



Spring 2018

# Down Syndrome Association of Central Kentucky

Support • Educate • Celebrate



*Jayla Boggs* with mom Jennifer  
By Scott Mandl Photography

**MISSION STATEMENT** | To celebrate and support people with Down syndrome and their families and to educate ourselves and others throughout Central and Eastern Kentucky.



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DSACK Bylaws and financials are open for review, and the Board of Director Meetings are open to our community. Agenda items are determined well in advance.

DSACK does not endorse the opinions or views expressed by third parties or the products or services they offer. Reference to any specific commercial products, brand names, processes or services, or the use of any trade, firm, or corporation name is for the information and convenience of the public and does not constitute an endorsement.

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## Stay Connected



You can now RSVP for events right from our website calendar at [www.dsack.org](http://www.dsack.org)



To receive our weekly email blitz, email be Terri at: [dsack.org@gmail.com](mailto:dsack.org@gmail.com)



To join our private facebook group where you can communicate with other DSACK families, go to <https://www.facebook.com/groups/82674673490/> and request to be added to the group.



To "like" our official facebook page and receive updates from our association, go to <https://www.facebook.com/TheDownSyndromeAssociationofCentralKentucky>. [dsack.org@gmail.com](mailto:dsack.org@gmail.com)



Follow DSACK @DSAofCentralKY on Twitter.

Visit our calendar on [www.dsack.org](http://www.dsack.org) to see current events, activities and educational opportunities!

## A square peg just won't fit into a round hole, so let's stop trying

By Traci Brewer

Let's face it, I'm never going to be an astrophysicist. Science and math are not my thing, and besides, I'm not even sure what an astrophysicist does. So, putting me to work as an astrophysicist is not going to have a good outcome. I'd be set up to fail.



By the same token, my daughter Emily, who has Down syndrome, is never going to be a greeter at a big box store, as is often suggested. She has communications challenges, requires adaptive equipment because of limited mobility, and quite frankly is anything but a social butterfly. Placing her in a greeter's job is not going to have a good outcome and she, too, would be set up to fail.

My point? You can't fit a square peg into a round hole, as the old adage goes.

Too often, that's what we do when it comes to people with Down syndrome. We make assumptions based on preconceived ideas and push them into jobs/careers for which they may not be a good fit.

That's where DSACK's We Work! career planning program comes in. Instead of focusing on what we think an individual would be good at doing, we focus on what he or she thinks they'd be good at doing. Plus, we help them explore their likes and dislikes, their strengths and weaknesses, and their abilities.

The We Work! program, which we're highlighting in this issue, has been an

undeniable success. As you will read on pages 6, 7 and 8, six students graduated from the first session. Two have been placed in employment, and three are still in high school but have attained internships. And my Emily? After going through the We Work! process, she uncovered a talent for designing floral ar-

rangements and is in the process of starting her own online floral design business.

Our valuable partner in We Work! is our neighbor Build Inclusion, an education and employment organization that builds networks and community access for people with disabilities. They work tirelessly to find internships and jobs for our We Work! graduates.

We Work! is open to individuals with Down syndrome ages 13 and up and young adults who are either unemployed or underemployed. But they're not the only ones who are required to make a commitment to the program. Parents/caregivers are also important to its success. They meet separately for the first eight weeks of the program to hear speakers on a variety of related topics and come away from the experience with the increased knowledge they need to help their students succeed.

I hope you enjoy reading more about this great program. Let us know if you think We Work! is a great fit for your loved one!

Best,

*Traci*

By Courtney Elbert

I recall a day this summer when my son Sam was really struggling with something. He and I had gotten frustrated with one another and with ourselves. I was exasperated like a parent of any teenager can feel sometimes. I was talking to him about needing to try harder, and that he can't be lazy, and that I was frustrated with him because I knew he could do this task if he would set his mind to it.

In the midst of this conversation, I was beginning to feel overwhelmed and even sorry for myself my day-to-day life as a mom to a teenager with Down syndrome (which, by the way, in some ways is not all that different than raising other teenagers...and, yet, in other ways... I'm certain now is a path that's differently daunting, frustrating and lonely at times – not necessarily superlatively as "more" – just "different").

So, right as those feelings were gripping hold of my chest with a tightness of anxiety and as my eyes stung with tears as I felt like flopping down on the floor defeated, like a heap of dirty clothes ... Sam responded back with a clarity, sincerity and despair that jolted me out of my moment of self-pity.

Sam said, teary-eyed with exasperation and clarity: "Mom, I have Down syndrome."

I get weepy as I type this. Those simple words, and the enormity wrapped up in them; the different worlds in



Courtney Elbert



Sam Elbert

which Sam works so darn hard to exist, and yet doesn't ever quite fit. That often things are confusing or too fast-paced for Sam to process. That often he can't find the words to express how he's feeling.

The constant, daily struggles Sam endures to try to get his body to do things that he knows how to do in his head - yet can't make his body do. The frustration and awareness that he's failing, that no matter how hard he tries sometimes, he can't get it...that in some people's eyes, he's never enough and they seem disappointed in him. That people stare.

That certain smells, sounds, memories and situations are really hard for him to process and navigate through. That every single day, he has to repeat himself to others so that they understand what he is saying. That he's been doing the same type of math problems for a decade. The sheer number of hours of therapies he's attended for 13 years. The number of times he knows he's being left out but doesn't know why – left out of the privilege, the sleepover, the con-

versation, the dance, the class, the joke, the game, the friendship, the team.

As my heart broke open and my tears flowed, I sat down in the middle of the floor with Sam and gave him a hug. My precious boy who is growing into a young man before my very eyes, yet in other ways he still comprehends the world as a child.

Sam and I talked and he cried a little, too. About how he has Down syndrome and how he has to work extra hard at most everything he does, and how that must get so tiring and frustrating. I told him that I am sorry he has to work so hard and feel so frustrated, but that he has a lot of people in his life that love him and he can always talk to us and we can try to listen and to help him. I told him that I wish things weren't so hard for him, but that I'd never wish that he didn't have Down syndrome because it's who God created him to be, and that God has great plans for him. I told him that I love him exactly as he

"Mom, I have Down syndrome!"  
Sam Elbert

is, but that as his Mom I'm also always going to challenge him to try to help him reach his dreams and his fullest potential. I told him that God needs Sam to keep working hard and to keep smiling his smile because no one else in the entire world smiles just like him ... and that he has to keep shining his light for all the world to see ... and that God gave us each other because we need each other to get through this world together.

And that I am the luckiest and most blessed person in the whole world to be chosen as his Mom.

**Courtney Elbert is DSACK medical and community outreach coordinator, as well as Mom to 13-year-old Sam. She has three other children: Ethan, Sydney and Jade.**

## World Down Syndrome Day 2018

Mark your calendars for World Down Syndrome Day March 21 as DSACK once again joins the global chorus to raise awareness and advocate for the rights, inclusion and well-being of those with Down syndrome.

Activities begin at 9 a.m. with a drop-in breakfast in Room 171 of the Capitol Annex building in Frankfort. Invitations are being sent to legislators, the executive branch, commissioners and cabinet employees inviting them to join us as well. Then at 11 a.m., we



will move to the Capitol Rotunda for a rally with special speakers.

DSACK also encourages you to meet with your legislators to talk about what it means to have Down syndrome and how people with Down syndrome play a vital role in our lives and communities. Specific topics include the

**DID YOU KNOW?** The date for World Down Syndrome Day is always the 21st day of the third month to signify the uniqueness of the triplication (trisomy) of the 21st chromosome, which causes Down syndrome.

importance of Medicaid Waivers, education and employment, and the STABLE Act.

"Our voice is so much stronger when we all work together to

raise awareness of Down syndrome," said Traci Brewer, DSACK executive director. "We hope everyone will join us as we take our case to the state capital."

### Speaking of Advocacy ...



Advocating for your student with Down syndrome may seem like a daunting task. And no wonder! At the very least, it requires a basic understanding of advocacy strategies, the legal basis for your

concerns and creative options to academic challenges.

In DSACK's continuing efforts to arm parents and caregivers with the information they need, DSACK will once again bring in Ashley Meier Barlow of the law firm Meier & Barlow for a special education clinic from 10 a.m.-noon on April 21, during our monthly Coffee Chat. Topics include:

- How to build an advocacy toolkit with the basics of special education law
- Building your binder, preparing for ARC meetings
- Creating an "All About Me" book for your student
- Advocacy for parents and when you might need a lawyer
- Kentucky-specific case law and statutes
- Where to find resources when problems arise

This clinic is open to parents of children with any type of disability who has a child in the special education system, as well as to the advocates and professionals who assist them.

To sign up for this free training, go to the calendar on our website – [www.dsack.org](http://www.dsack.org) – and register.

### Wish Granted

DSACK has received its first grant for 2018 - \$5,000 from the Rite Aid Foundation's Holiday Wishes initiative. The funds will go toward development of a Summer Enrichment Program for children in kindergarten through fifth grade, with the goal being to combat student regression when

school is not in session.

The Holiday Wishes initiative is part of Rite Aid Foundation's KidsCents program, which DSACK has been involved in for three years. KidCents allows Rite Aid customers to round up their purchases to the nearest dollar and donate their change to a general fund that supports kid-focused charities. Keep on rounding up!

### Family Care Toolkit

Emergencies happen. Vacations and respite are sometimes needed. It is essential to have important information in one place when a caregiver comes in to care for a person with Down syndrome.

That's why the National Down Syndrome Congress, with support from the Global Down Syndrome

Foundation, has created a toolkit for caregivers and other members of the family. There's a Parent Guide, which shows you how to complete the toolkit. The toolkit itself is divided into six sections – Home, Family, Daily Living, medical, Resources, and Emergency.

You can download the Parent Guide at and the toolkit by visiting [www.ndsccenter.org](http://www.ndsccenter.org) or contacting [info@ndsccenter.org](mailto:info@ndsccenter.org).



### Update on Tax Reform

From the National Down Syndrome Congress: In late December, The Tax Cut and Jobs Act was signed into law. The final bill contained some concerning provisions, such as the repeal

of the Individual Mandate of the Affordable Care Act and a predicted \$1.5 trillion in the federal deficit, which may lead to massive cuts to Medicaid through entitlement reform. NDSC will continue to advocate against Medicaid cuts, per capita caps and block grants, and will keep you informed as entitlement reform efforts progress.

**Note:** This is yet another reason we need you at World Down Syndrome Day March 21 – we must let our Kentucky legislators know the importance of waivers!

### New Parent Dinner

Every parent needs a night out. If you have a child with Down syndrome who is 3 years old or younger, you'll want to join us March 16, 6:30 - 8:30 p.m. for an evening of getting to know other parents with young children and getting to meet DSACK staff. In the meantime, call DSACK's medical and community outreach coordinator Courtney Elbert at 859-494-7809 or email [courtney.dsack@gmail.com](mailto:courtney.dsack@gmail.com) to learn more about becoming involved in DSACK.

# DSACK employment training program helps high schoolers, young adults in search of meaningful employment

# We Work!

By Terri McLean

If Traci Brewer has her way, the day will come when every person with Down syndrome who wants a job will have a job. And not just any job; one that is meaningful and that pays a prevailing wage.

A tall order? Perhaps. But not impossible, she insists.

"I envision the day when people walk into a restaurant or a law office or a retail store and see people with Down syndrome working and not think twice about it," said Brewer, executive director of the Down Syndrome Association of Central Kentucky. "I believe we'll get there. We have a lot of work to do, but it will happen."

The work is already underway at DSACK where the organization's We Work! employment training program is in its second year. Started in 2016 in partner-



Callie Baesler, Conor Healy, Traci Brewer, Emily Wright and Kate Boudreaux

ship with Build Inclusion, the free program is open to high school students ages 13 and above, and young adults with Down syndrome who are either unemployed or underemployed.

There are five phases of the months-long program aimed at all facets of workplace readiness.

"Everything we do is geared toward getting them into jobs, but it's so much more than that," Brewer said. "We begin by helping students learn self-determination and self-advocacy, and then we move into job exploration and counseling."

The key to the program's success has been avoiding a

## We Work!

- Phase One – Self-determination, self-advocacy, workplace readiness training; parent training
- Phase Two – Job exploration counseling
- Phase Three – Leadership development, socialization, team-building, peer-to-peer mentorship, service project planning and implementation
- Phase Four – Work-based learning experiences, including job shadowing, internships, dual enrollment opportunities and postsecondary counseling
- Phase Five – Students who complete Phases One through Four are partnered with students entering Phase One, leading them as peer mentors

one-size-fits all approach.

"A lot of times when you have a Down syndrome diagnosis, people make assumptions that aren't always

accurate. So what we do is find out what they're good at, what they excel at, and what would be the best fit. It has really astounded me the



different interests of the students. The things that were drawn out of them surprised even some of their parents," Brewer said.

Recent graduate Tage Cook entered the We Work! program knowing he liked to work with food. But he had always been encouraged to find a job in fast food restaurants. After completing the program, a whole new world of possibilities opened up.

"There's nothing wrong with working in a fast food restaurant, but as we worked with this student we quickly realized he needed to be in the kitchen dicing and cooking and mixing. He was good at it," Brewer said.

And into the kitchen he went. The 19-year-old landed an internship with the Golden Corral in Lexington

and spent a month getting experience in his newfound career.

"Tage is on track to seek permanent employment in the food industry that will offer meaningful, competitive employment," said Annette Jett, executive director of Build Inclusion, who seeks out employment for the We Work! students. "The job experience he received at the Golden Corral benefit both him and the business."

Unlike other local employment training programs for people with intellectual disabilities, We Work! includes a parent component. During the first eight weeks, while students are in training, the parents meet separately to hear speakers and build a community for themselves.



Emily Wright

**HIRING PEOPLE WITH DISABILITIES MAKES \$ENSE FOR BUSINESS!**

**84% of businesses report having difficulty hiring staff...**

**A READY AND ABLE WORKFORCE**  
At least 32% of Kentuckians with disabilities want a job.

**ON WHOM YOU CAN DEPEND**  
The turnover rate for people with disabilities is 8%, compared with 45% for other workers.

**FOR A VERY REASONABLE INVESTMENT**  
Employers see a \$28.69 average return, for every dollar invested in accommodation.

**WITH HUGE POTENTIAL**  
Customers with disabilities and their families, friends, and associates represent a \$3 TRILLION market segment.

**TO IMPROVE THE COMPANY'S BOTTOM-LINE**  
87% of customers say they would prefer to shop at businesses that hire people with disabilities.

References Available at:  
[www.KentuckyWorks.org](http://www.KentuckyWorks.org)

These six individuals completed DSACK's first We Work! session and are on their way to establishing meaningful careers. They are an inspiration to their families, friends and co-workers.

## Emily Wright, 28

Now works as administrative assistant at Down Syndrome Association of Central Kentucky in Lexington



## Emily Brewer, 20

In the process of creating her own online floral design business



## Callie Baesler, 19

Now works at the new University of Kentucky Student Center bakery in Lexington



## Tage Cook, 19

Finishing high school; completed an internship at Golden Corral in Lexington



## Conor Healy, 19

Finishing high school; completed an internship at the Drum Center in Lexington



## Kate Boudreaux, 17

Finishing high school; completed an internship with Allegro Dance Project in Lexington



## Following my child's IEP ...What Can I Do?

By Bob Cunningham

**Q: My son's classroom teacher doesn't seem to be following his IEP. What can I do to make sure my son gets the accommodations and services he's supposed to be getting?**



The first thing I want to say is that you've already done something very important. You've stayed on top of your child's IEP and identified a problem. That's part of the critical role you play in the entire IEP process.

The second thing is that following an IEP is not a teacher's choice to make. It's the law. But if that's not happening, for whatever reason, there are a number of things you can do—starting with talking to your child's teacher.

### 1. Meet with the teacher.

It's a good idea to ask to meet as soon as possible. You'll want to make sure the teacher has a copy of the IEP and that she has reviewed it. Take a copy of the IEP to the meeting so you can leave it with the teacher.

At the meeting, be conversational rather than confrontational. Explain that the IEP helps you understand your child's needs, and you hope it can help the teacher understand them as well.

Go through each section of the IEP and mention why the information in that section is helpful to you. Assuming you were at the meetings where the IEP was developed, share with the teacher why certain things are included in the IEP.

For instance, "Last year the IEP team noticed that he got confused trying to read his own notes, so the team added an

accommodation that allows him to get notes from the teacher or another student."

Try to make this a two-way conversation. As you go through the IEP, ask the teacher how the information in each section might relate to your child's performance in her class.

It's possible that this meeting will be enough to remind the teacher to follow what's in your child's IEP. If not, you'll need to take it to the next level.

### 2. Take it up with school administrators.

If your meeting with the teacher is unsuccessful, your next step is to take it up with school officials. But you'll need to be able to document what's been going on before you do.

Start keeping a journal that specifies which aspects of the IEP are not implemented and when. You can attach work samples to the journal entries. For example, if extended time wasn't provided on a test, note that date in the journal and attach a copy of the test.

You'll need to have a few entries that show a pattern of not following the IEP. Once you do, ask to meet with the assistant principal or other school administrator.

Before your meeting, think of a few positive things to say about the teacher or the class. Open the conversation by saying something like, "My child really enjoys social studies

because he loves history," or "My child loves the teacher's sense of humor." That will set a positive tone for the meeting.

Follow that by pointing out that the teacher isn't following the IEP, and that this is making things more challenging for your child than they should be. Show the journal as a way to back up your point. Ask if the administrator can talk to your child's teacher to get things on track.

### 3. Take it to the IEP team.

If after that your child's IEP still isn't being followed, request an IEP team meeting to discuss your concerns. (To get guidance ahead of time, you can speak to your local Parent Training and Information Center. You can also bring an advocate to the meeting with you.)

At the meeting, go over your conversation with the teacher and the administrator with the whole team. Provide specific examples from the journal.

Let the team know that it's unacceptable that the teacher does not follow the IEP. Ask about how the team will intervene to ensure compliance with the IEP, and what concrete steps will be taken. Also ask for a team member to be assigned to closely monitor the situation.

Then schedule a follow-up IEP meeting for a few weeks later. At that meeting you can all assess the effectiveness of the team's plan together.

If the IEP team is unsuccessful or unresponsive, you can consider filing a complaint with the district's special education administrator. You can also use your due process rights and pursue dispute resolution options, like mediation. Another possibility is to ask to have your child switched to another teacher's class.

If the compliance issues are significant, there are other steps you can take. You might be able to seek an independent school placement. Or you might be able to get extra educational services, like tutoring, at the school's expense.

Another thing you can do is file a state complaint, saying you think the school has broken the law. If it gets to this point, however, you might want to hire a lawyer or contact your local P&A Center to help you consider your options.

It's always best to begin with a collaborative approach. But ultimately, you need to make sure your child gets the support he's legally entitled to and that will allow him to reach his potential. You can help do that by understanding his rights under special education law, and tracking his IEP goals and progress.



Bob Cunningham, Ed.M. serves as adviser-in-residence on learning and attention issues for Understood.org.

# What's Happening?

## FEBRUARY

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
				<b>1</b>	<b>2</b> Strategic Planning Weekend Taekwondo 4:15 p.m.	<b>3</b>
<b>4</b>	<b>5</b> Healthy Movements 5:30 p.m. & 8:15 p.m.	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b> Learning Program L3 9:30 a.m. Taekwondo 4:15 p.m.	<b>10</b> Learning Program L2 10:30 a.m.
<b>11</b>	<b>12</b> Healthy Movements 5:30 p.m. & 8:15 p.m.	<b>13</b>	<b>14</b>	<b>15</b>	<b>16</b> Taekwondo 4:15 p.m.	<b>17</b> Coffee Chat 10 a.m.-noon
<b>18</b>	<b>19</b> Healthy Movements 5:30 p.m. & 8:15 p.m.	<b>20</b>	<b>21</b>	<b>22</b>	<b>23</b>	<b>24</b>
<b>25</b>	<b>26</b> Healthy Movements 5:30 p.m. & 8:15 p.m.	<b>27</b>	<b>28</b>			

## MARCH

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
				<b>1</b> Lunch Bunch-Homeschooling noon - 1 p.m.	<b>2</b> Learning Program L3 9:30 a.m.	<b>3</b> Learning Program L2 10:30 a.m.
<b>4</b>	<b>5</b> Healthy Movements 5:30 p.m. & 8:15 p.m.	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
<b>11</b>	<b>12</b> Healthy Movements 5:30 p.m. & 8:15 p.m.	<b>13</b>	<b>14</b>	<b>15</b> Board Meeting 7-9 p.m.	<b>16</b>	<b>17</b>
<b>18</b>	<b>19</b> Healthy Movements 5:30 p.m. & 8:15 p.m.	<b>20</b>	<b>21</b> World Down Syndrome Day! DSACK Goes to Frankfort	<b>22</b>	<b>23</b>	<b>24</b> Coffee Chat 10 a.m.-noon
<b>25</b>	<b>26</b> Healthy Movements 5:30 p.m. & 8:15 p.m.	<b>27</b>	<b>28</b>	<b>29</b>	<b>30</b>	<b>31</b>

## APRIL

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>
<b>8</b>	<b>9</b> We Work! Phase 3 7 p.m.	<b>10</b>	<b>11</b>	<b>12</b>	<b>13</b> Learning Program Level 3 9:30 a.m.	<b>14</b> Learning Program Level 2 10:30 a.m.
<b>15</b>	<b>16</b> We Work! Phase 3 7 p.m.	<b>17</b>	<b>18</b>	<b>19</b> Board Meeting 7-9 p.m.	<b>20</b>	<b>21</b> Coffee Chat 10 a.m.-noon
<b>22</b>	<b>23</b> We Work! Phase 3 7 p.m.	<b>24</b>	<b>25</b>	<b>26</b>	<b>27</b>	<b>28</b>
<b>29</b>	<b>30</b> We Work! Phase 3 7 p.m.	<b>31</b>				

## LET'S CELEBRATE!



Jase turns 4 on March 18. Happy Birthday!!! Love Mom, Dad and Sissy Gracie. We love you!



Our handsome boy is turning 19 on March 6. Happy birthday Conor! We love you!



We are so excited that Harrison is turning 4 years old on April 21! He is one amazing little boy!



Troy is celebrating his 26th birthday on March 7. He enjoys working and spending time with his friends bowling and horseback riding. He is also a huge Kentucky Wildcats fan.



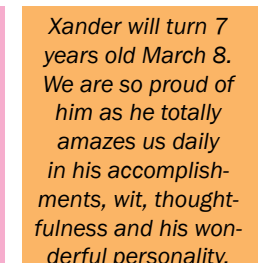
Clay is 4! This year's birthday weekend brought snow fun and Clay's first ride on a sled. This smile says it all!"



March 10: We want to wish Madeline a very happy 4th birthday. We love you baby girl to the moon and back!



Happy 18th birthday Kate! We look forward to watching as you continue to blossom.



Xander will turn 7 years old March 8. We are so proud of him as he totally amazes us daily in his accomplishments, wit, thoughtfulness and his wonderful personality.



Olivia turns 5 on March 31. You are so full of joy and surprises, and we are so lucky that we get to share all of it with you every day. My how these five years have flown by, and we are so proud of all that you are!

1050 Chinoe Road, Suite 204  
Lexington, KY 40502  
Return Service Requested



## Join DSACK for World Down Syndrome Day

**Wednesday, March 21  
State Capitol, Frankfort**

- **Drop-in breakfast begins at 9 a.m. in Room 171 of the Capitol Annex building.**
- **Rally in the Capitol Rotunda begins at 11 a.m.**
- **Meetings with legislators in the afternoon**

**Advocacy has never been more important!**

Bank of Opportunities

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**Discover financial solutions  
and personal service  
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*Be part of a bank that's proud  
to call Lexington home.*



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