IDS CASE STUDY:
South Carolina

The Circle of Love:
South Carolina's Integrated Data System

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ACTIONABLE INTELLIGENCE

FOR SOCIAL POLICY

❖ The Circle of Love: South Carolina's Integrated Data Warehouse

In the early 1970s, Governor John West hired Pete Bailey, an accomplished statistician, to develop a health statistics section to inform policy across the state. The Office was initially a sub-unit of the Governor's Office, but was eventually moved to the South Carolina Budget and Control Board, which is a multilateral organization that handles the higher functions of South Carolina state government. The governor, a separately elected controller general, a separately elected state treasurer, and finally, the chairmen of the House Ways and Means Committee and the Senate Finance Committee direct the Budget and Control Board. For years, the organization served as an advisory group to help answer research questions and guide state-level policy.

In the early 1990s, the organization received a grant from the Robert Wood Johnson Foundation to link patient/client data with administrative data to gain a deeper understanding of what was happening in the health care sector. This grant enabled staff from the Office of Research and Statistics to link these data with a new level of confidence. It also allowed them to demonstrate to agencies how outcomes of critical importance are actually measured in other agency data systems. In other words, these data linkages helped them show the agencies how their program outcomes were tied to program outcomes across other agencies. The grant gave ORS staff a reason to convene partners across a wide array of agencies and the resources to complete the initial demonstrations of the integrated data system (IDS). Dave Patterson, ORS section chief, suggests that these linkages "began part of the interagency process" (Patterson, interview, March 3). ORS currently consists of 36-38 full-time employees who work on a variety of integrated data projects to promote policy-driven research and analyses. The system collects data from over 20 state agencies and other organizations (see figure 1).
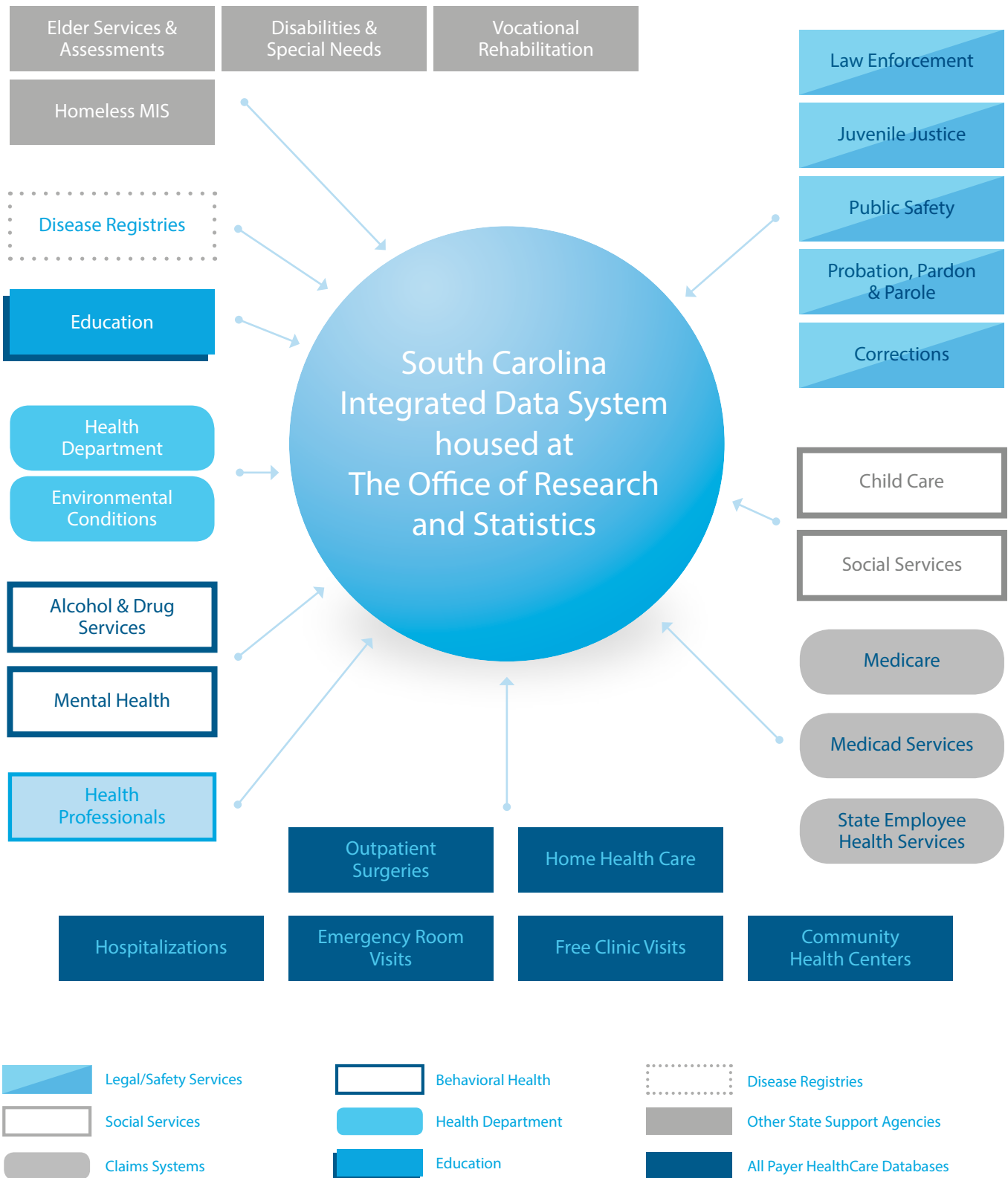
During the site visit, I conducted semi-structured interviews with ORS staff. The interviews were based on an interview protocol developed with the University

standard qualitative methods, I structured these interviews using four themes—securing and maintaining legal agreements, establishing governance processes, data analytics management and processes, and economic and political realities to sustain operations. The themes all helped to illuminate and better understand the policy evolution and benefits of South Carolina's IDS.

(see next page)

FIGURE 1.

South Carolina Integrated Data System housed at The Office of Research and Statistics

Elder Services & Assessments

Disabilities & Special Needs

Vocational Rehabilitation

Homeless MIS

Disease Registries

Education

Health Department

Environmental Conditions

Alcohol & Drug Services

Mental Health

Health Professionals

Law Enforcement

Juvenile Justice

Public Safety

Probation, Pardon & Parole

Corrections

Child Care

Social Services

Medicare

Medicad Services

State Employee Health Services

Outpatient Surgeries

Home Health Care

Hospitalizations

Emergency Room Visits

Free Clinic Visits

Community Health Centers

Legend:

Legal/Safety Services

Social Services

Claims Systems

Behavioral Health

Health Department

Education

Disease Registries

Other State Support Agencies

All Payer HealthCare Databases

of Pennsylvania's Actionable Intelligence for Social Policy (AISP) team. Using

❖ ORS Mechanics: Legal Issues and Data Analytics

ORS staff members are required to participate in FERPA and HIPAA training and to sign a confidentiality agreement to ensure that they understand the federal, state, and local laws that govern data use and practice. Staff members also complete web trainings to keep them up-to-date on any changes or modifications to these laws. In addition, ORS has a privacy handbook that addresses various state and local mandates for staff.

ORS has a clear process for cleaning and maintaining their data. ORS meets with staff members at each agency to determine how and when the agencies will transfer their data. These data transfer protocols are stipulated in each memorandum of understanding (MOU). In most cases, ORS relies on a secure file transfer protocol (FTP) to transfer the data to their servers, but they also use web servers and on-site data deposits. The data are linked using algorithms that ORS developed—weights are assigned to different variables based on their reliability. For the most part, ORS retains false positives in their data to preserve information. However, for health care data, they run a second linking system that is much less tolerant of false positive matches. As one data analyst suggested, this process often requires one to decide between retaining information or increasing positive linkages (ORS staff, interview, March 5).

ORS routinely works with data contributing agencies to ensure that the data they receive are accurate and complete. For example, ORS receives uniform billing data on a monthly basis from hospitals throughout the state. When they receive these data, ORS examines the data carefully to determine if there are problems with the data. One analyst remarked that they begin by looking for problematic or invalid social security numbers and relay any questions or concerns to the agency that contributed the data. After this, they send the data to an ORS staff member who encrypts and prepares these data for research use. First, ORS staff runs the data through a SAS program to clean the data. Then, they load the data into an SQL server to examine the data elements and begin the linkage process. Essentially, this process involves checking every record against ORS's statewide data set to link the uniform billing data to the existing statewide data. The program looks at each name and queries whether the names are

exactly the same, whether they are off by a few characters, whether they have a first name in a last name field or vice versa, etc. The program runs a similar process on social security numbers and birthdates to increase the match rates and identify any problematic data (ORS staff, interview, March 5).

❖ The Data Use Pipeline: Moving from a Research Proposal to a Final Study

Each agency maintains control of its data and mandates the process for data use. Some of the agencies have strict processes for reviewing and approving data use. Other agencies have established working protocols with South Carolina ORS. In these cases, ORS staff work closely with agency staff and discuss the project aims and data needs. If they are uncomfortable with any of this, they convey their concerns to the staff members and revise the proposal or, if no compromise can be reached, refuse to allow their data to be used in the project. When this happens, ORS staff members contact the external researcher or internal analyst to see if they might be willing to scale their work back or to use another data source.

Generally speaking, researchers contact the ORS staff member who oversees their research domain and discuss their ideas with these individuals. In some cases, researchers contact Dave Patterson or one of ORS's state partners. Patterson and/ or state partners then connect these researchers with the appropriate staff member so that he or she may review the research proposal and data needs. The first set of conversations focuses on the proposal's data needs—what agencies they would like to work with and what linkages need to occur. Patterson states that ORS analysts have developed a robust understanding of state-level data, and that they leverage their understanding of these data to make them useful to state agencies. Patterson says that ORS provides these agencies with another tool set—the IDS—to analyze their programs and enhance policy outcomes (Patterson, interview, March 4). Once they have approval from the appropriate state agencies, the researchers must secure permissions to use the

data. ORS requires external researchers to share their findings with them before they publish any results.

❖ Leveraging ORS Data to Impact Policy-Driven Research and Outcomes

Although ORS routinely partners with external researchers to conduct their work, they are also committed to devising innovative approaches to policy-driven work that enhances the program outcomes and policy initiatives within the state. For example, ORS has developed a web application for the ABC Child Care Program housed in the South Carolina Department of Social Services. ORS sends representatives to visit each of the licensed childcare centers in South Carolina to conduct quality reviews and safety assessments. The representatives document their findings in an ORS-created application that they have on their state-issued tablets. Since many of these facilities are located in rural parts of the state with limited internet access, the application saves the reviews and automatically uploads them to an ORS server when the representatives have a secure internet connection (Laura Kelley, interview, March 5). When the reviews are completed, ORS staff link these data to administrative data on supplementary childcare voucher payments. The state created a voucher reimbursement scale based on the quality of the childcare center and relies on ORS to evaluate the quality of these childcare programs to ensure that their reimbursement scale matches the actual quality of these programs (Patterson, interview, March 5).

ORS is also engaged in an innovative project with the Department of Health and Human Services community and long-term care division. This division provides a series of waivers to Medicaid participants that enables them to receive medical services and supports to keep them in their homes and communities rather than placing them in a skilled nursing facility. Laura Kelley explains that this program is particularly important for the state's rural population who often live far from regional hospitals or qualified nursing facilities. Like the ABC Child Care Program, ORS found many of the Medicaid

recipients lived in rural areas of the state that lacked decent internet connections, and thus, they had develop a program that worked both on and offline. The Medicaid caseworker enters the client's name and date of birth, which brings up a dashboard with basic information about that individual. The dashboard shows the different waiver programs that the individual is participating in or applying to as well as basic demographic information about the individual. The caseworker assesses the individual and documents any changes in their medical providers or needs (e.g., Have they fallen? Have they visited the emergency room? Have they been admitted to the hospital?). The caseworker also evaluates the individual's ability to continue daily activities (e.g., Can they walk on their own? Can they bath themselves? Can they monitor and pay their own bills? Can they administer their own medication?).

The caseworker answers these questions on the application, and the system then uses a formula to determine the level of care and support for this individual. This program is fed into a service plan that locates the service providers closest to the individual's home. The caseworker uses this information to schedule appointments and home visits to ensure that each client receives the level of care that they need. ORS also decided to make these data compatible with Geographic Information System (GIS) programs so that emergency medical teams and Medicaid caseworkers could easily find their clients' homes. This decision has spurred other research studies, such as ones that examine the distance between residential homes and emergency room and dental care. ORS has evaluated this program and found that patients who remain in their homes recover more quickly from their illnesses and save the state millions of dollars in unnecessary stays in skilled nursing facilities. Although the program has been praised for improving Medicaid bureaucracy and patient care, ORS is constantly looking for ways to enhance it. They meet with DHHS staff and application developers every other week to review what has been done, what changes have been made, and what needs to be improved in the future (Laura Kelley, interview, March 5).

❖ Sustaining Operations: Economic and Political Realities to ORS Data Use and Practice

ORS receives approximately 20% of its annual budget from state appropriations. Most of ORS's operational budget is funded through a variety of contracts, grants, and partnerships. For example, they have several agency contracts with the Department of Health and Human Services and the Department of Social Services. ORS does not charge a data usage fee since they do not own the data, but they do bill external researchers and state agencies for the data analysts' time. For large projects, ORS generally writes a fixed cost contract to cover the analysts' time and any other costs associated with this work (Sandra Kelly, interview, March 4). As a politically neutral entity, ORS sees its role as a service to the state. This neutral position helps them sustain their operations and develop continuity across various administrations and budgets.

Since its inception, ORS has proven that they are good data custodians to their data-sharing agencies. Dave Patterson said that Pete Bailey, the individual responsible for ORS's development and success, worked tirelessly to cultivate relationships built on trust and mutual respect with the state agencies that contributed their data. Patterson recalled that Pete was "very good at convincing people to take a chance on it [ORS] and that it was the right thing to do." After decades of working with these agencies, the staff still remembers that they are custodians of these data. As one staff member said, "we don't own any of the data…we house it, we maintain it, and we analyze it. But, we work at the discretion of the data owners" and remain transparent about how these data are stored and used. Patterson believes that these relationships are as important as the neutral position that ORS maintains. In his interview, he stated that ORS has worked tirelessly to maintain their relationships with agency staff across the changes that have occurred in the governor's office and budgetary cycles. Patterson points out that "you have to keep those lines of communication open, otherwise everything breaks down" (Patterson, interview, March 5).

ORS staff members are proud of the work that they do and are committed to providing first-rate service to improve the social service programs and policy outcomes within

the state of South Carolina. Dave Patterson noted that ORS is a highly recognized research organization both within the state and beyond its borders. He believes that this recognition is well deserved for two reasons. First, he has never seen a project that was too difficult for his staff to do. Second, ORS has never had a security breach of its data. As Patterson suggests, they have created a first-rate organization with very limited resources. Sarah Crawford, Research and Planning Administrator, believes that ORS's integrated data system brings agencies together to understand how social services are intertwined. For example, ORS conducted a study to examine the services that vulnerable youth use throughout the state. The findings suggested that these youth use a myriad of services and forced state agencies to recognize that their work with these youth is connected to other agencies that are engaged in similar work (Sarah Crawford, interview, March 4). Patterson and his staff stress that ORS is a service to the state that is crucial for understanding the challenges that South Carolina residents face and the solutions available to alleviate them. As he said, ORS aims to provide "continuous feedback between the research community and practitioners all using the same data" (Patterson, interview, March 4).

ORS has received national recognition for its work—the organization was one of three Microsoft International Interoperability Finalists in 2008. In 2010, ORS received an award from the Ash Center for Democratic Governance and Innovation at the John F. Kennedy School of Government, Harvard University, for innovations in governance. While these awards validate the work that ORS is engaged in, Patterson notes that this recognition does not drive their work. Rather, he believes that the conversations that he and other ORS staff members have with state agencies and policy researchers who are pleased with the level of effort, the data expertise, and devotion of ORS staff to improving program and policy outcomes throughout the state is what really motivates the organization. For the past four decades, ORS has set the standard for this work and enhanced the program delivery and policy outcomes for residents throughout the state.

❖ 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.

❖ Recommended Citation

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