

“Have You Asked a Parent Yet?” Parent Involvement in MIS Design

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A quality, cross-system, electronic management information system (MIS) can be a meaningful and useful tool to children’s service systems and to the youth and families served. As human services become more integrated and outcomes-oriented, the electronic MIS supporting the services must change and evolve as well. There are many decisions to be made during development of information systems—as well as during implementation when revisions are inevitably required. Several key players should be a part of this process, including Information Technology (IT) staff, clinical staff and other front-line workers, data entry technicians, data analysts, and parents and caregivers of children with complex needs (from here on referred to as “parents”).

While IT staff have generally been regarded as necessary players in the **development** phase of MIS, there is often less support for the involvement of other partners such as clinical and data entry staff. As recent system reform efforts have placed greater emphasis on collaboration, additional players have been welcomed to the “design” table—resulting in better outcomes such as increased efficiency and improved data accuracy and comprehensiveness. One notable party often excluded in MIS development, however, has been parents.

Designers of integrated MIS rarely recognize the value, understanding, and insight parents can bring to the process in order to streamline systems, ensure confidentiality, and increase validity of outcome measurements.

In my role as the MIS Manager for Wings for Children and Families for almost six years, parents have been primary players in the development of our database. The Wings’ MIS has been designed, maintained, and revised in-house to allow for maximum flexibility to meet the constantly changing climate of our children’s services. Parents’ input has repeatedly improved our data management efficiency by “cutting to the chase” and quickly focusing on the true needs of families. By supporting their active involvement in the initial stages of system design (rather than bringing them in later to review/revise work already done), parents have had the opportunity to provide indispensable and timely input on relevant measures of outcomes, effectiveness, and quality control. We have found that their insights often contrast or enhance other professionals’ views of outcome measurements in evocative and enlightening ways.

For example, if your MIS design team asked educators how to measure success for a child, they might emphasize grade point averages. When you ask parents of children with special needs how they measure success in the educational environment, they might tell you “when the school doesn’t call me as much.” Similarly, in our early years of collecting educational outcomes without the benefit of ample parental input, we made assumptions about the desirability of specific indicators. For instance, we assumed that an increase in the number of children receiving special education

services was a negative outcome. Parents explained to us that this could be viewed instead as a positive indicator—representing delivery of a needed service. As a result, we now interpret this measurement as a service and cost indicator, not an outcome indicator.

When you ask a juvenile correctional worker to measure effectiveness, the answer typically involves “compliance with probation officers” or “no further arrests or law enforcement contacts.” These are very important and desirable outcomes. Yet when we talked with parents, they told us that sometimes their child does not comply with all probation and parole visits because of issues such as transportation or family need, not because the child is being defiant. This greatly impacts data analysis conclusions.

Parents KNOW which data elements measure effectiveness. They KNOW which items are not helpful and don't get to the real issues. They KNOW what is really meaningful to them and their family across different service systems. They KNOW what policy makers need to hear. And they KNOW which elements, if worded or used inappropriately, can be harmful to the cause of children and families.

From a design standpoint, we have asked parents to review the database user-interface. Parents have provided excellent feedback such as pointing out data labels that promote stigma and suggesting changes that better protect privacy and security (such as moving a field with sensitive information so it is not easily viewed when the program is first opened). Parents have been able to look at our design and ask questions such as “Why aren't you tracking this item?” which often results in a very helpful revision.

From a cross-systems perspective, parents have first hand knowledge of where duplication of information occurs as well as legitimate concerns with privacy and security of information. At the very least it is respectful to involve parents and ask about their concerns and ideas for responsible use of information policies. Our experience has been that parents have a very reliable sense of how quality data systems can inform and improve children's systems of care. It is important to remember that simply having a parent in the room or even as an employee is not going to provide effective results. The parent should be currently or recently involved in multiple systems of care on behalf of their child.

That parent will also require training to look for, identify, and advocate for quality. The parent should have the opportunities not only to provide input but also to receive cross-training from the team so as to understand fully the needs of the agency on behalf of the families they serve. Ideally you should also include more than one parent to avoid isolation and to encourage creative thinking. Support and respect from agency leaders must be strong and constant. Wings has truly embraced this concept with amazing results, and the phrase “**Have you asked a parent yet?**” rolls off the tongues of Wings staff as easily as asking about the weather.

Susan Amero's experience as a family member enhances her work as Data Manager for Wings, a system of care serving five counties. Susan provides ongoing technical assistance and support to the State of Maine on their statewide evaluation and management information systems development. For more information, please contact her at: SAmero@wingsinc.org.