While effective treatments exist, many people with behavioral health conditions do not receive the help they need. Families report that finding a treatment provider who understands the issues, makes a correct diagnosis, can build a working rapport with your child, create a treatment plan that the patient can follow, and also is acceptable to your insurance carrier can be a tall task indeed. My family has experienced this reality first hand. It started one morning in second grade, when my daughter couldn’t walk into the school, absolutely refused! I didn’t understand what was happening and she couldn’t tell me why. I forced it; she had to go to school! Then the “rages” started. The school said she needed to see her doctor. They wondered what’s happening at home? The primary care doctor said use behavior management at home, or maybe send her to a group home. She asked unusual questions: “Mom what is 4 times 4, what is 4 times 16, 4 times 64, 4 times 256?...I began my search and tried desperately to find a therapist, an answer, a referral to neurologist. Soon this became working with three therapists, a hospitalization and a cocktail of useless medications. All of that and we still had no diagnosis other than bad parenting, or maybe it could be ADHD, or maybe a mood disorder, or maybe childhood schizophrenia and even maybe your husband abused her. We still didn’t know what was wrong and neither did the professionals.

Finding a therapist who can diagnose and effectively treat behavioral health conditions is a challenge for many patients and families.

Cathy Hickey (L) and her daughter Katie (R)
It’s Annual Appeal Time at the Federation!

The Federation’s Annual Appeal letter is mailed out each year in early November and we are grateful for the support of all who donate. Families tell us that “I don’t always need the Federation, but when I do – you are always there!” We are able to be there for families whenever they need us because of the donations we receive from all of you, and we hope you will consider making a generous gift to the Appeal this year. With your support, we are able to be there for families as they make the journey with their children who might otherwise be isolated, discouraged and excluded.

Mike and Susan donate to the Federation so that other families can benefit, the way their family did. Susan first called the Federation when their son was 11 years old, and they were having trouble getting educational services for him. They feel that the supports and services their son received over the years were the direct result of the work the Federation has done in advocating for high quality health and education programming for children with special needs. And that because of those supports and services, their son’s potential was unlocked and he was able to make the successful transition he has made to adulthood. When people ask Mike how to navigate for their child with special needs he tells them “Call the Federation...there is no better place...”

If the Federation has been there for you, we hope you will give generously to our Annual Appeal – so that we can continue to be there when other families need us!

Make your donation online at www.fcsn.org or mail your check today to the Federation for Children with Special Needs
529 Main Street, Suite 1M3 | Boston, MA 02129
From the Executive Director:
“We may not always need the Federation, but you are there when we do!”

I was recently standing at the Federation display table as a conference exhibitor. A parent came up to me and said: “The Federation was so helpful to me when my daughter was moving from Early Intervention to the Public Schools. You were really there for me!”

A while later another parent stopped by the table and told me: “The Federation helped me when my son was having behavior issues in his Middle School. They helped me know what to say and how to get him some help.”

Finally, another parent was talking with me and said: “The Federation helped us when we needed help, but gladly, we don’t always need it, though you were there when we did! I really appreciate the work you do.”

The Federation best work is always done – when needed and just in time. Yes, we offer workshops and training materials, Facebook and twitter, our annual Visions of Community Conference and much more. But like many of the support services any of us need to use, whether it is your doctor or public safety or legal assistance, we are most appreciative when someone can help in our time of need.

“The Federation for Children with Special Needs provides information, support, and assistance to parents of children with disabilities, their professional partners, and their communities. We are committed to listening to and learning from families, and encouraging full participation in community life by all people, especially those with disabilities.”

You may not always need us, but we are here for you whenever you do!

Thanks to each and everyone of you who help the Federation help others – We are here for you!

Best wishes,

Rich Robison

For info on how you can help us help families, please see the article on page 2 regarding our Annual Appeal
The weather was beautiful for the Federation’s third annual Walk, Roll, Shobble*, Stroll for children with special needs, held on September 27, 2015, at the Massachusetts Hospital School in Canton, MA. The walkers, rollers, shobblers, and strollers arrived at the school, where DJ Kevin Sullivan had set up his table under a pavilion.

Sullivan got everyone dancing to the latest pop tunes from Taylor Swift, Katy Perry, and Andy Grammer. He also led the participants in games such as Hot Potato and Limbo. Participants also had the opportunity to decorate paper hats with googly eyes, stickers, colored mini fluff balls, glitter, and sequins; get their faces painted, get temporary tattoos, play with beach balls and hula hoops, or get a massage.

After a few words of introduction from Federation Executive Director Rich Robison, the walk began! Participants of all ages and abilities, set off on the mile long nature trail along the shore of “Reservoir Pond”. As they made their way down the accessible path, they played musical instruments and blew bubbles. They were encouraged by volunteers who cheered them on along the way as they passed the quarter mark, the halfway mark, the three-quarter mark, and the finish line. The walkers, shobblers, and strollers also participated in a scavenger hunt and kept their eyes out for plush stuffed birds that were cleverly hidden along the path. As they found each bird, they checked it off on their cards which they handed in at the end of the walk to receive their prize.

Once the participants returned to the pavilion, there was more music, dancing, and games, and then prizes were handed out to the teams and the individuals who raised the most money. The event raised $9,000 for the work of the Federation. It was a great success, and all of us at the Federation for Children with Special Needs appreciate the enthusiastic support of our families and friends! (See pictures below)

*where a shuffle meets a hobble

Many thanks to our sponsors: Eastern Bank, the Reichenbach Family, Crystal Springs and Franciscan Hospital for Children.
A Desperate Search (continued from page 1)

I stayed up nights surfing the internet looking for answers. Katie was tapping and touching everything 4 times. I suspected OCD but really didn’t understand it. And every “professional” said no this is not what OCD looks like. I came across a research study on treatment for OCD. More rages. I signed up immediately, went to the interview (had to bribe my daughter to go, she was tired of being labeled a bad kid).

After a three hour evaluation she was diagnosed with severe OCD. Katie did not want to go home, she wanted to start the treatment immediately. Someone understood her, she was not crazy. We spent the next 12 weeks in outpatient treatment, Katie’s affect was improving!! She was so successful in treatment that we could not continue counseling there.

I was scared, where would we go now? I begged for referrals only to learn they did not accept our insurance, or they had no openings...Finally found someone that could see her in two months. It was the best. She listened to us, respected us, spent time with us (sometimes up to 1 ½ hours!!). She asked us what we needed. We spent the next five years with her. Then she moved out of state. Where would we go now? Katie was 16 yrs. old. No one has openings for adolescents, and has experience treating OCD. Katie became depressed, angry, school refusal. We cycled through 3 different providers settling on one who didn’t treat OCD but was able to help Katie survive adolescence.

Meanwhile I was searching for an adult provider while I could still be involved...again no one was out there. I was trying to help Katie transition to adulthood, giving her the phone numbers and a script...She hated talking on the phone, leaving messages, hearing that they could not treat her. It was difficult to watch but what was I to do? Soon she would be 18 and I could not make these phone calls anymore. Thoughts in her head would not stop.

Exposure Response Therapy is known to be the most effective treatment for OCD. One Therapist stated that she knew how to treat OCD. After 4-5 weeks into therapy Katie asked her if she could help her with ERP. The therapist (sarcastically) told her that was an experiment she could try at home. Katie never went back to see her! So again we were in search of another provider.

We attend the International Obsessive Compulsive Disorder Foundation conference annually, it being a lifesaver for our whole family to be able to connect with others. This past summer we saw the name of a therapist in the program who resides near Katie’s college and is trained in ERP. Our attempts to stalk her and find her were unsuccessful. Katie called her a week later. Katie says Mom, she is so easy to talk to! But she has no openings and doesn’t take our insurance... She called me back and said she talked to the counseling center at my school, found me a therapist there that can treat me! She will help me set up a support group at school, she can help me meet others at my school with OCD...I can’t wait to go back to school! So here we are back on the right track, again. I am hopeful.

Tips for finding a mental health provider:

- Ask your health insurance company for a list of covered providers.
- Seek a referral or recommendation from your primary care provider.
- Ask trusted friends or family.
- Check to see whether your company’s employee assistance program (EAP) or student health center offers mental health services.
- Contact a local or national mental health organization, such as the National Alliance on Mental Illness (NAMI).
- Search websites for professional associations that have directories of mental health providers.
- Search the Internet under categories such as community service numbers, counselors, psychologists, psychiatrists or social service organizations.

When choosing a mental health provider, consider these issues:

- Education, training, licensing and years in practice
- Areas they specialize in and specific services they offer
- Treatment approaches and philosophy
- Which insurance providers they work with
- Office hours, fees and length of sessions

Don’t hesitate to ask lots of questions. Finding the right match is crucial to establishing a good relationship and getting the most out of your treatment.
Una búsqueda desesperada

Por Cathy Hickey, Project Coordinator, Family to Family Health Information

Encontrar un terapeuta que pueda diagnosticar y tratar efectivamente los problemas de salud conductual es difícil para muchos pacientes y familias.

Aunque hay tratamientos eficaces, muchas personas con problemas de comportamiento no reciben la ayuda que necesitan. Las familias dicen que encontrar un proveedor de tratamiento que comprenda sus dificultades, que haga el diagnóstico correcto, que pueda establecer una relación de confianza con el niño, que haga un plan de tratamiento que el paciente pueda seguir, y que sea aceptable para la compañía de seguros puede ser una tarea bastante ardua. Mi familia ha vivido esta realidad en forma directa. Empezó una mañana en segundo grado, cuando mi hija no podía entrar a la escuela, y se negaba rotundamente a hacerlo! Yo no entendía lo que pasaba y ella no podía explicarme el motivo.

Decidí que iría a la escuela a la fuerza. Fue entonces que empezaron las rabietas. La escuela dijo que tenía que ver a su médico, y se preguntaron qué estaba pasando en casa. El médico de atención primaria dijo que usáramos el manejo de la conducta en el hogar o que tal vez la enviáramos a un hogar grupal. Katie hacía preguntas extrañas: “Mami, ¿cuánto es 4 por 4? ¿Y 4 por 16? ¿Y 4 por 64? ¿Y 4 por 256?… Yo empecé a buscar desesperadamente un terapeuta, una respuesta, una recomendación de un neurólogo. Pronto terminé con tres terapeutas, una hospitalización y un cóctel de medicamentos inútiles. Todo eso y seguimos sin diagnóstico, sólo la sospecha de mala crianza, o tal vez trastorno por déficit de atención e hiperactividad (TDAH), o esquizofrenia infantil o quizás su marido la abusó. Seguimos sin entender el problema, y los profesionales también.

Yo me quedaba despierta hasta navegando la Internet en búsqueda de respuestas. Katie le estaba dándole cuatro golpecitos a todo. Yo sospeché que podía ser trastorno obsesivo-compulsivo pero en realidad no lo comprendía. Y todos los profesionales me decían que el TOC no es así. Encontré un estudio de investigación sobre tratamiento del TOC. Más rabietas. Me anote de inmediato, fui a la entrevista (tuve que sobornar a mi hija para que fuera; estaba cansada del rótilo de nena mala). Después de una evaluación de tres horas le diagnosticaron TOC grave. Katie no quiso volver a casa, quería empezar el tratamiento de inmediato. Por fin alguien la entendía, no estaba loca. Los 12 meses siguientes los pasamos en tratamiento ambulatorio. ¡El ánilo de Katie mejoraba! El tratamiento fue tan exitoso que no pudimos continuar la consejería ahí… Yo me asusté. Pensé, y ahora, ¿adónde vamos? Imploré que me dieran referencias, pero no aceptaban nuestro seguro, o no había turno… Hasta que encontré alguien que podía verla en dos meses. Fue fabulosa. Nos escuchaba, nos respetaba, nos dedicaba tiempo, a veces, hasta una hora y media! Nos preguntaba qué necesitábamos. Pasamos los cinco años siguientes con ella. Luego se mudó a otro estado. Pensé, ¿y ahora, ¿adónde vamos? Katie tenía 16 años. Nadie tenía turno para adolescentes, mi experiencia tratando a jóvenes con TOC. Katie se deprimió, se volvió irracunda y no quería ir a la escuela. Cambiamos tres veces de médico hasta encontrar uno de no trataba el TOC pero pudo ayudar a Katie a sobrevivir la adolescencia. Mientras tanto, yo seguía buscando un proveedor de adultos… Pero nuevamente, no había nadie disponible. Trataba de ayudar a Katie con la transición a la vida adulta, dándole el número de teléfono y una receta… Ella odiaba hablar por teléfono, dejar mensajes, oír que no podían tratarla. Era difícil verlo, ¿pero que podía hacer yo? Pronto cumpliría 18 años y yo no iba a poder seguir haciendo llamadas telefónicas por ella. Los pensamientos no le paraban en la cabeza.

La terapia de exposición y prevención de respuesta es el tratamiento más eficaz para el TOC. Un terapeuta dijo que sabía cómo tratar el TOC. Después de 4 o 5 semanas de terapia, Katie preguntó si podía ayudarla con la terapia de exposición y prevención. La terapeuta le dijo (sarcásticamente) que ese era un experimento que podía probar su casa. ¡Katie no la quiso volver a ver nunca más! Así que hubo que volver a buscar un terapeuta.

Nosotros vamos a la conferencia anual de IOCDF. Es un verdadero salvavidas para mi familia poder conectarnos con otros. El verano pasado vimos el nombre de alguien del programa que reside cerca de la universidad de Katie y que ha recibido capacitación en la terapia de exposición y prevención. Nuestros intentos de localizarla no fueron exitosos. Pero Katie la llamó una semana más tarde. Y me dijo, “Mamá, es tan fácil hablar con ella”. Pero no tiene turno disponible y no acepta nuestro seguro… Me llamó de vuelta y me dijo que hablaría con el centro de consejería de mi escuela, y me encontró un terapeuta ahí que puede tratarme. Me va a ayudar a organizar un grupo de apoyo en la escuela, me puede ayudar a encontrar a otros estudiantes con TOC… ¡Ahora sí tengo muchas ganas de volver a la escuela! Así que ahora estamos bien encaminados otra vez. Tengo esperanzas.
Consejos para encontrar un profesional de salud mental:
• Pida a su compañía de seguro una lista de los proveedores cubiertos.
• Pídale un referimiento o una recomendación a su proveedor de atención primaria.
• Pregúntele a amigos de confianza o familiares.
• Averíe si el programa de asistencia a empleados de su compañía o el centro de salud estudiantil de su lugar de estudio ofrece servicios de salud mental.
• Comuníquese una organización de salud mental local o nacional, como la National Alliance on Mental Illness (NAMI).
• Busque sitios web de asociaciones profesionales que tengan directorios de profesionales de salud mental.
• Busque en Internet categorías como números de agencias de servicio comunitario, consejeros, psicólogos, psiquiatras u organizaciones de servicios sociales.

Al elegir un profesional de salud mental, considere lo siguiente:
• Educación, capacitación, licencia y años de experiencia.
• Campos de especialidad y servicios específicos y ofrece
• Enfoque y filosofía de tratamiento
• Compañías de seguro con las que trabaja
• Horario, honorarios y duración de las sesiones

No dude en hacer muchas preguntas. Encontrar la persona adecuada es crítico para establecer una buena relación y aprovechar al máximo el tratamiento.
Tips for Working Effectively with Your Special Education Advocate or Parent Consultant

By Elizabeth Bostic, Parent Consultant

Being the parent of a child with special needs comes with a unique set of challenges, not the least of which is advocating for them in their school. Navigating the special education system, deciphering the law, and interacting with school personnel can be emotionally challenging. Some parents have found help by working with a trained Parent Consultant or Advocate. Hiring a Special Education Parent Consultant can provide you with expertise regarding the law, strategies for working collaboratively with your child’s Team, and the ability to address your child’s needs based on facts, not emotions. Here are some tips on how to partner with your Parent Consultant most effectively.

Communicate, Communicate, Communicate!
In order to be most effective, your Parent Consultant will need access to all assessments, progress reports, and IEPs that have been generated in the recent past. Prepare a chronology of important school related occurrences with the dates for the last two years to give your Parent Consultant. Write down your concerns and share them with him or her. The more data you provide the better! Keep your Parent Consultant in the loop regarding ongoing relevant events and/or interactions with school personnel. This will enable your Parent Consultant to provide you with the best possible advice and ensure that he or she is not surprised by information raised for the first time during a Team meeting.

As the parent, you are the expert on your child. No one knows your child better than you. Be open, direct, and clear about your goals expectations for your child. Help your Parent Consultant to see your child as you do so he or she can advocate effectively for you.

Always Be Respectful
It is essential that you be respectful toward all members of your child’s IEP Team. When emotions run high, keep them in check; focus on your child and the important issues and facts. Having a difference of opinion is never an excuse for losing control. Always keep the big picture in view and don’t allow your emotions to get in the way of what is in the best interests of your child. Agree to disagree.

Trust Your Parent Consultant’s Expertise
Your Parent Consultant will give you a realistic view of what to expect and make recommendations on how to best work with your Team to address your child’s unique needs.

At times, your Parent Consultant may tell you something you don’t understand. Don’t be afraid to ask questions until you are clear about the reasoning behind the recommendations. Thoughtfully consider his or her input when determining your next step. Should you choose a different approach, your Parent Consultant will appreciate being informed so he or she can continue to support you effectively.

Have Realistic Expectations
Your Parent Consultant can assist you to identify the most appropriate accommodations, services and placement based on the data and assessments. He or she will help you work with your Team to ensure your child receives what the law guarantees, a free and appropriate public education in the least restrictive environment. While some services or methodologies may be ideal, they may not be necessary to facilitate effective progress. Similarly, what a child could benefit from does not always equate to an essential service. You want what is best for your child and your Parent Consultant can guide you to ensure that your child is positioned for success.

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Students with complex childhood trauma can have severe responses to typical challenges of adolescence which makes it difficult for them to learn and teach. In order for these students to learn efficiently, students must feel safe in supportive classrooms. When a student fails to stay in good control, positive behavioral supports can be in place to allow the student to re-align his or her behavior. If a school diligently follows one of the many evidence-based social-emotional curriculum, the student can develop appropriate emotional responses to everyday stressors.

Unfortunately, for students who have suffered toxic stress or complex childhood trauma, the challenge is even greater. According to the Centers for Disease Control (CDC), almost half (47.9%) of students in a typical classroom have experienced one or more adverse childhood experiences or (ACEs), which can serve as a measure for childhood trauma. Complex childhood trauma influences brain development and learning and the effects can be more profound as a student enters adolescence. Common factors such as teenage hormonal changes, the process of developing their own personality, and the emphasis on peer relations (including romantic ones) thrust youth into adulthood even though they have not yet developed “adult” age-appropriate social and emotional responses. This can result in classroom disruptions like verbal outbursts, late arrivals, school refusal, and disciplinary removal. Further complicating this situation, many middle and high school teachers feel unprepared to manage a classroom with students with trauma backgrounds.1

The impact of poor nutrition and food insecurity can contribute to these challenges. In some large school districts (e.g. Boston, Springfield and Worcester included), 100% of students can receive free or reduced-price breakfast and lunch through the Community Eligibility Provision, an indicator of the number of families living under the federal poverty level.

Research by the CDC also indicates that a lack of sleep can negatively affect academic success. Typical adolescents need about 9.25 hours of sleep every night. Most students get two hours less than that. Students with trauma backgrounds also have chronically high levels of the hormone cortisol, which, along with serotonin and adrenaline, help control sleep schedules. Problems occur when cortisol levels do not decrease enough for deep, uninterrupted, restful sleep. These hormone levels rise as sunlight increases, allowing our bodies and brains to wake up. Students who wake after a restless night may have trouble focusing on schoolwork, and can be fidgety and irritable in the classroom. The impact of these conditions can be a root cause for challenging behavioral issues.

Another factor can be that adolescence is a time when social relationships are immensely important. A student who has not yet developed the social-emotional skills to form lasting, healthy friendships will be at risk for depression and isolation. Many youth who suffer from childhood trauma have not developed the ability to feel in control of their behavior and social environment, and lack confidence about their future. Successful relationships require the ability to empathize and understand another person’s perspective. Physiological changes and delays in the brain development of students with toxic stress may leave them behind their peers in developing these skills. As a result, relationships may be especially hard to make; self-esteem may plummet, and long-standing mental health issues can develop.

How can school districts help these students? While solutions may seem overwhelming, some schools have made a difference in their students’ lives. We now have examples of high schools which have changed their approach to discipline from zero tolerance to trauma-informed interventions. Paper Tigers, a new documentary by James Redford, is an intimate look into the lives of some of the students at Lincoln High School in Walla Walla, Washington which examines the “promise of Trauma Informed Communities.” This is a new movement that is showing great promise in healing youth struggling with the dark legacy of adverse childhood experiences.

Editor’s note: The third article in a three-part series on how challenging behaviors influence the ability to learn. Part one, ages 0-5, appeared in the Spring edition of Newsline. Part two, ages 12-18 appeared in the Summer edition of Newsline.

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"Establishing" a SEPAC

By Leslie M. Leslie, MassPAC Coordinator and APPLE Faculty Leader, FCSN

Over the years, I have heard many interpretations on the School Committee’s obligation under the law to “establish” a parent advisory council on special education. The word “establish” has a broad definition including according to Merriam-Webster’s Dictionary – all of which are very appropriate to SEPACs:

• to institute (as a law) permanently by enactment or agreement
• to make firm or stable
• to introduce and cause to grow and multiply
• to bring into existence: found
• to bring about, effect
• to put on a firm basis : set up
• to gain full recognition or acceptance of

Most school districts delegate the coordination of the SEPAC to the administrator of special education and rely on the SEPAC to come before the School Committee on an annual basis to report on matters that pertain to special education. The law states, the SEPAC “shall receive assistance from the school committee without charge, upon reasonable notice, and subject to the availability of staff and resources.” Usually this is in the form of free meeting space, access to copying of materials, a presence on the district website and options to post notices in district publications, such as principals’ newsletters, similar to the resources provided to other school parent groups.

Once the SEPAC is established, it sets its own by-laws and operational procedures and functions independently. The SEPAC is a public body and must follow the Open Meeting and Public Records laws, but can meet in any public accessible space, such as the Public Library. SEPAC meetings are open to the public and membership shall be offered to all interested parties. The SEPAC can, in its by-laws, delegate decision-making/voting to a specified class of members – such as parents or guardians of children with special needs. It is advisable that the SEPAC share their meeting agendas with the school district, but the agenda, speakers and other activities are under the control of the SEPAC and its executive board.

The SEPAC can create a spin-off group such as a Parent Support Group that can meet to share parental concerns or personal situations outside of a public meeting. This group does not have to follow the open meeting law as no SEPAC business would be conducted.

MassPAC can assist any parent or group of parents who wish to form a SEPAC. We suggest that an Interim Team begin the process, contact their district special education administrator to notify them of their intentions and start to hold meetings to develop a group and adopt a set of by-laws. Once by-laws are adopted, formal elections can be held to elect officers. An option to have two or more co-chairs under a SEPAC’s by-laws helps meet the challenging demands on parents’ time, especially those raising a child with special needs. The newly formed SEPAC officers should be sworn in by the Town Clerk and sign a certification of knowledge of the Open Meeting laws. They should also request an opportunity to come before the School Committee to announce the formation of the SEPAC and instruct the School Committee of their advisory role under the law.

It takes parents to form and run a SEPAC, although the school district is a key player to help bring it into existence, help put on a firm basis to grow and multiply, assist the SEPAC to gain full recognition of its advisory role, as well as put the SEPAC in a favorable position to collaborate with other parent organizations and the whole school community – truly “established”!
Uma Busca Desesperada
Por Cathy Hickey, Project Coordinator, Family to Family Health Information

Encontrar um terapeuta que possa diagnosticar e tratar eficazmente condições de saúde comportamental, é um desafio para muitos pacientes e famílias.

Embora existam tratamentos eficazes, muitas pessoas com condições de saúde comportamental, não recebem a ajuda que necessitam. As famílias relatam que encontrar um provendedor de saúde que entenda os problemas, faça o diagnóstico correto, possa construir um relacionamento de trabalho com o seu filho, crie um plano de tratamento no qual o paciente pode seguir, e que também seja aceitável pelo seu plano de saúde, pode ser realmente uma tarefa difícil. Minha família já experimentou esta realidade em primeira mão. Começou em uma manhã, na segunda série, quando minha filha não pôde entrar na escola, sendo absolutamente recusada! Eu não entendia o que estava acontecendo, nem ela podia me dizer o por quê. Eu insisti; ela tinha que ir à escola! Em seguida, “os acessos de raiva” começaram. A escola informou que ela precisava ir ao seu médico, eles indagavam o que estava acontecendo em casa? Seu clínico geral aconselhou o uso em casa de um gerenciamento comportamental, ou talvez enviá-la a um grupo em uma casa. Ela fazia perguntas não comuns: “Mãe, o que é 4 vezes 4, o que é 4 vezes 1, 4 vezes 64, 4 vezes 256…? Eu comecei minha busca e tentei desesperadamente encontrar um terapeuta, uma resposta, e uma referência para um neurologista. Logo isso passou a ser um trabalho com três terapeutas, uma hospitalização e um coquetel de medicamentos. Tudo isso e ainda não tínhamos um diagnóstico, além de de sermos maus pais, ou talvez poderia ser ADHD (Transtorno do Déficit de Atenção/Hiperatividade - TDA/H), ou talvez um transtorno de humor, ou talvez esquizofrenia infantil e talvez um neurologista. Logo isso passou a ser um trabalho com três terapeutas, uma hospitalização e um coquetel de medicamentos. Tudo isso e ainda não tínhamos um diagnóstico, além de de sermos maus pais, ou talvez poderia ser ADHD (Transtorno do Déficit de Atenção/Hiperatividade - TDA/H), ou talvez um transtorno de humor, ou talvez esquizofrenia infantil e talvez até mesmo o seu marido tenha abusado dela. Nós e nem mesmo os profissionais sabíamos o que estava errado.

Passei noites acordada, buscando por respostas na Internete. Katie estava batendo e tocando tudo 4 vezes. Eu suspeitei que era OCD (Transtorno Obsessivo-Compulsivo - TCO), mas realmente eu não entendia nada daquilo. Eu me deparei com uma pesquisa sobre o tratamento para OCD. Mais acessos de raiva. Eu me inscrevi imediatamente, fui para a entrevista (tinha que subornar a minha filha para ir, ela estava cansada de ser rotulada como uma garota ruim). Depois de uma avaliação de três horas, ela foi diagnosticada com grave OCD. Katie não queria ir para casa, ela queria começar o tratamento imediatamente. Alguém havia entendido, ela não estava louca. Passamos as próximas 12 semanas em tratamento ambulatorial, a afetação de Katie estava melhorando!! Ela obteve tanto sucesso com o tratamento que nós não poderíamos continuar recebendo aconselhamento lá... Fiquei com medo, onde poderíamos ir agora? Implorei por referências e o único que ouvi foi que eles não aceitavam nosso seguro de saúde, não tinham aberturas... Finalmente encontrei alguém que poderia vê-la dentro de dois meses. Foi o melhor que podia acontecer. Ela nos ouviu, nos respeitou, passou algum tempo conosco, (às vezes até uma 1 ½ horas!!). Ela nos perguntou do que precisávamos. Passamos com ela os próximos seis anos. Então ela se mudou para um outro estado. Onde iríamos agora? Katie tinha 16 anos de idade. Ninguém tem aberturas para adolescentes, e tem experiência com o tratamento de OCD? Katie ficou deprimida, irritada, recusava a escola. Nós seguimos uma sequência regular de 3 provedores diferentes, decidindo por um que não tratava de OCD mas que foi capaz de ajudar Katie a sobreviver a adolescência. Enquanto isso, eu estava procurando por um provedor para adultos enquanto ainda me era possível envolver... novamente não encontrá-lo. Eu estava tentando ajudar Katie em sua transição para a idade adulta, dando-lhe os números de telefone e uma anotação do que dizer... Ela detestava falar no telefone, deixar mensagens, ouvir que eles não podiam tratá-la. Era difícil assistir a tudo isso, mas o que eu podia fazer. Logo ela teria 18 anos e eu não poderia mais fazer esses telefonemas. Os pensamentos em sua mente não paravam.

A Terapia de Exposição de Resposta é conhecida por ser o tratamento mais eficaz para o OCD. Uma terapeuta declarou que ela sabia como tratar o OCD. Após 4-5 semanas de terapia, Katie perguntou se ela poderia ajudá-la com o ERP (Planejamento de Recursos Empresariais). A terapeuta (sarcasticamente) disse-lhe que era uma experiência que ela poderia tentar em casa. Katie nunca mais voltou a vê-la! Então, novamente, estamos em busca de outro provedor.

Nós participamos anualmente da conferência anual do IOCDF (Fundação Internacional de TOC), que é um salva-vidas para toda a nossa família conectar-se com os outros. Este verão passado nós vimos um nome no programa, de uma pessoa que reside perto da faculdade de Katie e é treinada em ERP. Nossas tentativas de persegui-la e encontrá-la não tiveram êxito. Katie chamou-a uma semana mais tarde. Katie diz mamãe, é tão fácil de falar com ela! Mas ela não tem aberturas e não aceita o nosso seguro de saúde... Ela me ligou de volta e disse que falou com o centro de aconselhamento na minha escola, e lá encontrou um terapeuta que pode me tratar! Ela vai me ajudar a criar um grupo de apoio na escola, pode me ajudar a conhecer outras pessoas com OCD na minha escola... Estou com enorme vontade de voltar para a escola! Então, aqui estamos novamente, de volta no caminho certo. Estou esperançosa.
SpedEx: An Option for Parents and Schools to Resolve Their Own IEP Dispute

By David Scanlon, Ph.D., SpedEx Administrator

When parents and schools disagree on a child’s IEP another perspective can sometimes help. Massachusetts schools and parents are fortunate to have SpedEx. SpedEx is a free, voluntary, and student-centered dispute resolution option when there is a rejected IEP. SpedEx may be used when the IEP dispute concerns free and appropriate public education (FAPE) or the least restrictive environment (LRE).

In the SpedEx process an experienced and unbiased professional considers the student’s records, proposed program, and input from parents and schools, in addition to observing the child in her/his current placement. The Consultant then issues a recommendations report. The parties (parents and school) use the SpedEx report to resolve their dispute themselves. They are not required to adopt the recommendations in the report and the SpedEx Consultant does not participate in Team planning for a new IEP. Instead, the SpedEx process empowers the parties with a new and unbiased perspective on what will constitute FAPE and LRE for the student. The parties are free to make their own decisions about a new IEP. While certainly a signed IEP is one desired outcome of the process, SpedEx’s mission includes helping the parties to build and maintain positive working relationships.

The SpedEx process is fast. Cases can begin almost as soon as the day schools and parents agree to use the service. The Consultant then typically takes 30 school days to gather all information and issue the recommendations report. The parties have the option of meeting with the Consultant to review the recommendations report together. Then, it is up to the parent and school to meet and see if they can now agree on an IEP for the child. When a new IEP is signed following a SpedEx consultation the parties have the option of inviting the Consultant back to observe the child in her/his new placement and offer a brief report on whether or not the new FAPE and LRE are being provided.

Parents and schools never give up their due process rights by engaging in the SpedEx process. They are not bound by the Consultant’s recommendations and they are free to pursue mediation, a hearing, or any other dispute resolution option available to them. The SpedEx Recommendations report must become part of the student’s permanent school file.

You are eligible to use SpedEx if there is a rejected IEP and the dispute concerns FAPE or LRE. It is also possible to use SpedEx if mediation or a hearing has already been scheduled.

Does SpedEx Help?
SpedEx has been used by parents and schools in 24 of Massachusetts school districts and collaboratives. Both parents and schools have initiated requests to use SpedEx. Of 27 completed cases, 24 have resulted in signed IEPs.

For more information on SpedEx please visit the website www.spedexresolution.com. SpedEx is a free service supported by the Massachusetts Department of Elementary and Secondary Education.

Dicas para encontrar um provedor de saúde mental:
• Pedir à empresa que fornece o seu seguro de saúde, uma lista de cobertura dos provedores
• Procurar uma referência ou recomendação de seu provedor de cuidados de saúde primários.
• Perguntar aos amigos ou familiares de confiança.
• Verificar se o programa de assistência ao funcionário da sua empresa (EAP) ou o centro de saúde de estudante oferece serviços de saúde mental.
• Entrar em contato com uma organização de saúde mental local ou nacional, como a NAMI (Aliança Nacional sobre Doença Mental).
• Buscar na Internet associações de profissionais que têm catálogos de provedores de saúde mental.
• Buscar na Internet em categorias, tais como números de serviços comunitários, conselheiros, psicólogos, psiquiatras ou organizações de serviço social.

Quando escolher um provedor de saúde mental, considere estas questões:
• Educação, treinamento, licenciatura e anos de prática
• Áreas nas quais se especializaram e os serviços específicos que oferecem
• Abordagem de tratamento e filosofia
• Quais são os provedores de seguro de saúde que trabalham com eles
• Horário de atendimento no consultório, taxas e duração das sessões

Não hesite em fazer muitas perguntas. Encontrar a combinação certa é crucial para estabelecer um bom relacionamento e tirar o máximo proveito de seu tratamento.
On July 14, 15, and 16, 2015, I participated in the Youth Leadership Forum (YLF) at Bridgewater State University. The forum was run by Easter Seals, and this year the Federation for Children with Special Needs was a Collaborator. It allowed youth with disabilities to connect and learn about becoming leaders in their own lives.

Over 50 high school students attended the forum as delegates. Older youth, who had graduated high school and had served as delegates twice in the past, served as peer leaders. The youth went to workshops on topics such as transition to adult life, the disability rights movement, and self-advocacy and self-determination. The youth stayed in the dorms and ate meals in the cafeteria. This way, they got a taste of what it was like to live on campus, which was a first-time opportunity for many of them.

I attended the forum as a staff captain. Staff captains were the adult leaders who served as support to the peer leaders and helped ensure that everything ran smoothly. I also presented a workshop called “Achieving Dreams.” I began by telling the youth that I had always dreamed of being an author; and that I achieved my dream in October 2013. That was when my memoir “Distracted Girl” was published. I mentioned it as an example of how my dream came true and to let them know that they can achieve their dreams as well.

I asked the youth for some of their own dreams that they wanted to achieve. Several youth gave answers such as wanting to go to college, to own a business, and to pursue a career in music. I went on to explain the process of self-determination and self-advocacy. I ended my presentation by saying, “You’re not weird, crazy, or abnormal. You’re just outside the box, because the box is too small to contain all your awesomeness.”

The forum also provided the youth opportunities to socialize and connect with each other. There was a dance one night, and an open mic another night. Several of the young people proved to be quite talented at singing, rapping, impersonating cartoon characters, and stand-up comedy. Friendships were formed as the youth made connections with each other and realized they were not alone.

As I reflect on my time at YLF, I feel extremely hopeful for the next generation. I went to YLF thinking that I would inspire the youth. Now that I am back, I realize that they inspired me just as much. I was inspired by their ambition, their drive, their strengths, their eagerness to participate, and their desire to become the leaders of tomorrow.

I also encourage youth to take part in a future YLF, particularly if they have not done so in the past. YLF offers a safe, supportive, and fun community for youth with all disabilities: physical, intellectual, autism, sensory, emotional, ADHD, learning disabilities, and mental illnesses. Some of the youth attend four year colleges upon graduating from high school, some attend two year colleges, and some do not go to college. Unlike other situations where they had been exclusively among other youth with disabilities; YLF is not a stigmatizing environment, but an empowering one. Most of the staff members are also people with disabilities, which gives the youth a sense of optimism for their futures.

To get more information on YLF, go to: www.easterseals.com/ma/our-programs/youth-services/youth-leadership-forum.html

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**Doggy Adventures**

By Scott Lentine

Jumping up and down to greet you; Wagging tails and running out to play
Playing fetch and tug of war; Devouring little pieces and big bones
Taking walks across the neighborhood; Meeting new friends of diverse breeds and sizes
Going for an afternoon swim in the pool or at the beach; Getting sad when guests have to leave
Good at standing still and sitting down; Discovering new places and smells
Drooling at the sight of food; Barking at people when they pass on through
Bringing joy to owners and friends; Having fans of various ages
Sticking heads out of car windows and doors; Anticipating life’s next stages

Scott Lentine, a 26 year old man with high-functioning autism (PDD-NOS/Asperger’s) from Billerica, MA. He graduated from Merrimack College magna cum laude with a Bachelor’s Degree in Religious Studies with a Biology minor. Scott is currently an office intern at the Arc of Massachusetts in Waltham, where he lobbies for key disability resources legislation to improve the lives of people with developmental disabilities.
“Getting From Me to We: How to Help Young Children Fit In and Make Friends” by Shonna Tuck, M.A., SLP, is a helpful book for parents whose children are having trouble making friends. The book acknowledges that many children with special needs, such as ADHD or autism, have trouble making friends. At the same time, it also mentions that not all children who have trouble making friends have special needs, and discusses ways that parents can help their youngsters (with or without special needs) learn to make friends.

In the introduction to the book, Tuck says that there are seven skills that children need to master in order to make friends. She refers to them as “rungs,” as they happen in order as a child matures and develops. A child must master each of the previous rungs, in order, before progressing to the next, just like rungs on a ladder. The seven rungs are joint attention, emotional awareness, imitation, early perspective taking, later perspective taking, narratives, and conflict resolution/executive function.

Each of the first seven chapters of the book is about one of the seven rungs, in order. In these chapters, Tuck briefly describes what each rung is, how children reach the rung, possible reasons why children may not reach it, how a failure to reach the rung can impede a child’s ability to make friends, and tips on how to help your child reach the rung if he or she has failed to reach it.

The last several chapters offer helpful tips and suggestions for parents on how to help their child make friends. For instance, when you invite another child over for a playdate, observe the children playing together so that you can intervene if you see your child behaving in ways that are socially inappropriate and not conducive to making friends.

This book is a helpful resource for anyone whose child is having trouble making friends, whether they have special needs or not.

SNAP Matters for People with Disabilities

Poverty, hunger, and food insecurity disproportionately affect Americans who have communicative, mental, or physical disabilities. For these children, adults, and seniors, the Supplemental Nutrition Assistance Program (SNAP) serves as a vital support.

Access to affordable, nutritious food often is even more critical for Americans with disabilities than for others. Not only are people with disabilities more likely to experience poverty and food insecurity, but they also are more likely to suffer from chronic conditions that can be aggravated by poor nutrition. These conditions can exacerbate existing disabilities or even lead to new disabilities. Good nutrition is a key component of good health for all Americans, but for those who have a disability, eating nutritiously, even during periods of economic difficulty, is critically important.

According to USDA’s Economic Research Service (ERS), food insecurity impacts one-third of households with a working-age adult who is out of the labor force due to disability, and one-quarter of households with a working-age adult with a disability who has remained in the workforce. SNAP Matters for People with Disabilities

1. The population of Americans with disabilities, including factors that lead to increased poverty and food insecurity among them;
2. SNAP’s role among programs targeted to assist people with disabilities;
3. SNAP program rules and policies that make it both accessible and responsive to the needs of Americans with disabilities; and
4. Recommendations for strengthening SNAP’s support for people with disabilities through state policy options, agency practices, and outreach.

FRAC, the leading national nonprofit organization working to improve public policies to eradicate hunger and undernutrition in the United States concluded: Americans with disabilities are particularly vulnerable to poverty and food insecurity. Because of this, they are also more likely than Americans without disabilities to participate in SNAP. SNAP serves as a vital component of the safety net for this population, providing essential benefits for people struggling with food insecurity because benefits offered by other disability related program are not adequate. A number of special rules and policies make the SNAP program both accessible and responsive to the needs of Americans with disabilities. For more information about FRAC go to: www.frac.org.
Save the Date
March 5, 2016

Visions of Community

FEDERATION FOR CHILDREN WITH SPECIAL NEEDS

A Conference for Families of Children with Special Needs and the Professionals Who Serve Them
Seaport World Trade Center | Boston, MA