IDS CASE STUDY: University of South Florida

Fulfilling a Statewide Need to Enhance Policy Analysis and Service Delivery

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FOR SOCIAL POLICY

John Petrila, who currently serves as the chair and professor in the University of South Florida's College of Public Health, first became interested in integrated data when he was working in New York. As a lawyer and state employee, he wanted to see if he could leverage his own expertise in forensic psychology and law to enhance health and human services programs and policies. Petrila believed that integrated data across these three domains could provide a better understanding of the challenges that the state faced and generate knowledge about the programs and policies necessary to enhance social service provisions and outcomes. When Petrila accepted his position at the University of South Florida, he wanted to use what he had learned in New York to create a university based statewide-integrated data system to promote policy-driven research and improve outcomes. Petrila hired Dr. Paul Stiles, a lawyer and a Ph.D. trained psychologist, to lead the development of the integrated data system. Petrila and Stiles negotiated access to the Medicaid claim files, and from there, they began to create the Policy and Services Research Data Center (PSRDC), an integrated database to enhance social services and policy outcomes.

Today, PSRDC resides within the University of South Florida's College of Behavioral and Community Sciences under the Department of Mental Health, Law, and Policy and consists of two distinct integrated data systems: the Statewide Data System and the Pinellas County Data Collaborative. Dr. Paul Stiles, who currently serves as an Associate Professor and Associate Chair of this department, oversees the operations of the PSRDC and Charles Dion, who currently acts as the director of PSRDC, manages its operations. In addition, PSRDC has several faculty affiliates that use PSRDC data in their research and administrators and data analysts that ensure a smooth transition from study proposals to final publications.

FIGURE 1. Contributing Agencies, Statewide Data System

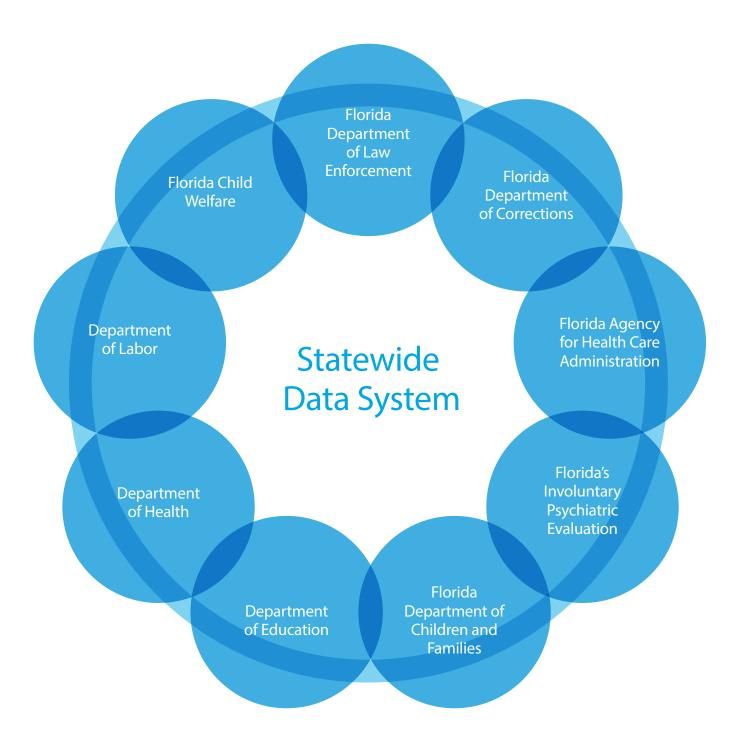
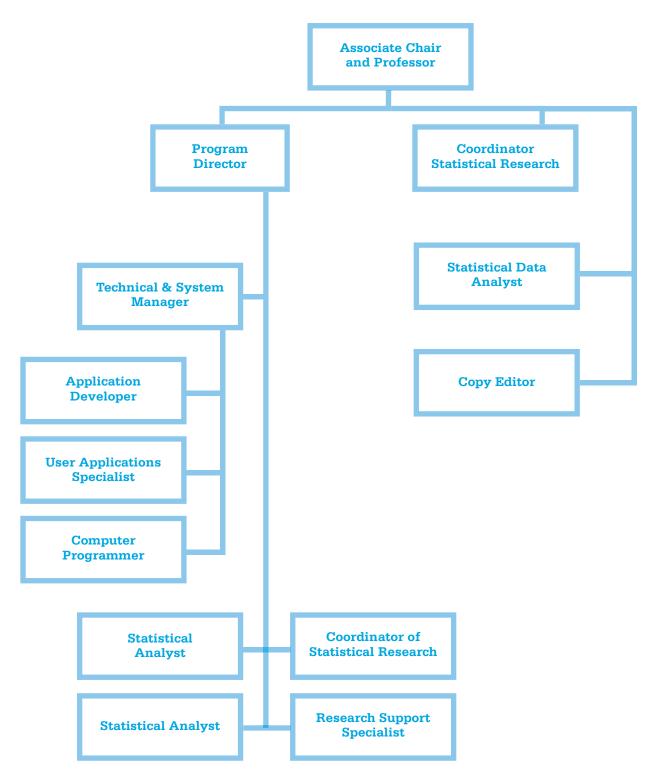


FIGURE 2. Contributing Agencies, Pinellas County Data Collaborative

Pinellas County Criminal Justice Information **System Pinellas Pinellas County Pinellas County Emergency Medical** Health and **County Data Human Services** Services Collaborative **Pinellas County** Juvenile Welfare Board

Integrated Data System Org Chart



During the site visit, I conducted semi-structured interviews with University of South Florida faculty and staff who work directly with PSRDC's integrated data system.¹ The interviews were based on an interview protocol developed with the University of Pennsylvania's Actionable Intelligence for Social Policy (AISP) team. Using standard qualitative methods, I coded these interviews for four themes—securing and maintaining legal agreements; establishing governance processes; data analytics management and processes; and economic and political realities to sustain operations—to understand the evolution and benefits of the University of South Florida integrated data system.

Securing and Maintaining Legal Agreements and Ethical Data Use

The University of South Florida's PSRDC has developed individualized memoranda of understanding (MOUs) with the various agencies who contribute data to the integrated data systems. According to Charles Dion the process for securing these MOUs depends largely on data use and practice, and as a result, is often established on a project-by-project basis. Usually, PSRDC staff work closely with the contributing agencies and principal investigators to draft a MOU that governs a particular project. To facilitate this process, PSRDC staff members provide an initial data use template, and then work with the agencies and the principal investigators to tailor the MOU for a particular project. Once they have drafted an MOU that meets the needs of the contributing agencies and the principal investigators, the PSRDC staff works closely with the university's legal team to ensure that the MOU complies with university policies as well as local, state, and federal laws, such as HIPAA and FERPA. Once the MOU has met the needs of the contributing agencies, the research personnel, and the legal team, the PSRDC staff members pass the MOU to the dean's office for his signature and approval (Interview, PSRDC Staff, March 26).

¹ For a complete list of interviewees, see Appendix A.

In addition to these individualized MOUs, the PSRDC has established long-term, broad contracts that govern data use and practice. Paul Stiles, Associate Professor and Associate Chair of the Department of Mental Health Law & Policy, notes that these MOUs outline the policies and procedures for housing and protecting the data in the warehouse. These MOUs evolved over time as the PSRDC staff developed trusting relationships with key personnel at each of the contributing agencies. Stiles compared these relationships to a marriage where each party understands its role in providing, protecting, and accessing the data. With these long-term relationships in place, Stiles notes that USF researchers "could go in a variety of different directions with new studies and then each year still maintain the data we already have" (Stiles, Interview, March 26). For example, the PSRDC has an agreement with the Department of Children and Families (DCF) that is more like a business associate agreement. Rather than proceeding through a complicated process, the PSRDC staff notifies DCF staff when they receive a research proposal. The PSRDC staff members provide the DCF personnel with a study title, the name(s) of research personnel involved in the study, and a short description of the study and its research questions. In most cases, DCF grants permission to begin the research as long as the PSRDC researchers agree to share results with the DCF staff before publishing their results. While this clearly streamlines the research process, PSRDC faculty and staff emphasized that these policies and procedures exist because they have developed trusting relationships with the various agencies over time and have proven that they are able to protect the data and guarantee that these data sharing and use agreements meet the established policies and procedures among the agencies that contribute data to the systems.

PSRDC faculty and staff also believe that these relationships have helped them address agency concerns about local, state, and federal laws. They firmly believe that the relationships they forged with state agencies over the past 20 years have enabled them to meet the demands of federal mandates, such as HIPAA, in a seamless manner. As one individual stated, HIPAA and other government mandates might have "become almost insurmountable barriers" without the trusting relationships and esteemed reputation the USF staff has developed with the agencies over the past two decades (PSRDC Staff, Interview, March 26). The relationships and reputation are directly

connected to the PSRDC staff's ability to maintain the security of the data and to ensure ethical data use and practice.

Like the other sites in the AISP network, the PSRDC has never had a data security breach, and thus, the agencies use the PSRDC data system as a data repository. Beyond the relationships and reputation, PSRDC researchers believe that their approach towards HIPPA and other local, state, and federal mandates promoted a seamless transition to meet the demands of this legislation. Charles Dion noted that the PSRDC team took a proactive rather than reactive stance. Dion's staff followed HIPAA from its inception, and as he suggests, his staff was aware of HIPAA's implications before it was mandatory. This awareness, Dion recalled, enabled the PSRDC to address the federal mandate as it developed rather than simply reacting to it once it had become law (Dion, Interview, March 26).

Leveraging the PSRDC's Organizational Structure to Support Policy-Driven Research

Whenever someone is interested in using the PSRDC's data, they must first provide Lisa Holcomb, who serves as PSRDC's Technology & Systems Manager, with a short description of the proposed study and data needs. Holcomb reads the proposal to assess whether it meets the aims and objectives of PSRDC and verifies that the necessary MOUs and other paperwork are up-to-date. Once she approves the proposal and confirms that the relevant data sharing and use agreements are in order, she passes it to PSRDC's data team. The data team consists of several data analysts who provide critical support to internal and external researchers as they move from a research proposal to a feasible project. Mary Rose Murrin, a data analyst, describes her role as the liaison between the principal investigator and the data warehouse. When a researcher has a proposal, he or she speaks with Murrin or another analyst about the study aims and data needs. Together, the data analyst and principal investigator assess the feasibility of the proposed research study and the potential for using PSRDC's data. As Murrin

suggests, the data analysts listen carefully to the principal investigators, and then, "look at it [the proposed study] in terms of the data" and explain to the researchers what the "data can and cannot do" (Murrin, Interview, March 26). Each PSRDC analyst is assigned to a particular part of the data warehouse—for example, Medicaid services—to streamline requests and to promote expertise in one dataset. If the analyst and principal investigator agree that the study is appropriate, the analyst conducts the statistical analyses on the data and provides these analyses to the principal investigator rather than providing the data to the principal investigator directly. Since only a handful of analysts actually access the data on regular basis, this approach ensures that the data are used in a secure and ethical manner.

The majority of PSRDC's research projects are tied to state contracts that faculty and staff have negotiated over a period of several years; however, faculty also use the data warehouse to conduct independent research. In either case, faculty members rely on the university's institutional review board (IRB) to secure permissions to use the data and publish research findings. In some cases, researchers must also secure permissions from the agencies that contribute data to the warehouse. Like other sites in the AISP network, PSRDC researchers give the agencies copies of publication drafts for review before they publish the results. Although the agencies do not have editorial rights on the publications, they have two weeks to provide feedback on the study findings. The PSRDC faculty affiliates follow a similar protocol with conference presentations. These policies and procedures are outlined in the permissions that the faculty have secured with the agencies as well as the standing MOUs that the PSRDC has with each of the agencies.

In addition to influencing the nature of moving a proposal to a publication, this organizational structure also affects the data cleaning, storing, and retrieval processes. Since the data are only used by a select group of individuals, PSRDC staff members rarely de-identify data unless there is a legal mandate, such as HIPAA, for doing so. Instead, they receive data from the contributing agencies, typically via file transfer protocol (FTP), and then store the data on the university's password-protected servers. The agencies send their data to the PSRDC on a daily, weekly, and monthly basis depending on what they have stipulated in their MOUs. The analysts conduct matches

on the data using specific fields including first name, last name, social security numbers, and Medicaid identification numbers. These procedures are documented in an analyst manual to ensure that everyone follows the same protocols for data matching. The analysts use a combination of custom made and SAS programs to conduct matches, and then use Link King software to clean the data (Holcomb, Interview, March 26).

Using the Integrated Data System to Enhance Policy and Programs: An Example of Best Practices

While the primary consumers of the PSRDC are University of South Florida researchers, external researchers often contact PSRDC staff to use the data system. In addition, USF researchers often work with external researchers to conduct studies with PSRDC data. For example, researchers affiliated with the Research Triangle Institute and North Carolina State University collaborated with University of South Florida PSRDC faculty and staff to conduct a study on the effects of outpatient treatment on the risk of arrest of adults with serious mental illness. Specifically, these researchers examined whether the possession of psychotropic medication and receipt of outpatient services reduced the likelihood of post-hospitalization arrests among adults with serious mental illnesses. The study also compared the service system costs for the individuals who were involved with the justice system and those who were not. Using Florida Medicaid data in the PSRDC, the research team identified an adult population with schizophrenia and bipolar disorder who had a hospital discharge in 2004 or 2005.

Then, researchers examined a variety of arrest outcomes—any arrest, felony arrest, and misdemeanor arrest—and whether outpatient treatment, including routine medications and outpatient interventions, affected the possibility of future arrests. The study found that high medication possession and receipt of routine outpatient services reduced the risk of arrest. Moreover, the study indicated that the individuals who were arrested after hospital discharge used a different, and more costly, mix of social services than those who were not arrested (Van Dorn, Desmarais, Petrila, Haynes, & Singh, 2013.)

Economic and Political Realities for Sustaining USF's Integrated Database

When USF faculty members founded the PSRDC, the dean of the school was intimately involved with the process and served as a principal investigator on several projects. This has changed over time, and the PSRDC staff members have had some difficulty publicizing their work. Despite these challenges, PSRDC is able to sustain itself through its long-term connections with state agencies and its streamlined infrastructure. Currently, PSRDC employs four full time analysts, two staff members who manage the development of applications, and a full time director. Beyond these individuals, the PSRDC consists of a few part-time employees and faculty affiliates who conduct the studies.

Like many of the other university sites in the AISP network, PSRDC researchers and analysts have experienced some tensions in negotiating the costs associated with this work. As one of the data analysts suggested, these tensions fall into two distinct categories. First, analysts often find that their time is often split between contract-driven work, which has set deadlines and deliverables, and research-driven work, which has more flexibility. This split sometimes makes it difficult for analysts to appropriate their time to meet the needs of each type of work. In addition to these challenges, the analysts routinely find that PSRDC faculty affiliates have difficulty estimating the costs of data analyses in their grant proposals.

However, even with these tensions, PSRDC remains a leader in the use of integrated data to enhance policy outcomes for residents throughout the state. When I asked the faculty affiliates and staff members how they have been able to sustain this work over the past two decades, several of them cited the relationships that they have cultivated with the various agencies that contribute data. As John Petrila said, the key to PSRDC's success stems from the organization's commitment to a "long-term process of negotiation" as well as demonstrating "from the beginning that you understand about keeping data secure." He continued stating, "I think it'd be impossible to go down this path without realizing how you have to stress that [negotiation and security] from the beginning as part of building the trust" (Petrila, Interview, March 26). Charles Dion built on Petrila's comments and stated that the trust that the PSRDC has built is

connected to its ability to offer state agencies the research that they need to improve their policies and programs. Dion pointed out that the contributing agencies are willing to give the PSRDC much more access to their data because they understand that PSRDC faculty and staff are helping the agencies integrate and examine data across a variety of sectors to enhance state programs and policies (Dion, Interview, March 26). The success and impact of PSRDC is directly tied to its ability to cultivate trusting relationships and its commitment to manage a secure, integrated data warehouse that provides these agencies with first-rate policy-driven research.

When I asked PSRDC faculty and staff what made them the most proud of their work, John Petrila quickly responded that he is proud that the PSRDC exists. When he began this work, very few people understood the benefits of an integrated data warehouse. Over the past several years, PSRDC faculty and staff have met with state agencies to explain the benefits of the data warehouse and to persuade them to provide data on a regular basis. This required careful negotiations and deliberate discussions about how the database could benefit the contributing agencies. Petrila and his colleagues believed that an integrated database, like the PSRDC, was an important resource for these agencies, but even today, they are amazed that they have been able to move from an idea to an integrated data warehouse, and perhaps more importantly, that they have been able to sustain it over the past two decades (Petrila, Interview, March 26).

About AISP

AISP is an initiative funded by the John D. and Catherine T. MacArthur Foundation through a grant to University of Pennsylvania Professors Dennis Culhane, School of Social Policy and Practice, and John Fantuzzo, Graduate School of Education. The principal aim of AISP is to improve the quality of education, health and human service agencies' policies and practices through the use of integrated data systems. Quality integrated data systems are designed to help executive leaders in municipal, county, and state government evaluate and establish effective programs for the people they serve.

Works Cited—Data Use and Practices

Van Dorn, R. A., Desmarais, S. L., Petrila, J., Haynes, D., & Singh, J. P. (2013). Effects of outpatient treatment on risk of arrest of adults with serious mental illness and associated costs. *Psychiatric services (Washington, D.C.)*, 64(9), 856–862.

List of Interviewees

Mary I. Armstrong

Associate Professor and Director Division of State and Local Support Department of Child and Family Studies

Timothy Boaz

Associate Professor

Department of Mental Health Law and Policy

Roger Boothroyd

Chair and Professor in the Department of Mental Health Law & Policy

Dave Chiriboga

Professor, Department of Child and Family Studies

Charles Dion

Director of the Policy and Services Research Data Center

Christina Guenther

Lisa Holcomb

Technology & Systems Manager

Department of Mental Health Law and Policy

Susan Jentz

Statistical Data Analyst Department of Mental Health Law and Policy

Brian Jim

Marie McPherson

Director of Operations, Pharmacy Program
Department of Mental Health Law and Policy

Mary Rose Murrin

Statistical Data Analyst Department of Mental Health Law and Policy

John Petrila

Chair and Professor College of Public Health

Lodi Rohrer

Social and Behavioral Researcher Department of Child and Family Studies

John Robst

Research Associate Professor Department of Mental Health Law and Policy and Department of Economics

Paul Stiles

Associate Professor and Associate Chair Department of Mental Health Law & Policy

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