Integrating Data to Improve Children’s Health and Well-Being: Lessons in Improvisation From Children’s Outcomes Project (COP) Teams

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Three centuries ago, the French playwright Voltaire observed that “the perfect is the enemy of the good.” The phrase often is invoked to suggest that while we await a perfect solution or system, we may miss opportunities to move forward with more pragmatic — albeit imperfect — workarounds.

In the arena of data about children’s health and well-being, the “perfect” is the ideal of an integrated data system that would consolidate multiple data points across various systems, including public health, physical and behavioral health, education, social services, and child welfare. Moreover, such an ideal system would not only consolidate and integrate these data, but would also make them accessible, meaningful and useful to providers and families alike.

Over the past decade, the advent of health information technology has made this ideal vision seem more attainable, yet a variety of challenges and obstacles have made progress elusive. Consistent data and technology standards across systems, organizational barriers, concerns about confidentiality, and a lack of resources to pilot and implement integrated systems are just a few of the persistent obstacles. This case study highlights some ways that Children’s Outcomes Project (COP) initiatives have circumvented these obstacles, finding ways to put “good-enough” data about children and families to good use, even when these data are far from perfect.
About the Children’s Outcomes Project

The Children’s Outcomes Project (COP) is a learning community funded by Nemours, The California Endowment and an anonymous donor. The learning community includes eight state- and community-based initiative teams and a group of national program and advocacy experts. Each team is pursuing strategies to promote integrated, multi-sector, place-based initiatives across the country — in Alameda and Orange counties, California; in Colorado, Connecticut, and Delaware; in Palm Beach County, Florida, and Evansville, Indiana; and in Montgomery County, Maryland.

In addition to establishing and sustaining a learning community to share knowledge, insights and ideas, COP goals include advancing innovative policies and practices at the community and state levels and working collaboratively to inform federal policy. This case study, based on interviews with COP team members in Orange County, Calif.; Connecticut; Palm Beach County, Fla.; Evansville, Ind.; and Montgomery County, Md., is one example of how COP community teams are sharing strategies with each other and with their community and state partners across the country.
Improving Imperfect Data —
Examples From COP Initiatives

How have COP teams worked around obstacles to integrated data systems concerning children’s health and well-being? Examples highlighted below include:

- building local capacity to make better use of a standard children’s health assessment form in Conn.;
- leveraging existing data, when available, and addressing information gaps, where needed, in Orange County, Calif.;
- connecting infancy to school with early student identifiers in Palm Beach County, Fla.;
- serving as a data warehouse in Evansville, Ind.; and
- implementing Quality Service Reviews (QSRs) to better understand how multiple systems are serving clients in Montgomery County, Md.

Form Reform: Building Capacity for Early Childhood Health Data and Planning in Connecticut

The Connecticut Department of Education requires completion of a two-part Early Childhood Health Assessment Record before Connecticut youngsters can enter a licensed early care and education program, whether it is a center, group or family care setting. (A similar form is required for entry into kindergarten and again in middle school and high school.) The first part of the early childhood form, completed by a parent or guardian, asks for basic information on the child — name and date of birth, health care provider and dentist, health insurance coverage, health history, medications, and any particular health or developmental concerns. The second part, completed by a health care provider, records the results of a physical exam, screenings (e.g., for vision, hearing, TB, dental concerns, lead, anemia), developmental assessments, immunizations, and chronic disease assessments (for asthma, allergies, diabetes and seizures).

Although the paper forms were completed, at least in part, they were never aggregated into any sort of database — and thus could not be used to track any overall trends or pinpoint areas to be addressed in communities, schools, or individual students and families. To address both the accuracy and completion rates of the individual forms as well as their broader usefulness, the Child Health and Development Institute of Connecticut (CHDI) collaborated with the William Caspar Graustein Memorial Fund to create a pilot project designed to build capacity for using the data from the assessment forms to inform early childhood planning.
Through a competitive application process, CHDI awarded capacity building and technical assistance grants to eight grantees, covering 11 communities. Each granteecommunity included at least two school-based and/or licensed early childhood education (ECE) programs. With support from the grants, teams from each community attended a series of learning sessions that coached team members on entering data from the two-part assessment forms into a database. Although each individual ECE program had access to data about the children in its care, the data that were aggregated and shared were de-identified to protect confidentiality.

Over 2,000 records were entered, but problems with the forms surfaced quickly. The forms had not been translated into Spanish, making them inaccessible to many families; even native English speakers found some of the questions and terminology confusing. Many forms were incomplete, and even those that were completed were difficult to enter and interpret (especially, as the data entry staff reported, the physicians’ handwriting on the paper forms). The lack of electronic health records made everything more laborious, including re-entering immunization records. HeadStart records, which rely on a different system, also had to be re-entered.

Despite these glitches, the pilot project has been a success. The problems with incomplete data, English-only forms, and laborious data entry have spurred efforts to translate the forms into Spanish and a push to make the forms electronic, possibly linking them to electronic health records and immunization registries. A second round of grants to the same communities is in the works to explore how the data can be used at both identified (i.e., within each ECE setting) and de-identified levels (for state and community-wide data-monitoring purposes), along with hopes of expanding to family child care settings as well.

CHDI also has engaged state policy groups and legislators on the issue by showing the potential of these data for tracking and understanding early childhood indicators across the state, if only they could be aggregated and integrated. For example, at the community level, one grantee identified previously unknown gaps in dental screening and used this information to pursue grant funding to address them. Similar trends could be uncovered for BMI, developmental concerns, asthma, health insurance coverage, access to medical homes and immunizations if the forms were more accurately used and aggregated.

If the forms themselves can be improved and more ECE settings and communities can see their usefulness, eventually CHDI hopes the Early Childhood Health Assessment Records will become much more than just another requirement parents and providers check off their lists in order to enroll a child in school.
Painting a Countywide Picture of Children’s Health in Orange County, California

In terms of population size, Orange County is larger than almost half of the nation’s states, yet advocates for children’s health in the county face a challenge familiar to their counterparts in diverse communities elsewhere: countywide data portray the county as doing very well across most indicators, but overlook the significant pockets of need in many Orange County communities. Unfortunately, data are not always available at a sub-community level (e.g., by city or census tract) to represent the significant needs and inequities across communities that contribute to an accurate countywide picture. Using aggregate countywide and even citywide data for grant writing and planning leads to Orange County not being competitive for funding opportunities and to developing service approaches that could be non-responsive to local community needs.

An additional challenge is that some data related to early childhood development are unavailable in a standardized manner either countywide or at sub-county levels. One such example is the seemingly straightforward question of how many of the county’s children have received some sort of developmental screening using a validated instrument (e.g., the Ages & Stages Questionnaire [ASQ] or Parents Evaluation of Developmental Status [PEDS]). One option for obtaining the data without implementing a countywide survey would be to look at existing data and test the feasibility of collecting data through other methods. With roughly a third of Orange County children enrolled in Medi-Cal (California’s Medicaid program), another third in Kaiser Permanente’s health plan, and another third in Blue Cross/Blue Shield, a robust dataset could be available based on what is already collected, if data were defined similarly.

In order to address the need for countywide data, the Children and Families Commission of Orange County works with community partners to develop the annual Conditions of Children in Orange County Report and Community Indicators Report, which publish existing data in order to provide important standardized data.
for county planning. These reports are well received and used by the community. Recently, local researchers reviewed data that were available at a level of sub-geography and created the *Healthy Places, Healthy People* report, which maps the differences of populations across the diverse county. In addition, the commission has recently prepared a *Children’s Health Policy Brief* that uses existing local data to create a baseline portrait in exploring various aspects of the Affordable Care Act and how changes in the health care systems could affect children’s health in Orange County. The report also recommends future data-sharing opportunities to address data gaps.

To address the need for more robust data, the commission has leveraged an American Recovery & Reinvestment Act grant received with the University of California, Irvine to build the health science research infrastructure for the university’s Institutional Clinical Translation Science Center. The commission worked with its partners in developing the Orange County Alliance for Community Health Research partnership (known as the Alliance) to promote discussion around health science research topics of interest, including streamlining data-collection processes and making the yield from various data projects and research studies more accessible.

In order to address the gulf that sometimes arises between the community-based organizations that provide services to children and families and the researchers who collect data about the impact of those services, the Alliance has created a central data repository and Web portal (www.healthieroc.org) that would be accessible and useful to both groups. The Web portal features workshops, research results, databases, tools and reports. In addition to its Web presence, the Alliance has also promoted face-to-face meetings between researchers and service providers to explore topics of mutual interest in more depth, identify resources useful to researchers and practitioners, and generally strengthen relationships and understanding between these perspectives that may have different approaches and priorities, but share a common purpose of improving outcomes for children and families.

Another example of the Alliance’s workaround data is a countywide planning group convened to address obesity prevention for young children, which recommended an approach for shared data from the Women, Infants, and Children (WIC) program. The Commission is helping fund a data-sharing initiative that involves the four WIC agencies in the county. The goal is to put formal Memoranda of Understanding (MOUs) in place that would allow the agencies to share data on childhood obesity, BMI and breastfeeding
— using existing data and systems to answer questions that apply to a broader population of children. Without such a data-sharing arrangement, each agency currently submits its data to the state of California, but the data cannot be released back to them to be aggregated across the agencies.

A similar Alliance project seeking to address an Orange County data gap is focused on sharing birth and child welfare data and using mapping software to highlight how geography and place matters to children’s health outcomes. The Alliance has developed an extended partnership with the Children’s Data Network, which is centered in neighboring Los Angeles County, to participate in their data mapping project.

Finally, in recent years, the commission and its partners have undertaken an ambitious project to collect population-level data on children’s vulnerability in all the county’s communities using the Early Development Index (EDI). The EDI provides a developmental census of children in kindergarten in five domains: physical health and well-being, social competence, emotional maturity, language and cognitive development, and communication skills and general knowledge. EDI data are presented using GIS mapping and show the percentage of children entering school who are developmentally vulnerable in each developmental domain and by geographic communities; community services and other assets; and other population-based indicators (e.g., parent education levels, parent-child reading at home, residential mobility, poverty level, etc.).

As noted above, a challenge in Orange County is the combination of pockets of poverty and significant areas of high vulnerability, alongside areas with very ready and resilient children. The EDI has positioned the commission and its partners to better understand the community needs and to target resources to those most in need. For example, a recent EDI report showed a cluster of unmet service needs that turned out to be a mobile home park — a park that had been invisible to service providers. Armed with the new and revealing information, community stakeholders plan to move and rotate staff closer to the park. This is just one example of how eliciting local and neighborhood-level data can reveal hidden needs and help programs be more responsive and targeted in their provision of services.

**Using Data to Support a System of Care in Palm Beach County, Florida**

When the Children’s Services Council (CSC) of Palm Beach County began operating in 1986, it was a fairly typical funding agency, supporting stand-alone programs across the county. Despite considerable and well-intentioned efforts, CSC and its partners were frustrated that the outcomes they sought for children and families — healthy births, reduced child abuse and neglect, and improved school readiness — never seemed to materialize. Gradually, CSC changed its focus to a more integrated system of care, with individual agencies aligned more intentionally and strategically
to achieve their common purpose. This is the network of services now known as Healthy Beginnings.

The Healthy Beginnings system of care approach required shifts in operations, infrastructure and outlook, as well as a different and more integrated data system. In order to operate as a single program dedicated to supporting children and families, agencies needed to be able to share access to client information so that services could be coordinated across agencies and systems. This, in turn, would help agencies become more responsive to the needs of children and families, improving their health and school readiness outcomes. In addition to providing services in a more coordinated and efficient way, CSC wanted its integrated data systems to support longitudinal research studies and evaluations, several of which were conducted by Chapin Hall researchers at the University of Chicago at the same time that CSC was redesigning its approaches and systems. They also wanted to avoid over-collecting data — becoming “data rich, but knowledge poor.”

Embedded in several broader data and service integration efforts was a very specific initiative: convincing new parents participating in the Healthy Beginnings program to obtain a student identifier for their newborns, so that CSC and researchers could more fully understand the returns on investing heavily in the first year of life. By tracking infants into their school years, could CSC connect the dots between the overlapping web of services represented by systems of care and improved school readiness and third-grade achievement outcomes, as well as reductions in child abuse and neglect? If no single agency or intervention could yield these results alone, what about the system as a whole?

Still a work in progress, the student identifier portion of the integrated data system was preceded by data-sharing agreements. The CSC has data-sharing agreements in place with the school district, Department of Children and Families (for child abuse and neglect data) and the Department of Health (for vital statistics including births, fetal deaths and infant deaths). These data-sharing agreements allow CSC to access client-identified data so that the agency can complete outcome studies and longitudinal analyses on the impact of its programs. CSC also funds a position with the school district to assist in the matching process, formulation of evaluation questions and conducting analyses that guide program development efforts.

Healthy Beginnings staff capture the data that will eventually be needed to generate a student identifier, even though the infant is years away from enrollment in school. The data are sent to the school district, where a staff member (paid for by CSC
to reduce burden on the school district) enters the data and generates a student identifier. CSC receives the information, prints a student ID card, and forwards it to the family or provider working with the family. Due to the lack of a unique identifier across all of the administrative datasets, matching is heavily dependent on names, birth dates, social security numbers (if that exists) and other demographic parameters. The student ID initiative was conceived as a way to increase the likelihood of matching across the school district’s dataset.

As the data needed to establish a student ID number for an infant is the same as when a child enters school, and the school district generates the actual ID number, it is expected that the same identifier would be generated at infancy or at time of school enrollment. Although not enough time has passed to confirm that the ID system will work for the first cohort of children (900 young children were enrolled as of 2010), Palm Beach County anticipates few duplicate records will be created even if the physical cards and identifiers are not with the children when their parents enroll them.

CSC conducted focus groups to identify potential concerns among parents. Parents have voiced few objections in terms of confidentiality, but do express some puzzlement about why their infant needs a student ID so far ahead of entering a classroom. Some parents also worried that their child might be labeled as a student needing services, giving a future teacher a potentially negative view of a child’s behavior or learning potential based on earlier need for services. However, staff are quick to reassure parents that teachers do not see individual service use patterns and cannot label a child as “at-risk” — nor can guidance counselors or principals. Only school registrars have access to the data; it does not reach the classroom. In addition, now that many children in Florida are enrolled in universal pre-kindergarten and obtain student identifiers through that earlier pathway, the process has become more routine and the data on individual students masked by the volume of how many younger children receive identifiers. A bigger hurdle appears to be the $9 cost that low-income parents must pay for an official copy of their child’s birth certificate, which is required by the school district to generate the student ID.

CSC leaders report that the data-sharing agreements with schools and across agencies have been key, along with training that conveys the importance of protecting families’ confidentiality. If staff members are well versed in how to protect their clients’ confidentiality, they are better able to build trust with families. As the handout for families puts it, in explaining why a parent should apply for a student ID number for his or her infant:

“You and your family are spending precious time receiving services that are intended to make a difference in your child’s life. With your help, we can see if these services are making a difference, what other services may be needed and how we can continue to make services better.”
Warehousing Data and Screening Access: The Evansville Vanderbergh School Corporation’s Approach

In classrooms and school districts across the country, school staff see how students’ struggles outside the classroom — with health, housing, poverty, nutrition and safety — affect learning and educational achievement. As a result, many school districts have developed strong partnerships with community organizations to coordinate wraparound services that support students and their families inside and outside the classroom. Anecdotally, school leaders and staff believe these programs support student learning — but demonstrating results and returns on investment with hard data has been a challenge.

As part of a broader investment in becoming as data-driven as possible, the Evansville Vanderbergh School Corporation contracted with a company to build a central data warehouse. The warehouse project is managed by the corporation’s Office for Performance, Assessment and Research, which also manages all major student assessments for the corporation and serves as a liaison to universities and other agencies researching ways to promote student learning and achievement. Working closely with other district offices and departments (including the Center for Family, School and Community Partnerships that is part of the COP), the Office for Performance, Assessment and Research helps screen research and data requests in a consistent, objective way that protects the schools, students, families and the research organizations seeking data.

As the data warehouse project took shape, each department in the school district made its own decisions about which data would be most relevant to house in the central data warehouse. If a community partner or research group wishes to access the data, the agency applies to the Office for Performance, Assessment and Research with a detailed proposal explaining how the data would be used. For example, a health provider or agency working on childhood obesity or another health issue might want to know whether its program is affecting student achievement in a measurable way, and could use data stored in the data warehouse to identify test scores for children who have participated in the program. A committee made up of school district representatives, community partners and researchers reviews each proposal just as an Institutional Review Board (IRB) would; research guidelines and a copy of the application form can be accessed from the Corporation’s website (http://www.evscschools.com/evsc-offices/office-performance-assessment-and-research/request-conduct-research).
Examples of data-sharing projects and studies include the state’s Prevention Research Center’s request to link student data on drug and alcohol use, which already has helped the district secure additional grant funding. Another involves a partnership between a youth-serving organization — Youth First — whose social workers are paid partly by Youth First and partly by the school district, but are Youth First employees. Guided by a data-sharing MOU and a parental release form, Youth First social workers can share specific data about a student’s grades, attendance and discipline history, to help understand how after-school and mentoring programs affect performance. Future plans include linking students’ early childhood experiences to kindergarten readiness screening and academic achievement milestones in first grade and beyond, providing more frequent data points than kindergarten and third grade. Data also are used to gauge progress for individual School Improvement Plans for schools within the district.

Obtaining parental releases can be time-consuming, but is crucial. Staff need to be aware of restrictions and protections, and should be able to communicate these clearly and respectfully to address any parental concerns. Making sure that all staff are trained in and comply with the confidentiality requirements dictated by the Family Educational Rights and Privacy Act (FERPA) and Health Insurance Portability and Accountability Act (HIPAA) is necessary to support the types of research projects made possible by the data warehouse approach, but it is also important for staff and administrators to understand how these protections actually work. Likewise, it is important for research and community partners to understand why schools are protective of students and data about them.

Investing in a data warehouse and in the staff and resources required to manage the data flow and screen data requests increases access to useful data that can serve multiple purposes: yielding insights that improve services for students and families, streamlining reporting for grants and evaluations, supporting planning for the future, and documenting the results of school and community partnerships, so that these can move from the anecdotal realm to a more persuasive, data-driven one.

How’s Our System Really Doing? Getting Better Answers in Montgomery County, Maryland

When child- and youth-serving agencies try to meet the needs of their most service-intensive clients, they quickly find that they must cross agencies and sectors — such as education, public health, mental health and child welfare. Crossing agency and sector boundaries makes it harder to coordinate services, but it also makes it harder to gauge whether services are truly making a difference to children and families.

The Montgomery County Department of Health and Human Services (DHHS) is working to integrate case practice for the approximately 30 percent of clients who receive multiple services. The objective is both prevention and intervention. Individuals and families first applying for services will have the opportunity to apply for a range of services to meet their specific needs. For clients already receiving multiple services,
collaboration between the multiple programs and disciplines on an as-needed basis is the cornerstone.

For the small percentage of clients with multiple, complex and difficult needs in which service providers and the client are struggling to reach desired outcomes, a collaborative approach using intensive team meetings with all involved service providers and the client is used where possible. In team case planning meetings, goals are established and assignments made for both providers and clients to complete actions toward meeting the case goals.

From both a system and client perspective, the objective of integrated case management is to provide adequate intervention and to prevent deeper client penetration into the system. The department has focused on the intensive level of integration and is now beginning to develop both the intake level and the less intensive levels of integration.

As part of a broader look at outcomes, Montgomery County DHHS began using a Quality Service Review (QSR) approach to examine results for agency clients engaged across multiple programs. Originally used in single programs such as child welfare, the multi-program, cross-agency use of QSR is unusual. (QSR is a proprietary set of tools developed by Human Systems and Outcomes, Inc. and customized for Montgomery County DHHS under a contract.)

QSR is intentionally very different from the types of performance reviews familiar to many frontline social service professionals. It relies on an in-depth case review method to get at the stories, contexts and factors that underlie results for individuals and families. Instead of the “gotcha,” compliance-oriented approach of many performance appraisals, it looks for opportunities for learning and system-wide improvement, providing these through immersion and feedback.

At the Montgomery County DHHS, the QSR process has started small, hitting some capacity constraints because of the intensive nature of the reviews. Still, even by reviewing a limited number of cases, the process has unearthed some hidden trends and patterns that affect multiple programs. Addressing these, staff believe, has improved case practice and effectiveness within the agency, and possibly yielded better outcomes for clients and families — although conclusions at this stage are very preliminary. Knowing whom to call (even within the department) for referrals and resources, establishing who is accountable for following up on referrals, closing information loops, broadening case practice perspectives to include long-range planning and not just crisis intervention alone — all of these have helped frontline and supervisory staff think more holistically about their clients, and about whether or not their services are truly meeting needs and leading to better long-term outcomes.
Because the process is so time-intensive, agency leaders are seeking ways to develop a more streamlined “QSR-lite” for specific, complex, multi-program involved cases that yields similar insights and changes in practice, especially in collaborative planning, goal-setting and action (by multiple program practitioners and the client). The team also wants to find ways to track client outcomes and how these are affected by changes in processes and practices, although this is a formidable challenge given the very different situations presented by the agency’s clients across domains such as education, housing, physical and emotional health, employment, and permanent connections.

The QSR process, while challenging, is just one facet of a broader agency exploration of how data can reveal more about the relationship between efforts and outcomes — and build better processes and teams along the way.

**Conclusion**

Even though technological advances have made the ideal of integrated, cross-sector data systems seem more attainable, the reality is that truly integrated systems are still not in place. When health and education data are available, they rarely follow children from birth into school systems, and a variety of real and perceived legal and procedural obstacles make meaningful data sharing difficult.

Despite these challenges, COP teams have found ways to make imperfect data better, more comprehensive and more useful. Investing in the capacity of early childhood staff to collect and share meaningful data; providing forums and mechanisms for researchers, service providers and community groups to interact and better understand each other’s needs; investing in a data warehouse that both protects and provides data across a community; and finding new ways to understand and capture client outcomes and staff roles — all of these are ways that COP teams use and improve the best available data, while continuing to hope for better systems in the future.

We hope the examples highlighted in this case study will help others inside and outside the COP learning community make better use of their own data, no matter how these data are currently collected, housed and shared.