During the COVID-19 shutdown, the Federation kept families and others connected through a popular series of daily Facebook Live virtual workshops. Topics ranged from how to deal with school closures to activities to do with homebound children. Above left, Patricia Cameron, Director of Family TIES, leads a workshop on making facial masks at home. Top right, Mary-Beth Landy of the Recruitment, Training and Support Center for Special Education Surrogate Parents, and Eileen Sandberg, Coordinator for the Pathways Program, conduct a workshop on “The Brain and Anxiety.” Videos of the workshops are available on the Federation’s Facebook page and YouTube channel.

Responding to Community Needs
During the COVID-19 Shutdown

Federation staff hosts daily virtual workshops to keep parents, others connected

By Nancy Mader
Director of Transition Projects

I remember sitting at my desk in early March thinking that, at most, Federation staff would be working from home for a couple of weeks due to the looming COVID-19 public health crisis.

My colleague Leslie Leslie and I were talking about how we could serve our families while working remotely, as this was going to be a completely new experience for everyone. Most importantly, we knew we had to make our services accessible to as many families as possible.

We started brainstorming about how we could use Facebook Live to reach families and provide important information without taking up too much time, as parents were going to be home, juggling their students’ education and their own work.

I had been using the Livestream platform through Facebook for my “LINKed over Lunch” transition series, so I felt somewhat comfortable with the platform. However, for the majority of the Federation staff, this was a completely new ballgame... and an uncomfortable one at that.

Continued on page 4

Editor’s note:
The third installment of Newsline’s series of articles on prevention of bullying has been rescheduled to the next issue so we can bring our readers up-to-date information about the Federation’s response to the COVID-19 outbreak.
FEDERATION FOR CHILDREN WITH SPECIAL NEEDS

Dear Federation Family,

So much has changed in past months due to the COVID-19 pandemic. For example, here at the Federation, we went from gathering nearly 1,000 guests at our Visions of Community Conference in February – something unthinkable today - to conducting virtual online workshops with attendees surely “socially distancing” on the other end.

This issue of Newsline takes an in-depth look into the Federation’s response to COVID-19. From the first announcement of the stay-at-home order, we became determined to do what we could to continue to provide our much-needed services.

COVID-19 and the stay-at-home guidelines required Federation staff to adapt and become more creative than usual. Families asked for our workshops and other services to stay in place, and we responded. I am so proud how our staff overcame the challenges.

We have held daily, virtual workshops through our Facebook Live and YouTube platforms. One example of our success - our presentation on “School Closure and Special Education Rights,” done in partnership with the Special Needs Advocacy Network (SPAN), has drawn over 2,500 views on YouTube.

We know it has been challenging for families. Some individuals have faced the difficulties of being caregiver plus teacher plus work-from-home employee. That has required patience and fortitude.

Our gratitude goes out to the first-line responders, medical and other essential workers who faced the pandemic head on. Our sympathies are with all the families who lost a loved one during these trying times.

Please visit our Facebook Live and YouTube channels to view our virtual workshops at www.facebook.com/fcsnfb/. If you need individual advice and help, our Information Center remains a valuable resource to answer specific questions and provide guidance. Visit our website, FCSN.org, and complete the Information Center Intake Form or call 800-331-0688. We will get back to you as soon as possible.

Our behalf of the staff, the Board of Directors and myself, I wish all of you good health and better days ahead.

Pam Nourse
Executive Director
Staff member organizes online commencement for her son and others; VIPs respond with video speeches

Earning a high school diploma is so much more than a graduation ceremony. However, for members of the Class of 2020, the COVID-19 pandemic and stay-at-home guidelines has meant their senior year ended without the usual pomp and circumstances.

That is why Federation staff member Kristin LaRose took action to assure her son and other graduates were recognized for their accomplishment by hosting a “virtual” graduation including some distinguished special guests.

“My goal with this virtual ceremony is to show students, their families and friends that even though we cannot celebrate in person at this time we can still join together in new ways to celebrate such a huge achievement,” said Kristin, who is the Workshop and Conference Coordinator/Executive Assistant at the Federation.

Kristin launched a social media campaign asking high school seniors and parents or guardians of graduating seniors from across Massachusetts to email their name, school, and yearbook or senior photo along with a favorite quote. Because the Federation believes in promoting an inclusive community, Kristin invited students living with and without disabilities.

The Federation then shared the commencement announcements in early June on its website and Facebook page in a celebratory tribute to the Class of 2020.

Kristin also contacted VIPs to request that they submit video salutes to the graduates. Massachusetts Senator Elizabeth Warren, Boston Mayor Martin Walsh and Karen Hallion, an illustrator known for her work for Marvel and Lucas Arts, responded.

“As a mom to a graduating high school senior, the idea to host a virtual graduation ceremony came from wanting to show my son and his peers that being proud of earning your high school diploma is so much more than the ceremony we all picture in our heads,” Kristin said.

Federation Holds Virtual Ceremony for Graduating High School Seniors

When is a good day to start something new? Any day that ends in a “Y”!

What To Do Today?

By Mary-Beth Landy
Trainer, Support and Recruitment Specialist

During the shutdown, many of us have struggled to find some sense of balance between responsibilities of work – if you were fortunate to be able to work remotely – with those of home and family. This could be even further complicated by homeschooling children if you have school-aged children. But for some, the challenge of finding activities to keep themselves busy was just as daunting.

I hope, during this period, that you continued to find your desire to make a difference, your understanding of working with students, and your knowledge of putting years of education to good work!

The Recruitment, Training, and Support Center (RTSC) is looking for your help. Currently there are students in the custody of the Department of Children and Families (DCF), who need to have someone to support them in their special education journey by serving as their special education decision-maker. A Special Education Surrogate Parent (SESP) is a volunteer who serves as the parent decision-maker in the special education process for these students whose parents are not available to support and guide them.

What do you need to do? Visit RTSC for information on becoming a special person in the life of a vulnerable child. More information can be found at www.fcsn.org/rtsc/. Become that superhero that you know you are! (Cape not included, but the feeling is great!)

“I am a SESP because when it was described to us during our PTIC training last spring it seemed like the right thing to do. There are kids in need without supports all across the commonwealth. Since becoming a SESP, I am convinced that it was the right thing to do. Especially during this time of educational uncertainty and at times inequity. Having a SESP as part of the team can help in acquiring much-needed access for these children. Having a designated member of the team with the sole responsibility of special education has made a difference in the educational opportunities of these children.”

Bridget Koetsch, M.Ed.,
Training, Support and Outreach Specialist for The Recruitment, Training and Support Center for Special Education Surrogate Parents
I feel so proud of my colleagues for jumping in head first. We have “gone live” every weekday for 14 weeks, (as of June 24) providing meaningful content to parents, families and professionals. We know that our families and professionals crave guidance and information so they can better serve their students with special needs and we have tried to provide the most up-to-date information possible.

If you have not tuned into the Facebook Livestreams you should check them out weekdays at 2 p.m. on our Facebook homepage. If you have tuned in, you have watched real people, most of us parents of children with special needs, put ourselves out there to reach you on a personal level with the hope of teaching you something new or helping to ease a worry that may be keeping you up at night.

If you have missed a Livestream, you can find them on our YouTube channel. https://www.youtube.com/channel/UC49Pm0bpL01WDjzUrCQ173A?view_as=subscriber

Our daily content schedule:
- MassPAC Monday
- Transition Tuesday
- Wellness Wednesday
- Thriving Thursday
- Friday Facts

All of us hope that you have found the Livestreams valuable and that you keep watching. The Federation is here to help you and we look forward to brighter days.

Thank you all so much, and know that we are all in this together.

**Family TIES is ready to help!**

During the pandemic, Family TIES of Massachusetts, a program of the Federation, has seen a change in the reasons families reach out.

Families are searching for resources to meet their basic needs – food, housing, accessing both educational and medical services remotely, and more.

Family TIES also continues to be the resource for families looking for early intervention services for their infants and toddlers.

Regional Coordinators are working remotely and are more than happy to assist in any way they can. Please call us at 800-905-8437. Also, you can find your Regional Coordinator on our website and email, or complete the form on the Federation’s webpage: fcsn.org

We continue to connect families in our Parent-to-Parent program. Find out more here: https://www.massfamilyties.org/parent-to-parent-program

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**Make a Difference in a Student’s Life. Become a Special Education Surrogate Parent.**

- Are you a parent of a child with special needs?
- Are you an education professional or student looking for a one of a kind experience?
- Do you have experience with the IEP process?
- Can you commit 30-40 hours a year to make a difference in the life of one of our state’s neediest children?

**Online Orientation Trainings**

Special Education Surrogate Parents make educational decisions for children in state custody whose parents cannot. To learn more, contact the Recruitment, Training, and Support Center (RTSC) for Special Education Surrogate Parents by calling (617) 399-8342, emailing rtsc@fcsn.org, or check out our website at www.fcsn.org/rtsc

A project of the Federation for Children with Special Needs
Nuestra respuesta a las necesidades de la comunidad durante COVID-19

Miembros del personal auspician sesiones diarias de Livestream para mantener a los padres y a la gente conectados

Por Nancy Mader
Directora de proyectos de transición

Recuerdo sentarme en mi escritorio a principios de marzo pensando que el personal de la Federación, como mucho, tendría que trabajar desde casa por un par de semanas por la inminente crisis de salud pública del COVID 19.

Mi colega Leslie Leslie y yo hablábamos de cómo podíamos servir a nuestras familias trabajando a distancia porque ésta iba a ser una experiencia nueva para todos. Y más importante aun, sabíamos que había que poner nuestros servicios al alcance del mayor número posible de familias.

Comenzamos a pensar en cómo usar Facebook Live para llegar a las familias y ofrecer información importante rápido, porque los padres iban a estar en sus casas haciendo malabares con la educación de sus hijos y el trabajo.

Yo había estado usando Livestream por Facebook para mi serie sobre la transición, “Linked over Lunch”, así que me sentía más o menos cómoda con la plataforma. Pero para la mayoría del personal de la Federación era una experiencia totalmente nueva... y bastante incómoda.

Me siento muy orgulloso de mis colegas por aceptar el desafío. Transmitimos en vivo todos los días por 14 semanas (para el 24 de Junio) presentando contenido útil para los padres, las familias y los profesionales. Sabemos que ellos anhelan orientación e información para servir mejor a sus estudiantes con necesidades especiales y hemos tratado de brindar la información más actualizada posible.

Si no ha sintonizado a un Livestream de Facebook, debería hacerlo de lunes a viernes a las 2 p. m. en nuestra página de Facebook. Y si lo ha hecho, vio a gente real —la mayoría padres de niños con necesidades especiales— que trata de conectarse a personalmente con la esperanza de enseñarle algo nuevo o aliviarse una preocupación que tal vez lo mantenga despierto de noche.

Continúa en a página 8.
Respondendo às necessidades da comunidade durante o COVID-19

Nossa equipe realiza livestreams (transmissões) diárias para manter os pais e outras pessoas conectadas

Por Nancy Mader
Diretora de projetos de transição

Lembro-me de estar sentada no meu escritório no início de março, pensando que a equipe da Federação estaria trabalhando em casa, no máximo, por algumas semanas devido à iminente crise de saúde pública da COVID-19.

Junto com a minha colega Leslie, pensamos sobre como servir nossas famílias durante o trabalho à distância, o que seria uma experiência completamente nova para todos. Mais importante ainda, sabíamos que tínhamos que tornar os nossos serviços acessíveis ao maior número possível de famílias.

Começamos a debater sobre como usar o Facebook Live para contactar as famílias e fornecer informações importantes sem ocupar muito tempo, já que os pais estariam em casa fazendo malabarismos com a educação dos filhos e com o seu próprio trabalho.

Eu já estava usando o livestream do Facebook para a minha série de transição “LINKed over Lunch”, por isso me sentia um tanto confortável com a plataforma. No entanto, para a maioria dos funcionários da Federação, este seria um mundo completamente novo ... e desconfortável.

Estou muito orgulhosa dos meus colegas terem pulado de cabeça nisso. Estamos a 24 de junho, e já faz 14 semanas que estamos fazendo os livestreams de segunda a sexta, proporcionando informações importantes para pais, familiares e profissionais. Sabemos que nossas famílias e profissionais desejam orientação e informações para atender melhor seus alunos com necessidades especiais e estamos tentando oferecer as informações mais atualizadas possíveis.

Se não tiver visto os nossos livestreams do Facebook, confira de segunda a sexta às 14h na nossa página inicial do Facebook. Se você assistiu nossos livestreams, deve ter notado que somos pessoas reais, a maioria de nós pais de crianças com necessidades especiais, que nos disponibilizamos para chegar a você de forma mais pessoal, com a esperança de ensinar-lhe algo novo ou aliviar uma preocupação que pode estar deixando-o acordado à noite.

Se você perdeu um livestream, pode vê-lo em nosso canal do YouTube. https://www.youtube.com/channel/UC49Pm0bpL01WDjzUrCQ173A?view_as=subscriber

Nossa agenda diária de conteúdo:
Segunda-feira: MassPAC (MassPAC Monday)
Terça-feira: Transições (Transition Tuesday)
Quarta-feira: Bem-Estar (Wellness Wednesday)
Quinta-feira: Prosperar (Thriving Thursday)
Sexta-feira: Fatos (Friday Facts)

Esperamos que tenha encontrado os livestreams úteis e que continue assistindo. A Federação está aqui para ajudá-lo e estamos ansiosos por dias melhores.

Muito obrigado a todos vocês, e saibam que estamos todos juntos nisso.

Nota do editor:
A terceira parte da série de artigos da Newsline sobre prevenção de bullying foi remarcada para a próxima edição, para que possamos trazer aos leitores informações atualizadas sobre a resposta da Federação ao surto de COVID-19.

Nuestra respuesta a las necesidades de la comunidad durante COVID 19

Continuación de la página 5.

Si se ha perdido los Livestream, están en nuestro canal de YouTube. https://www.youtube.com/channel/UC49Pm0bpL01WDjzUrCQ173A?view_as=subscriber

Programación diaria:
Lunes: MassPAC
Martes: Transición

Miércoles: Bienestar
Jueves: Prosperidad
Viernes: Hechos

Esperamos que hayan encontrado los Livestream valiosos y que los sigan mirando. La Federación está aquí para ayudarles. Ya llegarán días mejores.

Gracias a todos, sabemos que estamos en esta lucha juntos.
**Federation Names New Members of Board of Directors, Staff Appointments**

The Federation recently announced two new members of the Board of Directors and promotions and new hires among its staff.

*Michel Rbeiz* and *Melanie Jarboe, Esq.*, have joined the Federation’s Board.

Michel is Global Head of Strategy and Corporate Development for State Street Corp. He and his wife are parents of two children, including a 12-year-old son who has an expressive receptive language disorder. For the past 10 years, Michel has volunteered for Massachusetts Institute of Technology, his alma mater, as an Educational Counselor for students seeking admission.

Melanie counsels and assists families with a wide range of special education issues, including eligibility, navigating the team process, participating in mediation, and litigating disputes before the Bureau of Special Education Appeals. She also works with individuals and their families to secure and modify services from state agencies such as the Department of Developmental Services and to navigate disability-related issues in higher education settings. Prior to law school, she taught elementary school in Harlem, New York.

*Cambria Russell* has been named Director of the Statewide Family Engagement Center. She replaces *Marilyn Favreau*, who will focus on her consulting practice.

Cambria has worked at the Federation since 2018 and was a frequent volunteer before that. She is a versatile and accomplished leader with experience as a teacher, program administrator, education professor, educational advocate, teacher educator, and school board member.

Cambria has a Doctor of Philosophy and Master’s degrees in Comparative and International Education from Teachers College, Columbia University, New York City, and a varied background in education including working in schools, non-governmental organizations (NGOs), and academia.

*Bridget Koetsch* has joined the Federation as the Training, Support and Outreach Specialist for The Recruitment, Training and Support Center (RTSC) for Special Education Surrogate Parents.

Bridget has a Master’s degree of Education in Special Education and has taught for over 22 years in public schools. She established Children First: Educational Coaching, which provides tutoring, advocacy/consultant and professional development services throughout Massachusetts.

Bridget has volunteered for the Federation’s Information Center in Turners Falls and has taken on several pro bono cases. She presented RTSC’s February webinar on Understanding Reading Disabilities and Assessment and serves as a Special Education Surrogate Parent.

*Ruth Esther de la Cruz Done* has joined the Federation as its Latino Outreach Coordinator. Ruth is originally from Santo Domingo, Dominican Republic, where she earned a Bachelor’s degree in Criminal Justice in 2014.

She has two daughters. The younger child has a special condition.

She attended the Leadership Series and Advocacy Boot Camp through Massachusetts Families Organizing for Change, the Federation’s first Parent Leadership Training offered in Spanish, and the Federation’s Barbara Popper Institute. She is involved with Fuente de Luz, a support group for parents at Boston Children’s Hospital.

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**在 COVID-19 關閉期間回應社區的需求**

工作人員每天主持 Livestreams，家長和其他人保持聯繫

*Nancy Mader*撰稿

過渡專案主任

我還記得三月初時坐在書桌邊，心想由於 COVID-19 引發的公共衛生危機，Federation 的工作人員頂多會在家裡工作幾個星期。

我的同事 *Leslie Leslie* 和我當時討論如何在遠端辦公時服務我們的家庭，因為這對每個人都是全新的體驗。最重要的是一些我們知道必須盡可能讓最多的家庭獲取我們的服務。

我們開始腦力激盪如何使用 Facebook Live 來聯繫家庭以及提供重要資訊而不占用太多時間，因為家長將必須留在家裡以求在晚上無法成眠的憂慮。

我已經使用 Facebook Livestreams 平台来进行我「午餐 LINKed」過渡系列，因此對於這個平台有點把握。然而，對於 Federation 的大部分工作人員，這是一個全新的體驗，而且感到不知所措。

我對於同事勇於嘗試深以為榮。連續九週來（截至 5月 15 日）我們都在每個工作日「現場直播」，向家長、家庭及專業人員提供有意義的内容。我們知道我們的家庭和專業人員渴求指引和資訊，以便更好地服務他們有特殊需求的學生，而且我們設法提供盡可能最新的資訊。

如果您還沒有進入 Facebook Livestreams，請在每個工作日下午兩點查看我們的 Facebook 網頁。如果您已經進入，您就看到了真實的人（我們大都是子女有特殊需求的家長）在個人層次上敞開心胸與您交流，希望教您一些新知識，或是幫您減輕可能使您在晚上無法成眠的憂慮。

如果您錯過了某次 Livestream，可以在我們的 YouTube 頻道查看。 https://www.youtube.com/channel/UC49Pm0bpL01WDjzUrCQ173A?view_as=subscriber

我們的每日內容時間表如下：

- MassPAC 星期一 (MassPAC Monday)
- 過渡星期二 (Transition Tuesday)
- 安康星期三 (Wellness Wednesday)
- 健壯星期四 (Thriving Thursday)
- 實情星期五 (Friday Facts)

非常謝謝您，我們知道我們將會同舟共濟。
Special Education Parents Advisory Councils Step Up to Help

“When I was a boy and I would see scary things in the news, my mother would say to me, ‘Look for the helpers. You will always find people who are helping.’”
— Fred Rogers

By Leslie Leslie
MassPAC Project Director

Things changed overnight in mid-March as schools abruptly closed and families were left with many questions. However, the Massachusetts Association of Special Education Parent Advisory Council (MassPAC) was not surprised to see its councils step up to the plate. These volunteer, parent-driven advisory groups were ready to go. Thanks to their email lists and Facebook groups, Special Education Parent Advisory Councils (SEPACs) were able to provide timely information and support to families in their communities. The helpers were working.

SEPACs were included in a Department of Early and Secondary Education (DESE) presentation to special education administrators. “Consulting with SEPAC Leadership” was defined as an essential component in developing and improving systems for providing remote services. DESE recognized the strong role that SEPACs play in advising a district and bringing families’ concerns to the district.

Over the past months, MassPAC has seen the other side of this pandemic. Good things are happening in our new virtual world. SEPACs met remotely - helping their communities, addressing parent expectations, assisting in rolling out remote learning, and providing valuable feedback to school administrators. Therefore, MassPAC thought everyone would appreciate some “good news.”

The Melrose SEPAC held virtual information sessions, as well as question and answer sessions (the SEPAC sent out a survey before the meetings) with the Assistant Superintendent.

The Acton-Boxborough SEPAC had an information session and Q&A with the Interim Special Education Director to address issues raised through the SEPAC’s school closure feedback form. Twenty parents and three team chairs attended. The SEPAC got the following thank you from one of the team chairs:

“I wanted to take a moment to thank you for the advocacy, education, and support you provide to our special needs students and families. The presentation you provided at the SEPAC meeting Wednesday evening was truly amazing. I found it incredibly clear, comprehensive, articulate, and informative. That, paired with your manner or presentation, provided all who attended a level of critical, walk-away knowledge that I presume parents craved and appreciated. Thank you also for your kind words and support toward our teachers and special education leadership...THANK YOU!”

The Amesbury SEPAC collaborated weekly with the Director of Students Services and held a parent support group every two weeks. The SEPAC helped create a survey to assess families’ experiences during the COVID-19 closure and improve special education remote learning.

Westwood SEPAC held bi-weekly Zoom support groups for parents to share distance-learning experiences. The district supported the SEPAC by advertising and having a Special Education Department head attend each meeting.

The Tri-Town SEPAC’s meetings had high attendance from both parents and staff due to the virtual nature of the meetings. In addition, the Assistant Superintendent of Student Services set a weekly meeting with the SEPAC board to update them on issues and gather feedback from families.

Westborough SEPAC saw increased interest and involvement from members due to Zoom meetings and support groups. The SEPAC did check-ins on families that they think may be more at risk. They also participated in a read-aloud during “Kindness Week” and donated copies of the book to each elementary school.

Nashoba SEPAC gathered parent feedback and many of those suggestions were incorporated into the framework. For example, there was a noticeable surge in teacher-led video learning.

Somerville SEPAC hosted its first online workshop thanks to Massachusetts Advocates for Children. They also had a productive meeting with the Special Education Director.

The Cambridge SEPAC continued to meet virtually, alternating between business meetings and opportunities for fun. They worked together to communicate the needs of children to the school district. The SEPAC also watched movies together through “Netflix Parties” and relied on one another for emotional support.

The Wayland SEPAC Co-Chairs and Director of Student Services met weekly to communicate and discuss parent concerns and questions, working together in a positive way to find solutions to the current challenges.

The North Andover Parent Advisory Council (NAPAC) started a Community Chat with parents meeting twice a week on Zoom, The NAPAC started a YouTube channel to provide fun workshops for kids!

We are all in this together. So join the SEPAC movement. Get connected to other families in your district, provide feedback and create a better system for all students. If you need help finding your SEPAC, send an email to masspac@fcsn.org.
Public Toxins and the IDEA: In Quest of an Accountable Economy and a Fully-funded IDEA

By Robert K. Crabtree, Esq

Mr. Crabtree was a founding partner of Kotin, Crabtree & Strong, LLP, a general practice firm in Boston with a major concentration in special education and disability law. He now serves the firm as “of counsel”.

People often ask what major changes I have witnessed across the decades of my work advocating for those with intellectual, behavioral, emotional and/or physical disabilities. My answer always includes the large increases we have seen in the numbers of children identified as having autism spectrum disorders, learning disabilities, intellectual disabilities, attentional issues and behavioral and mental health disorders.

Why the increases? Much of the answer lies, I think, in the choices that we make as a people – political, economic and cultural choices that permit materials to be introduced into our environment that are not rigorously tested for their effects on the neurological development (including learning, emotional and social navigation skills) of our children. When a substance is toxic, manufacturers too often refuse to acknowledge the problem, and regulatory agencies, often vastly underfunded, too often fail to take control of the situation.

Imagine a corporation that wishes to reduce the cost of manufacturing a certain product by injecting ingredient X. Let’s say that Ingredient X, which can be made by combining several chemicals in the corporation’s laboratories, is much less expensive than another substance that serves the same function and has been known and used for generations as safe and reliable. However, Ingredient X can only be made with a substance that has been shown to have carcinogenic effects in the neurodevelopment of laboratory animals, though its effects on humans have not – and cannot – be effectively tested without long-term, large-sample experiments. Should the corporation be allowed to introduce its product containing Ingredient X before the product’s potential cost in harm to humans – and especially young children – is clearly understood? Suppose the corporation’s ability to stay in business depends on whether it can use the ingredient and suppose that its going out of business would mean a loss of thousands of jobs in an economically struggling area? Suppose the product in question is a medical device or medicine on which thousands of critically ill patients depend for their lives? These are the sorts of questions that ought to be openly addressed and resolved in a system where all values – including the undeniably precious value of having children protected against exposure to carcinogens.

In “Mind Games,” an eloquent article published in Orion Magazine in 2011 (https://orionmagazine.org/article/mind-games/), biologist Sandra Steingraber, Ph.D., reflected on the search she had made some years previously for a nursery school for her child. She grappled with the question why the outdoor play structures at a school close to her home had been built with pressure-treated lumber – a material that contained arsenic, identified as a likely carcinogen when the play structures were built. She noted that it took seven years after she spotted that problem in the local playground before the EPA released a risk assessment finding that children who played frequently on structures using such materials were at significant risk, over their lifetimes, of contracting cancer. Arsenic, by the time Steingraber wrote, had also been found to impair the growth of the brain and undermines learning.

As she researched several more chemicals and materials that could affect learning and other brain functions, Steingraber happened across a 1936 medical volume in a used bookstore called Holt’s Diseases of Infancy and Childhood. In an entry called “Miscellaneous Diseases, Lead Poisoning” she read that exposure to lead was clearly a cause of irreversible damage to the brain, causing cognitive and behavioral impairments. The entry lamented the lack of laws to prevent lead in toys or furniture and the lack in all but three states of any requirement to label paint.

Some 35 years elapsed after the entry in that medical volume before Massachusetts enacted one of the nation’s first lead poisoning prevention laws, and it took another 40 years for the removal of lead from the manufacture of paint.

Steingraber’s article discusses several more examples of unseen agents that are regularly introduced into our environment without sufficient screening for the possibility of harm to children. The consequence is that children and their parents are “left to serve, as best they could … as their own poison-control centers.” And their ability to act effectively is typically hindered by a lack of information and by defensive misinformation issued by manufacturers, similar to cigarettes manufacturers’ denial of the harm of tobacco.

For our community of stakeholders in the world of disability advocacy I suggest that there are at least three major implications of the challenges we have described:

First, advocates should support a robust, well-funded and independent regulatory system – state and/or federal – that emphasizes the use of reliable scientific methodology to determine the potential effects of any material that may cause neurodevelopmental injury to children before that material is allowed into the marketplace. That system should be insulated against the predations of corporate interests.

Continued on next page
who, when the stakes are high, will sometimes aggressively attack the scientists who produce information that threatens their use of products; the history of treatment given to those who reported studies showing the devastating toxicity of lead in children amply demonstrates this point.

If it is decided that, despite the likelihood of harm to a predictable population of children, a product’s potential benefit to the public outweighs that risk – in jobs, in convenience or whatever that benefit may be said to be – then at least there will be a record of the likely cost to children and their families and a decision can follow regarding how and by whom that cost shall be borne. A truly humanitarian regulatory system should look out a dangerous product when the presumed “benefit” for consumers is not essential for the public’s well-being but is only likely to make the product more “convenient,” “entertaining,” or aesthetically pleasing.

Second, while we wait for Congress and our state legislatures to strengthen our regulatory systems to protect our children, parents will need to pay as close attention as they can to the best available information about substances that may cause harm. While the task may be impossible to fulfill to perfection, adults should at least strive to learn of any scientifically supported findings relevant to children’s health and, to the extent possible, shape their choices to minimize risks of exposure.

Following the science, for the layperson, is complex. Scientific methodology rarely leads to definitive conclusions: it is in the very nature of science to be tentative – to set out probabilities instead of certainties, subject to the next peer-reviewed research report. For many, the built-in ambiguity of science is intolerable as they desperately seek certainty where the safety of their children is at stake, and they may be tempted to hold tightly to an answer that seems definitive, but that is not truly an answer. For all parents, including those who are especially prone to latch on to what seem to be black-and-white conclusions even against growing evidence to the contrary, it is important to cultivate an intelligent skepticism as findings are reported, and to make decisions cautiously and tentatively, based on findings that gather increasing scientific support as new research is conducted over time.

One dramatic illustration of this point in our times is the growing evidence that vaccines given to children to prevent measles, mumps and rubella (MMR) do not cause autism. There was a surge of alarm about vaccines in 1998 when a British doctor claimed to have established a causative connection between MMR vaccines and autism. Those data were later found to have been fraudulently skewed and of no validity, and the paper reporting that false conclusion was removed from the magazine, Lancet, that had originally published it. Unfortunately, however, despite unequivocal scientific dismissal of the fraudulent findings, suspicion of vaccines has persisted in some quarters and reluctance to have children vaccinated has led the World Health Organization to list vaccination hesitancy as one of the ten most robust threats to global health in 2019.

Third, as I noted in an earlier essay (see “Five Issues that Candidates Should Address,” Fall 2019 Newsline), Congress has never fully funded IDEA to the extent – 40% - promised in the original enactment of the law; I urged in that light that political candidates stand for full funding. In light of what we have discussed here, I submit that there is no valid reason to deny that promised level of funding, and more. Though the findings vary from substance to substance, it is certain that a significant portion of the disabilities that undermine children’s learning and developmental growth and that make a child eligible for special education are caused by, or amplified by, harmful products that are in the marketplace because of inadequate screening, both by the makers of the products and by weak regulatory systems. Part of the societal price of that systemic failure is the extra cost involved in providing specialized instruction and related services to the affected children. The costs of harmful products are thus borne by the victimized children twice over: first in the injury they suffered in exposure to the product, and then in the burden they bear when they are not provided with adequate educational and supportive services to help them achieve their full potential. And to those costs must be added the dollars spent by families providing, to the extent they can, private services to supplement what their schools do not or cannot provide, as well as the deep and chronic intangible costs to those families in time and emotional stress as they attempt to support their injured children.

Any choice to foster business growth in our economy without protections that are sufficient to prevent and minimize children’s exposure to harmful substances is indefensible. The harm that a poisonous product will cause is a cost of production, whether or not it is acknowledged openly. In the face of that harm, a humane and child-centered culture should ensure that the cost of the harm is not paid by children and their families, but “internalized” by the maker of the product or sufficiently minimized by law and regulatory action. To the extent that children still suffer harm caused by the product – and no system can perfectly prevent all harm – the educational and supportive services that can help the child maximize his or her potential and enjoy a full and productive life despite the injury should be fully and gladly provided without argument.

This war-horse will return with further reflections on environmental issues and the world of disability advocacy, but for now, I will close by urging readers to track down the Steingraber article (https://orionmagazine.org/article/mind-games/) that I have alluded to in this piece. There is much more in her discussion than I have described, and it is all worthwhile reading for those who need to navigate the shoals of advocacy with good information and an intelligent framework for thinking through their positions and their actions.

Editor’s note: This article has been shortened due to space limitations. Please visit the online version, at https://fcsn.org/newsletter/2020-2/spring-2020-2/public-toxins-and-the-idea-in-quest-of-an-accountable-economy-and-a-fully-funded-idea/.
Remembering Visions of Community Conference

In February, the Federation hosted its 21st annual Visions of Community (VOC) Conference for approximately 1,000 attendees from across Massachusetts, portions of which were livestreamed.

Approximately 85 organizations and agencies took part in the conference, which is the largest gathering of disability organizations in the commonwealth. VOC provides essential information and resources along with inspiration and encouragement to lighten the isolation many parents and youth with disabilities typically feel.

The Federation presented its annual Impact Award to Marylou Sudders, Secretary of the commonwealth’s Executive Office of Health and Human Services, in recognition of her leadership in public policy including the requirement that some health insurers cover mental and behavioral health services.

FCSN Executive Director Pam Nourse describe the addition for mental and behavioral health insurance coverage “a real game changer.”

“Because she has touched all of our lives, it is my pleasure to thank Secretary Sudders for the work she does on behalf of children and youth with special needs,” Nourse said.

The Federation also presented Impact Awards to three parents for their advocacy to support families with children with special needs: Laurie McCarron of Chelmsford, Angela Ferreira of Attleboro, and Monique Johnson of Boston.

Former U.S. Representative Patrick Kennedy delivered the keynote address after the scheduled speaker, his wife Amy L. Kennedy, education director for The Kennedy Forum, could not do so due to illness.

This year, just before the pandemic forced most events to go online, VOC brought together parents and professionals from across the state to offer 24 workshops in English on topics organized by interest strand. Twenty-one workshops were offered in six languages for 216 attendees speaking Chinese, Haitian, Brazilian Portuguese, Spanish, Vietnamese, and Somali.

Five free buses from underserved communities brought 96 parents from western, central, northeast and southeast regions. Childcare stipends were provided for 30 children.

The Federation also provided reduced registration fees to 346 parents and free registration to 28 youth from underserved communities.

Reflections On the Expanded VOC Youth Track

By Nancy Mader
Director of Transition Projects

What a great day! The 2020 Visions of Community Conference was incredible and the two youth tracks at the conference exceeded all expectations. I will fully admit that I was nervous about running two different youth options on such a busy and hectic day, but it was absolutely worth all of the hard work.

I spent most of the day working in the youth forum for self-advocates where we learned about preventing bullying, assistive technology, theater arts, and engaged in expressive arts movement exercises. The smaller group enabled attendees to engage more with each other and spend more face-to-face time with FCSN staff. Spending the day with this group is one of my favorite days of the entire year. They bring so much joy to my life and I love it when they make a connection with each other or a presenter. We all learned a lot and laughed a lot.

The College Navigator youth track was presented by Alexandra Ullrich of Easterseals Massachusetts. I wasn’t able to spend as much time as I would have liked with the College Navigator students but the moments that I did were awesome. These incredible young adults were so engaging, so open to new information, and immediately formed a supportive little team. During the jam-packed day the students learned about college options, understanding their IEPs and accommodations, the hidden curriculum of college, disability disclosure, and much more. Alexandra reported that the students were so engaged and asked so many questions that she wasn’t able to get to all of the topics that she planned. This was such a great addition to the youth programming at VOC and it will be so exciting to keep building on it next year.

Once again, friendships were forged, lessons were learned, and spirits were lifted. We are living in a difficult time but the VOC and youth forums bring some much needed joy and positivity to our lives.
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