



Family Support Services News



ONE hour play at the
Arnot Mall location.



\$15 card to play at Bonus Round
Arnot Mall location.



\$10 voucher for Sweet Frog
Horseheads Location.



Receive a dinner voucher for
Red Robin, Horseheads Location.

Please choose one option for this month's Recreation activity. Although we have a larger number of options this month, for some of the vouchers we only have limited amounts. We are asking you that this month you request first and second choices in case we are out of vouchers for your selection. Voucher availability is first come first serve.

To request your voucher, please [CLICK HERE](#); call Ariana 607-734-6174*284 and/or email: alevi@cseop.org.

Playgroups

This month all 4 playgroups will be attending Knoebels Amusement Park. This trip is funded with the monies raised through the Spaghetti Dinner and the Community Foundation Grant.

August event is as follows:

What: Knoebels Day Trip (charter bus provided)

When: Saturday, August 10th- please arrive at EOP by 8:00AM.

We will be leaving in the charter bus at 8:30AM.

EOP will provide \$40 worth of tickets per family: \$20 ride only tickets and \$20 ride/water games/food tickets. Tickets will be provided the day of the event at the park, location TBD.

Second Quarter Satisfaction Survey

We would like to thank all the families that participated in our quarterly survey. As always, we use this information to make our program better, meaning that we are working for you to give your family member a better experience.

thank you

Another Voice: Fetal alcohol spectrum disorders demand more

I find myself in a small, nondescript meeting room in my county's Department of Human Services. Again. The faces are familiar — the judge, the developmental service agency representatives and the disability rights lawyer who has invited me again to testify. The only person new to this room is the caregiver — a grandmother of a 10-year-old boy whom we'll call "Marcus."

As a researcher and psychologist I have been through this before. Ahead lies an uphill battle to get Marcus qualified for the developmental disabilities services he desperately needs. I am discouraged and frustrated. If Marcus had autism or Down syndrome, things would be different. But he has a fetal alcohol spectrum disorder. In New York State, a [child with FASD is not eligible for disability services](#). While everyone here agrees Marcus has a "substantial handicap," the diagnosis still doesn't count.

[FASD affects 2 to 5% of children in the U.S.](#), more than autism or other similar disabilities. Yet, FASD remains largely unknown. Many teachers, doctors or even mental health professionals don't talk about it, leaving families unsure where to turn.

The stigma surrounding FASD is considerable, partly because alcohol and other substance use are still considered in our society to be moral flaws. No woman uses alcohol during pregnancy to hurt her baby. Often, she is unaware she is pregnant, or struggles with a (treatable) substance use disorder. The stigma, however, keeps people from talking about the problem and finding solutions.

Research shows that most providers receive little if any training in FASD. [An estimated 80% of children with FASD go undiagnosed](#). Prenatal alcohol exposure changes how the brain develops, often making it harder for people with FASD to pay attention, learn and remember new things, solve problems and control their emotions.

Without the right diagnosis and services, it is assumed that individuals with FASD aren't trying hard enough, or are being difficult on purpose, causing frustration for everyone and potentially worse issues such as trouble with the law or mental health problems.

But it doesn't have to be this way.

Three factors are important in preventing devastating outcomes: early diagnosis, access to developmental disabilities services and a nurturing home and family.

Yet we can't do any of these things if we aren't even talking about the problem. Teachers and providers need FASD training, which is very feasible if made a priority.

To solve this, creativity is a must. Services are already stretched thin. Researchers in the Collaborative Initiative on FASD (www.cifasd.org) are currently using technology to bridge geographical barriers for providers and families by developing new tools and interventions. These include electronic screening and diagnostic tools for providers and a mobile app for caregivers of children with FASD. But it's a small group of researchers worldwide trying to tackle a big problem.

The [Centers for Disease Control and Prevention](#) and NOFAS's [Stamp Out Stigma campaign](#) are good resources to start with. We need the public to start talking about FASD.

Christie Petrenko is an assistant professor and associate director of clinical training at the Mt. Hope Family Center at the University of Rochester.

https://buffalonews.com/2019/07/01/another-voice-fetal-alcohol-spectrum-disorders-demand-more-attention/?fbclid=IwARiweSTvc7yKQ-rIDo1y84MRwG2RZjw7kX4Icu_xKEQNM5fqrTRyU7ea5R0

High school students offer a silent ovation while a classmate with autism receives his diploma

(CNN)At his high school graduation, Jack Higgins approached the stage to receive his diploma with his fingers in his ears to block what he thought would be applause and cheers.

Instead, he was met by silence.

Higgins is a familiar face in the cafeteria, library, hallways and classrooms of Carmel High School, and he's well-known there. He has a severe form of autism and is sensitive to noise. After eight years in the school's program for students with cognitive, learning or behavior challenges, he was ready to graduate on June 20.

His parents, Barbara and Pat, wanted him to participate in the ceremony, and they approached his teacher Erin Appelle about it. However, there were concerns that he would be overwhelmed sitting for hours in a large auditorium surrounded by hundreds of people.

"In our school we have a banner as you enter all of our school buildings # WhatsBestforKids," Lou Riolo, principal of Carmel High in Putnam County, New York, wrote in an email. "It sounds corny but makes sense. But in this case what was best for Jack?"

Riolo had an idea: have everyone sit in silence as Higgins walked across the stage.

Knowing that this was an important moment for Higgins, Riolo approached members of his staff, and they immediately bought in. Higgins' parents were thrilled with the idea as well. "It was important to pull this

off," Riolo said. "First off for Jack, second for his family who could experience the same event as every other parent/family whose child reaches this milestone was of great importance. Lastly to give the opportunity to everyone in that arena a chance to assist in making one young man's and his families graduation dreams a reality."

Students can often be unpredictable and rebellious, and getting everyone to agree would not be easy. But when people asked Riolo whether the staff thought they could pull it off, his answer was always yes. "You often have to give people the opportunity to rise to an occasion," he said. "I truly believe people have a kind, compassionate soul and they want to help and this was one of those occasions."

Before calling Higgins to the graduation stage, Riolo asked everyone in attendance at Western Connecticut State University's O'Neill Center to keep quiet and offer only a soft golf clap.

Flanked by his two brothers and school aide Rob Ancona, Higgins approached the stage with his fingers in his ears, but the loud

noises he expected after weeks of practice runs with his teacher were nowhere to be heard.

He received a silent standing ovation.

"The students were amazing," Riolo said. "They are a class act and superseded expectations. For example them rising to their feet after Jack received his diploma was them. It was not preplanned and no one told them to act like that. They felt compelled to show their support in that way. They made that amazing compassionate gesture on their own."

"I have been lucky and blessed to see some really remarkable things in my 31 year career but this so far has to be the most incredible. But as much as the students rose to the occasion so did Jack. Since Jack is very limited verbally, how overwhelming was it for him with a large crowd and expectation that it would be loud? It was so brave of him to take that walk which must have seemed like forever and he did it with grace, class and strength."

https://www.cnn.com/2019/07/09/us/jack-higgins-autism-silent-graduation-trnd/index.html?fbclid=IwAR0Iu1cM6QrZ8tUBaL5zkbNLlj442e_ltg3HfaV4h1Cg9sR-puZHXIXdaM



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Family Support Services

Community Events August 2019

- 4th - **Splash Zone Free Food and Family Fun 2019:** 2 PM - 6 PM | Corner of Davis and Warnick in ELMIRA | **FREE**
- 8th - **Movies in Riverfront Park: How to Train Your Dragon 3:** 8 PM - 10 PM | Riverfront Centennial Park, Corning, New York 14830 | **FREE**
- 9th - **Mary Poppins - Original - at Movies in the Park:** 9 PM - 11:30 PM | Stewart Park Rd, Ithaca, NY 14850, United States | **FREE**
- 15th - **Woofstock at Wisner,** family and pet friendly event: 4PM - 9PM | [Wisner Park](#): N Main St, Elmira, New York 14901 | **FREE**
- 28th - **Steele - Telling Stories With Music:** 6:30 PM - 7:30 PM | 101 E Church St, Elmira, New York 14901 | **FREE**

Big moment: Akron senior with Down syndrome named prom queen



AKRON, N.Y. — Madisyn Ross isn't your typical teenager.

This fun loving Akron High School student has a spirit that shines as bright as the stars, no matter what she's been through.

Madisyn has Down syndrome, and she was born with a rare heart condition. She went through three open heart surgeries all before her second birthday.

Fast forward to today.

This 19-year-old is the captain of her school's cheerleading team, a member of the student council, drama club, and so much more.

And of course, when prom season came around, Madisyn was ready to have some fun.

Little did she know that days before the prom, someone nominated her for prom queen.

When the big day arrived, Madisyn picked out a beautiful lilac dress and got her hair and makeup done like the stars.

She took pictures with her friends before the limo ride to the venue.

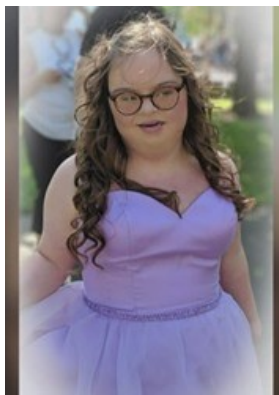
And when the moment

came to announce prom queen, guess who won?

"They announced my name to be prom queen and my face turned red," she said.

And no, the story doesn't end there.

The guy named prom king actually happened to be Madisyn's crush, Nick, who surprised her at the homecoming game with a bouquet of flowers with a note that read: "Thank you for being you and making our school brighter."



https://www.wgrz.com/article/life/big-moment-akron-senior-with-down-syndrome-named-prom-queen/71-658671ee-f1ae-4234-b4e9-878ea092e2a5?fbclid=IwAR1r7c2thk94b6EX7CqdZt0CzLYwHqG004IJM4lbaRI13Q_9hARqJDWZXsY