

# California Cradle-to-Career Data Request Process Homework Team Meeting Summary

October 19, 2020

This document provides a summary of a meeting to refine a proposal for the Cradle-to-Career data system data request process. Information is grouped by topic, rather than in the specific order in which statements were made.

More information about the meeting, including support materials, a recording of the meeting, and the PowerPoint, are available at <https://cadatasystem.wested.org/meeting-information/policy-analytics-advisory-group> (click on “Meeting Materials”).

The following individuals attended the meeting:

## **Policy & Analytics Advisory Group**

Su Jin Jez, California Competes; Evan White, California Policy Lab; Efrain Mercado, California Teacher’s Association; Samantha Tran, Children Now; Heather Hough, Policy Analysis for California Education; Jacob Jackson, Public Policy Institute of California; and Angela Perry, The Institute for College Access and Success.

## **Workgroup**

Randy Bonnell, California Department of Education; Akhtar Khan, California Department of Social Services; Jennifer Schwartz, California Health and Human Services Agency, Amy Fong & Rima Mendez, CSIS; Patrick Perry, California Student Aid Commission; and Ed Sullivan, California State University.

## **Clarifying the Proposal Options**

The meeting began with Kathy Booth of WestEd outlining the three options under discussion: making minor clarifications to the original proposal; delegating authority for approving unitary data requests to the Research Advisory Board; or eliminating the Research Advisory Board and having requests be approved by data providers. She also provided an update on the role of data providers in approving third-party research requests for personally identifiable information in Texas and Washington—in both cases data providers are part of the approval process, even though the state has delegated authority to either the managing entity or an advisory board.

Jennifer Schwartz of CHHS noted that, due to federal laws, authority cannot be delegated to an advisory board regarding the release of personally identifiable data. If California passes such a law, federal funding such as Medicaid could be jeopardized, and California could lose its ability to match data with the Social Security Administration. Furthermore, under federal law, medical providers need to be able to inform clients when and how their data are used, so CHHS cannot be removed from the approval process.

Several homework team members clarified their rationales for supporting specific options. Patrick Perry of CSAC felt that the first option created the possibility of ongoing conflict between the Research Advisory Board and data providers, and the legal implications of delegation eliminated option two. Option three is preferable because it is more realistic for the managing entity work with requestors to

prepare requests for review than a volunteer board. Also, option three protects the managing entity from being in conflict with data providers about approvals.

Evan White of California Policy Lab felt that option two was preferable because it could lead to more generous interpretations of FERPA than the typical stance of California state agencies.

Heather Hough of PACE suggested that the group consider the underlying concerns that had led to the proposal that the Research Advisory Board approve requests—namely that data providers could veto a decision that had gone through a public review process without good cause. For example, having the data providers be involved at the outset to review requests might help. But it is also important to have a larger group of people, which includes non-data providers, assess which proposals are accepted or denied.

### Role of the Managing Entity

The group considered whether it would be appropriate to delegate the work of refining requests to the managing entity, rather than tasking an advisory board with this work. The group was supportive of this option on several grounds:

- This process is already used successfully by entities like PACE
- The act of refining a request can be done in a neutral manner and will provide transparency into the data request process
- The managing entity will have a thorough understanding of the information available in the data system
- Having staff do the work on a daily basis, rather than once a month by volunteers, will be more efficient

However, Ed Sullivan of CSU was concerned that this could politicize the managing entity and create a log jam for requests. He noted that having a board with rotating members helps to integrate diverse perspectives into the review process, which can help to reduce politicization.

### Use of a Rubric

The group felt that the proposed rubric did not provide a value-add to the request review process.

Concerns included:

- Excellent research projects may not fit into the rubric, particularly for emerging issues
- Researchers might try to craft their proposals to fit the rubric in ways that make it difficult to assess the true intent of the project
- The managing entity will need to prioritize requests from stakeholders like the Department of Finance, Governor's Office, and Legislative Analysts Office, so these priorities should be expressly stated in the review process

Homework team members felt that it would be more valuable for the managing entity to provide a summary of the proposal, which could call out relevant features, such as whether the proposal is addressing a timely or urgent need. Rather than enshrine these factors in a rubric, the managing entity could highlight aspects of the proposal that would be relevant for the data provider.

## Data Providers' Roles in Approving Requests

Homework team members noted that the data request process should make clear that the intent is to approve allowable requests. Jennifer Schwartz of CHHS noted that requests are rarely denied based on health privacy laws if they have successfully passed an Institutional Review Board (IRB) process.

This stance is facilitated by:

- Clarity about what the request is for and how the data will be used
- Opportunities for data providers and requestors to work together to determine allowable means for providing information
- Fulfilling requests with summary data when possible, so FERPA and HIPAA constraints are not triggered

## Legal Expertise

The group discussed where legal expertise should be enshrined in the review process: with the managing entity, the Research Advisory Board, or the data provider.

Homework team members agreed that the managing entity will need legal expertise. Not only is this important for its own operations—such as contracts, legislation, and human resources—it would enable the managing entity to help requestors understand allowable circumstances for requesting unitary data.

Patrick Perry of CSAC urged care in hiring the lawyer for the managing entity and suggested that an individual be selected that takes a more permissive approach to data sharing, within legal limits. The Governing Board could examine the legal stance of the managing entity as one of its responsibilities.

Evan White of California Policy Lab indicated that non-lawyers could be involved in interpreting laws such as FERPA and HIPAA. However, Jennifer Schwartz of CHHS disagreed, noting that the laws had to be applied per subsequent court cases. Heather Hough of PACE wondered if a legal advisory board could weigh in on possible interpretations of the law, particularly in cases where requests are denied on legal grounds.

After some discussion, the group felt that it was not necessary to try to replicate the expertise of the data providers on the Research Advisory Board. Key ideas included:

- Lawyers provide information on a client's benefit, which is kept confidential. Asking lawyers to provide generic advice is not in keeping with their role.
- If the data providers have ultimate say over whether to release information, then it is duplicative to have that expertise on the Research Advisory Board.

Jennifer Schwartz of CHHS noted that for disclosure policy, suppressions, and reviewing reports to ensure there is no disclosure, a specific expertise is needed, which may not be the same as the expertise needed to determine whether data was mischaracterized.

## Public Role in Reviewing Requests

Akhtar Khan of CDSS noted that the public still needs to play a role in reviewing data requests, so that benefits for Californians and data actionability remain central to the process.

Heather Hough of PACE noted that, if the process is working as intended, there should be no problem with approving requests. However, a mechanism is needed in cases where that processes breaks down.

The homework team endorsed the use of the Data & Tools Advisory Board to provide this oversight, and recommended that the Research Advisory Board be eliminated from the data request review process.

Evan White of California Policy Lab suggested that the Data & Tools Advisory Board be tasked with annually reviewing the decisions made about access to unitary data and making recommendations for how to improve the request process. This review could also identify tools that would help requestors navigate the application process.

### Editing the Proposal

Homework team members will have until the end of October 20 to give final edits on the revised proposal. The final version will be posted on October 21 and presented to the workgroup by Evan White of California Policy Lab and Randy Bonnell of CDE (instead of Tom Vu, who could not attend the October 19 meeting) on October 29.