

AB 1296 Eligibility Expansion Stakeholder Workgroup  
Thursday, May 3, 2012  
Data Collection & Confidentiality Protections

Meeting Notes

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- Meeting was convened just after 1:00PM. Bobbie Wunsch (Pacific Consulting Group), the workgroup meeting facilitator, welcomed everyone to the meeting, introduced the goals of the workgroup session and facilitated introductions. See list of meeting attendees/represented organizations also posted on the [AB1296 webpage](#).
- Elizabeth Landsberg, Western Center on Law & Poverty, gave a brief presentation of what the ACA and AB 1296 say about data collection; specifically about race, ethnicity, primary language and disability status.
- Elizabeth also mentioned the limits on the types of information to collect that are only necessary to determine eligibility; however, the law also requires the application to have voluntary information that shall be used for data collection on race, ethnicity, primary language and disability status
- DHCS informed advocates that gender/sex is required on Medicaid applications.
- Len Finocchio, DHCS, introduced Ignatius Bau, consultant, who gave a [presentation](#) on data collection options. Mr. Bau's presentation is included with the meetings materials on the AB1296 webpage. Topics covered in the presentation included the importance of how questions are worded, where on the application form questions should be located, what response options are most user-friendly and examples were provided on how state and the federal government currently collection demographic data.
  - Advocates stated that "not-English proficient" isn't sufficient; that it is important to know what language an individual speaks proficiently.
  - Advocates stated there is a need for a visual presentation of the options which signals to the applicant how to answer the question.
  - Advocates requested that the question asking about language proficiency be part of the demographic information up front, as it is on the current application.
  - Advocates stated that there is a need for questions about disability that are not for medical reasons but for demographic measures.

- Advocates stated that the application needs to be accessible to disabled persons (i.e. large font, page readers, etc.)
- Mr. Bau discussed how ethnicity and race are different. The definition of race has been fluid, it's a social construct, not biological and has evolved over time.
- DHCS mentioned that we need to be mindful of the difference between an online application and a paper application. The online application provides us with many avenues to ask questions whereas the paper version is more limited; including every question asked on-line (i.e. using drop-down menus, etc) on a paper application often causes the paper version to be long and unwieldy.
- Advocates mentioned that there are 13 Medi-Cal threshold languages, 16 CDSS threshold languages and asked if we go back and revisit how we determine threshold languages.
- Cary Sanders, California Pan-Ethnic Health Network, representing the advocates, gave a [presentation](#) on recommendations for data collection. The presentation addressed the need for California to accurately collect the race/ethnicity of applicants, the use of drop down menus for user-friendliness and permitting applicants to list more than one race/ethnicity.
  - Advocates suggested that if applicants are told they are being asked these optional questions in order to improve their quality of care, they would be more likely to complete the optional questions.
  - Advocates suggested that perhaps asking applicants their preferred spoken language makes more sense than asking primary language. They questioned if it is important to capture the primary language on the application.
  - Advocates questioned what provisions will be available to specify language if someone is helping the applicant complete the application.
  - Advocates discussed accessibility in regards to how the state cannot assume that applicants are aware of what assistance is available.
  - Advocates stressed the importance of how questions are framed will directly correlate with the ease at which the applicant can answer the question.
  - The county consortia mentioned that in their experience with online applications, drop down boxes are easier to use with screen readers (a tool used by blind individuals).

- Advocates stressed there is a fine line between what is optional and what people need to answer to complete the application. Also, we need to ensure we aren't asking questions that are going to overwhelm the applicant and discourage him/her from completing the application.
- Advocates and the State had a brief discussion on the use of a granular level of detail for outreach, eligibility and enrollment and how this level of detail can benefit the applicant.
- Daniel Gould with Equality California, gave a presentation about sexual orientation. The presentation outlined the need for states to ask about sexual orientation, how the lesbian, gay, bisexual and transgender (LGBT) populations are more susceptible to certain types of diseases and the need to have policy in place to be able to address situations where someone marks themselves a certain gender on the application when their birth certificate identifies them as another gender.
- Steve Murata, Chief, Office of HIPAA Compliance, gave a brief overview [presentation](#) on HIPAA. The presentation outlined HIPAA and the protections that the law grants individuals.
- Terry Daffin, a representative of the Health Benefits Exchange gave a brief overview [presentation](#) on the CalHEERS IT security requirements. The presentation outlined the federal requirements for data protection and ways CalHEERS is planning on implementation of the requirements.
- Julie Silas, Consumers Union, and Kate Block, Center for Democracy and Technology, represented the advocates and gave a [presentation](#) on advocates' recommendations for data security and confidentiality.
- Advocates gave their recommendations for data security & confidentiality
  - Julie Silas gave a presentation on all aspects of advocate recommendations for data security and confidentiality.
  - Advocates asked if data could be used for eligibility purposes and then deleted as opposed to stored. The State mentioned the need to keep some data in the event of federal audits.
  - The Department gave a brief explanation of the Verification Plan provisions under 435.945 (j) of the final federal eligibility regulations.
  - Advocates stressed the importance of thinking about what we are collecting, what we need to collect and safeguarding what is collected.

- Advocates mentioned the need for future discussion on point of service, customer service and assistors; specifically, if an assistor makes a mistake, how it can be traced.
- Bobbie Wunsch conducted a wrap-up of the accomplishments of the meeting and the meeting was adjourned slightly after 4:00PM.