Self-Advocates and Research: Working on Research Teams Studying COVID-19

Marquis Garner, Edward Kastern, and Hannah Laufenberg
With Allison Caudill, Libby Hladik, and Karla Ausderau

Co-researchers at the University of Wisconsin - Madison in the Ausderau Lab
Who we are

... and many more!

Marquis Garner
Co-Researcher

Edward Kastern
Co-Researcher

Allison Caudill
Libby Hladik
Hannah Laufenberg
Karla Ausderau, PhD, OTR/L
Ground Rules

1. Protect privacy/confidentiality. Safe space.
2. Respect others. All opinions are important.
3. Make sure everyone has the opportunity to participate and share how they want to. Be inclusive. Simple language.
4. Every question is a good question
5. Have fun!
Ice breaker: Who are YOU?

Raise your HAND/FAN/REACT ONLINE if ... 

- This is your **FIRST** time at the Self-Determination Conference
- You are from the **WISCONSIN DELLS**
- You came from **TWO OR MORE** hours away
- You came from **FOUR OR MORE** hours away
- You have been a part of a **RESEARCH PROJECT** before
- The **COVID-19 PANDEMIC** changed your day-to-day routine
Today’s “chat”

WE ARE ALL RESEARCHERS

COVID-19 RESEARCH STUDY

PHOTOVOICE

ASK OUR RESEARCHERS
WE ARE ALL RESEARCHERS

We do research every day!

Some examples of everyday research:

- Finding a fitness class in your neighborhood
- Looking up information on a new medication
- Checking the web for information on mental health therapy

What kind of research do you do everyday?
Participating in a research study

Before participating in a research study, it is important to learn more information about the research study by asking questions.
What questions should I ask the researcher?

- Do I have transportation to get there?
- Will I be paid for my participation?
- Where will the research study be?
What questions should I ask the researcher?

- How many times will I come in?
- When will I start and be done participating?
- How are you keeping people in the study safe?
When should you agree to participate in research?

- You have transportation to get there
- You will be paid for your participation
- The study will be done at a place you trust
- You have time to participate
- Researchers are using safe practices
- You understand the study and you feel safe and supported
When should you NOT participate in research?

- You do **not** have transportation to get there
- You will **not** be paid for your participation
- The study will **not** be done at a place you trust
- You do **not** have time to participate
- Researchers are **not** using safe practices
- You do **not** understand the study or feel safe and supported
Time for an activity!

Should you participate in this research study?
Would you participate in this research study?

Example 1

- Researchers are **not** using safe practices
- You do **not** know where the study will be done
- You do **not** understand the study or feel safe and supported
Would you participate in this research study?

Yes!  OR  No!

☐  ☑
Would you participate in this research study?

Example 2

- You have time to participate
- You will be paid one million dollars!
- You do not feel safe and supported
Would you participate in this research study?

Yes!

OR

No!

☐ [ ]
Would you consider participating in this research study?

You have time to participate
You will be given a $50 gift card
The study will be done at a local university
Would you participate in this research study?

Yes!

No!

OR

[Yes] [No]
Let’s take a quick break!
So What?! Why is this important to us?

- Why is this important to us as a team?
- People with disabilities are not always included in research.
- Inclusive research practices are important.
- Positive representation matters.
OUR RESEARCH: COVID-19

SURVEYS, INTERVIEWS, AND PHOTOVOICE
OUR RESEARCH: COVID-19 RESULTS

Surveys (Nonprofit organizations)

- 66% ↓ number of volunteers
- 52% ↓ number of staff
- 60% ☓ a major fundraising event
- 77% + an emergency grant
- 77% 📢 with the government or other organizations
OUR RESEARCH: COVID-19 RESULTS

Interviews (Nonprofit organizations)

- Changed feelings about health and wellness
- Flexibility: we had to pivot!
- Changes to services and programming
- New opportunities & silver linings
Surveys (People with disabilities)

- 73% had **difficulty getting reliable transportation**
- 68.2% had **difficulty going to the grocery store or pharmacy**
- 69% had **difficulty buying or paying for things they needed**.
Interviews (People with IDD and Carepartners)

- We are still working on completing all of our interviews.
- We are looking for participants to reach our goal, are you interested in being a part of our study?
PHOTOVOICE: OVERVIEW

Photovoice is...

- A research method to gather information about experiences and opinions
- Using photographs as your voice
- A way to communicate ideas or experiences that can be hard to describe
- A helpful tool to answer a question and share what you think
PHOTOVOICE: OUR STUDY

Our Research Question:
How has the COVID-19 pandemic changed things you do every day for your health and well-being?
For example:
...your life at home or living situation?
...your work?
...your community?
...your healthcare?

Captions: P I C

Purpose: Why did you choose to take this picture?
Information: Describe what is happening in this picture.
Caption: What does this picture tell us about you, your experience, or your health?
PHOTOVOICE: RESULTS

“I learn how to cook and bake, which increased during COVID. Take baked goods / treats to grandma and her friends.

It was hard realization that I couldn't give your grandma a hug.”

“Killing germs and keeping people safe. I'm washing hands. Soap on hands. Keeping other people safe and not spreading germs around.”

“I'm distancing myself from everything. Protect self and follow all safety procedures to prevent COVID. I'm still doing socially distancing to prevent self from getting COVID.”

“Playing bingo via Zoom. Used to play bingo at bowling alley but moved to Zoom.”
PHOTOVOICE ACTIVITY

On your table: Photos + Captions

Practice some of the research skills we used exploring the photos and captions.
PHOTOVOICE ACTIVITY

Activity Instructions:

1. Look at the photos
2. Have someone read the captions to the group
3. Discuss what you see.
4. Create groups of similar ideas, name each group

For those joining us on zoom, scan the QR codes with your phone to see the photos and captions!
PHOTOVOICE ACTIVITY

On your table: Photos + Captions

Things to Think about:
- Why was this photo taken?
- How does it represent their unique experience throughout the pandemic?
- What is the same in the photos?
- What is different across the photos?
ACTIVITY WRAP UP

- What were some of your groups?
- Was this similar or different from your own experience?
- Did your group always agree, or did you disagree?

Thank you for doing this activity!
# PHOTOVOICE: RESULTS

<table>
<thead>
<tr>
<th>01</th>
<th>HOME</th>
</tr>
</thead>
<tbody>
<tr>
<td>02</td>
<td>WORK</td>
</tr>
<tr>
<td>03</td>
<td>HEALTHCARE</td>
</tr>
<tr>
<td>04</td>
<td>COMMUNITY</td>
</tr>
<tr>
<td>05</td>
<td>OTHER</td>
</tr>
</tbody>
</table>

## HOME
- Family
- Staying healthy at home
- Home as a Location (spent time here, had to be there)
- Technology
- Activities at home

## WORK
- Changes (coming back, different tasks, location)
- Grateful for Work (online, opportunity for work, meaningful activity of work)
- Time (stop/wait/restart; loss of job=extra time)

## HEALTHCARE
- Keep Others Safe
- Keep Self Safe
- Experience of COVID/pandemic
- Staying Healthy

## COMMUNITY
- New Activities
- Changed Activity (in the community)
- Community Places as Locations
- Time lead to self-reflection
- Staying In touch with technology
- Things I missed
- Health
- Social

## OTHER
- Technology
- God/Belief System
- Emotions/Feelings
- New or Different easy of doing things
Edward AOTF Talk

HANNAH J LAUFENBERG
ASK OUR RESEARCHERS

Marquis Garner
Co-Researcher

Edward Kastern
Co-Researcher
Interested in joining a research study?

We would love to interview you and hear about your experiences as a part of our COVID-19 study!

Come see us after the presentation, we have consent forms and could interview you today!

Have to go? Stop by our table!
Thank you for joining us!

Any questions?