

*The Building Blocks of Impactful Advocate Storytelling*

# SKILLS FOR THE HILL

Get Loud!

Speak Up!

**BE HEARD!**



# Genevieve Thompson

*Manager of State and Grassroots Advocacy*

- Works for the National Down Syndrome Society
- Has a sister with Cerebral Palsy
- Fun Fact: Fluent in ASL!
- Favorite Movie: Finding Nemo



# Together we will...

①

**Get to Know One Another**

②

**Learn About Advocacy & Policy**

③

**Become Advocate with Tips and Tricks**

# ICEBREAKER

*Share your name and favorite movie!*



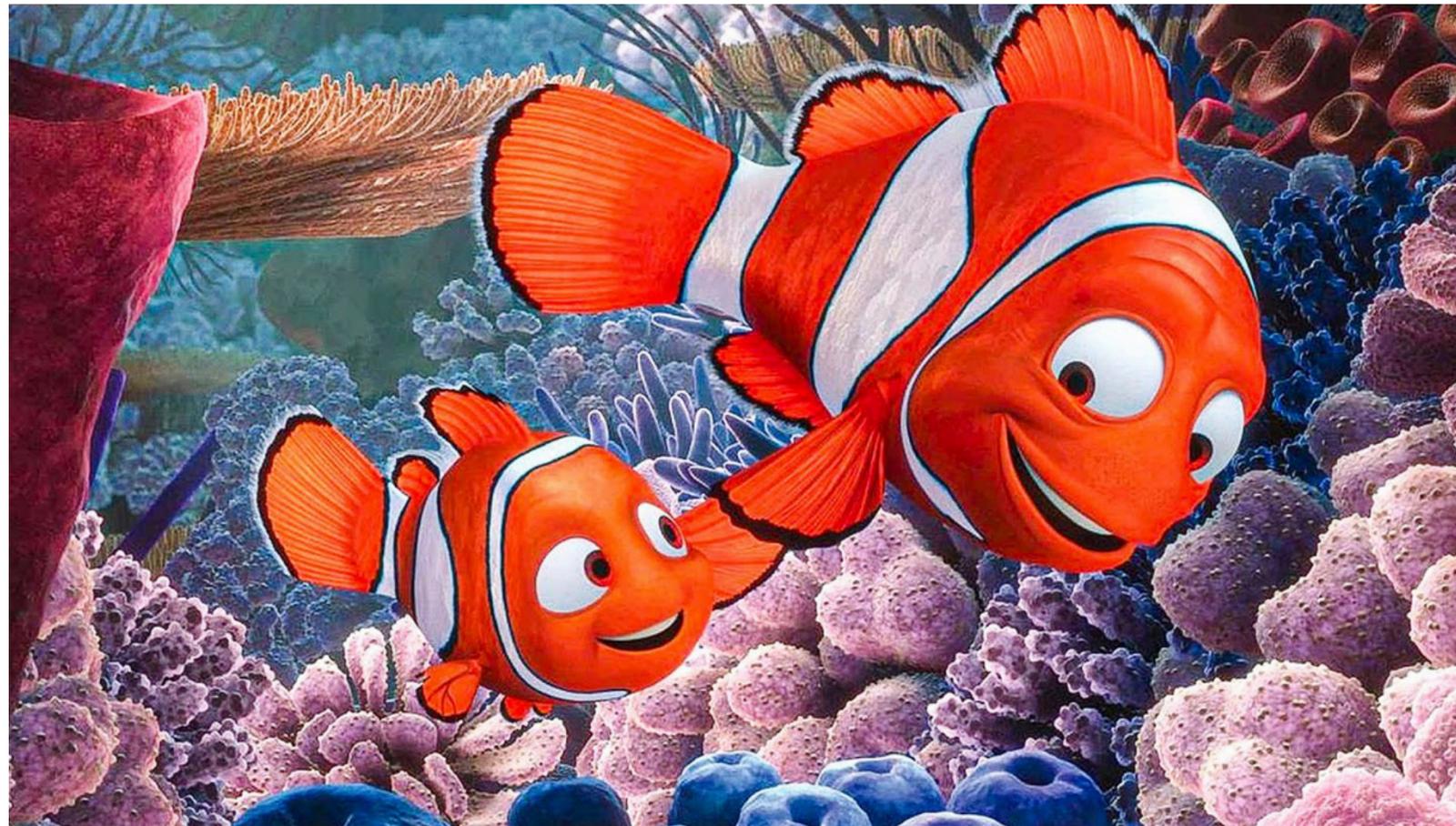
**Any  
volunteers  
to go first?**



**3 Volunteers Please!**

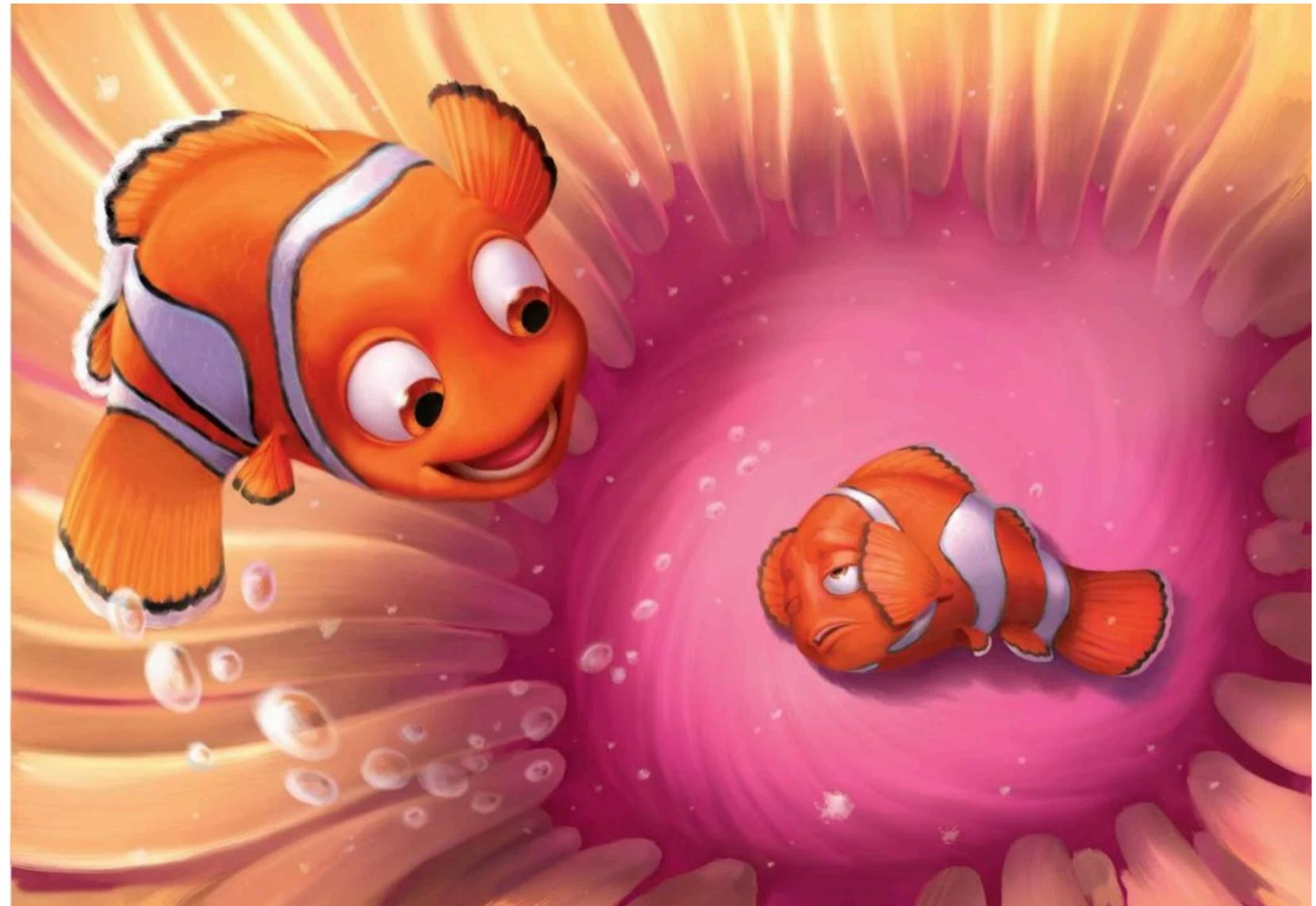
**What do all of our favorite  
movies have in common?**

# **A GOOD MOVIE TELLS AN IMPACTFUL STORY!**



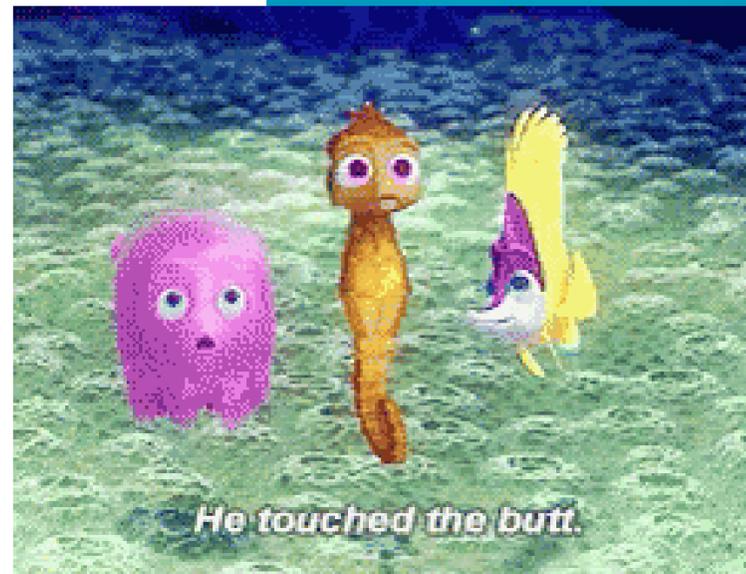
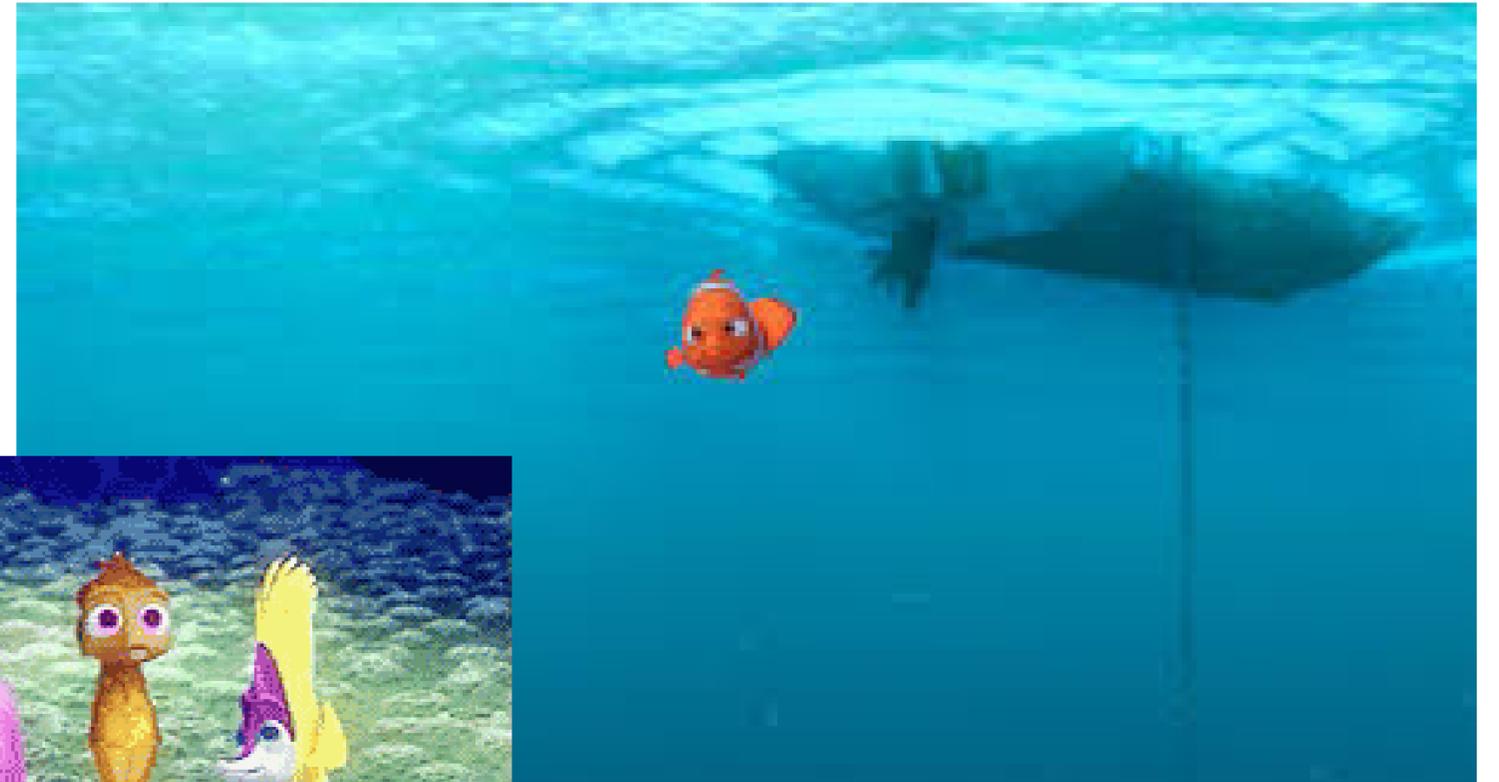
# BACKGROUND INFORMATION

- Nemo — a young clownfish with a small "lucky fin" who desperately wants independence and to prove himself.
- Marlin — an overprotective clownfish who lost his wife and nearly all his eggs to a barracuda attack. Nemo is his only surviving child. He lives in fear and refuses to let Nemo take risks.

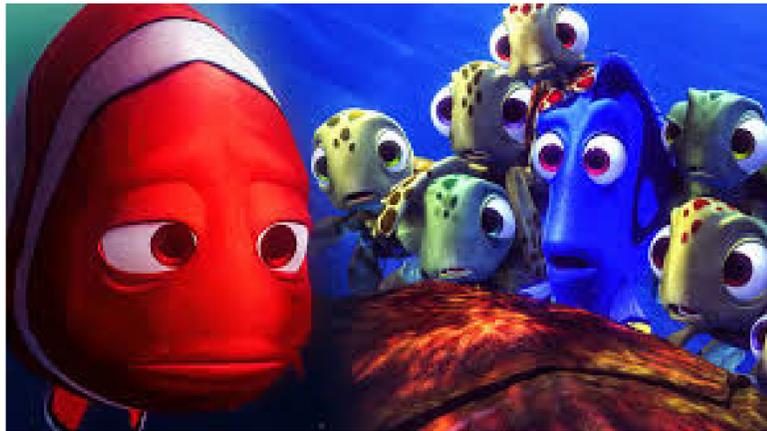


# THE ISSUE

Nemo gets captured by a scuba diver and taken to a fish tank in a dentist's office in Sydney, Australia.



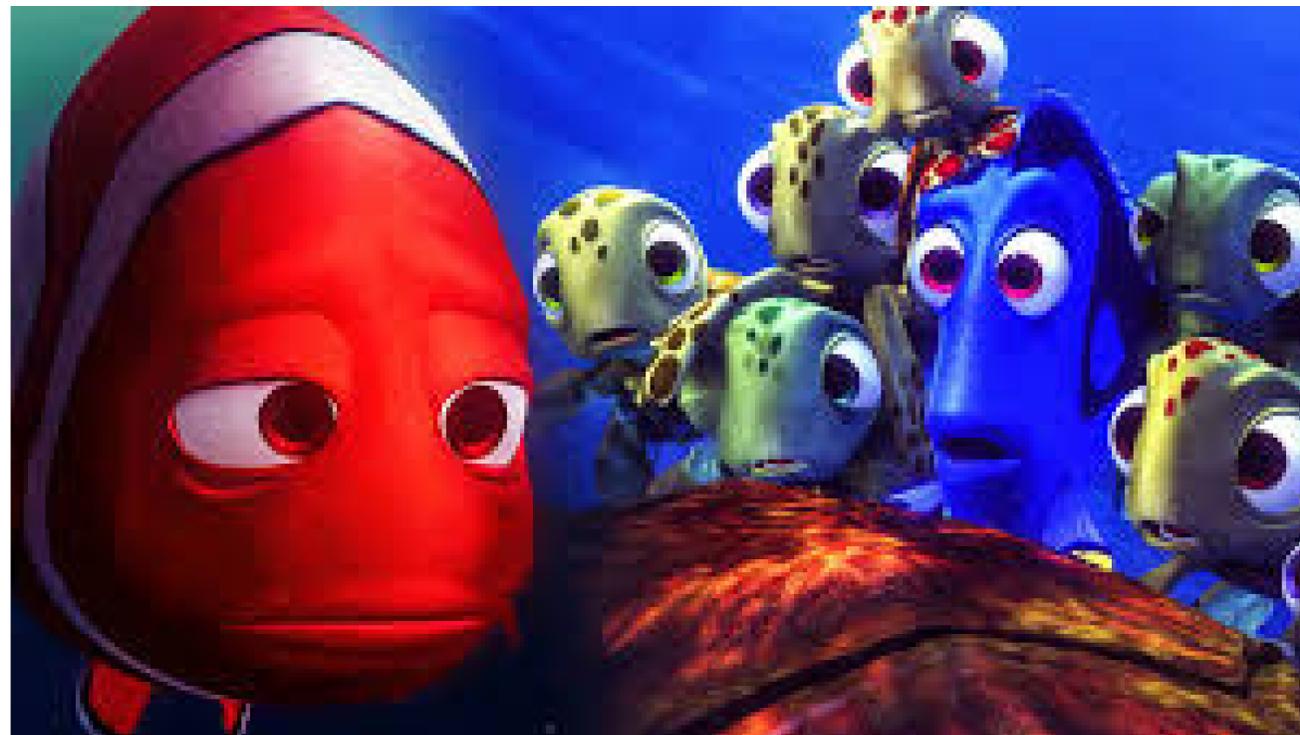
# TAKING ACTION



Marlin took action in finding Nemo by getting out of his comfort zone to speak with sea turtles, sharks, Dory and pelicans to join his efforts and share his story.

# THE ASK

Marlin's ask is clear and specific: "My son was taken. He's in Sydney. I need to find him." He repeats this ask to every single creature he meets. He doesn't give up when people say no or can't help.



# THE SOLUTION

Marlin didn't have a map. He didn't have a plan. He was just a dad who knew what he loved, knew what he lost, and knew he wasn't going to stop until he got it back. Every single person he met, he told his story. Every single door that closed, he knocked on another one. He was scared the whole time — and he kept going anyway.

**That's what advocates do.**



# Together we will...

①

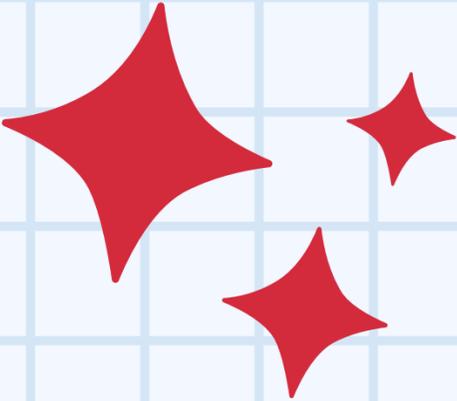
**Get to Know One Another**

②

**Learn About Advocacy & Policy**

③

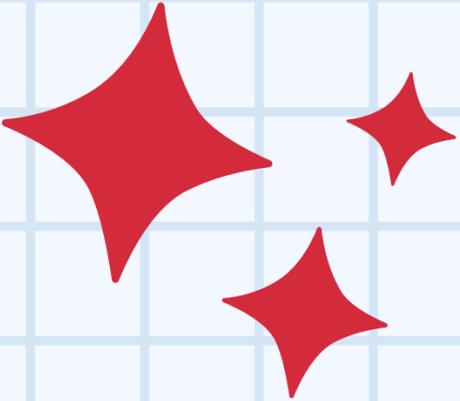
**Become Advocate with Tips and Tricks**



# Stand Up If...

*Or Raise Your Hand*

**national down syndrome society**

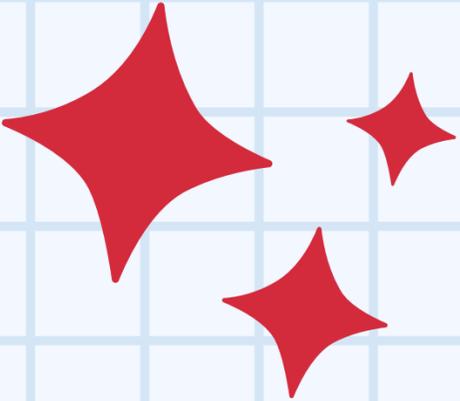


**Stand Up If...**

*Or Raise Your Hand*

**You've ever  
helped a friend...**

**national down syndrome society**

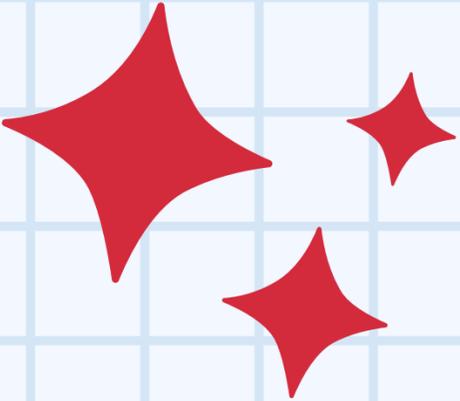


# **Stand Up If...**

*Or Raise Your Hand*

## **You've ever changed someone's mind...**

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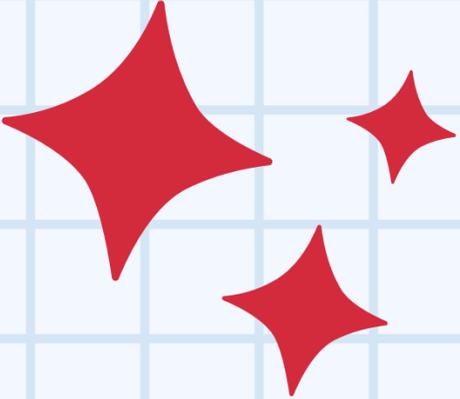


**Stand Up If...**

*Or Raise Your Hand*

**You've ever felt  
misunderstood...**

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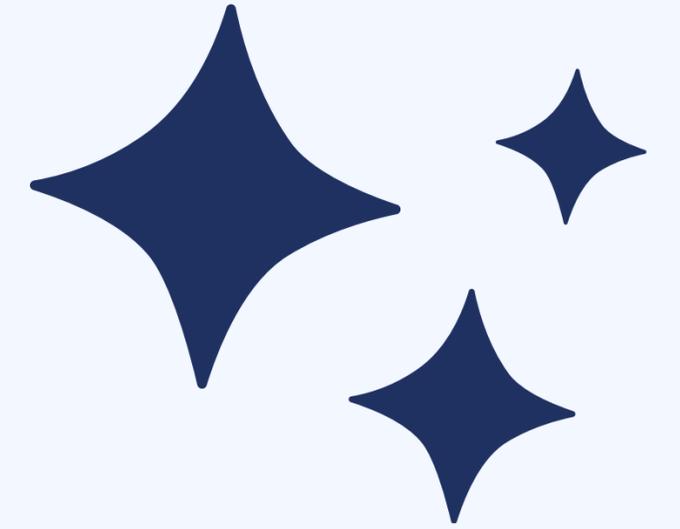
**Stand Up If...**

*Or Raise Your Hand*

**You know YOUR  
voice matters!**

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# Goals for our Session!



- Understand Advocacy & Policy
- Strengthen your Advocate Story



*Ready to jump in?*

# Together we will...

②

**Learn About Advocacy & Policy**

③

**Become Advocate with Tips and Tricks**

# Advocacy & Policy 101

## *What is advocacy?*

Advocacy is speaking up for yourself or others to make change happen.

It means **sharing your story, educating decision-makers, and asking for what your community needs** — through meetings, calls, emails, or public action.



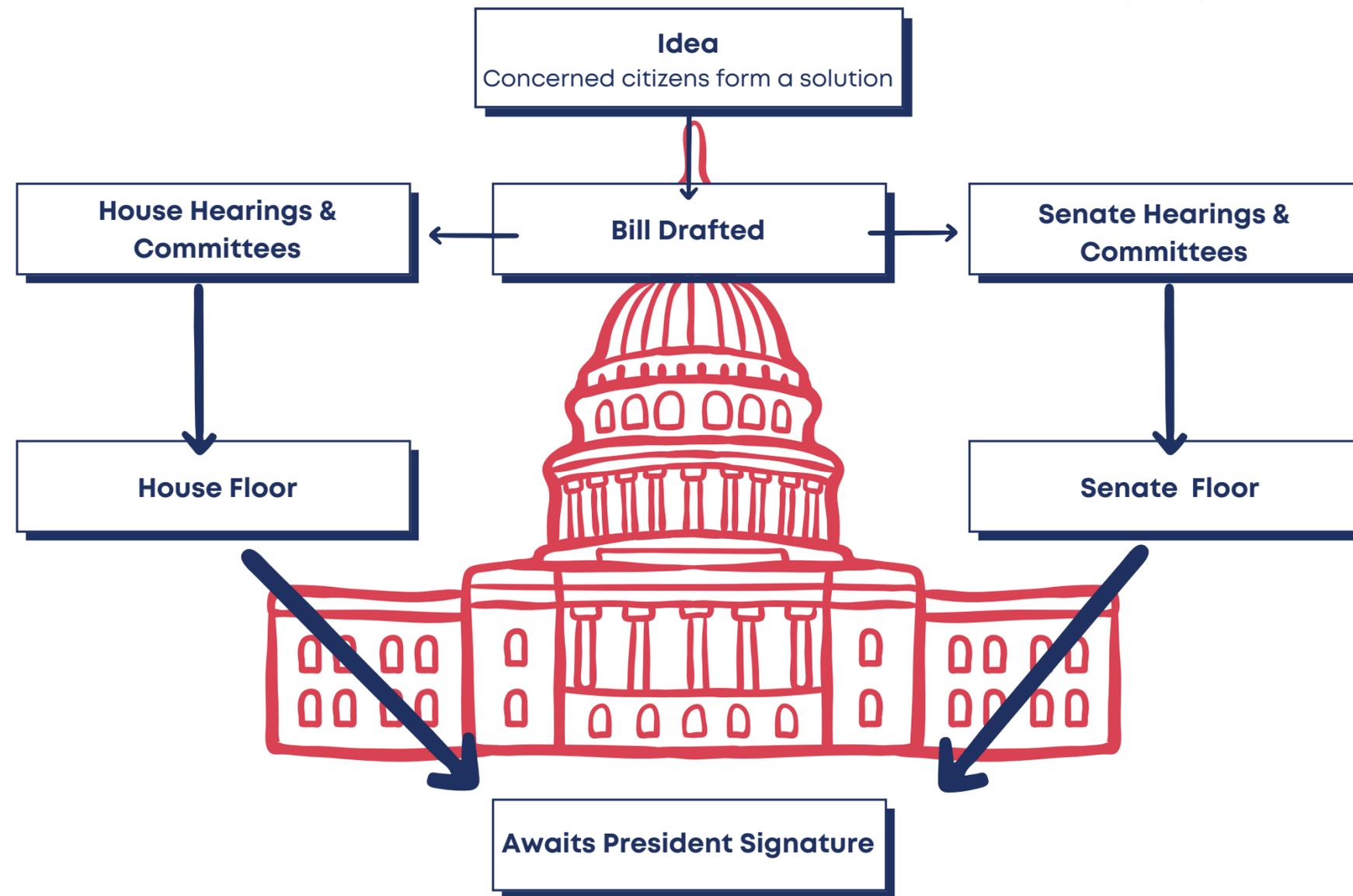
# Advocacy & Policy 101

*Where does advocacy happen?*



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*Where does advocacy happen?*



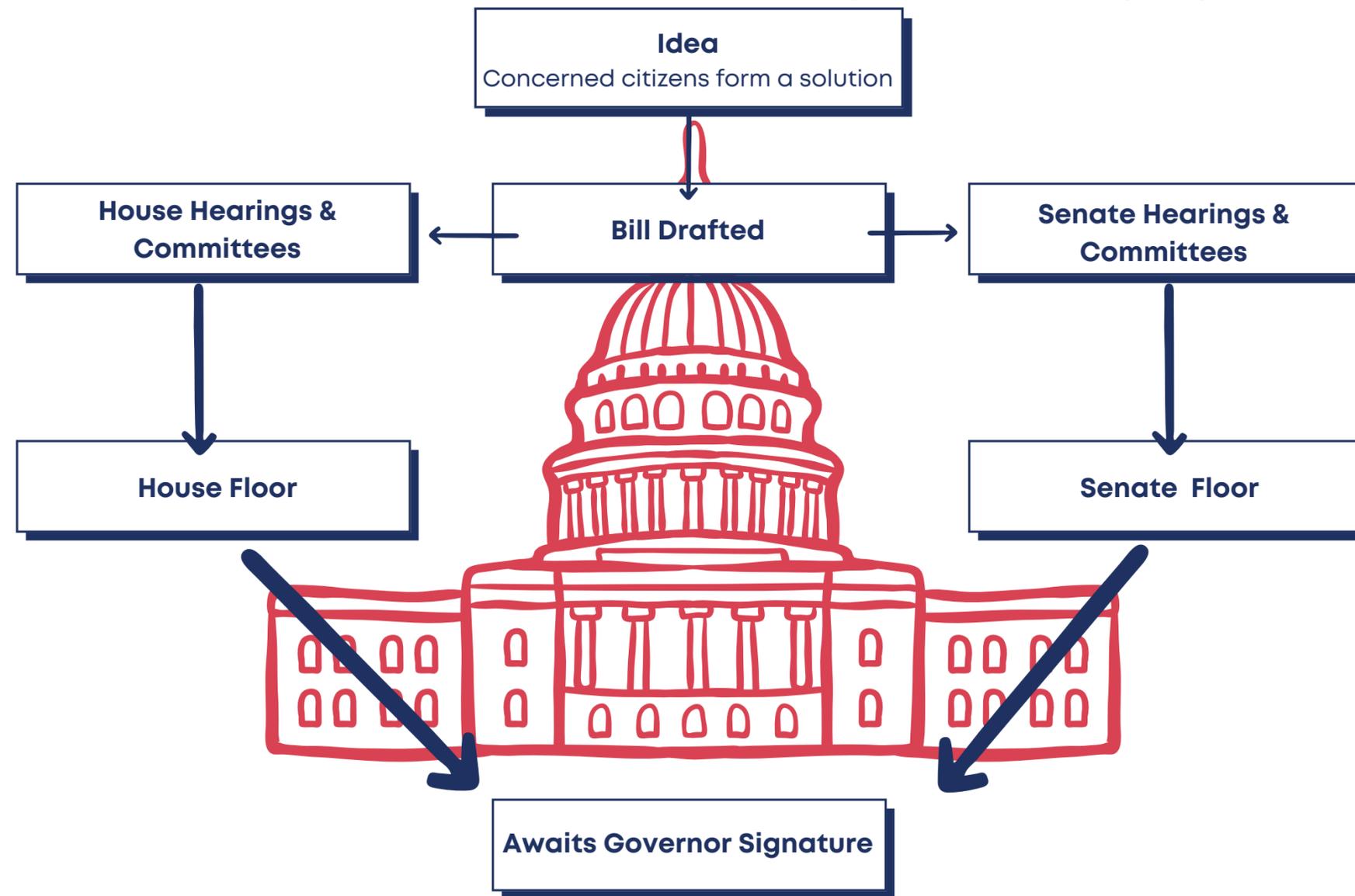
# Advocacy & Policy 101

*Where does advocacy happen?*



# Advocacy & Policy 101

*Where does advocacy happen?*



# Advocacy & Policy 101

*Who can be an advocate?*



- Everyone is an advocate!
  - Advocates have to learn, practice and build relationships to be effective.

# Advocacy & Policy 101

*Advocates Speak Up To Instill Change*



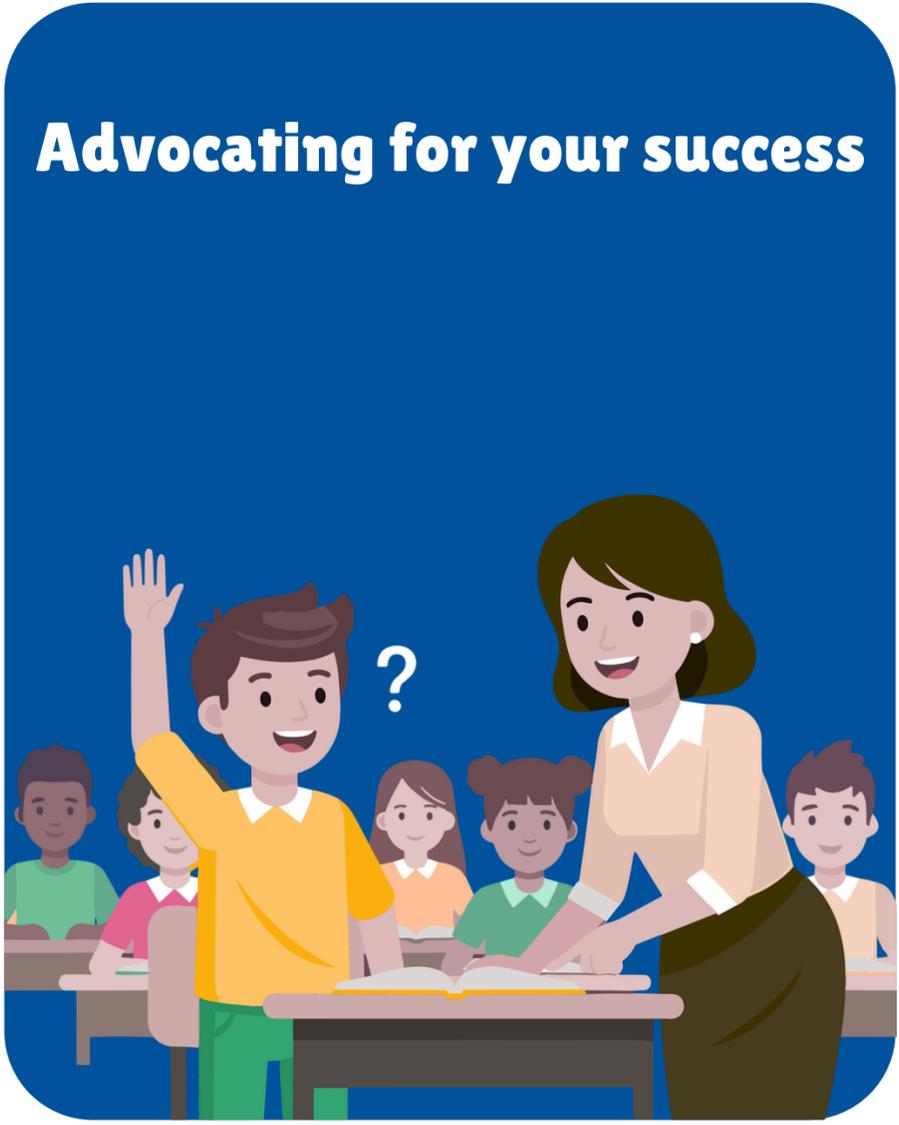
# Advocacy & Policy 101

## Where does advocacy happen?

Advocating for your health



Advocating for your success



Advocating for your needs



# Advocacy & Policy 101

*Advocacy is not...*

**Voting for your favorite singer on a TV show**



**That is showing support!**

**Choosing what's for lunch**



**That is your preference!**

**A personal wishlist**



**Wanting something for yourself is not advocacy!**

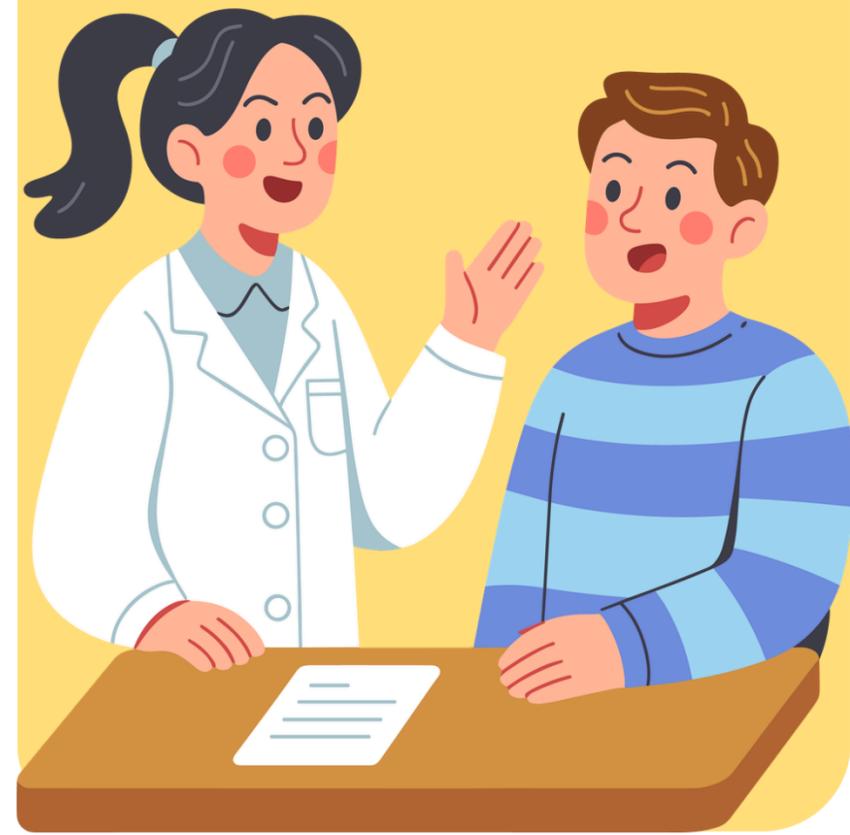
**Advocacy is when you speak up for change concerning an issue affecting your rights or your community**

# Advocacy & Policy 101

At Work



At the Doctors



Policy



# Advocacy & Policy 101

## *SSI Savings Penalty Elimination*

### What is SSI?

- **Supplemental Security Income** is monthly money from the government that helps people with disabilities pay for basic needs like food, housing, and transportation.

### What is the issue?

- Single people can only have \$2,000 in assets (savings, checking, etc.).
- Married couples can only have \$3,000 combined.
  - These limits have not changed since 1989 - over 35 years ago!
- If adjusted for inflation, the limit would be about \$4,800 today.
- Going over these limits means losing SSI benefits entirely.

# Advocacy & Policy 101

## *SSI Savings Penalty Elimination*

### What are Advocates doing?

Asking Congress to raise the individual limit--and double it for married couples--so people with disabilities can save money, get married, build independence, and plan for their lives without being penalized for it.



# Advocacy & Policy 101

## *How To Advocate*

### 1. Understand the issue

- How does this issue work? How has it impacted you and others?

### 2. Share your experience with the right audience

- Is this a state issue? School district? Federal?

### 3. Stay consistent with your advocacy

- Keep sharing your expert experience to influence change!

# Advocacy & Policy 101

## *Who makes the policies?*

**Policymakers** write, vote on, sign, and implement laws and policies.

- State officials - laws and policies for your state.
- Federal officials - laws and policies for the whole country.

# Advocacy & Policy 101

## *Understanding Types of Policymakers*

### Local

- City council, county commissioners
- They meet, discuss problems, vote on new rules
- Park hours, school lunch programs, bus routes
- These rules affect your daily life in your neighborhood

### State

- State representatives, state senators, governor
- Lawmakers write bills, vote in the state capitol, governor signs them
- Special education requirements, Medicaid services, employment laws
- These rules affect everyone in your state

### Federal

- Congress (House and Senate), President
- Bills written in Washington D.C., both chambers vote, President signs
- IDEA, Americans with Disabilities Act, Social Security
- These rules protect people with disabilities in America

# Advocacy & Policy 101

## *SSI Savings Penalty Elimination*

My name is [NAME]. I am from [CITY, STATE].

I have Down syndrome and I [one thing about your life — I work, I go to school, I live in my own apartment].

I want to [one dream — get married, buy a car, save for my future, live independently].

But right now, if I save more than \$2,000 the government cuts my benefits. That limit has not changed since 1989.

That is not fair. And it holds me back from the life I want to live.

I am asking you to support the SSI Savings Penalty Elimination Act so that people like me can save money without being penalized.

My independence matters. My future matters. And my voice matters.

Thank you.

# Advocacy & Policy 101

## At the Doctors



*You have been waiting three weeks to see the doctor for foot pain.*

*When you get to the appointment, the doctor is not listening to you as much as you'd like and you feel rushed.*

*How can you advocate for yourself?*

# Advocacy & Policy 101

## At the Doctors



"Excuse me, Doctor. I want to make sure I am understood."

"I want to tell you exactly where it hurts and when it started. Can I have a moment to explain?"

"I want to make sure I understand what you are telling me. Can you explain it in simple words?"

"What are my options? I want to be part of deciding what happens next."

"Before I leave today, can I have everything written down so I remember it?"

## Be sure to follow up!

- Picking up your prescription.
- Email questions, results or, outcomes to your physician.
- Consistent communication makes it easier next time!

# Advocacy & Policy 101

## At Work

- Ask for what you need
- Request supports
- Document everything
- Follow up

## At the Doctors

- Doctor knows you!
- No follow up
- Ask for information

## Policy

- Share Background
- Dress Professional
- Bring information
- Be Specific
- ALWAYS follow up!

# Advocacy & Policy 101

*What's YOUR advocate snapshot?*

My name is [NAME].

I am from [CITY, STATE] and I am your constituent.

I have Down syndrome.

Something that matters to me is [independence, my job, my family, my future].

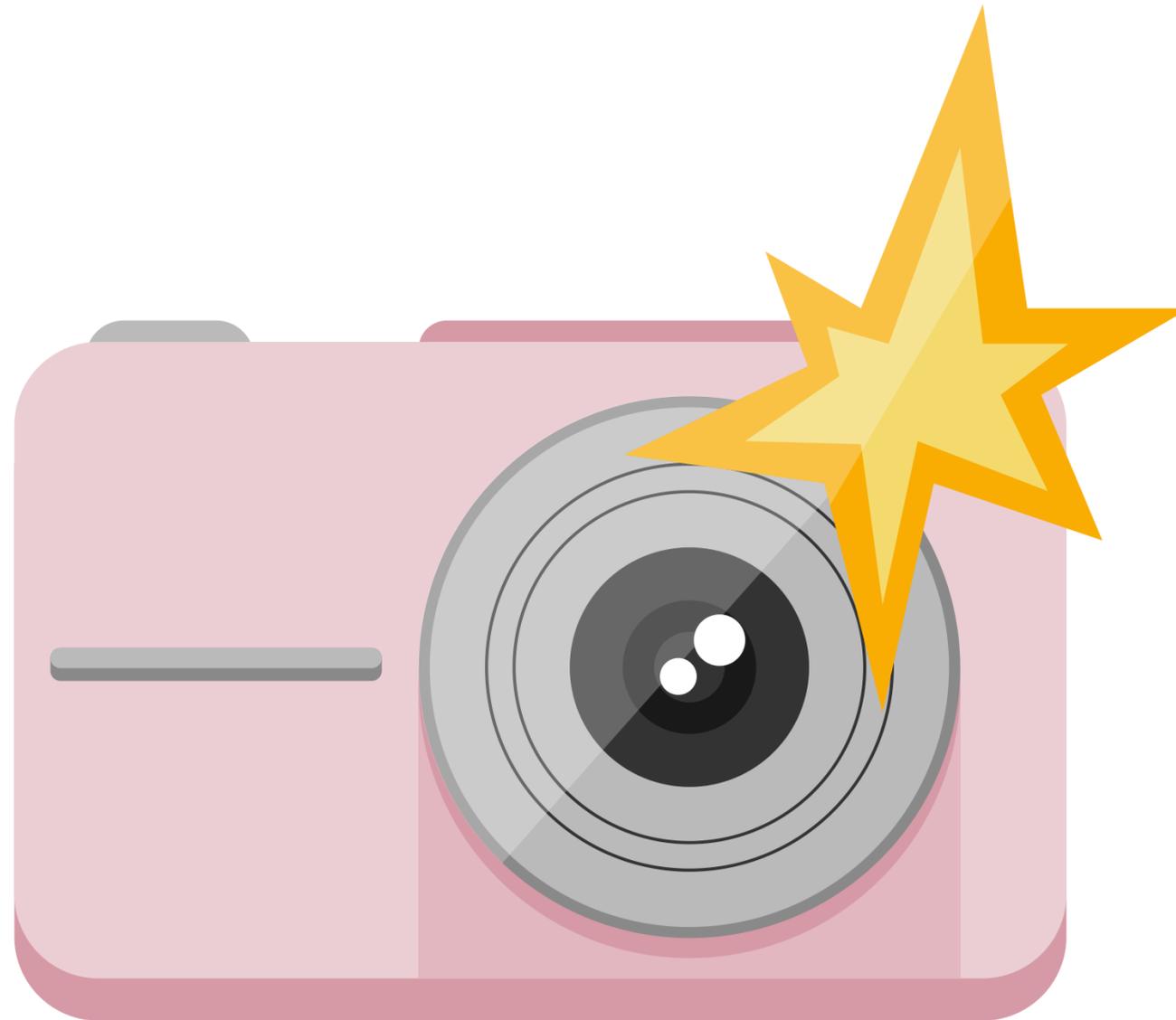
A rule that affects my life is [I can't save more than \$2,000, I don't always get listened to at the doctor, I need accommodations at work].

I want to change this because [what it means for YOUR life and community].



# Advocacy & Policy 101

*Share Your Advocate Snapshot*



# Together we will...

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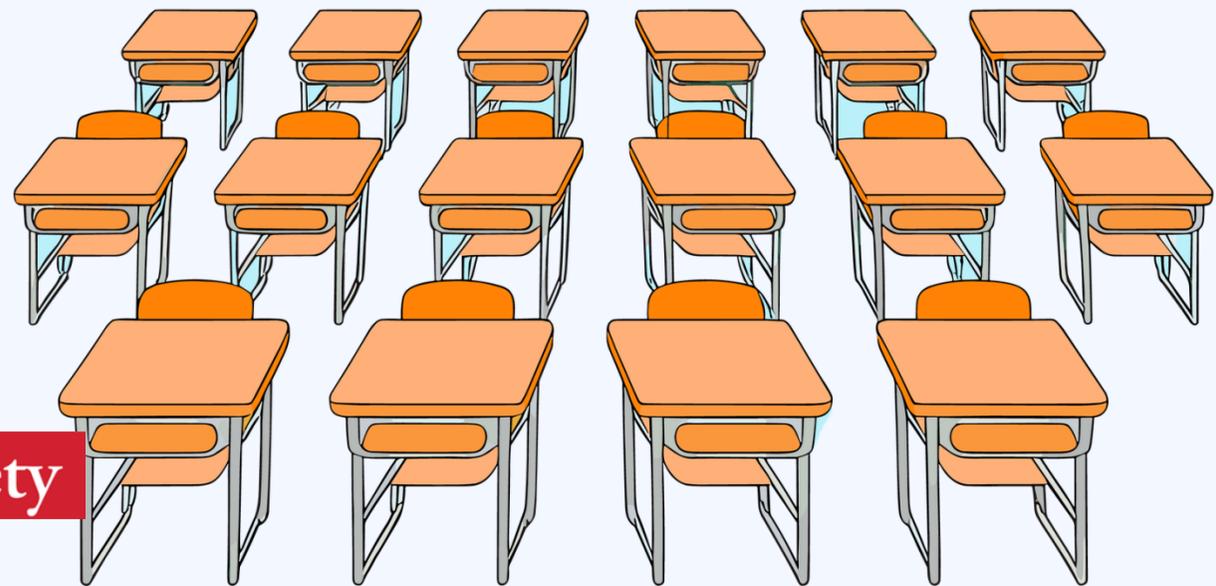
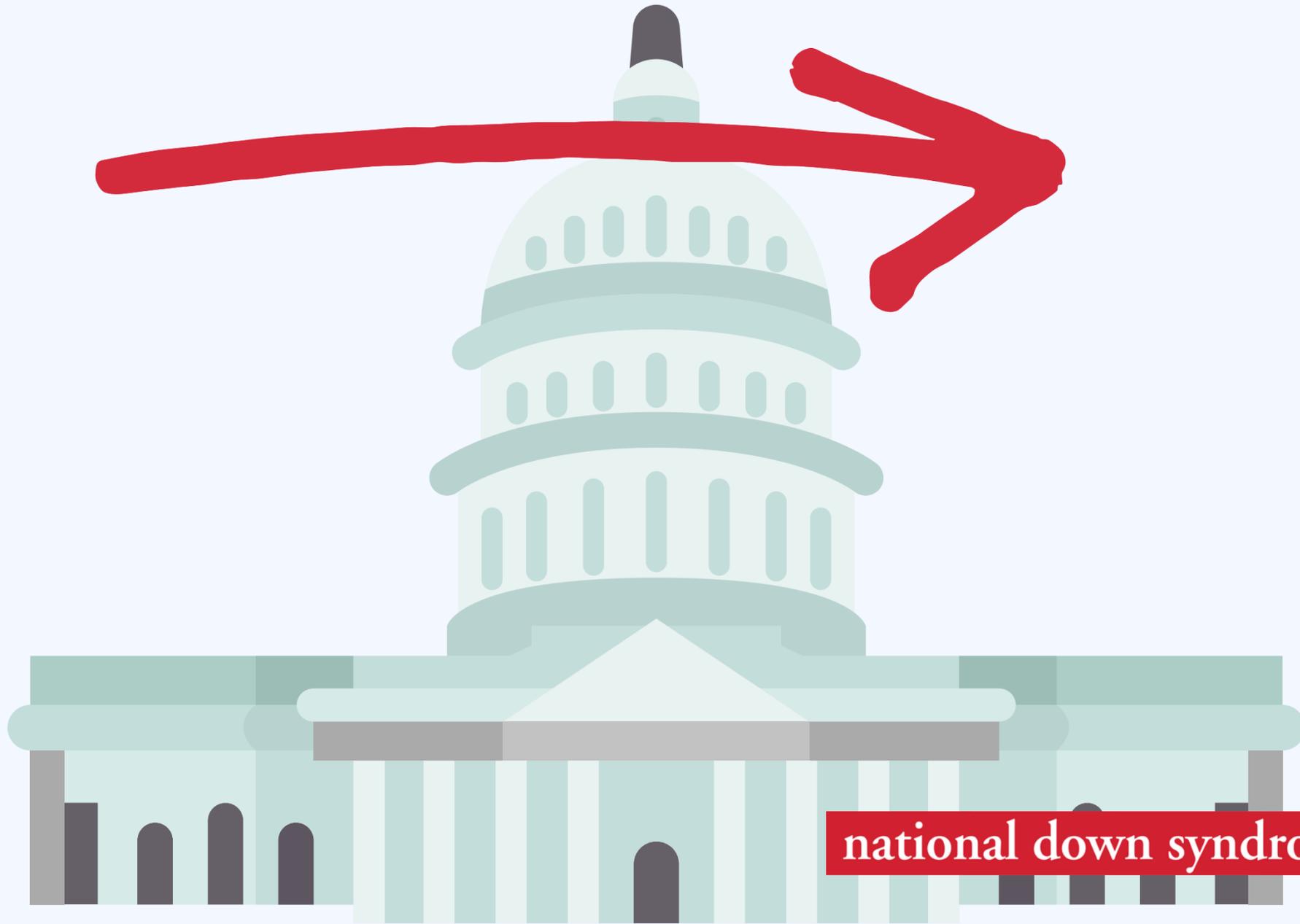
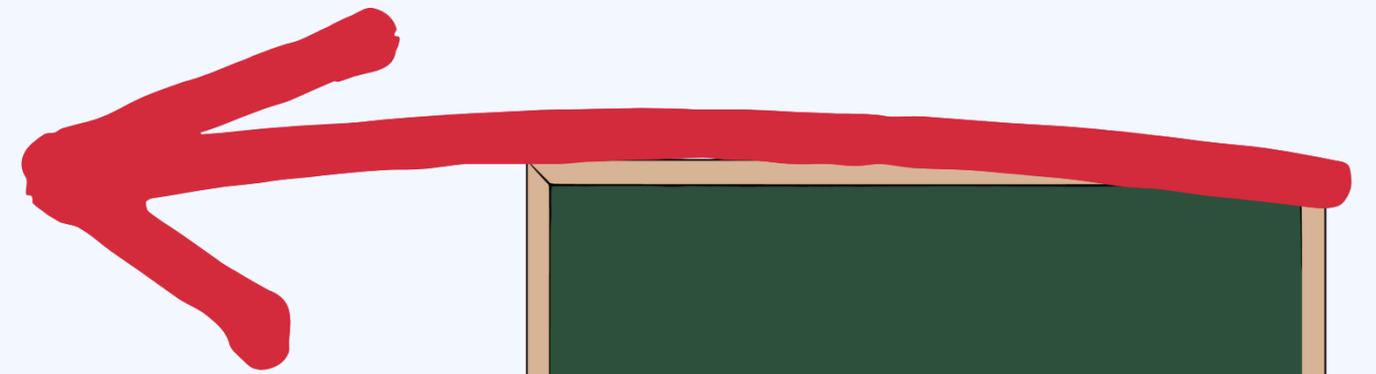
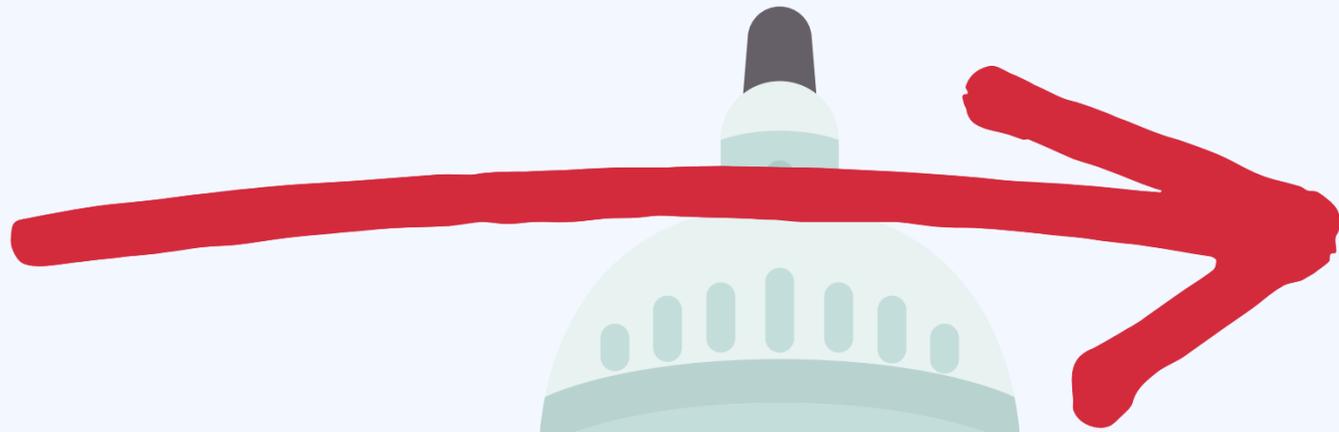
**Become Advocate with Tips and Tricks**

# Advocate Tips and Tricks

When we share our experiences  
we want to be *impactful!*



# Skills On and Off the Hill



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# Advocate Tips and Tricks

*Which statement is more impactful?*

“There are millions of people with Down syndrome in the world and many of them don't have access to the services they need.”

"My name is Marcus. I have Down syndrome. I work at a bakery, I live in my own apartment, and I love my life. But last year my services got cut, and I almost lost my job. I need my lawmakers to protect those services — because without them, I lose my independence."

# Advocate Tips and Tricks

*What is important to voice when wanting to make change?*

- **Your name and your connection**
  - Who are you and why does this issue affect YOUR life? A lawmaker needs to know they're talking to a real person from their community, not just a talking point.
- **The specific change you want**
  - Not just "things need to be better" but "I need you to vote yes on this bill" or "I need you to raise the SSI savings limit." Vague asks get vague responses.
- **What happens if nothing changes**
  - This is your most powerful tool. Not abstract consequences — YOUR consequences. "If this doesn't change, I could lose my job. I could lose my apartment. I could lose my independence."

# Advocate Tips and Tricks

*When speaking up, what else is important to be impactful?*





# *Business Professional*

*Not ALL advocacy requires this, but policy does!*

- Dress like you mean it
- Clean and neat clothes
- No rips or logos
- Closed toe shoes
- Think: job interview ready



# *Being Prepared*

- **Know your story**
- **Practice out loud**
- **Learn one fact about your issue**
- **Know your legislator's name**
- **Bring your notes**



**LET'S GO BACK TO THE BASICS**

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# BUILDING CONFIDENCE



**DOESN'T HAPPEN OVER NIGHT!**

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# Get Loud!



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# Volume



Volume is how loud or soft your voice is. You should speak loudly enough so that everyone in the room can hear you, but not so loud that it sounds like shouting. Adjust your volume depending on the space and the size of the audience.



# Expression



Expression is about using your voice, face, and body to show meaning and emotion. For example, raising your eyebrows or smiling can add energy to your message. Using expression helps your audience connect with you.

# Tone

Tone is the feeling or attitude in your voice. It helps show how you feel about what you're saying.

For example, a friendly tone can make the audience feel comfortable, while a serious tone can show that your topic is important.



# Practice Makes Perfect!



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**QUESTIONS?**

