

KEEPING MAINE YOUTH CONNECTED

Data Available to Support Improved Public Policy for Keeping Maine Youth Connected

Background:

The Maine Children's Alliance received funding from the Maine Health Access Foundation to develop an annual or semi-annual report on the status of children's mental health in Maine. Through the process of working with our Advisory Council we learned about data availability through the child serving departments and through other public and private sources. The Advisory Council was composed of staff from the child serving state agencies and modeled on our KIDS COUNT Advisory Council. KIDS Count data standards were applied.

KIDS COUNT is an annual publication on the status of Maine's children and youth in relation to a variety of indicators. KIDS COUNT standards for acceptable data were adopted. The Maine Children's Alliance applies accepted research standards to data considered for inclusion in KIDS COUNT. The indicators should:

1. be from a reliable source
2. be consistent over time
3. be understandable to the public
4. reflect an important outcome or measure of children's well-being
5. represent children of all ages
6. be available at the county level

MCA focused its data gathering on four areas identified through a public and private partnership at the federal level. The Substance Abuse and Mental Health Services Administration (SAMHSA) used this collaborative agreement to guide its grants to the states for data system development. Those areas are access to, utilization of, and expenditures for children's mental health services, and intersystem involvement and outcome data.

Available Data:

Public Agency Data:

We found that a great deal of information exists but also found that there are serious gaps in data. Child Welfare and Juvenile Justice have very little information about services, who gets them and what result is achieved.

We found that the Department of Education has the potential to report:

- Who is served (demographic characteristics including disability information);
- What services are provided and at what cost; and
- What outcome was achieved?

DOE is several years away from being able to report these data for a cohort of students who have completed their education. In the meantime, it has very valuable point in time data for students.

Children's Behavioral Health Services (CBHS) has some of this information through the DHHS Enterprise Data System and through MaineCare reports. DHHS received a Systems of Care grant from the Substance Abuse and Mental Health Services Administration (SAMHSA) to develop a comprehensive data system able to link demographic characteristics with services provided and by outcome. It is referred to as the Enterprise System.

The Office of Quality Assurance and Integrated Services (OQAIS) is beginning to produce reports on children and youth served through CBHS. Limited outcome data are potentially available. For example, the new system is designed to capture how consumers feel about the service they received and the degree to which it was helpful. Other measures like pre and post Global Assessment of Functioning (GAF) scores are available. Information about crisis intervention and its outcome is also available.

Two problems exist with MaineCare data. In January 2005 the Office of MaineCare Services began using new software for its client billing system. It failed almost immediately. Data available for the SFY 2005 are suspect because of MECMS (the new MaineCare software system) failure and the fact that problems remain for millions of dollars in bills and reimbursement.

In addition, the Office of MaineCare Services has very limited ability to produce MaineCare data reports that might be requested by program Offices like Child and Family Services. Potentially available time is being directed at fixing MECMS. Raw data are available to organizational units like the OQAIS. Dr. Jay Yoe has been and is doing research that will inform policy makers.

For example, in process is an analysis of the presence of health and mental health diagnoses in MaineCare children. This project copies an earlier project that helped to understand the co-morbidity of diseases like depression and heart attacks and their impact on our understanding of the importance of integrated primary and behavioral health care, as well as suggesting the impact on MaineCare and health care costs in general.

MaineCare data are potentially available for MaineCare clients of state programs like child welfare, juvenile justice and the Office of Substance Abuse. Reports are not available for these client groups except that available through OSA under MYDAUS. Reports might be available if three things are present:

- MaineCare ID numbers for the client group (like children in state custody);
- MaineCare approves the request; and
- Staff time is available through Muskie Institute staff and the Maine Health Information Center.

The Maine Health Information Center (MHIC) does most of the data reports and analysis for state agencies and other entities like MCA. Raw data runs from OMS are structured for use in program reports by Muskie staff. MHIC staff develops reports and analysis as requested by organizations approved by OMS.

Data reports about children and youth served by more than one public program like OCFS, CBHS, Juvenile Services and OSA are potentially available if each organization is able to provide its clients' MaineCare numbers. Unfortunately, the Department of Education does not consistently capture and report by MaineCare number making direct comparison with public behavioral health or health care programs very difficult, if not impossible. Some promise exists for understanding the over-lap of DOE data and other public programs through probability matching software and integrated data architecture.

The Department of Labor does capture data about the youth served through its Bureau of Rehabilitation. Children/youth reaching age 16 can be referred to the Bureau of Rehabilitation for assistance in developing their transition plan required under the Individuals with Disabilities Act (IDEA). The Bureau provides largely vocational assessment and non-cost services like case management through its rehabilitation counselors. Whether the Bureau's data can be linked to other state programs through a MaineCare number is not known, though it seems unlikely.

Other data gaps include:

- Health care including dental care and prescription drugs;
- Hospitalization for mental health reasons in non-psychiatric hospitals;
- Residential placement costs that are not MaineCare reimbursed; and
- Co-morbidity of behavioral and other health diagnoses.

Private Agency Data:

The Maine Health Data Organization (MHDO) collects claims data for all private health insurance carriers doing business in Maine. "Claims data" means the bills submitted for payment by medical or behavioral health care providers. Recently, OMS received federal approval to transfer MaineCare data to the MHDO. As a result, MHDO's "All Claims" database includes claims data for all health care and behavioral health care. Maine is the only state in the Union to have this capability.

Data analysis and comparison have significant challenges. Public systems like MaineCare use different coding systems for services and billing. Thus, it is difficult to achieve a comprehensive picture of the health and behavioral health services provided to Maine children and youth through public and private sources. Two things are clear, however:

- The range of services available to non-MaineCare children and youth is much more limited; and
- MaineCare is the largest payer of behavioral health services by a very large margin.

Other survey based data sources offer information about consumer perceptions of their health and behavioral health. When compared with available data about reported instances of health or behavioral health diagnosis and care, direct comparison is problematic. The value of the survey data is in the information conveyed about how parents and their children perceive their health and health care needs.

For example, OSA collects survey data about Maine youth. One data element has to do with suicide. Youth report that they think about suicide and actually engage in suicidal behavior or self injurious behavior at rates substantially above actual reported instances.

Summary:

Data availability is limited for several reasons:

- Some major state programs do not capture disability and services data about their clients;
- DOE does not capture MaineCare numbers for students in a consistent way and does not report them;
- Public and private health and behavioral health programs do not use the same coding system; and
- MECMS problems render data after 2004 suspect for MaineCare recipients.

National and state survey data provide very useful information about how youth and their families perceive their health and behavioral health needs.

The DOE system offers the promise of data about students, their educational needs, the services provided and their cost and the outcomes achieved.