REPORT TO THE OREGON LEGISLATURE:

Race, Ethnicity, Language, and Disability (REAL+D) Data:
House Bill 2134 Baseline Assessment

JULY 2014

Oregon
Health
Authority

DHS
Oregon Department
of Human Services

Report to the Oregon Legislature:

Race, Ethnicity, Language and Disability (REAL+D) Data:
House Bill 2134 Baseline Assessment
July 2014

EXECUTIVE SUMMARY

Data collection and analysis are key tools for improving the health and well-being of a population. With high quality data, health and human service programs can engage in effective and targeted actions to improve access to services and related outcomes. Quality data help us understand community or client challenges and prioritize intervention and prevention strategies.

Differences in health and human services are often masked when programs combine data on diverse populations with dissimilar outcomes. As Oregon's population becomes more diverse, leaders face a growing need to understand how health and human service disparities are impacting Oregon's numerous population groups. Through more granular data collection, health and human service programs can more effectively identify and address community and population health and human services challenges.

Response to the data challenge

In response to a need identified in the State of Equity Report, the Department of Human Services (DHS) and the Oregon Health Authority (OHA) adopted the Race, Ethnicity, and Language (REAL) Data Policy in July 2012, setting a common standard for race, ethnicity and language data collection across all programs in both agencies. The effort to standardize data collection within the two agencies was advanced through the passage of HB 2134, which requires DHS and OHA to develop a standard for collection of race, ethnicity and language (REAL) data in conjunction with community stakeholders. The legislation also includes new requirements to standardize the collection of disability-related (+D) data.

HB 2134 Baseline Assessment

HB 2134 requires all programs of OHA and DHS that collect demographic data to report biennially to OHA on the following:

- Progress in implementing the REAL+D standards.
- Challenges to full implementation of the standards.
- Plan for addressing identified challenges.

To meet the HB 2134 requirements in 2014, DHS and OHA conducted a Baseline Assessment of current compliance with HB 2134 REAL+D data collection standards. The assessment included a survey of all identified DHS and OHA data systems, as well as the identification of barriers to compliance and next steps.

Key findings from the Baseline Assessment

Among 55 OHA datasets that collect demographic information:
- 87% currently collect data on client/respondent race and ethnicity. However, few datasets use the specific race/ethnicity options established by HB 2134 (e.g. "Laotian," "Hmong") and offer broad categories (e.g. "Asian") instead.
- 24% of datasets currently ask an open-ended race and ethnicity question.
- 65% use client/respondent identification of race and ethnicity, as opposed to staff-identified demographic information.
- 65% allow multiple race responses.
- 45% collect some data on client/respondent language.
- 16% collect data on client/respondent disability.

Among 14 DHS datasets that collect demographic information:
- 64% of the datasets collect data on race and ethnicity. Similar to OHA, most record information limited to a few broad race and ethnicity categories.
- 43% capture data on clients who choose multiple race and ethnicity categories.
- None of the DHS datasets include an open-ended field for race and ethnicity.
- 43% record client race and ethnicity through self-identification.
- 57% of the DHS datasets collect data on preferred spoken language.
- Ten systems (71%) collect data on client/respondent disability status. 14% collect the age at which the disabling condition began.

These findings support the need to standardize the collection of REAL+D data and provide key information for DHS and OHA leaders and stakeholders. Challenges to meeting the HB 2134 requirements include:
- funding;
- nationally-defined standards;
- external systems;
- staff discomfort; and
- client/respondent burdens or concerns.

However, plans to address these challenges include pursuing state and federal funding, assessing business processes for improvements and developing a staged business plan for implementation.

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I.   Introduction

Data collection and analysis are key tools for improving the health and well-being of a population. With high quality data, health and human service programs can engage in effective and targeted actions to improve access to services and related outcomes. Quality data help us understand community or client challenges, and prioritize intervention and prevention strategies.

Differences in health and human services are often masked when programs combine data on diverse populations with dissimilar outcomes. As Oregon's population becomes more diverse, leaders face a growing need to understand how health and human service disparities are impacting Oregon's numerous population groups. Through more granular data collection, health and human service programs can more effectively identify and address community and population health and human services challenges.

In 2000, the Governor's Racial and Ethnic Health Task Force identified data on racial and ethnic communities as key to supporting the State's efforts to eliminate health disparities in Oregon. Governmental and community groups, including the Oregon Health Policy Board, the Urban League of Portland and the Coalition of Communities of Color, reiterated this recommendation. These groups released several community-specific data reports to illustrate the disparities experienced by communities of color in Oregon.

On a national level, standardized race, ethnicity and language data collection policies have been recommended by the National Public Health and Hospital Institute, the National Association of Public Health and Health Systems and the National Partnership for Action to Eliminate Health Disparities.

State of Equity Reports
In 2011 and 2013, OHA and DHS published the *State of Equity Report[1],* documenting disparities experienced by communities of color in the delivery of health and human services. These reports improve understanding as to what disparities exist and how we can improve relationships with diverse communities. The reports also identify policy and program solutions that could be implemented to improve outcomes.

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[1] State of Equity Report, Phase 1 and State of Equity Report Phase 2 available at:
www.oregon.gov/oha/oei/Pages/soe.aspx

Additionally, these reports reveal significant inconsistencies in how the two agencies collected and captured health and human service data. In response to this challenge, the OHA and DHS Race, Ethnicity and Language Data Leadership Workgroup (formed in 2010 to publish the *State of Equity Report*) developed a policy to improve data quality by standardizing the collection of race, ethnicity and language (REAL) data.[2] The REAL Data Policy was adopted in July 2012, setting a common standard for REAL data collection across all programs in both agencies.

Legislation

To ensure that the policy met the needs of Oregon's diverse communities to understand and address their own health disparities, the Asian Pacific American Network of Oregon (APANO), as part of the HOPE Coalition and Oregon Health Equity Alliance, introduced HB 2134 in the 2013 legislative session. Passed with strong bipartisan support, the legislation requires DHS and OHA to develop a standard for collection of REAL data in conjunction with community stakeholders. The legislation also includes new requirements to standardize the collection of disability-related demographic data.

As a result of the legislation, OHA's Office of Equity and Inclusion convened a rules advisory committee of diverse stakeholders to finalize the standards. (See Appendix A for rules advisory committee roster). The collection and analysis of more detailed race, ethnicity, language and disability status (REAL+D) data is vital to promoting equity in health and human services for diverse populations in Oregon. The rules are located in OAR 943-070-0000 to 943-070-0070.

II.   OHA and DHS data collection

DHS and the OHA both established equity (service equity and health equity, respectively) as part of their Core Values. However, problems with data prevent both agencies from knowing the full extent of disparities and from measuring the impact of efforts to ensure equity.

This report reflects the results of a Baseline Assessment of OHA and DHS data system compliance with the HB 2134 REAL+D data collection standards (See Appendix B for REAL+D Baseline Assessment survey tool). Per HB 2134 and OAR 943-070-0000 to 943-070-0070, OHA will update the report every two years to document the advances made by DHS and OHA to bring all relevant data systems into compliance. Further, this report identifies barriers to compliance and suggests plans for action.

The Baseline Assessment documents numerous opportunities for improvement. The plan for compliance will remain general until both agencies complete a full assessment of barriers and a feasibility study of approaches and business plan.

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[2] Available at: www.oregon.gov/oha/oei/Documents/REAL_Data_Collection_Policy.pdf

III. Meeting the HB 2134 REAL+D Standards: Current status of data collection

OHA

HB 2134 requires all OHA datasets that collect, record or report demographic data to meet a set of common standards with regard to collection of REAL+D data. The HB 2134 Baseline Assessment identified 65 distinct OHA datasets through existing documentation of agency data systems and vetted the data system lists with division/office leadership, then surveyed the owner/manager of each (See Appendix C for a list of OHA Data Systems). With a 100% response rate, survey data identified 55 OHA datasets that collect some form of demographic data and are thus subject to HB 2134 REAL+D data collection standards.

Among these datasets, 87% currently collect data on client/respondent race and ethnicity. Most datasets, however, make use of broader categories (e.g. "Asian") than those established by HB 2134 (e.g. "Laotian," "Hmong"). Only 24% of datasets currently ask an open-ended race and ethnicity question, though compliance rates are better for other HB 2134 REAL+D standards such as always using client/respondent self-identification (65%) and allowing multiple race responses (65%). Less than half (45%) of OHA datasets collect some data on client/respondent language. Only 16% of OHA datasets currently collect any data on client/respondent disability.

DHS

The Office of Equity and Multicultural Services (OEMS) within DHS conducted a survey to collect data as part of the Baseline Assessment of compliance with HB 2134 REAL+D requirements. The assessment focused on 15 DHS data systems' capabilities to record specific data elements including various race, ethnicity, language and disability categories. Management staff representing the five major programs of DHS completed the survey. The survey collected data on all of the 15 systems in review (See Appendix D for a list of DHS Data Systems).

Based on the survey results, the majority of DHS data systems (93%) collect at least some demographic information. Only the Client Notice Writer System data system does not collect any client demographic information. However, the 14 systems subject to HB 2134 REAL+D data collection standard do not meet the granular level that the standard requires. For example, vocational rehabilitation systems collect more in-depth disability data while collecting less in-depth language data.
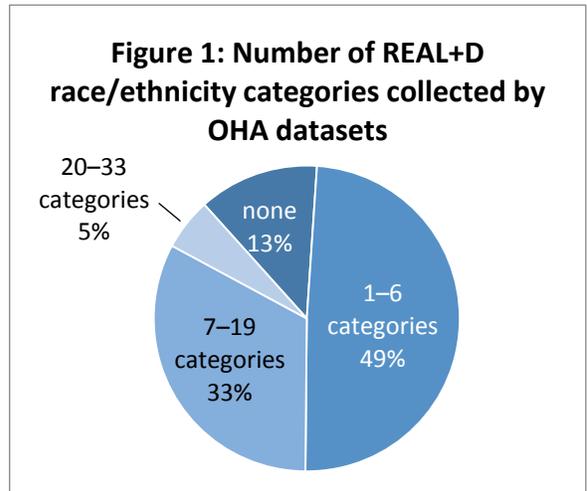
Racial or ethnic identity

OHA

HB 2134 requires datasets to collect an open-ended question with regard to race and ethnicity, and to list 33 distinct "racial or ethnic identity" categories. These categories and the percentage of OHA datasets collecting each are listed in Table 1.

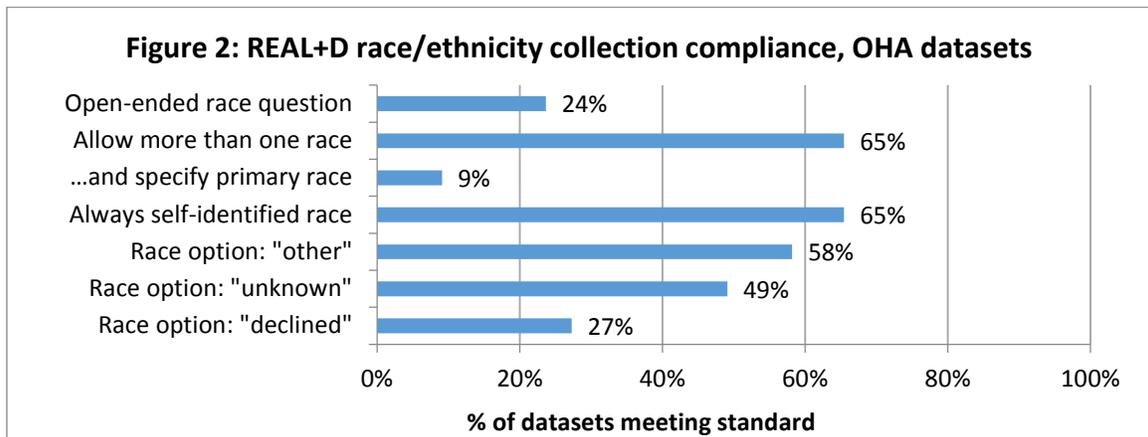**Table 1: REAL+D race and ethnicity category collection rate among OHA datasets**

American Indians / Alaska Natives	# collecting	% collecting
American Indian/Alaska Native (together)*	38	69%
American Indian	7	13%
Alaska Native	5	9%
Canadian Inuit, Metis or First Nation	0	0%
Indigenous Mexican, Central or South American	0	0%
Other Alaska Native*	0	0%
Other American Indian*	0	0%
Asians		
Asian*	40	73%
Filipino/a	15	27%
Japanese	13	24%
South Asian	4	7%
Chinese	15	27%
Vietnamese	10	18%
Korean	12	22%
Hmong	3	5%
Laotian	3	5%
Asian Indian	12	22%
Other Asian	15	27%
Blacks / African Americans		
Black or African American	40	73%
African	2	4%
Caribbean	2	4%
Other Black	3	5%
Native Hawaiians / Pacific Islanders		
Native Hawaiians/Pacific Islanders (together)*	28	51%
Native Hawaiian	14	25%
Pacific Islander*	7	13%
Samoan	11	20%
Guamanian or Chamorro	11	20%
Other Pacific Islander	11	20%
Hispanics / Latinos		
Hispanic or Latino*	30	55%
Mexican	16	29%
Central American	3	5%
South American	3	5%
Other Hispanic or Latino	14	25%
Whites		
White*	45	82%
Middle Eastern	2	4%
Northern African	2	4%
Western European	1	2%
Eastern European	2	4%
Slavic	2	4%
Other White	2	4%

*Category included in survey but not in HB 2134 Administrative Rules

The most commonly collected categories are White (82%), Asian (73%), and African American/Black (73%). Four American Indian/Alaska Native categories in the HB 2134 standard are not collected by any dataset, though several datasets do ask open-ended questions about race and/or tribal affiliation. Figure 1 shows the number of REAL+D categories collected by OHA datasets; most collect six or fewer categories.

Figure 1: Number of REAL+D race/ethnicity categories collected by OHA datasets

- 20–33 categories 5%
- none 13%
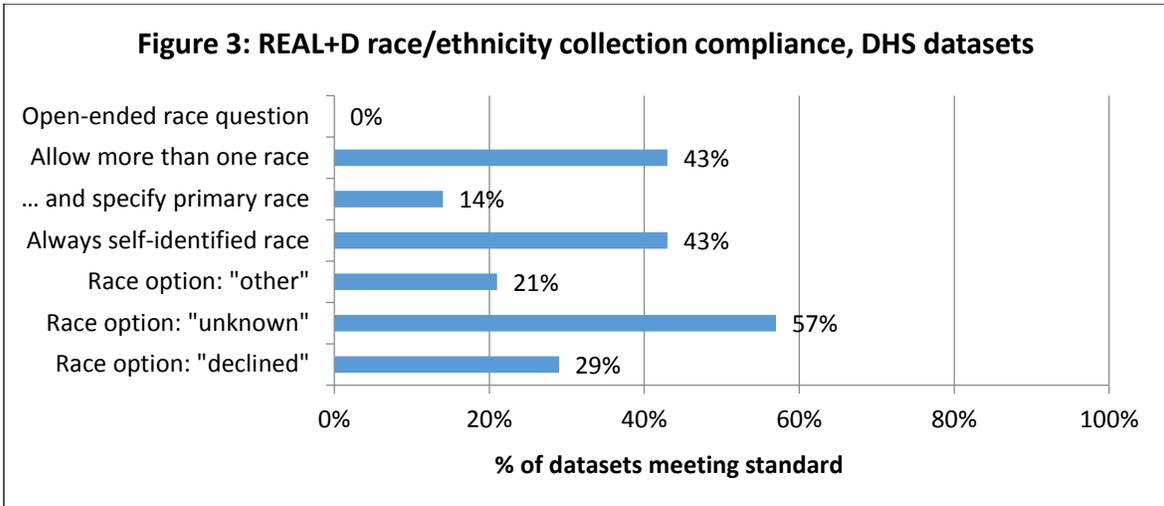- 7–19 categories 33%
- 1–6 categories 49%

HB 2134 also requires that clients/respondents be allowed to identify with more than one race, including a primary race identification, and that their race and ethnicity data is always based on self-identification. Clients/respondents should also be offered the race and ethnicity response options of "other," "unknown" and "declined to answer." The percentage of OHA datasets complying with each of these requirements is displayed in Figure 2.

Figure 2: REAL+D race/ethnicity collection compliance, OHA datasets

Category	% of datasets meeting standard
Open-ended race question	24%
Allow more than one race	65%
…and specify primary race	9%
Always self-identified race	65%
Race option: "other"	58%
Race option: "unknown"	49%
Race option: "declined"	27%

% of datasets meeting standard

DHS

There was a 100% survey response rate among DHS data systems. Over half, (64%) of the DHS data systems surveyed, collected information on the client's race and ethnicity. All nine of these data systems record information on the six broad race and ethnicity categories of American Indian/Alaskan Native, Asian, Native Hawaiian/Pacific Islander, Black/African American, Hispanic/Latino, and White/Caucasian. The 33 more specific racial/ethnic categories could not be computed due to a misinterpretation of the survey by respondents.
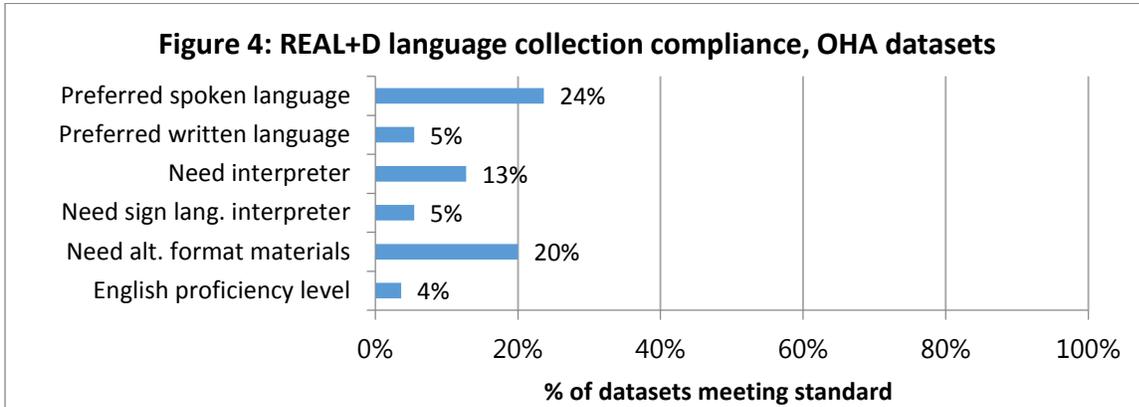
Figure 3 summarizes the percentage of the nine DHS data systems recording client race and ethnicity information that allow clients to enter other, unknown, and/or declined to answer as response options, as well as those that allow for multiple racial/ethnic response options, allow for a primary race/ethnic option, and allow clients to self-identify their race/ethnicity.

Figure 3: REAL+D race/ethnicity collection compliance, DHS datasets

Category	%
Open-ended race question	0%
Allow more than one race	43%
… and specify primary race	14%
Always self-identified race	43%
Race option: "other"	21%
Race option: "unknown"	57%
Race option: "declined"	29%

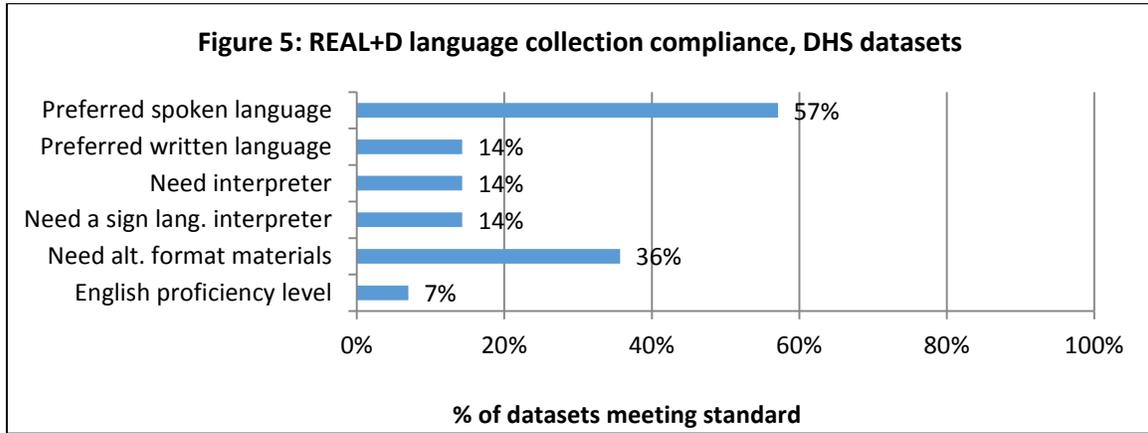% of datasets meeting standard

Language

OHA

HB 2134 requires that data collection asks clients/respondents for their preferred spoken language, preferred written language, need for an interpreter, need for a sign language interpreter, need for alternate-format written materials and English proficiency level. Forty-five percent (45%) of OHA datasets collect some information on client language. The percentage of OHA datasets complying with each of the HB 2134 REAL+D language standards is displayed in Figure 4. No OHA dataset currently meets all of the language standards.

Figure 4: REAL+D language collection compliance, OHA datasets

Category	%
Preferred spoken language	24%
Preferred written language	5%
Need interpreter	13%
Need sign lang. interpreter	5%
Need alt. format materials	20%
English proficiency level	4%

% of datasets meeting standard

DHS

Of the 14 DHS data systems collecting information on client demographics, nine (64%) collect data on client language. Figure 5 below summarizes the percentage of data systems

that collect client language information that is compliant with HB 21345 standards. No DHS dataset is compliant with all standards.
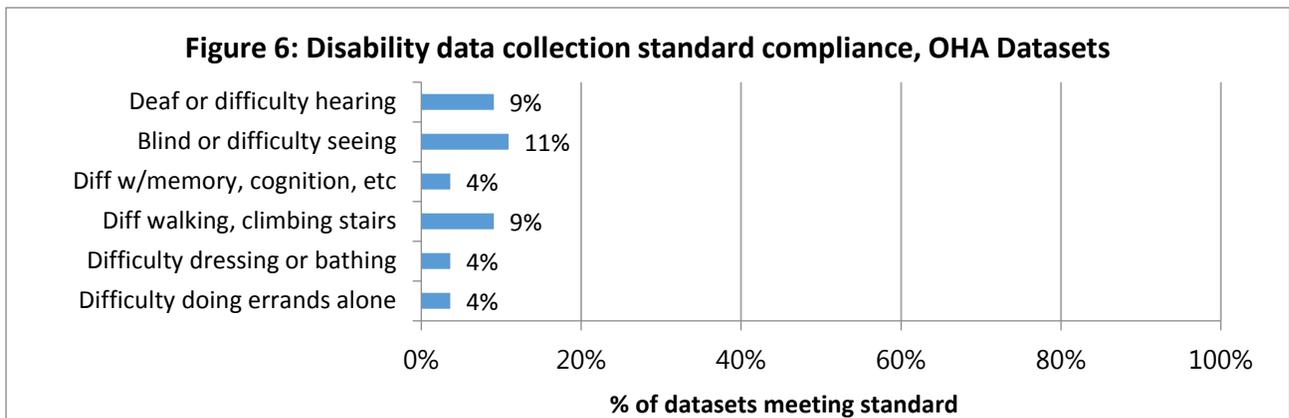
Figure 5: REAL+D language collection compliance, DHS datasets

Category	%
Preferred spoken language	57%
Preferred written language	14%
Need interpreter	14%
Need a sign lang. interpreter	14%
Need alt. format materials	36%
English proficiency level	7%

% of datasets meeting standard

Disability

OHA

HB 2134 requires asking clients/respondents if they are "limited in any way in any activities because of physical, mental or emotional problems." If clients/respondents answer "yes", they should be asked if they have difficulty hearing, difficulty seeing, difficulty concentrating, remembering, understanding or making decisions (for clients/respondents ages 5+), difficulty walking or climbing stairs (ages 5+), difficulty dressing or bathing (ages 5+), or difficulty doing errands alone (ages 15+). For each "yes" response to these questions, clients/respondents are also to be asked at what age the condition began.
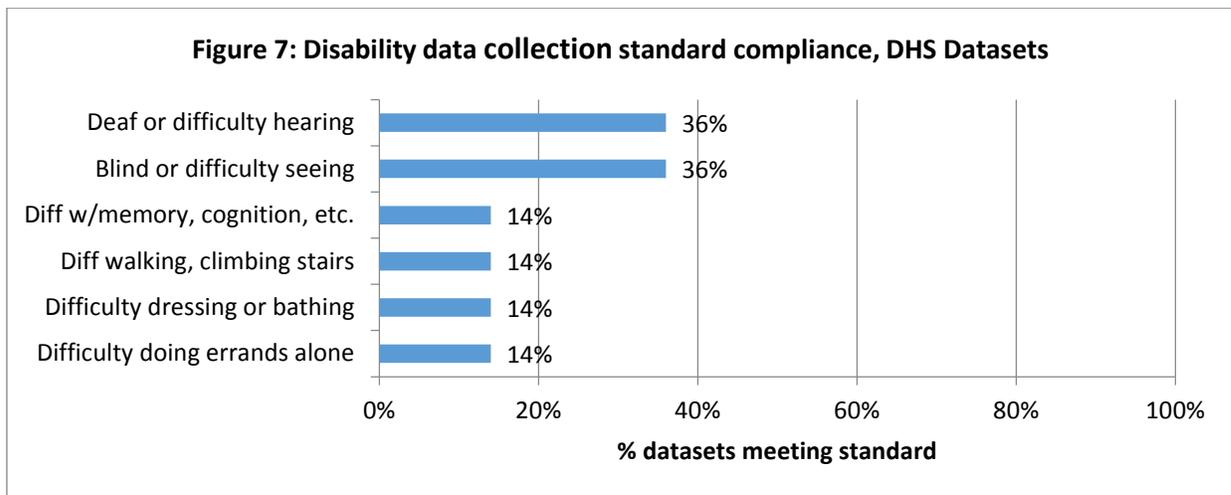
Only 16% of OHA datasets currently collect any information on client disability, and the percentage of OHA datasets complying with each HB 2134 REAL+D disability standard is displayed in Figure 6. No OHA dataset collects the onset age for any disability condition.

Figure 6: Disability data collection standard compliance, OHA Datasets

Category	%
Deaf or difficulty hearing	9%
Blind or difficulty seeing	11%
Diff w/memory, cognition, etc	4%
Diff walking, climbing stairs	9%
Difficulty dressing or bathing	4%
Difficulty doing errands alone	4%

% of datasets meeting standard

DHS

Out of 14 DHS data sets recording client demographic information, ten (71%) data systems collect information on client disability status. Figure 7 depicts the percentage of DHS data systems that are compliant with HB 2134 REAL+D standard in collecting disability information.

Two (14%) DHS data systems record at what age blindness or deafness began. One (7%) DHS data system records at what age the client began experiencing any of the other disability conditions.

Figure 7: Disability data collection standard compliance, DHS Datasets

Category	% datasets meeting standard
Deaf or difficulty hearing	36%
Blind or difficulty seeing	36%
Diff w/memory, cognition, etc.	14%
Diff walking, climbing stairs	14%
Difficulty dressing or bathing	14%
Difficulty doing errands alone	14%

% datasets meeting standard

IV.   Challenges to meeting HB 2134 requirements

Tremendous inconsistencies exist in the data that different government, health and human service agencies, and agency programs collect. Even the definition of the terms "race," "ethnicity" or "disability" vary across key government and health and human service institutions (e.g. Census, Office of Management and Budget, Institute of Medicine, Oregon Health Care Quality Corporation, etc.). In addition, agency and contractor staff often lack training in best practice methodology for collecting race, ethnicity, language and disability demographic information in a respectful, non-intrusive manner. Inadequate data collection standards make it difficult to analyze how race, ethnicity and language impact individual and community health. This makes services addressing community needs more expensive and less effective. Improving data systems is a key component of continuous quality improvement efforts that lead to health and service equity.

Contributing to these challenges are the number, age, stability, and variety in the nimbleness of numerous data systems within OHA and DHS. Differences in the mandated federal and funding partner requirements on specific data categories and the manner of reporting add to the variety and complexity of the systems. For example, some federal programs require staff to assign a race or ethnicity category to clients who decline to answer these demographic questions. The adopted standard requires staff to identify when they assign

race, ethnicity and other demographic data to a recipient of services. OHA and DHS must identify resources to invest in extensive system upgrades, business process redesign and staff training to meet data collection standards.

Implementation challenges

Responders to the HB 2134 Baseline Assessment were offered the opportunity to provide general feedback about HB 2134 implementation, and a number of survey responses included such feedback. Themes and specific concerns expressed in this feedback included:

- Lack of additional funding associated with HB 2134 implementation;
- Rigid and/or external data systems:
  o Datasets and/or collection processes based on nationally-defined standards;
  o Data gathered from external systems (such as clinics) with their own structures and standards; and
  o Obsolete data systems that will be phased out rather than upgraded.

- Data collection experience:
  o Additional burden/annoyance to clients/respondents by lengthening interviews or forms;
  o Staff uncomfortable asking some questions in data collection scenarios that are brief/limited or that lack any ongoing relationship with the responder; and
  o Responder concerns over confidentiality of personal information.

- Specific concerns:
  o Young children unable to self-report race and ethnicity;
  o Pregnant women may meet certain criteria for physical disability (difficulty walking, running errands); and
  o Race and ethnicity categories may be too granular for statistical inference and sometimes confusing.

Plans to address challenges

Addressing the inconsistency in data collection standards involves understanding and adjusting current business processes, and training staff. It also means revising Information Technology (IT) systems that collect, maintain, and report on REAL+D data to conform to the new standards.

During the remainder of the 2013–2015 biennium, a DHS and OHA workgroup established with the purpose of implementing HB 2134 will perform a more in-depth analysis to inform the implementation plan. The Baseline Assessment identified 69 systems that are impacted by HB 2134. In-depth analysis is required to confirm these estimates and identify business processes and stakeholders that will benefit from improved systems. The three-stage process includes the following overarching activities:

1. Conduct a complete and in-depth inventory audit of all systems, business processes, programs and stakeholders that collect, maintain and use REAL+D data.

2. Identify any current projects that may be impacted by the REAL+D requirements.

3. Working with the Office of Information Services, develop a roadmap and a staged business plan that conforms to new state processes AND addresses the people, process and technology components to bring DHS and OHA into compliance with the REAL+D standard.

Based on known challenges, DHS and OHA have submitted a Policy Option Package to address findings from the Baseline Assessment and facilitate improvements identified through the three-stage process outlined above. The Policy Option Package supports architecting and implementing a master client data collection solution. This will support current and future unified client data collection requirements to address health and human service equity for all programs and activities within DHS and OHA. The proposed activities address both the business and technical changes required to create a unified, sustainable model for collecting client data across both agencies.

Intended outcomes include:

- OHA and DHS data systems will be user-friendly for collecting detailed demographic data and sufficiently nimble to allow for updates in the race, ethnicity, language and disability standard over time.

- Staff and contractors for OHA and DHS will increase competence in consistently and respectfully collecting race, ethnicity, language and disability data.

- Race, ethnicity, language and disability demographic information will consistently be recorded by OHA and DHS data systems.

- Missing data and insufficiently granular data points will be eliminated to support more robust analysis of survey, service and outcomes metrics. Granular data will be easily aggregated to more general federal reporting categories.

- Effective analysis of OHA and DHS data by race, ethnicity, language and disability will identify disparities, target opportunities for continuous quality improvement and track progress toward achieving service and health equity.

- Standardized data collection methodology will improve the ability of OHA and DHS, community stakeholders, elected officials and other decision makers to recognize, address, target and eliminate disparities experienced by distinct racial, cultural and linguistic communities, and by people with disabilities.

Using this comprehensive plan for action, DHS and OHA will continue to make important advancements toward having sufficient data available for agencies, programs, communities of color and the disability community. This will support the state, health and human service systems partners and community stakeholders in developing quality improvement efforts, ensuring appropriate funding, determining priorities, and eliminating health and human services disparities in Oregon.

Appendices

        A. HB 2134 Rules Advisory Committee
        B. REAL+D Baseline Assessment Survey Tool
        C. OHA Data Systems
        D. DHS Data Systems

Appendix A: REAL+D Rules Advisory Committee

- Jesse Beason, Northwest Health Foundation

- Ann Curry-Stevens, Portland State University, School of Social Work

- Victoria Demchak, Oregon Primary Care Association

- Nafisa Fai, Multnomah County Health Department

- Dr. Dena Hassouneh, OHSU School of Nursing

- Tim Holbert, Program Design and Evaluation Services

- Willi Horner-Johnson, OHSU Institute on Development and Disability

- Bob Joondeph, Disability Rights Oregon

- Marjorie McGee, Portland State University School of Education, Regional Research Institute

- Julia Meier, Coalition of Communities of Color

- Alberto Moreno, Latino Health Coalition

- Andrew Riley, Center for Intercultural Organizing

- Joseph Santos-Lyons, Asian Pacific American Network of Oregon

- Karis Stoudamire Phillips, Moda Health

- Claudia Vargas, Cornelius Vision For An Accessible Community

- Victoria Warren-Mears, Northwest Portland Area Indian Health Board

- Maija Yasui, Hood River Commission on Children and Families/PacificSource Columbia Gorge CCO

Appendix B: REAL+D Baseline Assessment survey tool

House Bill 2134 Baseline Assessment Survey

Passed by the 2013 Oregon Legislature, House Bill 2134 (HB 2134) requires the Oregon Health Authority (OHA) and Department of Human Services (DHS) to standardize the collection of data on race, ethnicity, language, and disability (REAL-D). In addition, HB 2134 requires OHA and DHS to submit a biennial progress report to the legislature on policy implementation. This survey will help inform the first legislative progress report due July 2014 and will serve as a *baseline* for measuring progress on implementation. It is not expected that all OHA and DHS data systems will currently be in compliance with the HB 2134 Oregon Administrative Rules.

SURVEY DEADLINE: Noon on July 13th - Please complete a separate survey for each dataset you manage. The survey should take less than 10 minutes.

Survey notes:

We have used the word 'dataset' to describe all data systems that are being assessed in this survey.

Depending on the answers you provide, additional questions may appear on the same page.

It is recommended that you have a copy of how your dataset collects REAL-D data as you answer the questions.

For questions about completing this survey, please contact Kristen Rohde at 971-673-0592 or kristen.rohde@state.or.us.

Read the HB 2134 Oregon Administrative Rules here.

- General Information -
1. Name of dataset that you are providing information on (remember to complete a separate survey for each dataset you manage): [text box]

2. Your name: [text box]

3. Your Agency, Division/Office, and program: [text box]

4. Your phone number: [text box]

5. Your e-mail address: [text box]

6. Does your dataset collect any information on client/respondent demographics including, but not limited to: age, gender, address, race/ethnicity, language, or disability? [yes/no]
   If yes: proceed to 7
   If no: skip to end

- Race and Ethnicity -
7. Does your dataset collect information on client/respondent **race and ethnicity**? [yes/no]
   If yes: proceed to 7.1.0
   If no: skip to 8, Language section

7.1.0 Does your dataset collect information on **American Indians/Alaska Natives**? [yes/no]
   If yes: proceed to 7.1.1
   If no: proceed to 7.2.0
7.1.1 Which of the following specific categories are used in your dataset to collect information on **American Indians/Alaska Natives**? [check all that apply]
   American Indian/Alaska Native (listed or read together)
   American Indian
   Alaska Native
   Canadian Inuit, Metis or First Nation
   Indigenous Mexican, Central or South American
   Other Alaska Native
   Other American Indian
   Some other category (specify): [text box]

7.2.0 Does your dataset collect information on **Asians**? [yes/no]
   If yes: proceed to 7.2.1
   If no: proceed to 7.3.0
7.2.1 Which of the following specific categories are used in your dataset to collect information on **Asians**? [check all that apply]
   Asian
   Filipino/a
   Japanese
   South Asian
   Chinese
   Vietnamese
   Korean
   Hmong
   Laotian
   Asian Indian
   Other Asian
   Some other category (specify): [text box]

7.3.0 Does your dataset collect information on **Native Hawaiians/Pacific Islanders**? [yes/no]

If yes: proceed to 7.3.1
If no: proceed to 7.4.0

7.3.1 Which of the following specific categories are used in your dataset to collect information on **Native Hawaiians/Pacific Islanders**? [check all that apply]

Native Hawaiian/Pacific Islander (listed or read together)
Native Hawaiian
Pacific Islander
Samoan
Guamanian or Chamorro
Other Pacific Islander
Some other category (specify): [text box]

7.4.0 Does your dataset collect information on **Blacks/African Americans**? [yes/no]
If yes: proceed to 7.4.1
If no: proceed to 7.5.0

7.4.1 Which of the following specific categories are used in your dataset to collect information on **Blacks/African Americans**? [check all that apply]

African American
African
Caribbean
Other Black
Some other category (specify): [text box]

7.5.0 Does your dataset collect information on **Hispanics/Latinos**? [yes/no]
If yes: proceed to 7.5.1
If no: proceed to 7.6.0

7.5.1 Which of the following specific categories are used in your dataset to collect information on **Hispanics/Latinos**? [check all that apply]

Hispanic or Latino
Mexican
Central American
South American
Other Hispanic or Latino
Some other category (specify): [text box]

7.6.0 Does your dataset collect information on **Whites/Caucasians**? [yes/no]
If yes: proceed to 7.6.1
If no: proceed to 7.7.0

7.6.1 Which of the following specific categories are used in your dataset to collect information on **Whites/Caucasians**? [check all that apply]

White
Middle Eastern
Northern African
Western European

Eastern European
Slavic
Other White
Some other category (specify): [text box]

7.7.0 Are clients/respondents in your dataset allowed to identify with **more than one race**? [yes/no]
        If yes: proceed to 7.7.1
        If no: proceed to 7.8
7.7.1 Are clients/respondents in your dataset who identify with more than one race asked a **primary race** identification question? [yes/no]

7.8 Are clients/respondents in your dataset offered any of the following response options when asked about their race/ethnicity? [check all that apply]
        Other
        Unknown
        Declined to answer

7.9 Are clients/respondents in your dataset asked an **open-ended question** on race and ethnicity? (i.e., clients/respondents are writing or typing their answer, rather than checking race and ethnicity boxes) [yes/ no]

7.10.0 Are the racial and ethnic data in your dataset **always** based on client/respondent **self-identification**? (i.e., the data are reported by the client/respondent and not assessed by someone else) [yes/no]
        If yes: proceed to 7.10
        If no: proceed to 7.9.1
7.10.1 How is the racial and ethnic data of your clients/respondents determined in your dataset? For example, is race/ethnicity determined by an interviewer? [text box]

7.11 Anything else you would like to tell us about racial and ethnic data in your dataset? [text box—not required]

- Language -
8. Does your dataset collect information on client/respondent language? [yes/no]
        If yes: proceed to 8.1
        If no: proceed to 9, disability section

8.1 Does your dataset record client/respondent preferred **spoken language**? [yes/no]

8.2 Does your dataset record client/respondent preferred **written language**? [yes/no]

8.3 Does your dataset record if a client/respondent needed an **interpreter**? [yes/no]

8.4 Does your dataset record if a client/respondent needed a **sign language interpreter**? [yes/no]

8.5 Does your dataset record if a client/respondent needed **written materials in an alternate format**? [yes/no]

8.6.0 Does your dataset record client/respondent **English language proficiency**? [yes/no]
    If yes: proceed to 8.6.1
    If no: skip to 8.7.0
8.6.1 When **English language proficiency** is recorded, what categories are used in your dataset? (e.g. How well do you speak English? Very well, well, not well, not at all) [text box]

8.7.0 Does your dataset collect information on client/respondent language in some other way? [yes/no]
    If yes: proceed to 8.7.1
    If no: proceed to 8.8
8.7.1 In what other way(s) does your dataset collect information on client/respondent language? [text box]

8.8 Anything else you would like to tell us about language data in your dataset? [text box—not required]

- Disability -
9. Does your dataset collect information on client/respondent **disability**? [yes/no]
    If yes: proceed to 9.1.0
    If no: proceed to 10

9.1.0 Does your dataset record if a client/respondent is **deaf or has serious difficulty hearing**? [yes/no]
    If yes: proceed to 9.1.1
    If no: proceed to 9.2.0
9.1.1 When your dataset records a client/respondent is **deaf or has serious difficulty hearing**, does it also record at what age this condition began? [yes/no]

9.2.0 Does your dataset record if a client/respondent is **blind or has serious difficulty seeing**, even when wearing glasses? [yes/no]
    If yes: proceed to 9.2.1
    If no: proceed to 9.3.0
9.2.1 When your dataset records a client/respondent is **blind or has serious difficulty seeing**, does it also record at what age this condition began? [yes/no]

9.3.0 Does your dataset record if a client/respondent, because of a physical, mental, or emotional condition, has serious difficulty **concentrating, remembering, understanding, or making decisions**? [yes/no]

       If yes: proceed to 9.3.1
       If no: proceed to 9.4.0

9.3.1 When your dataset records a client/respondent has serious difficulty **concentrating, remembering, understanding, or making decisions**, does it also record at what age this condition began? [yes/no]

9.4.0 Does your dataset record if a client/respondent has serious difficulty **walking or climbing stairs**? [yes/no]

       If yes: proceed to 9.4.1
       If no: proceed to 9.5.0

9.4.1 When your dataset records a client/respondent has serious difficulty **walking or climbing stairs**, does it also record at what age this condition began? [yes/no]

9.5.0 Does your dataset record if a client/respondent has difficulty **dressing or bathing**? [yes/no]

       If yes: proceed to 9.5.1
       If no: proceed to 9.6.0

9.5.1 When your dataset records a client/respondent has difficulty **dressing or bathing**, does it also record at what age this condition began? [yes/no]

9.6.0 Does your dataset record if a client/respondent, because of a physical, mental, or emotional condition, has difficulty **doing errands alone such as visiting a doctor's office or shopping**? [yes/no]

       If yes: proceed to 9.6.1
       If no: proceed to 9.7.0

9.6.1 When your dataset records a client/respondent has difficulty **doing errands alone such as visiting a doctor's office or shopping**, does it also record at what age this condition began? [yes/no]

9.7.0 Does your dataset collect information on client/respondent disability in some other way? [yes/no]

       If yes: proceed to 9.7.1
       If no: proceed to 9.8

9.7.1 In what other way(s) does your dataset collect information on client/respondent disability? [text box]

9.8 Anything else you would like to tell us about disability data in your dataset? [text box—not required]

10. Anything else you would like to share regarding the implementation of HB 2134 requirements for the collection of REAL-D data in your dataset, including any challenges you foresee? [text box—not required]

Thank you for taking the time to complete this survey. Your responses will assist OHA and DHS in the implementation of HB 2134. Please contact Kristen Rohde at kristen.rohde@state.or.us with any questions.

Appendix C: OHA Data Systems

Adolescent Suicide Attempt Data System	ALERT (Oregon Immunization Information System) IIS
All Payers, All Claims Database (APAC)	Ambulatory Surgical Center (ASCs) Discharges
Automated Survey Processing Environment (ASPEN)	Behavioral Risk Factor Surveillance System (BRFSS)
Birth Certificates	Breast & Cervical Cancer Program (BCCP)
Client Maintenance (CM) System	Client Process Monitoring System (CPMS) and CPMSE Forms
Consumer Assessment of Health Plans Survey (CAHPS)	Death Certificates
Decision Support/Surveillance & Utilization Review System (DSSURS)	Dialysis Technicians
Dissolution of Domestic Partnership	Divorce
Domestic Partnership	Early Hearing Detection and Intervention (EHDI)
Electronic Surveillance System for the Early Notification of Community-Based Epidemics (ESSENCE)	Employee BRFSS (BSSE)
EMS Patient Encounter Database	Family Planning (Title X and CCare)
Fetal Death Records	GENIS
Health Alert Network (HAN)*	Health care Volunteer Registry (SERV-OR)*
Health Care Workforce Database	Health care Acquired Infections
Hospital Capacity Web System (HOSCAP)*	Hospital Discharge Data (HDD)
Induced Terminations of Pregnancies (iTOP)	Lead Poisoning Database
Licensing for EMS Providers and Ambulance Agencies (License 2000)	Marriage
Measures and Outcomes Tracking System (MOTS)	Medicaid BRFSS
MHSIP Survey for Adults	Newborn screening
Oral Health Surveillance System: SMILE Survey	Oregon Health Insurance Survey (OHIS)
Oregon Healthy Teens (OHT)	Oregon Medical Marijuana Data System (OMMR)
Oregon Patient/Resident Care Systems (OPRCS, OP/RCS)	Oregon Public Health Epidemiology User System (ORPHEUS)
Oregon School Health Profiles Survey (SHPS)*	Oregon State Cancer Registry (OSCaR)
Oregon Trauma Registry	Oregon Violent Death Reporting System (OVDRS)
Physician Orders for Life Sustaining Treatment (POLST)	Pregnancy Risk Assessment Monitoring System (PRAMS, PRAMS-2)
Prescription Drug Monitoring database (PDMP)	Public Employees Benefits Board (PEBB)
Radioactive Materials Licensing (RML)*	Safe Drinking Water Information System (SDWIS)*
SafeNet (211 and Oregon SafeNet)	School-Based Health Center (SBHC) Encounter
School-Based Health Center (SBHC) Patient Satisfaction Survey*	SPIDER
Student Wellness Survey	Tanning Registrations*
WISEWOMAN	Women Infant Children (WIC) Data System TWIST
X-Ray Registration*	Youth Services Survey
Youth Sexual Health Cuidate Evaluation database	

Appendix D: DHS Data Systems

Caseworker Automated Processing Interface (CAPI)	Express Payment and Recording System (eXPRS)
Child Welfare Data Warehouse and Reporting (CSDM)	Medicaid Management Information System (MMIS)
Client Index System (CI)	Oregon Access (Non-CAPS)
Client Maintenance System (CM)	Oregon ACCESS (CAPS)
Client Notice Writer System (CN)	Oregon Rehabilitation Case Automation (ORCA)
Client Process Monitoring System (CPMS)	Refugee Administration System
DD Eligibility System	Service Authorization System
Decision Support Systems and Surveillance Utilization Review System (DSSURS)	