

Guide to Asking Participants for Demographic Data:

Intake Part 2 – Client Info



Adapted from the Oregon Health Authority and their “REALD Response Matrix”; updated 3/7/2024.

Purpose of this Guide:

This document provides IDA Staff some best practices and sample responses when asking IDA Participants questions about their Race and Ethnicity, Language, Functional Difficulties, and Gender.

Recommended messaging for *why* we collect demographic data:

“We ask all clients the following questions about race, language, disability, and gender. IDA providers use this information to improve services in our communities and understand who is able to access IDAs. Your answers do not affect your eligibility and are confidential. Your individual answers are not shared with local, state, or federal government.”

Best practices:

Transparency: Explain that we ask this of everyone, to improve services in our communities and understand who is able to benefit from IDAs.

After Eligibility: Clearly label that this is not part of eligibility. Ask demographic questions after eligibility is determined.

Respect Self-Identification: Recognize the value of allowing a client to self-identify. Give time and space. Avoid rushing. Allow people to respond and use as much of their own descriptions as possible.

Follow Up: Follow up with clients as needed. For example, if the form is returned to you blank, ask the client to read through and answer the questions. Clients need to provide their responses, after approval of their IDA, as part of the intake process.

Offer Choice: If after hearing your explanation a person continues to be reluctant to answer a question, let them know they can always mark “don’t want to answer” and move on. Knowing that “don’t want to answer” is an option can sometimes restore a sense of agency for the client.

Feel free to use your own style and wording, as long as you are sharing accurate information.

Remember that by asking these questions, even if we cannot address all the barriers or accessibility needs that may come up in them, we are opening our programs to the work of advancing equity.

What *not* to say:

- “I’m asking you these questions because the State says I have to.”
- “This will help us hire staff to better meet your needs.” (These questions aren’t being asked solely for the participant’s benefit, but to inform the Initiative overall.)
- Avoid starting with “If you want, you can just mark ‘don’t want to answer’”.

What to say:

- “This will help us make sure that everyone receives the highest quality of services.”
- “We appreciate the opportunity to know a little more about each of our IDA clients as you enter the program.”

If a person takes offense to the questions:

- Acknowledge their feelings or experiences.
- Refocus on the here and now.
- Ask if they would like to come back to these questions another time, then shift to other questions or take a break.

Some ways to name what you are noticing in their emotions:

- *I think I may have asked a question you're not comfortable with. It's your choice to answer it or not; we ask everyone the same questions.*
- *I can see that it doesn't make sense to you why we'd ask these types of questions. I get that. It's your choice to answer it or not; we ask everyone the same questions.*
- *I can see that you're really not happy that we're asking these questions. I get that. It's your choice to answer it or not; we ask everyone the same questions.*

General Questions

Participant: Why are you asking me all these questions?

These questions were designed to help us identify and address avoidable differences in IDA services. We collect the same information from everyone. [If client continues to be hesitant:] You can always select "don't want to answer."

Participant: How should I answer this question?

Let's read the question together. I can't tell you how to answer the question. You should answer however you are most comfortable answering. [If client continues to be hesitant:] If you are uncomfortable answering the question, you can always select "don't want to answer." If you don't know, you can choose "don't know" or "unknown."

Participant: I don't know.

It's OK not to know and I'm happy to give you some time to think about it if you want. You can answer however you are most comfortable answering. [If client continues to be hesitant:] Do you want to choose "don't know" or "unknown" as your response?

Participant: It's none of your business.

I understand why you might feel that way. It is important that we have the opportunity to hear from everyone. You can always select "don't want to answer".

Participant: Will my answers to these questions affect my ability to get an IDA?

Absolutely not! Your responses will not negatively impact your IDA or your eligibility for other benefits in any way.

Participant: Who looks at this information?

Only staff involved in the IDA program will see this information. This information is used for reporting and evaluation purposes—to understand who is and is not getting access to IDAs, and to improve services for everyone. Your name or other personal information are not used for reporting or evaluation. It will not impact your services or ability to receive benefits in any way.

Participant: Will you provide accommodations based on the information I provide here?

When possible, yes. Our goal is to do whatever we can to support a successful IDA experience. Can you tell me more about what accommodations would be helpful for you?

Language

Participant: Why are you asking me about preferred language?

While we do not have services available in all languages, whenever possible, we want to provide you information in a language that best meets your needs. This also helps us understand what languages we might need to translate materials in for future clients.

Participant: Why are you asking me how well I speak English?

This question helps us understand whether there is a language barrier, since most services and materials are provided in English. Understanding this will help us improve services for everyone. It is OK to choose “don’t want to answer.”

Race and Ethnicity

General guidelines if you are walking a participant through the form:

- Provide an intro to the questions:
 - *We are going to ask you a couple questions about race and ethnicity. Before we get into specific categories, we ask everyone a general question first. This question asks how you identify yourself, so you can answer in your own words.*
- When asking the question about racial categories, begin by asking:
 - “Which one or more of the following would you say is your race?”
 - Read each of the category headings, for example, “Hispanic and Latino/a/x”, “Native Hawaiian and Pacific Islander”, etc.
 - If the respondent chooses a category, read/review the subcategories associated with this group.

Participant: Are you trying to find out if I’m a US citizen?

No. IDAs are available to anyone who lives in Oregon, regardless of citizenship. Also, we do not share any information with immigration authorities.

Participant: I was born in X (e.g. Nigeria), but I’ve really lived here all my life. What should I say?

That is up to you. You can use any term you want. It is fine to say that you are X (e.g., Nigerian), or to say something else.

Participant: I’m American.

Would you like to use an additional term, or would you like to just put American?

Participant: Can’t you tell by looking at me?

We find it is better to let people tell us. We don’t want to assume anything about how people want to describe themselves. If you don’t identify with any of the choices, you can choose “other” or “don’t want to answer.”

Participant: Why do you care? We’re all human beings.

Thank you, I understand that you feel that way. There is a lot of evidence that people are treated differently based on race or ethnicity. Your responses will help us make sure everyone is treated fairly.

Participant: I’m human.

Yes. Did you want to choose one of the existing categories, fill something in as “other”, or choose “don’t want to answer?” You are welcome to choose multiple categories as well.

Functional Difficulties

What *not* to say:

- “These next 4 questions ask if you are disabled.” (Avoid using the word ‘disability’ unless the other person brings it up first.)

What to say:

- “These next 4 questions ask about functional difficulties.”

Participant: Why are you asking me about disability?

This will help us make sure that everyone receives the highest quality of services. We ask everyone the same questions to help us identify and address avoidable differences in access and services.

If the participant states that they have a disability within their description of their condition, you can suggest that they can answer “yes” to the applicable question. Example:

- **Participant: I have a learning disability.**
Thanks for letting me know. It’s fine to check “yes” for “serious difficulty concentrating, remembering, or making decisions.” Does that feel accurate?

If the participant is unsure if they should say “yes” to a question containing the words “serious difficulty,” ask if the condition causes serious difficulty. Example:

- **Participant: Well, I have attention deficit disorder (ADD).**
Does that cause you serious difficulty concentrating, remembering or making decisions?

If the participant describes a characteristic associated with the limitation, refer to the question at hand. Example:

- **Participant: I forget to take my medication sometimes.**
Would you say that you have serious difficulty remembering?

Deaf or hard of hearing

Participant: I have a hearing loss but it’s not a problem with my hearing aids.

Probe to see if the hearing aids corrects serious difficulty hearing. Example: “Even with the hearing aid can you hear well when there is a lot of background noise or when someone is speaking softly?”

Participant: Sometimes I can’t hear when it’s noisy...

Probe to see if this is specific to certain settings such as rock concerts (where everyone would have the same difficulty hearing).

Blind or serious difficulty seeing, even when wearing glasses

Participant: I can see well enough to do X (e.g., drive a car, read a normal sized newspaper). -or- With my glasses or contacts I don’t have a problem seeing.

It’s fine to check “no” if you can see well with glasses or contact lenses.

Walking or climbing stairs

Participant: I get around fine with my wheelchair (or with my crutches, or other mobility devices).

It's fine to check "yes" if without those you would have difficulty walking or climbing stairs.

- Anyone who has a prosthetic body part or needs to use an assistive device such as a wheelchair should respond "yes" to this question. This is regardless of how much their difficulty is eased by assistive devices.

Difficulty remembering, concentrating, or making decisions

Participant: Yes, when I am under a lot of stress.

Would you say that it's because of a physical, mental or emotional condition that you have serious difficulty remembering, concentrating, or making decisions?

Gender

Participant: Why do you have all these options?

Having more than two options allows us to better understand the gender of our participants in order to identify and address avoidable differences in access and services.

Participant: What does "non-binary" mean?

"Non-binary" is an identifier used by a person that does not identify as a man or a woman. People whose gender is not male or female can use many different terms to define their gender, with "non-binary" being the most common.

- [Click here to learn more.](https://transequality.org/issues/resources/understanding-non-binary-people-how-to-be-respectful-and-supportive) (https://transequality.org/issues/resources/understanding-non-binary-people-how-to-be-respectful-and-supportive)

Participant: What does "two-spirit" mean?

"Two-spirit" is a modern umbrella term used by some Indigenous North Americans to describe their gender.

- [Click here to learn more.](https://archive.ncai.org/policy-research-center/initiatives/Pruden-Edmo_TwoSpiritPeople.pdf) (https://archive.ncai.org/policy-research-center/initiatives/Pruden-Edmo_TwoSpiritPeople.pdf)

Participant: This question seems silly. I can select multiple options? Why are you asking?

We want to understand who we're serving and give people options that make sense for them. You can choose whichever option you want.