



**THE OHIO STATE UNIVERSITY**

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**CHILDHOOD COGNITION,  
COMMUNICATION, AND  
BRAIN INJURY LAB**

# **Your Story Can Change the Narrative**

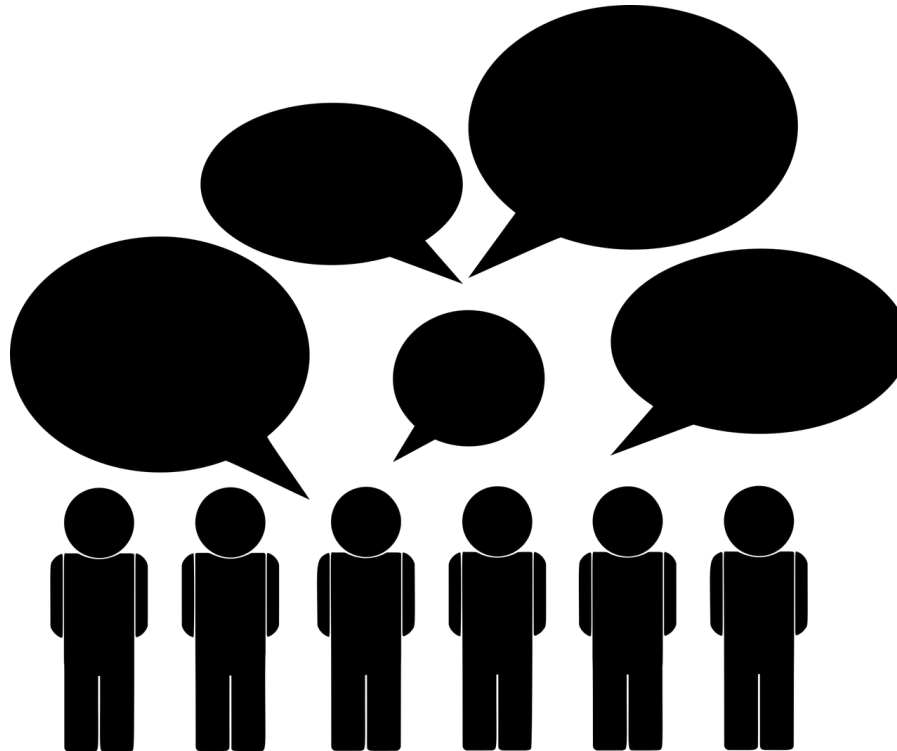
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1. The importance of telling your story
2. Some research examples
3. Some ideas to help you tell your story





# The importance of telling your story





Your story normalizes other peoples' experiences.



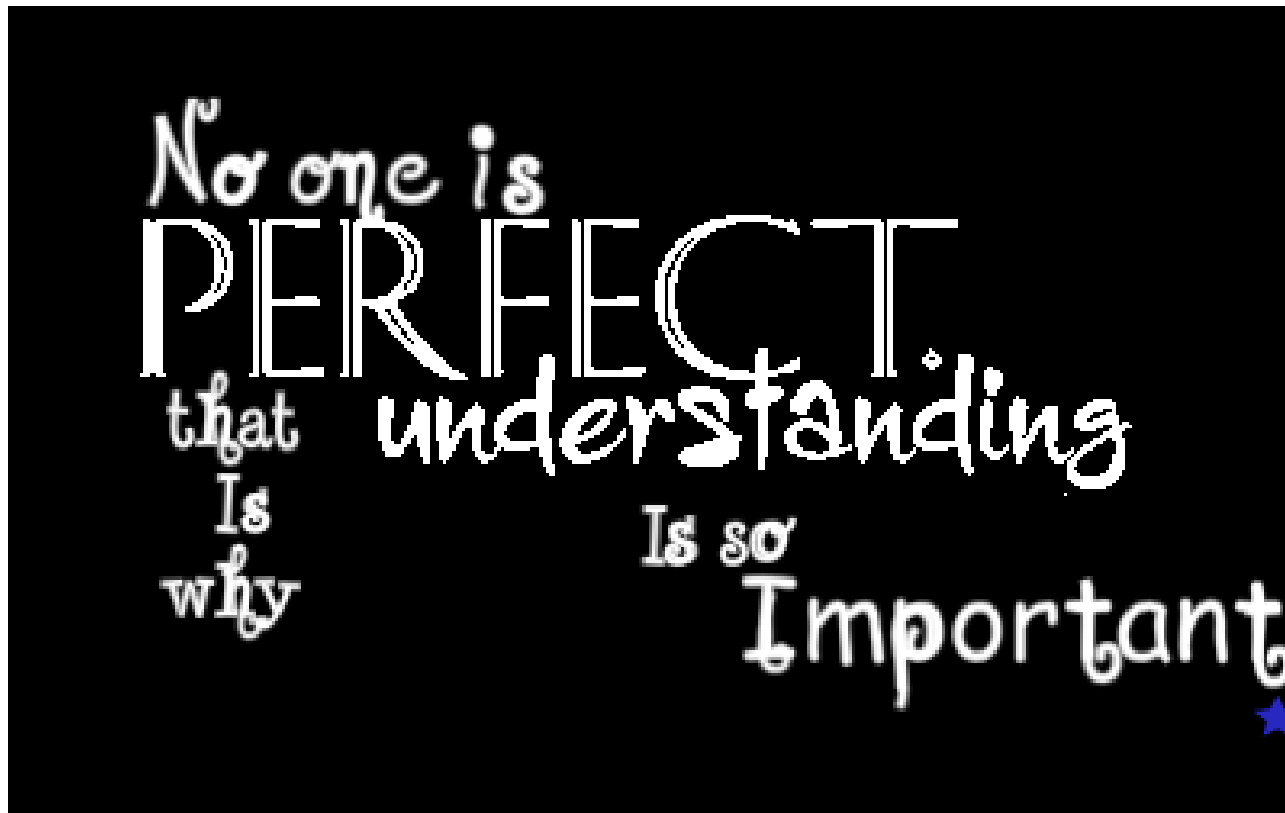


Your story connects you to others with similar experiences.





Your story helps other people understand your experiences.





# Your story can personally and positively impact your care: **ADVOCACY**





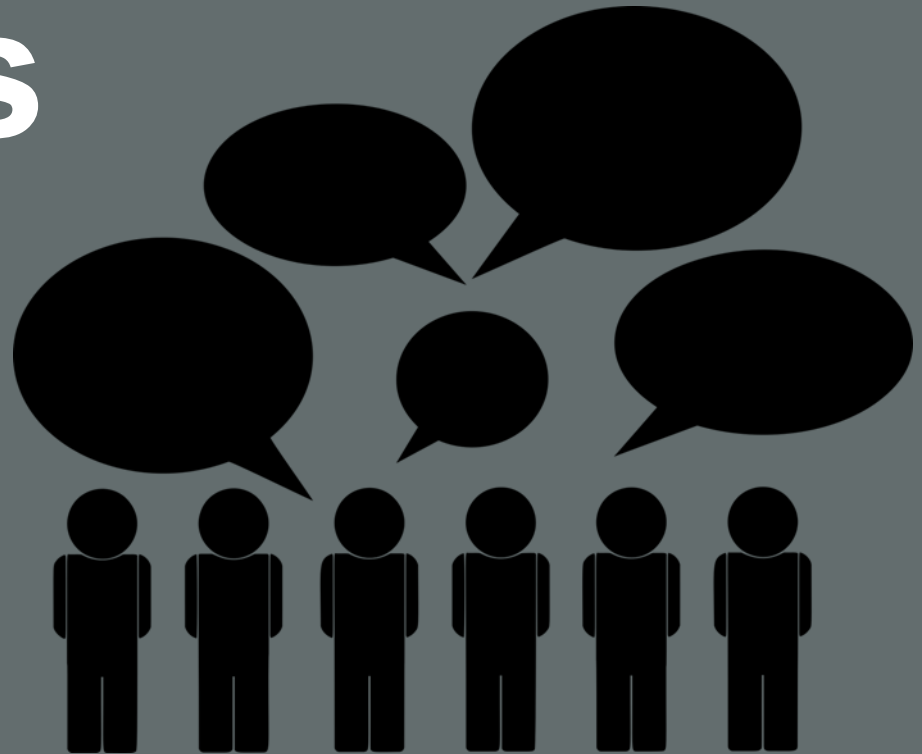
# Your story can personally and positively impact your care: POLICY







# Some research examples





## Caregiver Interview Study

(Lundine, Utz, Jacob, & Ciccia, 2019)

- Inconsistent recommendations
- Multiple medical providers → confusion
- Problems that emerge over time → unique challenges



# Engaging stakeholders to improve care for children with TBI

(Lundine, Koterba, & Ciccia; funded by Ohio Department of Public Safety)

- Ohio State University
- Nationwide Children's Hospital (Columbus)
- Case Western Reserve University
- University Hospitals (Cleveland)



## **Engaging stakeholders to improve care for children with TBI**

- Step 1: Caregivers of children with TBI
- Step 2: Medical Providers

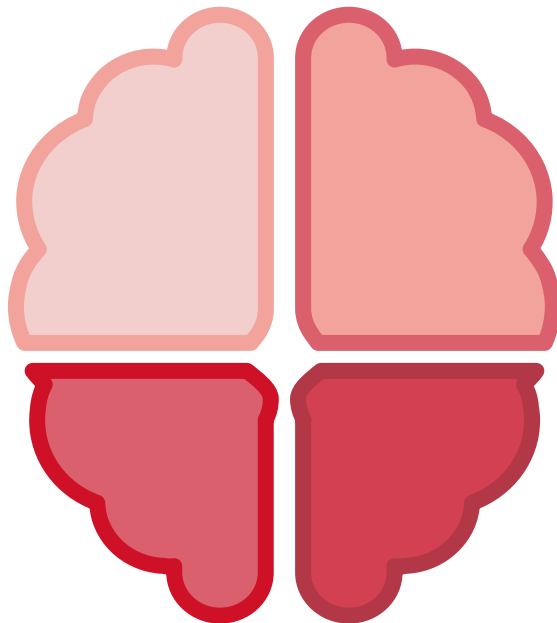


## Engaging stakeholders to improve care for children with TBI

- 19 caregivers interviewed
- Child's average age at injury = 16 years (range: 2.7 – 18.1 years)
- Average time since injury = 5.2 years (range: 1.2 – 9.6 years)



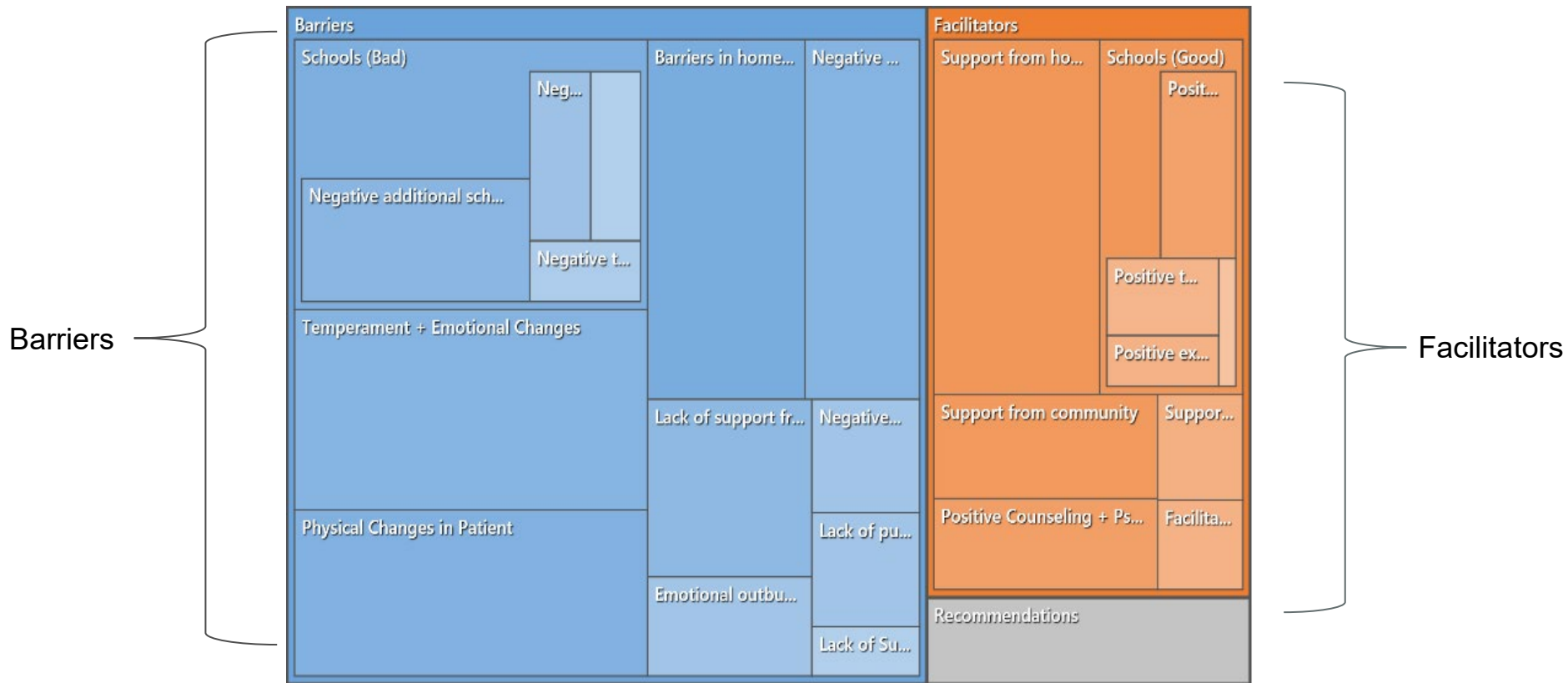
# Major Themes Identified from Interviews



- 01 Hospital-related experiences
- 02 Home life + family dynamics
- 03 Counseling
- 04 School, educational experiences
- 05 Life in the community, public knowledge of TBI
- 06 Physical & emotional changes in the child



# General overview of themes





## Hospital-Related Experiences

***You may have said something a week ago, but I didn't hear you because my kid was on a vent we didn't know if she was gonna live. So, I feel like it's hard because everyone throws themselves at you but then that's it, they never come back. And so then it's like oh maybe I remember that, maybe I don't, I don't know. It's just, you're kind of in a fog at that point and you don't really, you don't hear anybody.***

*... when you're inpatient you're treated amazing, but I think that **there's a disconnect for the outpatient clinics.** I mean, just to continue her therapy we waited forever to get orders and changes and no one calls you back for weeks on end and it's frustrating.*

***It would've been nice** for me to have had **someone** that could've **came here maybe to work with me in my home environment to teach me a little bit***

*I felt like they **gave us a wealth of information** about what to expect and, you know, just what going home would look like.*





## School, Educational Experiences

*At school I'm really glad that **the school recognized he needs extra help.***

*I can't really think of anything further they could've done because **they worked with me every step of the way.***

*Because in my area, I don't know about the bigger cities, **they don't know a lot about brain injury** so you're **fighting with the school all the time.***

***There is not enough resources for people with traumatic brain injuries nor is there enough education. I feel like they have as school for the blind, they have a school for the deaf they have all type of schools for people and kids with disabilities but when it comes to traumatic brain injuries, I feel like they throw them out to the wolves. They put them back into these regular schools, public schools that they attended before their injury. They throw them out to the wolves. There are no resources. The schools are not educated enough. They do not take it serious enough either.***

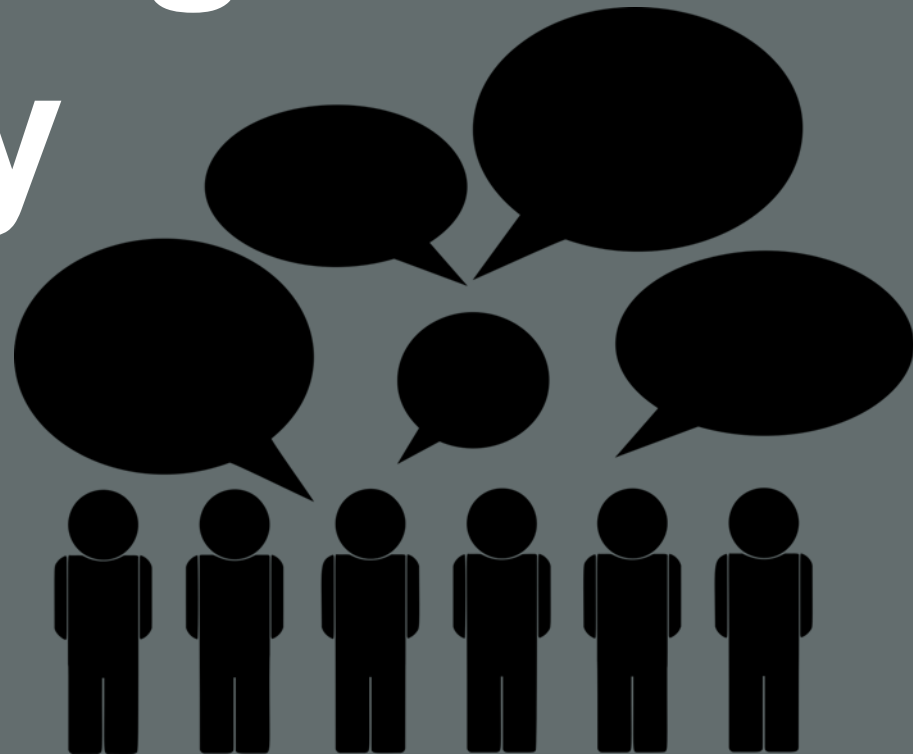


## Next Steps

- Complete analyses of caregiver interviews
- Focus groups with medical providers
- Prospective study to trial strategies

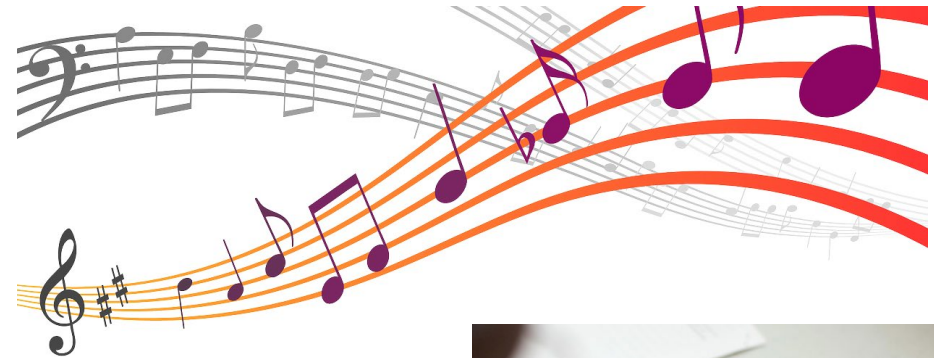


# Basic steps to begin telling your story





# There are different ways to express your story.





## Sample questions to think about:

- How has your life changed since your injury?  
Positives? Challenges?
- What struggles do you experience? How could those be addressed?
- What do you wish people knew about you now?  
Your injury? Your experiences?
- What about your story might help someone else?
- What information do you wish you knew before your injury? How would that have helped you?



## Whose perspective?

- Survivor
- Care partner, caregiver, significant other
- Friend
- Medical provider



## Be engaged...

- Research opportunities
- Talking with your care providers or support groups
- Advocacy and policy groups
- Social media



We are all  
connected by  
simple wish, to be  
visible, to be  
heard, to know  
that we matter.

*Vlada Mars*