ISSUE BRIEF

DECEMBER 2008
NUMBER 2

TRENDS IN LONG-TERM CARE

Databases Strengthen Long-Term Care Partnerships

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The Community Partnerships for Older Adults (CPFOA) program provided grants to eight community partnerships to develop and implement creative strategies for improving awareness about long-term care and supportive services systems. This brief examines three partnerships with different levels of information technology (IT) expertise that designed databases to help improve communication among service providers. The providers were case managers from health and social service agencies, hospitals, and home- and community-based aging providers. This brief summarizes the experience to provide information for communities considering similar initiatives.

Need for Coordination and Communication

With the number of Americans needing long-term care projected to reach unprecedented levels over the next 20 years, improving coordination of care for older adults is growing in importance. Many elderly community residents have complex health and social service needs, receive services from more than one agency, and have contact with multiple case managers. In the absence of interagency coordination, their care can become fragmented, resulting in redundant services or unmet needs.

This brief focuses on three CPFOA partnerships— Aging Atlanta's Care Options, El Paso's Successful Aging Through Long-Term Strategic Alliances, and the San Francisco Partnership for Community-Based Care & Support—that developed databases as part of their efforts to improve the long-term care system. User-friendly databases that track services hold promise both for improving coordination and reducing duplication of services. Each of the partnerships hoped that a shared database would help health and aging services agencies to (1) keep up-to-date information about available long-

ABOUT THE STUDY

CPFOA is an eight-year, $20 million program funded by the Robert Wood Johnson Foundation to improve long-term care and supportive services systems to meet the needs of older adults. The program encourages community partnerships of providers of aging services, public officials, senior citizen groups, and other stakeholders to:

- Create greater awareness of the unique contributions and growing needs of older adults
- Educate the community about long-term care and supportive services
- Strengthen community collaboration through increased communication and coordination among the community's health care, long-term care, and supportive services providers
- Leverage public and private resources in response to identified needs
- Address the needs of diverse and underserved populations

term care services; (2) link agencies that share clients; and (3) improve coordination of services to individual clients through enhanced interagency communication.

Aging Atlanta's Care Options system includes client and agency components. The client component contains limited demographic information (such as name, address, telephone number, and date of birth) to enable agencies to identify shared clients. It also includes information on the status (active vs. inactive) of clients in an agency's program, as well as care-related details (such as hospital admissions or discharges). The agency component serves as an electronic address book for those using the system and includes contact details for each case manager, as well as a description of goals, mission, and services. Having contact information facilitates direct communication with the person most knowledgeable about a client's care. The system also includes online communication tools, such as email, which providers can use to hold online meetings or conferences through a secure chat room (similar to instant messaging). Users can also create and share documents.

Maintaining up-to-date information in a database requires vigilance, as Aging Atlanta's Care Options discovered. The pilot version included information on 2,500 clients served by 12 agencies and initially appeared very successful. Case managers reported that the system saved them time and eliminated service duplication. However, two years after implementation, program managers realized that client information was not updated and the agency component, email, and team conferencing features were the only ones used. Program managers may have overestimated the number of agencies and clients that could be effectively managed, but they believe the original version of the system (which included both the client and case management components) was well designed and could be successful in a smaller setting. Future plans include rolling out the original version for use among a smaller group to see if it is useful on a smaller scale.

El Paso's **Successful Aging Through Long-Term Strategic Alliances** developed and implemented a case management system, referred to as the Q System, that includes basic client demographic information (such as age, address, and telephone number); case management notes; an assessment form (modeled after the form all participating agencies are required by the state to use); care plans; referrals; and a resource directory. The database was developed to provide case management and referral services for a mental health agency, a primary care clinic, an organization providing case managers, and the county nutrition program. The local Area Agency on Aging (AAA) hired a developer to create the database, and each agency under contract with the AAA purchases the software and licensing agreements. Participating agencies can customize the system. For example, one agency requested a tracking function to identify clients and costs per unit of service by funding source, to assist with billing. The database is used by the city and county, as well as the AAA and the county nutrition program. Funding for several of the original users has expired, and the case management function is inactive.

Based on a survey of case managers and an unsuccessful attempt to establish a full case management system, the **San Francisco Partnership for Community-Based Care & Support** set up an electronic address book similar to the one in Atlanta. The system, called Case Management Connect, includes a resource guide that lists all case management programs citywide (with contact information and descriptions of services), as well as a client component that lists clients served by participating organizations. When a client's profile changes—such as when a new case manager is assigned—an email notification is sent to other participating case managers. The resource guide includes indicators for levels and standards of care, to address

the lack of existing standards, help agencies assess their resources and caseloads, and match case management needs to the appropriate level of care. The partnership hopes the system will generate broader change in the way San Francisco agencies provide case management.

How Sites Set Up Systems

Sites had to address several common issues in setting up their databases. First, each had to ensure that procedures were in compliance with the Health Insurance Portability and Accountability Act (HIPAA). Second, program managers had to coordinate database development across a large number of organizations with diverse information needs. Third, program managers had to work with IT staff to translate organizational needs into system specifications. Finally, the databases had to be populated with client and agency information.

HIPAA Compliance. None of the sites expressed concerns about complying with HIPAA requirements. Each site discussed options during the planning stages and employed measures to facilitate compliance. For example, Atlanta collected only minimal client informa-

tion and excluded Social Security numbers. In San Francisco and El Paso, database users had to sign a privacy pledge. All databases were designed as secure, password-protected, web-based applications limited to registered users in the participating agencies. An additional security feature defined different access levels. For example, in Atlanta, some users can access agency information but not client information, whereas database users in mental health and senior protective services agencies may not be able or willing to share client information but can view information in the system.

Coordinating Information Needs. Each site used a work group comprised of agency representatives, case managers, and potential users to assist in database development. Participants provided advice and recommendations on the types of features and functions to incorporate in the system. The work groups met regularly (usually monthly) during the early planning phases but less frequently as the systems were implemented. None of the work groups is currently active.

Working with IT Professionals. Experience with information technology varied widely across the three sites. Before it began work, the Atlanta Regional Commission had developed a statewide database for all AAAs. An in-house IT expert at the commission served as the technical liaison between Aging Atlanta's Care Options and the software developer, assessing business needs, conducting beta testing and training, and monitoring the contract to ensure the developer met its obligations.

In contrast, El Paso did not have an in-house IT expert but tapped staff from participating organizations to identify system requirements. The work group shopped around for software and relied on product demonstrations to understand how their needs would be translated into an electronic system. The San Francisco site did not have its own IT expert but worked with staff of the San Francisco Department of Public Health (DPH) to develop the system as an add-on to DPH's case management system.

Populating the Databases. Most agencies using Aging Atlanta's Care Options populated the database with client lists from their existing case management systems, which required a one-time transfer of data. Agencies then entered information for additional clients as necessary. In El Paso, database users are publicly funded agencies under contract with the AAA and mandated to use the system. San Francisco's system is comprised primarily of agencies associated with the Department of Aging and Adult Services (DAAS) or DPH. DPH and participating organizations can share information only with providers in the network. DAAS and DPH underwent a lengthy legal process to establish a Memorandum of Understanding to incorporate all of DAAS's contractors into the DPH network.

Tallying Costs and Challenges

Sites reported development and implementation costs in dollars or in labor hours. Aging Atlanta's Care Options spent approximately $45,000 to set up and implement its system. El Paso spent $17,924 on implementation and pays $6,374 annually in licensing and user fees. In San Francisco, DAAS did not pay any direct costs for setting up and implementing the database because DPH offered to develop the system and covered the cost of staff time—approximately 240 hours of programming time and an additional 60 hours of an IT director's time. For all three sites, the reported expenses represent direct costs and do not include labor hours contributed by volunteers.

Sites encountered a number of challenges during the process of developing their databases:

Double Data Entry. Double data entry was the most common problem. Most case managers already used reporting systems mandated by their funding source. Agencies had different systems serving varied functions and types of clients. Establishing a new system not compatible with existing ones required that client information be entered into a second system. Even if case managers were willing to do this, most felt they did not have time. Furthermore, even the perception of double entry can pose a serious barrier to system use. In Atlanta, program managers tried to minimize double data entry by limiting the amount of client data included in Aging Atlanta's Care Options, but they were unable to eliminate double entry entirely. Case managers had too many clients and were too busy to enter even minimal information into a second database, which resulted in the client component quickly becoming outdated. Although mandating use of the system might improve how frequently it is used and updated, most felt this approach would not be effective unless the need for double data entry were eliminated (for example, if the new system became the standard for the organization).

Coordinating Data Needs for Disparate Agencies. Coordinating system functions and features among numerous agencies with different data needs proved challenging. Even though each site's work group sought to narrow the list of desired features, the process of developing a new database is complex, particularly for people without prior experience. Perceptions about which features were essential evolved over time, and two sites revised database specifications during the development process.

Implementation Delays. Database development and implementation involved a lengthy process in all three sites. In Atlanta, essential system features became clear only after several years of use. Providers also realized that they did not need client information to attain their

goal of enhanced communication. The development of El Paso's system took several years because it was difficult to narrow down features of the database to meet the needs of different agencies. Furthermore, the database went through numerous rounds of changes before implementation. In San Francisco, the partnership was dependent on another group (over which it had no authority or control) to get its database up and running. Because the database was not the top priority of that group, work proceeded more slowly than it might have had the partnership had an IT department of its own.

Reported Successes

Despite some challenges, all three sites developed fully functional, secure, web-accessible databases. In two sites, the systems are not being used as originally envisioned, but they are used and important lessons were learned. Atlanta noted that its software works well and shows how technology can enhance interagency communication. Its greatest achievement was bringing agencies together in a collaborative, productive environment. Despite the fact that El Paso's system is used by a limited number of agencies, it has dramatically increased the quality and efficiency of information exchanged between the AAA and its contractors. San Francisco's database development efforts brought about collaboration between two very large health service agencies that have always operated in silos. In addition, the partnership developed case management guidelines for defining levels of care, a potentially revolutionary approach to matching client needs with the most appropriate care and improving service efficiency.

Advice for Others

These sites gained the following insights into dealing with the challenges of database development:

- Clarify the purpose of the database and decide how data will be used by different organizations before undertaking any developmental activities. Plan to incorporate the information into decisions about the types of features and functions that will be needed, which will affect development time and costs.

- Keep the database simple. Decide whether collecting and sharing client health information is necessary. If not, limit the amount and type of client information collected to streamline development. Developers should be aware of existing systems in use by each organization and consider ways to build onto them, if possible. Case managers already feel overburdened, so simplicity will encourage greater use.

- Involve potential users in the development process. They can provide practical advice on features they need, resulting in a more efficient system. Agencies and case managers may have preferences or issues, such as lack of internet access in the field, which can influence the ability to move to a web-based system. Seeking advice early can limit costly changes later.

- Involve IT professionals early on. They can translate agency needs into software specifications and ensure that the technology developed is appropriate to the setting in which it will be used. Ideally, draw on in-house IT staff or an established relationship with a software vendor. If outside assistance is needed, obtain references and ask for demonstrations and examples of finished products.

- Draw on the experiences of others to avoid unnecessary and costly steps. San Francisco received advice and input from Atlanta to help decide how to limit system features. El Paso consulted with San Francisco early in the development of its database.

Looking Ahead

Communities that are considering creating communitywide, client-level databases to enhance the coordination of services should be cautious about such an effort. The CPFOA partnerships profiled here implemented databases but failed to achieve communitywide utilization. Even though the databases did not improve the long-term care and supportive services systems as originally envisioned, they did enhance provider communications. Furthermore, the sites continue to test their systems with new populations and settings, so their work may eventually demonstrate that databases are successful in alternative settings. In the meantime, their experiences may assist others in developing technology to enhance client outcomes in the future.