

THE NETWORKER

a publication of Matrix Parent Network & Resource Center • Fall 2018

Matrix Parent Network is a 501(c)(3) organization founded in 1983 to serve families of children with special needs. We serve Marin, Napa, Solano, and Sonoma counties.

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SOME MUSINGS FROM THE EXECUTIVE DIRECTOR...

It Can't Stop with You!



For as long as I can remember, the Matrix mantra has been to *“help families become their child’s best advocate.”* We all know the struggle that we, as parents, have been through. We had to learn about our rights. We had to uncover appropriate options and learn how to find and use our voices. We had to make sure that our children would receive the services needed to grow and thrive.

The parent is the constant in a child’s life. We know our children better than anyone and are therefore more qualified to speak up for their needs. All of this should sound very familiar to anyone who has attended one of our trainings, spoken to a Parent Advisor, or read through our materials. We have always viewed our primary “customer” as the parent.

This mantra has served us well. However, it needs to expand to include a vision of our children as they grow up and become adults. All the blood, sweat, and tears we have shed to become knowledgeable advocates does not take into account that at some point, those little ones will need to become their own self-advocates.

We educate families and support each parent to be his or her child’s best advocate. However, when children become empowered self-advocates, parents need to take a more supportive and less active role.

It feels as though we need to do more to prepare parents for this shift in roles. It’s like we left off the ending of our mantra... *“Help families become their child’s best advocate and help families support their child’s development of self-advocacy skills as they grow up.”* These words complete the mantra we need to chant.

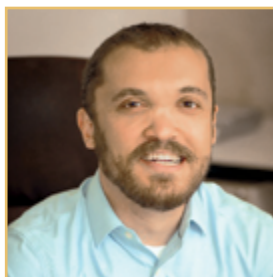
This issue of the Networker will feature articles with tips and tools for families to start early to build self-advocates. *The parent/super advocate role is only one of our roles. It’s one step of this journey that our children are taking.* We will do our best at Matrix to remember the entire mantra and support you as you take that next important step—passing the advocacy baton to your young person.

A handwritten signature in black ink that reads "Nora".

Nora Thompson,
Executive Director

Self-Advocacy Tips and Tools





Self-Advocacy: The Lessons I've Learned and the Lessons I'm Still Learning

ARTICLE BY ELI GELARDIN. ELI SERVES AS THE EXECUTIVE DIRECTOR OF MARIN CENTER FOR INDEPENDENT LIVING (MCIL) AND IS A MEMBER OF THE MATRIX BOARD OF DIRECTORS.

I vividly remember my first lesson in self-advocacy. I was a young boy navigating a raucous school playground. A group of big, aggressive kids rolled into our area, seeking out easy marks for their ritual hazing. Being short stature and visibly different, I was easy prey. As they launched into their harassment, I recall thinking two things: What can I do right now to get out of this situation? What can I do in the future to make sure this doesn't happen again?

Nearly 35 years later, I view self-advocacy and self-determination through the same lens. [Self-advocacy and self-determination are skills gained over a lifetime. Whether advocating for your child's IEP \(Individualized Education Plan\) or empowering your child to make his or her own decisions, the work is constant and unending. It requires strength, courage, and self-pacing.](#) You and your child will experience intense ups and downs as you navigate the system together. The objective is to empower your child to be the best self-advocate he or she can be and live their best life.

Self-advocacy is different for everyone. None of us has the same disability or background. A network of others who support self-advocacy is essential. I truly believe that this network is critical and will nurture you and your child along the way.

Our daughter Olivia was diagnosed with a rare seizure disorder at birth. This exposed our family to the value of self-advocacy. We learned the importance of support networks within minutes after her birth. The medical staff

immediately began urging us to make decisions about our daughter's health. We were not comfortable making these decisions. We felt flustered, exhausted, and left in the dark. We didn't know what was best. Most importantly, we wanted to ensure that the decisions we made were the right ones to preserve her overall health and well-being. We searched for more information.

Fortunately, we work professionally in the field of social services. This helped us establish a strong support system early on. Our support system included a medical social worker and a friend who worked in the healthcare system. She helped us to navigate the system. Thanks to her experience and the support of family and friends, we brought our little girl home from the hospital.

This early experience with Olivia laid the foundation for more success. We continued to build and strengthen our interdisciplinary team. [We sought out friends, family, and professionals who deeply understood our daughter and our family's needs. This system nurtured all of us. Olivia reached milestones and development goals both in and outside of the classroom.](#)

A year and a half ago, when our young daughter passed away suddenly, we reached out to our support system. We faced a new set of barriers and obstacles. We turned to our support network to guide us through these difficult times. Our family's journey towards self-advocacy and self-empowerment continues for our son. With humility and gratitude, we are forming a new team that will be customized to our family's new circumstances and needs. The work continues...

ALGUNAS REFLECCIONES DE LA DIRECTORA EJECUTIVA: No Puede Parar Contigo!

Desde que puedo recordar, el mantra de Matrix ha sido "ayudar a las familias a convertirse en el mejor defensor de sus hijos". Todos conocemos la lucha que nosotros, como padres, hemos sufrido. Tuvimos que aprender sobre nuestros derechos. Tuvimos que descubrir opciones apropiadas y aprender a encontrar y usar nuestras voces. Tuvimos que asegurarnos de que nuestros hijos recibieran los servicios necesarios para crecer y prosperar.

El padre es la constante en la vida de un niño. Conocemos a nuestros hijos mejor que nadie y, por lo tanto, estamos más ca-

pacitados para defender sus necesidades. Todo esto debería sonar muy familiar a cualquiera que haya asistido a uno de nuestros entrenamientos, hablado con un asesor de padres o leído nuestros materiales. Siempre hemos visto a nuestro "cliente" principal como padre.

Este mantra nos ha servido bien. Sin embargo, necesita expandirse para incluir una visión de nuestros niños a medida que crecen y se hacen adultos. Toda la sangre, el sudor y las lágrimas que hemos derramado para convertirnos en defensores bien informados no toman en cuenta que, en

Autodefensa: Las Lecciones que Aprendí y las Lecciones que Todavía Estoy Aprendiendo

ARTÍCULO DE ELI GELARDIN. ELI SIRVE COMO DIRECTOR EJECUTIVO DE MARIN CENTER FOR INDEPENDENT LIVING (MCIL) Y ES MIEMBRO DE MATRIX BOARD OF DIRECTORS.

Recuerdo vívidamente mi primera lección de auto-defensa. Yo era un niño que navegaba en un patio de recreo escandaloso. Un grupo de niños grandes y agresivos entró en nuestra área, buscando marcas fáciles para sus novatada de rituales. Al ser de baja estatura y visiblemente diferente, fui presa fácil. A medida que se lanzaron al hostigamiento, recuerdo haber pensado dos cosas: ¿Qué puedo hacer ahora para salir de esta situación? ¿Qué puedo hacer en el futuro para asegurarme de que esto no vuelva a ocurrir?

Casi 35 años después, veo Autodefensa y Autodeterminación a través de la misma lente. [Autodefensa y Autodeterminación son habilidades adquiridas durante toda la vida. Ya sea abogando por el IEP de su hijo \(Plan de educación individualizado\) o facultando a su hijo a tomar sus propias decisiones, el trabajo es constante e interminable. Requiere fuerza, coraje y autoestimulación.](#) Usted y su hijo experimentarán intensas altas y bajos a medida que navegan por el sistema juntos. El objetivo es capacitar a su hijo para ser el mejor defensor de sí mismo que él o ella pueda ser y vivir su mejor vida.

[La autogestión es diferente para todos. Ninguno de nosotros tiene la misma discapacidad o antecedentes. Una red de otros que apoyan la autodefensa es esencial. Realmente creo que esta red es crítica y te nutrirá a ti y a tu hijo en el camino.](#)

Nuestra hija Olivia fue diagnosticada con un extraño trastorno convulsivo al nacer. Esto expuso a nuestra familia al valor de la Autodefensa. Aprendimos la importancia de las redes de apoyo minutos después de su nacimiento. El personal médico inmediatamente comenzó a instar-

nos a tomar decisiones sobre la salud de nuestra hija. No nos sentimos cómodos tomando estas decisiones. Nos sentimos nerviosos, agotados y dejados en la oscuridad. No sabíamos qué era lo mejor. Lo que es más importante, queríamos asegurarnos de que las decisiones que tomamos fueran las correctas para preservar su salud y bienestar general. Buscamos más información.

Afortunadamente, trabajamos profesionalmente en el campo de los servicios sociales. Esto nos ayudó a establecer un fuerte sistema de apoyo desde el principio. Nuestro sistema de apoyo incluía un trabajador social médico y un amigo que trabajaba en el sistema de atención médica. Ella nos ayudó a navegar por el sistema. Gracias a su experiencia y al apoyo de familiares y amigos, trajimos a nuestra pequeña del hospital a casa.

Esta experiencia temprana con Olivia sentó las bases para más éxito. Continuamos construyendo y fortaleciendo nuestro equipo interdisciplinario. [Buscamos amigos, familiares y profesionales que entendieron profundamente a nuestra hija y las necesidades de nuestra familia. Este sistema nos nutrió a todos. Olivia alcanzó hitos y objetivos de desarrollo dentro y fuera del aula.](#)

Hace un año y medio, cuando nuestra hija pequeña falleció repentinamente, nos comunicamos con nuestro sistema de apoyo. Nos enfrentamos a un nuevo conjunto de barreras y obstáculos. Recurrimos a nuestra red de apoyo para guiarnos a través de estos tiempos difíciles. El viaje de nuestra familia hacia la autodefensa y el autoapoderamiento continúa para nuestro hijo. Con humildad y gratitud, estamos formando un nuevo equipo que se personalizará para las nuevas circunstancias y necesidades de nuestra familia. El trabajo continúa ...

DE LA DIRECTORA EJECUTIVA: No Puede Parar Contigo!

algún momento, esos pequeños necesitarán convertirse en sus propios defensores de sí mismos.

Educamos a las familias y apoyamos a cada padre para que sea el mejor defensor de su hijo. Sin embargo, cuando los niños se empoderan como autodefensores, los padres deben asumir un papel más solidario y menos activo. Parece como si necesitáramos hacer más para preparar a los padres para este cambio de roles. Es como si dejáramos el final de nuestro mantra ... "Ayude a las familias a convertirse en la mejor defensora de sus hijos y ayudar a las familias a apoyar el desarrollo

de sus habilidades de autodefensa a medida que crecen". Estas palabras completan el mantra que necesitamos para cantar.

Este número de Networker incluirá artículos con consejos y herramientas para que las familias comiencen temprano a formar autodefensores. El rol de padre / superdefensa es solo uno de nuestros roles. Es un paso de este viaje que nuestros hijos están tomando. Haremos nuestro mejor esfuerzo en Matrix para recordar el mantra completo y apoyarlo mientras da el siguiente paso importante: pasando el bastón de defensa a su joven.

Nora Thompson, Directora Ejecutiva



The Early Edition

a publication of Matrix Parent Network & Resource Center • Fall 2018

The Early Edition is a publication of the Matrix Family Resource Center (FRC) program — part of California's interagency system of early intervention services for children from birth to 36 months. Our FRC staff is here to provide information and support to help you care for your baby. Additional information and resources are also provided in a designated Birth to 3 section on our website, www.matrixparents.org.

BIRTH TO 3

Teaching Your Little One to be an Effective Self-Advocate

By Alyssa DiFilippo, Matrix Parent Network Director of Parent Services

Even when your little ones are still babies, it's essential to recognize that their self-advocacy, self-esteem, self-confidence, and self-respect are all connected. *Once you help to build one skill, you're helping to build them all. The best way parents can teach these skills is to model them for their children.*

In our family, we chose to offer choices very early on, applauding whatever decision our little daughter made: an apple instead of an orange; The Wiggles, not Sesame Street; and yes, that yellow and green striped shirt looks great with those purple and pink polka dot pants! Our positive feedback helped build her confidence in her ability to make decisions that affected her life.

Another strategy we found effective was explaining to our daughter about her disability, Prader-Willi Syndrome (PWS), at an age-appropriate time.

Many people with PWS are hyper food focused and not able to think about anything else if someone is eating in front of them. Teachers have said they were impressed with how our daughter advocated for herself. Even at an early age she explained that she felt distracted and uncomfortable when they ate breakfast in front of her.

Recently, my now 20-year old daughter had this to say upon learning that her Individual Education Plan (IEP) meeting was scheduled without her input:

“It’s my IEP. Didn’t anybody think to consult me about my schedule? It’s not right. It’s disrespectful. Why do they tell me I’m a grown-up and that my opinion matters and I should make my own decisions, and no one even thinks to consult me about my IEP? I feel betrayed. What were they thinking?”

Needless to say, her IEP was re-scheduled, and the team praised her for her self-advocacy and apologized for not including her in the scheduling.

The earlier your child takes control of his or her own decisions, the better the chance that he or she will live as independently as possible. And isn't that what we want for all our children?



We can help with transition to preschool. call 800.578.2592

EXPERTS AGREE THAT THE FOLLOWING TIPS MAY HELP



YOUR LITTLE ONE GROW INTO A CONFIDENT YOUNG ADULT:

- Step back and let your child take risks, make decisions, and solve problems. Make sure your child's goals are within reach and at a level appropriate to his or her ability.
- Focus on strengths and provide your child with opportunities to develop these strengths.
- Avoid over-praising. Continually telling your child that he or she is doing a fantastic job may give your child the message that there's no longer the need to push himself or herself. Confidence comes from doing, from trying and failing and trying again—from practice.
- Encourage kids to make their own (developmentally appropriate) choices.
- Let kids help with chores around the house. Even toddlers can help set the table, pick up after themselves, etc. Give them opportunities to demonstrate their competence and feel that their contribution is valuable and valued.
- Make it clear that your love is unconditional. Let your child know you love him or her regardless of failures or bad decisions.

RESOURCES (IN ENGLISH)

- <https://esme.com>
- <https://www.smartkidswithld.org>
- <https://www.todayparent.com>
- <https://educateempowerkids.org>
- <https://kidshealth.org>



La Edición Temprana

una publicación de Matrix Centro de Recursos Familiares • Otoño 2018

La Edición Temprana es una publicación de Matrix Centro de Recursos Familiares (FRC) programa como parte del sistema interinstitucional de los servicios de la intervención temprana para niños de California desde el nacimiento hasta los 36 meses. Nuestro personal de FRC esta aquí para proporcionar información y apoyo para ayudarle a cuidar de su bebé. Información adicional y recursos también están proveídos en un área designada en la sección recién nacido a tres en nuestro sitio de web, www.matrixparents.org.

NACIMIENTO A 3

¿Cómo Empieza a Enseñarle a tu Pequeño a Ser un Auto Defensor Efectivo?

By Alyssa DiFilippo, Matrix Parent Network Director of Parent Services

Incluso cuando sus pequeños todavía son bebés, es esencial reconocer que su autodefensa, autoestima, confianza en sí mismos y respeto por sí mismos están conectados. *Una vez que ayuda a desarrollar una habilidad, está ayudando a construir las todas. La mejor forma en que los padres pueden enseñar estas habilidades es modelarlas a sus hijos.*

En nuestra familia, elegimos ofrecer elecciones desde el principio, aplaudiendo cualquier decisión que tome nuestra pequeña hija: una manzana en lugar de una naranja; The Wiggles, no Sesame Street; y sí, ¡esa camisa de rayas amarillas y verdes se ve genial con esos pantalones de lunares morados y rosados! Nuestros comentarios positivos ayudaron a construir su confianza en su capacidad para tomar decisiones que afecten en su vida.

Otra estrategia que encontramos efectiva fue explicarle a nuestra hija sobre su discapacidad, el Síndrome de Prader-Willi (PWS), en un momento apropiado a su edad.

Muchas personas con SPW se centran en la hiper alimentación y no pueden pensar en otra cosa si alguien está comiendo frente a ellos. Los maestros han dicho que estaban impresionados con la forma en que nuestra hija abogó por ella misma. Incluso a una edad temprana, ella explicó que se sentía distraída e incómoda cuando desayunaban frente a ella.

Recientemente, mi hija de 20 años de edad tuvo esto que decir al enterarse de que su reunión del Plan de Educación Individual (IEP) estaba programada sin su aportación:

“Es mi IEP. ¿Alguien pensó en consultarme sobre mi agenda? No está bien. Es irrespetuoso ¿Por qué me dicen que soy un adulto y que mi opinión importa y que debo tomar mis propias decisiones, y nadie siquiera piensa consultarme sobre mi IEP? Me siento traicionado. ¿Que estaban pensando?”

No hacia falta decir que; su IEP fue reprogramado, y el equipo la elogió por su autodefensa y se disculpó por no incluirla en la programación.

Mientras más temprano su hijo tome el control de sus propias decisiones, mayores serán las posibilidades de que él/ella viva de la manera más independiente posible. ¿Y no es eso lo que queremos para todos nuestros hijos?



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LOS EXPERTOS ACEPTAN QUE LOS SIGUIENTES CONSEJOS PUEDEN AYUDAR A SU PEQUEÑO A CONVERTIRSE EN UN ADULTO JOVEN SEGURO DE SÍ MISMO:



- Retroceda y deje que su hijo tome riesgos, tome decisiones y resuelva problemas. Asegúrese de que los objetivos de su hijo estén al alcance y en un nivel apropiado a su capacidad.
- Enfóquese en las fortalezas y brinde a su hijo oportunidades para desarrollar estas fortalezas.
- Evite el elogio excesivo. Continuamente decirle a su hijo que está haciendo un trabajo fantástico puede darle a su hijo el mensaje de que ya no es necesario esforzarse más a sí mismo. La confianza proviene de hacer, de intentar y fracasar e intentarlo de nuevo, desde la práctica.
- Anime a los niños a hacer sus propias elecciones (apropiadas para el desarrollo).
- Deje que los niños ayuden con las tareas de la casa. Incluso los niños pequeños pueden ayudar a establecer la mesa, recoger después de ellos, etc. Deles oportunidades para demostrar su competencia y sentir que su contribución es valiosa y valorada.
- Deje en claro que tu amor es incondicional. Deje que su hijo sepa que lo ama, independientemente de sus fallas o malas decisiones.

Make An Impact

Interview with Dr. Deborah Ross-Swain, CCC-SLP

KRISTIE ANDERSON, MATRIX DEVELOPMENT DIRECTOR, INTERVIEWS DR. SWAIN OF THE SWAIN CENTER



Dr. Deborah Ross-Swain, CCC-SLP

The Swain Center
Advanced Treatment for Listening, Communicating and Learning



Listening



Communicating



Learning



Kristie Anderson with Mighty Milers

The Swain Center is our signature sponsor for Mighty Milers. Partnering with The Swain Center was a natural fit for our Matrix Mighty Milers program. Their programs are centered around social skills, communication, and development for children of all ages and all abilities. We are grateful to Dr. Swain and her wonderful team for their support.

Kristie: Tell me a little bit about The Swain Center and whom you serve.

Dr. Swain: We provide speech and language services and Learning Services to a broad spectrum of clients, from Early intervention through transition to adulthood.

Our clients and unique program offerings include:

- **Early intervention, (birth to three),** primarily two to four year olds. Tiny Talkers™, for two to three year olds, is one of the rich groups offered. TARPSing™ is a parent education/training for communication development. Both programs are offered in Spanish.
- **Children with Auditory Processing and Autism Spectrum Disorder.** Our Let's Adapt!® program is specifically for the development of Social Skills. We currently have fifteen classes, ranging in ages, all the way through transition into adulthood.
- **Children with Down syndrome.** We have a specific Let's Adapt!® program for the Northern California Down Syndrome Association.

What sets us apart from others is that we're Family Oriented and Family Centered. We keep the whole family in mind when implementing a family centered plan.

Kristie: Several Mighty Milers have been participating in your Let's Adapt program. How do programs at The Swain Center tie into an inclusive program like Mighty Milers?

Dr. Swain: Our Let's Adapt social skills groups get out into the community. My belief is being different doesn't mean you're disabled or disordered. Programs like Mighty Milers educate our community and bring awareness. This child has a learning difference, or this child has a behavioral difference. It doesn't matter!

Kristie: What is your vision for our community as it relates to inclusion and health?

Dr. Swain: My vision is two-part.

- As educators write IEP (Individualized Education Plan) goals and objectives for reading, spelling, and math, they include a goal and objective for confidence and joy.
- That children with learning differences always be included in academic and social programs regardless of their differences

Kristie: How much of an impact does movement and being outside have on our kids with special needs?

Dr. Swain: Movement is essential. The literature about play and development reveals that children

should be playing outdoors, running, skipping, and exploring. Play promotes better physical development, cognitive skills and social skills. When children are moving and playing together, learning differences, behavioral challenges, or any other differences don't matter.

Kristie: Tell us a little about your upcoming book, *Confidence & Joy in Children with Learning Differences*.

Dr. Swain: I've seen a common thread over the years of doing this work—there are many unhappy children because of their learning differences. They feel educationally defeated. They feel that they can't do what the other kids are doing and don't fit in. Kids with learning differences can be academically successful and/or socially successful. ***It's up to us as parents and professionals to get ALL of our children from little people to big people with confidence and joy in their hearts.*** There's no reason why they should feel defeated. They can experience the same kind of confidence and joy that all human beings feel.

Kristie: We are excited for your new book to come out! Thank you for talking with me and supporting our Matrix Mighty Milers program.

Make an Impact

Mighty Milers Brings Families Together If Not for You...

FRIENDS AND FAMILIES ENJOYING THE SANTA ROSA MARATHON 5K RACE



The Galligan family completed their second 5K as Matrix Mighty Milers!



Coaches, families, and the participants all came together to make sure every child got across the finish line!

SENDING GRATITUDE TO OUR COACHES



Our coaches spent countless hours training our kids over the last 13 weeks. This program would not have happened without them. Thank you Coach Jonathon, Coach Mark, Coach Peter, and Coach Tiffany. (Pictured left to right). *Coach Peter won the ENTIRE 5K race! Not just in his age group, but he was the very first person to cross the finish line out of 2000 people!*



Our families make this program special! Thank you to the Myers/Munoz Lovee family for joining the Mighty Milers this year!



New and old friendships were celebrated on race day!

New Hires

**JUANA MADRIZ
BILINGUAL PARENT ADVISOR**



Juana, our new bilingual Parent Advisor, lives in Sonoma County with her family. She has two daughters, one who has an invisible disability. Juana learned English

as a second language and earned a science degree from Sonoma State University. She is passionate about reading, learning and community, and enjoys tutoring others on a volunteer basis.

MIKE TOBY, PARENT ADVISOR



Mike joins Matrix as a Parent Advisor. He has served on Parent/Teacher Associations, Site Council, and the Sonoma County Special Education

Local Plan Area (SELPA)/Community Advisory Committee (CAC). Mike's wife is an experienced educator. They have an adult son with Autism Spectrum Disorder (ASD). Mike has experience with the transition to adulthood.

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<http://www.matrixparents.org/upcoming-trainings/>



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- El Formulario IEP: Una Página a la Vez
- Advocating for Your Child with Special Needs
- Abogando por su Estudiante con Necesidades Especiales
- IEP Basics (Individualized Education Program)
- URL Fundamentos Básicos del IEP (Programa de Educación Individualizado)
- Goal Night at Dominican
- Comprensión de IHSS (Servicios de Apoyo en el Hogar)
- Assessments: The Key to Special Education
- Evaluaciones: La Clave de la Educación Especial
- Understanding Conservatorship

Trainings held in both English and Spanish at several locations in Marin, Napa, Solano, and Sonoma Counties

NETWORKER

Self-Advocacy Issue • Fall 2018

Our mission: To empower families of children with special needs to successfully understand and access the systems that serve them.

Nuestra misión: Capacitar a las familias de niños con necesidades especiales para entender y acceder a los sistemas que los sirven.

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