# CDII Legislative Report 2022



# **Submitted by:**

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# **Executive Summary**

In 2020, California Health & Human Services Agency (CalHHS) established CDII as a resource to ensure compliance of state law on confidentiality of medical information and further innovation through better use of data. CDII was created to provide health information-sharing guidance that balances the need for patient privacy with the benefits of data sharing to support and encourage integrated care and services to assist California health and social services organizations.

The 2021-2022 year brought about many transformations for us at CDII, including further enhancements of our Agency Data Hub, planning and implementation of the Data Exchange Framework (DxF), the coordinating DxF Data Sharing Agreement (DSA) and DxF Grant Program, and an office realignment to focus resources on data insights and analysis.

Efforts in 2022 also included furthering the integration and standardization of CalHHS Agency datasets through the Open Data Portal (ODP), administering the State Committee for the Protection of Human Subjects (CPHS), collecting data and publishing reports on the quality of care and patient experience, and improving and strengthening the security of data processes within Agency.

By continuing to lead inter-departmental collaboration, CDII strives to incubate and innovate data-driven ecosystems of products and services designed to improve data sharing and analytics processes for CalHHS while encouraging increased stakeholder engagement from our partners.

# Mission and Vision Statements

Our **mission** at CDII is to improve the lives of all Californians by turning data into insights, knowledge, and equitable action. We accomplish this through our **vision** of developing, supporting, and improving programs within the California Health & Human Services Agency, so they are person-centered, equity-focused, and data-driven.

# **Guiding Principles**

In alignment with CalHHS' Strategic Priorities to advance healthier outcomes, we have adopted these four Guiding Principles:

- Focus on Equity Advise on and lead strategic data initiatives with California Health & Humans Services Agency-wide data standards, projects, and outcomes to improve equitable service delivery across all our programs.
- 2. **Use Data to Drive Action** Build tools and provide insight on projects that help deliver quality data and insights to decision-makers and provide reporting on key topics.
- 3. **Put the Person Back in Human-Centered Design** Improve ease of data sharing and integration through data standards and mappings.
- 4. **Cultivate a Culture of Innovation** Increase data literacy across CalHHS by creating communities of data practitioners and promoting data-driven decisions.

# **Major Endeavors**

At CDII, we are steadfast in our mission to align data-sharing strategies, improve tactics in data analytics, and deliver engaging, person-centered communications to help build our CalHHS data community. Highlights of CDII's ongoing major endeavors are as follows:

- Data Exchange Framework The Data Exchange Framework (DxF) is not a new technology or centralized data repository; instead, it's an agreement that will accelerate and expand the secure exchange of health information among health care entities, government agencies, and social service programs beginning in January 2024.
- Agency Data Hub A service platform being developed to build on the 2020 Research Data Hub initiative. The Agency Data Hub (or 'Data Hub') is a secure, cloud-based, data-sharing ecosystem for curating, hosting, and sharing integrated CalHHS data collected by and through CalHHS departments and offices.
- All-Hazards Dashboard The All-Hazards Dashboard (AHD) is a situational awareness and decision-making tool created for CalHHS. The AHD provides a unified approach to emergency response, focusing on impacts on CalHHS-licensed facilities and the vulnerable populations they serve across California.

- Equity Dashboard The CalHHS Equity Dashboard, once completed, will be a data-driven, cross-Agency tool that will help multiple stakeholders to assess the collection of programmatic demographic data to better understand the richly diverse populations that CalHHS departments' and offices' serve, and identify and address disparities.
- Insights Lab The Insights Lab builds partnerships with internal and external stakeholders to drive purposeful data initiatives and help transform CalHHS information into actionable insights. The Insights Lab provides statewide leadership in data standards, sharing, analysis, and literacy (in alignment with CalHHS priorities) and is responsible for the All-Hazards Dashboard, the Data Hub, the CalHHS Equity Dashboard, the Common Application, and other data research endeavors.
- Open Data Portal The Open Data Portal (ODP) platform was launched by CalHHS to increase public access to one of the State's most valuable assets – non-confidential health and human services' data. CDII assumed oversight and administration of the ODP in 2022, and it remains a key source of COVID-19 data requested by public researchers.
- Policy and Compliance: Quality Reporting CDII's public reporting programs inherited from the former Office of the Patient Advocate (OPA) are dedicated to providing Californians with data to help them make informed health care decisions. CDII produces three annual Health Care Quality Report Cards and an annual Health Care Complaint Data Report. Additional products addressing health care quality are also in development.
- Policy and Compliance: Oversight Program CDII's Policy and Compliance Oversight Program is responsible for ensuring applicable California state departments are compliant with the Health Insurance Portability and Accountability Act (HIPAA) and other related state and federal laws. This program also maintains and publishes the Statewide Health Information Policy Manual (SHIPM) and State Health Information Guidance (SHIG).
- Committee for the Protection of Human Subjects CDII staff support the operations of the Committee for the Protection of Human Subjects (CPHS).
   Under the federal Common Rule, Food and Drug Administration

regulations, Privacy Rule of the Health Insurance Portability and Accountability Act (HIPAA), and the California Information Practices Act (IPA.) CPHS serves as the Institutional Review Board (IRB) for all of the departments under CalHHS. The role of the CPHS is to ensure that research involving human subjects is conducted ethically and with minimal risk. Under the HIPAA and IPA, CPHS is also required to review and approve all research-related requests for California state data that can be linked to an individual that is held by any state department. Additionally, CPHS is guided by principles delineated in the Belmont Report.

- Data Expo For the seventh annual Data Expo, CDII used new
  communication tools and techniques to promote the 2022 Data Expo and
  engage with event registrants and attendees before, during, and after
  the live event. Each year, the Data Expo is a learning forum for all CalHHS
  staff to attend so employees can experience presentations by subject
  matter experts in data-centric fields while also finding out about new
  data-related projects and initiatives at CalHHS.
- Data Professionals Recruiting Endeavor This endeavor was started in 2022 to help CDII provide education about career opportunities at CDII and other CalHHS departments while helping potential candidates navigate the State's complex and sometimes confusing application process. There is a growing need to establish a State of California presence at local colleges, universities, and community groups to network with and recruit potential candidates in data-related fields.
- Webinar Learning Series CDII's webinars were specifically designed to complement CalHHS data literacy efforts while also providing a holistic human-centered approach to educate, inform, and inspire staff throughout CalHHS. These webinars provide a learning environment where the CalHHS data community can not only grow and thrive but also network and explore new ideas.

# Agency Data Hub

The Agency Data Hub (or 'Data Hub') is an ecosystem of services and tools in a cloud-based analytics platform. The Agency Data Hub was developed to operationalize CDII's guiding mission to improve the lives of all Californians by turning data into insights, knowledge, and equitable action.

The primary purpose of the Agency Data Hub is to provide a focal point for data-sharing across CalHHS and assist with data curation, consolidation, management, analytics, and creating data linkages for integrated department records. This improves interoperability between multiple CalHHS departments and increases the ability of universities and independent researchers with prior Institutional Review Board (IRB) approval to work with CalHHS data.

The Data Hub provides services to promote data-sharing and collaboration between CalHHS Departments and researchers with the goal of transforming program-centric analytics into person-centered insights. This includes, (but is not limited to):

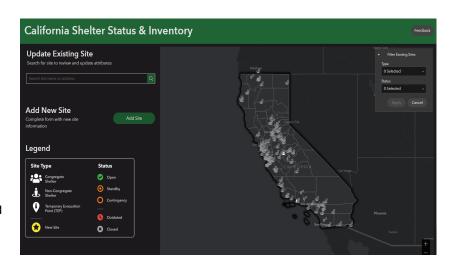
- Providing ongoing support for Insights Lab products and platforms, including the All-Hazards Dashboard and the CalHHS Equity Dashboard. The Data Hub is instrumental in building, securing, and maintaining the data connections necessary for our dashboard teams.
- Partnering with the Children's Data Network (CDN), the Data Hub is
  developing the data infrastructure to provide the ability to link information
  from across CalHHS programs and data sources to better recognize
  common clients across multiple programs. This partnership has resulted in
  development of a cloud-based research enclave for securely hosting
  research datasets and the accompanying linkage keys.
- Supporting the California Department of Social Services (CDSS) Early
   Childhood Integrated Data System (ECIDS) pilot by hosting the needed
   cloud-based research project workspace, and by providing ongoing data
   strategy and architecture support for the proposed program. This pilot will
   better inform our future data sharing with the Cradle to Career Data
   System being launched at GovOps.

## All-Hazards Dashboard

The All-Hazards Dashboard (AHD) is a situational awareness and decision-making tool created for CalHHS. The AHD provides a unified approach to emergency response, focusing on impacts on CalHHS-licensed facilities and vulnerable populations across California.

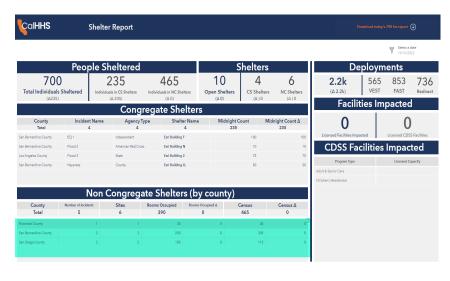
The AHD offers many beneficial features for the evaluation and analysis of data from various disaster-related incidents. New tools in 2022 for the AHD include the California Shelter Status & Inventory (CASSI), which is a digitized collection of

shelter data and automates the sharing of shelter data with other partners such as the California Office of Emergency Services (CalOES). CASSI helps decrease the time needed to retrieve data for after-action reports and reimbursement requests.



Additional new tools/features for the AHD in 2022 are the CalHHS Fire and

Shelter Reports, which gives the option for the "Agency Snapshot" view of all Shelters being used (both congregate and noncongregate), and an "Impacted Facilities" view, which shows the location and name of any shelters affected or in an impacted area of a disaster.



# Data Exchange Framework

# Data Exchange Framework

AB 133 (2021 (codified as CA Health & Safety Code § 130290) required CalHHS to consult with stakeholders and local partners to establish, on or before July 1, 2022, the CalHHS Data Exchange Framework (DxF). CalHHS delegated authority to CDII to perform these tasks and help implement the DxF. This DxF, "includes a single data sharing agreement and common set of policies and procedures that will govern and require the exchange of health and human services information among health care entities & government agencies in California." 1



To meet this mandate, CDII was instrumental in helping CalHHS institute a stakeholder Advisory Group (AG) and a Data Sharing Agreement (DSA) Subcommittee.

CalHHS/CDII provided leadership and oversight of the AG and Subcommittee, which met monthly (approximately) between September 2021 and June 2022. The subcommittee provided input on key development decision points; those decision points were then

presented back to the broader DxF Stakeholder Advisory Group, and their recommendations were advanced to CDII and CalHHS leadership for consideration.

In March 2022, the DSA Subcommittee reviewed and provided feedback on initial drafts of the DSA, the first set of Policies and Procedures (P&Ps), and other <u>Data Sharing Agreement P&P</u> issues. In the May 2022 AG meeting, the DxF Stakeholder Advisory Group reviewed and provided feedback on drafts of the DSA and the initial set of P&Ps.

CalHHS subsequently posted drafts of the DSA and the initial set of P&Ps on the CalHHS website for public comment. All public comments were logged,

<sup>&</sup>lt;sup>1</sup> Data Exchange Framework, "Timeline," <a href="https://www.chhs.ca.gov/data-exchange-framework/">https://www.chhs.ca.gov/data-exchange-framework/</a>.

categorized, and posted on the DxF website, and input was considered and, where appropriate, integrated into the DSA and P&Ps. The updated DSA and P&Ps were reviewed by CDII and CalHHS leadership, and the finalized DSA and the initial set of finalized P&Ps were posted on the CalHHS DxF website in July 2022.

In addition to the establishment of the AG and DSA Subcommittee, CDII's DxF division published the cornerstones of the Data Exchange Framework. These foundational components include DxF Guiding Principles, a Data Exchange Landscape, Data Exchange Scenarios, a synopsis of DxF Governance, a review of Data Exchange Gaps and Opportunities, and a Strategy for Digital Identifies.

In July, the AG and the DSA Subcommittee were sunset, and an interim DxF Implementation Advisory Committee (IAC) and the DSA Policy and Procedures (DSA P&P) Subcommittee were established to guide the implementation of the Framework and additional P&Ps. The IAC and DSA P&P Subcommittee meet approximately every six weeks and have advanced recommendations for a series of additional policies. They have also guided the development of a Qualified Health Information Organization (QHIO) program, and a CDII implementation grants program (described further below).

In September 2022, CDII released the "DxF Information is Power Webinar Series." The "Information is Power" series began on September 13, 2022, and was created to educate the public and many health care organizations about the importance of the DxF and DSA-related requirements. These 2022-2023 webinars allowed DxF leaders and advisors to educate stakeholders on the purpose and scope of the DxF, and share details on key findings from previous Grant Listening Sessions. Additionally, the webinar series provides updates on the Educational Initiatives Grants, preliminary Grant Program design parameters, and shared next steps for the Qualified Health Information Organization (QHIO) Onboarding and Technical Assistance Grant Programs.

To supplement the implementation of the DSA, the California Governor and State Legislature allocated \$50 million for the <u>Data Exchange Framework (DxF)</u> Grant Program, which launched in October 2022 and is being facilitated by

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<sup>&</sup>lt;sup>2</sup> Data Exchange Framework, "Data Exchange Framework Public Webinars," https://www.chhs.ca.gov/data-exchange-framework/#past-dxf-webinar-materials

CDII. "This grant program exists to help health and human services providers and other healthcare entities understand and implement DxF requirements." 3

In 2022-2023, CDII was charged with awarding the three types of DSA Signatory Grants to subsidize signatories' investments to implement the DSA.

- **Educational Grants** for associations to provide outreach and education on the DxF to help increase DSA signature rates and participation.
- Qualified Health Information Organization (QHIO) Onboarding Grants will provide assistance to organizations who choose to connect to a QHIO to help meet their DSA requirements. A Health Information Organization (HIO) is an organization that offers services and functions to support the exchange of health and social services information. The HIO serves as an intermediary, assisting health and human services organizations as they send information or initiate, receive, and reply to requests for information. So, in this context, a Qualified Health Information Organization (QHIO) is an HIO that has demonstrated its ability to meet DxF data exchange requirements and other requirements set forth by CDII. As part of the DxF implementation, CDII will establish QHIO criteria, requirements, and a process to qualify HIOs.
- Technical Assistance (TA) Grants will provide funding for organizations that
  may seek technical assistance support to meet DSA requirements that
  may not require the use of a Qualified Health Information Organization
  (QHIO) Intermediary Qualified Health Information Organization

Following the September 2022 launch of the DxF Information is Power series, in October 2022 CDII organized, coordinated, and released the DxF Grant Program Webinar Series. In this stakeholder engagement webinar series, CDII invited stakeholders to join one of two public listening sessions to provide input on the design of the Data Exchange Framework (DxF) Grant Program. The input and feedback received during the listening sessions shaped the ongoing and future design of the program to more accurately address the needs of prospective DxF signatories.

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<sup>&</sup>lt;sup>3</sup> Data Exchange Framework, "Data Exchange Framework Grant Program," <a href="https://www.chhs.ca.gov/data-exchange-framework/#dxf-grant-program">https://www.chhs.ca.gov/data-exchange-framework/#dxf-grant-program</a>.

We are happy to report that by the January 31, 2023, signature deadline, more than 1,400 Health Care Organizations have joined the Data Exchange Framework Data Sharing Agreement (click here for the full list of signatories). The DxF and DSA are leading the transformation to safer, more effective, whole-person care for all Californians. CDII is proud to be an integral part of these efforts.



# Data Expo



CDII directed and produced the seventh annual CalHHS Data Expo on May 4, 2022. Hosted by CDII Director, John Ohanian, and co-host, Equity Dashboard Program Manager Christine Blake, the 2022 Data Expo was a live, three-hour all-virtual event. The theme for 2022 was Data Equity, a topic chosen to bolster one of the California Health & Human Services Agency's strategic priorities.<sup>4</sup>

The Data Expo was started by the CalHHS Data Subcommittee in 2016. It began as a showcase of CalHHS data achievements and has become an increasingly large informational and networking event for data professionals across CalHHS Departments and Offices.

The keynote speakers for 2022 were CalHHS Secretary, Dr. Mark Ghaly, and Undersecretary, Marko Mijic, who set the tone by reminding participants of CalHHS guiding principles of being person-centered, equity-focused, and data-driven through the services they deliver at their respective CalHHS departments. The 2022 Data Expo featured a diverse set of equity-focused panelists, including Equity Officers Dr. Rohan Radhakrishna from the California Department of Public Health (CDPH), Marcela Ruiz from the Department of Social Services (DSS), Secretary of Government Operations Amy Tong, Dr. Eric Schneider from the National Committee of Quality Assurance (NCQA), Julia Caplan from the Public Health Institute (PHI), CDPH's Lazaro Cardenas, and Jazmine Delgadillo Garcia from Strategic Growth Council.

Through thought-provoking panel discussions and presentations, guest speakers shared their insights on equity through data. They spoke about the various programs created to address data equity and how collaborative initiatives can lead to better outcomes for all Californians.

The Expo also aims to foster a data community, another of CDII's guiding principles, by creating a virtual atmosphere to involve our participants in two-way discussions instead of merely sharing information one way. Attendees were treated to engaging discussions with panelists, the opportunity to participate in Q&A sessions, and some fun interactions with other attendees through chat room quizzes and crafted intermission game breaks.

The virtual event featured 11 guest speakers and panelists who covered six presentations about equity, data, and innovations. In all, 31 California State

<sup>&</sup>lt;sup>4</sup> CalHHS Guiding Principles and Strategic Priorities, "Our North Star," <a href="https://www.chhs.ca.gov/guiding-principles-strategic-priorities/#focus-on-equity">https://www.chhs.ca.gov/guiding-principles-strategic-priorities/#focus-on-equity</a>.

departments and organizations actively engaged in the 2022 Data Expo, with 15 other state organizations being represented in addition to CalHHS Departments and Offices.

CDII saw 85% of registrants attending the live virtual event on May 4th, an increase over 2021's numbers. An exit poll provided to attendees reflected that 96% of respondents rated the 2022 Data Expo as good to excellent, with nearly three-quarters (71%) rating it as excellent.





Year-over-year, the

Data Expo continues to see a promising increase in the registrant and attendee numbers, and CDII aims to keep that trend going.

Plans for the 2023 Data Expo are already well underway, with a proposal to expand participation and engagement by featuring an in-person networking event in Sacramento after the live virtual show.

A recording of the 2022 Data Expo can be viewed on CDII's YouTube channel. The direct link to the video-on-demand is <a href="https://bit.ly/37A2EJE">https://bit.ly/37A2EJE</a>.

# Data Professionals Recruiting Endeavor

CDII sought to improve employment recruitment by developing a collegiate outreach and engagement strategy to attract and retain data professionals at CalHHS Agency Departments and Offices.

In late Spring of 2022, the State had more than 370 vacant Information Technology (IT) and Research Data positions<sup>5</sup>, with many more opening after July 1, 2022. The State and CalHHS struggle to recruit and retain the staff needed to carry out these critical data activities.



CDII, as the data innovation office within CalHHS, requested Agency executive level support in the summer of 2022 to implement engagement activities for a data professionals recruiting initiative to increase awareness of opportunities and create a pipeline of skilled data professionals to CalHHS. The State Chief Data Officer, with support from CalHHS, CDII, and other Agencies, began working to address several recruitment and retention barriers for data professionals.

In 2022, CDII accomplished two of the six overall recruiting objectives for the data professionals recruiting endeavor. Those two objectives were:

Establish Partnerships with Higher Education Institutions: Sacramento has
several universities and colleges with which CDII and CalHHS can establish
partnerships to create direct channels to recruit data professionals. In late
Summer/early Fall 2022, CDII conducted engagement outreach to 32
universities and colleges across California to establish a working

<sup>&</sup>lt;sup>5</sup> CalCareers, "Job Search - Keyword Data," <a href="https://www.jobs.ca.gov/">https://www.jobs.ca.gov/</a>.

relationship with their student recruiting departments and inquire how CDII could sponsor and participate in campus activities such as job fairs, advertisements, internships, and connections to data programs. This outreach resulted in establishing networking relationships with the University of California San Diego (UCSD), the University of California Los Angeles (UCLA), and Stanford University. CDII and CalHHS registered to be a participating organization at the 2022 Fall Career Fairs at each of these schools.

2. Establish Virtual Presence at Fall Career Fairs at California Universities: CDII paid the registration fees for CalHHS to be a participating government agency at three 2022 Fall career fairs, which occurred in October and November. UCSD, UCLA, and Stanford University had open, virtual Fall career fairs for students to explore various data-related job opportunities at private sector firms and with the State. CDII organized pre-event training for CalHHS recruiting representatives, facilitated the virtual online sessions, developed marketing materials (see below images), created post-event surveys for feedback from students and presenters, and then conducted a debrief session for CalHHS staff who were involved to explore areas of opportunity for the 2023 Career Fair engagements.

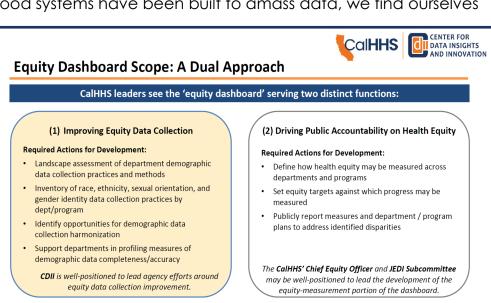
In future data professional recruiting events, additional funding at the Agency level would be recommended for expanded marketing and student outreach. Membership packages at each school range from \$5,000-\$15,000 annually, depending on the level of marketing outreach and student engagement desired by CDII and CalHHS. This effort will continue to evolve and expand so that a solid pipeline of data professionals is available for the growing need for data-related employees at CalHHS and across the state.

# **Equity Dashboard**



Since its inception in 2020, CDII has taken several steps in advancing CalHHS' mission to better understand the diverse population it serves. CDII aims to, "Leverage data better to understand the current conditions in our communities, the impact of existing programs, and the opportunities to improve service delivery. While good systems have been built to amass data, we find ourselves

data-rich but information poor.
Actionable and timely data will help advance social and economic mobility and improve the health and well-being of children,



families, and individuals."6

The CalHHS Equity Dashboard will be the first step to ensuring CalHHS can identify and address disparities in the health and human service needs that Californians face. The CalHHS Equity Dashboard will be a cross-agency tool that will help CalHHS, departmental leadership, and the public to measure progress in the collection of demographic data, understand the richly diverse populations our programs serve, and identify and address disparities.

In early 2022, during the discovery phase, the Equity Dashboard team sent program inventories to each department to discover user needs and gather information on department programs currently collecting demographic data and the data standards used to collect that data. The team also identified demographic data collection challenges, opportunities, and what support would advance their demographic data collection efforts. Version 1 of the

<sup>&</sup>lt;sup>6</sup> CalHHS Guiding Principles and Strategic Priorities, "Our Guiding Principles - Use Data to Drive Action," <a href="https://www.chhs.ca.gov/guiding-principles-strategic-priorities/#use-data-to-drive-action">https://www.chhs.ca.gov/guiding-principles-strategic-priorities/#use-data-to-drive-action</a>.

CalHHS Equity Dashboard (slated to debut in Spring 2023), will focus on four primary demographic data areas: Race, Ethnicity, Sexual Orientation, and Gender Identity.

By focusing first on these initial four demographic areas, the Equity Dashboard team will be able to create a minimal viable product to share with CalHHS and stakeholders. Future iterations of the dashboard will include a wider range of demographic data, including language, housing status, age, rurality, disability status, and income.

#### Equity Dashboard 2022-2023 Milestones

#### Summer 2022:

- The Equity Dashboard held its first Townhall in June to obtain participant feedback on user profiles developed during the initial discovery phase. The user profiles or personas depicted the potential users of the CalHHS Equity Dashboard. During this Townhall, participants provided feedback on the user profiles to better understand each user's motivations, frustrations, and expectations for the Equity Dashboard.
- A second Townhall in July showcased two potential wireframes or visuals of the CalHHS Equity Dashboard. Participants provided feedback on their likes, and dislikes, suggested changes, and general comments to improve the wireframes. The Equity Dashboard team then incorporated this feedback into an updated wireframe shared with the development team.

#### • Fall 2022:

Throughout the Fall/Winter of 2022 and into 2023, the Equity Dashboard team has worked diligently to develop a minimal viable product that will be ready for user experience/user interface testing in the Spring of 2023. In the Fall of 2022, the scope of the Equity Dashboard expanded beyond the original demographic data collection to include a separate section dedicated to the CalHHS Department Impact Goals and Equity Metrics. At the request of the CalHHS Agency leadership, the Equity Dashboard team began creating data visualizations for these Impact Goals and Equity Metrics. The Equity Dashboard design team used the comments from Townhall #2 and feedback from stakeholders to create a

prototype to demonstrate the basic functionality of the Equity Dashboard.

#### • Winter 2022-2023:

Through the development of the Equity Dashboard, the team identified an opportunity to further the CalHHS mission to provide services and programs that address the whole needs of every Californian we serve. The Equity Dashboard team is in the process of establishing a Data Standards Community that will lead CalHHS efforts to provide best practices in sharing, storing, and interpreting data.

Closing out 2022, the Equity Dashboard team worked with three CalHHS Departments (Department of Rehabilitation, Department of Managed Health Care, and Department of State Hospitals) to build data pipelines from department data sources into the CDII Agency Data Hub that will then flow to the CalHHS Equity Dashboard. This data was used to develop a prototype of the Equity Dashboard, which will be modified to create a minimal viable product used in user experience and user interface testing, scheduled to be completed during Spring/Summer 2023.

# Insights Lab

In 2021, the Insights Lab was known as the Data & Engineering Division; however, that designation did not accurately portray the work being researched and innovated by the team. The newly renamed CDII Insights Lab Division is tasked with providing the tools to facilitate better decision-making supported by reliable data.

CDII's Insights Lab provides integrated Health & Human Services solutions with the purpose of whole person, whole life wellness and resilience. The Insights Lab is a think tank and knowledge generator for innovating and developing datasmart tools and services for CalHHS employees and the communities they serve. The Insights Lab also assists with streamlining data management workflows, advancing user experience, and unlocking open data as a strategic CalHHS Agency asset. The Insights Lab is where projects such as the All-Hazards Dashboard, Equity Dashboard, the Common Application, and other interactive data-smart decision-making tools are developed, tested, and refined.

In 2022, the focus was building out the Insights Lab, defining workstreams, and identifying/establishing project managers for the All-Hazards Dashboard, the Equity Dashboard, and the Common Application. The Insights Lab has incorporated the Agile methodology, an approach that emphasizes collaboration with stakeholders. CalHHS stakeholders will be encouraged to give feedback, ask for new requirements or features, or identify areas of improvement – at any stage of the projects that Insights Lab works on.

# Open Data Portal



The CalHHS Open Data Portal (ODP) is a research data repository that provides the public with a single entry point to access CalHHS departments' deidentified, publishable data. CDII is responsible for administering the ODP in accordance with Health and Safety Code section 130205 (b), pursuant to AB 133 (Statutes of 2022).

"The California Health and Human Services Agency (CalHHS) launched its Open Data Portal (ODP) initiative in 2016 in order to increase public access to one of the State's most valuable assets – non-confidential health and human services data. Its goals are to spark innovation, promote research and economic opportunities, engage public participation in government, increase transparency, and inform decision-making. "Open Data" describes data that are de-identified, freely available, and formatted according to national technical standards to facilitate visibility and reuse of published data.

The portal offers access to standardized data that can be easily retrieved, combined, downloaded, sorted, searched, analyzed, redistributed and re-used by individuals, businesses, researchers, journalists, developers, and government to process, trend, and innovate."<sup>7</sup>

<sup>&</sup>lt;sup>7</sup> CalHHS Open Data Portal, "About," <a href="https://data.chhs.ca.gov/about">https://data.chhs.ca.gov/about</a>.

In 2021, CDII assumed primary oversight and administration of:

- The ODP platform. The ODP website and platform are currently managed and maintained by a partner vendor.
- The Open Data (OD) + Geographic Information Systems (GIS) Workgroup.
  The purpose of the OD+GIS workgroup is for ODP and GIS Administrators
  from CalHHS, its departments, and other key stakeholders to collaborate
  on strategy, identify required activities, dependencies, inputs, and
  outputs, align schedules, and discuss support needs for the ODP and
  Agency-wide GIS activities.
- The ODP Twitter account. A public Twitter account for communicating ODP-related announcements and updates to the general public.
- The CalHHSDataNews news feed. A bot that posts announcements of new or updated data set postings to the ODP Twitter account: https://twitter.com/chhsdatanews.

The ODP remains the primary location for researchers to review and download California COVID-19 datasets and statistics for study.

# Policy and Compliance: Quality Reporting

With CDII's establishing legislation enacted in October 2021, many activities were undertaken in 2022 to transition former Office of the Patient Advocate (OPA) program operations and staff under the CDII umbrella and establish new administrative systems and processes.

The CDII Policy and Governance Division now includes health care quality reporting programs that were formerly a part of OPA. CDII is statutorily required to produce annual publications about health care quality and access issues, including a quality of care report card, an annual legislative report about the problems and complaints by consumers about health care coverage, and report card information based on timely access data from the Department of Managed Health Care (DMHC). The CDII statute enacted in October 2021 also expanded the scope of OPA's reporting requirements to address new data sources and topics, such as the impacts of socioeconomic status on health and access to social services programs.

CDII supports the data analysis and production of three annual online <u>Health</u> <u>Care Quality Report Cards</u> about health plans and medical groups. These

Report Cards are designed for consumers to ensure they have easy-tounderstand and reliable data to inform their health care decisions.

Prior to publication, CDII undertakes many steps, including:

- Updating the Report Cards to reflect current data availability, which regularly changes based on the latest medical standards and health care system collection targets.
- Conducting multiple levels of quality assurance reviews to ensure the reliability of the ratings.
- Creating data displays and educational content and translating the Report Cards into Spanish and Chinese languages.
- Consumer testing the Report Cards to ensure the primary audience understands and finds value in the information.

In 2022, the Health Care Quality Report Cards contained more than 17,000 data points about the clinical quality, patient experience, and cost of health care in California. The Health Plan Report Card released in December 2022 provided quality and patient experience ratings for the 16 largest HMO and PPO plans in California, with over 60 composite star ratings and individual measure scores on different health care topics. The Medical Group – Commercial Report Card released in May 2022 provided quality, patient experience, and cost ratings for nearly 200 medical groups that serve Californians in commercial health plans, with over 30 composite star ratings and individual measure scores. The Medical Group - Medicare Report Card released in May 2022 provided quality ratings for nearly 170 medical groups that serve Californians in Medicare Advantage plans, with 25 composite star ratings and individual measure scores.

CDII also produces an annual report about health care complaints from California consumers to DMHC, Department of Health Care Services (DHCS), California Department of Insurance, and Covered California. For this multi-departmental report, CDII collects and analyzes complaint records and other information from seven state consumer assistance centers that typically handle around 5 to 7 million consumer contacts each year for various health care issues. The four departments report data using standardized complaint data categories established by CDII.

The <u>Annual Health Care Complaint Data Report</u> to the Legislature released in May 2022 addressed nearly 39,000 health care complaints closed by state consumer assistance programs in 2020. The state consumer assistance programs from the four departments reported 7,830,377 total consumer inquiries and complaints about health care issues in 2020. In 2022, CDII collected and analyzed nearly 35,000 records of complaints closed in 2021, as well as other information about the state consumer assistance program activities, which will be addressed in the next report publication.

#### **Future Public Reporting Efforts**

DMHC is statutorily required to work with OPA to incorporate timely access data

about health plans into the annual Health Care Quality Report Cards.
CDII is now managing this project to develop a new Timely Access
Report Card. In 2022,
CDII continued OPA's collaboration with
DMHC to plan the new
Report Card based on timely access to survey data and the performance benchmarks that are



expected to be available for the first time for measurement year 2023.

Depending on resource availability, CDII also will be developing additional products to meet the expanded scope of data to be addressed in its *Health Care Quality Report Cards*. The CDII statute specifies new data sources and topics not included in the current products, such as the socioeconomic impact on health and access to social services. In 2022, CDII identified this reporting gap and began developing a proposal for new Equity Report Cards to help meet a portion of the expanded statute.

#### **OPA Transition to CDII**

Several OPA staff positions were redirected to higher-priority CDII activities, so the OPA public reporting programs were scaled back to minimal operations. without sufficient resources to complete the consumer education outreach and stakeholder engagement activities that are required for a greater impact on health care quality advancement.

Additional CDII resources will need to be secured to succeed in meeting the statutory intent for providing beneficial quality advancement tools based on the expanded scope of data from public health coverage programs and other state entities about the cost of care, quality of care, patient experience, socioeconomic status impact on health, access to care, and access to social services programs.

# Policy and Compliance: Oversight Program

CDII's Policy and Compliance Oversight program assumes statewide leadership, coordination, policy formulation, direction, and oversight responsibilities for compliance with state and federal health information privacy laws and implementing regulations. CDII exercises full authority relative to state entities to establish policy, provide direction to state entities, provide guidance on data sharing, monitor progress, and report on compliance activities.

The legislative language identified five broad categories of responsibilities that guided the CDII Policy and Governance, more specifically, the Policy and Compliance Oversight team's tasks and priorities throughout 2022:

- Leadership: Provide training and tools, represent the State on health data sharing and consult about HIPAA Preemption
- 2. **Coordination**: Coordinate and communicate with affected entities (e.g., California Department of Technology and State Chief Data Officer)
- 3. Policy Formulation: Develop policies and standards
- 4. **Direction**: Provide recommendations to CalHHS for HIPAA Preemption, provide technical assistance, and support integrated health and social services by providing guidance on health information
- 5. **Oversight**: Assess and monitor compliance activities

#### **Leadership Accomplishments:**

- Published 52 weekly round-up communications. These communications are internal to the Compliance and Policy group and keep everyone apprised of events related to the privacy and security of health information at a state and national level.
- Published 12 monthly communications to state organizations. CDII
  provides updates on the CDII Policy and Governance team activities as
  well as Federal Health and Human Services (HHS) updates.
- Tracked, evaluated, and provided analysis (as needed) on more than 500 pending federal and state bills.
- Developed recommendations and plans for external training and education related to HIPAA compliance and review. Started creating new training modules for stakeholders impacted by HIPAA rules.
- Facilitated gathering comments from CalHHS Departments on Notice of Proposed Rule Making(s) with the federal government.

#### **Coordination Accomplishments:**

- Reviewed and revised over 97 pages of input to prepare for website migration
- Migrated and maintained internal and external SharePoint sites
- Monitored and responded to more than 100 email correspondences related to the privacy and security of health information
- Created and maintained new SharePoint instance for other CDII departments

#### **Policy Formulation Accomplishments:**

Revised the California Statewide Health Information Policy Manual (SHIPM)
in June 2022. CDII maintains the SHIPM to provide State departments with
a resource that provides guidance on protecting patient privacy and
helps state entities avoid fines and sanctions resulting from unauthorized
disclosures of health information. The SHIPM is a living document updated



- annually with changes to all applicable state or federal laws. The latest SHIPM revision (June 2022) can be accessed <u>here</u>.
- Revised the California State Health Information Guidance (SHIG) in December 2022. The SHIG was a collaboration of the former California Office of Health Information Integrity (CalOHII), absorbed by CDII, with various organizations to develop specific materials to help clarify federal and state laws that affect the disclosure and sharing of health information.
- The 5 volumes of SHIG are reviewed, revised, and republished each year.
- The SHIG efforts include comprehensive research, drawing from a broad group of stakeholders that reflect cross-industry insights and experience, to provide a clear understanding of the problems different groups were facing in the field. Five volumes of the SHIG have been published covering the following topics: sharing behavioral health information in California, sharing health information to address food and nutrition insecurity in California, sharing HIV/AIDS information in California, sharing health information of people living with intellectual and/or developmental disabilities in California, and sharing minors and foster youth information in California. The SHIG volumes include how sharing of information can affect older Americans who are impacted by the above topics.
- Developed the CDII Information Privacy & Security Training, Policies and Procedures, and HIPAA-required training.

#### **Direction**

- Provided technical assistance to state entities dealing with health information privacy and security issues and questions.
- Provided assistance to other states looking at California's SHIPM and SHIG products.
- Supported the CDII Legal Office in HIPAA compliance review.

#### **Oversight Related Activities:**

 Conducted compliance reviews focused on Patient Rights for six state organizations. CDII has a statutory responsibility to evaluate, monitor, and report on state departments' HIPAA compliance. The Policy and Governance Division manages and maintains the Compliance Oversight Program.

- The goals of CDII's Compliance Oversight Program are to:
  - Create a collaborative culture of compliance for state departments.
  - Keep Californian's health information safe.
  - Provide technical assistance and leadership on California's HIPAA compliance.

These evaluations (or compliance reviews) are based on the SHIPM, which is described above. State entities, including all state departments, boards, commissions, programs, and other

"We work with state and non-state entities to enforce State and Federal Health Information Privacy Laws that protect Californians' medical and personal information." **Oversight** Conducted compliance reviews focused on patients' rights Revised CDII Compliance and Policy Team's Compliance Program Conducted biennial Health Insurance Portability and Accountability Act (HIPAA) **Entity Assessments** Developed and supported budget change proposals as needed Monitor State Covered Entities (CE) and Business Associates (BA) organizations' Corrective Action Plans and hosted monthly meetings to correct gaps

organizational units of the executive branch of state government that are required to comply with HIPAA must comply with the California SHIPM policies.

In 2022, the oversight team also:

- Revised the CDII Compliance and Policy Compliance Oversight Program to create a more user-friendly experience for state organization stakeholders.
- Conducted the biennial Health Insurance Portability and Accountability Act (HIPAA) entity assessments on more than 400 state organizations.
- Monitored state-covered entities and business associate organizations'
   Correction Action Plans (CAPs) four organizations.

# Committee for the Protection of Human Subjects

CDII staff support the operations of the Committee for the Protection of Human Subjects (CPHS). Under the federal Common Rule, Food and Drug Administration regulations, Privacy Rule of Health Insurance Portability and Accountability Act

(HIPAA), and the California Information Practices Act (IPA), CPHS serves as the Institutional Review Board (IRB) for all of the departments under CalHHS. The role of the CPHS is to ensure that research involving human subjects is conducted ethically and with minimal risk. Under the HIPAA and IPA, CPHS is also required to review and approve all research-related requests for California state data that can be linked to an individual that is held by any state department. The CPHS is guided by principles delineated in the Belmont Report, which was issued by the U.S. Department of Health, Education, and Welfare in April 1979. These principles include: Beneficence, Respect for Persons, and Justice.

CPHS utilizes IRBManager, an electronic protocol submission and approval system for managing all research projects submitted for review and approval. Depending on the type of research being executed, the CPHS review may be conducted at a convened public meeting. The Committee shall address projects that have any contact with human subjects and may also discuss data-only projects.

#### CPHS Accomplishments in 2022 Include:

- Updated the CPHS Policies and Procedures handbook
- Worked with the IRBManager vendor for Improvements to xForms and applications
- Recruited and hired two new committee members.
- Reviewed and processed 128 Initial Research Submissions
- Reviewed and processed 821 Continuing Review Applications
- Reviewed and processed 448 Amendment Applications
- Reviewed and made a determination on 125 Exempt/Not Research Determination Applications
- Reviewed and processed 62 Final Reports
- Conducted a Full board review of 17 Adverse Event Reports

## Webinar Learning Series

Building a data-literate community by developing a webinar series aimed at increasing comprehension of data for all employees at CalHHS is another priority for CDII. Communicating data in a visual way is crucial to conveying complex



information in a simple, and easy-to-understand manner to CalHHS' many stakeholders. Developing and using dashboards to tell the human story as a whole are now necessary tools for many employees within CalHHS.

In Fall of 2022, CDII hosted the webinar, "The Seeds of a Dashboard Story: Creating and Revealing Human Stories in Dashboards" on Tuesday, October 18th. This webinar showcased how CalHHS staff could transform their data into relevant and impactful visualizations that track program objectives while also conveying the most important data for stakeholders.

Guest speakers from the Department of Social Services' (DSS) Research, Automation, and Data Division (RADD) shared their expertise in using data not just to share information, but humanizing that data to bring relevance and meaning to the diverse stakeholders that CalHHS departments serve.

This webinar had 426 registrants from 16 of the 17 CalHHS Departments and Offices, and more than 290 employees attended the live session. Post-webinar, the CDII communications team also shared out the slide deck and recorded video to a distribution list of more than 1,300 employees for on-demand viewing and additional engagement.

The purpose of producing these consistent, engaging webinar series for data learning is to build better collaborative relationships within CalHHS and grow the foundation for the data community which CDII helped establish.

# **Data Sharing and Collection Practices**

# **Data Sharing Practices**

The CalHHS Agency Data Hub provides a focal point for data-sharing across CalHHS and assists CalHHS Departments and Offices with data curation, consolidation, management, analytics, and creating data linkages for integrated department records improving interoperability. Currently, each CalHHS department captures and manages its own data concerning individual use of their specific programs. The Data Hub will streamline the process for accessing record-level research data sets and multi-program data from all participating CalHHS Departments and Offices that have signed on to the Participation Agreement.

#### **Data Collection Practices**

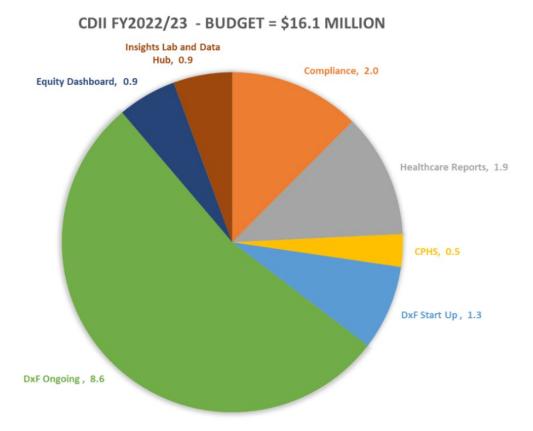
CDII adheres to all required state guidelines, rules, regulations, and principles regarding the collection and management of personal information. CDII collects personal information on individuals only as allowed by law. CDII limits the collection of personal information to what is relevant and necessary to accomplish the lawful purpose of CDII and its units and divisions.

CDII uses information security safeguards. Reasonable precautions are taken to protect the personal information of individuals collected or maintained against loss, unauthorized access, and illegal use or disclosure. Such personal information is stored by CDII in secure locations. CDII's staff is trained on procedures for the management of personal information, including limitations on the release of information before they can access any confidential or sensitive information. Access to personal information is limited to those members of CDII's staff whose work requires such access. CDII conducts periodic reviews to ensure proper information management policies and procedures are understood and followed.

# **Financial Overview**

# 2022 Budget Analysis

Since launching the office in October 2021, CDII spent the 2022 year organizing our team into a more streamlined operating model (formerly 4 different offices) to become more efficient and project and workstream focused. The reorganization meant aligning our work with key service areas. We are working at a budget-neutral level with a focus on fortifying our operations and emphasizing advancements in data analysis, research, and stakeholder engagement in data-sharing use cases. The below chart reflects the allocation of the CDII annual budget to the various CDII divisions and projects.



# Conclusion

# Summary

CDII was formed by CalHHS to both strategize and organize data-sharing policies, but also to find the stories within the data to close knowledge gaps and expedite decision-making. Data is a fundamental asset for all governmental organizations and private-sector businesses. The need to find ways for this asset to be fully utilized without compromising privacy and data security is what inspires our staff and leadership every day. Data infrastructure and security are critical to the delivery of every single service provided by CalHHS to all Californians.

We know that improving and streamlining data collection, stewardship, and sharing practices will foster person-centered decision-making, rather than program-centered ones. Our targeted data-sharing efforts will help improve health and social services outcomes because we are developing systems with usable analytics that are part of a larger integrated system to identify underserved populations, detect service gaps, and better target programs and services. CDII seeks to be an example, not only within CalHHS but within the State, on how government can change paradigms to advance toward progress.

2022 was another monumental year for CDII, full of growth and workstream innovation, as well as various challenges and organizational pivots. As we look forward to what 2023 has in store, CDII is evolving our operations to incorporate equity, diversity, and whole-person views into each project we develop and support.

#### **END OF REPORT**