



ReachOut e-Diversity News

An Electronic Publication of the Ohio Developmental Disabilities Council

Important Information This Month:

1. A Passion for Advocacy
2. Advocating for Policy Change
3. Advocating for Inclusion
4. Advocating for Autism

April 2020 Edition | Volume 15 Issue 2

Read, Pass on to Friends,
Family Members, Colleagues
& Constituents



Don't
Miss an
Issue!

It is the policy of the Ohio Developmental Disabilities Council to use person-first language in items written by staff. Items reprinted or quoted exactly as they originally appear may not reflect this policy.

Introduction

**You see things; and you say 'Why?'
But I dream things that never were; and I say 'Why not?'
- George Bernard Shaw**



This month's edition focuses on having a passion for advocacy. The importance and benefits of advocacy are discussed at the outset and set the framework for the following articles in which each author chooses to share a unique and compelling story. While they chose different platforms, each was passionate about advocating for their specific cause or issue with a desire to increase awareness and influence decision making within our political, economic, educational, social systems.

At the end of the articles, you are invited to answer 'Why not you?' and take action related to the platform used. A resource is identified that you can use to assist you in acting. We invite you to share your actions on ODDC's social media platforms.

Additionally, some important facts are identified at the end of each article in a "Did You Know?" section.

When we each take action,
we all grow stronger
together!

Inside this edition...

- A Passion for Advocacy
- Advocating for Policy Change
- Advocating for Being Inclusive
- Advocating for Autism

A Passion for Advocacy



What does Advocacy mean?

A big word with simple meaning. If you believe strongly in someone or something, and feel the world at large pays too little attention, it may be up to you to change the equation. When you think of human trafficking, extreme poverty, disease, lack of basic freedoms – how can everyone be too busy? – Ed Tessaro

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Advocating for Policy Change

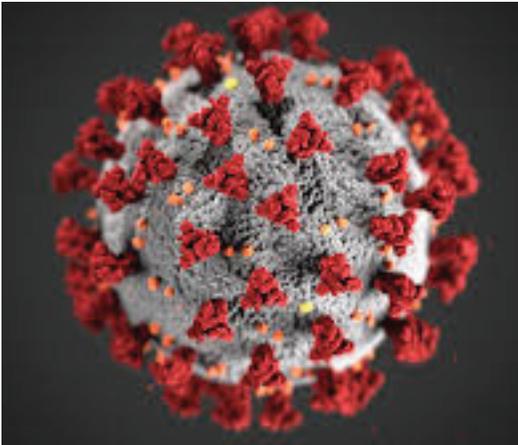
Public Policy connects people with programs and services. Government serves as the conduit or agent for those activities. While Legislators are authorized to make public policy, the most successful public policies are those that have been crafted by all or most of the following groups: legislature and staff, governor's people, affected interest groups, affected local governments, and the public. Policies are rarely without conflict because there is generally a group that is offended by the proposed policy. Policies in their original form are rarely permanent because over time situations and circumstances change that demand enhancement to existing policy or the introduction of new policy.

[-READ MORE-](#)



Rep. Erica C. Crawley

Advocating for Inclusion



The Coronavirus, COVID-19, is a global crisis that is dramatically impacting how things are done. One primary change has occurred in the use of technology. The order by our government to engage in social distancing has increased the use of technology. Because people are unable to personally connect, they are exploring how to use technology to stay connected with their family, friends, neighbors, customers, clients, students, colleagues, members, etc. Unfortunately, if unintended, those without easy access to broadband will be further disadvantaged.

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Advocating for Autism

The number of American children diagnosed with autism is on the rise yet again, according to new government data. The Center for Disease Control and Prevention said that 1 in 54 kids have the developmental disorder. That's a jump from 1 in 59 rate that was reported just two years ago.



Despite the gains seen in identification of African American children, the latest report found that Hispanic children continue to be diagnosed at lower rates. And, both groups were evaluated for the developmental disorder at older ages than their white peers.

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This product is funded all or in part by the Ohio Developmental Disabilities Council.



A Passion for Advocacy

Several advocates have been identified who unpack the idea of advocacy: what is it and why it is necessary for others to follow their examples. Their responses follow.

What does Advocacy mean?

A big word with simple meaning. If you believe strongly in someone or something, and feel the world at large pays too little attention, it may be up to you to change the equation. When you think of human trafficking, extreme poverty, disease, lack of basic freedoms – how can everyone be too busy? – Ed Tessaro



Advocacy to me means supporting a project or cause that is important to you. Support can be volunteering your time, working on Policy to make change at the congressional level,

Fundraising to fund the project, cure or mission.

You can work full/part time, volunteer, donate, write letters to important people in the field to gain additional support and networking. Advocacy also doesn't always mean trying to change the regulations and laws, but working towards a solution for a need. – Michelle Erwin



Advocacy means to me: Having a strong and passionate voice. – Bridget Simpson

To me, being an advocate means, first and foremost, knowing who you are as a person and what things in life are important to you (including your needs on a daily basis). Only then can you truly be an advocate — someone who can effectively communicate to others who you are, what you need and how you want or prefer to have those needs met. This applies to medical situations (dealing with hospitals, doctors, nurses and other health professionals), educational settings, your legal rights and many other situations. In our early years, we often don't

have all the skills needed to be the best possible advocates for ourselves and rely on parents, siblings, relatives and other people in our individual “communities of care” (i.e., support networks) to be our voices. But as we grow older, we can develop the sense of self and necessary life skills to be able to stand up for ourselves, have other people respect us and have those people work with us to have our needs and desires in life met. – Mario Damiani

Why is Advocacy necessary?

People are often unaware of how to help, even after being introduced to a cause. Creative advocacy brings solutions/therapies to the foreground. The list of targets includes accessible airline travel, responsible rules to accommodate the disabled, and more access to clinical trials. These changes would not happen without strong advocacy, thoughtful philanthropy and dedicated professionals. – Ed Tessaro

There are a lot of people with the same great idea who don't know how to make it achievable. There are a lot of people who wish they could help and don't know how. When an organization or individual advocates, it shows that the “something” that is important to them is important to other people and they are not alone. Advocating together will get any one project further than one small voice. Advocacy is necessary because there are still issues that many people do not even realize are issues. Once you get

people's attention, hit a nerve and make it important to them, you gain one more voice in your mission. With advocacy you have a vision and that creates a path for change.

– Michelle Erwin



Advocacy is necessary, because there is more love & strength in numbers. – Bridget Simpson

I sincerely believe that, without advocacy, people would be robbed of their needs and their rights. By trying to advocate for ourselves and others, we can take care of one another and achieve things that might not otherwise be possible. – Mario Damiani



WHY NOT YOU?

Become an advocate

Congress is writing the next bill to respond to the needs of Americans in the COVID19 crisis. In order for the needs of people with disabilities and their families to be addressed in the next bill, members need to hear about the real impacts upon all stakeholders, not limited to you,

your family, your position as a caregiver, service provider, educator, etc.

Write your story and send it to your congressional representatives or send to AUCD (Association of University Centers of Disabilities). AUCD is happy to compile stories and send them to your members of Congress and to Congressional leaders. If you want us to send your story simply email it to roddgers@aucd.org.

Post on ODDC Social Media Platforms the Congressional contacts you have made.

Did You Know?

What to send in a story:

- A picture of you at home (Members of Congress need to SEE the diversity of the disability community)
- Story template
 - My name is _____ and I am _____ (a person with disability, family member, friend). I am from _____ (town and state). The COVID-19 emergency has _____ (stopped services – explain which). I am worried about _____ (explain what the impact is). I know you are working on the fourth relief package for COVID-19. I want to learn more about how you are going to help people with disabilities in this package. Thank you very much for your time.

If you need help locating the right email addresses for your members please email roddgers@aucd.org.

EXAMPLE

My name is Liz Weintraub and I am a person with an intellectual and developmental disability. I am from Rockville, MD. The COVID-19 emergency has me working from home. I am worried about getting help from staff coming into my home while “stay home, saves lives.”

I need information about COVID-19 to be in plain language as its hard for me to understand and feel safe during these hard times if information is not accessible. I know you are working on the 4th relief package for COIVD-19. I want to learn more about how you are going to help people with disabilities in this package. Thank you very much for your time.



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Advocating for Policy Change

Rep. Erica C. Crawley (District 26)

ISSUE

Public Policy connects people with programs and services. Government serves as the conduit or agent for those activities. While Legislators are authorized to make public policy, the most successful public policies are those that have been crafted by all or most of the following groups: legislature and staff, governor's people, affected interest groups, affected local governments, and the public. Policies are rarely without conflict because there is generally a group that is offended by the proposed policy. Policies in their original form are rarely permanent because over time situations and circumstances change that demand enhancement to existing policy or the introduction of new policy.



Rep Erica C. Crawley

“Experiences from our youth shape what we do later in life.”

1 Response

One person answered “why not you?” and decided to become a state representative.

Erica C. Crawley represents District 26 and is championing legislation that ensures individuals with developmental disabilities are able to live a better quality of life. She shared her story and passion at the Ohio Developmental Disabilities Council meeting in March, 2020.



State Rep. Erica C Crawley's Personal Story (see rpts from Council Presentation and Columbus Dispatch, February 17, 2020)

Rep. Crawley grew up on the South Side of Youngstown (OH) where she lived with her mother, who suffered a long list of health problems and was addicted to crack for much of Crawley's youth and early adult life. She would see her father on regular occasions, but he, too, was dealing with crack and alcohol addiction. She now



suspects it stemmed from her father's service in the Vietnam War. "I can say now, what I didn't understand as a child is that he was doing the best he could managing PTSD that had been untreated," she said.

Near-constant financial trouble caused her and her mom to move about a half-dozen times. She remembers living with her aunt and cousins, at times with no electricity or hot water. They lived with her mom's friend, both sleeping on a couch. "I felt like I was trapped. I felt like I had no voice," Crawley said. "People knew what was going on in my household and nobody did anything.

But there was "Auntie Marvel" who would pick Crawley up on Sundays and take her to church, and at times would let her stay over and take her shopping, something she rarely got to do otherwise. "She would always tell me I was loved and could do anything I wanted," Crawley said. Auntie Marvel was a stable adult in whom she could confide and vent the frustrations in her life.

Life interrupted her plans many times... an unexpected and bedridden pregnancy, lack of health care, lack of food, a failed attempt at college, unemployment, a sick mother. But there was a singular event that would chart her course to become an advocate for the unserved and underserved populations.

In 2007, her Auntie Marvel went into the hospital. During one visit that occurred during the presidential election, they talk~~e~~d about who would advocate for change for her generation. "She took down her oxygen mask and said, 'Why not you?'" They were the last words her Auntie Marvel would speak to her. She never left the hospital and died three months later.

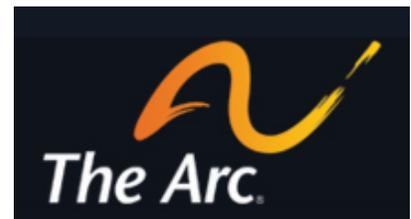
After praying on the decision of running for State Representative, it became clear to Crawley she was running for office because "why not me?" The most effective tool we have in creating stronger policy solutions is the representation of diverse backg~~g~~rounds and diversity of thought. As a part of the Ohio House of Representatives, Crawley is doing her best to introduce and support legislation that supports individuals with developmental disabilities living their best lives.

Just one response to the call to elected office: increasing awareness of parental rights for the disabled (House Bill 188); supporting authoria~~a~~tion of refundable tax credit for certain caregiver (House Bill 454); eliciting support for prescription drug readers for visually impaired patients (House Bill 214).

WHY NOT YOU?

If there is a cause that you know needs to be addressed, become a self-advocate.

Share your cause and advocacy effort on ODDC's social medial platforms.



[Click for more information](#)

Did You Know?

House Health Committee

Rep. P. Scott Lipps- District 62 (Chair)

Rep. Janine R. Boyd- District 9
(Ranking Member)

Rep. Niraj J. Antani- District 42

Rep. Jim Butler- District 41

Rep. Sara P. Carruthers- District 51

Rep. Randi Clites- District 75

Rep. Timothy E. Ginter – District 5

Rep. Diane V. Grendell- District 76

Rep. Adam Holmes – District 97

Rep. Candice Keller- District 53



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Advocating for Inclusion

Shari Cooper

ISSUE

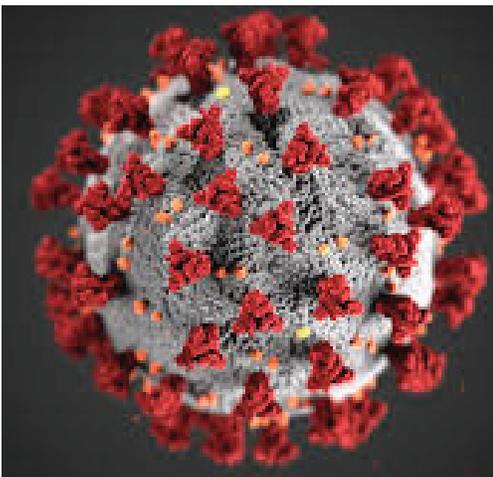
The Coronavirus, COVID-19, is a global crisis that is dramatically impacting how things are done. One primary change has occurred in the use of technology. The order by our government to engage in social distancing has increased the use of technology. Because people are unable to personally connect, they are exploring how to use technology to stay connected with their family, friends, neighbors, customers, clients, students, colleagues, members, etc. Unfortunately, if unintendedly, those without easy access to broadband will be further disadvantaged.



1 Response

Have you heard of taking a lemon and turning it into lemonade? One person did just that and decided to use blogging to advocate for people with disabilities.

AS COVID19 Turns



Well, I made it through my first week of being unemployed and the stay at home mandated rule, due to, COVID19.

I must admit, I was going a little stir crazy then I realized, there's plenty to do when owning a house, like cleaning. Since it's spring, spring cleaning is what I did. Talk about thinning out my closet. I got rid of so many clothes and shoes that when COVID19 ceases, I'll be ready to buy new ones. Of course, giving away clothes and shoes to buy new ones, was my motivation. Whatever you must do to stay motivated in this time of crisis, do it.



Visit Sharri's Blog!

I also had my first facetime doctor's appointment. How this works is, your doctor sends you a text on your cell phone with a secured link requesting your presence. After clicking on the link, both the doctor and you, can see each other. I liked this set-up. I was able to tell my doctor the prescriptions I needed refilled and get a prescription for a new scooter. When this pandemic is over, Mustang Shari will be ready to ride!

Although, I liked the doctor's appointment set-up, I was thinking, there's no way my 87-year-old mom would ever be able to do this by herself. For one, she's not techno savvy and she uses the phone, to place calls only. Unless someone is by her side to assist, she won't be seeing a doctor. *This may also be a problem for people with disabilities as well if they don't have the right technology and support to assist.*

Hopefully by Ohio being a Technology First state allowing Ohioans with disabilities to get the necessary technologies needed through their waiver to enhanced independences, *they'll consider providing classes for those who need it.* Classes would also be beneficial to programs that serve the aging population.

Since blogging to you last, I was asked by an advocacy organization to *develop a survey asking Ohioans if-advocates how's COVID19 affecting their life.* If you want to take the survey to help inform the powers that be of what we're in need of and assist in developing a plan for future crises, please drop me a comment and I'll send it to you.

I was also *asked to lend my writing skills to an advocacy newsletter* on the pandemic which should be published in a week or so. Thanks to all who are keeping me busy. You know who you are!

Just one response is making a difference: increasing awareness of the need to... consider people with disabilities as technology is being used to increase connectivity; provide training; survey and gather feedback.



WHY NOT YOU?

If you have a story and like to write, identify what you can blog about and start blogging.

the **BLOG STARTER™**

Share your blog on ODDC's social media platforms.

Did You Know?

The Trump administration is warning states and health care providers not to discriminate against people with disabilities as coronavirus spreads.

In a bulletin issued March 28, 2020, the U.S. Department of Health and Human Services' Office for Civil Rights said that the American with Disabilities Act, Section 504 of the Rehabilitation Act and other laws prohibiting discrimination in federally-funded health programs remain in effect.

Read More [HERE](#) (PDF File)

[BULLETIN: Civil Rights, HIPAA, and the Coronavirus \(COVID-19\)](#)

As such, persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person's relative 'worth' based on the presence or absence of disabilities," reads the bulletin. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence."



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Advocating for Autism

Angela Ramos Fields

ISSUE

The number of American children diagnosed with autism is on the rise yet again, according to new government data. The Center for Disease Control and Prevention said that 1 in 54 kids have the developmental disorder. That's a jump from 1 in 59 rate that was reported just two years ago. Despite the gains seen in identification of African American children, the latest report found that Hispanic children continue to be diagnosed at lower rates. And, both groups were evaluated for the developmental disorder at older ages than their white peers.

1 Response

An interview with a parent who wrote and published her story.

Q How would you describe what it has been like to be a parent of a child with autism?

A At age 3, my child began to show behavior signs that caused me concern. He was attending pre-school and had difficulty following directions, integrating into the structured environment, and tended to withdraw from other children. The physician told me not to worry, "he was a boy," and would probably develop these behaviors later. But increasingly I was concerned because my son was not learning. After being placed on a waiting list, my son was evaluated and almost immediately during the evaluation, I was told "he is on the autism spectrum." Needless to say, I was in a state of shock and from that point on experienced a myriad of emotions- devastation, resentment, disappointment, depression, fear of the unknown. I was not prepared to hear the news nor know how to navigate the systems to ensure that my son received the support he needed. There were many unanswered questions to include: Who is the best physician? What therapies are needed? Do I medicate? What type medications? What about schools?



How do we maintain consistency and continuity as he spends time with other family members in other spaces? And so many more. Parenting has been like a revolving door of emotions and continuous learning.

Q How would you describe your child?

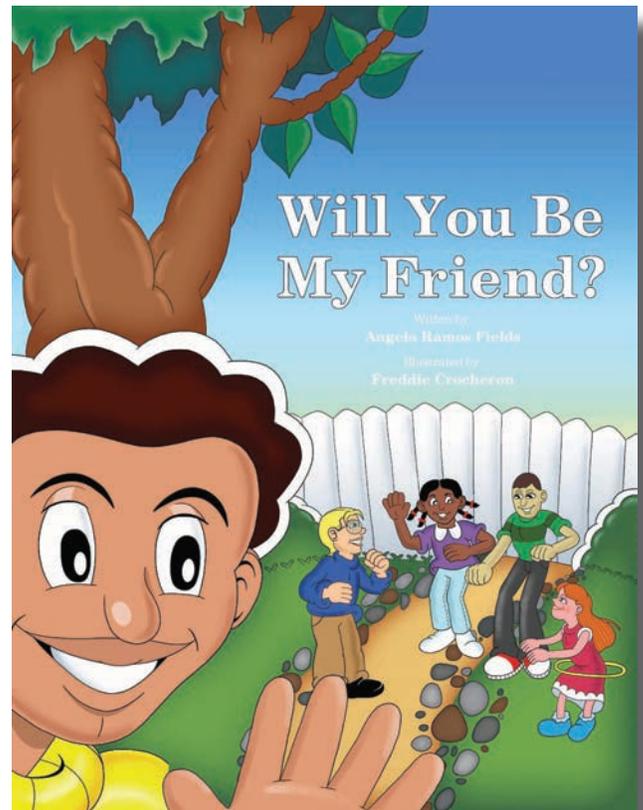
A My son is now 18 years of age. He loves going on walks, likes to be engaged, feel valued, and happy when he is contributing. He has limited verbal skills, needs lots of verbal prompts. His favorite movie is “Ice Age,” which he can watch 5x a day. And he loves all things Elmo and Sesame Street.

Q What made you decide to advocate on behalf of children?

A As a mother, you want the best for your child. It is also the love that fills my heart for my own son that motivates and inspires me to build a world for him and others where the goal of our efforts and actions is to find more solutions and best practices for assessment, intervention and medications.

Q What will be gained from reading, Will You Be My Friend?”

A *Will You Be My Friend?* is a heart-felt story about Samuel who is six years old and in the first grade. He has an amazing ability to share his life as he manages his autism that makes it relatable to young learners. The book is designed to prime the next generation of empathetic leaders. With the goal of raising autism awareness in communities, it promotes principles of acceptance, embracing differences and gratitude. The book also provides insight on how Samuel promotes anti-bullying behavior. An autism guide and anti-bullying worksheet accompanies the book. I believe the book serves as a great resource to increase awareness and educate others about Autism.



Will You Be My Friend
By Angela Ramos Fields
[Click here to find the book](#)

Q What impact do you think your book can have on getting Millennials to be empathetic and potential advocates for children with autism?

A. While I believe this book is a valuable resource for any generation, I do think that it can be a resource that engages Millennials in better understanding the dynamics of society. The book provides guidance in opening conversations on topics of autism, bullying, and perseverance, despite challenging circumstances. The main character has the ability to connect with people from all generations, particularly millennials, to promote the importance of diversity and inclusion.

Q. What has been some of the feedback that you have received from individuals who have read your book?

A. “Will You Be My Friend? is an educational, celebratory children’s book that teaches our kids about embracing the things that make us different and welcoming those differences in other people.” -- **Mayor Andrew J. Ginther, City of Columbus, Ohio**

Reading *Will You Be My Friend?* with your children or to students is the perfect way to open up a discussion about children with special needs, accepting differences, celebrating differences, respecting and including others. -- **LaVerne Thomas, Grade 3 Teacher, Grindstone Elementary School, Berea, Ohio**

Will you be my friend? This book makes it understandable for anyone that may not understand autism and some of its characteristics. Sam accepts being different and recognizes that we all are different. I loved how he recognizes that. It is a great read. -- **Salina Miller, Diversity & Inclusion, Milestone Autism Resources, Cleveland, OH**

MAKE SURE YOU WATCH THIS



WHY NOT YOU?



Consider writing and publishing your story in a book.
Share your book title on ODDC's social medial platforms.

[Click here to learn more](#)

Did You Know?

- **Boys were four times more likely to be diagnosed with autism than girls.**
- **About a third of children with autism had intellectual disability too.**
- **Median age of autism diagnosis remained greater than age 4 even though the condition can be reliably identified by age 2.**
- **Prevalence rates vary from stet to state which could be due to differences in availability of services for children with autism and their families by location.**
- **The earlier children are diagnosed and the earlier they start intervention, the better their prognosis.**



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