southern California WINTER 2024

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Making an Impact in the Media



Message from our Chief Advancement Officer Nancy Weintraub

Happy Winter Everyone,

As you have heard me say many times, this is my absolute favorite time of year. I just got back from a quick trip through New England to witness the changing of the leaves and the dropping of the temperatures. It was renewing and a great way to kick off the holiday season.

This issue of Leading the Way is chock full of impactful stories and exciting Easterseals developments. We will be exploring the powerful role media and pop culture play in shaping perceptions of disability and address a very pressing issue today: the digital divide for individuals with disabilities. We will also spotlight our new Behavior Health Center of Excellence, which will provide innovative supports and services for individuals with intensive behavioral needs and their families.

Other highlights to look forward to include:

- Updates on our new Disability is Not a Dirty Word pride campaign
- A child development center family's personal success story
- Learning disability advocacy skills is life changing for one adult day participant

Along the way, we demonstrate immense gratitude to the many corporate partners who show unwavering support for ESSC, through initiatives like our Strides for Disability signature event—a fun way you can get involved and make a difference.

As we enter this holiday season, I invite you to explore many more ways to get involved and continue to support the impactful work Easterseals is doing in our shared community. With our year-end Empowerment campaign, it's easier than ever.

Thank you for your continued dedication to ESSC. Your generosity ensures we can continue to provide exceptional services, create inclusive communities, and empower individuals with disabilities to live their best lives.

With deep appreciation,

Mellad

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#### On the Cover:

Nic Novicki, ESSC Board Member and the founder/director of the Easterseals Disability Film Challenge, addresses the importance of disability inclusion and authentic representation across media and entertainment during a recent panel.



Easterseals Disability Film Challenge at Sony Studios in Los Angeles - photographer Tommaso Boddi

## **Amplifying Voices** Easterseals Southern California is Leading the Charge for Authentic Disability Representation in the Media

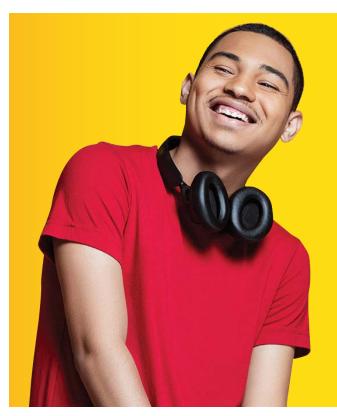
ou may have heard these statistics before: there are more than 1 billion disabled people around the globe, and in the United States, 1 in 4 adults have a disability. These numbers alone are powerful evidence of why it's essential to create more inclusive communities across all areas of life. But people with disabilities aren't just statistics. They are a vibrant, diverse group with stories to tell—stories that can change hearts, minds, and attitudes toward disability. To amplify these stories, Easterseals Southern California (ESSC) has built strategic partnerships by tapping into the megaphone of the entertainment industry right here in our own backyard.

Countless talented disabled people are already sharing their stories and making change at all levels throughout the media industry. These efforts have paid off in recent years, as there have been some big wins for disability in Hollywood. For instance, in 2021 the groundbreaking Netflix documentary *Crip Camp*—the story of a summer camp that galvanized a group of teens with disabilities to help build the disability rights movement—was nominated for an Academy Award for Best Documentary. Then, in 2022, the film *CODA*—a coming-of-age dramatic comedy about a deaf family and their hearing daughter—won the Academy Award for Best Picture.

But we must take action to ensure that authentic representation and inclusive cultures throughout the media industry are a mainstay. As ESSC's Chief Advancement Officer, Nancy Weintraub, shares, "While we celebrate the advancements we've seen in media representation of disability, there's more work to be done. Watershed moments like Ali Stroker winning a Tony Award in 2019 for her performance in Oklahoma are just the start of what we know is possible to achieve." For over a decade, ESSC has been actively collaborating with key players across the entertainment industry to drive disability inclusion and authentic representation. *"We're making real, tangible progress," says Mark Whitley, CEO of ESSC, "especially through our signature initiatives such as the annual Easterseals Disability Film Challenge. These efforts shine a spotlight on the many creatives with disabilities building careers in entertainment, while also supporting the industry in moving toward a more inclusive culture." This year, ESSC also launched 'Disability is Not a Dirty Word'—a bold campaign celebrating disability pride—on a national stage during the Paralympics on NBC.* 

Most recently, ESSC released a powerful multimedia project highlighting the current state of disability inclusion in the media industry with Variety and The Wrap, two respected industry publications, as well as our partners at Hollywood Radio & Television Society (HRTS) and Film Independent. This effort builds on a 2018 special report released in partnership with Variety, "Abilities Unlimited: How People with Disabilities are Helping Hollywood Win." Featuring wisdom from the disability community, we've covered what's working and what needs to change, both in front of and behind the camera.

Easterseals Southern California is committed to changing the way the world defines, perceives, and experiences disability. Authentic media representation is essential to achieving this. Indeed, there is a common saying among people with disabilities: *nothing about us without us.* This means disabled people must be at the center when it comes to telling their stories. Alongside the disability community, ESSC's goal is to shift the narrative once and for all, and to recognize the disabled talent that's been there all along. It's time for a true disability representation revolution.





D1\$@B1L\*tY IS NOT A DIRTY WORD

> Say it. Celebrate it. Share it.

#### **#DISABILITY**PRIDE

## **Awesomely Autistic**

Nik Sanchez's Journey to Self-Advocacy and Disability Pride Hollywood's Disability Representation Revolution

Discover how Easterseals Southern California (ESSC) is partnering with the entertainment industry to amplify authentic disability stories, shifting attitudes, and fostering inclusion onscreen. From the Easterseals Disability Film Challenge to bold national campaigns like "Disability is Not a Dirty Word," see how ESSC is paving the way for a true representation revolution.

Nik Sanchez is a 19-year-old actor, college student, Target cashier, big and little brother, and gamer who is working to get a degree in Film and TV Production. He likes to call himself "Awesomely Autistic."

As a member of Easterseals Southern California's (ESSC's) Advisory Board for Autism Services and a cast member of our new "Disability is Not a Dirty Word" campaign, Nik's pride in his disability shines through. But it wasn't always this way. "I am very open about my autism and other disabilities now," Nik shared, "but I used to be afraid to speak about my disability. I was so afraid that if I didn't fit in and people found out about my autism, they wouldn't like me."

Instead of embracing his disabilities, Nik put his time and energy into trying to hide them. Even so, he often experienced bullying, both from fellow students and from teachers. To help ease this, Nik's mom supported him in gaining self-advocacy skills.

"Communication helps get rid of some of the fear people have of the things they don't fully understand," Nik said. "If I didn't start to speak up and advocate for myself, I don't think my journey would have taken a more positive turn."

Indeed, Nik has been on a journey toward loving himself exactly as he is. And now, he's sharing his insight with the world through his role in the "Disability is Not a Dirty Word" campaign. As Nik reminds us: "Disability or not, we all have our strengths and weaknesses and deserve to be treated with kindness and respect."

## Bridging the Digital Divide:

#### EMPOWERING PEOPLE WITH DISABILITIES THROUGH TECHNOLOGY

Access to technology is essential, but the digital divide remains a barrier for many people with disabilities. Learn how ESSC is addressing this challenge with its technology lending library, digital literacy training, and virtual community. Discover the powerful impact of closing the gap and how you can help build a more digitally inclusive future.

We've long known about the digital divide—the disparity between those with and without access to technology, connectivity and opportunities to learn digital literacy but for people with disabilities, this disparity runs deep.

According to a 2021 Pew Research survey, there is a nearly

20% gap between the number of people with disabilities who have access to the necessary hardware and connectivity, compared to those without disabilities. Regarding smartphone ownership, there is a gap of
16% between people with and without disabilities. Addressing this sharp divide is a critical human rights issue, as access to technology is essential for the disability community to ensure their needs are met.

Without a reliable source of hardware and connection to the internet, people with disabilities are denied access



from pursuing educational and employment opportunities, to seeking essential healthcare services. Further barriers often stem from a lack of access to the necessary assistive

technology and adaptive equipment that people with disabilities need to successfully navigate the web.

That's why ESSC created a technology lending library, in partnership with Los Angeles area-based regional centers. This library provides individuals with the opportunity to access technology like cell phones, iPads, tablets, laptops, and tech support—a vital means of easing the financial burden that can prevent the disability community from staying digitally connected.



However, even if people do have a way to get online, there maybe additional barriers, such as adequate training on the effective use of the technology.

"The pandemic opened our eyes to how vast the digital divide was for our participants," said Nancy Weintraub, Chief Advancement Officer at Easterseals Southern California (ESSC). "We realized that our participants not only needed access to the technology but also digital literacy instructors to bridge the gap between access to our virtual services and successful technology usage. Without the training and literacy to fully utilize technology, it's just tech. The ability to use technology in ways that support an individual's life, goals, and full potential is crucial to overcoming this divide."

Technology can also play a key role in fostering a sense of belonging and sustaining social connections. ESSC is committed to reducing social isolation for people with disabilities via a virtual community—a hub with everything from physical exercise videos, cooking classes and links for art exploration, to guided lessons about navigating Zoom and Internet safety.

Through a continually expanding virtual presence, ESSC has been able to offer even more service options for Adult Day participants. Many of these services and classes are led by participants and organized by participant-led committees, empowering these individuals to actively shape their own experiences. This includes initiatives like the "Our Voices Matter" group and peer-to-peer self-advocacy programs. One of the top outcomes of providing virtual services has been the opportunity for participants to learn from each other and strengthen self-advocacy skills by both teaching and supporting their peers.

Despite the enormous success of ESSC's virtual programs, there is more to do to close the digital divide. ESSC supporters can get involved in many ways: donate funds, volunteer to teach digital literacy classes, or donate hardware, such as phones, laptops, or tablets.

Technology is a bridge to independence and opportunity for the disability community. Together, we can pave the way to equitable access to technology for all.

## Easterseals Participants Make an Impact at the Capitol





his past spring, a group of Easterseals Southern California participants put their advocacy skills into action by heading to Sacramento to meet with legislators. They joined hundreds of other disabled Californians and activists to reject the Governor's delay of funding for critical disability services.

Among the advocates were Betty, Preeti, and Andy, members of Our Voices Matter, a participant-run advocacy and advisory committee with Easterseals Adult Day Services (ADS). Members of the group gather virtually from across Southern California's ADS sites to discuss matters that impact them, both as Easterseals participants and as members of the disability community. When they were given the opportunity to make their voices heard in front of lawmakers, several of them jumped at the chance.

"At first I was nervous," said Betty, "but then I thought, if my voice is not heard, how in the world are people going to know what we need? So, I said to myself 'let's do this." During the Legislative Affairs Conference in March, Betty and Preeti had one-on-one conversations with California state assembly members and senators to share their personal stories, current challenges, and their fears for the future if support services are cut. Kathleen Kolenda, VP Easterseals Adult Day Services, said that many legislators leaned into these conversations and demonstrated immediate support for the cause.

"There is no substitute for hearing from the people impacted," said Kolenda. "Theirs are the most important voices for legislators to hear from directly about the impact of budget decisions to delay or cut funding."

At the California Disability Community Advocacy event in April, Our Voices Matter President Andy had a similar experience. At his first advocacy event, he was excited to represent Easterseals staff and his peers. He hopes to participate in more advocacy efforts in the future saying, "It's important to advocate because it defends equal rights and accessibility in the community." Preeti, who has been an outspoken member of Our Voices Matter since its inception in 2022, shared how candid she became when she met with legislators. Not only did she provide personal details about her disability, but she also asked direct questions about the funding delay.

"When I spoke to the legislators, I told them that I am a quadriplegic, which means I can't use all four of my limbs," said Preeti. "I asked them why there is a delay and told them we cannot wait for another year for funding. I just wanted to put my face out there and let them know, we are people also. We need services."

All three participants used their voices and stories to show lawmakers the impact that funding cuts will have on their own lives. This gave legislators insight into the stark and potentially devastating reality of these budget delays. It also empowered the participants to speak up for themselves and know that they really can and do make a difference.

## **REVOLUTIONIZING CARE**

#### with Easterseals Southern California's New Behavioral Health Center of Excellence

amilies navigating the complexities of severe behaviors and co-occurring mental health challenges face limited options for support in California, sometimes having to relocate. Easterseals Southern California (ESSC), led by Dr. Paula Pompa-Craven, ESSC's Chief Clinical Officer, is set to change this with the new Behavioral Health Center of Excellence—an innovative facility providing community-based care for individuals with autism and developmental disabilities.

Many individuals with autism—up to 85 percent—have co-occurring mental health conditions and severe behaviors, including aggression and self-injury. ESSC's new center is the first facility on the West Coast dedicated to addressing these complex behavioral needs.

"Families come to us after feeling like they've exhausted every option. Some of our participants have been removed from school or hospitalized due to behaviors that put them or others at risk," explained Dr. Pompa-Craven. "Our goal is to offer them the best-inclass, individualized treatment programs that improve their quality of life and allow families to stay together in their communities."

The center will offer nonresidential, outpatient services with personalized treatment programs, crisis intervention, and





care coordination to support both participants and their families with technology playing a critical role in enhancing the effectiveness of the treatments offered. ESSC has partnered with companies like T-Mobile to leverage advanced technological solutions that help monitor, prevent, and manage severe behaviors. For example, wearable technology can track a participant's heart rate and other biometric data, offering staff realtime insights into when someone is becoming agitated and might escalate into a behavioral episode. This proactive use of biofeedback allows for early interventions, such as providing soothing stimuli to de-escalate potentially harmful situations. Furthermore, the center will implement automated data

Our goal is to offer them the best-in-class, individualized treatment programs that improve their quality of life and allow families to stay together in their communities.

– DR. PAULA POMPA-CRAVEN

collection and note-taking systems, freeing staff to focus on direct care.

Set to open in 2025 in Irvine, the Behavioral Health Center of Excellence will revolutionize the treatment of severe behaviors with cutting-edge technology and a multidisciplinary approach. Dr. Pompa-Craven emphasizes the future lies in data-driven, personalized care that enhances the quality of life for individuals and their families. "The more we understand about the physiological and psychological aspects of behavior, the better equipped we are to design effective treatments that improve the quality of life for individuals and their families."



## **Create Your Legacy with Easterseals: Free Will Planning Tools and Estate Guide**

**Thank you** for your generosity—Here's a gift from us! We know that creating a Will can feel overwhelming and costly. As a token of our gratitude for your support throughout the years, Easterseals has partnered with GivingDocs.com to provide you with a FREE set of tools to easily create or amend your Will or Trust and document your Legacy gift intentions, ensuring your values live on.



## CREATE YOUR LEGACY WITH GIVING DOCS

In addition, we're offering a free, user-friendly, Estate Planning Starter Guide that walks you through the estate planning process step by step. Whether you're new to estate planning or looking to revisit your current plans, this guide answers key questions and provides helpful insights that will benefit you and your loved ones. Use this resource on its own or in preparation for meeting with an estate planning attorney or other professional advisor.

Prefer to speak with someone directly?



Call our Planned Giving Team at 714-653-5041 and we'll be happy to answer any questions.

By making Easterseals part of your legacy--whether it's during or after your lifetime—you'll ensure every one of us is valued, respected and accepted. Your impact will continue to make a difference for generations to come. Learn more about how to leave a lasting legacy with Easterseals.



https://easterseals.mylegacygift.org/





#### for making Strides for Disability 2024 a tremendous success!

#### Congratulations to the Top 4 fundraising teams!



Amway Nutrilite DreamMakers



The Morris Clan



Cash Flow Crusaders



Joey, Topa, Nugget & Family

\* This ranking has been updated based on additional donations received as of 10/25/2024.

#### We are grateful for the incredible generosity of our corporate sponsors.





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Stay tuned for information on the 25th anniversary of Strides in October, 2025!

# easterseals HEART



## Kathleen Kolenda's

#### **Dedication to Empowering People with Disabilities**

As Maya Angelou wisely said, "Do the best you can until you know better. Then when you know better, do better." This ethos captures the heart of Kathleen Kolenda's leadership as Vice President of Adult Day Services at Easterseals Southern California (ESSC), where she's continuously driven to improve the lives of people with disabilities in the services she oversees.

With a career dedicated to supporting adults with disabilities, Kathleen has been a passionate advocate for fostering independence, inclusivity, and growth. She is known as a lifelong learner and connector of people.

She first joined ESSC because of the organization's innovative and forward-thinking approach as she was drawn to its diversity of services and the opportunity to make

a tangible impact. "I fell in love with the mission," Kathleen shared, "and being empowered to create a change and connect people with the services they need."

Her proudest achievements reflect this commitment. From championing Senior Day Services that integrates older adults in the community with adults with disabilities to, more recently, adding an intergenerational component, Kathleen is focused on ensuring quality support and opportunities for independence.

One of her highlights was leading an annual advocacy event where she traveled to Sacramento with participants to advocate for service funding and support-empowering individuals to speak directly to legislators.

For Kathleen, the heart of ESSC lies in its people: the individuals they serve and the dedicated staff who make it all possible. Whether arranging special experiences like an outing for a karaoke-loving senior or supporting communication for participants who don't use spoken words to ensure we're listening to their hopes and dreams, Kathleen enjoys seeing people thrive in day services, their homes, and their communities.

She is motivated by the joy and progress she witnesses. As she says, "There's always so much more to do, and that's what keeps me going."



### Preeti Subramaniam

#### **Championing Advocacy and Community**

For many, the heart of a community is its people—their stories, dedication, and passion for everything they do. One such person who embodies this spirit is Preeti Subramaniam. A longtime advocate and participant in Easterseals Southern California's (ESSC) Adult Day Services (ADS), Preeti has spent years empowering and advocating for people with disabilities.

Preeti first became involved with ESSC when she began attending Citrus College. "Easterseals became my service provider," she recalls. "My aide would accompany me to my classes, ensuring all my personal and academic needs were met. I was grateful for that support." Preeti was first drawn to ADS because she saw an opportunity for growth. "I thought, what the heck, let me give it a try—and I'm glad I did," she said.

ADS led to Preeti's involvement with the Our Voices Matter advocacy group and gave her a platform to speak up for herself and others with disabilities. One of her proudest moments came during a trip to Sacramento, where she and other advocates persuaded lawmakers to release crucial funds for disability services. "By the time we left, 32 lawmakers had already signed the petition. We knew we had done our part successfully."

# **OF ESSC**

Preeti's time with ESSC continues to help her grow in new ways. "Without the support of ESSC, it would have been hard for me to finish college and get my degree," she said. "Now, I'm getting more involved with ESSC because I know I have good people on my side. I'm ready for new challenges."

What is at the "heart of" ESSC? For Preeti, it's perseverance. "To me, 'heart' means keep going—don't ever give up." It is this tenacity that guides her.



### Maria Serrao

#### Championing Change & Inclusion Through Sports & Service

Maria Serrao, an Easterseals Southern California (ESSC) board member and host of Playing the Field, embodies the passion and advocacy for change that defines the heart of ESSC. Known as the only female sports reporter covering professional sports from a wheelchair, Maria's relationship with ESSC began through her work as a reporter, but her commitment to the mission has become personal.

Maria first encountered ESSC while covering a community event featuring the Los Angeles Dodgers in Irvine near a Dodgers Dream Field, designed as an accessible green space and baseball field for neighborhoods and families across Los Angeles. After Maria did a story on ESSC and the Dodgers, ESSC asked Maria if she'd be interested in joining their board. "I researched and met with them, and

I saw how they are open to new ideas about disability," Maria said. Her involvement has grown ever since, as she champions ESSC's efforts to reshape perceptions of disability.

Maria's professional experience as a sports reporter has uniquely positioned her to advocate for change. "In sports, there isn't one athlete who has felt strange around me or is unsupportive. Sometimes people fear things they don't understand," she said. Maria's presence on the sidelines and in locker rooms shows that disability is not a barrier to success. She strives to demonstrate that living with a disability does not limit what one can achieve.

A key part of Maria's work with ESSC has been changing perceptions of disability through storytelling and media. Currently, she is spearheading a series of public service announcements (PSAs) featuring athletes from every major Los Angeles sports team. These PSAs aim to showcase disability in a new light, highlighting stories of perseverance and inclusion. "The athletes have been amazing. It's about showing that change is possible, that it's happening," said Maria. Through this project, she hopes to reach audiences who may never have considered how disability is part of the human experience.

Maria's advocacy also extends to the halls of Congress. With ESSC, she's participated in trips to Washington, D.C., to raise awareness about the needs of people with disabilities. "Big change has to come from there," she said. For Maria, these experiences have reinforced the importance of showing up and being heard, whether in a legislative office or reporting from the field.

For Maria, the heart of ESSC lies in its dedication to helping people and changing how disability is perceived. "It's about normalizing disability—that's the barrier we're trying to overcome."

Maria's vision for the future of ESSC is one of continued growth and expanded awareness. She believes that by involving more people and sharing more stories, the message of inclusion can reach even more audiences. "The need is still there, and because it's so huge, Easterseals is just getting bigger." Maria hopes that through social media and evolving platforms, awareness will continue to build, reaching beyond traditional media outlets to connect with the next generation.

Through her work with ESSC and as a respected voice in the sports world, Maria Serrao is changing perceptions one story, one PSA, and one interaction at a time. Her dedication to breaking down barriers and showing disability as a part of life is the essence of Easterseals Southern California's mission.



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# **ENPOWERNEN** — Your Year-End Gift Empowered —

During the holiday season, we are always humbled by those in our community who value the importance of giving and creating meaningful impact in the lives of others. Your gift provides thousands of people in our shared community with essential programs.



You are helping the world truly become a better place as we lead the way to FULL equity, inclusion and access for people with disabilities, their families and our communities. Creating a world where we are all EMPOWERED AND INCLUDED!

