

MCH DATASPEAK
Health Status Indicators-- Rhode Island's Experience
October 12, 1999

Thank you, Beth and hello everyone. I've included a brief outline (*slide 2*) of what I'll be discussing during the next few minutes. I will first briefly describe Rhode Island's overall experience with the health status indicators and touch on a few challenges. Next, I'll describe in more detail an example of data linkages in Rhode Island. I'll then touch on our initiatives around family involvement and conclude with how these indicators tie in with other indicator work we've been doing here in Rhode Island.

Overall Experience

Overall, our experience with collecting the data for the 25 pilot health status indicators was positive. We had a pretty good understanding of what was expected when we volunteered to be a pilot state and actually, one reason we did volunteer was because we already were collecting data for the majority of the indicators. One of our challenges was completing the list in the short time frame given and we were just completing our Title V Application. As a result, we may not have been as thorough as we would have liked.

Oral Health

As I mentioned, we were able to collect data for the majority of the indicators. However, there were a few indicators for which data were more difficult to obtain, such as: oral health and data linkages (*slide 3*). In the case of oral health, most of the 8 pilot states, including Rhode Island, had difficulty in obtaining population-based data for the oral health indicator which was the percent of third grade children receiving an oral health screening. Although many states, including Rhode Island, could obtain Medicaid data, most could not get data at the state level. In Rhode Island we do have an initiative in Providence elementary schools, however, we do not have data on all third graders in Rhode Island. I believe several suggestions were made around this indicator, including using the HCFA 416 measure and focusing on ages 6-9.

State MCH Data Capacity--Data Linkages

One of the health status indicators dealt with State MCH Data Capacity. Specifically, it asked about the ability of states to access and link MCH related data sets. A subgroup of the pilot states met to try to rework this indicator and I believe Linda Bultman will be speaking on this in more detail. However, I'll just briefly mention Rhode Island's ability to access and/or link data sets. Of the datasets listed in the health status indicator, Medicaid paid claims or eligibility data are the only datasets for which we do not have direct access. Those data are maintained by the Department of Human Services and are not linked to any of our MCH data sets. We can access the data on request, and only in report format.

Data Linkage Example: KIDS NET

One good example of data linkage in Rhode Island is our KIDS NET system. In an effort to ensure children receive the preventive services they need and improve coordination of services, we have linked 9 program databases together. This has created an information

system called KIDS NET, which allows us to determine whether children are behind in their preventive services and to provide follow-up and referral services to those children. The system is first initiated with our Universal Newborn Developmental Risk data. Every baby born in Rhode Island is screened for developmental risks. These data, which include selected medical and demographic information, are collected and used to populate KIDS NET. Selected data are then extracted from 9 Health Department programs that serve young children. These include 6 universal programs: Newborn Developmental Risk Screening; Newborn Hearing Assessment; Newborn Metabolic Screening; Immunization; Childhood Lead Poisoning; and Vital Records. In addition, 3 targeted programs are also included and they are: WIC, Early Intervention and Family Outreach (Home Visiting). I've included a slide (*slide 4*) which illustrates this system.

KIDS NET is initiated at birth and includes all Rhode Island births as of January, 1, 1997 and on. It is a data warehouse model and offers on-line access to providers. It also includes an immunization registry. It provides well child reminders, provider monthly reports, immunization recalls and home visiting/ risk response services. Confidentiality issues were taken into account with the system design. Access is based on a need to know and providers have been assigned ID's and passwords. Depending on the user, they are given read vs write ability. All providers are required to sign confidentiality agreements.

Groups using KIDS NET include parents, physicians, including primary care providers, hospitals, ERs and treatment centers; managed care providers and those in public health. Some of the benefits include: (*slides 5-7*)

- Tracks childhood immunization status, lead screening and all KIDS NET affiliated program data
- Generates a list of children behind in receiving services
- Generates phone and computer well baby reminders for parents
- Provides comprehensive data to pediatric providers
- Identifies children at-risk
- Promotes comprehensive follow-up and access to care
- Reduces duplication of services and missed opportunities
- Increases direct contact with providers
- Increases the opportunity for data analysis

We are still working to get providers on to KIDS NET and still have a ways to go. Currently, we have about 20% of the pediatric providers on-line and they represent just over 50% of the children.

KIDS NET is also an example of involving parents and enhancing communications with families. Parents were involved in the development of KIDS NET and continue to be involved at the community level. KIDS NET also provides comprehensive information to parents through its home visiting and follow-up component.

Family Input—SSDI 2000

We believe we can increase our ability to monitor the health status indicators, as well as our Title V performance measures and our needs assessment by improving our ability to communicate with the families we serve. In the past, qualitative data in addition to quantitative data have enhanced our needs assessments. We are committed to having parents directly involved in our programs. Our Parent Consultant Program currently includes 12 parent consultants who offer their perspectives and ideas around program planning, policy development and assessment.

Through our SSDI project, called Parents as Partners, parents worked directly with families in two communities to learn why they were not utilizing services for which they were eligible and to help educate them about programs available. Our SSDI project for FY2000 will build on this effort and expand it to other communities. Our goal is to create a continuous feedback loop through a variety of methods that will allow us to maintain ongoing contact with families. These efforts will include increasing our telephone survey capacity; expanding our Parents as Partners community level assessment and outreach initiative, and exploring innovative strategies, such as the use of an electronic network to communicate with families (*slide 8*). We plan to explore the use of computers to engage in a two-way interaction with a formal network of families trained in community outreach, as well as in telecommunication technology and qualitative assessment. We want to provide families with electronic access in order for them to provide us with their issues and concerns and for us to provide them with information.

Other Indicators

Our Title V needs assessment and plan, which we refer to as Family Health in Rhode Island, is built on data from public surveillance, program data, Rhode Island KIDS COUNT, and community and school surveys, to name a few of our data sources. In addition, we obtain community input from public forums, discussions with partners in the Children's Cabinet, Governor's Juvenile Justice Reform, the Danforth Policymakers Institute and other leadership forums. Family Health in Rhode Island priorities pull together state and national priorities and measures.

Currently, we are participating in an interagency initiative funded by Health and Human Services to define a core group of indicators that can be used to:

- track the impact of welfare reform, health care reform, child care expansion, and education reform;
- develop new indicators to measure the well-being and school readiness of young children;
- examine the ability of using state agency administrative data, state surveys and state supplements of national surveys as data sources for producing indicators a set of child indicators and link them to policy goals;
- institutionalize the use of indicators in policy work.

Utilizing these indicators, the health status indicators, the Title V performance measures, and our community input, should enhance our ability to assess our progress in meeting the maternal and child health needs of Rhode Islanders.