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DIVISION 70

RACE, ETHNICITY, LANGUAGE, AND DISABILITY DEMOGRAPHIC DATA **COLLECTION STANDARDS**

943-070-0000

Purpose

These rules establish uniform standards and practices for the collection of data on race, ethnicity, preferred spoken or signed and preferred written language, and disability status by the Oregon Health Authority (Authority) and Department of Human Services (Department). Standardized data collection methodology will improve the ability of the Authority, Department, community stakeholders, elected officials, and other decision makers to recognize, address, target and eliminate inequities experienced by distinct racial, cultural, and linguistic communities, and by people with disabilities. Based on local, state, and national best practices, these standards allow the Authority and Department to meet federal reporting expectations; compare Oregon's progress with national trends; improve quality service delivery; and ensure equitable allocation of resources.

Stat. Auth.: ORS 413.042 & 413.161 Stats. Implemented: ORS 413.161

Hist.: OHA 2-2014, f. & cert. ef. 3-10-14

943-070-0010

Definitions (will come back to this last after firm up changes, etc)

The following definitions apply to OAR 943-070-through 943-070-0070:

- (1) "American Indian/Alaska Native" is a federal demographic category meaning an individual having their origins in any of the original peoples of North, Central or South America who maintains tribal affiliation or community attachment, including an individual that is:
- (a) An individual defined as "Indian" at 25 USC 1603(13), 1603(28), or 1679(a), or who has been determined eligible as an Indian, under 42 CFR 136.12. This means the individual is a member of a federally recognized Indian tribe or resides in an urban center and meets one or more of the following criteria:
- (i) Is a member of a tribe, band, or other organized group of Indians, including those tribes, bands, or groups terminated since 1940 and those recognized now or in the future by the state in which they reside, or who is a descendant, in the first or second degree, of any such member;
- (ii) Is an Eskimo or Aleut or other Alaska Native;
- (iii) Is considered by the Secretary of the Interior to be an Indian for any purpose;
- (iv) Is determined to be an Indian under regulations issued by the Secretary of the Interior.
- (b) Considered by the Secretary of the Interior to be an Indian for any purpose or is considered by the Secretary of Health and Human Services to be an Indian for purposes of eligibility for Indian health care services, including as a California Indian, Eskimo, Aleut, or other Alaska Native.

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- (c) A member of the Indigenous People of Canada and Latin America with origins in any of the original peoples of Canada, Mexico, Central America and South America.
- (2)"African" means an individual identifying with or descending from any of the racial groups of Africa whose national origin is from a country on the continent of Africa.
- (3) "African American or Black" is a federal demographic category meaning an individual identifying with or descending from any of the black racial groups of Africa.
- (4)"Asian" is a federal demographic category meaning an individual identifying with or descending from any of the original peoples of East Asia, Southeast Asia, or South Asia including Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.
- "Authority" means the Oregon Health Authority.
- "Contractor" means a person or governmental entity who has a legal agreement with the Authority or Department to provide goods or services.
- "Declined to answer" is a demographic designation used when the individual actively chooses not to provide information on their race or ethnicity.
- "Demographic data" means collected information related to age, gender, race, ethnicity, preferred (6) spoken, signed and written language, and disability status. Demographic data under these rules will be collected for the purpose of better understanding populations who interact with the Authority and the Department.
 - (7) "Department" means the Department of Human Services.
- (I 0) "Disability" means a condition meeting the criteria for establishing that an individual has a disability under ORS 659A.104.
- (11) "Ethnicity" means a demographic designation for a group of people sharing a culture that includes race, religion, language, and other cultural characteristics including ancestry or country of origin.
- (12) "Hispanic or Latino" is a federal demographic category meaning an individual of Cuban, Mexican, Puerto Rican, Dominican, South or Central American, or other Spanish culture or origin, regardless of race.
- (13) "Race" means a demographic designation for a group of people who share a common heredity.
- (a) Race includes shared ancestry, national origin and sociocultural characteristics.
- (b) Race is not a biological, anthropological or genetic distinction.
- (14) "Native Hawaiian or Other Pacific Islander" is a federal demographic category meaning an individual having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.
- (15) "Other" means an individual identifies with a demographic designation not listed.

- (16) "Primary racial or ethnic identity" means the race or ethnicity with which an individual most identifies when opting to choose from multiple designations.
- (17) "Subcontractor" means a person or governmental entity who has a legal agreement with a contractor as that is defined in this rule, to provide goods or services.
- (18) "Unknown" means a category used when a demographic designation is missing for some reason other than the individual declining to answer and includes, but is not limited to situations where:
- (i) The individual or caregiver is unable to provide an answer; or
- (ii) There is no available family member or caregiver to respond for the individual.
- (19) "White" is a federal demographic category meaning an individual having origins in any of the original peoples of Europe, excluding the Middle East or North Africa. It includes people who indicate their race as "White" or report entries such as Irish, German, Italian, Lebanese, Arab, Moroccan, or Caucasian.

(20)Middle Eastern and North African (MENA) includes people who report Middle Eastern entries such as Bahrain, Cyprus, Iran, Iraq, Israel, Jordan, Kuwait, Lebanon, Oman, Palestine, Qatar, Saudi Arabia, Syria, Turkey, United Arab Emirates and Yemen. And North African entries such as Algeria, Libya, Egypt, Morocco and Tunisia.

Stat. Auth.: ORS 413.042 & 413.161 Stats. Implemented: ORS 413.161 Hist.: OHA 2-2014, f. & cert. ef. 3-10-14

943-70-15 Accessibility and modifications (NEW SECTION)

- (1) Data collection tools used to gather the information required by these rules shall comply with the Americans with Disabilities Act (ADA) and Oregon statute, rule and policy related to the ADA, the provision of language access, and the advancement of health equity.
- (2) Data collection methods, such as anonymous surveys, surveys with youth, or phone surveys, shall account for the need to gather data from individuals with disabilities, non-English speakers and individuals with other access barriers and shall not be used to exclude subgroups of people based on the need to gather information from those subgroups differently.

943-070-0020

Demographic Data Collection Standards

(I) To the greatest extent practicable, all programs and activities of the Authority and Department, including activities to promote workforce diversity within the Authority and Department, Agency and Department licensees, and boards and commissions staffed by the Authority and the Department, that collect, record or report any demographic data through any means shall collect race, ethnicity, preferred spoken, signed and written language, and disability status data in accordance with these rules

and implementing policy.

 asked;

• And how often they should

Stat. Auth.: ORS 413.042 & 413.161 Stats. Implemented: ORS 413.161

Hist.: OHA 2-2014, f. & cert. ef. 3-10-14

(2) To the greatest extent practicable, contractors and subcontractors, who collect, record or report any demographic data on behalf of the Authority and Department shall collect race, ethnicity, preferred spoken, signed and written language, and disability status data in accordance with these rules and implementing policy

- (3) To the greatest extent practicable, the Authority, the Department, and-contractors and subcontractors should ask individuals to self-report race, ethnicity, preferred signed, written and spoken language and disability status information.
- (a) Authority, Department, contractor and subcontractor staff shall not assume or judge ethnic and racial identity, preferred signed, written and spoken language, or disability without asking the individual.
- (b)If an individual is unable to self-report and a family member, advocate, or authorized representative is unable to report on his or her behalf, the information shall be recorded by staff as unknown.
- (c) When a demographic category is listed as unknown, demographic data shall be requested at a subsequent encounter.
- (4) When an individual declines to identify race or ethnicity or preferred signed, written, or spoken language, or disability status the information shall be reported by staff as declined to answer.
- (5) When the race, ethnicity, signed, written or spoken language or disability status of an individual is required by federal law and an individual is unable or unwilling to self-report, this information shall be recorded in the data collection instrument and additionally identified as "staff determined," and combined with the "unknown" category for state level analysis.
- (6) Requests for demographic information shall be distinct from questions related to program eligibility criteria and an individual's decision not to answer questions related to demographic data shall not affect eligibility or inclusion in any related program or benefit-
- (7) Nothing in these rules shall be construed to prohibit the collection of information for purposes of establishing eligibility for a specific program or service.
- (8) Need text Need text to specify **addition of temporal field** to capture when the REALD questions were asked:
 - And how often they should be reviewed and asked again (e.g. annually)
 - Exception one-time data collection events such as the OHIS phone survey.

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48 49 Race and Ethnicity Demographic Data Collection Standard

- (1) To the greatest extent practicable, Authority, Department, contractor and subcontractor staff gathering demographic data from an individual shall ask open-ended questions designed to elicit an unprompted response related to ancestry, race, ethnicity, country of origin or tribal affiliation.
- (2) At minimum, the demographic data categories in this section shall be listed with the identifying label of "Racial or ethnic identity" on data collection and intake forms. These categories are designed to aggregate to existing federal reporting categories as those categories are defined in these rules.
 - American Indian (a)
 - (b) Alaska Native
 - (c) Canadian Inuit, Metis or First Nation
 - Indigenous Mexican, Central American or South American (d)
 - Hispanic or Latino Mexican
 - (t) Hispanic or Latino Central American
 - Hispanic or Latino South American
 - Other Hispanic or Latino
- (i) Chinese (new) Cambodian
 - (i) Vietnamese
 - (k) Korean
 - Hmong (1)
 - (m) Laotian (n)Filipino/a
 - (o)Japanese
- (new) Communities of Myanmar?
- (p) South Asian
- (q) Asian Indian
- Other Asian
- Native Hawaiian (s)
- Guamanian -
- (new) Chamorro (new) Communities from Micronesia (? - Marshallese/Micronesian/Palauan)
- Samoan (new) Tongan
- (u) Other Pacific Islander
- (v) African American
- (new) Ethiopian (new) Somali
- (new) Other Black African
- Caribbean (Black)
- (w) Other Black

- (dd) Middle Eastern
- (ee) Northern African

5 (aa) Western European

(bb) Eastern European

(new) Slavic and/or Eastern European

(cc) Slavic

(fl) Other White

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- (gg) Other
- (hh) Unknown
- (ii) Decline to Answer
- (3) The Authority and Department shall instruct individuals, either in writing or verbally, that more than one racial or ethnic category may be chosen.
- (i) All individuals who select multiple categories shall be asked an additional question regarding their primary racial or ethnic affiliation using the categories listed in section (2).
- (a) Individuals may decline to select a primary racial or ethnic identity.
- (b) Individuals shall be given the opportunity to indicate they do not have just one primary racial or ethnic identity.
- (4) Staff and contractors gathering demographic data from an individual shall ask: Are you a member of a federally recognized tribe? (yes/no). If yes, which tribe(s):
- (5) Staff and contractors gathering demographic data from an individual shall ask: Are you eligible, as an American Indian or Alaska Native, to receive services from the Indian Health Service, a Tribal Health Clinic, or an Urban Indian Health Program?

Stat. Auth.: ORS 413.042 & 413.161 Stats. Implemented: ORS 413.161

Hist.: OHA 2-2014, f. & cert. ef. 3-10-14

943-070-0040

Communication Demographic Data Collection Standards for client or service based settings

- (1) To the greatest extent practicable, staff and contractors gathering demographic data shall ask open-ended questions designed to elicit an unprompted response related to preferred spoken, signed and written language.
- (2) At minimum, the following questions shall be included on data collection and intake forms for client/service-based settings
- (a) In what language do you want us to speak with you? (age 5 and above unless there is a need to communicate directly with the child)

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- (b) In what language do you want us to write to you? (age 5 and above unless there is a need to communicate directly with the child)
- (c)Do you need or want an interpreter for us to communicate with you? (age 5 and above unless there is a need to communicate directly with the child)

(c)you need a sign language interpreter?

- (3) For each "yes" response to the interpreter questions, the individual shall be asked what type of interpretation is needed (The agencies provide templates to support this work).
- (4) If the person does not answer the preferred language questions in this section, the response option in online systems shall indicate "did not answer"; the use of English as the default answer is not acceptable.
- (5) Data collection tools using online platforms shall avoid the use of 'other' categories, such as Other African languages, and shall instead provide an option for the person to write in their preferred language.

Stat. Auth.: ORS 413.042 & 413.161 Stats. Implemented: ORS 413.161

Hist.: OHA 2-2014, f. & cert. ef. 3-10-14

943-070-0045 (NEW SECTION- could also combine with 0040 on previous page) Communication Demographic Data Collection Standards for all settings other than client or service based settings

- (1) At minimum, the following questions shall be included on data collection and intake forms for all settings other than those covered by the rules in section 943-070-0040 for client or service-based setting.
- (a) Do you speak a language other than English at home? (age 5 and above). There are four answer categories: yes, no (I speak English at home), unknown (or don't know), decline (or don't want to say
- (i) If the person says yes to (1)(a), the individual is asked
- (a) If yes, what is this language?
- (b) What language would you prefer to use when speaking with someone outside the home about important matters such as medical, legal, or health information)?
- (c) What language would you prefer to use to read important written information such as medical, legal, or health information?
- (2)In all situations except those described below (new 0080 section below) individuals are asked:
- (a) Do you need written materials in an alternate format? If yes, which? (age 5 and above)
- (b) How well do you speak English? (age 5 and above) There are four answer categories: Very well, well, not well, and not at all.
- (3) If the person does not answer the preferred language question in this rule, the response option in online systems shall indicate that the individual "did not answer."
- (4) Data collection tools using online platforms shall avoid the use of 'other' categories, such as Other

African languages, and shall instead provide an option for the person to write in their "language choice" or "choice for each available category".

943-070-0050

Disability Demographic Data Collection Standards

- (I) To the greatest extent practicable, Authority, Department and contractor or subcontractor staff gathering demographic data from an individual shall ask "Are you limited in any way in any activities because of physical, mental, or emotional problems?" Individuals may answer yes, no, don't know, or decline to answer.
- (2) The following set of questions shall be asked to identify sub-groups of individuals with disabling conditions.
- (a) Are you deaf or do you have serious difficulty hearing?
- (b) Are you blind or do you have serious difficulty seeing, even when wearing glasses?
- (c) Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, understanding or making decisions? (ages 5 years and older)
- (d) Do you have serious difficulty walking or climbing stairs? (ages 5 years and older)
- (e) Do you have difficulty dressing or bathing? (ages 5 years and older)
- (f) Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (ages 15 years and older) OR for youth under age 21 self-reporting: Because of a physical, mental, or emotional condition, do you have difficulty meeting your friends alone or going to the mall? (ages 15 years and older)
- (g) (new) Using your usual (customary) language, do you have (serious) difficulty communicating, (for example understanding or being understood by others)?
- (h) (new) Do you have serious difficulty learning how to do things most people your age can learn? OR Did you have difficulty learning in school or learning how to read or write?
- (i) new) Do you have serious difficulty with your mood, feelings, or controlling your behavior?
- (3) For each "yes" response, the individual shall be asked at what age the condition began.
- (9) Need text here...will be added to make sure current age (or dob) is captured so that length of time can also be determined by the analyst.

943-070-0060

Reporting Progress on Implementation

(1) All programs of the Authority and Department that collect demographic data shall report to the

(a) Progress in implementing these standards.

(a) Frogress in implementing these standards

(b) Challenges to full implementation of these standards.

(c) Plan for addressing challenges, including identifying responsible staff and timeline,

(2) The Office of Equity and Inclusion and Office of Equity and Multicultural Services shall use data provided by the programs to create a report for the legislature as required by ORS 413.162.

Office of Equity and Inclusion or Office of Equity and Multicultural Services, as appropriate, in

February of each even numbered year. Reports shall include information about each program's:

Stat. Auth.: ORS 413.042 & 413.161 Stats. Implemented: ORS 413.161 Hist.: OHA 2-2014, f. & cert. ef. 3-10-14

943-070-0070

Advisory Committee

(1) The Authority and Department may create and implement shared or parallel definitions, policies, processes and practices that expand on the minimum criteria of these rules.

(2) The Authority, in collaboration with the Department, shall appoint a permanent standing advisory committee composed of individuals or advocates of individuals likely to be affected by the inequities addressed in the collection of race, ethnicity, preferred spoken, signed and written language, and disability status data.

(3) The committee required by this section shall advise the Authority and Department about the creation of definitions, policies, procedures and practices to implement these rules, including recommendations related to:

(a) Protocols for collecting data in consistent, meaningful, culturally-competent ways.

(b) Protocols for protecting client privacy in compliance with state and federal law.

(c) The addition of demographic data subcategories for collection of more accurate and comprehensive data.

(d) Training.

(4) The Authority, in collaboration with the Department and the advisory committee shall review the standards at least once every two years from June 1, 2014, to ensure the standards are up to date, efficient, uniform and consistent with best, promising and emerging practices.

Stat. Auth.: ORS 413.042 & 413.161 Stats. Implemented: ORS 413.161

Hist.: OHA 2-2014, f. & cert. ef. 3-10-14

943-070-0080 (NEW SECTION)

Publishing using REALD data – applies to OHA and DHS staff only

- (1) Publishing in this section refers to the reporting of summary data with demographic information that is made available to the public.
- (2) While the federal government or other entities may require data to be reported according to the Office of Management and Budget (OMB) standards, staff from the Authority, Department, and their contractors or subcontractors who report demographic data alone or in combination with other data elements shall do so using the detailed REALD data categories while still protecting the privacy of individuals represented in the data. When reporting according to OMB standards is required, staff should roll up REALD data categories into OMB categories as shown in the Implementation Guide crosswalk.
- (a) MENA roll-up to OMB standards specify how
- (b) If there is a need to suppress detailed REALD demographic data before publication in order to protect confidentiality, the researcher shall follow the guidelines for suppressing or aggregating data categories specified in Section Five of the REALD implementation guide. The researcher shall consider aggregating data to the lowest level possible before it becomes necessary to suppress data due to small cell sizes.

Marjorie's notes to consider – do we include staggered compliance dates – esp for those systems that already were in compliance and now would need to do substantive changes? And how do we also consider the type of changes – substantive vs non-substantive?