

OUTLOOK

Supporting People with Disabilities



MEET ELLIE

It usually starts early. Our parents and teachers tell us “Your destiny is in your hands!” “You can shape your life in any way you choose!” “You are the one steering your ship!” And then we have kids...

Alexis Abramo was a mom-to-be 6 years ago, and she said, “I was planning to have the world’s first practically perfect person.” When her daughter, Ellie, was born with some obvious challenges, Alexis said “That all went out the window with her birth trauma and NICU stay. It was so overwhelming to think that she might not be ‘normal.’”

According to Alexis, “Ellie was born with a cleft palate, she inhaled some stuff, and she couldn’t breathe.” Revisiting that traumatic experience made Alexis pause to take a deep breath, and she continued. “We were at Schuyler Hospital – when they still had a birthing center – and fortunately, the nurse had 10 years of experience in pediatric Respiratory Therapy. Who knows what might have happened if we had someone with less experience?”

Ellie was, in Alexis’s words, “Swooped off to the N.I.C.U. at the Arnot Ogden medical Center,” where she stayed for a few days and was sent home after the immediate crisis had been brought under control. Very soon thereafter, the family was engaged by the Early Intervention specialists from Franziska Racker Centers, and the wheels were put in motion to create a game plan.

“I was a little leery at first,” Alexis recalled. “I thought it (the arrival of the E.I. team) meant there was something really disastrous going on. A cleft palate can be associated with numerous syndromes, and we didn’t know if there was something larger going on.” She called Ellie “a really squishy, floppy baby...her muscle tone was very compromised.”

When I met with Alexis to hear and share Ellie’s story, it didn’t take long to get comfortable. Ellie sized me up and decided that I was a nice guy, worthy of being gifted a piece of her artwork, and she put crayon to paper and got to work on a drawing of her mom holding her when she was a baby. By embarking on that artistic mission, she countered the bounce house-like energy of her little sister, Louisa, who told ten stories in the first 5 minutes.

Back to the beginning of the Abramo family’s connection to Franziska Racker Centers... within a few days after Ellie came home, speech pathologist, Sheryl Edwards and physical therapist, Cheryl Moore evaluated her and said, “This is outside the range of normal.” Alexis remembered that interaction very clearly, and she stated, “When you engage their services, they walk you through the whole process very thoroughly. There was some concern that Ellie might not be able to speak, so they initiated some speech therapy very early on.” Alexis said, “I thought ‘She’s just a baby,’ but at first it turned out to be feeding therapy, and they brought many different bottles, spoons, cups, and devices to stimulate her mouth and lips.” This strategy provided an emotional lift for Alexis, as she had so looked forward to nursing her first-born, and she felt a real sense of loss when she was unable to do so. “I’m a rational person,” Alexis shared, “but I grieved for what I thought was ‘the



Ellie (right) with her mother Alexis and sister Louisa.

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A NOTE FROM DAN

Our Vision: A world where all people know they belong! A simple statement that is the key to having a fulfilling life. For parents who have children on the Autism Spectrum, the social skills that they need to develop so that their child can feel belonging may seem unreachable. Our role as a parent is to be the person that we want our children to be, good role modeling. The following is a story from Laura Riker, Racker staff member and mother of Marco. She shares how Marco picked-up on her social skill role modeling and put it into action, much to her surprise.

Letting Our Children Be Our Tour Guides by Laura Riker

On a sunny April day, my husband and I met with the chairperson for the Committee for Special Education (CSE), the autism specialist, the school's principal, speech therapist, school psychologist, occupational therapist, OT assistant, special education teacher, physical therapist, and our youngest son Marco's teacher. Add myself and my husband to that mix and you've got twelve people at one table.

It's really no wonder at all that parents and caregivers are completely overwhelmed by special education and all that it entails.

Individualized Education Plan (IEP) meetings are important and can be highly productive, but daunting at the same time. You may hear about ways in which your child is delayed, as we did. You will hear about progress, and the importance of this growth. And you might hear your child's therapists say something like, "I'd really like to get him into a social skills group and help him develop lasting friendships".

This could have been a chance for me to say "Yes! I'd love for you to do that for him!" Instead, I said that unless they could find a person with a strong interest in nature documentaries, he really wouldn't be interested in having social interactions.

I couldn't have been more wrong. I would be corrected a week or two later, at the playground with the kids. There were two children there who may have been around the same ages as our boys.

Within seconds, Marco walked up to the younger child: "HI! I'M MARCO!" he shouted. He asked the name of the younger child, and then the boy's older sister spent time teaching Marco how to say her brother's name. Not long after, Marco sat down at the picnic table with the girl and asked her questions about herself. He found out that she was a seven year old girl who had just moved into our neighborhood with her family. He started the conversation with her, and the two of them chatted as though they were a couple of middle-aged coworkers who happened to run into each other in the supermarket.



HE started the conversation. I held my breath and watched.

Wow. It wasn't at all that he wasn't interested in socializing, rather that he needed to be given the freedom to do it in his own time.

I was reminded immediately of something that I talk about with families who are struggling. These kids of ours are incredible tour guides. We work hard to prepare them for the next stages, and we provide them with a whole rainbow of services, and at the end of the day they have the ability to completely shock us with what they can DO with all that information.

Simply put, I was wrong. I made an assumption that a lot of people do about autistic people- that they're not interested in friendships.

The thing that I'm taking away from all of this, and I hope you will too, is that we must see the potential. We must presume competence. And lastly, we must believe in ourselves and our loved ones. They have beautiful things to teach us, if we just give them the chance.



CELEBRATING OUR COMMUNITY!

Racker Centers had a chance to celebrate with our community partners this spring in both Tioga and Cortland Counties. Our community celebration in Owego saw a record attendance of over 230 people, and Cortland welcomed over 140!

At the Tioga Celebration, held on the 4th of May, two community partners were recognized along with two staff members.

- The Tioga Community Partner award recognizes a group or business that works to improve the lives of people with disabilities in our community and was presented this year to the deserving Spencer Van Etten School District for their ongoing support of Racker Centers over the years.
- The Tioga Special Friend award recognizes a community member in honor of their support, service, and devotion to Franziska Racker Centers and its ideals. This year's award was presented to the Dave Clark Foundation.
- The staff Inspiration award honors a staff member who inspires and motivates others in their role at Racker Centers. Two deserving staff were presented with this award in Owego including, Kimberly Johnson, LPN, Residential Program and Anne Seepersaud, Service Coordinator Team Leader.
- An additional Special Friend award was also presented to Senator Fred Akshar for his recognition of the importance and support of the #beFair2DirectCare initiatives

The Cortland Community came out to celebrate on May 19th, honoring two community partners and two Racker staff members as well, including:

- The Cortland Professional Firefighters Association, as this year's recipient of the Cortland Community Partner award.
- Kelly Davis, DJ Kelly Davis and Kelly Davis Weddings as the recipient of the Cortland Special Friend award.
- Friends and co-workers Nick Dalrymple, Family Support Coordinator and Roxanne McCall, Administrative Assistant were honored with staff Inspiration Awards, followed by a heartwarming speech made by Nick that stated, "It's the Dream, the Team and Steam" that enables them to do their best work here at Racker Centers. See the inspirational speech on Racker's Facebook page.

Congratulations to all of the deserving award recipients!



Pictured left, Tioga Celebration Award Recipients: Senator Fred Akshar, Kimberly Johnson, Dave Stevens and Doug Cornfield with the Dave Clark Foundation, Joe Morgan, Superintendent; Tina Lampila, Director of Special Education; Matt Stroup, Spencer Van Etten, Elementary School Principal, Connie Szczepanski, UPK teacher, Anne Seepersaud, (front) Sally Lawrence.

Pictured right, Cortland Celebration Award Recipients: Kelly Davis with DJ Kelly Davis with Kelly Davis Weddings, Jim Zelsnack, Vice President and Travis Marshall, Secretary of the Cortland Professional Firefighters Association, Roxanne McCall, Administrative Assistant, Nick Dalrymple, Family Support Coordinator



Special Thanks to our Tioga Celebration Sponsor:

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Special Thanks to our Cortland Celebration Sponsor:

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Both Community Celebrations featured an amazing panel again this year of individuals served by Racker Centers, staff who’ve worked with them, and family members willing to share thoughts on the topic of ‘belonging.’ Each year Racker Centers strives to communicate the importance of the Vision Statement, We envision a world where all people know they belong. No one can express that better than those the agency works to support and serve every day. Thank you to all of the panelists!

Tioga Panelists: Gary Tennant, Sara Matt, John Bement, Cathy McNulty, Linda Fargnoli, Gayle Pado, Christian Pado.

Cortland Panelists: Ken Smith, Colleen Tanner, Meg Givens, Wesley Hines, Susan Dubreuil, and Melissa Kiser

Thank you to our 2017 Business Partners who help to support these community events and the services and programs that Racker Centers is able to provide our community.



ADVOCACY UPDATE!



On Tuesday March 7th Kim Belden, Regional Director/Residential, Gayle Pado, Director of Family Resources, Nina VanWormer, Systems Coordinator/Residential, Dan Brown, Executive Director, Christian Pado, a fabulous kid and someone who has received services from Racker, and Perri LoPinto (taking the photo!) went to Albany to participate in Inclusive Democracy in Action. It was a great trip! Staff had candid conversations with Assemblywoman Barbara Lifton, Assemblyman Christopher Friend, Senator Seward, and Senator Akshar. These legislators expressed support for our #bFair2DirectCare campaign and increasing wages for our direct care workers.

Thank you so much to these Racker staff (and Christian) for taking the time to go represent all the staff at Racker Centers who work so hard for people with disabilities in our community!

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plan’.”

Sheryl and Cheryl were, Alexis said, “So proactive. A cleft palate is the most common birth defect, and it can be associated with speech problems, and since they (the children) can’t clear their Eustachian Tubes, they are prone to ear infections and hearing loss.” To that end, Racker Centers’ staff initiated sign language lessons, and Ellie was signing some basics – like Dog, Drink and Milk – when she was 8 months old.

Alexis and her husband brought Ellie to a “Cleft Clinic,” where they met a plastic surgeon, a dentist, and orthodontist, an ear, nose and throat specialist, and a social worker. Alexis said, “We met a little girl who was 2 years old and she had yet to speak. We felt a sense of gratitude that Ellie was doing so well.” Alexis also remembers a trip to Rochester for a therapy session, and she saw a woman holding her child in a Pediatric Oncology unit, and she shared how her heart ached for that family.

In fact, when Louisa came along, Alexis was provided with another dose of perspective regarding Ellie’s early challenges. “Louisa’s muscle tone and core strength were in place very early by comparison,” Alexis recalled. “Given Ellie was my first child, I really did not realize how much she had to work on that.”

A year after Ellie was born, she had surgery to close her cleft, and her mom said “She started speaking immediately!” By then, Racker Centers’ staff was at the Abramo’s home often, and “Ellie was never made to feel that she was having something ‘done to her’ when she was visited by Sheryl and Cheryl. In fact, the therapists are so skilled at making things feel like play, she looked forward to their playdates together; all the while they were assessing and tricking her into practicing!” Alexis laughed when she said “I stopped worrying about dog hair on the floor, a few dishes in the sink and a messy house. They felt like a part of our family.” Indeed, real life can be messy...

In a letter to Sheryl and Cheryl, Alexis wrote: “We just received

CORNELL RED KEY WELCOMES RACKER

On March 4th Cornell’s Red Key Society hosted individuals and families of Racker Centers at a Cornell women’s basketball game. The Red Key Society is Cornell University’s honor society for varsity athletes. The Society plans and assists in many community service events throughout the year. Membership in the society is limited to juniors and seniors who have been nominated by their head coach, displayed tremendous leadership, exhibited integrity and responsibility within their varsity program, shown a commitment to academics, taken part in community service in the Cornell/Ithaca community, and have been elected by the membership. Before the game, the group of varsity athletes organized a poster making pizza party where individuals served by Racker Centers and their families were able to create large posters to cheer on the Big Red! We had a great turnout and enjoyed snacks as we watched the women’s basketball team take on Brown university!



Ellie’s first report card and had our first parent-teacher conference, and according to her teacher, she is meeting or exceeding expectations for every kindergarten milestone. In fact, her teacher was surprised to hear about the PT, ST, etc. It was very emotional for me to take that in and remember where we were five and a half years ago. Thanks for starting that journey with us. You have both left an indelible imprint on our family. Thanks for helping Ellie and giving us the tools to help her become perfectly herself. Thank you! - Alexis” As we wrapped up our interview for this story, Ellie made sure I would not forget the picture she had so generously drawn for me, and she said. “I want you to put this in your story, okay?”



Her mom said, “I know that Early Intervention was critical in helping us understand what we could do to help Ellie reach her fullest potential and I’m so grateful for that. I’m also grateful for the perspective I gained from some very wise therapists.”

Looking back on Ellie’s journey, Alexis added, “Maybe it was a good wake up call for a new mom about the perils of perfection.”

LOVE FOR LULU

Cathy, Team Director in Residential at Gaskill Road in Tioga County, found a way to get involved in her community and have some fun. She, some of her colleagues and some of the individuals that Racker Centers supports in Tioga County, participated in the Binghamton Color Run.

Cathy engaged so many in this team event. When asked about the day, however, the true definition of team rang out. Cathy shares, “My non-verbal 10 year old daughter diagnosed with autism just walked away from my husband and I. Suffice it to say that once our Racker family found out, they all dispersed (if they weren't supporting one of our residents) to look for her. It’s ironic that it was Day 2 of Autism Awareness Month, April 2nd, the official World Autism Awareness Day. I can sincerely say that I have never been more aware of autism than I was today, Elopement is quite common with people affected by autism. Lulu is no exception.



PHOTO CAPTION: Left to Right; Cathy, Leslie Campbell, Annie McNulty and Lulu at the Color Run

At Racker, there is always a big emphasis on working together as a team, whether it’s a departmental team or an agency-wide team. Today was the Color Run, and I began working on forming this year’s work-sponsored team back in January. We did this last year with a team of 34 people. This year our team was up to 90, which is simply inspiring to me.

I was torn as to whether or not Lulu should participate in this event. There were just so many people there, and it was pretty likely that she would get overstimulated. But then there's the argument that she should be included in events like these because it's her right and she deserves to have a good time just like everyone else. I even talked to her behavioral therapist about it. After talking with some of my co-workers, they all agreed that Lulu should participate. There were more than 80 people who would be there to help. Lulu had a crazy outfit on just like the rest of us, that she even picked it out herself!!

I loved seeing everyone at the race – staff, the people we support, and family members all participating together. Everyone encouraged each other, and there were lots of laughs and hugs. Lulu made it the entire way, and though she wasn’t a fan of the slight hills, she seemed to like to get color thrown on her.

Fast forward to the end of the event, Lulu was ready to be done. John had her by the hand one minute with me standing right next to her. He opened a packet of color and took a few steps away. I turned to watch, then realized that Lulu wasn’t with him. She had taken off that quickly...and there was a sea of white t-shirts as far as the eye could see.

I tried to remain calm, yelling to John that Lulu was missing. One by one, my co-workers realized what was happening, and they all began to disperse in different directions. Because of where we work, they all knew the potential severity of the situation...they all knew that Lulu was non-verbal, and would not come when her name was called. Some knew that she was drawn to bubbles, water, music and bounce houses. They were on top of the situation from the word “go.”

I was taken over to the Lost and Found tent where I showed a police officer her photo. I have never been more grateful for technology. There were many questions – what does she look like? How old is she? What is she wearing? The police officer and the folks at the tent looked physically pained when I mentioned that Lulu was autistic and non-verbal, and that the likelihood that Lulu would respond when called was very slim. Around that same time, I mentioned to a co-worker that Lulu probably wanted to leave. My co-worker ran off to the parking lot to look there. After a few minutes, I received a call that Lulu had been found by one of my co-workers.

I have never been more frightened in my entire life. And I’ve never been more thankful to everyone who stopped what they were doing to help, whether it was to look for her or to keep me from falling apart. The African proverb, “It takes a village to raise a child” is not quite accurate. In Lulu’s case, it takes a whole damn army. And I am grateful to have my work army beside me.

Cathy McNulty has been employed with Racker Centers since 2014 in the residential program, however has been connected to the agency for much longer. Her daughter Laura received an evaluation through Racker Centers in 2009. Laura (LuLu) was diagnosed with autism and was enrolled in Racker Centers preschool, first in Owego, and then in a classroom in Cortland. Since, Laura has received various supports from a number of programs at the agency, all helping to foster connections within the community for her.

Come Celebrate our Super Heroes!



Join us for a luncheon to support Early Childhood Services At Franziska Racker Centers

Thursday, July 13, 2017 – 12:00 – 2:00 p.m. In the Sibley Conference Room, 3226 Wilkins Rd. in Ithaca

\$100 per person, \$175 per couple

Go online to register at www.rackercenters.org

or call/email Perri LoPinto 607.272.5891 x234, perri@rackercenters.org

Luncheon – Art Auction – Program Presentation – Meet the Superheroes!

All proceeds will support Racker Centers’ Early Childhood programs.

Mike Washburn of Wegman's is pictured here with children from the toddler classroom at the Tompkins Preschool with donations of goodies left over from the Easter holiday.



Jake Weidner and Beau Starrett present the proceeds from the 16-17 Teddy Bear Toss to children at the Tompkins preschool

SUMMER 2017

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www.rackercenters.org

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DESIGN Dawn Bricen LaMorte, Graphic Designer
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PHOTOGRAPHY Staff and Friends of the Centers

