

# Slacktivists or Activists?: Identity Work in the Virtual Disability March

---

**Hanlin Li**<sup>1,2</sup>, **Disha Bora**<sup>1</sup>, Sagar Salvi<sup>1</sup>, Erin Brady<sup>1</sup>

<sup>1</sup> *Indiana University - Purdue University Indianapolis (IUPUI)*

<sup>2</sup> *Northwestern University*

CHI 2018, April 26th

# Disabled Activism



# Disabled Activism



**“Nothing about us without us”**

People with disabilities must be able to engage in public policymaking (Scotch, 2009)

# Alternative Forms of Activism



# Alternative Forms of Activism

**Slacktivism:** Online activism has been long criticized by the public as ‘slacktivism’ for not contributing to democracy and civics.

## Critiques within activist communities:

- Only serve to increase the participants’ ego
- Negative impact on people’s offline actions
- Not the same as “putting your body in the street”

FEATURED

# Disability March

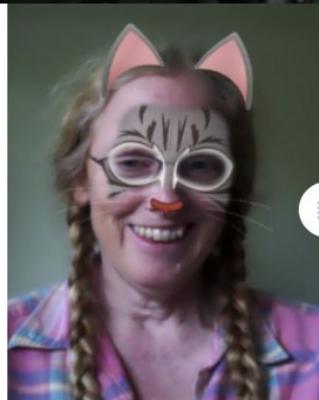
We marched online as a contingent of the Jan. 21, 2017 Women's March on Washington. We began posting on December 21 with our first marcher, Karrie Higgins. Our first major contingent marched Jan. 20. As of 7 pm on Jan. 21, we had 1,654 entries published, and thousands more we could not process. By Jan. 29, we had posted our final...



**Heidi  
Lasher-  
Oakes**

I am so many other things besides disabled. In my life I am, or have been, a/n

[READ MORE](#)



**Robin Rose**

I'm joining this march because I know that love, compassion, and kindness is the only way out of this big pickle we're in.



**Becky**

Why I am marching: I am joining the march because I believe in justice for all Americans, and a world free of ignorance and hate.  
About me: I'm a chronically ill femme, artist and witch.  
Find me at phl...  
[Follow](#)

# Methods

We interviewed 18 people with disabilities who participated in the Disability March.

15 respondents were Disability March participants; 3 were organizers.

Respondents' disabilities varied greatly, including physical disabilities and invisible disabilities (chronic health problems, and mental illness, PTSD).

\* We join disability groups and advocates in using identity-first language to reflect disability as an inseparable part of their identities. However, we would also like to acknowledge there are cases when our respondents strongly identify as activists, rather than "disabled person" (P14).

---

# Methods

We interviewed 18 people with disabilities who participated in the Disability March.

15 respondents were Disability March participant; 3 were organizers.

Interviews were conducted remotely, and lasted around 45 minutes with each respondent.

We transcribed the interviews, and conducted two rounds of analysis: an initial affinity diagramming to identify **current practices of disabled activism**, and a second inductive analysis grounded in **identity theory and identity work**.

---



# Current Practices



# Identity Work

---



# Slacktivists or Activists



# Current Practices



## Identity Work

---



## Slacktivists or Activists

# Current Practices

We see similar **accessibility barriers** that were described in HCI studies, but we also uncover **workarounds** that are used by disabled activists to engage with activism.

---

# Barriers to Disabled Activism

**Environmental barriers:** Aspects of the physical environment which may make it hard for people with disabilities or chemical sensitivities to reach or remain in a space.

*“There are so many rallies I am interested in. But for my safety and my health, **I do feel unsafe being around a large crowd.** Lupus (a chronic autoimmune disease) is very **light and sound sensitive.**” - P9*



# Barriers to Disabled Activism

**Social barriers:** Societal views of people with disabilities as incapable, different, or worthy of excess attention

*“People do things to blind people that they don’t do to others, like grabbing. **It is hard to tolerate.** I feel like they are petting me. The more upset I got, the more people do [it].” – P10*



# Barriers to Disabled Activism

Social barriers interacting with physical barriers:

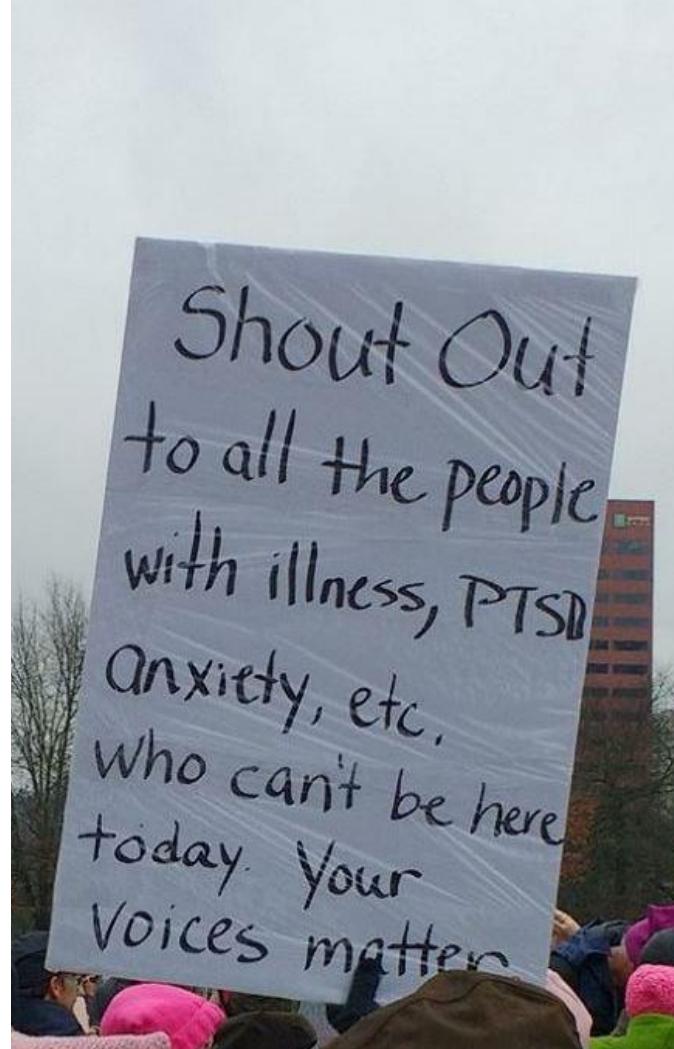
*“Most of these things it’s not clear how far you are gonna walk, how far it is going to last. **It’s not clear if you get too much pain or too tired, how do you deal with it.** Those kinds of things made me feel like that I don’t want to be a liability.” - P17*



# Workarounds for Disabled Activism

Offline:

*“A lot of participants **wrote their names** behind the back of other people as they couldn't physically participate.” – P12, organizer*



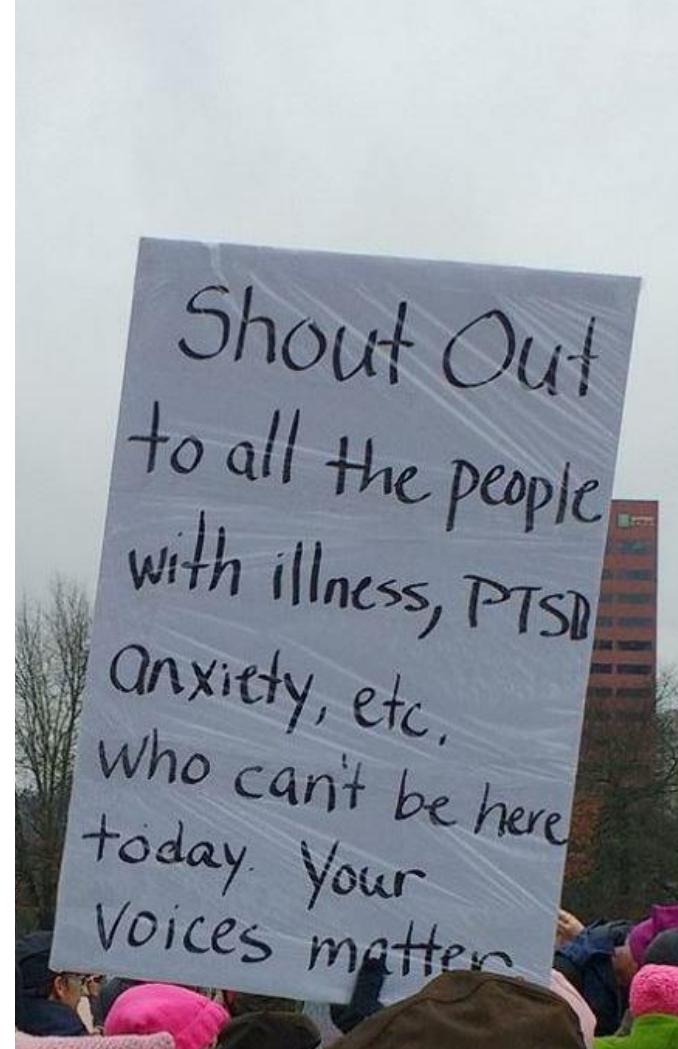
# Workarounds for Disabled Activism

Offline:

*“A lot of participants wrote their names behind the back of other people as they couldn't physically participate.” – P12, organizer*

Online:

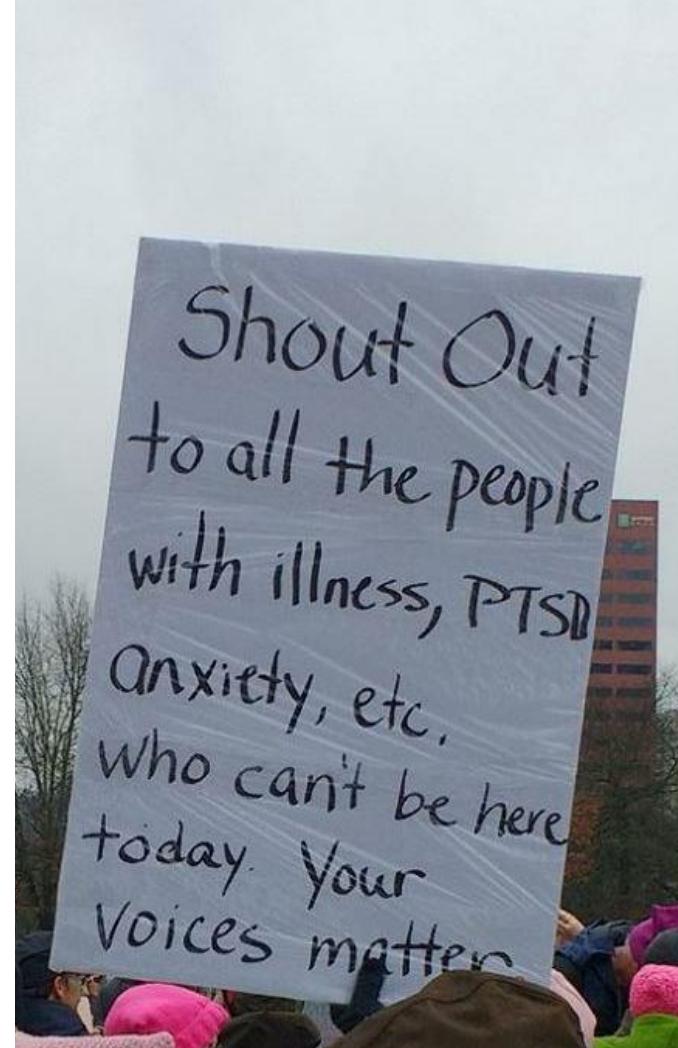
*“I joined a disability group... Through this group, I joined a more regional and progressive group. **I have these connected social activism.**” – P6, organizer*



# Workarounds for Disabled Activism

## Hybrid (online & offline):

- Interacting with in-person marchers through video-streaming and social media
- Participating in physical marches and contributing to online communities





# Current Practices



## Identity Work

---



## Slacktivists or Activists

# Identity Work

We noticed that respondents' **identities as activists and as people with disabilities** played a major role in their participation and technology use in the Disability March and other protests or civic engagement.

---

# Identity Theory and Identity Work

Social interaction and actions are shaped by meanings people attribute to themselves, i.e. self conceptions (Stryker, 1994).

# Identity Theory and Identity Work

Social interaction and actions are shaped by meanings people attribute to themselves, i.e. self conceptions (Stryker, 1994).

- the key to address the differences in social movement participation (Stryker, 2000)
- identities as a process of co-creation during social movement participation (Kiecolt, 2000)

# Identity Theory and Identity Work

Social interaction and actions are shaped by meanings people attribute to themselves, i.e. self conceptions (Stryker, 1994).

- the key to address the differences in social movement participation (Stryker, 2000)
- identities as a process of co-creation during social movement participation (Kiecolt, 2000)

In this paper, we explore our participants' **identity work**, where they define, reinforce, and change their individual and collective identities, as it took place situated in social movements (Snow et al.).

# Identity Work throughout the Disability March

**Identity-introduced participation**

(Stryker and Serpe, 1994)



**Identity construction and evolution**

(Snow et al., 1994)



**Identity change**

(Kiecolt, 1994)

# Identity-Introduced Participation

## Activist identity

*“I belong to a variety of illness groups and writer groups. **I am marching not as a disabled person. I want to participate in something huge.** It was for broader issues.” – P14*

# Identity-Introduced Participation

## Activist identity

*"I belong to a variety of illness groups and writer groups. **I am marching not as a disabled person. I want to participate in something huge.** It was for broader issues." – P14*

## Disabled identity

*"I would die if there is no treatment. **I need my congresspeople to understand that.** But it is difficult to go to a town hall meeting and stand in front of them." – P13*

# Identity Construction and Evolution

## Emergence of a shared identity

*“We [the volunteer group organizing the Disability March] wanted people to post pictures [for the March]. Because I think people with disabilities are invisible. People who participated said they never went to march before. **We discussed what people should include in their stories.**”*

– P12, organizer



Image used with consent

# Identity Construction and Evolution

## Collective meaning-making

*“People asked me - what is that [the Disability March]? **There is huge need to extend our presence to the street.***

*Somehow to connect who we are, what we are to what is going on the street. It is becoming important. Because we are being visible, active, and fighting for certain causes.” – P11*



# Identity Change

Meaning change around their potential accomplishments as a disabled activist

*“This virtual thing, it makes you feel good as it’s emotionally all good, and it helps **confirm your identity as a disabled person. You still have a voice, you still have an opinion, you are important**, coming together virtually with all the other people.” – P18*



# Identity Change

Meaning change around their potential accomplishments as a disabled activist

*“This virtual thing, it makes you feel good as it’s emotionally all good, and it helps **confirm your identity as a disabled person. You still have a voice, you still have an opinion, you are important**, coming together virtually with all the other people.” – P18*

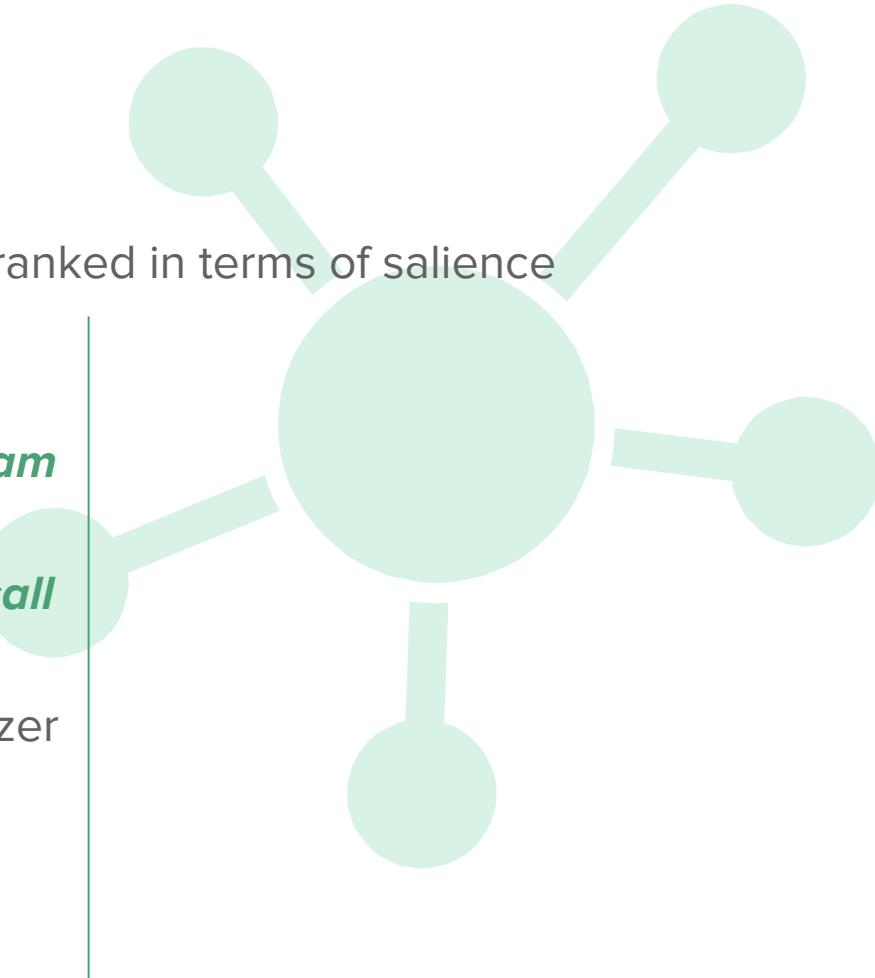
*“In a rally, **I felt more empowered**. Now I’m back to life, I noticed I’m not part of ‘we’. **I get more depressed and burned out.**” – P10*



# Identity Change

Hierarchy change as identities are re-ranked in terms of salience

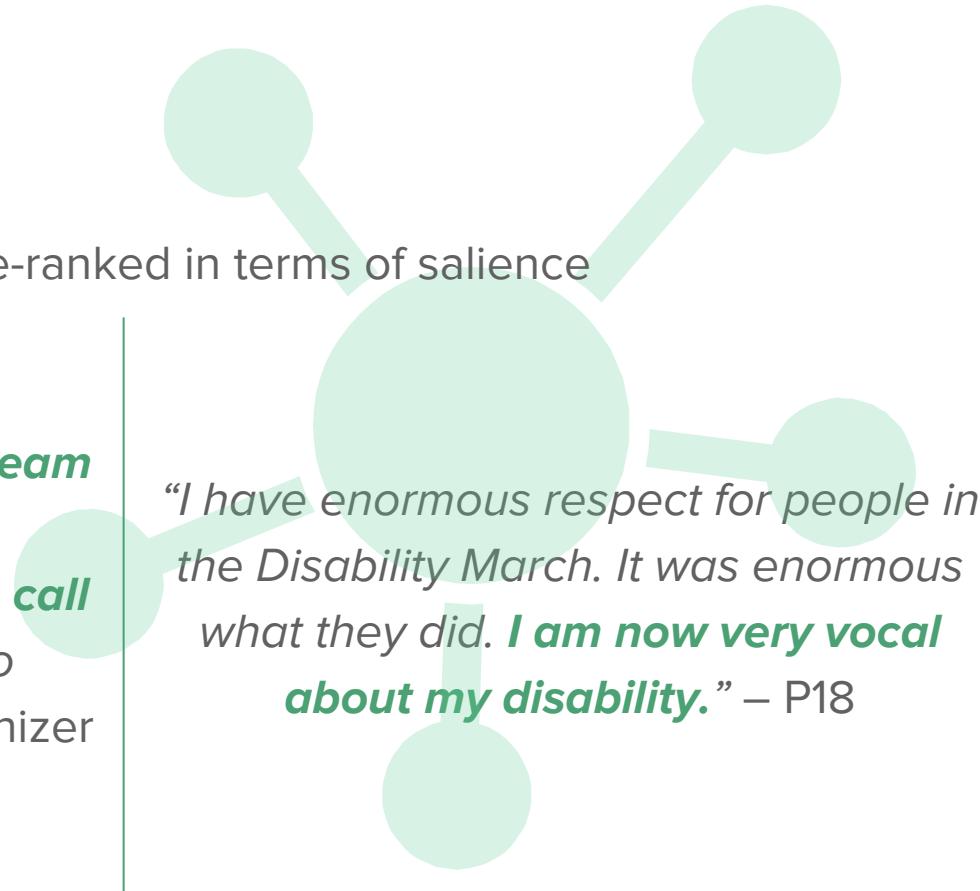
*"I'm in touch with the organizing team  
of the disability caucus of the  
women's march. I join their phone call  
regularly... I hope to continue to  
participate in that way." - P12, organizer*



# Identity Change

Hierarchy change as identities are re-ranked in terms of salience

***"I'm in touch with the organizing team of the disability caucus of the women's march. I join their phone call regularly... I hope to continue to participate in that way."*** - P12, organizer



***"I have enormous respect for people in the Disability March. It was enormous what they did. I am now very vocal about my disability."*** – P18



# Current Practices



## Identity Work

---



## Slacktivists or Activists

# Slacktivists or Activists?

Online activism has been long criticized by the public as ‘slacktivism’ for not contributing to democracy and civics.

# Slacktivists or Activists?

Online activism has been long criticized by the public as ‘slacktivism’ for not contributing to democracy and civics.

---

Our study provides additional evidence that online activism leads to **further engagement** in causes, and should not be viewed as ‘slacktivism’.

# Slacktivists or Activists?

Online activism has been long criticized by the public as ‘slacktivism’ for not contributing to democracy and civics.

---

Our study provides additional evidence that online activism leads to **further engagement** in causes, and should not be viewed as ‘slacktivism’.

Moreover, Disability March participants marched virtually not only because it was convenient, but a result of the **fundamental inaccessibility of public activism**.

# Slacktivists or Activists?

Online activism has been long criticized by the public as ‘slacktivism’ for not contributing to democracy and civics.

---

Our study provides additional evidence that online activism leads to **further engagement** in causes, and should not be viewed as ‘slacktivism’.

Moreover, Disability March participants marched virtually not only because it was convenient, but a result of the **fundamental inaccessibility of public activism**.

**Identity work is important**, as it often leads to identity changes afterwards.

# Design for Disabled Activism

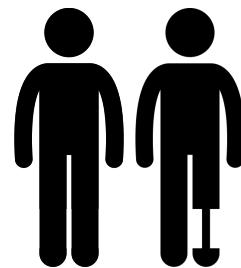
Connecting online and offline activism

# Design for Disabled Activism

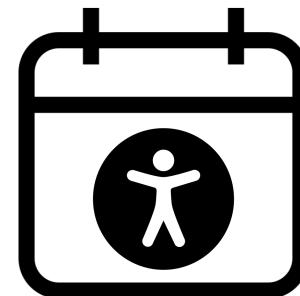
Connecting online and offline activism



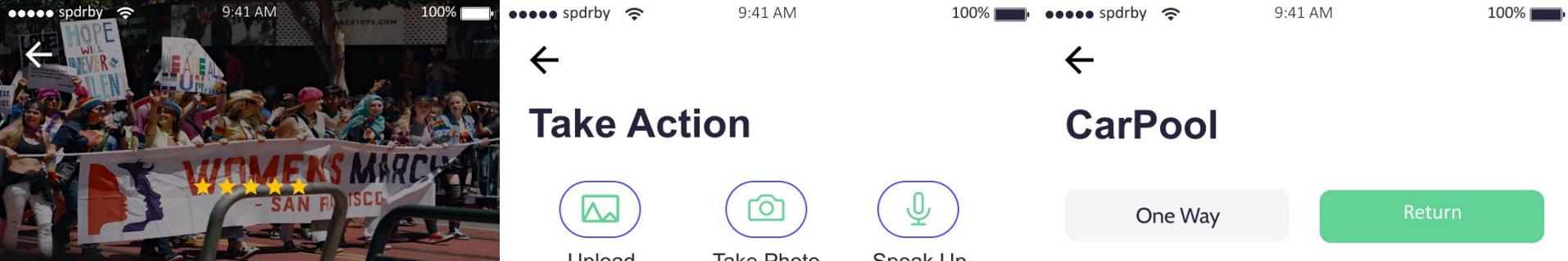
Interactive  
video-streaming



“Walk with me”  
collective activism



Accessible event  
planning



Going

Participate Online

### Brief Introduction

Thousands of women, many donning pink hats and brandishing brightly colored signs, gathered Saturday at the Indiana Statehouse to support women's rights...

more

Website

<https://www.womensmarch.com>



Save the Date

### How to get there?



## Take Action



Upload



Take Photo



Speak Up

#whyweresist women's bodies are their own and they have a fundamental right to make their own informed healthcare decisions.

Type here

Rome

Romantic

Romulus

q w e r t y u i o p

a s d f g h j k l

z x c v b n m

123 ☺ space return

## CarPool

One Way

Return

Pickup

My Location

Select March

Women's March

Start

Select Date

End

Select Date

Passengers

2 Adults

Find CarPool

# Takeaways

We provide empirical evidence showing how disabled activists **manifested their voices online** in lieu of or in addition to participating in physical activism.

We call for designing for disabled activism through **integrating online and offline experiences.**

---

# Co-Authors



**Hanlin Li**  
First-year Ph.D. Student  
Northwestern University  
[lihanlin@u.northwestern.edu](mailto:lihanlin@u.northwestern.edu)



**Disha Bora**  
M.S. IUPUI  
**(on the job market!)**  
[dishbora@iu.edu](mailto:dishbora@iu.edu)



**Sagar Salvi**  
M.S. Student  
IUPUI  
[salvis@iupui.edu](mailto:salvis@iupui.edu)



**Erin Brady**  
Assistant Professor  
IUPUI  
[brady@iupui.edu](mailto:brady@iupui.edu)

# Slacktivists or Activists?: Identity Work in the Virtual Disability March

To our participants, colleagues, anonymous reviewers, and audience:  
**Thank you.**

---

Our Lab

[balmlab@iupui.edu](mailto:balmlab@iupui.edu)

<http://balm.soic.iupui.edu>

Authors

[lihanlin@u.northwestern.edu](mailto:lihanlin@u.northwestern.edu)

[dishbora@iu.edu](mailto:dishbora@iu.edu)