

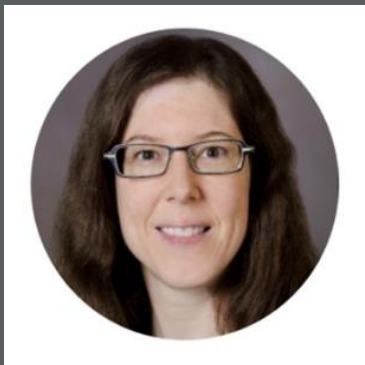


What's right for me?

Support for making choices about starting or expanding a family

Presented by: Kye Doran & Alix Herer

Who we are



Willi Horner-Johnson,
PhD
OHSU Professor
Principal Investigator



Alix Herer
Community Partner Lead



Kye Doran, MPH
Project Coordinator

In the chat:

1. What best describes your role?

- IDRPP or UCEDD staff
- Case Manager, Service Coordinator, or Personal Agent
- Researcher or other professional
- Self-Advocate
- Something else

What we'll talk about today

- Background info on sex, pregnancy and disability
- Reproductive life planning (RLP)
 - What is it?
 - Why is it important?
- What we are working on to support RLP
- How to get involved

Myths about sex and disability

- People with I/DD are not sexual
- People with I/DD can't control their sexual urges
- People with I/DD can't be parents

Result

- Limited opportunities to learn and talk about sex, pregnancy, or parenting

Sex happens

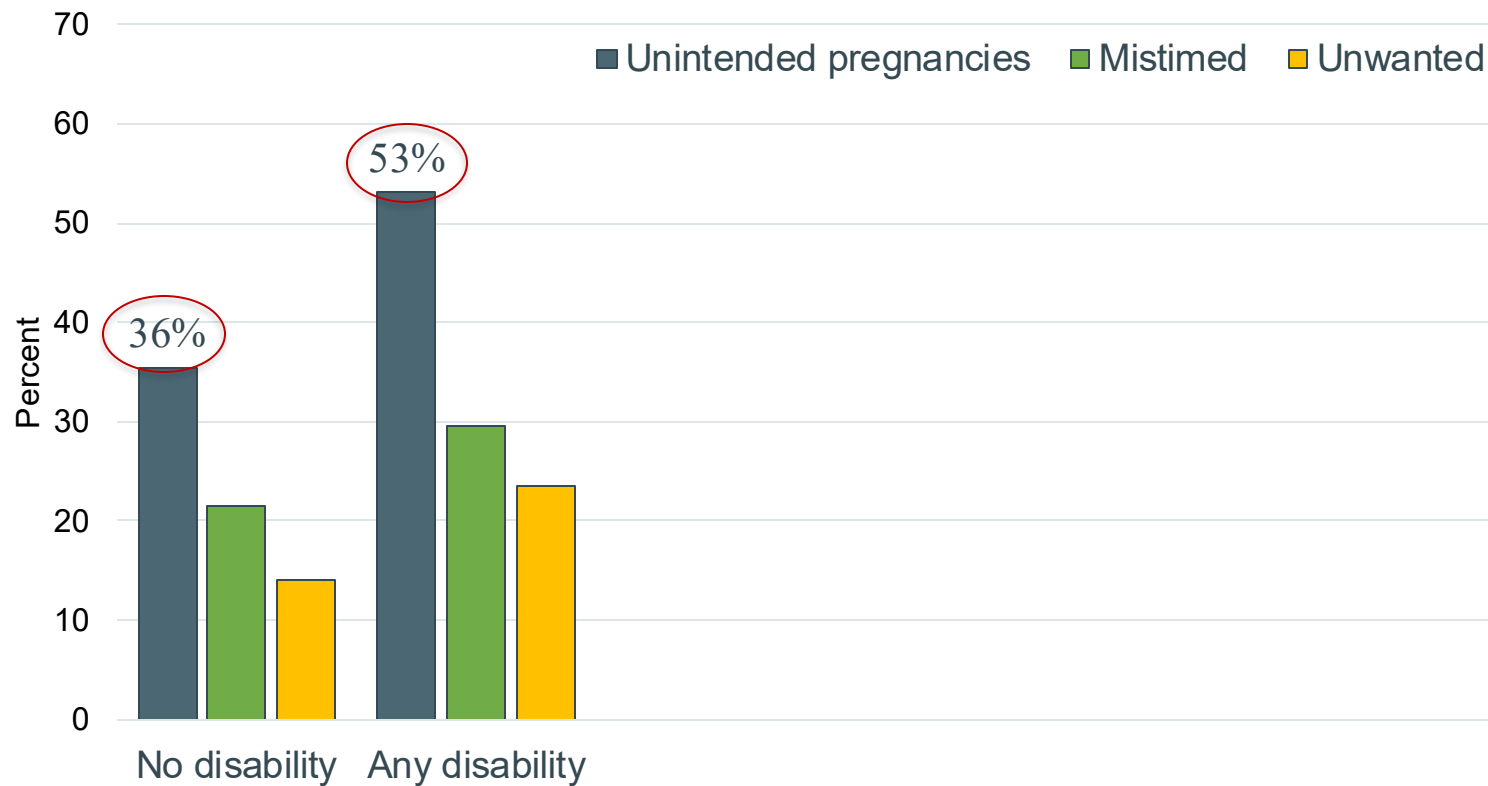
- People with I/DD have same sexual desires and desire to form intimate relationships
- If we don't talk about it:
 - Not preparing people to make good decisions
 - Not preparing for what might happen
 - Outcomes may not be ideal

Poll Question #1

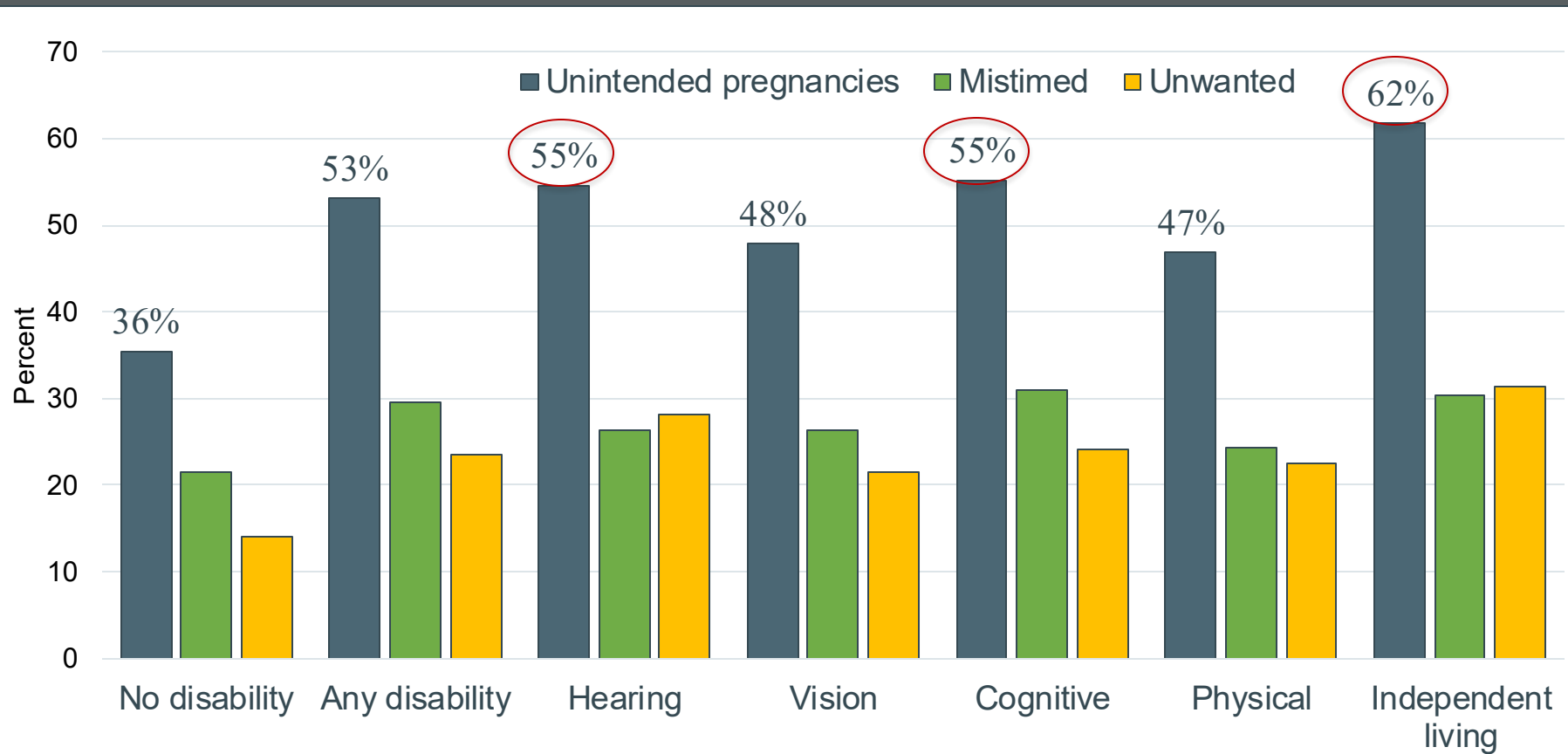
2. Compared to pregnancies in the general public, pregnancies among women with intellectual/developmental disabilities are:

- More likely to be planned
- Less likely to be planned
- About the same
- I don't know

Unintended pregnancies



Unintended pregnancies



Health before pregnancy

- Less likely to receive certain types of health care
- More exposure to interpersonal violence
- Lower income
- Less stable housing
- Less social support
- More health risks (obesity, mental distress)

Reproductive Life Planning (RLP)

- Personal goals about having or not having children
- Identify ways to support reproductive goals
 - Do I want to be a parent someday?
 - When do I want to start a family?
 - Do I want more children?
 - What do I do if I never want children?

Barriers to RLP

- Access
 - Not offered information – harmful misconceptions
 - Caregivers family members uncomfortable discussing topic
 - Limited control over contraceptive and reproductive choices
 - Presumed heterosexuality

Barriers to RLP

- Easy to understand materials
 - Materials not adapted for user
 - Plain language
 - Braille/low-vision materials
 - Sign language
 - AAC

Pregnancy Decisions App Project

Create a phone app to:

- Help make choices about getting pregnant or not
- Provide information to help with RLP goals
 - How to prepare for a healthy pregnancy and parenting
 - Birth control options

- The following are the reasons you said were true for you. In this activity, you will rank these from most to least important.
- Drag and drop each reason.



Most Important

⋮ I am worried about my health (for example, I am worried about how being pregnant or having a baby may affect my mental health; I am worried about how being pregnant or having a baby may affect my physical health)

⋮ I don't have the support I need right now (For example, from my family or friends or caregivers)

⋮ I want to be a parent

⋮ I love children

Least Important



Pregnancy Decisions App Project

- Downloadable/print out summary of user's preferences, questions and resources
 - Plain Language
- Conversation starters for talking to their doctor

Project steps



Interviews to learn how people make decisions about getting pregnant or not getting pregnant



National survey to learn what is most important to include in the app



Making and testing the app

Where we are now:

- Completed interviews with women with I/DD
- Completed interviews with case managers
- Recruiting women with I/DD for online survey
 - 215 complete; 300 goal
- Developing app prototype – in early accessibility testing



National survey to learn what is most important to include in the app

- Asks questions about:
 - What is important to people when deciding to get pregnant or not to get pregnant
 - What people would like to have in place before getting pregnant
 - What kinds of infographics are easiest to understand

In the chat:

- What do you think is most important to people with I/DD when considering pregnancy?
 - What are people's top concerns?
 - What things do people want in place before getting pregnant?

Preliminary results

What's important to people:

- Health and healthcare
- Money and housing
- Relationships
- Autonomy
- Support systems



How you can help

- Do you know anyone that may be interested and eligible to take the survey?
 - Please share our information
 - Personal connection; email list
 - No social media
 - We can attend groups (in person in Oregon or virtually elsewhere)

Who is eligible to take the survey?

- 18-50 years old
- Lives in the US
- Has a developmental disability (such as intellectual disability and autism)
- Has any possibility of getting pregnant (even if it is unlikely)

Do you have a disability that affects the way you think? (Such as autism or intellectual disability)

Take our survey!



Help us decide what to put in a new app about pregnancy.

People who complete this accessible survey get \$25

For more information

Website:

ohsu.edu/decisions-app

Email:

decisions-app@ohsu.edu

Call/Text:

(971) 322-2657

Sign-up form:



(Or go to: www.tinyurl.com/survey-sign-up-form)



How are we doing this?

- Community Based Participatory Research (CBPR)
 - Co-create and co-produce all parts of the project with members of the community
 - Community members are co-researchers



Community Partners Board

- Currently have a team of 7 women with intellectual and developmental disabilities
 - From all over U.S.
 - Some women with kids; some without
 - Paid for each meeting



Furra (ASD, SZA)



Alix Herer



Gabrielle Guendon



Adriann Davis

Not pictured: Lisa Wasikowski; Sequoia Holloway; Melissa Wyman

This model is based on AASPIRE

Academic Autism Spectrum Partnership in
Research and Education (aaspire.org)



- They developed this model and have been using it since 2006
- Led by Christina Nicolaidis and Dora Raymaker

Project Partners



Community Partner Lead role

- A 'bridge' position between Community Partners and study staff
- Attends both the Community Partner meetings AND staff only meetings
 - Represents the Community Partners at staff meetings
 - Supports everyone during Community Partner meetings
 - Paid staff (8 hr/wk)

Community Partner Lead Role

Before Meetings

Help edit materials and give opinions on ideas before they reach the Community Partners

Community Partner Lead Role

During Meetings

- Make sure everyone gets a chance to speak
- Monitor the chat
- Reach out to people if they need support
- Ask for a pause if needed
- Encourage people to share their ideas
- Help clarify information and help understand content

Why the lead role is important

- Encourage people to have a voice
- Make research more accessible
- Advocacy
- People with disabilities BELONG in research roles

Q&A



Thank you!

General inquiries: decisions-app@ohsu.edu

Website: www.ohsu.edu/decisions-app

