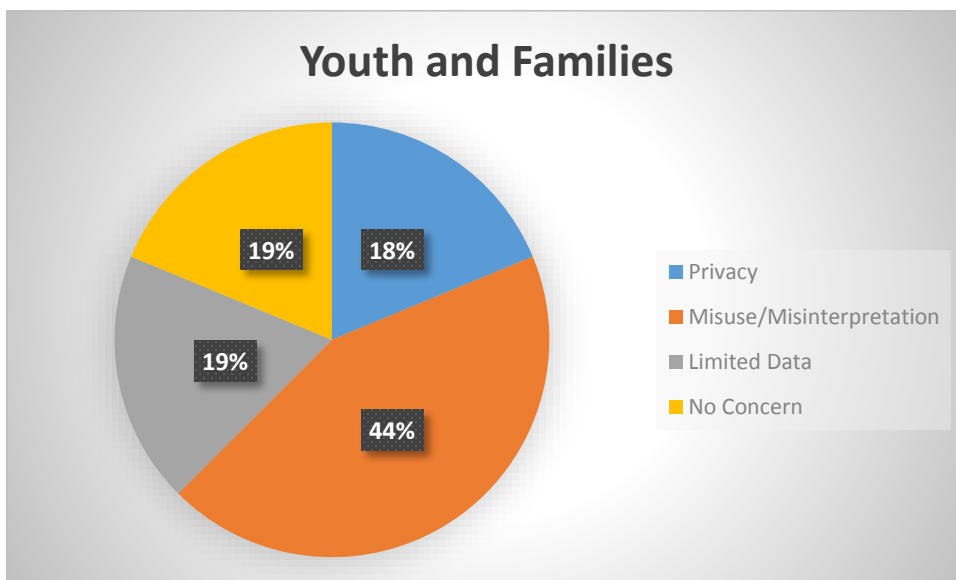
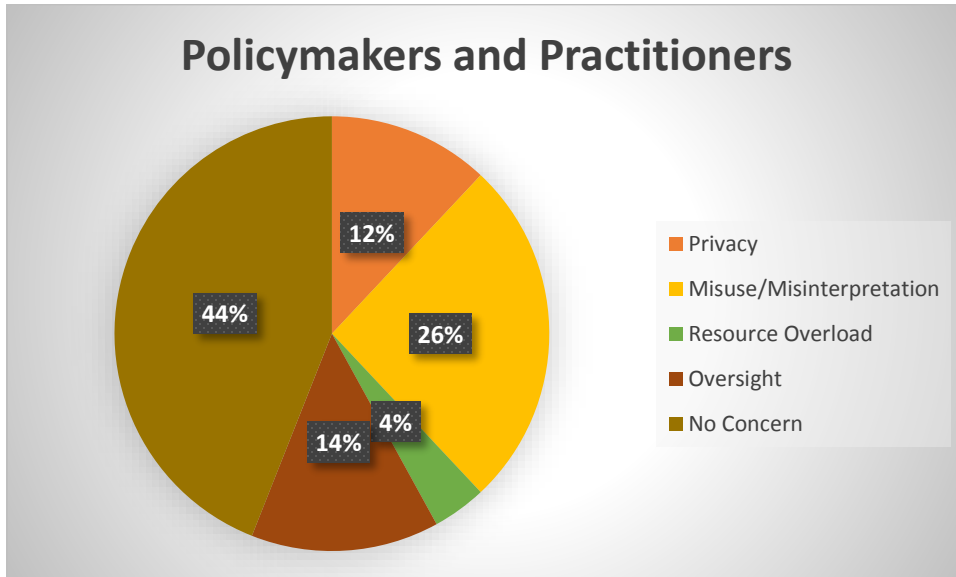
More so, youth and families stressed the shortage of mental health professionals as a major challenge to getting mental health services. Limited services are felt more in rural areas compared to the urban areas.



Concerns

We asked survey participants about their concerns related to the potential use of mental health data. The common concerns include privacy, misuse and misinterpretation. Other concerns are particular to different groups of participants. For example, key stakeholders are concerned about resource overload—adding more work to their plate and adequate oversight to the proposed system; while youth and families are concerned about not having enough data to show the gaps in mental health services.

The charts below shows survey participants' responses to the question about concerns related to how mental health data are used.



The responses helped us highlight some potential solutions to the concerns that were raised.

The table below shows concerns accompanied by potential resolutions in the proposed system.

Concerns	Resolutions
Privacy	<ul style="list-style-type: none"> • The proposed system will not show individual data or information that can be used to identify anyone receiving services • We will provide clear information to youth and parents about how data is used and shared
Misuse/Misinterpretation	<ul style="list-style-type: none"> • We will educate stakeholders (counties, tribes, practitioners and policymakers) on how to use the system • We will communicate the vision of the System of Care Expansion Project to improve mental health services for children and youth
Resource Overload	<ul style="list-style-type: none"> • No new dataset is expected for the system and, practitioners are not expected to input new datasets into the proposed system • The system proposes to use existing data from government agencies that provide mental health services to children and youth
Oversight—People and Resources	<ul style="list-style-type: none"> • Data will be properly monitored by applying state and federal rules related to data sharing • We will set up a committee that will oversee proper and adequate use of the system

Findings

The survey helped us understand how stakeholders use mental health data in the communities. These are what survey respondents would like to have in the integrated data system for children's mental health;

- Participants would like to have summary data listed by city, county/tribe, school district and state.
- Participants preferred a system that provides data to support improving mental health services.
- Participants would like the system equipped with features that will allow data to be compared across multiple programs and geographical areas.
- Participants would prefer to have data on to how children and youth with mental health services access services, service utilization and outcomes.

Recommendations

Based on participants' feedback, these are recommendations about how stakeholders might use the proposed system;

- Use data to identify mental health needs within communities.
- Highlight services that are working well for children and youth with mental health needs and their families.
- The system can be used to generate customized data for report to funding sources.
- The system can be used to establish a connection between different services
- The proposed system will furnish stakeholders with summary data useful for program reports and evaluation

Stakeholders can use summary data to;

- Identify gaps
- Monitor trends
- Establish determinants
- Understand how programs work together
- Identify correlations, etc.

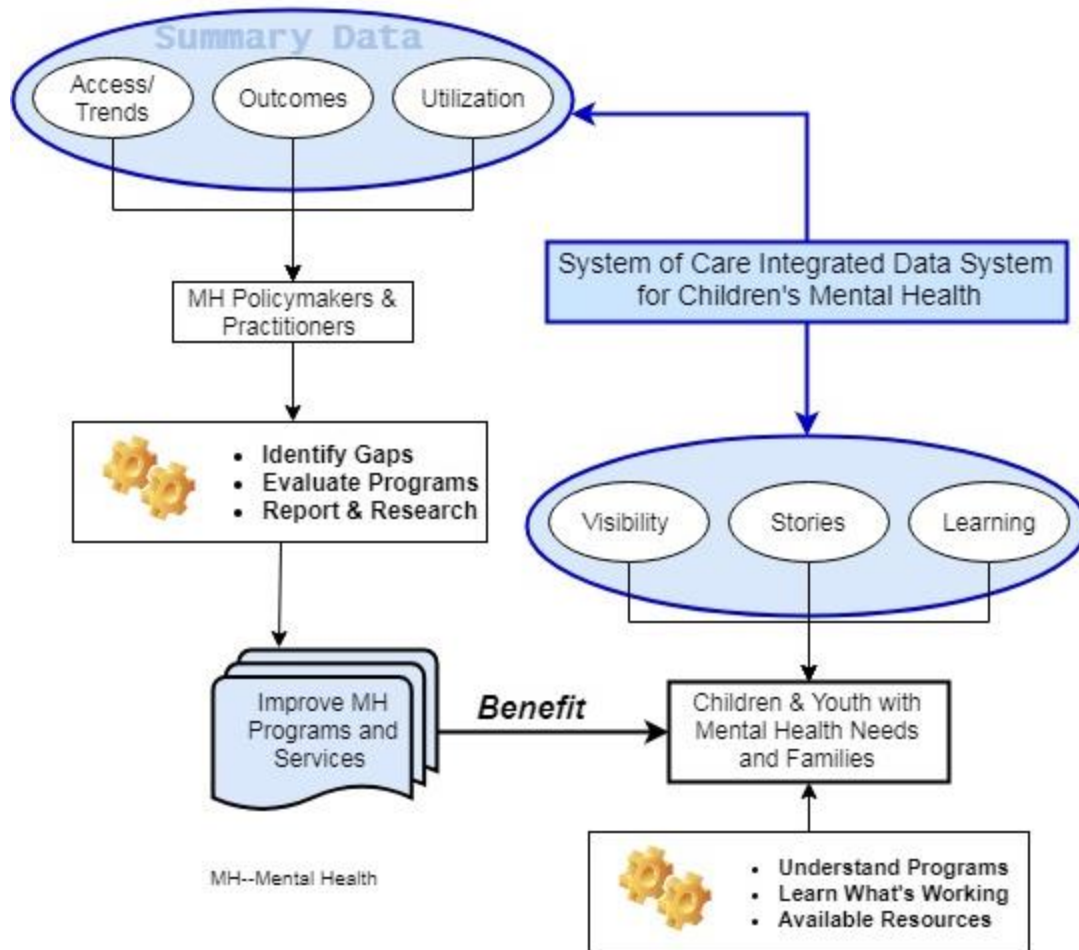
Example of How Stakeholders might use the Proposed System

One of the purposes of the Integrated Data System for Children's Mental Health is to help identify gaps that hinder children and youth from receiving mental health services through the different child caring systems (DOC, MDH, MDE, DHS). Once a gap is identified, policymakers and practitioners can design ways to improve services to children and youth with mental health needs.

The system will help highlight how children's mental health services are working in our communities. It will help stakeholders monitor service accessibility, outcomes, trends and utilization. Providers can compare summary data within school districts, counties, tribes and the state. It will provide policymakers with adequate data to make the case for service improvement in their communities.

Conceptual Diagram

Showing how children and youth with mental health needs would benefit from the proposed system



Next Step

The proposed next step is to convene a Data Governance Committee with key stakeholders. The team will be made up of policy and data experts from state agencies and other stakeholders providing mental health services to children and youth in the state. The committee will provide operational direction for the development of the Integrated Data System for Children's Mental Health.

Conclusion

For many years, mental health agencies have collected data about children and youth with mental health needs; however, there have not been many opportunities to give data back to key stakeholders. The proposed System of Care Integrated Data System is bound to bridge the data gap between government agencies and stakeholders providing mental health services and support. The proposed system will use data from public funded services to tell stories of how mental health services are working in communities. The goal of the Minnesota's System of Care Expansion Project is to improve overall behavioral outcomes for children and youth with mental health needs and their families.

Appendix

Some Qualitative Responses to Survey Questions

Section A: Youth with Mental Health Needs and Their Families

Q: What are the challenges to receiving mental health services in your community?

“Access to service providers - finding service providers. It can also be difficult for parents/families to realize that they need services and seek out the supports that they need.”

“Lack of resources and services providers in our rural towns. Lack of providers and waiting lists. Lack of Crisis Beds and placement options for children with significant mental health behaviors and needs.”

Q: What works well with how mental health services are provided in your community?

“Services in the schools that follow children throughout the year.”

“The best thing for our school district has been a school-based mental health grant.”

“Partnerships with various outside agencies to provide support to our students and their families.”

Q: What are your concerns about how mental health providers might use that data of people they serve?

“Burden of additional data tracking/reporting on a limited number of providers without it being billable for them - depending how much is tracked and the time it would take providers to complete forms, it could possibly reduce slots available to families.”

“There are many services in the metro area and it seems that most of the funding support centers in that area because of numbers.”

“Privacy. We need more data around outcomes of mental health services and how it’s helping.”

Section B: Policymakers, Providers, Health Partners, Counties, Tribes, Practitioners, Collaboratives, and Advocacy Groups

Q: What types of data from government agencies would be useful to improve mental health services in your community?

“Locally-based data on a compilation of education, health, human service and corrections risk and protective factors, cost-to-benefit ratios, consistent truancy data, out-of-home placement data, poverty rates, much better demographic data; data on health equity. Data on effectiveness of array of evidence-based practices.”

“Data about how many people are in need of mental health services, how are those needs being met, how far does a family have to drive to access those services.”

“Types of service utilization to assist with outreach, planning and program development that is valid cost trends to evaluate effectiveness and investment needs.”

“Data about how to keep mental health providers in the area and data about how to expand services offered. We could also use data about how to bring more money into our area for provision of mental health services.”

Q: What measures are used to determine progress in mental health services in your community?

“Fewer backlogs/waitlists in crisis/residential services. Fewer youth/young adults with mental illness being homeless or remaining in residential. Fewer suicides and attempted suicides. More intervention services (including training & connections) for families and youth (hopefully resulting in fewer youth requiring crisis/intensive/emergency services mentioned above). “Families reporting fewer headaches trying to navigate the system.”

“Timely access to service, affordable accessibility to providers (transportation to location), parent/child willingness to engage in services, availability and accessibility to specialty providers, person-centered care and ability to coordinate care via an integrated approach by service providers.”

“There is currently no system of coordinated data collection to know whether we're making progress in the delivery of mental health services.”

Q: What type of data would be helpful to inform mental health decisions in your community or organization?

“Data looking across the continuum of services; quality of life indicators that work across child-serving agencies. Detailed demographic data, not just high-level stuff. Having summary data developed from input of providers that takes the onus off local agencies/providers having to data dive; if there can be a conversation about important data collection points and summary reports that are helpful at the local level that y'all can provide, that would be awesome!”

“Trends defining needs Data showing results achieved with services and resources used. Data identifying the needs that are lacking treatment or resources. What resources might be available that we are lacking.”

“Information from other counties of innovative programs that have been implemented. Utilizing current data collection devices such as MHIS to provide county specific aggregate information on common diagnosis, services utilized, outcomes reported to determine current gaps of services.”

Q: What supports or strengthens your efforts to deliver mental health services?

“Collaboration with other counties and with our local MH facilities. Working together helps us come up with creative solutions to rural MH problems.”

“An integrative approach to case management/care coordination that includes all service providers (including school-based supports and services) and the child/family-ability to maintain the child within the family unit and function successfully in the school environment.”

“Human Services and the tribal affiliates.”

“Having resources available in the community or at least within a reasonable distance.”

Q: What are challenges you face when delivering mental health services to youth and children?

“Distances between providers or communities create the dreaded “high windshield time”. Fighting stigma. No shows and/or cancellations. Workforce shortages.”

“Disconnect between CMH services and the legal system.”

“Poor data, lack of funding and limited array of community based service in a rural setting. Transportation is a barrier for many families.”

Q: How do you measure progress in mental health services you provide to youth and family?

“CASII, Strengths and Needs, map, risk assessment, parent and child surveys, community satisfaction”

“Improved scores on functional assessments, less need for respite, less placements or less restrictive placements.”

“Number of utilization hours of services, CASII and SDQ Scores, Waitlists, Satisfaction Measures, Suicide rates.”

“Utilization data on various services County payment for services Rates of out of home placement Consumer satisfaction Court records.”

Q: What features would be helpful in a data system that connects data from government agencies providing services to children and youth needing or receiving mental health services?

“Aggregate reports on services utilized (i.e. out of 250 children/youth receiving services 20% received day treatment). Information on the length and number of children/youth on service waiting lists.”

“Valid data that is easy to assimilate and break out by categories for planning purposes User friendly and customizable real time data.”

“A merging of data and a look at trends data.”

“Data systems that are easily accessed. Ability to create reports.”

Q: What are your concerns about how government agencies might use mental health data?

“PRIVACY. Use it as a way to deny insurance coverage, limit future opportunities for children youth (employment, joining the military, running for office, student loans, etc.)”

“Additional requirements placed on county case managers and supervisors to gather and track data for outcomes purposes. Detracts from the ability to engage in direct service hours for the individuals we serve.”

“Stats can be used to justify ineffective programs or cut programs that cannot be easily track but provide better out comes.”

Sections C: Other individual not mentioned in Sections A and B

Question: What information would you like to share with us about how to make mental health data useful to the community?

“To be meaningful, the MGDPA may need to be changed. It is not realistic to think that creating a data repository of summary level data is really going to make a significant impact to improve the lives of youth and their families.”

“Using accurate mental health data as it relates to cities and/or school districts, would be helpful for our work. We are consistently trying to help our local legislators and city level officials understand the ever present needs in our community, specifically with youth. However, we can run up against messages of those things are happening in other places.”

Q: What are your concerns about how government agencies might use mental health data?

“My concern is typically governmental agencies are slow in response and too late in the game to provide meaningful proactive help.”

“If they were to use the data in a negative way. No one would choose mental health. No one would like to struggle with mental health or illness.”