

Breakout Session:

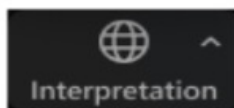
Legislative Advocacy for Children and
Youth with Special Health Care Needs

To Access Interpretation via Your Computer

Para acceder a la interpretación a través de su computadora

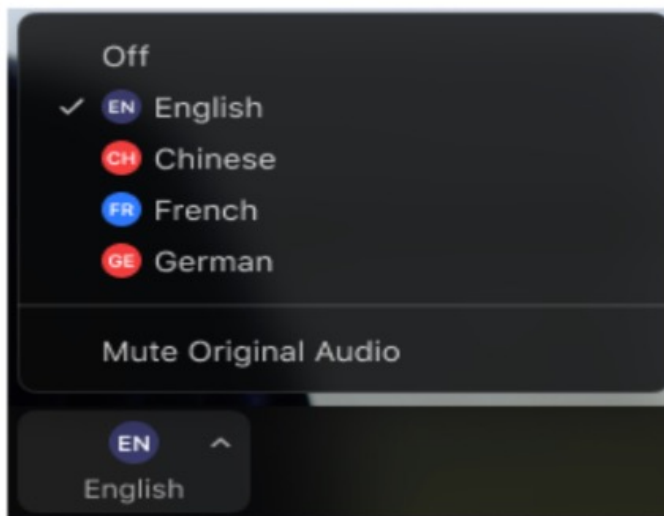
Windows | macOS

1. In your meeting/webinar controls, click **Interpretation**.



1. En el control de seminarios web, haga clic en interpretación

2. Click the language that you would like to hear.



2. Haga clic en el idioma que desea escuchar, español

3. (Opcional) si solo desea escuchar el lenguaje interpretado, haga clic en silenciar el audio original.


3. (Optional) To only hear the interpreted language, click **Mute Original Audio**.

To Access Interpretation via Your Mobile Phone

Para acceder a la interpretación a través de teléfono móvil.

Android | iOS

1. In your meeting controls, tap ... **More**.
1. En el control de seminarios web, haga clic en mas (3 puntos)
2. Tap **Language Interpretation**.
2. Haga clic en interpretación
3. Tap the language you would like to hear.
3. Haga clic en el idioma que desea escuchar, español
4. (Optional) Tap the toggle to **Mute Original Audio**.
4. (Opcional) si solo desea escuchar el lenguaje interpretado, haga clic en silenciar el audio original.
5. Click **Done**.
5. Haga clic hecho/Done



Language Interpretation	Done
Original Audio	✓
English	
Italian	

Mute Original Audio

FAMILY VOICES of California

Feel free to introduce yourself in the Chat section. Use the Q&A section to ask speakers questions.

All sessions are recorded and will be shared.

Live captions are available. Click the 'CC' icon to show captions.

FAMILY VOICES of California

Siéntase con la libertad de presentarse en la sección de Chat.
Use la sección de preguntas y respuestas para hacer preguntas a los
presentadores.

Todas las sesiones son grabadas y serán compartidas.

Los subtítulos en vivo están disponibles. Haga clic en el ícono 'CC' para
mostrar los subtítulos.

Breakout Session:

Legislative Advocacy for Children and
Youth with Special Health Care Needs

Panelists:

Kelly Mac Millan, Associate Lobbyist, Political Solutions

Jenny McLelland, Advocate, Little Lobbyists

Cecilia Rideout, Parent Advocate, Center for Autism and
Neurodevelopmental Disorders

Dawn Adler, Legislative Director, CA State Assembly – Office of
Assemblywoman Sharon Quirk-Silva



LEGISLATIVE ADVOCACY

★ KELLY MAC MILLAN LOBBYIST ★ POLITICAL SOLUTIONS



**ADVOCACY IS A
YEAR-ROUND ACTIVITY**



**YOU CONTINUE TO
PARTICIPATE IN THE
PROCESS IN SPITE OF
MULTIPLE PAUSES.**

WHAT IS ADVOCACY

An action directed at changing the policies, positions, or programs of any type of institution.

- **Wherever change needs to occur, advocacy has a role to play.**
- **Influencing policy decision-making and implementation by:**
 - **Educating**
 - **Reforming**
 - **Creating Accountability**

ADVOCACY VS. LOBBYING

- **ADVOCACY**

- **PUBLIC SUPPORT FOR OR RECOMMENDATION OF A PARTICULAR CAUSE OR POLICY**
- **NO LIMIT TO THE AMOUNT OF ADVOCACY A PERSON OR ORGANIZATION (SUCH AS A NONPROFIT) CAN DO**

- **LOBBYING**

- **SEEK TO INFLUENCE A POLITICIAN OR PUBLIC OFFICIAL ON AN ISSUE**
- **DIRECT LOBBYING**
- **GRASSROOTS LOBBYING**

EXAMPLES OF ADVOCACY VS LOBBYING

● **ADVOCACY**

- **TELLING AN ELECTED OFFICIAL HOW A POLICY AFFECTS CONSTITUENTS**
- **MEETING WITH AN ELECTED OFFICIAL TO EDUCATE/EXPLAIN HOW A PARTICULAR PROBLEM/ISSUE IS AFFECTING A PARTICULAR GROUP OR ORGANIZATION, ETC.**

● **LOBBYING**

- **ASKING A LEGISLATOR TO VOTE FOR OR AGAINST, OR TO AMEND OR INTRODUCE, PARTICULAR LEGISLATION**
- **CREATING AN ONLINE PETITION ASKING THE PUBLIC TO CONTACT THEIR LEGISLATORS TO SUPPORT OR OPPOSE A PARTICULAR LEGISLATION**

STATE LEADERS

- **GOVERNOR:**
 - **FOUR YEAR TERM.**
 - **THE GOVERNOR APPOINTS AGENCY AND DEPARTMENT HEADS, JUDGES, COUNTY SUPERVISORS FILLING PARTIAL TERMS, AND HUNDREDS OF POSITIONS ON BOARDS AND COMMISSIONS.**



2026 GOVERNOR'S RACE



Lieutenant Governor Eleni Kounalakis

- **First woman elected Lt. Governor in CA**
- **CA Representative for International Affairs and Trade**
- **President Barack Obama's Ambassador to the Republic of Hungary**
- **Campion for international trade, women's rights, higher education, and climate change .**



State Senator Toni Atkins

- **Senate Pro Tem**
- **Speaker of the Assembly**
- **San Diego City Council**
- **Campion for affordable housing, healthcare access, veterans, LGBTQ and women's rights, and the environment.**



California State Superintendent of Public Instruction Tony Thurmond

- **State Assembly**
- **Richmond City Council**
- **School Board Member**
- **Champion for education, mental health, literacy, and school meals.**



Former State Controller

- **State Board of Equalization**
- **Governor Gray Davis Budget Director**
- **Champion for economic opportunities, fighting discrimination, environmental causes and affordable health care.**

STATE LEADERS

- **40 Senators and 80 Assemblymembers**
- **Senators serve four-year terms.**
- **Assemblymembers serve two-year terms.**
- **Members are able to serve up to 12 years in state legislature in total.**



SENATE LEADERSHIP

Budget Chair Scott Wiener



Health Chair Richard Roth



**Budget Sub 3 Chair
Caroline Menjivar**



**Human Services Chair
Senator Marie Alvarado-Gil**



PRESIDENT PRO TEM

MIKE MCGUIRE

ASSEMBLY LEADERSHIP

**Budget Chair
Jesse Gabriel**



**Health Chair
Mia Bonta**



**Human Services Chair
Alex Lee**



**Budget Sub 1 Chair (Health)
Akilah Weber, M.D.**



**Budget Sub 2 Chair (Human Services)
Corey Jackson**



**SPEAKER
ROBERT RIVAS**

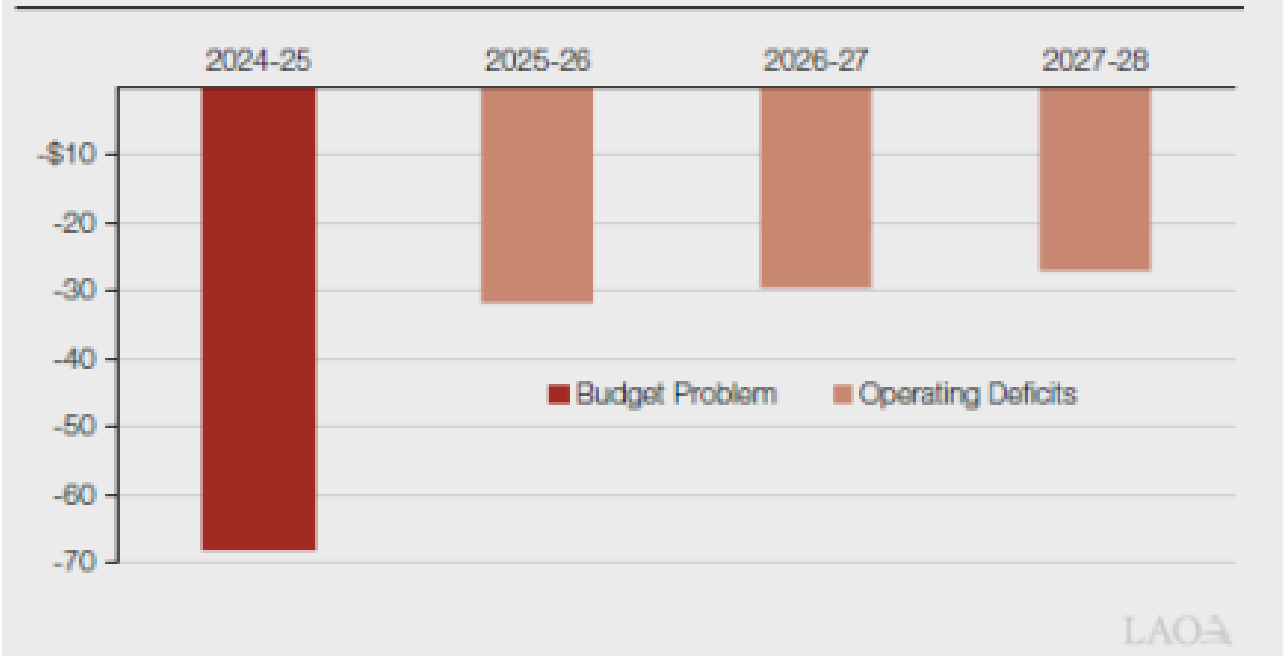
BUDGET

THE LEGISLATIVE ANALYST'S
OFFICE PROJECTED THE 2024-25
SHORTFALL AT \$73 BILLION

Figure 4

State Faces Serious Budget Problem in 2024-25, and Significant Operating Deficits in Future Years

(In Billions)



Find Your California Representative

Enter your California address and click the locate button to find your State Senate and Assembly representatives.

* Street Address

* City

* Zip

Locate

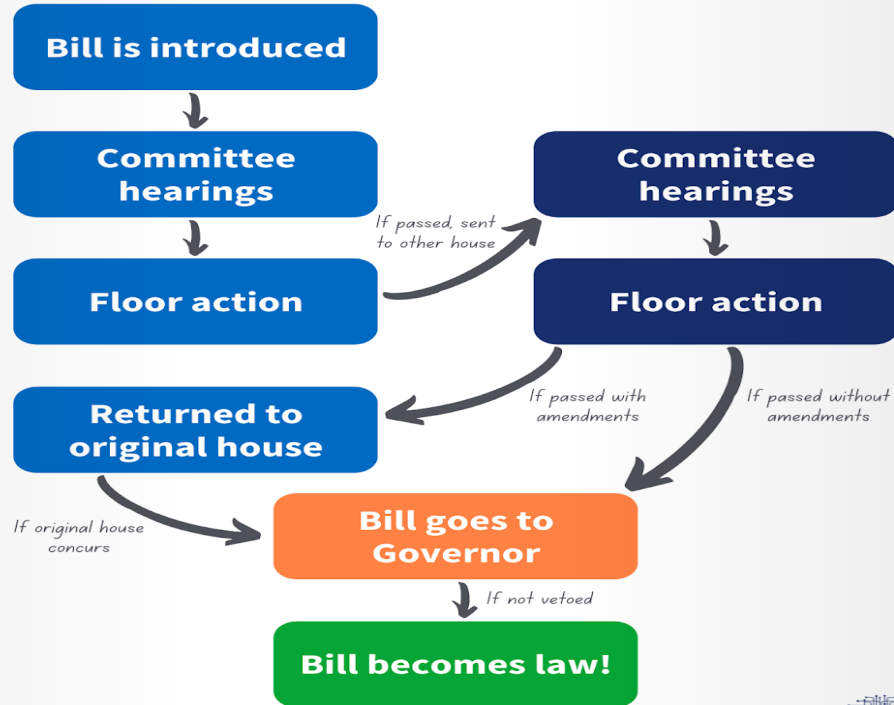
Reset



FIND YOUR CALIFORNIA REPRESENTATIVE

- [HTTPS://FINDYOURREP.LEGISLATURE.CA.GOV/](https://findyourrep.legislature.ca.gov/)

How a **BILL** becomes law in CA



LEGISLATION

- **2024 BILLS**

- **2124 TOTAL BILLS**
- **1505 ASSEMBLY BILLS**
- **619 SENATE BILLS**



CALENDAR

- **APRIL 26: LAST DAY FOR POLICY COMMITTEES TO HEAR FISCAL BILLS**
- **MAY 3: LAST FOR POLICY COMMITTEES TO HEAR NONFISCAL BILLS**
- **MID MAY: GOVERNOR'S BUDGET REVISE TO LEGISLATURE**
- **MAY 17: LAST DAY FOR FISCAL COMMITTEES TO PASS BILLS TO THEIR FLOOR**
- **MAY 24: LAST DAY FOR EACH HOUSE TO PASS BILLS IN ORIGINATING HOUSE**
- **JUNE 15: BUDGET BILL DEADLINE**
- **JULY 3: LAST DAY FOR POLICY COMMITTEES**
- **AUGUST 31: LAST DAY FOR EACH HOUSE TO PASS BILLS**
- **SEPTEMBER 30: GOVERNOR DEADLINE TO SIGN OR VETO BILLS**



SUBMIT A LETTER OF POSITION

CALIFORNIA LEGISLATURE

POSITION LETTER PORTAL

[HTTPS://CALEGISLATION.LC.CA.GOV/ADVOCATES/FACES/INDEX.XHTML](https://calegislature.ca.gov/advocates/faces/index.xhtml)

- **THE POSITION LETTER PORTAL IS FOR SUBMISSION OF POSITION LETTERS TO COMMITTEES AS BILLS MOVE THROUGH CALIFORNIA'S LEGISLATIVE PROCESS.**
- **WHO SHOULD USE THIS SITE? ANYONE WISHING TO SUBMIT A POSITION ON A CALIFORNIA LEGISLATIVE BILL CAN USE THIS SITE. PLEASE NOTE WE HAVE THREE CATEGORIES OF REGISTRANTS:**
- **REGISTERED LOBBYISTS WITH THE SECRETARY OF STATE**
- **ORGANIZATIONS – AN INDIVIDUAL AFFILIATED WITH AN ORGANIZATION**
- **INDIVIDUALS**



WORKING WITH ELECTED OFFICIALS

- **LOBBYING IS ALL ABOUT EDUCATION; YOU ARE SIMPLY EDUCATING THEM ABOUT THE ISSUE.**
- **PROVIDE THE TOOLS AND RESOURCES NEEDED (FACTSHEETS, ISSUE BRIEF).**
- **SOMETIMES LESS IS MORE – STICK TO THE FACTS.**
- **SHARE YOUR STORY.**
- **KNOW WHAT MOTIVATES THE DECISION MAKERS.**
- **UNDERSTAND THE IMPORTANCE OF THEIR STAFF AND STAY IN TOUCH.**



FAMILY VOICES OF CALIFORNIA PROJECT LEADERSHIP



Why Advocacy?



- **Protect and promote the issues you care about.**
- **What happens in the state capitol affects your quality of life.**
- **Laws impact your family, education, home, community, career and health.**



HOW TO BE AN ADVOCATE WHO SOLVES PROBLEMS

(AND NOT GET BURNED OUT)



Jenny McLelland (mom to James)



Have a role model

You changed the law?



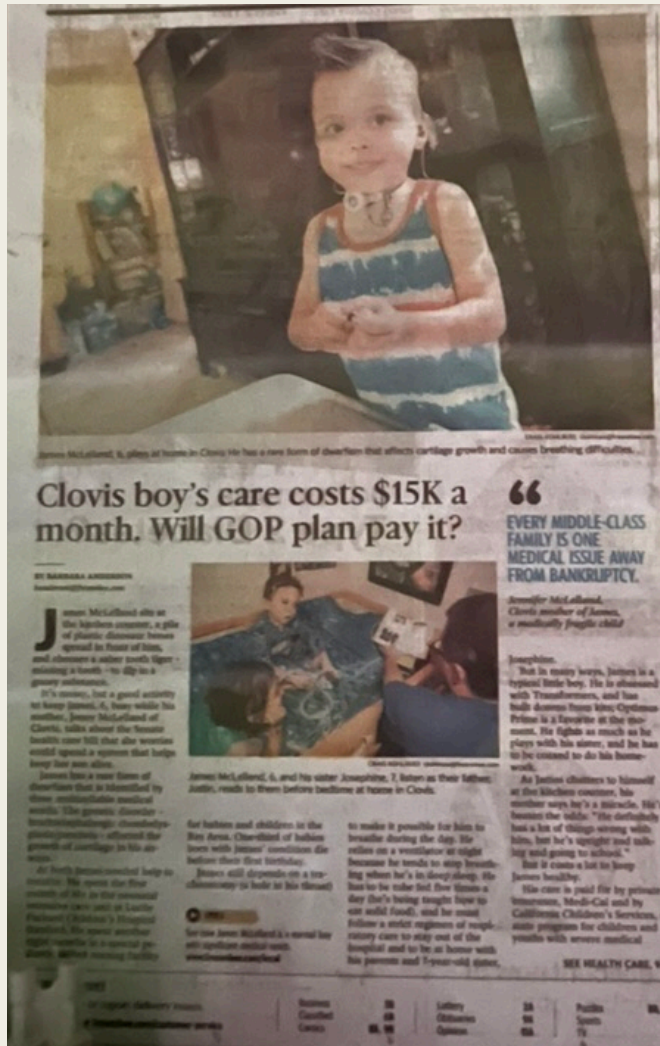
What, like it's hard?

Swing big – you can do big things!

We saved the Affordable Care Act!
(again, and again, and again)

National policy is really hard -
Pick your battles and be ready for a fight.

California policy is easy(ish) –
Pick a battle and be ready to win.



Have big goals... then get specific

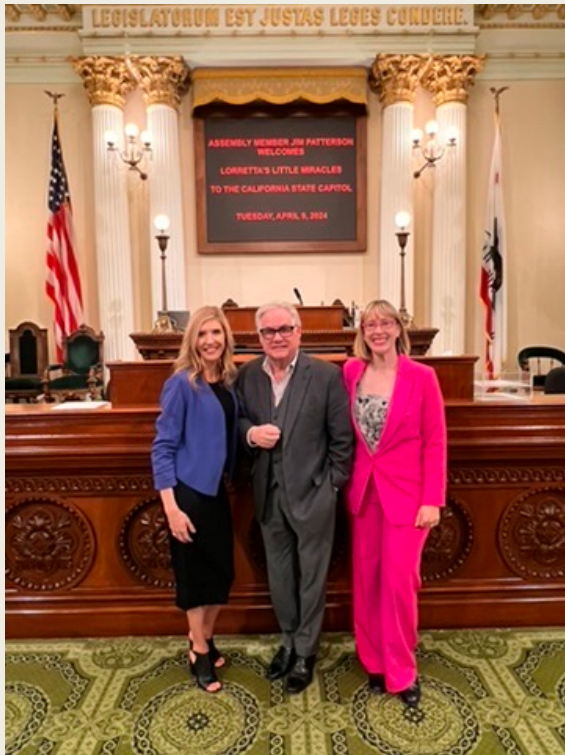
Big picture goal:

I want disabled, medically fragile children to be able get the care they need to live at home with their families.

The little things I have to care about to make that happen:

- Home nursing
- Pediatric Day Health Care
- Waiver programs
- IEPs and 504s for kids who need nursing care at school.
- IHSS paramedical services
- Access to medical supplies at home

Support other people's priorities – disability rights is a big tent!
But specialize in one thing.



Be singlemindedly obsessed with a niche program and become an expert in it.

Los Angeles Times

FRIDAY, NOVEMBER 5, 2010 latimes.com



CAITLIN MARTIN'S son Connor spent his first nine months in the hospital. Now he's home but will need care around the clock.

A long waitlist for vital home care

Thousands of Californians struggle without Medicaid

400 day to the annual intensive care unit at Children's Hospital of Orange County to help care for Connor, age 2, after leaving him for a

Porter, Schiff lead in poll for Senate

They appear headed to a runoff if rivals for Feinstein's seat don't gain traction soon.

By ROBERTO GONZALEZ

Rep. Adam P. Schiff and Sen. Dianne Feinstein are in a tight race in California's U.S. Senate race, with predictions to move ahead to a runoff, a new poll shows.

The two, with Sen. Feinstein's support, are leading the field over the long-standing incumbent, Democrat Sen. Barbara Boxer. Law and Republican former Gov. Arnold Schwarzenegger have so far not shown an ability to make the race more broadly competitive.

Porter, of Irvine, holds 27% support among voters likely to cast ballots in the March primary, and Schiff, of Burbank, is at 26%, in the latest ABC News poll.

I care about the Home and Community Based Alternatives waiver, a federal 1915(c) Medicaid program that authorizes additional services so that medically fragile, technology dependent children and adults can access private duty nursing at home

Zzzzzzzzz

See? You fell asleep because I got bogged down in the details.

Know the details!

But also be able to tell the story.

Kids need care, and this program provides it.

Secret weapon – ask your legislator for casework

Sometimes you don't have to fix everything for everybody –

If a state agency is a problem, your legislator's local office has people who help constituents (that's you!) fix problems with state programs.

Legislators WANT to fix things... when they help you fix a little problem, they're probably already scheming ways to fix the bigger problem.

Grow up

Make friends with adults in the disability community.

Learn about the programs that are going to exist for your child when they grow up.

Disabled children grow up to be disabled adults –
advocate for policies that help disabled PEOPLE not just disabled KIDS.



CECILIA RIDEOUT
parent advocate

Center for Autism and Neurodevelopmental Disorders
State Interagency Coordinating Council on Early Intervention

MY FAMILY



2023



2024




FAMILY ADVOCACY



my





Every child deserves a champion -
an adult who will never give up on them. Who
understands the power of connection, and
insists that they become the best that they can
possibly be.

- RITA PIERSON

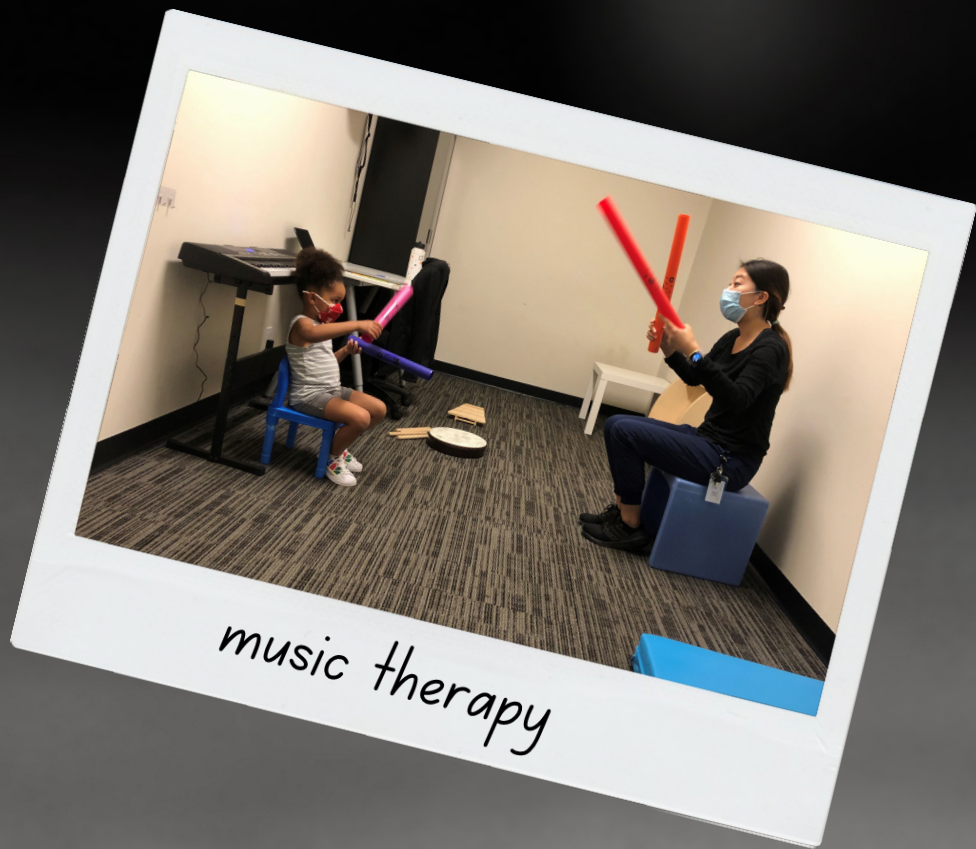


EMPOWERING WOMEN OF COLOR

Black children on average receive a diagnosis of autism at age 5.5 years. Other children are diagnosed on average at the age of 18 months - an alarming disparity! This difference often leads to delayed or no treatment.



does she play
appropriately with toys?



music therapy



Storytelling



DISCO AT THE CAPITOL



A close-up photograph of a piece of brown, textured paper that has been torn. The tear is irregular and jagged, revealing a white surface underneath. The text "Share your story" is printed in a black, monospaced font on the white surface. The brown paper has a fibrous, mottled texture and is set against a dark, shadowed background.

Share your story



FAMILY VOICES

LEGISLATIVE STAFF PERSPECTIVE & ADVICE TO FAMILY ADVOCATES

Dawn F. Adler, MA

Sacramento, CA ~ April 25, 2024



THE INSIDE LOOK AT POLICY

How Policy is Made

- Legislation (way to change current law)
 - Problem with current law
 - Need for law
 - Issues in the district
 - Lobbyist (clients experience issue in law or need law)
 - Organizations/Advocates
 - Personal Experiences (members, constituents)

FAMILY ADVOCATES

- You are the most important advocate for your child
- Your experiences make the most impact
- **Family engagement = outcomes**
(Examples: Dyslexia Screening, Cord Blood and Special Education Legislation)

FAMILY ADVOCATES

- **Do not reinvent the wheel**
 - Look to other similar advocacy groups – join a coalition with same mission
 - Local, state and/or national
- **PERSISTANCE**
 - Don't give up – some of our most impactful laws took years to pass. (American with Disabilities Act, American Care Act, Laura's Law)

FAMILY ADVOCATES

□ *STRATEGY*

- Talk to Members that *represent you* (one Senator and one Assemblymember)
- Reach out to Members who are on the committee(s) of your policy.
- Reach out to the Committee Consultants
- If the staffer is unable to help – ask for their advice.

FAMILY ADVOCATES

□ Make Contact

- Write letters
- Make Calls
- Use connections
- Get local and state leaders involved

FAMILY ADVOCATES

□ Set up a meeting

- Bring at least one child or young adult and one parent to share their personal story
- Bring a provider who can talk about the need
- Be prepared to educate
 - Have real numbers & statistics of the situation in your state & community

FAMILY ADVOCATES

- Convince them how *BIG* the need is
 - Visual
 - Personal stories/hardships
 - Education materials
 - Invite them to the Medical Clinic/Educational Program

FAMILY ADVOCATES

- **Show how government support will save money in the long run**
 - **Screening & Education = Prevention**
 - **Testing = Healthier Patients**
 - **Good Health Care = Able Citizens and quality of life**

FAMILY ADVOCATES

- Always ask for a follow-up meeting
 - Get their commitment
 - Keeps the line of communication open
 - Gives you the chance to provide additional information / statistics
 - Shows your commitment
 - PERSISTANCE!

Thank you for joining us!

**When this session ends, you'll see
the Event Lobby webpage.
Join us for the 1:30 pm Closing
Session.**

Gracias por unirte a nosotros!

Cuando finalice esta sesión, verá la página web del lobby del evento y podrá hacer clic para unirse a nosotros en la sesión de clausura de la 1:30 pm