Center for Disability Justice Research: Health Equity, Education, and Creativity

Making My Own Choices: Self-Determination and Advocacy with People with Intellectual and Developmental Disabilities Study Information

Thank you for clicking the link in our flyer to learn more about our study! We hope this study information answers your questions.

If you want to volunteer to be interviewed, click here!

If you have questions, please check out the info below.

Who is doing the study?
What is the study about?
What will happen if I say yes?
What will I do in the interview?
How long will it take?
What are the good or bad things about the study?
What are your rights?
What if I am not happy about the study?

Who is doing the study?

The study is being led by Dr. Sarah Taylor and Dr. Amy Conley Wright. Dr. Taylor and Dr. Wright have years of experience as social work researchers and advocates, and are both also parents of youth with intellectual disabilities.

Dr. Sarah Taylor is a Chair and Professor in the Department of Social Work at California State University, East Bay and the Co-Director of the Center for Disability Justice Research. Her email address is sarah.taylor@csueastbay.edu.

Dr. Amy Conley Wright is a Professor of Child and Family Social Work at the University of Sydney and the Director of the Research Centre for Children. her email address is amy.conleywright@sydney.edu.au.

Our team currently also includes a Research Coordinator, Tori Wong, a Community-Based Research Assistant, Diona Tran, and a Graduate Student Research Assistant, Melanie Gordon. If you fill out the interview interest form, you will receive an email from a member of the team!

What is the study about?

We are doing a study about what helps people with intellectual or developmental disabilities (I/DD) speak up for themselves and make their own choices. You are invited to be a part of our study if you are:

- A person over age 16 with I/DD
- A parent or adult family member of a person with I/DD
- A professional who supports people with I/DD and their families

You can choose to take part, but you don't have to. This sheet will tell you more about what will happen if you participate so you can make up your mind.

What will happen if I say yes?

If you decide you want to be in our study, here are options for participating:

- **Photo survey:** If you are a person over age 16 with I/DD, you can participate by completing our photo survey. The photo survey allows you to share photos about how you advocate and/or make decisions for yourself. You can just do the survey, or you can also participate in an interview if you would like to. Here's the link if you want to check it out: https://forms.gle/oc8aR9QjxNro7U9k7
- **Interview:** People over age 16 with I/DD, parents or adult family members of people with I/DD, and professionals who support people with I/DD can participate in an interview. **People who participate in an interview will receive a $25 gift card**. We will schedule the interview for a time when you are available, and it can be by online (in zoom) or in person, based on mutual availability with our team. If you are a person over age 16 with I/DD, you can bring a support person to the interview with you if you would like to. If you would like to sign up for an interview, please go to this link: https://forms.gle/pqZmmgPgYSpG8Sjq8

What will I do in the interview?

- A researcher will ask you questions about your experiences of speaking up for yourself and making choices, or your experiences of advocating with a person with I/DD and how you are helping them develop skills to make decisions and advocate for themselves.

- You can choose what you want to answer. If you don't want to talk about something, that's ok. You can stop talking to us at any time if you don't want to talk to us anymore.
- If you say it's ok, we would like to record what you say with Zoom. This helps us remember what we talk about.

How long will it take?

The photo survey takes 10-15 minutes to complete. The interviews will take 45-60 minutes.

What are the good or bad things about the study?

The study will take up some of your time. It may be uncomfortable to remember what it was like when you tried to speak up for yourself or for a loved one. You can talk to the interviewer if you are uncomfortable. When we finish the study, we will let you know what we found out.

What are your rights?

Whatever you tell us is private. We will write about the things we learn from you, but we won't use your name and we won't say anything that could tell other people who you are unless you give us permission to share. For example, some people might want credit for the photos they shared with our research team.

If you change your mind that's ok. All you have to do is tell us you don't want to be part of the study anymore and we won't use anything you tell us during the study.

If you have any questions about the study, you can contact the Principal Investigators, Dr. Sarah Taylor at sarah.taylor@csueastbay.edu and Dr. Amy Conley Wright at amy.conleywright@sydney.edu.au.

What if I am not happy about the study?

If you are not happy with how we are doing the study and want to contact someone else, you can contact the California State University Institutional Review Board at irb@csueastbay.edu or 510-885-4476.