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• INFORMATION FOR FAMILIES AND PROFESSIONALS

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Reaching Out: How Parents with Children with Special Needs Can Best Use Social Media

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This article is translated into Spanish on page 2. Ver la versión en español de este artículo en la página 3.

Produced by the State Department of Education Early Children Special Education Program and the Connecticut Birth to Three System in collaboration with the



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Social media is just for kids and socializing, right?

You've heard it before, "I don't care what other people ate for dinner! That's all you read on social media sites! It is a waste of time." Well, sometimes that's true, but there is a lot of serious, important, and timely information being shared on social media like Twitter, Facebook, LinkedIn, and Blogs. If you've ever been to an event and gotten into a deep conversation with another parent who shares your challenges and concerns, you know how important the connection can be.

Take Astrid, for example. She is a self-employed entrepreneur and mother of three children, including a daughter with severe physical and cognitive disabilities, who is overwhelmed with personal and professional responsibilities. Astrid uses social media avidly and adeptly as a professional, but reports that she and her husband Jeff "haven't connected with other parents much" and she said, "[I'm] sure we have missed opportunities and resources we would have known about if we were using social media to get information and recommendations from other parents." Astrid also said "I know many of my friends whose children have similar disabilities have learned a lot from social media connections."

Parents just like you, all over the world, are using social media or networking sites to research and share information about disabilities. What's so special is that social networking

sites offer two-way or multi-way communication, meaning you are sharing information directly with one or more people at the same time. This interpersonal communication is a lot like connecting "over the back fence" or at potluck dinners and cocktail parties. Social networking offers opportunities for people to build personal understanding, experiences, and compassion.

Parents of children with special needs are their first and most important advocate. It's you who can reach out to and get in touch with people who will best care for, nurture, and educate your child. Social media offers opportunities to be the "über-advocate" your child needs. It has never been easier to network with other parents for information and support, for real-life examples, testimonials, referrals and answers to complex problems; research educational programs, medical services, and support organizations. Social media makes those other parents and organizations so close you can almost reach out and touch them, whether they are right next door or thousands of miles away 24 hours a day, 7 days a week. Social media transcends geography and time.

Where to reach?

Twitter offers the ability to get and share information fast, and link to great resources. Learn what hashtags are (a search term preceded by the pound sign #) and use them

to quickly find the information you want to follow. For example: #autism, #ADHD, #sped (special ed), and so many more. Facebook is the most well-known and highly accessible site, and it might be your first choice because you are already set up with an account on the site. LinkedIn “Groups” offer opportunities to engage in deep threaded discussions and develop deeper relationships with others. Blogs, especially those offered by authors and reputable organizations are fabulous for topical and timely information.

Start reaching out!

Let’s assume you know what blogs, LinkedIn, Twitter, and Facebook are. If you don’t, it’s easy to find basic instructions about how to use these resources in videos on YouTube or Vimeo. If you’ve never used social media before, you’ll want to pick one site and master it before you try them all.

Using the most popular social networking sites actually might begin with some organizations that are already familiar to you.

For example, Connecticut’s Easter Seals, March of Dimes, St. Jude, and most of the large non-profit organizations, hospitals, mental health, and special education associations have social media presences on Twitter, Facebook, and YouTube. They may also have blogs that offer topical advice and opportunities to share stories with other families. Turning to familiar organizations’ social media presences is a great first step because you can see what other organizations they “like” or “follow” and use that as a clue to find other places to connect.

Another more direct (and perhaps, obvious) way to find great social networking sites that will provide opportunities to connect with other parents whose children’s diagnosis is like your child’s is to search the social networks using the diagnosis as a search term. For example, searching Facebook for “Aspergers” resulted in hundreds of “Pages”, many geared specifically to parents. Using broader search terms like “parents special needs” on Twitter, Facebook, LinkedIn, or YouTube may be even more helpful.

If you are someone who just prefers face to face networking to bits and bytes, there’s a hybrid social networking site that blends face to face meetings with the convenience of connecting online. Meetup.com offers the ability to connect with people in meetings around the world and includes groups for parents of children with disabilities. You can get started learning more about how to connect with other parents of children with special needs at: <http://spclneedsparents.meetup.com>.

Be sure to spend some time in the Parent Support Groups on the Parent Advocacy Center website, where you will find an incredible number of links to online and offline groups specific to various diagnosis and issues. <http://www.cpacinc.org/helpful-resources/parent-support-groups/finding-a-parent-support-group>. You will also find them on Facebook at: <http://www.facebook.com/cpacinc?ref=nf> And, the Family Support Network is another great resource with a Facebook Page: <http://www.facebook.com/CTFSN>.



We are currently in the process of updating our Birth through Five Newsletter mailing list. If you are a professional or a professional organization and would like to continue receiving this newsletter or would like to update your information please send

an email to: aileen.mckenna@ct.gov. If we don’t hear from you, your name will be removed from our mailing list. You can always access all issues of the newsletter at: <http://birth23.org/families/B5News/B5News.html>

Ampliando sus Recursos: Cómo los Padres con Niños con Necesidades Especiales Pueden Utilizar Mejor los Medios Sociales

Por Fran Simon, M.Ed.
Chief Engagement Officer,
Engagement Strategies, LLC.

Los medios sociales son sólo para niños y para socializar, ¿Correcto?

Usted ha oído esto antes: “¡No me importa lo que los demás comieron para la cena! ¡Eso es todo lo que se lee en las redes sociales! Es una pérdida de tiempo”. Bueno, a veces eso es cierto, pero hay una gran cantidad de información seria, importante y oportuna que

se comparte en las redes sociales como Twitter, Facebook, LinkedIn y Blogs. Si alguna vez ha estado en un evento y ha tenido una conversación seria y profunda con otro padre que comparte sus problemas y preocupaciones, usted sabe que tan importante puede ser la conexión.

Tomemos a Astrid, como ejemplo. Ella es una empresaria autónoma y madre de tres hijos, incluyendo una hija con graves discapacidades físicas y cognitivas, que está agobiada por las responsabilidades personales y profesionales. Astrid utiliza los medios sociales con avidez y con habilidad como profesional, pero reporta que “ella y su esposo Jeff no se han conectado mucho con otros padres”, y dijo: “[Estoy] segura de que hemos perdido oportunidades y recursos de los que nos hubiéramos enterado si hubiéramos usado medios sociales para obtener información y recomendaciones de otros padres”. Astrid también dijo: “Yo sé que muchos de mis amigos que tienen hijos con discapacidades similares han aprendido mucho de conexiones de medios sociales”.

Por todo el mundo, padres como usted, están utilizando las redes sociales o sitios de redes para la investigación y compartir información acerca de discapacidades. Lo que es especial de los sitios de las redes sociales es que ofrecen dos o más vías de comunicación multidireccional, lo que significa que están compartiendo información directamente con una o más personas al mismo tiempo. Esta comunicación interpersonal es muy similar a la conexión que “tiene con su vecino cuando están platicando en el patio” o en cenas o fiestas informales. Las redes sociales ofrecen oportunidades para que la gente comparta experiencias, compasión y entendimiento personal.

Los padres de niños con necesidades especiales son sus primeros y más importante defensores. Es usted quien puede llegar y ponerse en contacto con las mejores personas

que cuidan, nutren y educan a sus hijos. Los medios de comunicación social ofrecen oportunidades para ser los “súper-defensores” que su hijo necesita. Nunca ha sido más fácil conectarse con otros padres para obtener información y apoyo, para ejemplos de la vida real, testimonios, referencias y respuestas a problemas complejos, programas educativos o de investigación, servicios médicos, y organizaciones de apoyo. Los medios sociales hacen que los otros padres y organizaciones estén tan cerca que casi se les puede tocar con la mano, ya sea que están justo al lado o a miles de kilómetros de distancia las 24 horas del día, 7 días a la semana. Los medios sociales trascienden la geografía y el tiempo.

¿Dónde comenzará a seguir?

Twitter ofrece la posibilidad de obtener y compartir información rápidamente, y un enlace a grandes recursos. Aprenda lo que son “hashtags” o etiquetas (un término de búsqueda precedidos por el signo de número #) y utilizarlos para encontrar rápidamente información que desea obtener. Por ejemplo: #autismo, #TDAH #, #sped (Educación Especial), y muchos más. Facebook es el sitio más conocido y de muy fácil acceso, y que podría ser su primera opción porque ya está configurado con una cuenta en el sitio. LinkedIn “Grupos” son muy variados y amplios. Ofrecen oportunidades de participar en amplias discusiones enlazadas y establecer conversaciones más profundas con los demás. Blogs, especialmente los ofrecidos por autores y organizaciones de buena reputación son fabulosos para información actual y oportuna.

¡Comience a Enlazarse!

Vamos a suponer que usted sabe lo que son los blogs, LinkedIn, Twitter y Facebook. Si no lo sabe, es fácil encontrar las instrucciones básicas sobre cómo utilizar estos recursos en videos de YouTube o Vimeo. Si usted nunca ha utilizado las redes sociales antes, usted querrá escoger un sitio y conocerlo bien antes de probar otros sitios.

Para usar los sitios de redes sociales más populares en realidad podría comenzar con algunas organizaciones que usted conoce. Por ejemplo “Easter Seals” de Connecticut, “March of Dimes”, “Autism Speaks”, “St. Jude”, y la mayoría de las grandes organizaciones no lucrativas, hospitales, organizaciones de salud mental y educación especial tienen presencia en las redes sociales de Twitter, Facebook y YouTube. También pueden tener blogs que ofrecen asesoramiento de temas actuales y oportunidades de compartir experiencias con otras familias.

Visitar sitios de las redes sociales de organizaciones sociales con las cuales usted está familiarizado es un gran primer paso, ya que usted puede ver cuales organizaciones prefieren o siguen y usar eso como una clave para encontrar otros lugares para conectarse.

Otra forma más directa (y tal vez, obvia) de encontrar grandes sitios de redes sociales que ofrecen oportunidades para conectarse con otros padres de niños cuyos diagnósticos es como el de su hijo, es buscar en las redes sociales utilizando el diagnóstico como un término de búsqueda. Por ejemplo, la búsqueda de Facebook para

“Asperger” dio como resultado cientos de “Páginas”; muchas dirigidas específicamente a los padres. Con términos más amplios de búsqueda como “necesidades especiales de padres” en Twitter, Facebook, LinkedIn, o YouTube puede ser aún más útil.

Si usted es de los que prefiere conectarse con otras personas personalmente en vez de fotografías o mensajes de texto, hay un sitio de redes sociales híbrido que combina reuniones en persona con la comodidad de

la conexión en línea. Meetup.com ofrece la capacidad de conectarlo con la gente en las reuniones a nivel global e incluye grupos de padres de niños con discapacidades. Usted puede comenzar a aprender más sobre cómo conectarse con otros padres de niños con necesidades especiales en: <http://spclneedsparents.meetup.com>.

Asegúrese de explorar los Grupos de Apoyo para Padres en el sitio web “Parent Advocacy Center”, donde se encuentra un

número increíble de enlaces para grupos en línea y fuera de línea específicos para el diagnóstico y diversos temas. <http://www.cpacinc.org/helpful-resources/parent-support-groups/finding-a-parent-support-group>.

Usted también los encontrará en Facebook en: <https://www.facebook.com/cpacinc?ref=nf+Y>, la Red de Apoyo Familiar es otro gran recurso con una página de Facebook: <http://www.facebook.com/CTFSN>



Estamos actualizando la lista de correo del boletín Birth through Five Newsletter. Si usted es un profesional o es una organización profesional y le gustaría continuar recibiendo este boletín o le gustaría actualizar su información, por favor envíe un correo electrónico a: aileen.mckenna@ct.gov. Si no recibimos información de usted, su nombre será borrado de nuestra lista de correo. En todo caso, puede ver las publicaciones en: <http://birth23.org/families/B5News/B5News.html>

ICC Update

Social Media: What I know and what I don't know

By Dr. Mark Greenstein, ICC Chair/Developmental Pediatrician

I did not write “we” because, if anything is clear, it is that people differ on what they think they know and what they don't know. But still, there is value in sharing our thoughts and listening to see if we can learn more, and clarify our beliefs. I know that social media outlets are more and more with us; Facebook, Twitter and so many more are all around. I know that I should think before posting things, and that what I post is probably “forever”. What I don't know are the consequences for many of us of such a public presence. I do know that going public has helped people with differences and disabilities enter the world and has helped

families feel not so alone. I know that having parents on the Birth to Three Council (the SICC, the State Interagency Coordinating Council) sharing their thoughts with us is all to the good, though I don't know what they will say, what they will share. This is the benefit of wide participation, of sharing thoughts; we may not agree, but it seems that it can help all of us; professionals who need to learn what families think, what their children need; families learn from each other, and from those who wish to work with them, and all of us from the children we serve. Some of us are back from the large annual Leadership Conference in Washington, DC sponsored by the Office of Special Education Programs (OSEP). In Connecticut, we try to always have parent participation and this, again, has enriched our experience. Meeting with and hearing from people from all over (from Guam to Alaska to North Dakota to

Louisiana), parents and professionals shared their thoughts. We learned how much we share, and how others have dealt with the common issues of tightening budgets, and ongoing needs and creative solutions.

I know, that I don't know, what the future holds, but that we are better working with each other as we move forward. We are better when we share! Sharing is what we need. We have many new members on the SICC, but we can always use more voices, more thoughts to help all of us learn and grow. So, consider becoming part of OUR “social network”, either by sharing your thoughts or joining us on the council.

Want to learn more? Please contact me, Mark A. Greenstein, the Chair at 860-714-5319 or one of our support staff (Eileen McMurrer) at 860-418-6134. I look forward to hearing from you.



Parents' Perspective

Social Media: Making the difference and giving hope to children with special needs

By Laureen Morley - Parent

My son was born at the end of 2005 and diagnosed with Down syndrome within a week of his birth. Once we got past the NICU phase, we started researching Down syndrome on line; everything from the medical community was negative, lists of things my son would never do. It broke our hearts. But then we came across a web site that opened our eyes to a whole new world of Down syndrome, it was a site full of encouraging letters written by

parents who were on various paths in their journey with Down syndrome.

Probably the most defining thing about that particular site was the pictures, seeing children, teens, and adults with Down syndrome; all doing things that any other person their age would be doing. It made all the difference in the world; it gave us hope for our son's future. Through that site I found several blogs, and eventually found Facebook, where I now have a tremendous network of friends and advisors.



One thing I learned was, that I was not alone, sentenced to a life of nevers. I cannot imagine what parents did 30 years ago when they were handed their child with a pamphlet and told "Good luck!" The Internet, especially networking groups like Facebook, Twitter, or MySpace, and technology have brought together some of my now closest friends, many of whom I may never meet but will always be a part of my life.



Providers' Perspective

Let's Connect!

Nicole Feeney, M. Ed.
Assistive Technology Specialist
and Special Education Teacher
New England Assistive Technology
Center at Oakhill Hartford, CT

There is no denying that our children are being raised in a digital world. As parents of young children with special needs, we may find it very difficult to keep up on the ever-growing technologies and social media that are available to us on our cell phones, laptops and tablets. Most of our time is spent getting ready for work, getting our kids out the door to daycare, making dinner, giving baths, etc. While this is our day-to-day routine, it might be important to spend some time integrating

social media into your life. Don't panic...this does not mean you must spend every waking moment on your cellphone or sit at your computer until your eyes hurt; it is completely at your discretion.

Social Media can truly strengthen connections with friends and family, encourage participation in community/political service, create collaboration on projects, or enhance research opportunities. Parents of kids with special needs are no different. Social Media can provide a powerful community of people who are looking to find common ground. Facebook, Twitter, Blogger, and Pinterest are just examples of social networking websites that will allow you to connect with

other parents or professionals who may offer support, share ideas of reputable healthcare providers, or learn about local resources and/or recreational activities that may provide respite. My favorite part of social media is joining a network of people who can provide me with information on discounts of Assistive Technology tools, software or equipment, share ways to handle children's special needs, how to download iPad/app giveaways, or educate me about what other creative parents or teachers are doing to help their children. Social Media websites provide a wealth of information that you can gather in a short amount of time without having to navigate the entire Internet. If it saves me time, I'm all for it!



Birth to Three Update

By Linda Goodman,
Director, Birth to Three System

The Birth to Three System is always looking to improve. One of the areas we've chosen is to serve more children under the age of 12 months. In comparing ourselves to the other states, we've ranked 19th and although that's clearly a little better than average, we think we can do better. We've come up with quite a few strategies and we'll be measuring our results to see which ones work. So far, those have included:

- Talking to other states who are ranked higher than Connecticut to see what they're doing differently
- Convening roundtables of primary health care providers to look at what they think the barriers are to earlier identification and enrollment
- Having a Birth to Three representative stationed at the state's largest neonatal intensive care units to talk to parents about the benefits of enrolling in Birth to Three
- Mining data on children referred to Birth to Three by someone other than their parent but who are never evaluated because their parents decline the evaluation or were unable to contact those parents.
- Identifying more sensitive measures of progress because our current measure is a point-in-time look at the

number of children under the age of 12 months who have IFSPs on December 1 of each year divided by a Census Bureau estimate of the number of children under age one in Connecticut.

We're being advised by a committee of the Interagency Coordinating Council, chaired by Corinne Griffin, who had personal experience with having a child leave the NICU and enroll in Birth to Three and by Rita Esposito who is Director of REACHOUT, a Birth to Three program in the greater New Haven area. We appreciate their feedback and recommendations. As we progress, information on this "Under One" initiative will be posted on our website (<http://www.birth23.org/>)

Early Childhood Special Education Update

Maria Synodi, Coordinator ECSE

Back in the ol' days, welcome back to school was conveyed with posters and drawings plastered in school hallways and on classroom bulletin boards. Electronic forms of communication have now replaced how schools convey information. Social media is the new norm being used to share information, ideas, messages, and other helpful content such as videos. Social media can be a great tool for schools in communicating with parents as well as within the school and town community.

There are different types of social media including collaborative projects (for example, Wikipedia), blogs and microblogs (for example, Twitter), content communities (for example, YouTube), social networking sites (for example,

Facebook). Technologies include: blogs, picture-sharing, vlogs, wall-postings, email, instant messaging, to name a few. There are social media networks like Facebook, Twitter, Pinterest and MySpace.

Social media can be used to:

- aid in instruction and in the teaching and learning environment
- post examples of a child's or group of children's work
- provide information on school activities and announce opportunities for parent involvement and participation
- outline school rules and procedures
- network with other teachers, including an on-line learning community of practice
- network with parents and the community

Social media is booming and has its benefits. But there are also cautions. What's here today isn't gone tomorrow. There should be written standards of practice for the school community. Negative information, postings or inappropriate handling of information could lead to a negative situation. And there is always the importance of needing to protect confidential information.

With that said, there are some great opportunities. The National Dissemination Center for Children with Disabilities (NICHCY) recently posted a blog on the use and benefits of Pinterest which utilizes visual interest to highlight content information. Check out NICHCY and their blog at: <http://nichcy.org/whats-the-big-deal-about-pinterest>



BIRTH through 5 News

Birth through 5 News is published periodically by the University of Connecticut Cooperative Extension System in collaboration with the Connecticut Birth to Three System, the Connecticut State Department of Education and the Newsletter Advisory Board. We welcome readers' comments and contributions related to the special needs of infants, toddlers, preschoolers and their families. Please mail correspondence to the editor at 67 Stony Hill Road, Bethel, CT 06801.

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Resources

Websites:

Social Networks for Parents

Support for Special Needs, a social networking site for families raising kids with special needs: <http://supportforspecialneeds.com>, **Twitter:** @supportSN, **Facebook:** <http://www.facebook.com/supportforspecialneeds>

Connecticut's Easter Seals, provides exceptional services, education, outreach and advocacy so kids and adults living with disabilities can live, learn, work and play in their community. http://ct.easterseals.com/site/PageServer?pagename=CTDR_homepage, **Twitter:** @Easter_Seals, **Facebook:** <http://www.facebook.com/easterseals>

Parent Education Network, provides information and services to parents of children with disabilities to help them reach their full potential (RT and/or following does not imply endorsement). <http://parentednet.org>, **Twitter:** @PENYork, **Facebook:** <http://www.facebook.com/ParentEducationNetworkYork>

Especial Match.com is a social network helping families of special needs children find support and information. <http://www.especialmatch.com/>, **Twitter:** @especialmatch, **Facebook:** <http://www.facebook.com/eSpecialMatch>

Parenting Special Needs Magazine (PSN), is a FREE, online publication serving the special needs community by providing resources, information

and inspiration: <http://www.parentingspecialneeds.org>, **Twitter:** @PSNMagazine, **Facebook:** <http://www.facebook.com/parenting.specialneeds.magazine>

Special Needs Advisor helps you understand how to make your special education rights work for you! This blog is run by Dennise Goldberg: <http://www.specialeducationadvisor.com>, **Twitter:** @SpecialEdAdvice. Essential Special Education Twitter Feeds to Follow: <http://www.specialeducationadvisor.com/50-essential-special-education-twitter-feeds-to-follow/>

Social Networking Websites for Kids (age 7 and up)

Disney's Club Penguin
<http://www.clubpenguin.com>

What's What
<https://www.whatswhat.me>

Apps for Parents and Kids to Interact with Together

Toca Boca apps for the Apple iPhones/iPods/iPads
<http://tocaboca.com>

Grasshopper apps for the Apple iPhones/iPods/iPads
<http://www.grasshopperapps.com>

My Story – Book Maker for Kids This app for the iPad, will allow children and families to create personalized books with tools for drawing, photography, voice recording, writing, and sharing!



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Este boletín está disponible en inglés y español. Visite el sitio del Sistema para Infantes de Tres Años en www.birth23.org y pulse en Publicaciones o el sitio del Departamento de Educación en www.sde.ct.gov Luego pulse en Early Education (Educación Temprana en español).

CHILDREN'S ARTWORK WANTED!

You are invited to send pictures or other artwork that your child has done. We would like to start an "art collection" for possible inclusion in future Birth through 5 News newsletters. Please mark the artwork with the artist's first name and age then mail to:

Dr. German Cutz, Editor, UCONN CES
67 Stony Hill Rd.
Bethel, CT 06801-3056

Or send by e-mail to: german.cutz@uconn.edu

No artwork will be returned.
We look forward to receiving your child's works of art!

