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Crisis Response

Nancy C. Shank*

Brian Sokol†

Michelle L. Hayes‡

Christina Vetrano**

*University of Nebraska - Lincoln, nshank@nebraska.edu

†Abt Associates, Inc., Brian_sokol@abtassoc.com

‡Cloudburst Group, mlh@cloudburstgroup.com

**American Red Cross, vetranoc@usa.redcross.org

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HUMAN SERVICES DATA STANDARDS: CURRENT PROGRESS AND FUTURE VISION IN CRISIS RESPONSE

Nancy Shank

University of Nebraska Public Policy Center
nshank@nebraska.edu

Brian Sokol

Abt Associates, Inc.
Brian_sokol@abtassoc.com

Michelle Hayes

The Cloudburst Group
mlh@cloudburstgroup.com

Cristina Vetrano

American Red Cross
vetranoc@usa.redcross.org

ABSTRACT

Interorganizational coordination is crucial among human services providers responsible for responding to both personal and widespread crises. Too often, however, agencies providing disaster relief, shelter, and connection to other social service systems operate in information silos. Moreover, organizations that assist the same people may be duplicating services or ineffectively providing services to those in need. In the past, there has been no easy way for human service organizations to share information about clients, resources, and services. Over the last decade, distinct initiatives have begun to standardize data collection, storage, and transmission standards within human service domains. This paper describes several human services standards currently in use or under development in the United States and discusses how each support distinct, yet related, human service information management during disasters. The paper concludes with a call for the development of an overarching human services data interoperability standard.

Keywords

Human services, interoperability, data standards, XML, disaster, information and referral, homeless, CAN, HMIS, AIRS

INTRODUCTION

Human service organizations assist people affected by personal and widespread crises. Individuals experiencing hardship may need services such as shelter, clothing, food, and healthcare. In the United States, persons looking for appropriate services find it difficult to locate and access the multiple programs that may be available to help them (Agosta and Melda, 1995; Koening, Benjamin, Todaro, Warren, and Burns, 1995; Levinson, 2002). Too often, those needing human services are required to tell their story multiple times. Agencies expend scarce resources on duplicative tasks (e.g., cataloguing available resources, gathering client information) and are frustrated by their inability to coordinate services for clients and track availability of programs and resources. Beyond client and agency frustration, silos of information complicate efforts to aggregate data for community planning.

In times of disaster, interorganizational coordination is more difficult and yet more crucial, as both organizations and families are fractured and reconstituted, and the nature of both client needs and service availability are in flux. Services for victims are provided by many organizations, some pre-existing, others new to the locale and time-limited. Identifying and sharing information about clients and available resources in the context of spontaneous organizing is a challenge, but “when disasters strike, particularly large scale disasters, inter-organizational response is necessitated” (Topper and Carley, 1999, p. 69). In most communities and during most disasters, the human services field has fallen short of interorganizational coordination that effectively serves clients. After Hurricane Katrina, a Category 5 storm that hit the Gulf Coast of the U.S. in 2005, there was an effort to coordinate all non-governmental human service organizations through the Katrina Aid Today project (United Methodist Committee on Relief, n.d.). However, the need for greater coordination within the human services community was highlighted in the White House report (Townsend, 2006) which reviewed the response and concluded: “The Department of Health

and Human Services should coordinate with other departments of the Executive Branch, as well as State governments and non-governmental organizations, to develop a robust, comprehensive, and integrated system to deliver human services during disasters so that victims are able to receive Federal and State assistance in a simple and seamless manner” (pp. 49 and 59). The report recommended that each victim should be able to “go to one physical location, encounter one person who gathers all the necessary data and inputs it into a database that is shared and transparent among all human service providers at the Federal, State and local level as required” (p. 107). This level of coordination is a challenge very few communities have achieved during normal operations, much less during large-scale disasters.

This paper describes several major human services data standards in use and under development in the United States for client case management, human services categorization and resources, and disaster response. Specifically this paper will discuss technical standards that co-exist to support disaster response including standards for: 1) human service definitions and categorization jointly owned by 211 Los Angeles (LA) County and the North American Alliance of Information and Referral Systems (AIRS); 2) community human services resources documentation, developed by AIRS; 3) client data management and needs assessment administered through the federal U.S. Department of Housing and Urban Development (HUD) Homeless Management Information Systems (HMIS) Data and Technical Standards; and 4) disaster response and recovery being developed by the Coordinated Assistance Network (CAN).

These human services standards have co-existed and been simultaneously adopted by many of the vendors that offer information systems products to support client, service, and disaster response efforts in the United States as well as Canada. Based on preliminary research and through consultation with standards development organizations and other human service associations, the standards described in this paper are the known major client, service, and disaster response standards in the human services sector. The experiences described in this paper, although based in the U.S. may inform international efforts dealing with similar challenges in disaster data exchange. There are additional standards such as the People Finder Interchange Format (PFIF), focused on finding people, and the Emergency Data Exchange Language (EDXL) for exchange of logistics data to support disaster response. Neither of these standards, however, addresses the connection between services and clients. The standards addressed in this paper focus on the clients served and the services they need. The paper concludes with a call for interoperability among standards.

HUMAN SERVICES DATA AND CHALLENGES TO DATA SHARING

Human service information is fundamentally composed of three types of data (Figure 1): Client-based, resource-descriptives, and service usage. Within this simple framework, complexities abound as systems accommodate data idiosyncrasies, changes over time, and dynamic interrelationships.

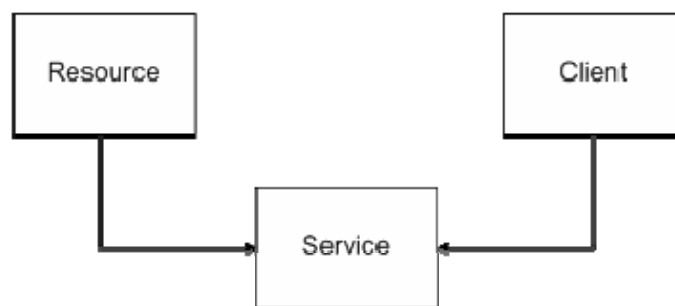


Figure 1. Human Services Data Types

Although the human services field has been a fairly late adopter of electronic information systems, many organizations now have data systems. As organizations move to electronic systems, they have not had client or resource data standards to rely upon to enable sharing. Given the United States’ distributed human services system

of public and private organizations serving various populations and catchments, the lack of standards has resulted in a patchwork of information systems that do not easily lend themselves to interoperability.

Beyond the specifics of data elements, any strategy for data sharing must include a process for accurately matching client records and ensuring privacy and security. Client matching is a non-trivial challenge. Even with data standards, clients may have changing names and spellings, and lack reliable identifiers (e.g., Social Security Numbers, FEMA case numbers). Security of client information is a concern: A complex web of state and Federal laws govern the privacy protection of personal and health data, as well as for protected populations such as youth, AIDS patients, domestic violence victims and substance abusers.

The challenges in human services data interoperability are similar to those currently being faced in healthcare in the United States. In healthcare, there are a multitude of organizations providing care, numerous vendors offering customized solutions, difficulties in matching clients across organizations, and concerns about security and privacy. In recent years, however, the healthcare field has made strides in improving interoperability (Brailer, 2006), demonstrating that the challenges to complex data sharing are surmountable. In contrast to traditionally under-resourced human services, Americans spend \$2 trillion annually for healthcare, representing 16 percent of the gross domestic product (National Coalition on Health Care, 2007). Healthcare simply has more money to spend on information technology. Additionally, the U.S. federal government has provided funding and visibility to interoperability in healthcare (Brailer, 2004).

The solution to the challenges of information sharing in human services must mirror the human services environment. Interorganizational response is benefited by distributed systems (Carley, 1992; Cohen, 1962; Comfort, 1994; Malone, 1987; Topper and Carley, 1999). Simply stated, human services is a distributed system that calls for a distributed, rather than centralized, information system.

EXISTING AND EMERGING DATA STANDARDS

In recent years, nationally recognized standards have introduced interoperability to several domains of human services (Figure 2). The AIRS/211 LA County Taxonomy of Human Services categorizes and names services. The AIRS XSD explicate programs (i.e., type of service available, location, hours of operation). The HUD HMIS XML documents client needs and service use (i.e., client demographics, intake information, needs assessment) for those clients served through homeless or homeless-related programs. The CAN XML will streamline client information sharing during disasters. In the following sections, each standard is described.

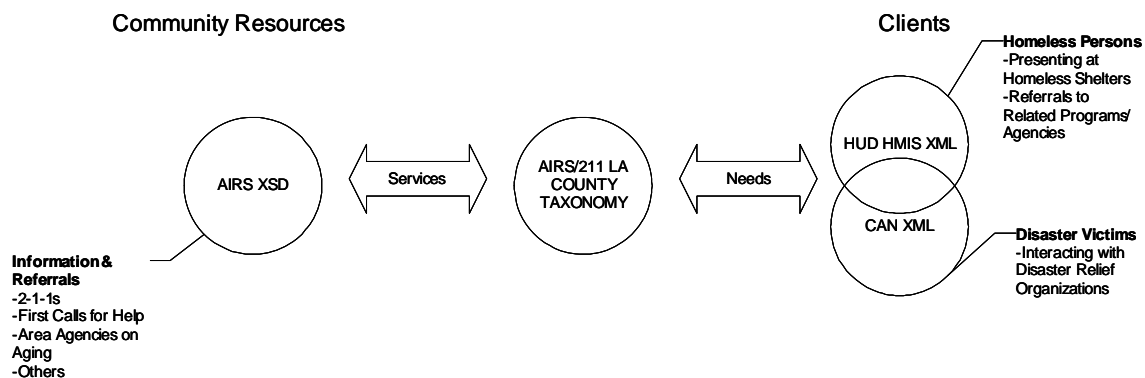


Figure 2. Human Services Standards Framework

Standardizing Human Services Definitions: The AIRS/211 LA County Taxonomy of Human Services

In human services same such as “*Counseling, counselling* (the correct spelling in Canada), *psychotherapy* and *therapy*...may all be used to describe essentially the same service. But *therapy* may not be specific enough to accurately pinpoint its meaning. In addition to being a synonym for ‘counseling’, *therapy* may refer to a variety of physical rehabilitation services. Similarly, *AIDS* (the health condition), *aids* (as in *mobility aids*) and *aides* (as in

classroom aides or home health aides) need to be distinguished” (AIRS/211 LA County, n.d., p. 1). Thus, a common language is needed to communicate clear information about services and needs.

In 1987, INFO LINE of Los Angeles (now 211 LA County) published *A Taxonomy Of Human Services: A Conceptual Framework with Standardized Terminology and Definitions for the Field*. Within several years more than 450 organizations throughout the United States and Canada had adopted the Taxonomy. Since then, the Taxonomy has grown and is now the most widely used classification system in North America for human services. In 1996, a Disaster Services taxonomy was developed through a joint AIRS/ National Emergency Resource Information Network project with substantial input from emergency management organizations (e.g., the American Red Cross, FEMA), and local organizations representing disaster social services, mental health, fire department, and health services (G. Sales, personal communication, December 5, 2007).

The Taxonomy contains more than 8,900 hierarchically arranged terms within an initial structure of 10 broad service categories and an eleventh target group, and up to six levels of increasing specificity. In Figure 3, for example, *Disaster Services* (TH) is one of a many services within **Organizational/Community/International Services (T)**. Within **Disaster Services (TH)** are multiple third level categories, denoted by the “TH” and followed by a hyphen and four digits. Within each successive category, the terms become more precise and in this example culminate in a fifth level term, **TH-2900.6500-680 Disaster Rebuilding Assistance**.

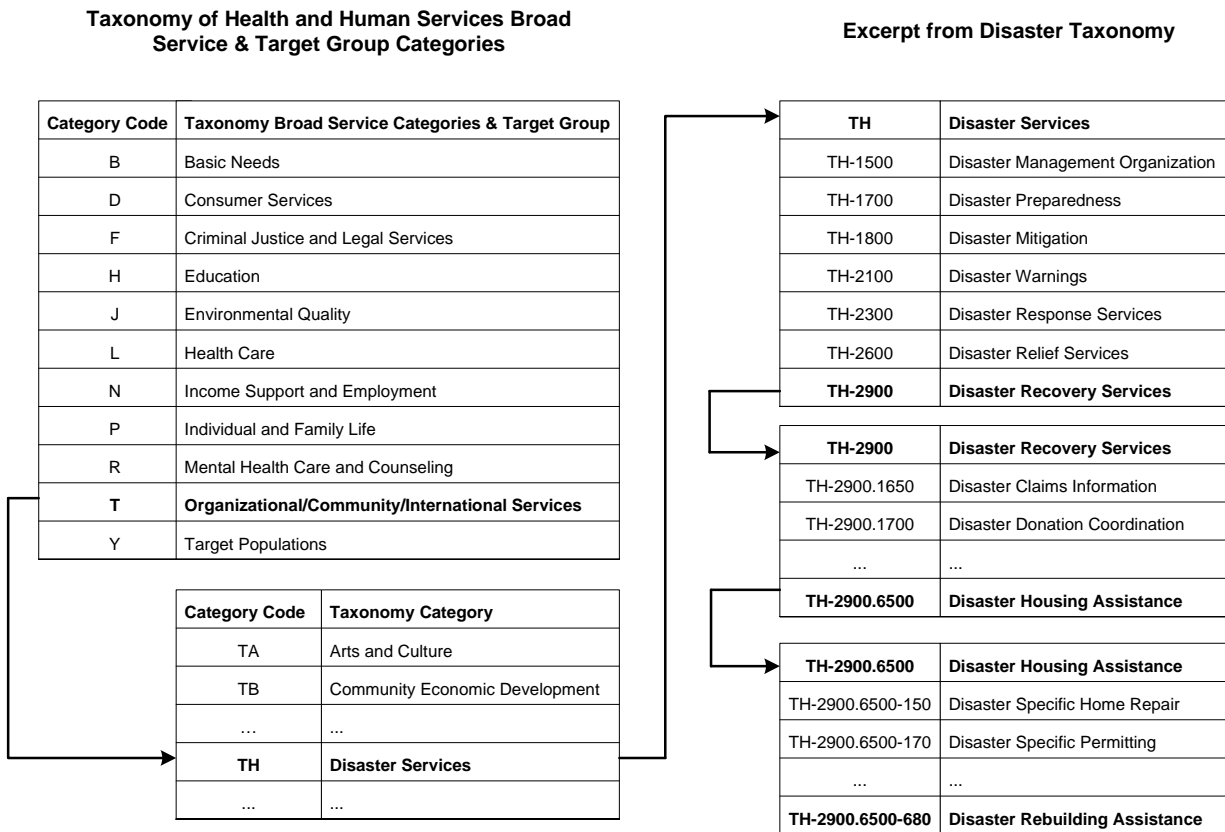


Figure 3. Disaster Taxonomy Excerpt from the Taxonomy of Human Services

Although the Taxonomy is widely used by human service organizations across the United States and Canada, it has sometimes faced criticism. Its comprehensiveness and frequent revisions, intended to keep pace with the field, have also made it difficult for non-specialists to grasp and use to its full potential. Other critics are concerned about the

taxonomy not being freely available. Despite its imperfections, the taxonomy has made great strides in imposing a theoretical order on the jumbled human services sector.

Standardization of Resource Information: AIRS XSD

Information and referral programs (I&Rs) help connect services to needs. To accomplish this goal, I&Rs maintain resource databases that contain information about services for specialized needs (e.g., aging population, respite services, child care, special education) or offer comprehensive information about a broad range of health and human services (e.g., 2-1-1¹ call centers). I&Rs maintain vital information about concrete aspects of services and programs, such as program names and addresses, hours of operation, eligibility requirements, and fees (Alliance of Information and Referral Systems, 2007a).

In a crisis, the need for information about community resources becomes more urgent. After September 11, 2001, Connecticut's 2-1-1 call center managed donor and volunteer information, received crisis calls, provided technical assistance to other agencies, and was able to quickly include resource information about newly-available services. After Hurricanes Katrina and Rita, Louisiana's 2-1-1 call centers became one of several "'go to' number[s] for evacuee support and services, for volunteers hoping to help, and for information about the storms. In many cases, 2-1-1 centers were the only source of information and support in an affected area" (United Way of America, n.d., p. 2). More recently, I&Rs have played a vital role in assisting people and communities, and in relieving pressure on the 911 system during the California wildfires of 2007 (see Graham, 2007; Phelps, 2007).

In April 2004, AIRS released its first national I&R data interoperability standards, named AIRS XSD 2.0. The standard was intended to address the real needs of communities, be workable for vendors who would use the standards in their proprietary products, and take advantage of sustainable, scalable, and logical computing sciences approaches. The first major revision to the standard, AIRS XSD 3.0, is expected in 2008. In this upcoming release, AIRS intends to create two distinct XSDs to cleanly distinguish structural elements from the elements that define the allowable content (i.e., picklists). This change is expected to provide flexibility in allowing for more regular content updates without altering the overall structure.

Standardization of Homeless Client Information: HUD HMIS XML

A homeless management information system (HMIS) is a data system that captures client and service information across multiple homeless shelters and related programs within a city, county, or other jurisdiction. Data entered about clients at one shelter are available to the case managers and staff at other shelters or service organizations. Predefined organizational networks adhering to local privacy and data sharing protocols ensures that sensitive client data are not shared inappropriately.

HMIS serves multiple purposes. On the individual homeless shelter level, it is a tool used to conduct client intakes and assessments, track bed availability, records services, conduct benefit eligibility screenings, and provide referrals. Reports or analyses generated from the data may be used to measure and report program outcomes. Local data are aggregated and reported to HUD, which compiles an Annual Homeless Assessment Report, first issued in 2007 (U.S. Department of Housing and Urban Development, 2007).

HMIS began receiving Federal funding in the mid-1990s for pilot programs to obtain unduplicated community-wide data on homeless populations across local jurisdictions (U.S. Department of Housing and Urban Development, 2004). As part of HUD's 2001 appropriation, Congress directed the Department to collect better homeless data through funding information systems (U.S. Department of Housing and Urban Development, 2004), and in 2004, HUD issued regulations (U.S. Department of Housing and Urban Development, 2004) describing the data to be captured in HMIS. Required data elements, known as *Universal Data Elements* (Table 1) include data that are necessary for identifying and matching clients and that are necessary for analysis of the characteristics of the homeless populations and their patterns of homeless service use. HUD defined both the field and, as appropriate, standard response values. HUD also standardized 17 other *Program-specific Data Elements* that are only applicable to a subset of programs (U.S. Department of Housing and Urban Development, 2004). HUD's data standards also included privacy and security requirements. The privacy rules govern client consent procedures, allowable disclosure, and the development of agency-specific privacy notices for data tagged as *Personal Protected*

¹ 2-1-1 is the three-digit dialing code assigned by the Federal Communications Commission for the exclusive purpose of providing widespread access to community information and referral services.

Information. The security requirements mandate authentication and minimal password standards, encryption of data while in transit, maintenance of firewalls and virus protection, secure data disposal, and other protections.

- Name
- Social Security Number
- Date of Birth
- Ethnicity and Race
- Gender
- Veteran Status
- Disabling Condition
- Residence Prior to Program Entry
- Zip Code of Last Permanent Address
- Program Entry Date
- Program Exit Date
- Unique Personal Identification Number
- Program Identification Number
- Household Identifier Number

Table 1: Universal HMIS Data Elements

The existence of HUD’s data standards made the translation of the HMIS data elements into an HMIS XML schema mainly a technical exercise of translating the regulatory mandate into a schema definition. The first version of HUD’s HMIS XML was released in January 2005 and has been significantly revised only once, in April 2006 (Sokol, Gutierrez & Jahn, 2006).

Standardization of Disaster Client Data: CAN XML

The Coordinated Assistance Network² (CAN) standards grew out of the terrorist attacks in the U.S. on September 11, 2001. The tragedy showed that making clients find their way through a web of service providers added confusion in an already trying time. To support major³ disasters, CAN created an electronic information portal consisting of a shelter module, resident module, resource module, and client registry database. Caseworkers use the secure, online database to track client and resource information provided by participating agencies. Caseworkers see the details of each client’s case and are better able to craft a comprehensive recovery plan. During 2003 and 2004, CAN’s portal was deployed during several disasters and in six communities (Washington, DC, New York City, New Orleans, Oklahoma City, San Francisco, and Seattle). CAN also deployed the portal in response to Hurricane Katrina. In the days immediately following Katrina, under the National Response Plan (U.S. Department of Homeland Security, 2004), CAN was tasked with implementation of the interagency technology portal through which shelter information was shared among responding agencies.

During Congressional Hearings, the U.S. Government Accountability Office stated: “While the [CAN] network databases are still largely in a pilot phase, both government and charity representatives have praised the potential of the network’s databases to improve collaboration.” The GAO went on to say “both government and charity

² The founding members of CAN are AIRS, the American Red Cross, National Voluntary Agencies Active in Disaster, the Salvation Army, United Way of America, Safe Horizon, and the 9/11 United Services Group.

³ CAN’s criteria for response includes: community request for assistance, a federal declaration, and approval from the CAN steering committee.

representatives...noted that [CAN] functioned well following the disasters, considering that it was not fully developed.” The GAO pointed to a perceived challenge facing the program when it stated, “the CAN case management system is still in its developmental stages and was therefore not ready to be activated on such a large scale and technological glitches had not been completely resolved” (Fangoni, 2005).

The portal required all agencies to use the same system, and abandon, for the disaster response, whatever products they typically used and in which all their data may be stored. Hurricane Katrina taught CAN that it needed greater interoperability with existing (e.g., local, state) community resources. Interoperability would yield better coordination during the response and in transition back to normative resources. Rather than replacing existing systems, or existing systems replacing CAN, interoperability could benefit the multiple systems. With the existence of client data exchange standards, agencies may use whichever system works best for them while simultaneously leveraging other information systems.

To this end, the American Red Cross began an effort (in process) to standardize client data collection and exchange standards among disaster relief organizations. A basic set of client data elements to support disaster recovery has been defined and a first draft of an XSD has been developed. In 2008 vendors will begin testing exports and imports. CAN has engaged HUD and AIRS representatives to ensure that it benefits from their experiences. CAN hopes that this standard will benefit the exchange of data in the midst of all disasters, not just those to which CAN responds.

HUMAN SERVICES STANDARDS AND DISASTER

The ubiquity of human services organizations make them an important resource during disasters. In many respects, the operational and reporting needs during disasters are similar to those faced by the human services community every day: services are developed and catalogued, client information is taken, services are coordinated, and gaps in services are addressed. The application of human services standards during “normal” operations create the relationships and infrastructure needed for information sharing during disasters. However, human services, too often, has fallen outside the disaster infrastructure. Many human services agencies are not prepared to fully engage in disaster response and recovery. They are unprepared to collect additional data, such as information required for obtaining disaster-related benefits and may overwhelmed in handling the volume of new clients that a large-scale disaster might require.

Despite these challenges, human services agencies may play a part in disasters, including in resource identification, mobilization, and client assistance. On the resources side, for example, the Taxonomy’s widespread adoption means that volunteer I&R specialists from outside the impacted community can be called upon. Having used the Taxonomy in their own communities, these volunteers are able to “speak the same language” as local communities who have adopted the Taxonomy. This can expedite accurate data collection and information dissemination (Shank, 2007; United Way of America, n.d.). I&Rs provide information but may also provide and obtain information about the extent of a disaster. For example, in Louisiana FEMA designated a 2-1-1 call center as the number residents should call to report property damage. Shank (2007) noted clients later benefited from the connection to the I&R “when further information became available from national disaster organizations about eligibility criteria, 2-1-1 called back those residents” (p. 27). Many I&Rs also regularly maintain volunteer and donation information which can be essential during disasters. All AIRS-accredited I&Rs, in fact, are required to comply with a number of disaster-related professional standards (see Alliance of Information and Referral Systems, 2007b).

On the client side, using HMIS for tracking persons homeless both *prior to* and *as a result of* disaster provides a better understanding of the impact of the disaster and may facilitates continuity of services as disaster programs conclude. To support disaster response, HMIS may be deployed in emergency shelters, administered by the local HMIS administrators and operated by trained end users “on loan” from local homeless shelters.

STANDARDS ACCEPTANCE AND ADOPTION

Both the I&R and HMIS markets encompass fewer than ten major software vendors each. Of these, several vendors have a presence in both domains. Moreover, in several places around the country, the HMIS and I&R functions are managed jointly by a single organization and through a single data system.

After the AIRS data standard was released, I&Rs across North America began considering vendor commitment to the standard when making purchasing decisions. By 2006, vendors began releasing commercially-available utilities through which their users could create AIRS XSD-compliant exports. This was a significant milestone to widespread information and referral data interoperability. There are now a number of statewide I&R collaboratives

using the standard to create comprehensive databases available through call centers and on websites, notably Texas (<https://www.211texas.org/211/>) and Nebraska (<http://www.ne211.org>).

In the HMIS sector, where a single vendor controls approximately 50% of the market, there were several early adopters, including the vendors with second and third highest market share, who were seeking to gain a competitive advantage and facilitate data migration to their systems. By mid-2007, several projects had begun using the HMIS XML schema, and the largest single HMIS vendor had adopted the standard. This bodes well for more rapid future adoption of the standard.

Vendor adoption has taken several years. Some vendors waited until client requests created a market for the upgraded product. The standard setting organizations have been reluctant to mandate the standards or certify software products generally. Vendors have been concerned that standards could change continually, making it financially and technologically difficult to stay current. To address this, HUD and AIRS committed to make major version releases no more frequently than annually. Vendor technical capacity has also been a barrier. To assist vendors, AIRS developed data mapping and validation tools and also worked individually with vendors. Technical capacity hindered HMIS XML adoption in a different way. Often the integration project consisted of an attempt to merge data from a single homeless service provider, typically using a Microsoft Access database, with an enterprise-level HMIS. The developers of the single-agency system were unable to convert their data to XML. In response to this problem, HUD released a parallel comma separated variable (CSV) standard in December 2006 (Sokol and Jahn, 2006). This standard contains all the same fields and options as the schema, simplifying the process of converting data back and forth between formats.

CAN, benefitting from AIRS and HUD's standards setting experiences, is applying such lessons as:

- Involving the vendors from the outset;
- Ensuring that standards focus on the structure and stable content;
- Developing a CSV standard;
- Creating a website to support vendors; and
- Using incentives to gain support from the vendors.

One final barrier to full-scale adoption may be the very existence of multiple standards. Although the standards relate to different types of data, vendors who cross markets have been reluctant to support multiple standards imposed by multiple organizations. Vendors may well be waiting for these standards to be tied more closely together.

OVERALL HUMAN SERVICES DATA STANDARD

There is an effort underway to standardize both client and services information under the umbrella of a human services (HS) data interoperability schema (HS XML). A HS XML would meet the needs of organizations wanting to share information beyond the confines of their particular human services domain. Since 2003, representatives from CAN, AIRS, I&Rs, HUD's homeless programs, as well as other practitioners and experts in data integration, have been participating in an informal working group (called the HS XML group) to solve the dilemma of data exchange among housing, homeless, information and referral, community resources, and disaster relief systems.

HS XML could take a number of shapes. It could be a single standard, incorporating the former standards into a new standard. It could be a standard that simply refers to versions of each standard. HS XML could also harmonize the overlapping sections of each standard, while leaving the details of specific domains to appropriate specialists. Whatever the form HS XML takes, it will require additional interorganizational communication between the current standards-setting organizations (i.e., 211 LA County, AIRS, HUD, and CAN). There has been progress. The standards have begun to reference the other standards, and will be harmonizing data element names and relationships in upcoming releases; however there is still no umbrella standard for integration of data across these various domains.

There are challenges. One challenge is funding to create and maintain the HS XML. Resources are needed to obtain user and vendor input, create the standard or interrelationships, work with vendors to adopt, make versioning changes, provide technological assistance, and manage a governance infrastructure. A second challenge is ensuring that users have the rights to use the standards. Currently, two standards, AIRS XSD and the HUD HMIS XML, are

publicly available. The intent for the CAN XML is to also be publicly available. The AIRS 211/LA County Taxonomy of Human Service, however, is privately held. A third challenge is educating the human services and disaster communities about the benefits of information sharing and obtaining support for the concept of a human services standard. Fourth, to represent the totality of human services, the participation of additional domains is needed. Finally, HS XML will have to bridge the government/non-governmental division to create a governance structure. The AIRS standardization effort was largely a community-based, grassroots effort. The HMIS standardization effort was an initiative spearheaded by the U.S. federal government. CAN began as a collaborative of not-for-profits. The diverse organizations that respond to human services require cooperation across these sectors, both in the standards development process and for the actual information exchange.

The desire for HS XML stems from the need for more effective, comprehensive, and accountable systems of care. The implementation will enable the human services sector to make the kinds of gains in productivity, efficiencies, and convenience that are expected in many other sectors. Widespread acceptance and adoption will result in better information and more effective service delivery across previously disjointed information silos.

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