

CONNECTING

The quarterly newsletter of Raising Special Kids

WINTER 2020

WHAT'S HAPPENING WITH AAC?

Changes for
DDD Members
Beginning 2021



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Raising
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Kids

5025 E. Washington St., #204
Phoenix, AZ 85034
800-237-3007

raisingspecialkids.org
info@raisingspecialkids.org

STATEWIDE SERVICES

Central Arizona

602-242-4366

Northern Arizona

928-444-8834

Southern Arizona

520-441-4007

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Parent to Parent support is the heart of Raising Special Kids. Information about local services, educational programs, advocacy, or special health care needs is available in English, Spanish and other languages. Services are provided at no charge to families in Arizona. Raising Special Kids is a 501(c)(3) non-profit organization.

STAFF SPOTLIGHT

Kathy Gray-Mangerson, MBA
Education System Administrator
Southern Arizona



KATHY Gray-Mangerson first began learning about special education when her son was diagnosed with a specific learning disability in third grade. As is her nature, she immersed herself in learning all she could about his diagnosis, the special education process and how to best advocate for him.

It wasn't long before Kathy left corporate America and joined the Arizona Department of Education as a Parent Information Network specialist. When the PIN duties were taken over by Raising Special Kids, we were lucky enough to have had Kathy join us as a family support specialist.

Earlier this year, Kathy's depth and breadth of special education knowledge and her keen training skills earned her the newly created position of Education Systems Administrator for Raising Special Kids. When March arrived, and with it an unfathomable amount of information about how education was to take place during a pandemic, Kathy rose to the challenge. Distilling that information has become her priority as she keeps the staff at Raising Special Kids apprised of the ever-changing educational landscape.

"I am very grateful to Raising Special Kids for asking me to step up and take on this challenge." Kathy shared. "It is so exciting to see how much our employees have learned in such a short amount of time."

From school closures, to remote learning, to mask mandates to compensatory educational services, Kathy continues to be in close contact with leaders at ADE to ensure our staff, and in turn, Arizona families, have the most current, accurate information so they can work with their children's schools during this educational adventure.

One 'adventurer' Kathy is assisting is her son who is now advocating for his own daughter who has an IEP and is attending developmental preschool.

Our thanks to Kathy for helping Raising Special Kids continue to meet every challenge when serving Arizona families of children with disabilities as we have done for more than 40 years.

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WHAT'S HAPPENING WITH AAC?

Changes for DDD Members as of Jan. 1

LIKE many parents, Nicole and Brett Guysi developed the habit of spelling words in front of their young children to keep conversations private. And it worked most of the time, especially with their daughter Brooke, who has limited verbal ability and uses an alternative communication device.

Although one time when the family stayed at a hotel, Nicole asked her husband if they could get some F-R-U-I-T as a snack for their children,

Brooke and her brother Blake.

Brooke went right to her alternative communication device and chose the word “fruit” to confirm. The family laughs about it now, but it demonstrates the importance of Brooke’s device to connect her to the world.

Diagnosed with a rare genetic condition, Brooke, now age 9, had previously been nonverbal but uses her device to communicate with others. It’s also improved her spoken communication by giving her familiarity and curiosity for words and phrases, says her mom Nicole Guysi.

Many individuals like Brooke rely on augmentative and alternative communication (AAC) devices to interact with others. Augmentative devices support existing speech, and alternative devices are used in place of speech that is absent or not functional. Historically the Division of Developmental Disabilities (DDD) coordinated this benefit for qualifying members.

As of Jan. 1, 2021, all new re-

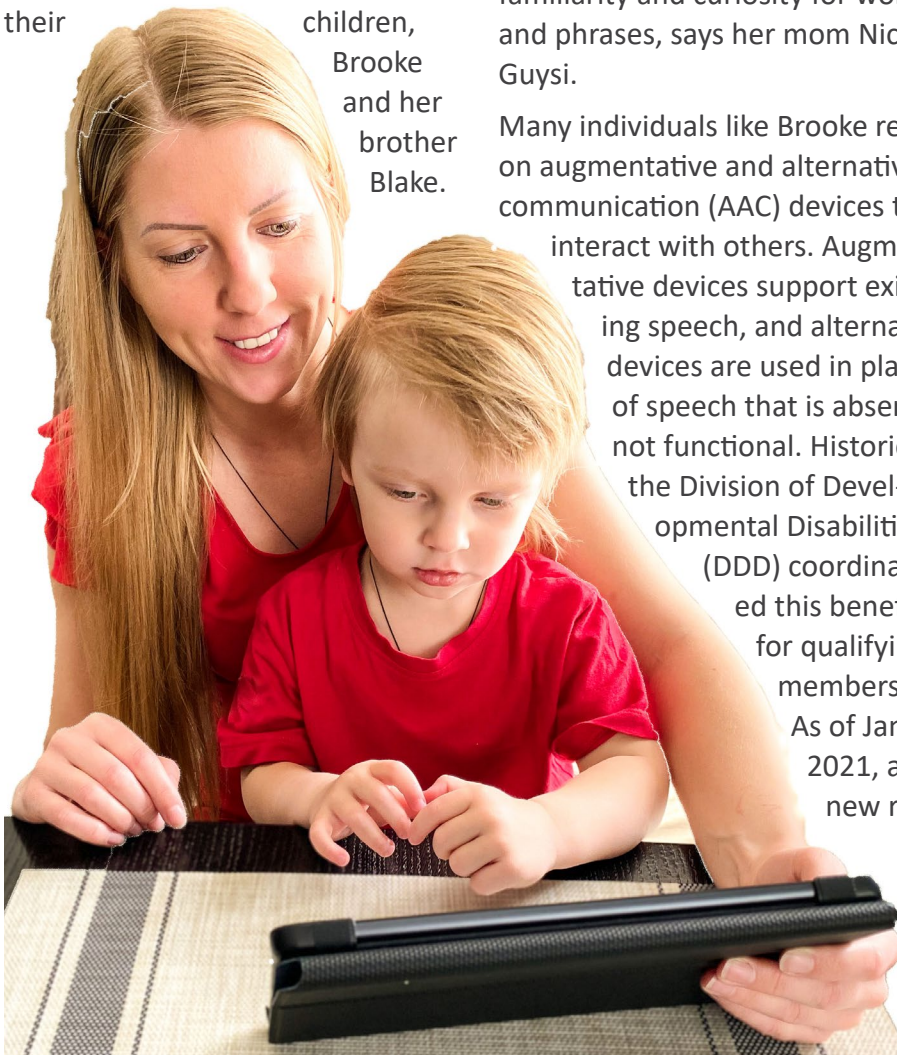
quests for purchases, replacements, repairs and training for AAC devices will transfer from DDD to the health plans, Mercy Care and UnitedHealthcare Community Plan.

“We are honored to expand the services we provide our members,” said Amy Pawlowski, executive director, complex care for UnitedHealthcare Community Plan. “Our goal is to develop efficiencies increase transparency and improve access to care. Assisting individuals in their communication journey is something we are well positioned to do.”

The health plans already manage all other durable medical equipment benefits except for AAC. DDD will continue to oversee the health plans to make sure members are getting quality and timely services.

WHAT THIS MEANS FOR DDD MEMBERS

As of Jan. 1, members who need assessments for AAC devices, or repair or training for current devices, will initiate the process with their support coordinators. The individual’s support coordinator will help gather documents and forms, and will send required information to the member’s health plan. The support coordinator will also monitor requests through the process until decisions are made. Members will need to use the same health plan for AAC services that they already use for other DDD services.



If parents have concerns about their child's new AAC request after Jan. 1, they can call their support coordinator or the DDD customer service number, 844-770-9500. Parents can also call the member services department for their health plan, Mercy Care, 800-624-3879 or UnitedHealthcare Community Plan, 800-348-4058.

In November, Raising Special Kids and the Autism Society of Greater Phoenix hosted listening sessions with Mercy Care and UnitedHealthcare Community Plan to gather feedback from members and their families about this change to the AAC benefit. Several questions arose about the timing for new requests and requests for repair, and also about training for new devices. Community information sessions hosted in December will provide more information as this change comes closer.

COULD MY CHILD BENEFIT FROM AN AAC DEVICE?

AAC devices are frequently associated with individuals who are nonverbal. But AAC devices can help anyone who has difficulty with verbal communication in any situation. According to the Arizona Technology Access Program (AzTAP), AAC devices offer a "voice" for individuals who can't speak, or can help those who don't speak clearly enough for others to understand. AAC devices can also enhance communication for those who can speak but need a boost. "Frequently, we may forget what both of the As stand for" in terms of augmentative and alternative communication, said Brandi Wentland, M.A., CCC-SLP, speech-language pathologist and AAC special-

ist with TherapyOne. "Alternative communication is what comes to mind, but augmentative communication adds to existing speech. Someone could be able to speak but they also have apraxia or selective mutism. Or someone with autism can work on expressive language." Wentland estimates that only a small percentage of individuals use AAC devices compared to the number of people who could truly benefit from them.

AAC devices can also expand on what a child is already trying to say. A child could be able to say the word "milk," but they might want to say that they don't want milk or they want more milk, said Candice Steel, B.S., SLP-L, ATP, speech-language pathologist and AT specialist with the Scottsdale Unified School District. "We want to help to expand the child's message when they have more to say."

If a parent thinks their child could benefit from an AAC device, they can speak to the child's private or school-based speech therapist and to see if it would be appropriate to bring in an AAC specialist. The parent would also need to also contact their child's DDD support coordinator to initiate the request pro-

cess through their health plan.

AzTAP offers a lending library so people can try out all types of assistive technology including AAC devices at no expense. AzTAP is federally funded and works through Northern Arizona University, with an office in Phoenix.

"Our role is to work with families to become more educated about their choices," said Clayton Guffey, MSW, CRC, ATP, CEAC, program director for AzTAP. "We serve as a beginning resource for them prior to an evaluation so they can identify which resources to ask about and to consider."

AzTAP can also offer suggestions for families who aren't enrolled in DDD or in one of the



health plans, Guffey said. AAC devices can be provided by a child's school when appropriate to access schoolwork, or could sometimes be covered through private insurance. Device manufacturers also have funding departments that can assist parents, Guffey noted.

Interested parents can contact AzTAP to request an initial consultation, currently taking place over video call. Once AzTAP and the parent identify an appropriate AAC device, AzTAP can ship it to the parent and provide additional training and consultation for the device over the phone.

AAC IN ACTION

Krista Howard, age 34, has cerebral palsy and uses an AAC device to communicate, navigating about 144 buttons per page on her system. Krista attends Arizona State University and Estrella Mountain Community College, pursuing a degree in speech and language pathology. She's also worked full time for the Gompers program, coaching staff and participants in communicating with AAC devices, and has assisted young AAC users as a paraeducator through Arizona's Empowerment Scholarship Account (ESA) program. She speaks at conventions and is one of the co-authors of a book coming out next year, *Exceptional AAC Leaders*.

Krista encourages parents to act as early as possible if they think their child would benefit from AAC.

"Don't give up," Howard recommended to parents. It took her some time to become comfortable using her AAC device, and she now uses it extensively as a college student and as a professional. Howard also advocates the impor-

tance of peer support, and helps to facilitate groups in Arizona called Out and About, where individuals of all ages meet and use their AAC devices together. Wentland and co-founders Dr. Caroline Musselwhite and Deanna Wagner also help facilitate these groups.

While an AAC device could be viewed as a sign of a disability, both Howard and Wentland prefer to see it as a gateway to an individual's potential.

"It's more than learning your child's wants and needs," Wentland said. "AAC gives people the ability to communicate their thoughts and feelings."

GOING FORWARD

As this change to the AAC benefit evolves, look for more information from the health plans and from DDD. Parents are encouraged to stay up to date by visiting the DDD website or by contacting their child's health plan, Mercy Care or UnitedHealthcare Community Plan. A list of FAQs are available on the DDD website here, and parents can also sign up for AAC update emails here.

It's also important for families to keep the lines of communication open with their support coordinator and other members of their child's care team if this change affects them. "There will be a transition period, but the heart and passion is there to make this process as good if not better than before," Steel said. "All the parties involved truly want to provide quality services to help meet the needs of individuals with disabilities."

AAC COMMUNITY INFORMATION SESSIONS

Mercy Care and UnitedHealthcare Community Plan will host sessions to provide more information on this change. Session schedule:

English:

Monday, Dec. 14, 11 a.m.

Thursday, Dec. 17, 4 p.m. & 7 p.m.

Spanish:

Monday, Dec. 14, 9 a.m.

Tuesday, Dec. 15, 6 p.m.

Visit www.MercyCareAZ.com or www.uhccommunityplan.com for information on how to register for these sessions.

FOR MORE INFORMATION

- Contact your DDD support coordinator
- DDD Customer Service - 844-770-9500 or DDDCustomerServiceCenter@azdes.gov
- Mercy Care - 800-624-3879
- United HealthCare Community Plan - 800-348-4058
- Office of Individual and Family Affairs (OIFA) - Mercy Care, OIFATeam@MercyCareAZ.org or United HealthCare Community Plan, advocate.oifa@uhc.com
- Arizona Technology Access Program (AzTAP) - 602-729-9534 or 800-477-9921 askaztap@nau.edu
- Out and About - Community group for AAC users - <https://www.facebook.com/groups/outandaboutAZ/> krista@wespeakaac.com
- FAQs about this change: <https://bit.ly/AAC-FAQs>
- To receive AAC update emails from DDD, visit [:https://bit.ly/AAC-Updates](https://bit.ly/AAC-Updates)

DOUBLE TIME

Dad gains, gives support through Raising Special Kids

If you think you're seeing double with the Macias family, you probably are! Their family consists of two sets of twin girls, Journey and Zaig, 13, and Skye and Aurelia, 11. Journey and Zaig both have autism, which brought dad Jesus Macias to Raising Special Kids for support.

Journey and Zaig received their autism diagnoses close to age 3. They are both nonverbal and attend a private special needs school near their home in Tempe. Skye and Aurelia attend a performing arts charter school in the East Valley.

Jesus knows his family is a little bit unusual, with two sets of twins and two daughters on the autism spectrum. Statistics show that boys are four times more likely to be diagnosed with autism than girls. But single dad Jesus handles it all with a sense of humor and love for his daughters. He works as a personal lending consultant for Wells Fargo, primarily working from home now. Support from caregivers helps the family live a busy life.

Like many families, the Macias' days are filled with activities -- in their case, music, art projects and outdoor time. Skye and Aurelia enjoy writing, drawing, singing and dancing. Zaig loves to climb and spend time with animals, and Journey likes puzzles and running. Both Journey and Zaig have participated in animal therapy, which can be a trigger to



Macias Family

help them talk, Jesus noted. He is also looking into getting a service animal for his girls.

Jesus came to Raising Special Kids for support when his daughters were initially diagnosed, and he recently came back to make sure they had all the support they needed.

As a single dad seeking resources for his daughters, Jesus recognizes his unique scenario. Over the years, he's dealt with serious and funny milestones, like when Journey and Zaig started their monthly cycles. Female caregivers offered great help and support to the family at that time.

Volunteering as a parent leader with Raising Special Kids, Jesus connects with other parents,

particularly dads, who might need support or advice. He also started a Facebook page for dads, called Fathers with Special Needs Children (Fathers with Special Needs: <https://www.facebook.com/Fathers-with-Special-Needs-Children-115728866926240>).

While his page is just getting started, Jesus hopes to grow and expand it to include all parents of children with any special need.

Connecting with others and sharing stories seem to be true motivators for parents like Jesus. Thank you for supporting others!

¿QUÉ ESTÁ PASANDO CON LOS DISPOSITIVOS CAA?

Cambios para miembros de DDD a partir del 1 de enero

Al igual que muchos padres, Nicole y Brett Guysi adquirieron el hábito de deletrear palabras delante de sus hijos pequeños para que no entendieran sus conversaciones privadas. Les funcionaba muy bien durante la mayor parte del tiempo, especialmente con su hija Brooke, que tiene una capacidad limitada del habla y usa un dispositivo de comunicación alternativo. Pero un día, cuando la familia estaba alojada en un hotel, Nicole le preguntó a su marido si podían pedir F-R-U-T-A como botana para los niños, Brooke y su hermano Blake. En ese momento, Brooke fue directo a su dispositivo de comunicación alternativo y eligió la palabra "fruta". Hoy la familia se ríe al recordarlo, pero es un claro ejemplo de la importancia que tiene el dispositivo de Brooke para conectarla con el mundo.

Brooke, de 9 años, ha sido diagnosticada con una enfermedad genética poco frecuente que le impide hablar; hoy gracias a su dispositivo puede comunicarse con los demás. Asimismo, el dispositivo ha mejorado su comunicación oral al ayudarla a reconocer palabras y frases y despertar su curiosidad, comenta su madre, Nicole Guysi. Muchas personas como Brooke dependen de los dispositivos de comunicación aumentativa y alternativa para interactuar con los demás. Los dispositivos aumentativos complementan el habla existente, mientras que los

dispositivos alternativos sustituyen el habla cuando ésta no es funcional o está ausente. Históricamente, la encargada de coordinar este beneficio para los miembros elegibles era la División de Discapacidades del Desarrollo (DDD, por sus siglas en inglés).

A partir del 1 de enero de 2021, todas las solicitudes nuevas para adquirir, reemplazar o reparar dispositivos de CAA, o para recibir capacitación sobre el uso de estos dispositivos, serán transferidas de la DDD a los planes de salud Mercy Care y UnitedHealthcare Community Plan. Los planes de salud ya están a cargo de todos los demás beneficios de equipos médicos duraderos, excepto los dispositivos de CAA. La DDD continuará supervisando los planes de salud para garantizar que los miembros reciban servicios de calidad y en forma oportuna.

QUÉ SIGNIFICA ESTO PARA LOS MIEMBROS DE LA DDD

A partir del 1 de enero, los miembros que requieran evaluaciones para determinar si deben usar dispositivos de CAA, que necesiten reparar dispositivos actuales o recibir capacitación sobre su uso, deberán iniciar el proceso con sus coordinadores de apoyo. El coordinador de apoyo de la persona ayudará a recopilar los documentos y formularios correspondientes y enviará la información solicitada al plan de salud del miembro. Asimismo, supervisará las solicitudes durante el proceso hasta que se tomen las decisiones. Para recibir

los servicios de CAA, los miembros deberán usar el mismo plan de salud que utilizan para otros servicios de la DDD.

A partir del 1 de enero, si los padres tienen alguna inquietud sobre la nueva solicitud de dispositivos de CAA para su hijo, podrán llamar a su coordinador de apoyo o al número de atención al cliente de la DDD, 844-770-9500. Asimismo, pueden comunicarse con el departamento de atención al miembro de su plan de salud Mercy Care llamando al 800-624-3879, o del plan UnitedHealthcare Community Plan llamando al 800-348-4058.

En noviembre, Raising Special Kids y Autism Society of Greater Phoenix organizaron jornadas comunitarias junto con Mercy Care y UnitedHealthcare Community Plan para conocer las opiniones de los miembros y sus familias sobre este cambio en el beneficio de los dispositivos de CAA. Se hicieron varias preguntas sobre los plazos para presentar las solicitudes nuevas y los pedidos de reparación, así como también sobre la capacitación para aprender a usar los dispositivos nuevos. Las sesiones informativas para la comunidad, que se llevarán a cabo en diciembre, brindarán más información a medida que se aproxime la fecha del cambio. Mercy Care y UnitedHealthcare Community Plan publicarán información en línea sobre cómo participar en estas sesiones.

¿QUÉ BENEFICIOS RECIBIRÁ MI HIJO AL USAR UN

DISPOSITIVO DE CAA?

Los dispositivos de CAA suelen asociarse con personas que no pueden hablar. Sin embargo, estos dispositivos también ayudan a las personas que tienen dificultades para comunicarse oralmente en cualquier situación. Según el Programa de Acceso a la Tecnología de Arizona (AzTAP, por sus siglas en inglés), los dispositivos de CAA le dan "voz" a las personas que no pueden hablar, o pueden ayudar a las personas que no hablan con la claridad necesaria para hacerse entender. Los dispositivos de CAA también pueden mejorar la comunicación de aquellos que pueden hablar, pero que necesitan mejorar.

"A menudo es posible que nos olvidemos de lo que representan las dos A" en términos de la comunicación aumentativa y alternativa, expresó Brandi Wentland, M.A., CCC-SLP, fonoaudióloga y especialista en CAA en TherapyOne. "La comunicación alternativa es lo que viene a la mente, pero la comunicación aumentativa se suma a la capacidad de hablar ya existente. Alguien podría ser capaz de hablar aunque tenga apraxia o mutismo selectivo; o alguien con autismo puede trabajar en el lenguaje expresivo". Wentland estima que solo un pequeño porcentaje de personas usan dispositivos de CAA frente a la cantidad de personas que podrían beneficiarse con su uso. Los dispositivos de CAA también pueden ampliar lo que un niño intenta decir. Un niño podría ser capaz de decir la palabra "leche", pero quizá quiere decir que no quiere leche o que quiere más leche, explicó Candice Steel, B.S., SLP-L, ATP, fonoaudióloga y especialista en tecnología asistiva en el Distrito Escolar Unificado de Scottsdale.

"Queremos ayudar a ampliar el mensaje del niño cuando tiene más para decir". Si los padres piensan que su hijo podría beneficiarse con el uso de un dispositivo de CAA, pueden comunicarse con el fonoiatra particular o de la escuela donde asiste el niño para decidir si sería conveniente convocar a un especialista en CAA. Los padres también deberían contactarse con el coordinador de apoyo de la DDD para su hijo a fin de iniciar el proceso de solicitud mediante su plan de salud. El programa AzTAP ofrece un servicio de biblioteca para que las personas puedan probar, sin costo alguno, todo tipo de tecnología asistiva, incluidos los dispositivos de CAA. El AzTAP está financiado por el gobierno federal y opera a través de la Northern Arizona University, con sede en Phoenix. "Nuestra función es trabajar con las familias para que estén mejor informadas al momento de tener que tomar decisiones", explicó Clayton Guffey, MSW, CRC, ATP, CEAC, director del programa AzTAP. "Actuamos como un recurso inicial previo a la evaluación para que puedan identificar los recursos que les interesan y solicitar información". El programa AzTAP también puede dar recomendaciones a las familias que no están registradas en la DDD o en alguno de los planes de salud, explicó Guffey. Los dispositivos de CAA pueden ser suministrados por la

escuela donde asiste el niño cuando fuesen necesarios para realizar las tareas escolares o, en ocasiones, pueden estar cubiertos por un seguro privado. Los fabricantes de dispositivos también cuentan con departamentos de financiación que pueden brindar ayuda a los padres, señaló Guffey.

Aquellos padres que estén interesados pueden comunicarse con el programa AzTAP para solicitar una primera consulta, que se realizará mediante una videollamada. Una vez que AzTAP y los padres elijan el dispositivo de CAA adecuado, AzTAP lo enviará a los padres y ofrecerá capacitación adicional y consultas telefónicas sobre el dispositivo.

Los dispositivos ACC en acción
Krista Howard, de 34 años,
tiene parálisis
cerebral infantil
y utiliza un
dispositivo
de CAA
para



comunicarse, en el que maneja unos 144 botones por página en el sistema. Krista asiste a la Universidad Estatal de Arizona y al Estrella Mountain Community College, donde estudia fonoaudiología. También ha trabajado tiempo completo para el programa Gompers capacitando al personal y a los participantes sobre la comunicación mediante dispositivos de CAA. Asimismo, ha colaborado con jóvenes usuarios de los dispositivos de CAA como auxiliar pedagógica en el Programa de cuentas de becas de empoderamiento de Arizona (ESA, por sus siglas en inglés). Participa como ponente en convenciones y es coautora de un libro que se publicará el año próximo, Exceptional AAC Leaders (Líderes excepcionales en CAA). Krista alienta a los padres a actuar lo antes posible si creen que su hijo se beneficiaría con el uso de un dispositivo de CAA. "No se rindan", recomendó Howard a los padres. Le llevó un tiempo sentirse cómoda usando su dispositivo de CAA, y ahora lo usa todo el tiempo como estudiante universitaria y como profesional. Howard también destaca la importancia del apoyo de los pares y ayuda a dirigir grupos en Arizona llamados Out and About, en los que se reúnen personas de todas las edades y usan sus dispositivos de CAA en forma grupal. Wentland y las cofundadoras, doctoras Caroline Musselwhite y Deanna Wagner, también ayudan a dirigir estos grupos. Aunque un dispositivo de CAA puede verse como un signo de discapacidad, tanto Howard como Wentland prefieren verlo como una puerta de acceso al potencial de una persona.

"Es mucho más que conocer los deseos y las necesidades de su hijo",

explicó Wentland. "Gracias a los dispositivos de CAA, las personas tienen la capacidad de comunicar sus pensamientos y sentimientos".

EN EL FUTURO

A medida que se produzca este cambio en el beneficio de los dispositivos de CAA, interiorícese sobre los planes de salud y la DDD. Se recomienda a los padres que se mantengan informados visitando el sitio web de la DDD o poniéndose en contacto con el plan de salud de su hijo, Mercy Care o UnitedHealthcare Community Plan. En el sitio web de la DDD aquí puede consultar una lista de preguntas frecuentes, y los padres también pueden registrarse aquí para recibir correos electrónicos de actualización sobre los dispositivos de CAA.

Es importante que las familias mantengan una comunicación fluida con el coordinador de apoyo y otros miembros del equipo de atención de su hijo en caso de verse afectadas por este cambio. "Habrá un período de transición, pero pondremos toda nuestra pasión y esfuerzo para hacer que este proceso sea tan fluido como el anterior, o incluso mejor", manifestó Steel. "Todas las partes implicadas desean realmente ofrecer servicios de calidad para ayudar a satisfacer las necesidades de las personas con discapacidades".

POSIBLES RECUADROS CON INFORMACIÓN DE CONTACTO:

Sesiones informativas para la comunidad sobre dispositivos de CAA Mercy Care y UnitedHealthcare Community Plan dirigirán las sesiones para suministrar más información sobre este cambio. Las sesiones están programadas para las siguientes fechas:

Español

14 de diciembre, 9 a.m.
15 de diciembre, 6 p. m.

Inglés

14 de diciembre, 11 a. m.

17 de diciembre, 4 p. m y 7 p.m.

Visite www.MercyCareAZ.com o www.uhccommunityplan.com para obtener información sobre cómo inscribirse para participar de estas sesiones.

¿A QUIÉN PUEDO CONTACTAR PARA OBTENER MÁS INFORMACIÓN?

- A su coordinador de apoyo de la DDD.
- Mercy Care: 800-624-3879
- United HealthCare Community Plan: 800-348-4058
- Atención al cliente de la DDD: 844-770-9500 o DDDCustomerServiceCenter@azdes.gov
- Oficina de Asuntos Personales y Familiares (OIFA, por sus siglas en inglés) - Mercy Care, OIFATeam@MercyCareAZ.org o United HealthCare Community Plan, advocate.oifa@uhc.com
- Programa de Acceso a la Tecnología de Arizona (AzTAP): 602-729-9534 o 800-477-9921
- askaztap@nau.edu
- Out and About - Grupo comunitario para usuarios de dispositivos de CAA <https://www.facebook.com/groups/outandaboutAZ/> krista@wespeakaac.com
- Las preguntas frecuentes sobre este cambio están disponibles en el sitio web de la DDD:
- <https://des.az.gov/services/disabilities/developmental-disabilities/augmentative-and-alternative-communication>
- Puede registrarse para recibir correos electrónicos de actualización sobre los dispositivos de CAA enviados por la DDD. Complete el formulario y envíelo aquí: <https://bit.ly/AAC-Updates>.

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