Q&A

Designing and Using an Effective Data Management System: Components and Considerations

Webinar, February 24, 2011

Presenters:

- Robert Ammerman, PhD (Every Child Succeeds and Cincinnati Children's Hospital Medical Center)
- Nova P. Rose, PMP (Children's Services of Palm Beach County)
- Albert Wat, MA (Pew Center on the States)

Contributors

- Jodie Short (Every Child Succeeds and Cincinnati Children's Hospital Medical Center)
- Electra Small (MDRC)
- Jill Filene, MPH (James Bell Associates, Inc.)

Data Management Systems

Q: How much did Palm Beach's data system cost and how long did assessment take?

The assessment ran from October 2009 until February 2010 at a cost of $110,000. We are launching the first phase of the data system in October of this year, and we are making an initial investment of $1.7 million. However, this is a broader data system with multiple programs involved, so the costs are higher than they might be for others. Costs are likely to be quite variable from state to state and program to program, depending on where they are starting out from, what they want, and what kind of personnel they have. Because this is a fast-moving industry, cost changes fairly quickly.

Q: It seems that there is an opportunity for states to pool resources and collaborate to create and open source data system that allows tailoring by each state. What are the pros/cons of this?

DHHS is not in a position to make specific recommendations. It is feasible; however, the idea needs to be carefully thought through and you would need to consider needs, feasibility, affordability, etc.

Q: Have any states included home visiting in their broader early childhood data system?

We are not sure if states have done that, but there's no particular reason why they could not.

Q: In the process of selecting data elements for inclusion in your systems, did you use nationally recognized standards to represent the data?

One of the issues we have in home visiting is that people do use different measures, and it is desirable that we use the same kinds of measures. We certainly recommend using common data definitions so that one can compare and contrast data easily.

Q: Can home visiting funds be used to buy or build a data system?

We believe that home visiting funds can be used to buy or build a data system; however, you should talk to your HRSA project officer to clarify.

Q: Would a data management system have functionality for scheduling?

It could. If you design your own, it can be built in. If a system is purchased, this is something to think about before buying.

Q: Would reports be shown in a fixed field or predesigned table for regular (i.e. quarterly) updates or queriable or both?

It depends. This is a good question to ask as systems are designed, adapted, or purchased.

Q: Do you recommend HL7?

We cannot recommend a specific system.

Use of Identifiers

Q: How do you link the mother with the infant with the father with the family? Do you use individual client identifier or family identifier?

We use both client identifiers and family identifiers. Each person is an individual client with a unique client ID, but they are also in a family unit with its own family ID.

Q: How have you been successful in gaining agreement to a single unique identifier? Many systems have a unique identifier; how do you agree on just one?

If there are multiple systems with unique identifiers, there needs to be a conversation on how to link them. Some programs or agencies may be able to link them by looking at other demographic variables, some may decide to convert everything to one identifier. It depends on what capacity is available. Having one identifier is usually preferable because there is less opportunity for error. One state was thinking of assigning an identifier to children when they are born since the Department of Health would have access to them at birth. In Palm Beach County, it has been a challenge working with different entities. They collect what is available, whether its' a state ID number or Medicaid number, so that there's always a way to search and find the right person.

Q: Has any state or developer tackled the problem with what happens when families move between states? Unique identifiers developed within a state will no longer be useful.

Yes, and families may leave the country, too. These are thorny issues and we are unaware of the solutions.

Q: Why not use social security numbers as unique identifiers?

It is possible to use social security numbers as identifiers. There are HIPAA and legal issues that must be addressed and state, tribal, and territorial resources should be consulted about this before using this variable.

Communication Between Data Systems

Q: How did Palm Beach get feedback from home visitors regarding your data system, and did you include supervisors in the process?

We included supervisors, home visitors, case workers. We sent out a form to get information back, and then we took the forms and met with individual programs. We met with supervisors and case workers face-to-face at their offices, where we were able to see what spreadsheets they used along with the data system and how they were using it.

Q: HIPAA and FERPA are often used to justify why a system will not/cannot share data with other systems. What are strategies to deal with those barriers?

As with any law, there are differences in interpretation, so there is no single strategy address HIPAA and FERPA requirements within the context of setting up an MIS system for home visiting. Legal resources within states, tribes, and territories should be consulted during the process. However, a number of states have created statewide data systems and have set up ways to integrate them in meaningful ways, so these laws do not erect insurmountable barriers to creating systems that share information.

Q: How can we, as home visiting programs, link to early intervention data?

We recommend talking to people in the departments that keep track of early intervention data, whether it is the Department of Education or Department of Human Services, and seeing what you can do to add home visiting data into their existing system. It can be helpful to have that conversation and make people aware of the data collection efforts that are going on. You may want to consider a low-hanging fruit strategy, where you look at the agency you are already in and see how you can make those connections first, and then maybe go into other departments that you want to link to.

Q: How do you link data systems to systems such as Medicaid?

What we do in Palm Beach is external referrals, so at this point we are just referring clients out to these entities rather than linking to data systems. It is our hope that over time we'll be able to do that.

Q: How have you set up your data system so that it can speak to other home visiting programs, or do staff have to double enter data into database?

Nova worked with the national service office of NFP to have an agreement where Palm Beach's IT department would download and extract the data from their system on a weekly basis and then upload it to NFP's system. It has worked well and the numbers match. We try to do that as much as possible because don't want to do double data entry. Once you have reached an agreement with a model developer, one can set it up so that data can be readily extracted and uploaded. It's a solvable issue.

Q: What kind of questions should I ask in order to make sure that the data system I want to use can talk to other data systems?

For a system to talk to another system, both systems need to be set up in a way so that talking occurs. That's a dialogue that has to occur between whoever oversees each system. You want to understand the definitions that the other data system is using. You want to have a data sharing agreement. Questions

you would want to ask could include: what platform is the system on? What kinds of files will you be sending and receiving? How will you be sending and receiving files? Is there a secure method? What kind of identifiers do you use? What is your methodology?

Others

Q: Could you distinguish between outcomes and benchmarks? Often, benchmarks are used to mean the community level, or population comparison data, whereas outcomes are individual level data. It seems to be used differently in this presentation.

A good MIS system will be set up to facilitate the collection and integration of multiple types of data to be used for both.

Q: Are there any plans to demonstrate eECS?

We are not in a position to recommend one system over another. States, tribes, and territories are encouraged to ask vendors multiple questions about their systems to ensure that they meet their needs.

Q: What resources are allocated for data collection/linking/management vs. the proportion allocated for interventions/programs?

We are unaware of a single rule of thumb for proportional expenditure for data collection/management vs. intervention. This will vary widely and be dependent on current resources and what kind of system is desired. One broad observation is that home visiting programs often underinvest in these systems, and are left with something that adds minimal value. Moreover, states, tribes, and territories are encouraged to consider data collection as integral to providing effective services, and in driving continuous quality improvement. As a result, the line between data collection and intervention should be viewed as flexible and permeable rather than a strict dichotomy.

Q: Are the data systems presented distributed or centralized data systems? What type of quality review and processes for ensuring good quality do you follow?

Ideally there is a centralized system that allows individual sites to extract and use their own data. Assuming that quality review pertains to data collection, it is important to produce regular reports that reflect the health of the data collection (e.g., completeness and timeliness) so that problems can be identified and repaired. This part of the program should be seen as part of overall continuous quality improvement. Accuracy is improved though adequate training, period monitoring and auditing, and booster trainings.