

# Self-Advocacy Focus Group Stories

**KU Center on Disabilities (KUCD) &  
Self-Advocate Coalition of Kansas (SACK)**

**Ryan Henley, Austin Myers**

# Meet the Team

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# Agenda

- Background
- Self-Advocate Questions
- Interactive Activity (Share Your Story!)



# Background



- We facilitated a series of focus groups at the 2024 SACK Conference in Wichita, Kansas.
- Each focus group contained 3-5 self-advocates with lived disability experience.

This focus group was held for self advocates who were:

- Over 18 years of age
- People with disabilities
- Self-advocates

# Background



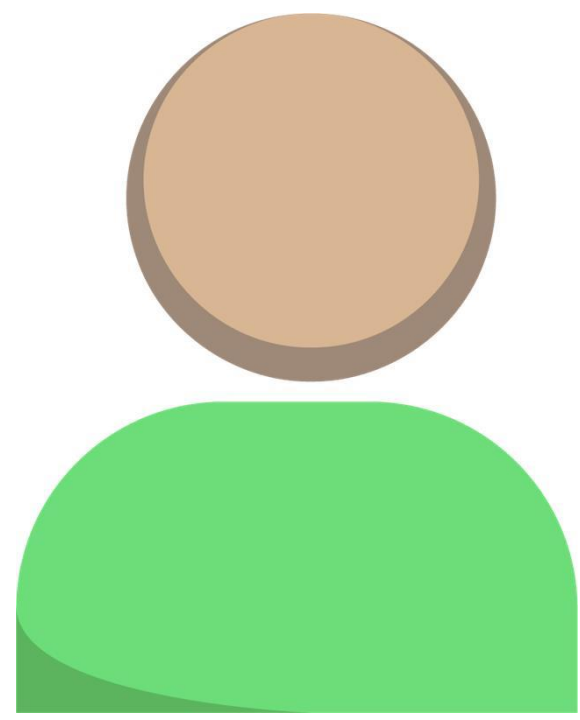
The self-advocates in this focus group shared their stories based around the following four questions:

1. Tell us about a time when you advocated for yourself.
2. Tell us about a time when you wanted to advocate for yourself, but you could not or did not.
3. What advice would you give someone who is learning to be a self-advocate?
4. Is there anything else you would like to say about being a self-advocate?

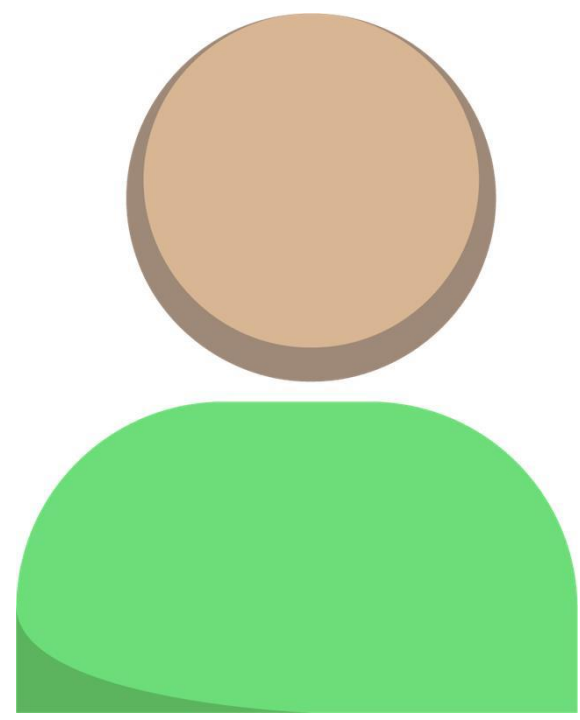


Tell us about a time when you  
advocated for yourself



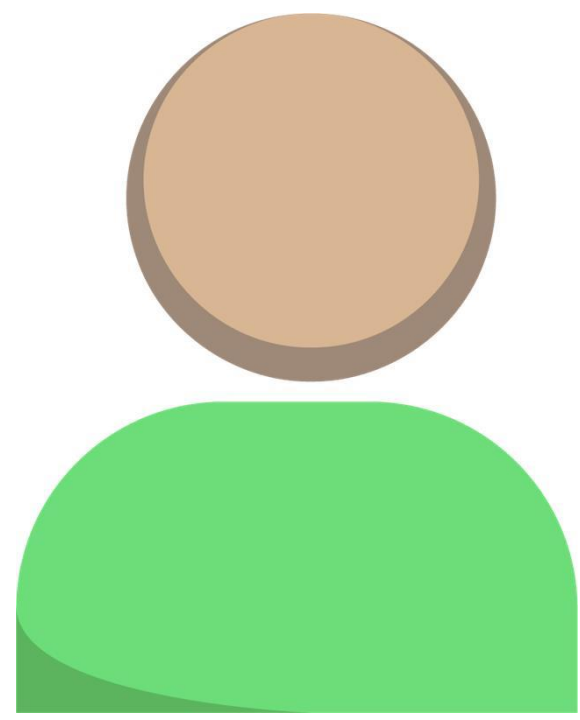


I went to the legislators. I was like, we need more transportation because we need more buses to be out there for advocates. Because we have advocates who work till 10 or 11 o'clock at night, can't even get home because there's not enough transportation. I said, you know what? We advocate, we'll tell them, we'll go to the city commissioners, and we'll keep going and pushing to our limit until we get transportation going.



A time when I advocated for myself is when I wanted to get my own apartment. I was living with my parents at the time and they didn't really think I would be able to handle it. I told them I could handle it. So they said we'd try it. So now I'm living on my own, been on my own for like on my own for like 2 years now, going on my third year. I love being on my own. I think I'm moving up in the world and I've got a job that I'm holding down in the community. So, I'm doing good.



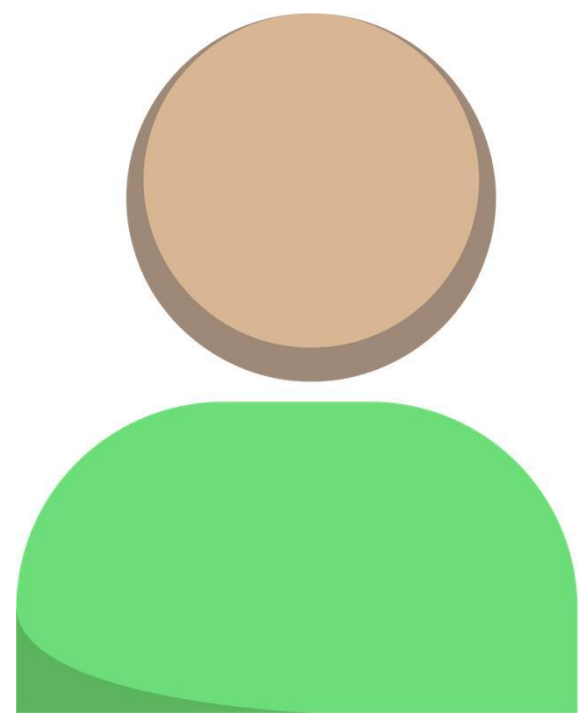


## **I Self-Advocate When...**

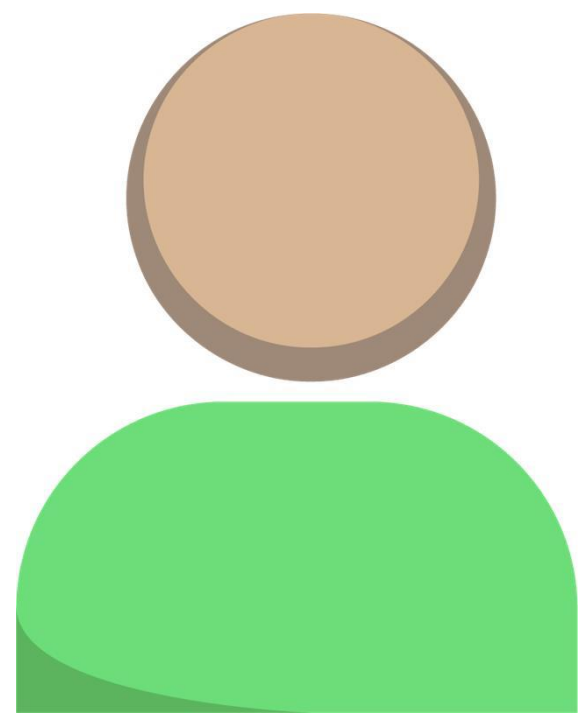
1. Someone does something that I do not like.
2. I have a personal or health need.
3. I have a support need in school or at work.
4. There is a community-based need.
5. I feel pressured to act a certain way in my relationships with family members or close friends.



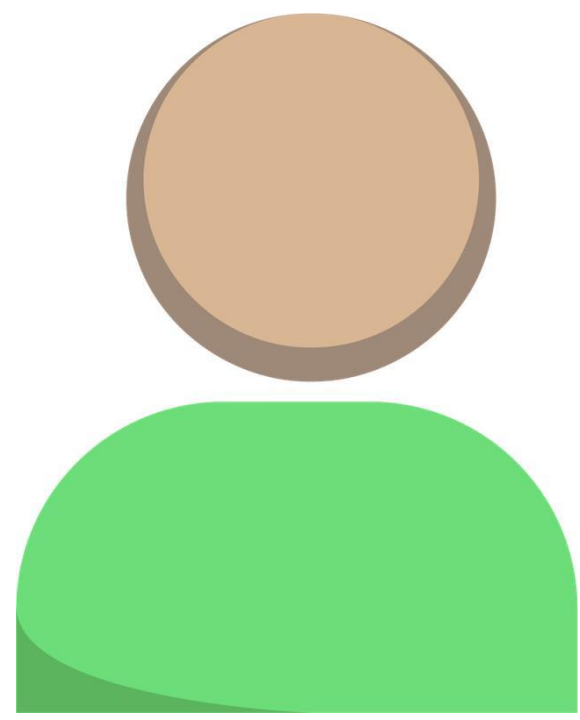
Tell us about a time when you wanted to advocate for yourself, but you could not or did not.



This is an example from my college days. There was a course about game creation. I took it for a little bit, but then was I was told you're probably going to have to spend 12 hours or so outside of class per week. I was just thinking... because I went to community college, I commuted from the city where I was living in, it just felt very overwhelming to me. After like a week or so, I was like no, I'm not going to do this class. I'm going to find another class that is just like a later start class, I was still able to get into which I did.

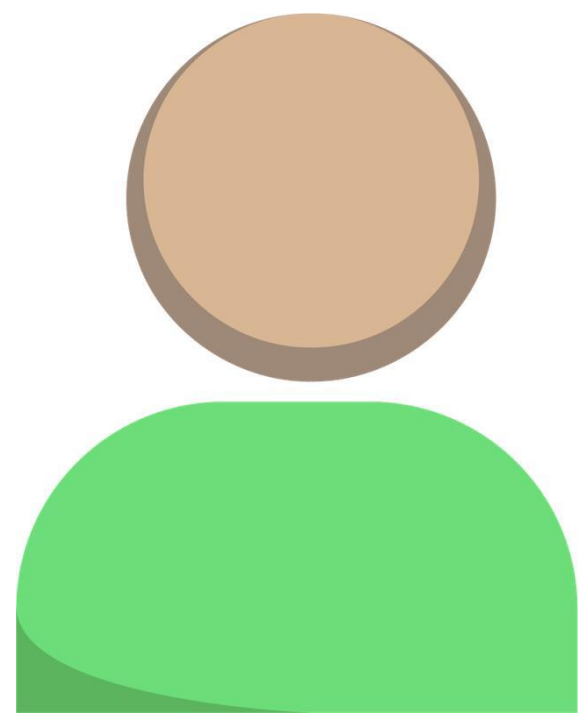


I recently left a job that I was at for almost 20 years. During that transition, they were bringing on a new director. And that last couple weeks of my job, I had to work from home. There was a lot of files on my computer that I wanted to get organized for the new person. The new person had shared with the board that I was withholding files. And like just making up stuff that wasn't true... I got called in to the room... I didn't know the whole board was there. They didn't identify themselves when I walked into the room... And then they sat me down and accused me of this stuff... I was done.



## **It Can be Hard to Self-Advocate When...**

1. Someone does something I do not like.
2. I feel pressured to act a certain way in my relationships with family members or close friends.
3. I have a support need in school or at work.
4. I am not given a chance to self-advocate due to systems or other people.
5. Other people do not listen to me.



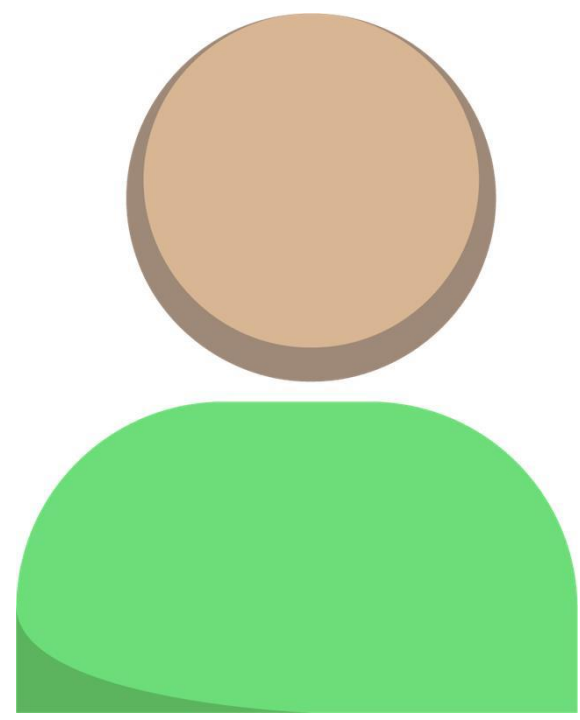
## **In Situations Where it is Hard to Self-Advocate, it is Difficult for Me to...**

1. Communicate my desires and needs.
2. Ask for support.
3. Put my foot down and set boundaries.

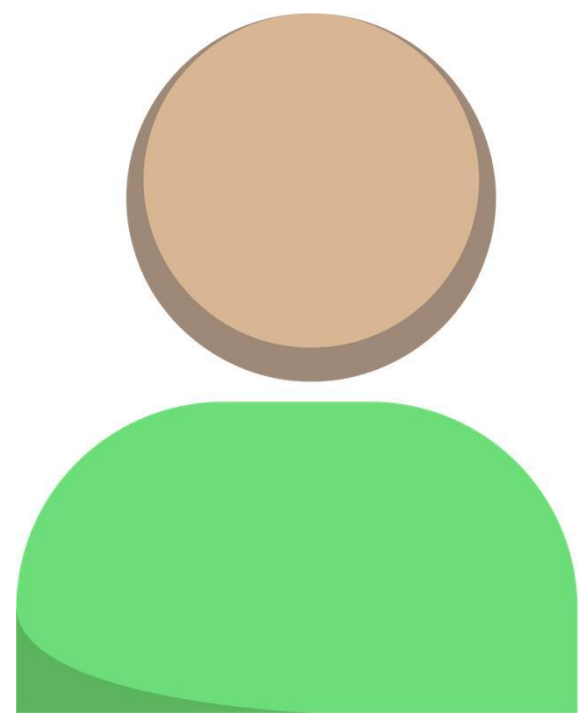




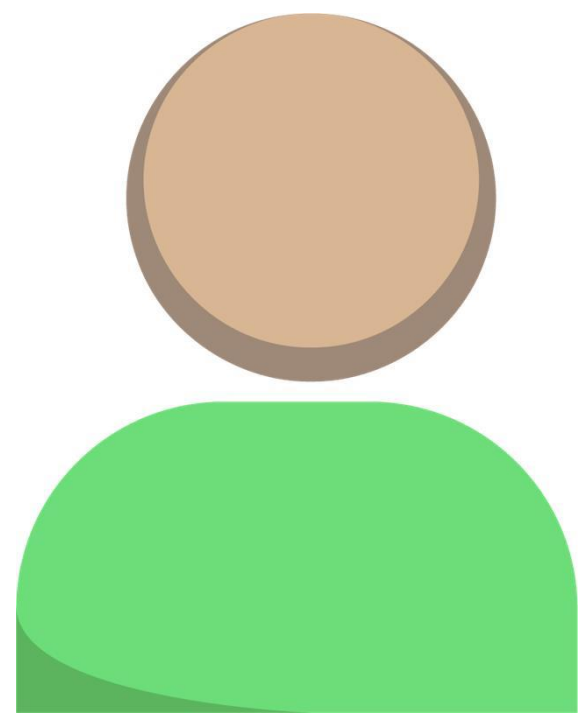
What advice would you give someone who is learning to be a self-advocate?



The biggest thing that I have learned is like, it's scary. Especially when you're first learning about it. So, but don't let the fear stop you. Like, it's scary but do it scared. And eventually it won't... I mean in some cases, it may not get less scary. You may always be scared, but just keep advocating for yourself because you're worth it.

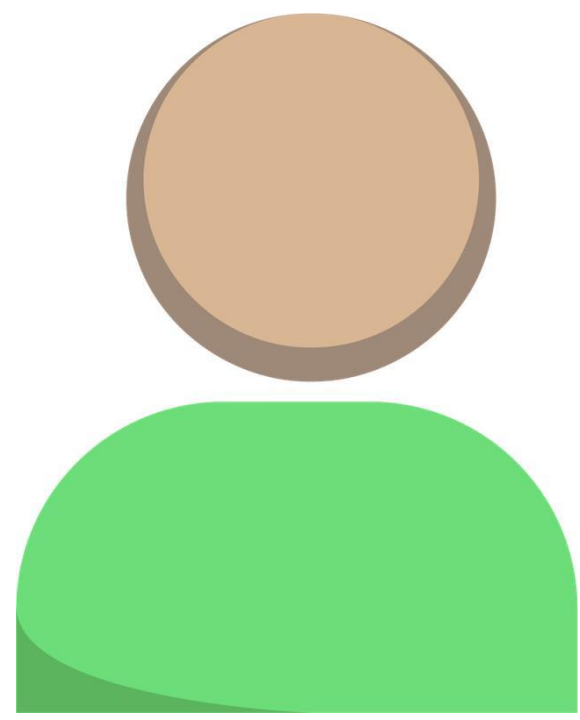


To me, advocating for people with disabilities, I mean it's hard to say. Sometimes I advocate for others, and sometimes I say, you know what? You need to speak up. If you don't speak up, how are they supposed to hear? And I say, you know what, we're gonna advocate, and we're gonna get this done... This is where enough's enough. And I said, we have to advocate for each other. And that's what I said, it's gonna stop right there.



## I Self-Advocate By...

1. Knowing my community's and my own wants and needs.
2. Communicating my wants and needs to others.
3. Being determined (being very focused on a goal).
4. Being persistent (continuing when it gets hard).
5. Problem-solving.



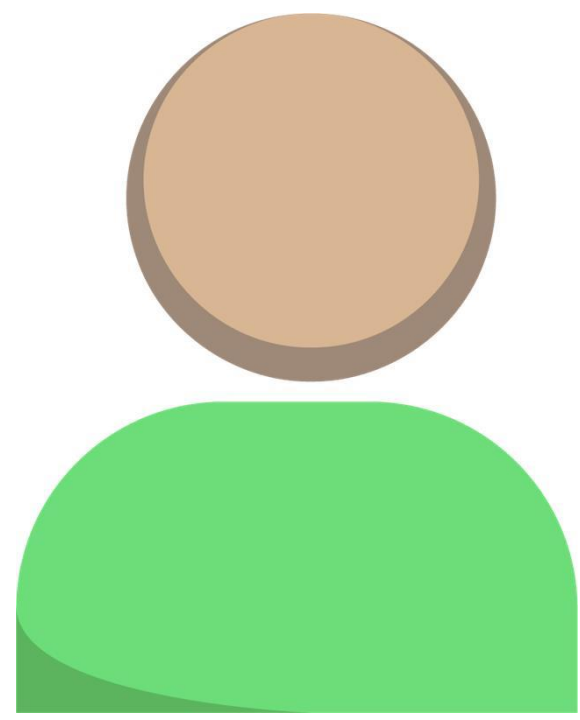
## What Helps Me Self-Advocate is When...

1. People with lived experience teach me to self-advocate
2. People without disabilities help me self-advocate.
3. I feel people recognize my abilities and my worth.
4. I know someone will support me.
5. I receive accommodations to help me achieve my goals.

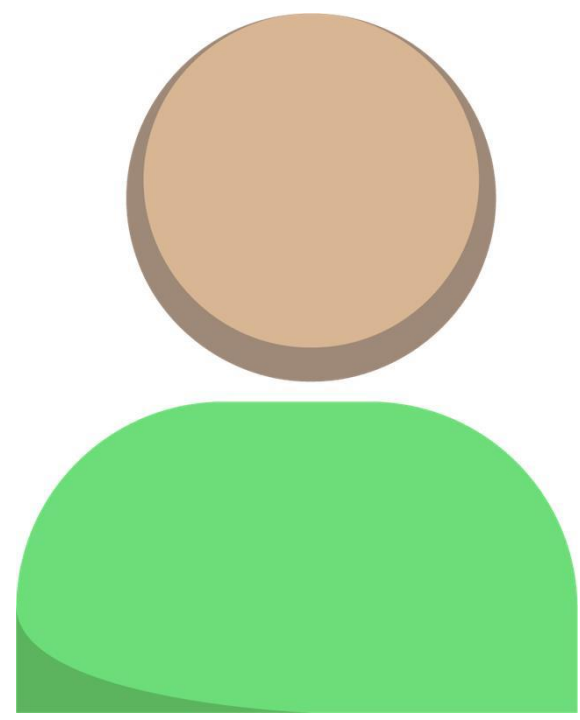


Is there anything else you would like to say about being a self-advocate?

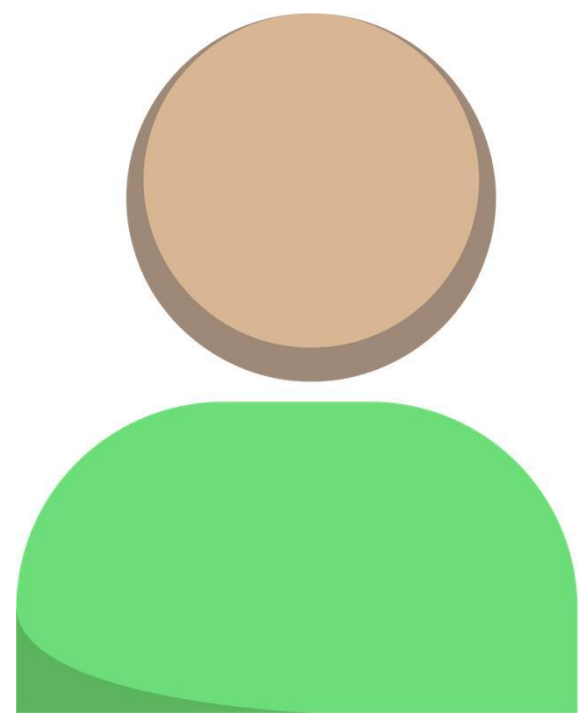




So we label people self-advocates who have intellectual disabilities. So I told people when they asked me how does it feel to be a self-advocate? I said I want to be trouble. And trouble's my name. So when I go, I want to cause trouble. If they want to be a self-advocate, they could be a self-advocate. I want to be my own individual. Label me who I am, because we don't label people, we label jars. Right?



One more thing. Advocacy comes in so many different forms and that's definitely something I've learned. I always thought advocacy was going up to the capital, you know giving testimony, being like [A politician]. And you know, not everyone's like that. It could be writing a letter, it could be silently standing by somebody. It comes in so many forms. And just find which method works for you the best because that's where you're going to make your voice be heard the most.



## **What it is Like to Be a Self-Advocate:**

1. View yourself positively and know your worth.
2. Asking for help is a good thing.
3. Practice often.
4. Mistakes are okay! Learn from them.
5. Make your voice heard.



# Share Your Stories!

# Contact Us

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# Thank you!

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