

## WELCOME & KEYNOTE ADDRESS

BIENVENIDA Y DISCURSO INAUGURAL

MONDAY, MARCH 6, 9:00 AM



**Elena Hung**  
Executive Director  
and Co-Founder,  
Little Lobbyists



**Patricia Moore,**  
**moderator**  
Director, Help Me Grow  
Santa Barbara County;  
FVCA Executive Council  
Member

### Speakers and Panels

The day started with our keynote address from Elena Hung, the Executive Director and Co-Founder of Little Lobbyists. She spoke profoundly about the need for parents to get involved and her journey, connecting with lawmakers and local organizations to ensure that systematic change happens. This was echoed by our second Keynote address by Senator Portantino, who spoke on mental health and the legislative initiatives he has put forth for children and youth with special healthcare needs. Both highlighted the Importance of the parent's perspective and how her personal story can change hearts and minds.

**Plenary: Cal-Aim and Enhanced Care Management** state agency leaders, advocates, providers, and parents shared their perspectives on various aspects of ECM and Cal-Aim, including:

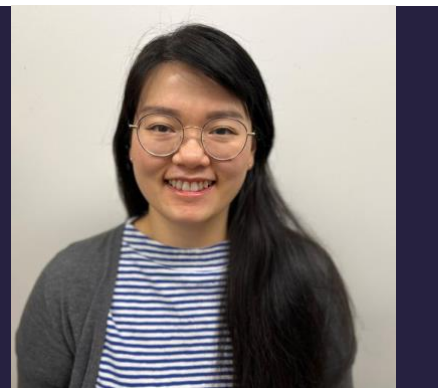
- Provide attendees with an overview of current policies for CCS classic counties and WCM counties.
- Discuss gaps and policy initiatives to address gaps
- Provide specific action items for attendees, and ways to relate these to their personal stories/experiences



**Senator Anthony J. Portantino (25-Burbank, Pasadena, San Dimas)**



**Elana Hung (Executive Director, and Co-Founder of Little Lobbyists)**



**Yingjia Huang (CA Department of Health Care Services)**

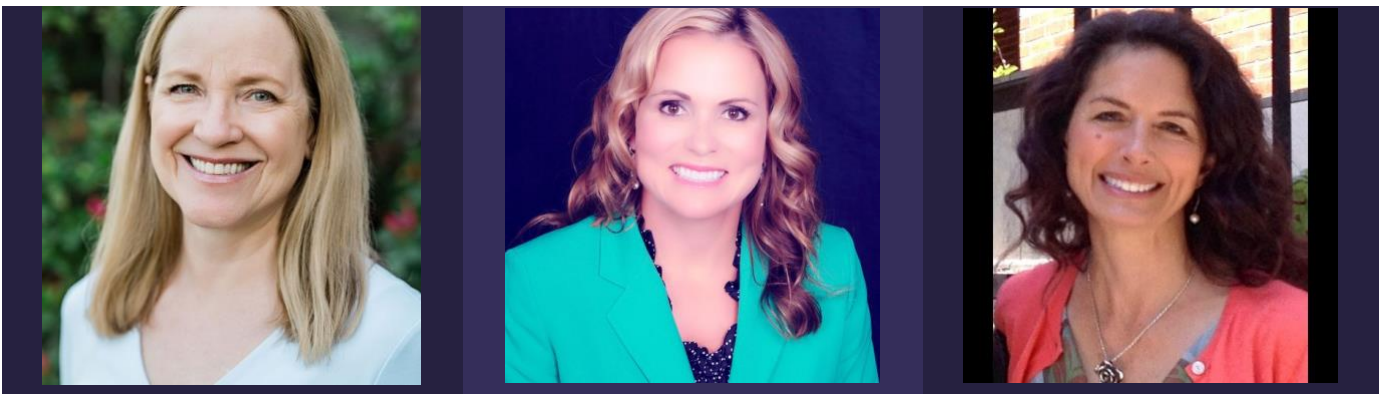
## Breakout Sessions

- **Cal-AIM and Enhanced Care Management for Children and Youth with Special Health Care Needs/Disabilities**

Cal-AIM (California Advancing and Innovating Medi-Cal) is a statewide initiative that seeks to improve health outcomes and reduce health disparities among Medi-Cal beneficiaries, including children and youth with special health care needs and disabilities. Enhanced Care Management (ECM) is a critical component of this initiative, providing targeted care coordination and support services to help individuals and their families navigate the complex healthcare system. The goal of ECM is to ensure that each child receives a personalized care plan that addresses their unique needs, considering factors such as physical and mental health, social determinants of health, and access to support services. By focusing on care coordination and integration, Cal-AIM and ECM have the potential to improve healthcare outcomes and quality of life for children and youth with special health care needs and disabilities.

- **Telehealth and Access to Care for Children and Youth with Special Healthcare Needs**

Telehealth has emerged as a crucial tool in increasing access to care for children and youth with special healthcare needs, especially during the COVID-19 pandemic. By utilizing technology to deliver healthcare services remotely, telehealth can provide consultations, monitoring, and management of patients' conditions, thereby reducing barriers to care such as distance, transportation, and availability of specialized providers. For children and youth with special healthcare needs, telehealth can enable more equitable and convenient care, allowing families to access the services they need without excessive travel or long waiting times. Moreover, telehealth can improve care coordination among providers, leading to better management of complex health conditions and ultimately improving health outcomes for this vulnerable population. The panel also discussed the issues surrounding telehealth and how it can be a detriment to those with special healthcare needs, and how to overcome those barriers.



*Ann Kuhns CEO (CA Children's Hospital Association)*

*Erin Kelly (Executive Director Children's Specialty Care Coalition)*

*Siri Vaeth (Executive Director Cystic Fibrosis Research Institute)*

- **Partnering with Your Regional Center to Meet Your Child's Needs**

Regional centers are community-based organizations that serve as a critical resource for children with disabilities and their families. By partnering with regional centers, families can access comprehensive support services, educational resources, and connections to specialized care providers. A regional center can help create a tailored care plan for a child with special needs, addressing their physical, emotional, and developmental well-being. By

working closely with regional centers, families can ensure that their child receives the individualized care and support they need to thrive.

- **CA Children's Services (Classic) and the Whole Child Model**

California Children's Services (CCS) is a statewide program that provides specialized healthcare services for children with certain physical and medical conditions. The Whole Child Model is an integrated care model that aims to improve the quality of care for children with special needs by addressing all aspects of their well-being, including physical, emotional, and developmental health. By integrating healthcare services and focusing on a holistic approach, the Whole Child Model can help ensure that children with special healthcare needs receive the comprehensive care they need to achieve optimal health outcomes.

- **A Rare Disease Advisory Council (RDAC) Opportunities and Challenges for the Community**

A Rare Disease Advisory Council (RDAC) is a collaborative body comprised of representatives from various stakeholder groups, including patients, families, healthcare providers, researchers, and policymakers. The primary goal of an RDAC is to address the unique challenges and opportunities faced by the rare disease community, such as promoting research, improving access to care, and raising awareness about rare diseases and their impact on individuals and families. By bringing together diverse perspectives and expertise, an RDAC can help drive meaningful change in the rare disease community and ultimately improve the lives of those affected by these conditions.



*Vance Taylor (Chief Office of Access and Functional Needs California)*

*Leinani Walter (Chief Equity Officer DDS)*

*Wendy Neikirk Rhodes (ED Support for Families of Children with Disabilities)*

- **Behavioral Health and Children and Youth with Special Health Care Needs: Challenges and Opportunities**

Behavioral health is an integral component of care for children and youth with special healthcare needs. This population often faces unique challenges related to mental health, emotional well-being, and behavioral issues, making it crucial for healthcare providers and support systems to address these needs. Early intervention, targeted therapies, and comprehensive support systems can help enhance overall well-being and improve health outcomes for these children and youth.

There are several opportunities in this area, such as increased awareness and understanding of behavioral health issues in children with special healthcare needs, the development of new and innovative treatment approaches, and the expansion of support services for families. However, there are also challenges, including limited access to specialized care providers, stigma surrounding mental health, and the need for greater collaboration between healthcare providers, educators, and community organizations.

- **Dental Care for Children and Youth with Special Healthcare Needs**

Dental care for children and youth with special healthcare needs requires specialized services, training, and resources to ensure their oral health is effectively managed. Poor oral health can have significant consequences for overall health and well-being, making it essential for this population to receive appropriate dental care.

Some of the challenges in providing dental care for children with special healthcare needs include a lack of dental professionals trained in treating this population, inadequate insurance coverage for specialized services, and limited access to care in rural or underserved areas. Addressing these challenges requires a concerted effort from policymakers, dental professionals, and advocacy groups to expand access to dental care, increase awareness of the importance of oral health, and develop targeted interventions to improve the dental health of children and youth with special healthcare needs.

- **Climate Change Effect for Children and Youth with Special Healthcare Needs**

Climate change disproportionately affects children and youth with special healthcare needs, exacerbating existing health disparities and complicating care access. The impacts of climate change, such as extreme weather events, air pollution, and infectious diseases, can exacerbate existing health conditions or create new challenges for children with special healthcare needs.

To mitigate these impacts, it is crucial to increase awareness and understanding of the relationship between climate change and health, particularly for vulnerable populations. Additionally, targeted efforts to address the unique challenges faced by children and youth with special healthcare needs in the context of climate change are necessary, including improving access to healthcare services, developing adaptive strategies for healthcare providers, and advocating for policies that address the health consequences of climate change.



*JC Aguirre (Self Advocate)*

*Nancy Netherland (Parent Advocate,  
The Children's Trust, MCHAP)*

*Amy Westling (ED Association of  
Regional Center Agencies)*

- **Impact of Pandemic on Child Development - Moving Forward**

The COVID-19 pandemic has had significant effects on child development, with implications for children's mental health, social interaction, and educational achievement. Moving forward, it is essential to address these impacts, particularly for children with special healthcare needs who may be more susceptible to the negative consequences of the pandemic.

Efforts to mitigate the impact of the pandemic on child development should focus on addressing mental health needs, fostering social connections, and closing educational gaps. This may involve increased access to mental health services, innovative approaches to facilitating social interactions, and targeted interventions to support children's learning and

development. By prioritizing these areas, society can help children and youth with special healthcare needs overcome the challenges posed by the pandemic and thrive in the future.

- **The Young Adults Panel - Lived Experience "Developing Positive Disability Identity"**

This discussion focuses on the experiences of young adults with disabilities as they navigate their identities. The panel provides a platform for young adults to share their lived experiences and discuss strategies for developing a positive disability identity. The goal is to promote awareness, understanding, and empowerment for people with disabilities and to challenge negative stereotypes and stigma associated with disability. Overall, the panel seeks to create a more inclusive society where people with disabilities can thrive and reach their full potential.



Alex Briscoe (Principal The California Children's Trust)



Tracey Tasker (Parent Advocate, El Program Manager)



Andy Imparato (Executive Director Disability Rights California)

**"I am honored to join you in the ongoing fight for progress." Andy Imparato Executive Director Disability Rights California**

**THE PROBLEM**

It's estimated that **25-30 MILLION AMERICANS** (almost 1 in 10) have a rare disease

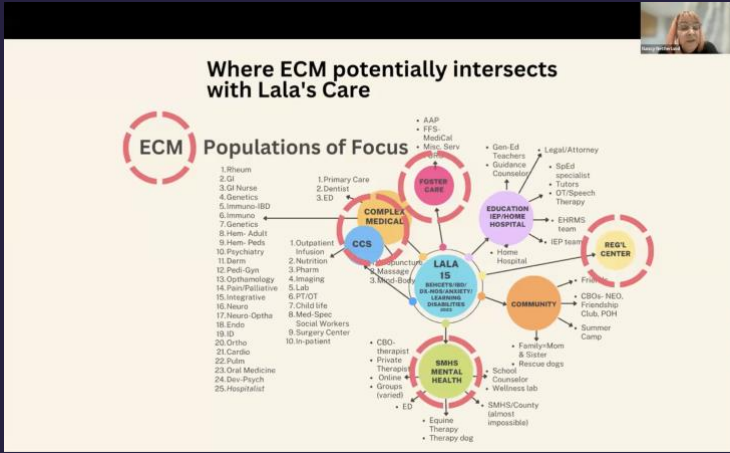
- Rare diseases are defined as a disease or condition that affects **less than 200,000 Americans**
- According to the National Institutes of Health (NIH), **there are more than 7000 rare diseases**, 2/3 of which have a genetic component to them.
- Approximately **90% of rare diseases** do not have an FDA approved treatment.

**Covid-19 impact on learning on school-aged children**

- Worldwide: Children **lost one-third** of a school year during the Pandemic (Nature Human Behavior, Bethausser et al. 2023, grades 1 to 12)
- Students have failed to rebound
- "Young children have struggled to reintegrate to classrooms quickly because they needed to **relearn basic socialization skills**" (Dr. Damon Korb, The New York Times, 1/30/2023)
- United States: **Half of students** across the country started the academic year below grade level in at least one subject (mainly reading and math) Washington Post 2/23/23
- "We're not seeing the upward trajectory that we would need to see in order to have pandemic recovery," said Dan Goldhaber, director of the Center for the Analysis of Longitudinal Data in Education Research
- Overall enrollment in public schools dropped by 3% nationally and by 13% among preschool and kindergarten
- Impacts on learning in K-5 were larger than in middle school (CRPE, West et al. 7/2021)
- California (EdSource 2022): The percentage of third-graders reading at grade level dropped in 2022 from 48.5% (2019) to 42.1%
  - Percentage of disadvantaged third-graders reading at grade level fell from 37% to 30%
  - Third graders from 2019 are now 6<sup>th</sup> graders and only 45.1% of them are reading at grade level, again not catching up
  - Only 1/3 of students performed at standard in math a decline of 6.5% points.

**So what happened to our youngest learners?**

# “Those closest to the pain should be closest to the power.” Elena Hung Executive Director of Little Lobbyist



### Medi-Cal Managed Care and County Behavioral Health

- Most children who are Medi-Cal eligible will have their behavioral health services arranged for by either their Medi-Cal managed care plan or their county's behavioral health plan.
- The State has recently adopted a policy called “no wrong door,” meaning a child who needs behavioral health services can receive them prior to a formal diagnosis, regardless of where they initially present to seek care (e.g., their primary care doctor's office or county behavioral health clinic).
- Under federal law, the state is required to cover all medically necessary behavioral health services for children, including therapy, psych consultation and medication monitoring, day treatment services and inpatient behavioral health services.

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