

Advocacy 101

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The North Carolina Serious Illness Coalition is a partnership of health leaders, providers and citizens that oversees and coordinates the implementation of the recommendations from the NC IOM Task Force on Serious Illness Care.

Session Objectives

- Define advocacy and why advocacy is important
- Review case studies:
 - Autism Speaks
 - Stem-cell campaign
- Explain how personal connections can lead to change
- Open Forum

What is Advocacy?

According to ChatGPT

Influencing legislation and public policy by individuals or organizations to advance specific interests or causes

What is Advocacy?

A more practical definition

Building legislator **relationships** to earn support for your issue(s) over the **long-term**

NC is Lobbying-Centric

Setting a record in 2022

Organizations lobbying: 1,071

Lobbying spending: \$65.3 million

Grassroots: The Difference Maker

Staffers agree

94%

Grassroots: The Power of Connection

More Personal = More Attention

“The truth is that more weight is given to groups of constituents who show up in person...”

“In-person engagement is always going to be better than online.”

But the NC legislature has supermajorities!

Grassroots is still important

Supermajority leadership still needs to generate support; they will be sensitive to:

- Members' priorities (and level of enthusiasm for each)
- Members from vulnerable districts

Not every issue is decided by partisan affiliation

- House vs. Senate
- East vs. West

The minority party will eventually become the majority

Case Study – Autism Speaks



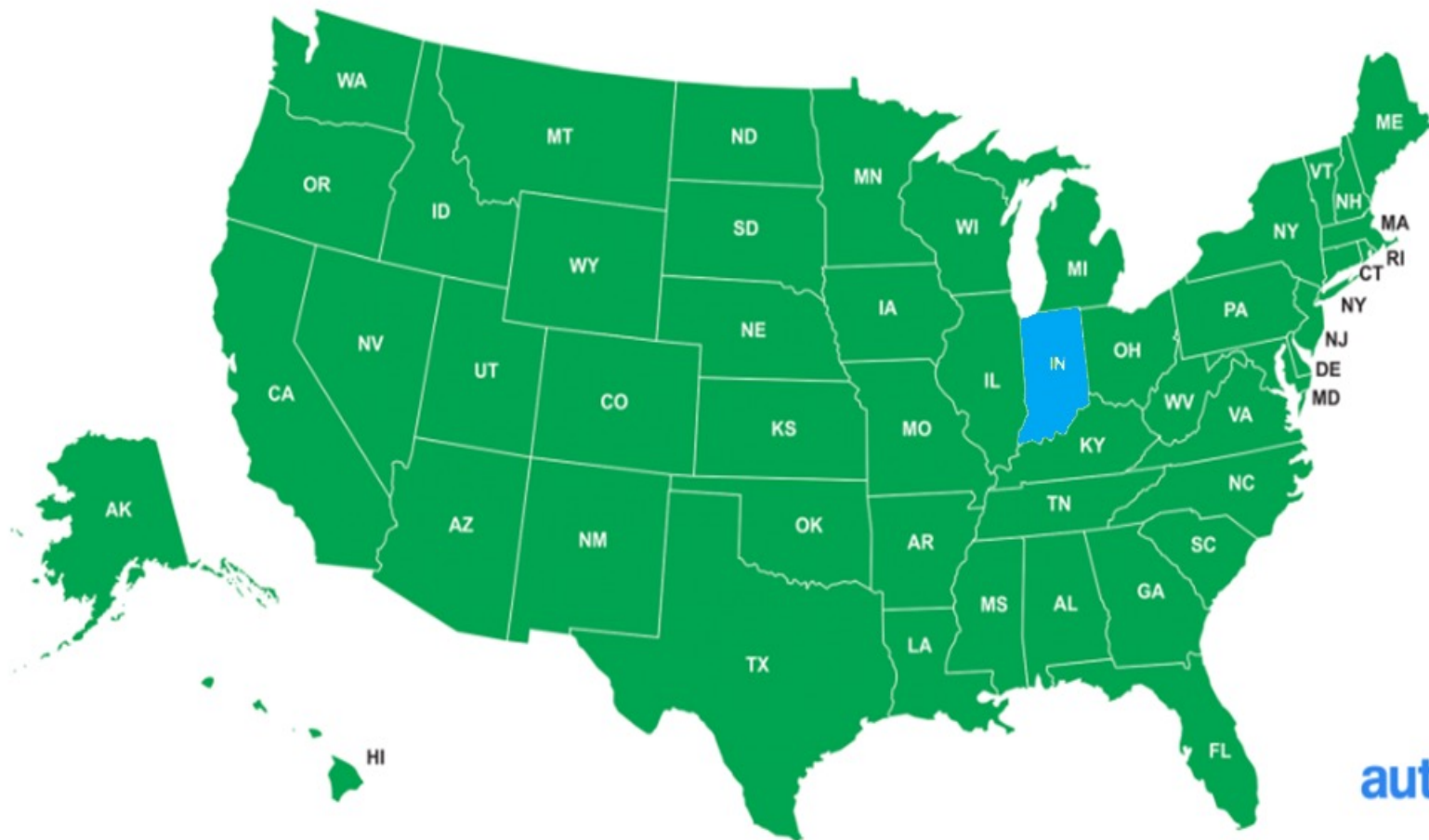
Zero to industry leader in > 20 years

Vision to coalesce around autism that leverages impact and reach.

Case Study

Successfully advocated for autism insurance benefits in all 50 states	Invested nearly \$215M in scientific grants and projects	Championed \$4.2B in federal funding for autism since 2007	Created an online database of nationwide autism services and resources viewed by over 21.6M people
Helped lead the world's largest genomic discovery about biology of autisms	Provided tool kits offering critical information and support to over 1.7M families and professionals	Funded research to lower the age of diagnosis , driving earlier screening and interventions	Provided more than 622K people with direct assistance by email, phone and chat
Increased understanding and acceptance by sharing stories with @autismspeaks social community of 2.8M	Aided nearly 26M people through services and supports	Funded more than \$15.9M in local grants and scholarships throughout the U.S.	Administered network of medical centers/academic facilities developing cutting edge care to more than 500K children

Autism Insurance Reform - 2005



autism speaks®

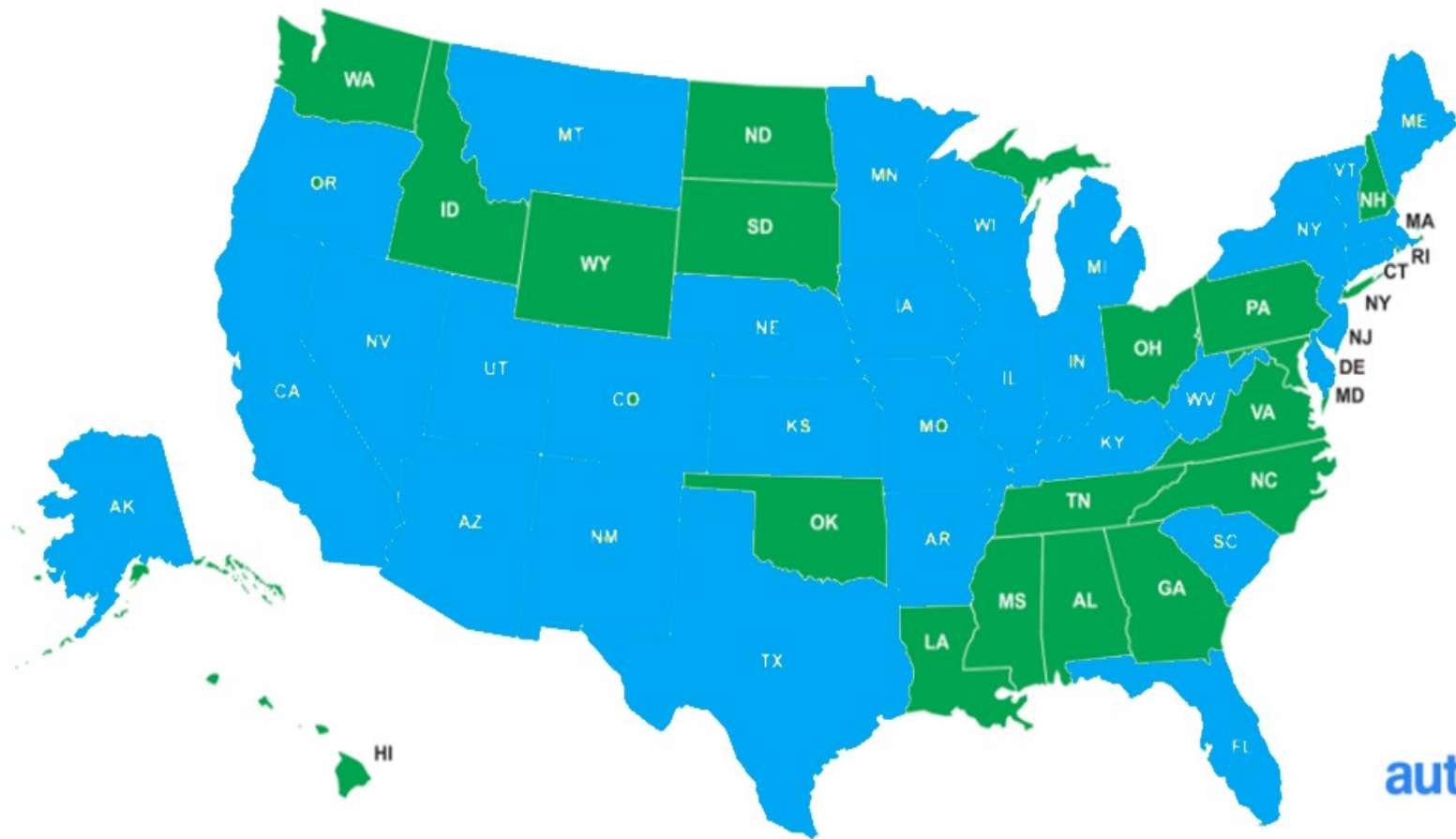


What led to ABA coverage in all 50-states?

Local approach to national goal

- Used evidenced-based data/info to create a **simple message** - early intervention and treatment improves outcomes and is a cost-saving
- **Started in one-state.** Replicated it
- **Identified state champions:**
 - Family advocates to put a face on the issue
 - Legislators to sponsor the bill
 - Community partners to show unity in voice and strength in numbers
- **Legislative engagement:**
 - Local lobbyist to open the door
 - Local stories to paint the picture

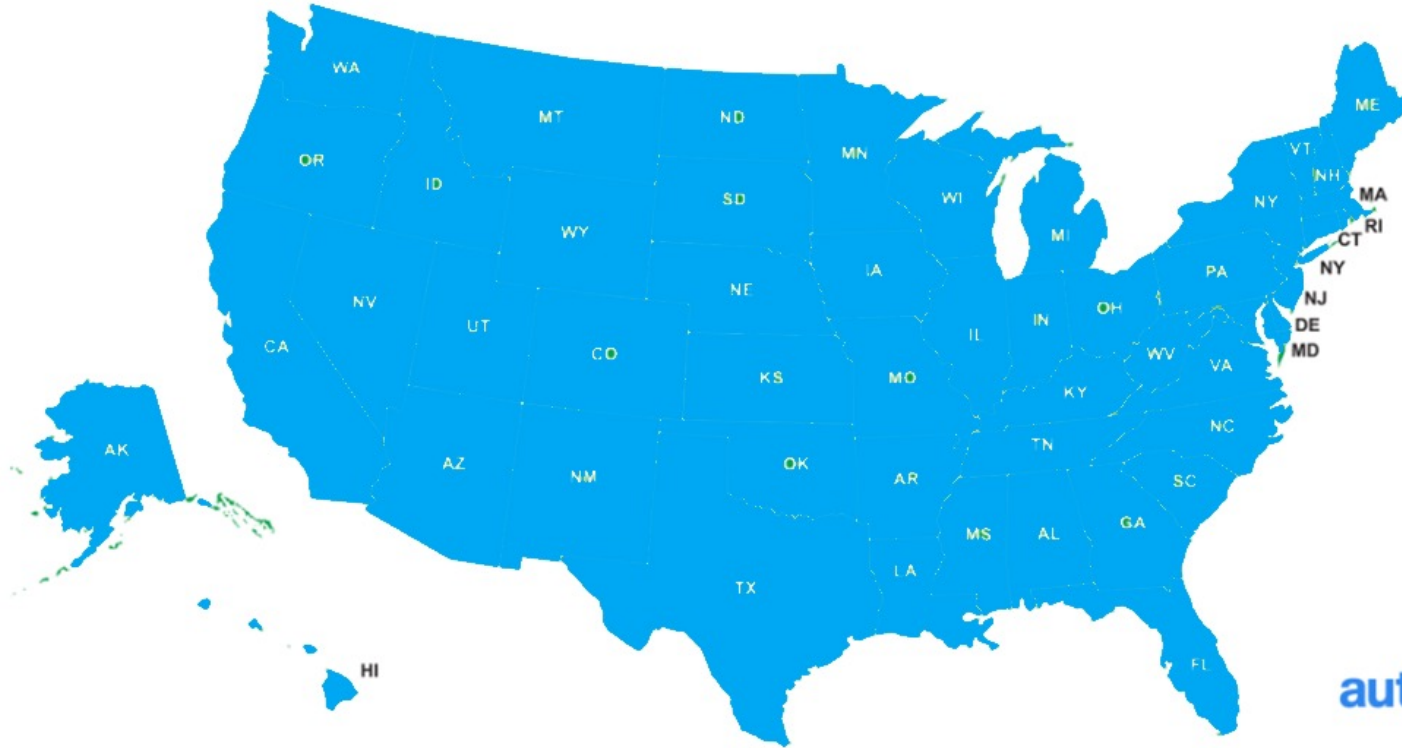
Autism Insurance Reform - 2014



autism speaks®

2019 Victory!

Autism Insurance Reform in 50 States



2019 Victory!

Take Away:

- Identify a problem and provide a solution
- Build relationship with decision makers
- Paint the picture with personal story
- Partner with others to have strength in numbers and unity in voice

Case Study - Stem Cell

Stem Cell Research Enhancement Act

Building consensus on an emotionally-charged issue

Goal: Provide federal funding for embryonic stem cell research

Challenges:

- GOP control of both congressional chambers
- Broad GOP opposition

Strategy:

- Coalition: Communicate unity and handle controversy
- Individual organization advocacy
 - JDRF: Execute a campaign of conversations

Stem Cell Research Enhancement Act (cont.)

Educate. Prioritize. Legislate.

2004: Begin with in-district meetings

- Meetings are longer, more engaging, and include more people
 - Goals: Educate and begin relationship building
 - Completed 300+ meetings in six months
- Lobbyists follow-up to assess opportunities to prioritize
- Advocates send follow-up emails directly to staff

2005: Continue building momentum

- May: House passes bill; now we need 60 votes in the Senate!
- D.C. fly-in with kids and families:
 - Introduce different messengers
 - Thank House allies

Stem Cell Research Enhancement Act (cont.)

Educate. Prioritize. Legislate.

2006: A significant victory

- More in-district meetings with more constituents
 - Goal: Pass the legislation
 - Completed 330 meetings
- July 2006:
 - Senate passes legislation with 63 votes!

**President Bush vetoes the
legislation; first of his
presidency**

Stem Cell Research Enhancement Act (cont.)

Educate. Prioritize. Legislate.

2007: Flipping the script

- Democrats take control of Congress
 - Top of the agenda: Among first bills introduced in each chamber
 - Bills passed by June

President Bush vetoes the legislation again

2009: Victory!



President Obama executive order removed certain restrictions on federal funding for human embryonic stem cell research

Case Study – Personal Connections

Personal Connections Matter

Why does it matter?

- Your elected officials care about you
 - You are the expert
 - Stories help drive our message home, making it personal
 - Their district matters to them
 - The importance of site visits and immersive experiences
- Maintain your knowledge
 - Keep a spreadsheet or a notebook
 - Schedule time to connect/refresh/follow up
 - Attend local events, show up
 - Utilize your connections

Personal Connections Matter

Why does it matter?

- Keep in mind - elected officials move around
 - Attorney General Josh Stein
 - NC Labor Commissioner Josh Dobson
 - Congressman Patrick McHenry
 - Congressman Dan Bishop
 - Congressman Don Davis



Questions?

Points of Contact

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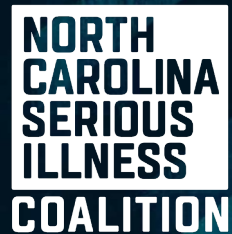
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Visit the website to learn more

<https://www.ncsicoalition.org/advocacy-101/>

Thank you.



Learn more at NCSICoalition.org

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