

Integrated Data System Profiles for NNIP & IDS Session

Tuesday, May 16, 2017

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# New to IDS, Advocates, Funders or Providers of Technical Assistance

## Bernardo Espinosa, *Research Analyst,* The Data Center

**Contact:** 504-648-5110, bernardoe@datacenterresearch.org

**Please describe your role at your organization:** As part of a team, I produce high-quality technical publications and design and implement applied research projects, including expansion and implementation of new indicator creation, data updates, and new data analysis.

**How you are connected to the IDS Field?** We applied for a grant to develop an IDS in partnership with the City of New Orleans that focused on workforce development. The grant was not funded, but the idea is still on the table. Furthermore, our new Executive Director will start June 12th and he was previously the Chief Information Officer for the City of New Orleans Office of Information, Technology, and Innovation under the Mayor. Moving forward, we anticipate our organization will likely develop an IDS in partnership with the City in the next 18 months.

**What do you hope to learn from others at this session?** Operationally what is needed to design and implement an IDS along with examples that could be used as a guide.

## Lena Geraghty, *Senior Implementation Advisor,* Johns Hopkins University Center for Government Excellence

**Contact:** 518-788-7033, lenag@jhu.edu

**Please describe your role at your organization:** I actively work with local governments through Bloomberg Philanthropies’ What Works Cities initiative on data management, and performance and analytics projects, helping them make progress toward city goals by using data and evidence to better serve their communities and residents.

**How you are connected to the IDS Field?** I’m working with several cities that are considering IDS in their efforts to increase internal access to data, in particular around youth employment and downtown revitalization focus areas.

**What do you hope to learn from others at this session?**

* How others are structuring their procurements for IDS.
* Insight into privacy and security policies for IDS.
* How to best structure data for effective IDS use across multiple teams/divisions.
* How to use automation to maintain data well in IDS.

## Bob Gradeck, *Program Manager,* University of Pittsburgh Western Pennsylvania Regional Data Center

**Contact:** 412-624-9177, rmg44@pitt.edu

**Please describe your role at your organization:** Program manager

**How you are connected to the IDS Field?** We use data from and collaborate with the Allegheny County Department of Human Services.

**What do you hope to learn from others at this session?** I’d like to learn more about the inner workings of IDS systems, get ideas for future collaborations, and understand what I can do to be a better partner for our IDS.

## Cindy Guy, *VP for Research, Evaluation, Evidence and Data,* Annie E. Casey Foundation

**Contact:** 410-547-3673

**Please describe your role at your organization:** Supervise grant making related to research, evaluation, evidence based programs, implementation science, and supporting and expanding public data resources.

**How you are connected to the IDS Field?** I manage technical assistance and field building grants designed to support development and use of IDS.

**What do you hope to learn from others at this session?** Better understanding of the issues and processes of IDS development.

## Tomi Hiers, *Director- Baltimore Civic Site,* Annie E. Casey Foundation

**Contact:** 410.949.1978, thiers@aecf.org

**Please describe your role at your organization:** I help lead the foundation’s investments in Baltimore City, and have an interest in education, workforce development and organizational capacity building.

**How you are connected to the IDS Field?** Casey is a huge supporter of the development and implementation of IDS’, and is supporting the efforts launched by Baltimore’s Promise to create an IDS for Baltimore.

**What do you hope to learn from others at this session?** I want to understand the promising practices and critical lessons learned, in the field to help inform our work in Baltimore.

##

## Matthew J. Hill, *Executive Director*, Actionable Intelligence for Social Policy (AISP)

**Contact:** 610-203-2850, mjhill@upenn.edu

**Please describe your role at your organization:** Represent and support the development, use and innovation of Integrated Data Systems at the state and local level.

**How are you connected to the IDS field?** Actionable Intelligence for Social Policy is a network for 13 IDS across the United States. We are the lead agency that coordinates this network.

**What do you hope to learn from others at this session?** The key challenges and opportunities that other organizations face in IDS development.

## Carlise King, *Executive Director,* Early Childhood Data Collaborative*,* Child Trends

**Contact:** 240-223-9329, cking@childtrends.org

**Please describe your role at your organization:** Ms. King is the executive director of the Early Childhood Data Collaborative at Child Trends, which promotes policies and practices that support the development and use of coordinated early childhood data across departments of education, social services, and public health to guide policy. Carlise regularly convenes experts from states and national and technical assistance groups to communicate effective strategies for data integration and use of data to support policy.

**How you are connected to the IDS Field?** Ms. King directed the survey design, data collection, production and dissemination of the 2013 State of States’ Early Childhood Data Systems final report and 51 state-level profiles documenting the capacity of states to link child-level data across early care and education programs and linkages to K-12, social services, and health data.

**What do you hope to learn from others at this session?** I hope to learn about advances states have made using IDS data as well as challenges they may face.

## Christopher Kingsley, *Senior Consultant,* Annie E. Casey Foundation

**Contact:** (202) 870-7798

**Please describe your role at your organization:** I advise Cindy Guy on opportunities to support the development and use of integrated data systems.

**How you are connected to the IDS Field?** Approximately seven years as a policy advocate, technical assistance provider and consultant.

**What do you hope to learn from others at this session?** I hope to get a better sense of what new work organizations and communities are undertaking, and where additional resources and connections to existing expertise may be helpful.

## Susan Millea, Ph.D., *Community Systems Analyst and Population Health Analyst*, Children’s Optimal Health

**Contact :** Smillea@cohtx.org

**Please describe your role at your organization:** Community Systems Analyst and Population Health Analyst

**How you are connected to the IDS Field?** I have been working across sectors toward development of a local community IDS, integrating health, social service and education data. As community efforts are developing I am playing a role in discussions around design of consent management, infrastructure requirements and data governance. Currently our actively engaged cross-sector board is perceived as a key resource in successful development of a local IDS. I am an advocate for IDS and providing technical assistance on data sharing/data acquisition, and am participating in planning stages for local IDS.

**What do you hope to learn from others at this session?** I want to learn from and prevent the mistakes others have made. I am reading the materials on Actionable Intelligence. We are undergoing transition toward a true IDS and are in active discussions around stakeholder engagement, data governance and consent management. Our data infrastructure is undergoing changes. We are working on demonstration project design that extends the work of Children’s Optimal Health. We are working on innovation around person-centered control/consent management.

## Baron Rodriguez, *Director of Contractor Resources*, U.S. Department of Education’s Privacy Technical Assistance Center

**Contact:** 240.818.2773, baron.rodriguez@ed.gov

**Please describe your role at your organization:** I’m the senior subject matter expert on education data privacy for the technical assistance team. I oversee the staff and provide input and expertise on publications and training material. I assist organizations and attorneys with FERPA compliant MOU (data sharing) reviews and advice. I also oversee the SLDS technical assistance centers which are state data systems provided by federal grant dollars.

**How you are connected to the IDS Field?** Many of our state SLDS grantees and/or local school districts partner with community organizations to get maximum value out of the data they collect.

**What do you hope to learn from others at this session?** What the barriers, challenges, and successes are in building and maintaining IDS.

## Ji Won Shon, *Research Assistant*, Annie E. Casey Foundation

**Contact:** jshon@aecf.org

**Please describe your role at your organization:** Research Assistant, Research, Evaluation, Evidence and Data (REED) Unit

**How you are connected to the IDS Field?** I work for an organization that supports the development and use IDS in our investment areas. We connect grantees and partners to an existing IDS to strengthen programs and policies. We also work with national partners for building the field and advocacy.

**What do you hope to learn from others at this session?** I hope to learn about existing IDS efforts, as well as from partners who are at the beginning stages of developing an IDS.

## Noah Urban, *Senior Analyst/Project Lead*, Data Driven Detroit

**Contact:** (313) 296-1402; noah@datadrivendetroit.org

**Please describe your role at your organization:** I manage workflow and execution on all D3’s projects, and directly supervise most of the analytical team. I also handle most of the organization’s grant writing, scoping, and proposal development.

**How you are connected to the IDS Field?** D3 is currently engaged in supporting Hope Starts Here, a comprehensive initiative to reform the early childhood system in Detroit. Funded by the Kresge and Kellogg Foundations, the initiative is currently in its strategic planning phase. As the initiative evolves, there is a strong likelihood that we will be asked to build our capacity in the IDS field, including potentially implementing full-scale IDS in the future.

**What do you hope to learn from others at this session?** I’m hoping to absorb a lot of different perspectives and insights that I need to consider and/or represent while participating in conversations with local funders. I’m quite new to the IDS concept in general, so in particular, learning how organizations operate existing IDS’s and considerations to keep in mind when structuring them will be very helpful to us as the conversations in Detroit move forward.

## Dabne Whitemore, *Director of Finance and Development*, The Data Center

**Contact:** 504-701-7871, dabnew@datacenterresearch.org

**Please describe your role at your organization:** I directly oversee all aspects of finance, administration and fundraising for the organization.

**How you are connected to the IDS Field?** We applied for a grant to develop an IDS in partnership with the City of New Orleans that focused on workforce development. The grant was not funded, but the idea is still on the table. Furthermore, our new Executive Director will start June 12th and he was previously the Chief Information Officer for the City of New Orleans Office of Information, Technology, and Innovation under the Mayor. Moving forward, we anticipate our organization will likely develop an IDS in partnership with the City in the next 18 months.

**What do you hope to learn from others at this session?** Operationally what is needed to design and implement an IDS along with examples that could be used as a guide.

## Jie Wu, *Director of Research Management*, Kinder Institute for Urban Research at Rice University

**Contact:** jie.wu@rice.edu

**Please describe your role at your organization:** Managing Houston Community Data Connections (HCDC), Urban Disparity & Opportunity and Kinder Houston Area Survey programs; Coordinating research projects.

**How you are connected to the IDS Field?** I am new to IDS but hoping to learn more in order to contribute to discussions in my community. The Kinder Institute has been constructing the Urban Data Platform, and I serve on the oversight committee, hoping to inform the decision making with the knowledge learned from the NNIP network.

**What do you hope to learn from others at this session?** What I’d like to get out of the IDS pre-session is all the pros and cons and how to apply FERPA and HIPAA in the IDS context. The research community here is very concerned about privacy issues related to IDS and how results could be used in an unethical way. Housed in a research university, our legal department is very concerned about the liability incurred.

# Operators of an IDS or Actively Planning an IDS

## Meghan Atwell, *Senior Research Associate*, Case Western Reserve University – Center on Urban Poverty and Community Development

**Contact:** 216-268-1874, mas486@case.edu

**Please describe your role at your organization:** I conduct research and evaluate programs using data from our CHILD System. I work also more generally with the CHILD System, convening the Advisory Group, drafting governance and strategic documents and managing data use agreements with some of our data providers.

**Name of IDS:** Childhood Longitudinal Data (CHILD) System

**Lead Agency/ Org.:** CWRU – Center on Urban Poverty and Community Development

**Phase of operation:** Institutionalization

**Major data sources:** birth/death records, lead data, Medicaid, child welfare, early childhood, home visiting, K-12 education (13 school districts), juvenile justice or courts, local jail, TANF, SNAP, Homeless Management Information System, housing assistance

**Geographic coverage and location:** Countywide- Cuyahoga County, OH

**Primary purpose of IDS:** policy or program analysis, research or evaluation

**Governance Structure:** Strict data use agreements are executed between the Case Western Reserve University (Center on Urban Poverty and Community Development) and all data providers that explicitly state the expectations of confidentiality and security. Through the specifications in these agreements, the data providers govern the use of their data.

The CHILD Data system is also governed by the Institutional Review Board at Case Western Reserve University. The Institutional Review Board assures that all data with personally identifiable information (PII) are handled according to the highest standards for data security and protection. They also assure that research conducted using data from the CHILD Data System are in compliance with all federal protections of human subjects, including privacy and risk

Additionally, the CHILD Data System has an Advisory Group that meets on a quarterly basis to represent the collective interests of public agencies and the community. The group works to ensure that the CHILD Data System adequately meets collective and community expectations of excellent data stewardship along the lines of governance, communication and sustainability.

**How long has the IDS been in operation?** About 18 years

**How many staff or FTE work on the IDS?** About 15 people work with the system, but the work is intermittent. It probably amounts to about the equivalent of 2-3 full-time employees.

**Expertise related to IDS that you can share:** Data governance, negotiating for data, using IDS data in analysis

**What do you hope to learn from others at this session?** IDS Governance.

## Julia Baez, *Executive Director*, Baltimore’s Promise

**Contact:** 443.838.2568, julia@baltimorespromise.org

**Please describe your role at your organization:** I am the Executive Director of Baltimore’s Promise, a citywide collaborative, composed of public, business, higher education, nonprofit, and philanthropic leaders that serves as a catalyst for organizing efforts and resources around a shared community vision that all Baltimore City youth will travel a safe, healthy, and successful educational path from cradle to career. The mission of Baltimore ‘s Promise is to coordinate strategy, identify quality programs, support alignment activities, establish shared measures for meaningful results, build public will, and advance policy on behalf of Baltimore City’s youth. Baltimore’s Promise is overseeing the development of a citywide IDS to further this mission. I oversee the Baltimore’s Promise Staff (Senior Director of Programs and Director of Data Analysis) and our partnerships with other IDS stakeholders including the Baltimore Education Research Consortium and public agencies.

**Name of IDS:** Currently unnamed- “Baltimore IDS” or “IDS” is the working title.

**Lead Agency/ Org:** Baltimore’s Promise is the lead agency and has administrative, project management, and fundraising functions, but BERC will be maintaining the IDS, structuring MOUs, and doing data analysis.

**Phase of operation:** Collaboration and planning phase

**Major data sources:** Our goal is to eventually have all of the data sources listed below as a part of the IDS, but the **bolded** sets are what are currently planned/in process for Years 1 and 2 of the IDS:

**birth**/death records, health claims, Medicaid, SCHIP, EMS, child welfare, **early childhood, K-12 education, post-secondary education**, juvenile justice or courts, local jail or state corrections, law enforcement, UI wages, **workforce training**, TANF, SNAP, WIC, Homeless Management Information System, housing assistance.

**Geographic coverage and location:** Baltimore City, MD

**Primary purpose of IDS:** Primary: Research or Evaluation**;** Secondary: Policy or Program Analysis

**Governance Structure**

**Baltimore’s Promise** will provide administrative, staffing, project management, partner accountability, and fundraising capacity for the IDS. Though there have been existing data collaboratives and project-specific evaluations using integrated data sources (largely through BERC), this citywide IDS demonstration originated within Baltimore’s Promise and was funded through Baltimore’s Promise funding efforts. BP will also build on the reports produced by BERC and translate them into different and accessible formats (such as infographics, data visualizations, etc.)

**BERC** will be responsible for securing MOUs with public agencies and data collaboratives, building the technical architecture, housing and managing the data (and ensuring its security), ensuring IRB compliance, conducting analyses, and producing reports.

**Baltimore City Health Department** is a public agency partner with extensive experience in driving health outcomes through the use of integrated data, strong partners to aid in execution and use of such a system, a community with significant health disparities who can benefit from such efforts, and civic leaders who are embracing data-driven decision making across our municipality. BCHD is also the lead applicant for the Actionable Intelligence for Social Policy IDS learning community, which provides technical assistance for cities, localities, and jurisdictions seeking to build an IDS in their respective locations. They will also serve in an advisory role when building the technical infrastructure due to BCHD’s CIO’s experience and network in this area.

**BERC, via Johns Hopkins University** will provide legal counsel and support

**IDS Governance Board** is currently in planning stages but is envisioned to be comprised of Baltimore’s Promise, BERC, and any entity providing data into the IDS will be responsible for vetting research requests and proposals and approving them. They will be advised by 3 ad-hoc subcommittees: The Technical Team, which will think about requests’ implications on existing technical architecture; Research Committee, which will provide context for requests and identify links between requests and existing work and data projects in the city and nationally; and Participatory Research Groups, which will be comprised of individuals “close to the data” for particular requests that are approved (practitioners, target population, community leaders, etc.) to be updated on research and provide feedback and input on methodology, additional complementary research questions, and products most useful to community and practitioners.

**How long has the IDS been in operation?** The IDS does not exist yet, but the Baltimore’s Promise Board approved moving forward with this demonstration model in January of 2017 and we have been in fundraising and planning stages since then.

**How many staff or FTE work on the IDS?** There will be one full time staff person at BERC (Data Manager position) dedicated specifically to the IDS. At Baltimore’s Promise, the Executive Director, Senior Director, and Director of Data Analysis hold the IDS as a priority project within a larger workload. At BERC, the Executive Director and Senior Data Manager will hold the IDS as a priority project within a larger workload.

**Expertise related to IDS that you can share:** BERC already has existing experience in regards to securing MOUs, analyses of linked data sets, data governance and security, data management and integration, FERPA, HIPAA, and data privacy. They have done and currently do this at a smaller scale across separate projects involving many of the same data stakeholders we seek to involve in the IDS.

**What do you hope to learn from others at this session?** We are interested in learning about the successes and barriers of others attempting to do this work. Also, it is our understanding that our model is atypical as an IDS is typically housed within a public agency, an Executive office, or wholly within a University rather our model, which is a partnership between a non-profit entity and a research consortium across multiple universities. If there are lessons learned about atypical organizational structures (particularly structures similar to ours) we would be very interested to learn about that as well.

## Brian Bell, *Analytical Unit Supervisor, Privacy Officer*, Allegheny County Department of Human Services

**Contact:** 412-350-2887, brian.bell@alleghenycounty.us

**Please describe your role at your organization:** I supervise an analytical unit focusing on aging services within our Department of Human Services. I also serve as the Privacy Officer for Allegheny County.

**Name of IDS:** Allegheny County DHS Data Warehouse

**Lead Agency/ Org.:** Allegheny County Department of Human Services

**Phase of operation:** *Institutionalization phase*

**Major data sources:** birth records, health claims, Medicaid, mental health, drug and alcohol, child welfare, early childhood, K-12 education (partial jurisdictions), juvenile justice, local jail, TANF, SNAP, SSI, Homeless Management Information System, housing assistance, aging services, criminal justice re-entry services, medical assistance transportation, intellectual disability, medical examiner, 911 emergency call data

**Geographic coverage and location:** Countywide- Allegheny County, PA

**Primary purpose of IDS:** Currently multi-purpose - case management; policy or program analysis, research and evaluation (originally created to support program analysis and evaluation)

**Governance Structure:** Supported by privacy officer in research office, and advisory board.

**How long has the IDS been in operation?** Approximately18 years

**How many staff or FTE work on the IDS?** Supported by direct staff, consultants, and an IT contract with Deloitte Consulting for over 100+ staff

**Expertise related to IDS that you can share:** High level data security, staffing, data matching, data management and integration, HIPAA and data privacy, negotiating for data, using IDS data in analysis

**What do you hope to learn from others at this session?** Always looking for new approaches and ideas for IDS development and implementation

## Richard Clinch, *Director*, Jacob France Institute

**Contact:** 410-837-4729 – rclinch@ubalt.edu

**Please describe your role at your organization:** Director

**Name of IDS:** Jacob France Institute

**Lead Agency/ Org.:** Jacob France Institute

**Phase of operation:**

**Major data sources:**

**Geographic coverage and location:** Maryland

**Primary purpose of IDS:** research and evaluation

**Governance Structure:** University Led Model

**How long has the IDS been in operation?** 25 years

**How many staff or FTE work on the IDS?** 10

**Expertise related to IDS that you can share:** data management and integration, data privacy, negotiating for data, using IDS data in analysis

**What do you hope to learn from others at this session?**

## Faith Connolly, *Executive Director*, Baltimore Education Research Consortium (BERC)

**Contact:**410-516-4044, faith.connolly@baltimore-berc.org

**Please describe your role at your organization:** I operate a consortium that conducts applied research and has initiated a few data sharing collaboratives.

**Name of IDS:** Baltimore’s Promise Data Collaborative

**Lead Agency/ Org.:** (that hosts or maintains the IDS) BERC

**Phase of operation:** Collaboration and planning phase

**Major data sources:** birth/death records, child welfare, early childhood, K-12 education, post-secondary education, UI wages, workforce training

Will expand to include juvenile justice or courts, local jail or state corrections, law enforcement, TANF, SNAP, WIC, Homeless Management Information System, housing assistance

**Geographic coverage and location:** Baltimore City Maryland

**Primary purpose of IDS:** policy or program analysis as well as research or evaluation)

**Governance Structure:** Baltimore’s Promise Board as well as a separate Governing Board

**How long has the IDS been in operation?** We have been in discussions and planning for 6 months

**How many staff or FTE work on the IDS?** 2.5

**Expertise related to IDS that you can share:** Data governance, data security, data management and integration, FERPA, HIPAA and data privacy, negotiating for data, using IDS data in analysis, etc.

**What do you hope to learn from others at this session?** Challenges and success that others have experienced so we can learn and adapt.

## Kelly Davila, *Senior Research Analyst*, The Polis Center at Indiana University-Purdue University Indianapolis

**Contact:** 317-274-4510 davilak@iu.edu

**Please describe your role at your organization:** Assists in developing research and analyses for the Community Informatics and Health Geoinformatics divisions.

**Name of IDS:** Domestic Violence Network (DVN); United Way Data Integration Plan (UWDIP).

**Lead Agency/ Org.:** DVN: Domestic Violence Network and the Polis Center; UWDIP: United Way of Central Indiana and the Polis Center.

**Phase of operation:** DVN: Institutionalization Phase; UWDIP: Demonstration Phase.

**Major data sources:** DVN: Courts, law enforcement, advocacy agencies, 2-1-1; UWDIP: nonprofit agencies, early childhood education centers, state agencies of education and workforce development (in progress).

**Geographic coverage and location:** DVN: Marion County, Indiana; UWDIP: Central Indiana.

**Primary purpose of IDS:** DVN: To formulate a community-wide picture of domestic violence in incidents where the legal system is involved in Marion County; UWDIP: To determine the impact of nonprofit services on its community of clients in Central IN.

**Governance Structure:** Polis’ internal Data Security team (as assigned in data management plans); Polis’ internal Data Security Task Force; Polis’ external Data Security Taskforce; as well, feedback is received by the many agencies involved in these projects.

**How long has the IDS been in operation?** DVN: Approximately 4 years; UWDIP: 1.5 years.

**How many staff or FTE work on the IDS?** Currently - DVN: 6 staff, approximately 1 FTE; UWDIP: 3 staff and an intern, approximately 1.5 FTE.

**Expertise related to IDS that you can share:** I’m here to gain expertise.

**What do you hope to learn from others at this session?** Ideas for streamlining administrative tasks associated with IDS efforts (including, but not limited to, IRB, BAA, etc.); Intern/student/temp staff involvement in IDS; quality control and assurance methodologies; managing groups with competing interests or in-group politics.

## Janelle Gendrano, *Senior Director of Pro*grams, Baltimore’s Promise

**Contact:** 443.873.6012, janelle@baltimorespromise.org

**Please describe your role at your organization:** I am the deputy to the Executive Director and will be co-managing the development of an Integrated Data System in Baltimore City (along with our Director of Data Analysis in partnership with the Baltimore Education Research Consortium (BERC), public agencies, and non-profit collaboratives supplying data sets.

**Name of IDS:** Currently unnamed- “Baltimore IDS” or “IDS” is the working title.

**Lead Agency/ Org.:** Baltimore’s Promise is the lead agency and has administrative, project management, and fundraising functions, but BERC will be maintaining the IDS, structuring MOUs, and doing data analysis.

**Phase of operation:** Collaboration and planning phase

**Major data sources:** Our goal is to eventually have all of the data sources listed below as a part of the IDS, but the **bolded** sets are what are currently planned/in process for Years 1 and 2 of the IDS: **birth**/death records, health claims, Medicaid, SCHIP, EMS, child welfare, **early childhood, K-12 education, post-secondary education**, juvenile justice or courts, local jail or state corrections, law enforcement, UI wages, **workforce training**, TANF, SNAP, WIC, Homeless Management Information System, housing assistance.

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**Baltimore City Health Department** is a public agency partner with extensive experience in driving health outcomes through the use of integrated data, strong partners to aid in execution and use of such a system, a community with significant health disparities who can benefit from such efforts, and civic leaders who are embracing data-driven decision making across our municipality. BCHD is also the lead applicant for the Actionable Intelligence for Social Policy IDS learning community, which provides technical assistance for cities, localities, and jurisdictions seeking to build an IDS in their respective locations. They will also serve in an advisory role when building the technical infrastructure due to BCHD’s CIO’s experience and network in this area.

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**How many staff or FTE work on the IDS?** There will be one full time staff person at BERC (Data Manager position) dedicated specifically to the IDS. At Baltimore’s Promise, the Executive Director, Senior Director, and Director of Data Analysis hold the IDS as a priority project within a larger workload. At BERC, the Executive Director and Senior Data Manager will hold the IDS as a priority project within a larger workload.

**Expertise related to IDS that you can share:** BERC already has existing experience in regards to securing MOUs, analyses of linked data sets, data governance and security, data management and integration, FERPA, HIPAA, and data privacy. They have done and currently do this at a smaller scale across separate projects involving many of the same data stakeholders we seek to involve in the IDS.

**What do you hope to learn from others at this session?** We are interested in learning about the successes and barriers of others attempting to do this work. Also, it is our understanding that our model is atypical as an IDS is typically housed within a public agency, an Executive office, or wholly within a University rather our model, which is a partnership between a non-profit entity and a research consortium across multiple universities. If there are lessons learned about atypical organizational structures (particularly structures similar to ours) we would be very interested to learn about that as well.

## Amy Hawn Nelson, *Director*, Institute for Social Capital, UNC Charlotte

**Contact:** 704-687-1197, amy.hawn.nelson@uncc.edu

**Please describe your role at your organization:** Director (head data nerd, designer of many methodologies, professional meeting attender, generalist of many things human service oriented)

**Name of IDS:** Institute for Social Capital

**Lead Agency/ Org.:** UNC Charlotte/ISC Inc. (we are a university/non-profit hybrid)

**Phase of operation:** Established, institutionalization (steady funding, steady flow of projects, well established governance process)

**Major data sources:** 40+ data partners, government agencies and non-profits, including: Charlotte-Mecklenburg Schools, Dept. of Social Services, Meck County Community Support Services, Homeless Management Information Services, Meck County Sheriff’s office, etc.

**Geographic coverage and location:** Mainly Mecklenburg County, a few school systems outside of county

**Primary purpose of IDS:** No case management, good amount of everything else. Typically process around 20+ data license requests annually.

**Governance Structure:** We have an Executive Board, Data and Research Oversight Committee (DAROC), and Scholar’s Advisory Council (SAC). Executive Board manages staff and sets direction, DAROC manages Data License Request’s and approves dissemination of research, SAC guides research agenda and seeds projects.

**How long has the IDS been in operation?** In name, since 2004. We successfully integrated data for the first time in 2013.

**How many staff or FTE work on the IDS?** Complicated answer. 3 FTE’s, but 10+ people that support the IDS as part of their job responsibilities.

**Expertise related to IDS that you can share:** All of the above except the technical data management stuff. My content expertise is around education and housing.

**What do you hope to learn from others at this session?** Bright spots in your work locally, how you are managing the technical aspects of this work, exemplar research and how this research is shifting policy/practice and improving lives.

## Seema D. Iyer, *Associate Director*, Jacob France Institute

**Contact:** 410-837-5797

**Please describe your role at your organization:** Associate Director

**Name of IDS:**

**Lead Agency/ Org.:** Baltimore Neighborhood Indicators Alliance.

**Phase of operation:** Demonstration Phase

**Major data sources:** Weatherization, Education

**Geographic coverage and location:** Baltimore City

**Primary purpose of IDS:** Neighborhood Research

**Governance Structure:** Advisory committee

**How long has the IDS been in operation?**

**How many staff or FTE work on the IDS?** 4.5

**Expertise related to IDS that you can share:** [Connecting People and Place Demonstration Project](http://bniajfi.org/equity-in-weatherization-assistance-programs-using-integrated-data-systems-to-measure-household-access-to-housing-investments-social-safety-net-programs/)

**What do you hope to learn from others at this session?** How can Baltimore set up an IDS to benefit neighborhoods?

## Sharon Kandris, *Associate Director*, The Polis Center at Indiana University-Purdue University Indianapolis

**Contact:** 317-278-2944, skandris@iupui.edu

**Please describe your role at your organization:** Developing, supporting, and promoting the overall strategic direction of the center. Directing the division of community informatics, including our IDS projects.

**Name of IDS:** (1) Domestic Violence Network (DVN);(2) United Way Data Integration Plan (UWDIP))

**Lead Agency/ Org.:** The Polis Center hosts and maintains both systems: (1) For the DVN project, the Domestic Violence Network is the core partner; (2) For UWDIP, United Way of Central Indiana is the core partner.

**Phase of operation:** (1) DVN: Institutionalization Phase; (2) UWDIP: Demonstration Phase

**Major data sources:** (1) DVN: Courts, prosecutor, law enforcement, domestic violence shelter, domestic violence advocacy agencies, 2-1-1; (2) UWDIP: 90 nonprofit service providers, early childhood education centers, state agencies of education and workforce development (in progress).

**Geographic coverage and location:** (1) DVN: Marion County, Indiana; (2) UWDIP: Central Indiana

**Primary purpose of IDS:** (1) DVN: To formulate a community-wide picture of domestic violence in incidents where the legal system is involved in Marion County; (2) UWDIP: To determine the impact of nonprofit services on its community of clients in Central IN.

**Governance Structure:** We established an IU Data Privacy & Security Task Force of university officials, United Way, and Polis for this purpose. For the UWDIP, we have an advisory committee of executives and program staff from all agencies that are sharing data, United Way, and Polis, and as needed members of the data privacy and security task force attend. This committee focuses on how the data will be used and also informed the process of developing protocols by raising concerns from their boards and legal representatives around privacy and security issues. Polis also has an internal task force to ensure compliance of the policies and protocols by our staff, and IU will conduct a technology audit to ensure our technology infrastructure and our protocols are properly implemented.

**How long has the IDS been in operation?** (1) DVN: Approximately 4 years; (2) UWDIP: 1.5 years.

**How many staff or FTE work on the IDS?** (1) DVN: 6 staff, approximately 1 FTE; (2) UWDIP: currently 3 staff and an intern, approximately 1 FTE; in six months when we start full technology implementation we’ll have 8 staff working on it, approximately 1.5-2 FTE.

**Expertise related to IDS that you can share:** Data security and privacy; analysis with the data (for our domestic violence project.

**What do you hope to learn from others at this session?** Negotiating agreements with state agencies for identifiable data….Big issue: Has anyone been successful in negotiating identifiable student-level data access from your state Dept of Education? If yes, how did you overcome the legal issues around FERPA? Identifiable individual level data from state Dept of Workforce Development? (or….what alternatives did you come up with to gain access to those data – e.g., the state as the repository?); examples of what data providers are getting out of the IDS? Is anyone dealing with data from nonprofit human service providers – any pitfalls we should avoid in dealing with those data?

The only way we could get buy-in from the nonprofit agencies was to treat the UWDIP project as a research project and as such must consent clients through an informed consent process. This means we will not be collecting data on 100% of clients from the nonprofits. Has anyone dealt with a sample data in their analysis? Is anyone linking records without passing PII data; for example, can 2 entities implement an identical hashing method to generate unique IDS without sending the PII between each entity. Has anyone tried this? What is the risk?

## Kim Pierson, *Director*, DataSpark

**Contact:** 401-874-5067, kim\_pierson@uri.edu

**Please describe your role at your organization:** Director of DataSpark, which maintains and operates the state’s IDS.

**Name of IDS:** Rhode Island DataHUB (DataHUB)

**Lead Agency/ Org.:** DataSpark at URI

**Phase of operation:** Institutionalization (with initial stakeholder engagement, vision, mission, principles, MOUs, etc. as a result of our parent organization transition)

**Major data sources:** birth records, child welfare, K-12 education, post-secondary education, local arrests and state corrections, UI wages, workforce training, state voting history, RI state IDs and driver’s licenses

**Geographic coverage and location:** Everything is statewide (RI) with the exception of municipal arrest data (only covers Providence, Woonsocket, Pawtucket)

**Primary purpose of IDS:** Policy analysis, research, and audit/evaluation support

**Governance Structure:** Currently in development. Formerly there was an advisory council, but we intend to develop state-led governance body(ies) with responsibility over policies, compliance, research, data use, etc.

**How long has the IDS been in operation?** Since 2009 (when the collaboration and planning phase started)

**How many staff or FTE work on the IDS?** 8

**Expertise related to IDS that you can share:** Data integration, negotiating for data, using IDS data in analysis, etc.

**What do you hope to learn from others at this session?** Data governance, data security, data management, etc.

## Lisa Pittman, *Sr. Research & Evaluation Analyst*, The Children’s Trust, Miami, Florida

**Contact:** 305.571.5700 x529, lisa@thechildrenstrust.org

**Please describe your role at your organization:** Oversees community-level research, evaluation and needs assessment, and contributes to community initiatives requiring collaboration-building and cross-agency/cross-systems efforts

**Name of IDS:** Miami-Dade County Partnership for School Readiness and Early School Success (but have been discussing changing the name)

**Lead Agency/ Org.:** University of Miami

**Phase of operation:** Demonstration Phase

**Major data sources:** Presently focused on early childhood into K-12 education; actively discussing with new partners to include child welfare and homeless population data

**Geographic coverage and location:** Countywide – Miami-Dade County, FL

**Primary purpose of IDS:** Research & Evaluation and Policy & Program Analysis

**Governance Structure:** Our Governance Agreement identifies a Steering Committee with representation from each of the current five (5) parties to the data-sharing agreement which governs the shared collaborative information system. A Community Advisory Policy Group provides for bi-directional links between the research, practice and policy communities.

**How long has the IDS been in operation?** Our IDS was initiated through an Institute of Education Sciences researcher-practitioner grant in August 2014; however, the data-sharing agreement took two (2) years to develop and sign, so data started to be contributed only in September 2016.

**How many staff or FTE work on the IDS?** At this stage, about 0.5 FTE spread across 5 organizations contribute to the IDS work. Obtaining additional funding would enable us to hire dedicated staff to support, expand and maintain the IDS.

**Expertise related to IDS that you can share:** We are in total learning mode and don’t feel we have sufficient expertise in any relevant IDS-related topics with the exception of patience.

**What do you hope to learn from others at this session?** We must establish a more formal governance structure to grow our IDS from a grant-funded project that could easily sunset to a vital, well-established part of our policy and researcher-practitioner community.

## Rebecca Shearer, *Associate Professor*, Department of Psychology, Child Division, University of Miami, Florida

**Contact:** 305.284.8439, rshearer@miami.edu

**Please describe your role at your organization:** a child clinical and school psychologist, teaches classes, and engages in community-based research conducted in close collaboration with key contributors to children's development

**Name of IDS:** Miami-Dade County Partnership for School Readiness and Early School Success (but have been discussing changing the name)

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