



Follow-up from [REDACTED] (at Stanford Law) re: scope of PRA request & 2 other issues discussed this morning

5 messages

To: "Scott, Jason@DDS" <Jason.Scott@dds.ca.gov>
Cc: [REDACTED]

Hi Jason,

I am glad we had a chance to touch base this morning. Going forward, I will keep in mind that you are rarely if ever reachable on your office phone because of the construction, so for the time being it is better to call you on your cell ([REDACTED]).

Below, I have summarized my understanding of where things stand on the three different "baskets" of issues we just discussed, so I can remind myself of what we discussed later on, and we can make sure we are on the same page.

These three baskets are: (1) clarifying scope of PRA (data) request in answer to questions posed by your staffers in IT department; (2) Clarifying next steps on more qualitative questions that are follow-ups on our meeting with your colleagues on Feb. 16th; and (3) Identifying the best person/people at DDS (in addition to [REDACTED] to help resolve issues around HIPAA (protecting security of high-risk protected health information) in preparation for submission of research protocol to the State Committee for Protection of Human Subjects. (We have been in dialogue with [REDACTED] about this for months now, but have learned that some portions of this process are outside her areas of expertise, so it might be wise to include others.)

Here are more details:

(1) Clarifying Scope of PRA Request

Below are responses (in black, bold, underlined type) to the questions posed by your staffers:

For Part A of the request, I'd like clarification as to whether the request for the number of consumers classified as status 2 (item 1) apply to all residence types.

For item 1, we need to redirect [REDACTED] to DSS, who has a part in SSI (Supplemental Security Income). See <http://www.cdss.ca.gov/inforesources/SSI-SSP>

RESPONSE: If possible, our preference would be to receive this information broken down by each residence type and status as well as total figures. (For example, one column or row in an Excel spreadsheet could correspond to each residence type and/or status, and a final row/column could provide total figures.)

And whether the request for counts by residential type (items 2-7) are for only status 2 consumers (item 1).

RESPONSE: For items 2-7, we would prefer to get this information separately for Status 2 consumers and other consumers (in two different spreadsheets if that is easier to manage). We realize that for many non-status 2 consumers, many of the "residence" cells will be empty. (For example, consumers who reside in developmental centers will not - by definition - reside at home). But all the same, if possible, it would be ideal to receive the data separately for Status 2 and non-Status 2 consumers.

Part B is as follows:

B. We are requesting annual data, for the past 10 years (2007-2017), disaggregated by Regional Center and by age (child or adult), the number of status 2 consumers:

1. receiving/enrolled in SSI;

RESPONSE: Are we correct in understanding that DDS does not maintain any data on the number of consumers who are enrolled in SSI or receive SSI? is the only data on consumers enrolled in SSI is collected by DSS? We know that many RC consumers use their SSI payments to help defray rental costs, so we thought there might be some records on the number who are receiving SSI payments maintained by DDS. But your reply suggests that that is not the case. If you can please confirm either way, that would be great.

2. receiving/enrolled in Medi-Cal (For item 2, should we include only those receiving POS?)

RESPONSE: If possible, we would prefer to receive this information separately for consumers that do and do not receive POS funds, and for Status 2 and Non-Status 2 Consumers (see comment above).

3. living in the community;

ADDITIONAL COMMENT: If possible, we would prefer to receive this information separately for consumers that do and do not receive POS funds, and for Status 2 and Non-Status 2 Consumers (see comment above).

4. enrolled in the 1915(c) HCBS Waiver;

ADDITIONAL QUESTION: We would like to confirm our understanding that *only* consumers that receive POS funds in any given year are on the 1915(c) HCBS waiver for that year. Is that correct?

5. enrolled in or receiving reimbursements through the 1915(i) HCBS State Plan Amendment;

ADDITIONAL QUESTION: We would like to confirm our understanding that *only* consumers that receive POS funds in any given year are on the 1915(i) HCBS State Plan Amendment for that year. Is that correct?

6. enrolled in/receiving Medi-Cal but not enrolled in either the HCBS 1915(c) Waiver or the 1915(i) State Plan Amendment.

For item 6, does “/receiving Medi-Cal” mean AND or OR receiving POS?

RESPONSE: If possible, we would prefer to receive this information (i.e., number of consumers receiving Medi-Cal but not enrolled in 1915(c) or 1915(i) programs) separately for consumers that do and do not receive POS funds, and for Status 2 and Non-Status-2 consumers.

(2) Clarifying Next Steps on More Qualitative Questions (follow-ups to last month's meeting)

I believe we discussed two questions that are more qualitative in nature, which were discussed at our meeting (or with other stakeholders) but for which we only have an approximate idea of what information DDS may or may not have. These two questions are the following:

- 1) The data/report mentioned during our meeting that contains various details, trends, totals and breakdowns on the issuance of Health and Safety waivers.
- 2) Any information the Department may have on the barriers to enrolling more consumers in either of these two federal programs (esp. 1915(c)), and strategies the Department has used in the past to increase enrollment in response to budget cuts (e.g., circa 2012).

My understanding is that you will check with your colleagues to see what additional information, if any, you might be able to provide on these two issues, whose meaning I tried to clarify during our phone call.

(3) Identifying Best Person/People with Whom We Should Consult on Protection of High-Risk Data (PHI) in Compliance with HIPAA

As we discussed, I have been preparing to submit a research protocol to the state IRB (Committee for Protection of Human Subjects) but first need to work out the best way to equip our system here at Stanford to handle PHI (Protected Health Information) in compliance with HIPAA. We have been in touch with Beth Hibbert on this issue, and are trying to arrange a joint conference call between Beth and others at Stanford (esp. Information Security Office) to make sure we are doing everything correctly. Beth has expressed a desire to include her Legal Staff in that meeting, which I think is wise. I know that this issue straddles several areas - IT, HIPAA compliance, and research/IRB issues - and am hoping to identify the right people upfront so we make the process as efficient as possible for everyone. Beth could be the correct person, but as we discussed, it might be helpful to bring in someone from IT and/or Legal as well.

Thanks again for your help, and please don't hesitate to reach out if I can provide any more clarification! I should be pretty accessible today and tomorrow.

Best,





