Dateline

Published by the Franklin County Board of Developmental Disabilities "Helping people to live, learn and work in our community"

Support platform evolves for families of kids with cerebral palsy

The phone for CP Parent Columbus still rings, and Lynne Fogel answers, generous as always with her time and knowledge about raising a child with cerebral palsy.

"With most of the calls, it's a new diagnosis. Or a family who thought they had it all figured out, and then they move to a new stage," she said. "Typically, it's an hour-long conversation. I send lots of information. And then, more often than not, I never hear from them again."

Easy access to online information, resources and social media has changed the traditional support-group landscape for CP Parent Columbus, launched by Fogel and Delaware County parent Patty Lyons in 2004. At the time, it was the area's first family-led support group for families of children with cerebral palsy, and for several years events and meetings drew dozens of participants.

"Then attendance started to drop off," said Fogel, who lives in the Blacklick area. "No matter what I did, it fell."

The central Ohio branch of United Cerebral Palsy also effectively ended operations in 2010, merging with Goodwill Columbus after struggling financially.



The Fogel family, going green for CP: Natalie, Jeff, Lynne and (seated) Erica.

Despite the challenges, Fogel remains as committed as ever to helping other families find what they need. She has shifted most CP Parent activity to its Facebook page, where she posts information, provides links to other groups and resources, and responds to messages. She also works as the central Ohio information specialist for Ohio Family2Family, a family-staffed virtual center that provides one-to-one support to families of children with special health -care needs.

"I send people to Lynne all the time," said Sha Clark, CP Program Clinical Coordinator at Nationwide Children's Hospital. "She and Patty and some other parents were actually instrumental in growing our program here. It really shows the power of families and advocacy."

Facts about CP

CP is caused by abnormal development or damage to the part of the brain that directs muscle movement. It is the most common lifelong motor disability.

More than 17 million people worldwide have CP, including 1 in 345 U.S. children.

About 11% of people age 6 and up who are served by the Franklin County Board of Developmental Disabilities have CP.

CP disability ranges from mild to profound. 1 in 3 people cannot walk; 1 in 5 cannot speak verbally.

Source: Cerebral Palsy Foundation. FCBDD

Clark, a veteran social worker at Nationwide Children's, said the CP program follows about 1,300 children and adults with cerebral palsy. Overall, the hospital provides care to about 4,000 people whose conditions include cerebral palsy.

Though cerebral palsy is the most common motor disability in childhood, it doesn't have "as much of an organized presence" as disabilities such as Down syndrome or autism, Clark said. The wide range of cerebral palsy also has made it difficult for families to unite around in-person support activities.

"The symptoms of CP vary from person to person and can range from very mild to profound," said Clark, whose adult daughter has a milder form of cerebral palsy.

She and Fogel, whose daughter Erica is now 20, would love to see more focus on older youth with cerebral palsy. "We need teen, young adult groups, so that they have connections, too," Clark said.

No matter the format, Fogel said she'll keep doing what she can for parents and kids of all ages. "I'm a librarian," she said with a smile. "I'm all about finding the info people need, and giving it to them."

Service systems work together to help youths with complex needs

Agencies that serve young people with developmental disabilities and complex behavioral needs continue to expand care options so that no Ohio family has to surrender custody in order to obtain treatment for a child.

"That once was the only option," said Melinda DelFratte, director of community living services for I Am Boundless. "Children Services got involved and took custody and put them in a residential setting, often out of state. How sad is that?"

DelFratte, who has worked in the disabilities field for nearly 30 years, is now happily overseeing the expansion of a local program that serves so-called "multisystem youth," or young people who require support from multiple public systems. Work is under way to add eight beds, for a total of 12, at a Boundless residential facility on Columbus' East Side.



Youth in the multi-system program at Boundless receive extensive services.

Jointly funded by the Franklin County Board of Developmental Disabilities, Franklin County Children Services and the Alcohol, Drug and Mental Health Board of Franklin County, the Boundless program provides residential care and specialized services for youth age 16 to 21 who cannot safely remain in their family homes.

Though the program is still fairly small, DelFratte said it has had a big impact. "The most beautiful thing is that families are together," she said. "And the youths have done really, really well."

Larry Macintosh, FCBDD director of administrative and support services, said the residential program at Boundless is "just one piece of a larger puzzle that's starting to come together" for families who struggle to find – and to pay for – the behavioral care their children desperately need.

In July, the Ohio Department of Medicaid is expected to launch OhioRISE (Resilience through Integrated Systems and Excellence), a specialized managed care program for youth with complex behavioral health challenges. The aim is to keep more families and children together by creating new access to in-home and community-based services – ideally, before an out-of-home placement occurs.



One-to-one support is key.

"OhioRISE is going to be a very big umbrella, and we want to make sure everyone is covered," said Mark Butler, a Whitehall parent who serves on the OhioRISE State Advisory Council. In 2014, Butler and his wife relinquished custody of their son, Andrew, and endured a long, painful separation when he was placed in residential treatment more than two hours away.

"Back then, no one knew anything about multi-system youth," Butler said. "What we have now is not perfect. It can never be perfect. But there are huge steps toward progress, and I think that's wonderful."

OACB has new interim leader

Bridget Gargan retired last month after nearly nine years as CEO of the Ohio Association of County Boards of Developmental Disabilities. The organization's trustees named Adam Herman, who had been chief operating officer, the interim CEO.

Steven M. Licciardi, president of the OACB Board of Trustees and a member of the Cuyahoga County Board of Developmental Disabilities, said in a news release that Gargan has been a "tireless advocate" for county boards and for people with developmental disabilities.



Adam Herman

"Always pushing for changes that will improve the lives of the people we serve and their families, Bridget's driving philosophy is grounded in a deep sense of empathy and the fundamental belief that the dignity of those we serve must outweigh all other considerations," Licciardi said.



Bridget Gargan

"As the brother of a person served in our system, I am grateful that Bridget has been in our corner for all these years," he said.

Herman is a former legislative staff member, government communications professional and strategic adviser to state and local elected officials. He joined OACB in 2011 as communications director and in 2021 was named COO.

Good For You

Notable achievements in the FCBDD community



Thanks to Scott Vawter of the Transportation Department for tackling a big reorganization job. Scott moved thousands of supply items from the old storeroom at the maintenance compound and arranged everything in the transportation parts room. That's some serious spring cleaning!

Sara McMullen, information and referral service coordinator, and Anne Russell, service coordination supervisor, represented FCBDD at the Columbus City Schools summer resource fair, happily answering questions for more than two hours. Thanks for the community outreach!

Congratulations to Patricia Davis for being named a participant of the month at Greenleaf Job Training Services. Patricia's service coordinator referred her

to Opportunities for Ohioans with Disabilities after she lost her long-time job during the pandemic. Now a kitchen associate at Fazoli's, she overcame many barriers. "I like to keep busy," Patricia said. "By having a job, you learn to take care of things by yourself."



Thanks to Insurance Coordinator Anna Oscard for organizing the recent Wellness Open Houses for FCBDD staff, which featured helpful information from Anthem, CME Federal Credit Union and Ohio Deferred Compensation. And we appreciated the encouragement from Sidney West of Body By Sid.

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We appreciate all the staff members who oversaw informative and productive staff development days last month when students were out. Thanks to Deb Viney of West Central, Amy Kulow in Transportation and Teresa Johnson of Early Childhood Education.

Career Milestones

30 Years George Barnette

20 Years

Stacey Coriell Theresa Hazlett

15 Years

Phillip Johnson

10 Years Sarah Thompson

> 5 Years Amy Peal



Christine Brown appears in a new video from the Ohio Department of Developmental Disabilities marking the 10th anniversary of the state's "Employment First" policy. Christine describes her various job experiences on the way to becoming a self-advocate faculty member and clinical research assistant at the Ohio State University Nisonger Center. Thanks for all you do, Christine!

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K.B. Sharp, niece of FCBDD retiree Dorcas Sharp, was recently inducted into the Ohio Basketball Hall of Fame. A Bexley High School graduate, Sharp went on to success at the University of Cincinnati, in the WNBA and in Europe. Congrats to the Sharp family.



We appreciate the visit from Ohio Department of Developmental Disabilities Director Kim Hauck, who joined a recent senior management meeting. Thanks for your commitment to speaking with staff at county boards, Director Hauck.

Social enterprise nursery ready for spring sales



Lettuce Work, a local nursery that provides jobs for young adults with autism, is now open daily.

Lettuce Work Nursery, a nonprofit social enterprise focused on employment opportunities for young adults with autism, is open for the growing season and stocked with Mother's Day flowers.

The New Albany-area nursery continues to expand and has improved its retail shopping space and increased inventory.

All sales proceeds support the Lettuce Work program, providing training and jobs for young adults with autism.

About 63% percent of participants who work at the nursery and graduate from high school move on to other jobs or to higher education, an outcome more than double the national average, Lettuce Work says. This year, the program is on track to provide 7,000 hours of training and work experience.

To learn more, go to lettucework.org or call 740-913-0495

Calendar

Editor's Note: The following calendar is tentative due to the COVID-19 pandemic. Call 614-342-5950 before attending any meeting to see if it is still scheduled.

May 2022

18 Family Support meeting, 10 a.m. via Zoom. Please contact Amy Magginis at 614-342-5950 for details or click the following link to connect:

Family Support Meeting Link (Zoom)

19 Franklin County Board of Developmental Disabilities Board meeting at 5:00 p.m. via Zoom. Please contact Amy Magginis at 614-342-5950 for details. Click on the following link to connect:

FCBDD Board Meeting Link (Zoom)

30 Memorial Day observed - Early Childhood Centers, West Central School and offices of the Franklin County Board of Developmental Disabilities will be closed.



Dateline

The Franklin County Board of Developmental Disabilities

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www.fcbdd.org

Technology spotlight

Jen Schlegel taps the power of tech to manage daily life

As an Ohio State University graduate, biomedical engineer, certified Americans with Disabilities Act coordinator and entrepreneur, Jen Schlegel has long used technology to help her go where she wants to go and do what she wants to do.



Jen Schlegel, Tech Ambassador

Some of her assistive devices are simple enough to work by way of duct tape or Velcro. Others involve complex software, apps and 3D printing.

"My life runs on technology," said Schlegel, 29, winner of the 2020 OSU President's Prize for her dedication to improving lives through accessible educational experiences.

Schlegel also is a new central Ohio ambassador for the Ohio Tech Ambassador Network. The statewide effort promotes the use of supportive technology through interactive web and in-person mentoring sessions led by people with disabilities.

You seem to have a very full plate. Why become a Tech Ambassador?

I ran across the Tech Ambassadors last year when I was pretty ill. I remember thinking how important efforts like this are, and how representation matters. I try to engage in opportunities that allow me to be the adult I was always looking for as a young person.

A peer called you 'The Idea Fountain.' You find, modify or invent all sorts of things, right?

I'm from a rural county, and I learned pretty early that the world around me was not accommodating. So I was going to have to adjust to accommodating the world. I think if I total all the various devices I have now, it's something like 75. I'm always looking for something different to solve a problem.

Describe one of your simplest creations.

In high school, I wanted to play this giant xylophone, but I couldn't hang onto the mallet. So we came up with a duct-tape glove.

You deal with both disability and chronic illness. How does that drive your creativity?

My creativity might be applauded, but it all really came about because of need. When I was born, my parents were told I wasn't going to walk, talk or be anything. I love defying that! In 2016, I got very, very sick in addition to my cerebral palsy and other conditions. I went home after five weeks in the hospital and had to get new door locks I could use. That's how my life turned into, 'How can I automate everything I can?'

Technology can be intimidating for many of us.

It's very important to me to meet everyone where they're at. I recognize that I'm in a unique position, and I want to use that to serve my community. We're all human, and we all deserve a great life experience. That's what I'm fighting for.

To learn more, go to ohiotechambassadors.org

FCBDD Community Star Awards Nomination Form

Do you know someone who should be recognized for extraordinary accomplishments or service supporting individuals with developmental disabilities?

If so, please take a moment to complete and return this nomination form. Nominations will be accepted until Monday, June 13, 2022. All nominations will be considered by an Award Committee, and winners in each category will be recognized at the FCBDD Community Star Awards Ceremony in the Fall of 2022. Please submit this nomination to: Awards Committee, c/o Amy Magginis, 2879 Johnstown Road, Columbus, Ohio 43219.

| | (PLEASE PRINT) | |
|-----|---|--|
| 1. | Name of Nominee: | Daytime Phone# |
| | Home Address: | |
| 2. | Please complete one nomination per form and check the category for which this person o organization is nominated. Nominees are not required to be staff members or affiliated with FCBDD. | |
| | □ Persons Receiving Services/Self-Advocates □ Parent/Family Member □ School Staff □ Provider Organization □ Volunteer/Good Neighbor □ Employer | □ Transportation Staff □ Early Childhood Staff □ Direct Service Professionals □ Management/Supervisory Staff □ Service Coordination Department Staff |
| 3. | Why should this nominee be recognized? | |
| 4. | Please describe any other achievements or information regarding this person or organization to support this nomination: | |
| | ominated by: (Please Print) ome Address: | |
| Cit | ity: State: | Zip Code: |
| Ho | ome Phone # Work/Daytime | Phone # |

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