Improving Outcomes through Data Sharing in Real Time and Over Time

The California Child Welfare Co-Investment Partnership is a collaboration of private and public organizations working to improve outcomes in the child welfare system. *in*sights is an ongoing publication of the Partnership that examines the links between data, policy, and outcomes for our state's most vulnerable children and families. This issue of *in*sights focuses on the potential for data sharing to improve outcomes for children in foster care.

For child welfare, and all of the systems that interact with children, youth, and families, there is a need to share *real time information* at both the individual and aggregate levels in order to identify, recognize, and support success. Systems also need data *over time* in order to design effective prevention and intervention programs.

In this issue, *in*sights will explore: Current Landscape • Examples • Benefits of Data • Moving Forward

A Tipping Point

"As the child welfare system has become more outcomes-focused the need to know more about children outside specific departments becomes more and more significant."
— Will Lightbourne, Director, California Department of Social Services

Over the last year, federal, state and local policymakers, practitioners, and researchers have worked to identify challenges, outline principles, and create processes to realize the vision of data sharing.

- The California Child Welfare Council[1] created a data sharing committee,[2] recognizing that children and families are more effectively served by an integrated system of care, and that data analysis is critical to inform policy decisions.

- Sharing information about children in foster care is an area of intense interest and study for the California Blue Ribbon Commission on Children in Foster Care,[3] which has issued several significant briefing papers addressing the legal barriers.

- On the legislative side, the Assembly Health and Human Services Committee held an informational hearing on May 14 on the topic of data sharing that provided valuable testimony from the state and county perspectives, as well as from foster youth, attorneys, advocates, foundations and the research community.[4]

- Most recently, the California Health and Human Services Agency, Office of Systems Integration convened a two-day California-based symposium, facilitated by the Stewards of Change[5], to discuss systems integration and interoperability issues that addressed the legal, cultural, and technical barriers to achieving the vision of data sharing and linkages to improve child welfare outcomes.

Adding momentum to the interest in data sharing are the requirements of implementing the California Fostering Connections to Success Act (AB 12),[6] the shifts in practice required under Katie A v. Bonta[7] to ensure mental health services and support for foster youth, educational data exchanges mandated by recent legislation, as well as provisions of the Affordable Care Act.

1   The California Child Welfare Council is an advisory body co-chaired by the secretary of the California Health and Human Services Agency and the designee of the Chief Justice of the California Supreme Court, with appointed members of state and county departments, nonprofit service providers, et al. http://www.chhs.ca.gov/INITIATIVES/CACHILDWELFARECOUNCIL/Pages/default.aspx
2   http://www.chhs.ca.gov/initiatives/CAChildWelfareCouncil/Pages/CommitteeInformation.aspx
3   http://www.courts.ca.gov/brc.htm
4   http://ahum.assembly.ca.gov/sites/ahum.assembly.ca.gov/files/hearings/BackgroundPaper051413.pdf
5   http://www.stewardsofchange.com
6   http://www.cafosteringconnections.org/
7   http://www.dhcs.ca.gov/Pages/KatieAImplementation.aspx

"We need the right information, in the right place, for the benefit of the children."
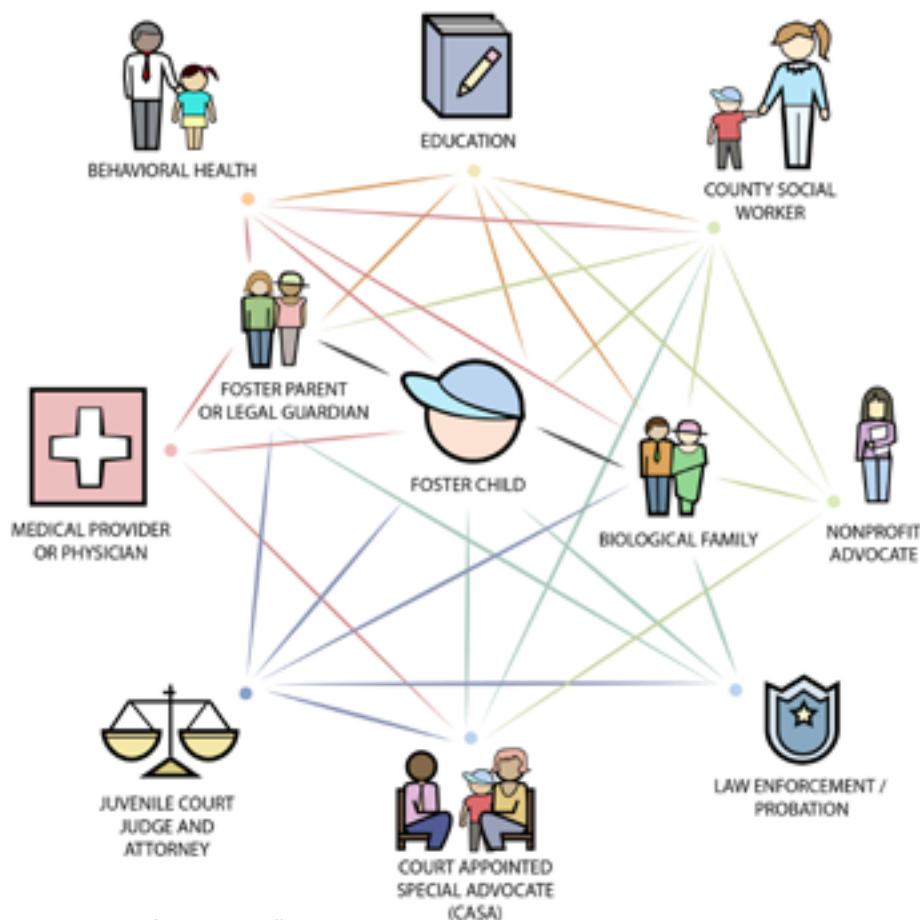— Mark Stone, California State Assembly member

"The technology exists. We must now overcome the legal and cultural challenges to data sharing."
— Barbara Needell, Principal Investigator/Research Specialist, California Child Welfare Indicators Project

Current Landscape

Children and youth in foster care represent a unique and important population that deserves an array of child-centered and family-focused services and supports, including health, education, and social services. It is an unfortunate reality that children in foster care face many more challenges and are often at greater risk than their peers. Instead of having a unified family unit with parents managing the numerous areas of their lives, there are often multiple individuals representing different agencies or organizations that are involved in the life of a child in foster care. Where possible and appropriate, these systems seek to involve the biological parents.

Guided by legitimate concerns for the privacy and confidentially of children and families, policy makers and administrators have created laws and regulations that make it difficult for individuals and agencies to share information. In addition, varying interpretations of these laws and regulations have resulted in a wide range of opinions regarding what information can and cannot be shared. Privacy concerns, technology issues, and the interpretation of laws and regulations are all challenges that need to be addressed to make data sharing a reality.

"From the perspective of youth, there is the fear of over-sharing or sharing misinformation."
— Jennifer Rodriguez, Executive Director, Youth Law Center

When the various groups involved are able to collaborate and appropriately share data, youth experience increased educational success and improved physical, emotional, and mental wellness. Conversely, the inability to share data brings stories of negative outcomes for foster youth.

"My caseworkers and schools failed to communicate with each other as I would transfer schools resulting in my not receiving credits to go on to the next grade." — Former foster youth R.J. Sloke wrote in the report "Hear Me Now".[8]

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8   "Hear Me Now," by R.J. Sloke, Congressional Coalition on Adoption Institute (CCAI). http://ccainstitute.org/images/stories/foster/fyi/final%20fyi%20report%20high%20resolution.pdf

Examples of Data Sharing

Progress is being made in California through a number of publicly and privately funded projects that show the promise of data sharing and linkages to improve outcomes for children and youth in foster care.

In Practice

The California Child Welfare Indicators Project (CCWIP)[9]

Challenge How to use data to track outcomes and performance in child welfare and link to other data sets to inform prevention and intervention strategies.

Solution The California Department of Social Services and the University of California at Berkeley created a publicly-accessible portal to store and share information on California's child welfare system, both at the county and state levels.

Additionally, private foundations, seeing great value in this data, have made investments to create demonstration data linkage projects. Through these projects, researchers have gained a better understanding of the children and youth involved with the child welfare system and are beginning to be able to answer important questions concerning maltreatment risk with implications for prevention.

For example, by linking birth records with child protective service (CPS) records, researchers have been able to document risks and identify those children in the overall population who are at greatest risk of reported and substantiated maltreatment before age 5. In a recently published article from this project, researchers found that while only 15 percent of all children born had three or more identified risk factors, this group made up 50 percent of children reported for maltreatment.[10]

Results Through this project, the general public, as well as the systems serving children in foster care have data to evaluate efforts, and policymakers are in a position to make more informed decisions. Through the data linkage demonstration projects, the value of integrated information spanning multiple data systems, and the new knowledge that can be generated, becomes increasingly clear.

What's Next The CCWIP website has recently been updated to make data even more accessible to interested parties.

Through ongoing collaborations and support from foundations and the research community, the project will continue to link with additional data sets. The inclusion of these data sets will enable the development of improved preventive measures, better decisions on legislation, and more focused research.

Foster Focus—Sacramento County Office of Education[11]

Challenge How to support children and youth in foster care to succeed in school.

Solution In 2000, Sacramento's County Office of Education partnered with local schools, mental health and probation departments, and child protective services to create Foster Focus, a database that links information from partner agencies with the goal of creating the best outcomes for children and youth in foster care. This password-protected online database tracks foster students' attendance, grades, courses and credits, placement and residential history, Individual Education Plans; and other education-related information. Data are available for practitioners to use in real time, from teachers to social workers to probation officers, to ensure a holistic understanding of foster youths' needs and circumstances. 2012-2013 school year users accessed Foster Focus records 145,000 times.

Results Today, Foster Focus is used by educators and social workers across California counties to track the services and outcomes for more than 12,000 foster youth in participating school districts.

What's Next More than 30,000 foster youth in California are now in a linked database system. Foster Focus will soon be extending to Los Angeles County and is currently looking to partner with more counties in California, as well as with other states. The database will soon include additional early warning capabilities that will alert social workers and foster youth education liaisons to potential grade or attendance problems.

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9   Collaborative venture between UC Berkeley and CA Dept. of Social Services. http://cssr.berkeley.edu/ucb_childwelfare/

10 Putnam-Hornstein E, Needell B. Predictors of child protective service contact between birth and age five: An examination of California's 2002 birth cohort. Children and Youth Services Review. 2011; 33(11):2400–2407. doi:10.1016/j.childyouth.2011.07.010.

11 Sacramento Countywide Foster Youth Services, Sacramento County Office of Education: http://www.scoe.net/fys/

In The Works

Social Services Integrated Reporting System (SSIRS)[12]

Challenge To better serve the children and families receiving services in Alameda County.

Solution In 2005, Alameda County began the process of creating an electronic, data warehouse –SSIRS– to engage the multiple agencies that interact with their children and families. The goal is that all families receiving public benefit/service through social services or probation be included in the database, which can be cross-referenced by the participating departments.

Intended Outcomes By collecting data on children and families from the moment they enter the system until after they leave, the county will be able to save money, improve efficiency, and provide more effective services for children and families.

Status This consolidated system has already saved the county money. The ambitious goal of migrating data from nearly a dozen different sources, from child welfare, to behavioral health services, to housing has brought to light a variety of technical challenges. Alameda County's technology experts continue to tackle these challenges and focus on bringing these tools to additional agencies.

Concepts

California State System Interoperability and Integration Project: Interoperability Proof of Concept for Psychotropic Medications[13]

Challenge To demonstrate options for electronic data sharing, the project is focused on the currently fragmented process for prescribing psychotropic medication for children and youth in foster care with mental health diagnoses.

Current Situation Children in foster care have a disproportionately high rate of psychotropic medication use compared to the general pediatric population. Numerous parties are involved in overseeing and administering psychotropic medications, often without a single, clearly designated adult to monitor their health and mental health care. Presently, much of the information exchange among the various different parties (e.g., judges, social workers, parents and foster parents) occurs on paper with multiple hard-copy forms.

Proposed Solution Using Alameda as a pilot county, California is developing a "proof of concept" on how to create a system that allows for appropriate levels of information sharing while, at the same time, safeguarding privacy.

The proposed integrated, electronic database system would eliminate the need for manual entry and ideally capture pharmacy claims data from Medi-Cal on psychotropic medication prescribed to children and youth in foster care, integrate additional forms for court approval of psychotropics, and potentially create a portable personal health record for children and youth in foster care to access after emancipation.

Intended Outcomes By linking the state's automated Child Welfare Services/Case Management System (CWS/CMS) with a county system, the project hopes to bring increased monitoring and oversight of psychotropic medication.

The belief is that improved data systems will reduce medication duplications, or enhance monitoring of the effects from such medications, and better ensure appropriate mental health treatment for children and youth in foster care.

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12 "Don Edwards Drives of Optimization at Social Services Agency of Alameda, CA," *IBM Master of Business Change*. http://www-935.ibm.com/services/us/gbs/consulting/pdf/AlamedaCS.pdf

13 http://www.chhs.ca.gov/SiteCollectionDocuments/ChildWelfareCouncil/Committee%20Information/Data%20Integration%20and%20Information%20Sharing%20Committee/06-05-13%20Meeting/Psychotropic%20Medication%20Proof%20of%20Concept%20Demonstration%20Project.pdf
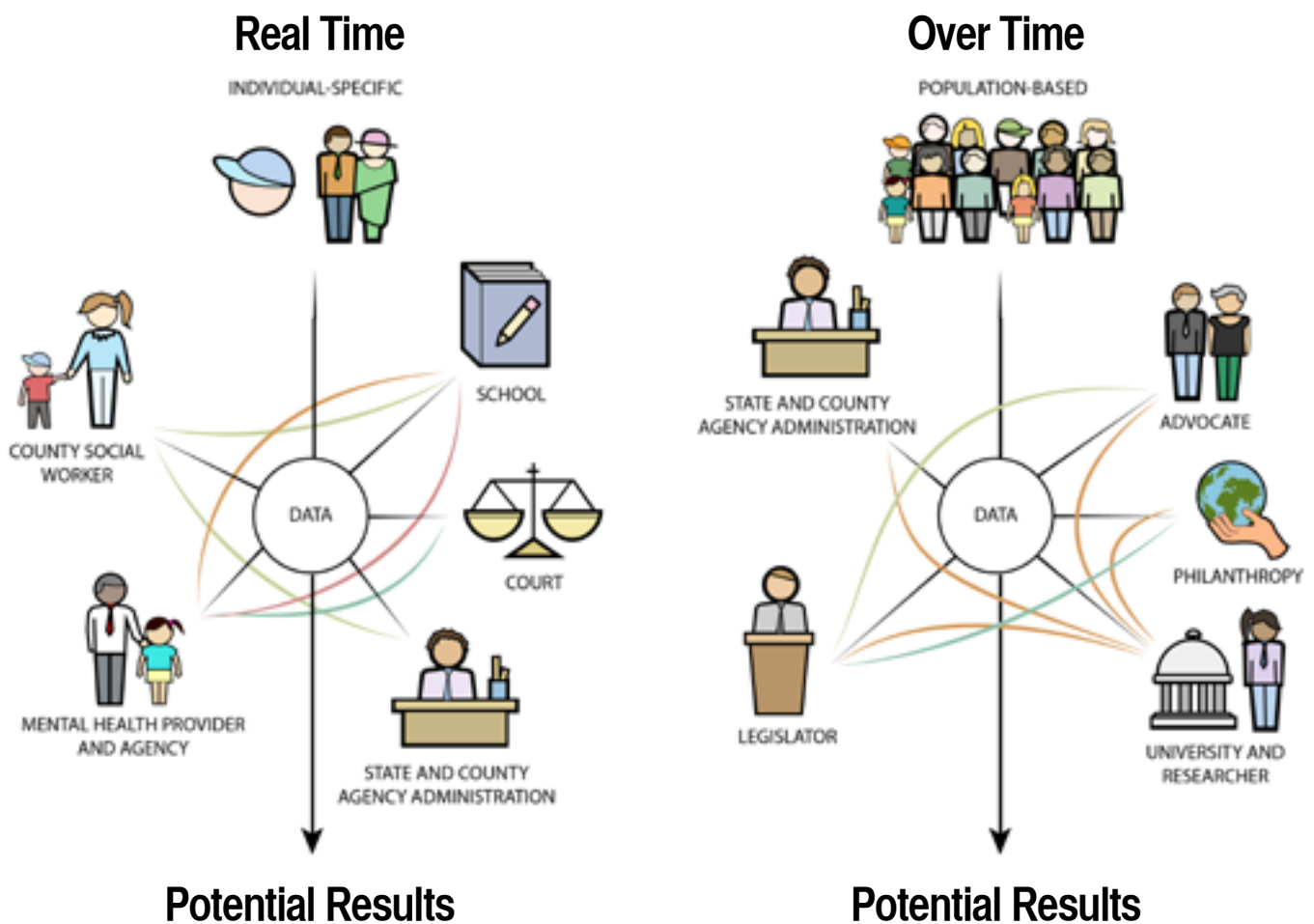
Benefits of Data Sharing

"Extensive analysis of data – both quantitative and qualitative – helps systems accurately identify their target population and that group's array of needs. Micro: Is the intervention working for this child? Macro: Are we getting better outcomes for the population?"
— Bryan Samuels, Commissioner, Administration on Children, Youth and Families

Foster children and their biological parents interact with many different individuals and agencies (see graphic of current landscape). Those interactions result in a great deal of data, collected and tracked by a variety of agencies, some of which share information, some of which do not.

The following graphic illustrates a few ways that information shared as it happens—in real time—could benefit the individual child and family, as well as how population-based data shared over time (longitudinally) can be used to improve overall policy and practice for the child welfare and associated systems.

Real Time

INDIVIDUAL-SPECIFIC

SCHOOL

COUNTY SOCIAL WORKER

DATA

COURT

MENTAL HEALTH PROVIDER AND AGENCY

STATE AND COUNTY AGENCY ADMINISTRATION

Over Time

POPULATION-BASED

STATE AND COUNTY AGENCY ADMINISTRATION

ADVOCATE

DATA

PHILANTHROPY

LEGISLATOR

UNIVERSITY AND RESEARCHER

Potential Results

• All youth in foster care who enroll in a new school seamlessly continue their education with the services needed to support their success.

• Youth in foster care find permanent connections with caring individuals who receive information about the youths' current mental health diagnoses and medications.

Potential Results

• State and county departments partner with universities to analyze data to measure the efficacy of child welfare interventions and services.

• Policymakers, state and county governments, and advocates identify trends to inform policy and general practice and secure funding as needed.
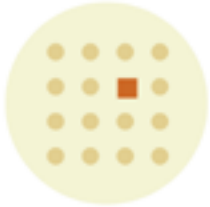
Moving Forward

Policymakers, practitioners, and philanthropy all have roles to play in tackling the current challenges to data sharing.

Remove legislative barriers.

There are both technical and practical challenges inherent in existing laws and policies that impede data sharing.

"Elected officials and policy leaders play an important role in setting the tone for greater data sharing."
— Congresswoman Karen Bass, Co-chair of the bi-partisan Congressional Caucus on Foster Youth

Challenge assumptions.

There may be concerns over privacy issues that do not actually exist.

"The real question for data sharing is how do we get to a place of 'yes' instead of 'no'?"
— Vernon Brown, Co-Founder, Stewards of Change

Strike a balance.

It is possible to protect privacy and integrity while also looking out for a child's best interests.

"There is a delicate balance of protecting privacy and getting the knowledge."
— Debra Zanders-Willis, Director of Child Welfare Services for San Diego County Health and Human Services

"We want to provide services to foster children, but we need the valuable information without over-stepping."
— Tom Ammiano, California State Assembly member

Be adaptable.

"Creating these new systems is incredibly important, but you should understand that the process can be long and your end result may look different than originally envisioned."
— Teri Kook, Director of Child Welfare, Stuart Foundation

Develop a common language.

"Providing a common vocabulary and mature framework to facilitate information exchange enables diverse communities to "speak the same language" as they share, exchange, accept, and translate information efficiently."
— Donna M. Roy, Executive Director, National Information Exchange Model (NIEM)

About the California Child Welfare Co-Investment Partnership

The California Child Welfare Co-Investment Partnership comprises five philanthropic organizations (Casey Family Programs, Conrad N. Hilton Foundation, Stuart Foundation, Walter S. Johnson Foundation, and Zellerbach Family Foundation) and the California Department of Social Services, Administrative Office of the Courts, and California Welfare Directors Association. The Partners meet regularly to share perspectives on federal, state and local policy, and to coordinate investments needed to improve the child welfare outcomes of safety, permanency, and well-being. Download previous editions of insights *and find out more about the Partnership at co-invest.org.*

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