

IDS CASE STUDY: Washington State

Washington State's Integrated Client
Data Base and Analytic Capacity

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The Department of Social and Health Services Research and Data Analysis Division (RDA) developed and maintains Washington State’s integrated client data base (ICDB). RDA provides the Department with a central research capacity that produces rigorous, policy-driven analyses of government-funded social and health services in the State of Washington. The division’s work offers state officials and taxpayers information necessary to enhance their understanding of the need for, cost of, and outcomes from the social and health services that DSHS provides throughout the state. These services include: economic assistance, food assistance, child support services, long-term care, child protective services, foster care, adoptions support, mental health treatment, drug and alcohol treatment, child care, supports for persons with disabilities, refugee services, vocational rehabilitation services, and institutional and community services for juvenile offenders. RDA’s integrated client data base makes them uniquely positioned to conduct in-depth analysis of clients who use services from multiple DSHS programs. They are then able to make these de-identified data available to local, state, and federal agency managers, the Governor’s office, state legislators, and the general public. The division also houses the Human Research Review Board, which protects the privacy and confidentiality of clients and members of the general public who are subjects in any research project that falls under the jurisdiction of DSHS or the Department of Health (DOH).

❖ **Creating a Statewide Integrated Client Data Base (ICDB)**

Sharon Estee, who serves as a senior research manager with RDA, recalled that RDA’s integrated client database evolved from a needs assessment project that Rebecca Yette and Liz Kohlenberg conducted in the mid-1990s. Although some vital foundational database work had been done, Yette and Kohlenberg realized that the department did not have a single administrative dataset that identified the services that clients received. Each of the administrative databases that are now housed in the state’s ICDB evolved through a variety of legal and administrative needs across several state agencies. For example, federal requirements spurred the creation of DSHS’s Automatic Client

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Eligibility System (ACES). This system, which is one of many feeding the state’s ICDB, contains information about TANF (Temporary Assistance for Needy Families) clients, and other federal programs that support low-income families in the state. ACES, like all of the data systems feeding the ICDB, has its own unique protocols for data privacy, security, sharing, and use that meet federal and state laws and guidelines. Over the years, RDA staff have developed data sharing agreements that outline data sharing policies for each of the agencies that contribute data to the state ICDB (Estee, interview, April 11).

Ron Jemelka, who served as the director of RDA when these interviews were conducted, notes that the state agencies are “particularly sensitive about the kind of data that goes out on their clients” (Jemelka, interview, April 11). Rather than having a standard template and procedure, RDA staff members respond to the agency’s sensitivity by drafting individual data use agreements for each project. In some cases, amendments to existing data use agreements suffice. While this process may differ depending on the project’s research needs, each data use agreement describes who may access the data, what they may do with the data, and what protections are in place to guarantee client confidentiality and data security.

❖ **Transferring, Cleaning, and Linking the Data**

Within RDA, staff members have different levels of permission for accessing the data. Only a handful of individuals who transfer, clean, and store data also have access to all the data. Like other AISP Network sites, RDA staff members have secure passwords for accessing the data and can only use these passwords on site. Rebecca Yette, Chief for the Office of Data Analysis, notes that RDA pulls data from a variety of agencies and departments housed

within DSHS. Usually, the data are transferred using a secure file transfer protocol (FTP). Once the data have been transferred, the staff runs several checks to verify the validity of the data that they have received. The following are over-simplified examples: RDA staff run a query to determine how many people were born on a particular day or investigate a social security number that is repeated several times. If they find that a disproportionate number of people are born on a specific day or that too many people have the same social security number, it most likely means that someone has used it as a default value or there is some other issue. RDA runs many more and much more complex data queries and checks monthly. If data appears invalid, it is not included in the ICDB, until issues are resolved. Once data are cleaned, RDA staff begins their client identify resolution (“linkage”) process. When the data are linked, they are ready for research (Yette, interview, April 11).

Before anyone may begin a research study, internal and external researchers must submit an application to the Washington State Institutional Review Board (WSIRB). In accordance with Washington State laws, and consistent with federal regulations pertaining to institutions that may receive federal agency support for research, the WSIRB is an independent regulatory entity with responsibility for providing review, approval and oversight of research involving human subjects, including research involving identifiable client records held by a number of Washington State executive agencies. The WSIRB is supported by the Human Research Review Section (HRRS), an office within RDA. Two HRRS staff serve as WSIRB members; other WSIRB members are drawn from other Washington State agencies, local government entities, academic institutions and other research institutions in Washington State. In addition to helping to ensure conformance with mandated human subject protections, this arrangement facilitates communication among and between RDA and other researchers who may use Washington State agency client records for research. This includes implementing and overseeing data sharing agreements between individual Washington State agencies that hold client data and researchers; and WSIRB review, approval and oversight of research in accordance with state and federal law and agency policies.

After WSIRB approval of research involving the use of identifiable client records where client consent or authorization are not obtained, HRRS staff develop confidentiality

agreements that conform to applicable Washington State law and the WSIRB-approved protocol. After the members of the research team who will have access to identifiable client records have signed these agreements, Washington State administrators of the agencies from which such client records are proposed for research must agree to and sign these confidentiality agreements. This process helps to ensure that all signatories to the confidentiality agreements—the state agencies that hold and disclose the data and the researchers who use the data—comply with the applicable law, agency policies and the WSIRB-approved protocols that govern research use of client records. WSIRB members are appointed and serve in accordance with federal and state laws pertaining to research involving human subjects and identifiable client records (Estee, interview, April 11).

❖ **Setting Research Priorities for Integrated Client Data Use**

RDA sits within the central administration of a large umbrella agency consisting of most major social service programs in Washington State. RDA does not have a formal governance structure. Staff administering DSHS programs approve its research agenda. Ron Jemelka, the director of RDA at the time of the review, believes that this arrangement is vital to the innovative work that RDA does because it creates a direct line of communication between agency directors, senior administrators and RDA researchers. RDA’s research priorities are set both externally and internally. The division responds to research requests from the Governor’s office, the DSHS Secretary and Assistant Secretaries, and its internal DSHS agency partners, and from state agencies such as the Healthcare Authority, the Department of Health, and the Department of Corrections, among others (Jemelka, interview, April 11).

RDA also responds to external research requests. External researchers often contact RDA with research proposals requesting ICDB data. RDA defers to the state agency or agencies whose data the external researchers would need to use in order to decide if the research is pertinent to agency needs. Ron Jemelka says that RDA staff members “see

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their services as supporting the state agencies. If the administration or state agency wants to partner with an external researcher or university, then we [RDA] become willing partners” in the research (Jemelka, interview, April 11).

RDA responds to the needs of each of these entities after carefully assessing the resources that the division has, its ability to execute the proposals that it receives, and the resources that might be necessary to conduct the work. This governance structure and research agenda setting process streamlines and expedites RDA's capacity to conduct research that aims to enhance service delivery and policy outcomes across the state. RDA and its agency partners reserve the right to review and approve research that uses the integrated client database. In most cases, the agency outlines this procedure in their data use agreement, all subject to IRB review and approval.

Increasingly, RDA itself is the research entity that not only integrates the relevant data, but does the actual research and issues a variety of policy briefs, research studies, economic impact studies, surveys and program evaluation reports. When research is completed, RDA publishes their study findings on a public website so that others may learn about the work and understand its policy implications. In 2012, the website generated over 25,000 downloads of these reports (<http://publications.rda.dshs.wa.gov/>).

❖ Use of the Integrated Client Data Base (ICDB): Examples of Policy-Driven Practice

In April 2013, five counties—Spokane, Snohomish, Cowlitz, Whatcom, and Mason—implemented the Ending Family Homelessness (EFH) pilot program. This program provides rapid re-housing and other services to homeless families who are receiving Temporary Assistance for Needy Families (TANF). Through a collaborative effort with DSHS Community Services Offices, the Employment Security Department’s WorkSource offices, housing providers, and local homeless school liaisons, the pilot aims to move homeless TANF families into permanent housing immediately and for families to have sufficient income to support that housing within six months. Although data are not yet available to determine whether the program has achieved its goal, RDA conducted an initial analysis using integrated data from the following sources: the Homeless Management Information System (HMIS) used by local housing providers; the Automated Client Eligibility System (ACES) and eJAS used by TANF caseworkers; and the DSHS Integrated Client Data Base, which contains information and data from over 30 different data systems.

RDA’s report examined baseline risk information on TANF parents and children participating in EFH compared to other TANF clients in the balance of the state. Almost all participants entered the program from emergency shelters or places not meant for housing, such as cars or the street. EFH parents were more likely than other parents on TANF to face barriers to housing. RDA’s study found that:

1. During a six-month period from April to September 2013, the pilot counties served 277 individuals (97 households) who could be linked to DSHS records.
2. Relative to other TANF parents, EFH parents are more likely to face barriers to housing and employment such as family violence, substance use, mental illness, and involvement with the criminal justice system.
3. EFH parents also have some protective factors to build upon. They are receiving substance abuse treatment at relatively high rates, have slightly

higher education levels, and are less likely to have had children in foster care at baseline.

RDA reported these findings to the EFH sponsoring agencies to help them understand the characteristics of EFH participants, revisit their service delivery aims, and, ultimately, enhance policy outcomes across these pilot counties (Shah, Black, Felver, Albrecht, & Krull, 2014; available at <http://www.dshs.wa.gov/pdf/ms/rda/research/11/203.pdf>).

Several years ago, RDA explored the idea of developing integrated managed care for high-risk clients who were receiving SSI benefits. Mancuso, who currently serves as the Director of RDA, explained that these individuals often had serious medical conditions that overlapped with other service needs. For example, they may have needed support for functional limitations, have serious mental health needs, or substance use disorders. RDA was brought into the project planning phase to work with integrated data across medical, long-term care, mental health, and alcohol and drug services, to create a series of descriptive tables and short reports that described who these individuals were and an integrated view of their service utilization. Mancuso asserts that this task “by definition requires an integrated client data base. You can’t talk about the client experiences across these delivery systems, without integrating the data to map out their experiences and create a more unified view of risks and challenges that they have.” This is particularly important because, as Mancuso notes, the “patients who are in these multiple systems are generally our most expensive and have the most complex care needs” (Mancuso, interview, April 11).

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In addition to these benefits, the state of Washington has been able to leverage its integrated client data base to conduct cost-effective quasi-experimental longitudinal evaluations of its programs and policies. The data are organized in a way that permits RDA researchers to access information in a quick and cost-effective manner. Mancuso explains that the state’s integrated client data base allows researchers to “flexibly pull out information on large populations for descriptive purposes, or to focus on subsets who meet well-defined risk criteria that would make them relevant for a given program evaluation.” In essence, the integrated client data base provides Mancuso and his colleagues with the ability to match or sample patients with similar kinds of baseline risk profiles to those receiving a particular treatment or intervention (Mancuso, interview, April 11). Estee echoes what Mancuso said and asserts that RDA’s integrated client data base has allowed them to efficiently analyze the outcomes of the state’s government-funded social and health services. Using integrated data creates a much more efficient research design for timely analyses of state policies and programs. Estee believes that the efficiency and effectiveness of this approach has “saved the state a lot of money and improved a lot of lives” (Estee, interview, April 11).

❖ **Lessons Learned: Political and Economic Realities for Sustaining the Integrated Client Data Base**

When Yette and Kohlenberg began the development of RDA’s integrated client data base over 20 years ago, they could have never imagined the obstacles that they would encounter along the way or the questions that this data system has answered in the past two decades. Yette believes that their optimism helped RDA persevere against great odds. When she started this work, she “didn’t realize how many barriers there would be and how resistant people would be, or that people would just think it wasn’t possible and they didn’t want their staff to spend time even dealing with it.” In their first year, Yette and Kohlenberg met with over 200 people to discuss their ideas and garner support for data integration. State officials were reluctant to invest in an idea that might not work.

When they reflected on what they had learned, Kohlenberg and Yette said that executive support was critical to their work. In the mid-1990s, DSHS had to write a report that required integrated data across several agencies. The secretary used this report to push agencies to share their data with RDA staff members. Gradually the value of the data and resulting research capacity overcame the reluctance and key leadership champions emerged (Yette and Kohlenberg, interview, April 11).

They also recalled that agency staff members were leery about sharing their data with individuals they did not know. Yette recalled that the agencies were concerned about what RDA might do with their data, but they were also worried that “it would end up being used against them because it would be used by people who did not understand the data limitations.” RDA had to develop trusting relationships to convince program staff to share their data (Yette and Kohlenberg, interview, April 11). David Mancuso believes that it is critical for RDA staff, who often have a researcher orientation, to build effective relationships with agency staff, who often have a practitioner orientation. These relationships are critical to the success of RDA’s work and sustainability. RDA researchers often staff program initiatives from their inception, and can therefore, provide program staff with information necessary to make data-driven decisions. This assistance from the program or policy’s inception enhances the benefits that RDA staff and the state’s integrated client data base offers to state agencies (Mancuso, interview, April 11).

Mancuso describes RDA as a group of individuals “who are researchers and IT professionals who are fundamentally intellectually interested in the data that we compile and what it means, who really take joy in discovering what the data means and understanding the reality of the experiences of the people we serve.” Mancuso believes that RDA has an entrepreneurial approach to building agency capacity that sets it apart from other state agency organizations. He explains, “RDA’s success reflects the entrepreneurial accumulation of research capability that has created a critical mass of skilled and intellectually engaged staff who are interested in social and health policy” (Mancuso, interview, April 11). Jemelka notes that the demands on RDA have increased even though direct state funding has not kept pace. Only 1/3 of RDA’s budget comes directly from its funding formula allocation (Jemelka, interview, April 11). Together

with the trusting relationships that RDA has built with agency staff, its entrepreneurial spirit and research expertise is the foundation of RDA’s ability to sustain its work across administrations and challenging budget environments so that its staff can provide the State of Washington with policy-driven research to enhance service delivery and program outcomes.

❖ 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 Uses and Practices

Shah, M. F., Black, C., Felver, B. E. M., Albrecht, C., & Krull, L. (2014). *The Ending Family Homelessness Pilot: Rapid Re-Housing for TANF Families* (No. 11.203). Olympia, Washington.

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