

# Pennsylvania Message

## WHY IS ALCOHOL DANGEROUS?



### Why is Alcohol Dangerous?

There is no known safe amount of alcohol use during pregnancy or while trying to get pregnant. There is also no safe time during pregnancy to drink. All types of alcohol are equally harmful, including all wines and beer. When a pregnant woman drinks alcohol, so does her baby.

Women also should not drink alcohol if they are sexually active and do not use effective contraception (birth control). This is because a woman might get pregnant and expose her baby to alcohol before she knows she is pregnant. Nearly half of all pregnancies in the United States are unplanned. Most women will not know they are pregnant for up to 4 to 6 weeks.

FASDs are completely preventable if a woman does not drink alcohol during pregnancy. Why take the risk?

Alcohol in the mother's blood passes to the baby through the umbilical cord. Drinking alcohol during pregnancy can cause miscarriage, stillbirth, and a range of lifelong physical, behavioral, and intellectual disabilities. These disabilities are known as fetal alcohol spectrum disorders (FASDs). Children with FASDs might have the following characteristics and behaviors:

- ✓ Abnormal facial features, such as a smooth ridge between the nose and upper lip (this ridge is called the philtrum)
- ✓ Small head size
- ✓ Shorter-than-average height
- ✓ Low body weight
- ✓ Poor coordination
- ✓ Hyperactive behavior
- ✓ Difficulty with attention
- ✓ Poor memory
- ✓ Difficulty in school (especially with math)
- ✓ Learning disabilities
- ✓ Speech and language delays
- ✓ Intellectual disability or low IQ
- ✓ Poor reasoning and judgment skills
- ✓ Sleep and sucking problems as a baby
- ✓ Vision or hearing problems
- ✓ Problems with the heart, kidney, or bones

Source: Centers for Disease Control and Prevention; check out the website for additional information at <https://www.cdc.gov/ncbddd/fasd/articles.html>.

# President's Message - Michael Marsh



## A SEASON OF GRATITUDE

Giving....This is the time of year when we think about giving as Thanksgiving starts the Holiday season for many traditions. Thinking back to the stories of the first Thanksgiving, we think about a time when people were new to this land and struggling. In fact, not everyone made it through those early years. And those who did needed to reach out for the help of people they did not know. Are there similarities when a family has a loved one with an intellectual or developmental delay (I/DD)? Just as the early settlers must

have been very overwhelmed, so too are families and the community until someone steps in to lend a hand and to share expertise and best practices. We have a long tradition in this country of trying to make things better for ourselves, our families, and those around us. The Arc was formed by families for that very purpose - to provide expertise, share best practices, and to create a foundation upon which future generations can be prosperous.

Thanksgiving would not be possible, however, without the ability of the early settlers to accept the help of others in an attitude of gratitude. As the story goes, those who benefited remembered to thank the people who shared and taught. They opened their hearts to people they did not know in order that others would benefit for years to come.

Right after the holiday of Thanksgiving we jump into several festivals and celebrations of light and hope. So many different traditions and beliefs with many of them centered on hope and bolstered again by the opportunities to share, give, and receive with gratitude. The experience is not complete unless the gift is received and the giver and recipient have a very human exchange. So, whether your traditions and beliefs include baking or sending cards, singing or lighting candles, or the rush of shopping (or placing orders on the Web), please take a moment to recall the reason for the many activities. Think of not only the intentionality of giving gifts, cards, or other symbols of caring, but also the importance of receiving the help, gift, or kindness in the spirit in which it is intended. Pause to experience the power of receiving with gratitude and the joy of giving.

In this issue, the area of focus is fetal alcohol spectrum disorder (FASD). Many families have been touched by FASD and it is one of the leading causes of I/DD. I hope this issue will provide you with some new insights and information.

This year's national convention was filled with opportunities to learn about what other states and chapters are doing across the country and to hear about some of their successes. One of the keynote sessions highlighted the efforts to include people with I/DD in the push for inclusion in media, advertising, and business. I'm very proud of the work being done by The Arc of PA and the chapters across the commonwealth. They are focused on employment and education. And it is good to see that there are efforts to be more inclusive in other areas to help open doors and opportunities for everyone.

Finally, I'd like to sincerely express gratitude for the leaders, staff, and volunteers of The Arc of Pennsylvania and all 33 chapters across the Commonwealth. The work and accomplishments of each organization requires incredible talent and impressive volunteer efforts. We are fortunate to have both in the local chapters and at the state level. Please take the time over the remaining weeks of 2017 to say thank you to the volunteers and our professionals for all they do day in and day out to make The Arc a strong voice for people with intellectual and developmental disabilities.



**The Arc**

*Pennsylvania*

Suite 403 — Pennsylvania Place  
301 Chestnut Street  
Harrisburg, PA 17101  
717-234-2621

[www.thearcpa.org](http://www.thearcpa.org)

The Arc of Pennsylvania

### Board of Directors

Michael Marsh, Montgomery  
President  
Sarah Holland, Lancaster  
1st Vice President  
John Goryl, Dauphin  
2nd Vice President  
Joshua Stranix, Schuylkill  
Secretary  
Jessica Capitani, Dauphin  
Treasurer  
Ken Oakes, Philadelphia  
Immediate Past President  
Maureen Westcott,  
Lancaster, PCE Representative

### At Large Members

Frank Bartoli, Luzerne  
Lisa Butler, Cumberland  
Richard Chamovitz, Delaware  
Cindy Dias, Greene  
Hallam Harper, Montgomery  
Gary Horner, Allegheny  
Gerald Krall, Dauphin  
Pat Leo, Philadelphia  
Lisa Long, York  
Michael Owens, Delaware  
Lucille Piggott-Prawl, Monroe  
Laura Princiotta, Philadelphia  
Phil Rosenbauer, Butler  
Christopher Schwenk, Delaware  
Sara Wolff, Lackawanna

### Ex-Officio

M.J. Bartelmay, Mercer  
Gerald Krall, Dauphin

### The Arc Staff

Maureen Cronin, Executive Director  
Anne Yanikov, Director, Advocacy  
& Governmental Affairs  
Diane Keefer, Director Finance  
Alexa Brill, Social Media & Website Manager  
Amy Houser, Administrative Support  
Matthew Stinner, Self-Advocacy Engagement  
Consultant  
Rita Cheskiewicz, Program Director,  
Include Me Preschool, School Age, & ADEPT  
Claire Sonneborn, Assistant Program Director,  
Include Me Initiative  
Mary Mahoney-Ferster, Program Specialist,  
Early Childhood, Include Me Initiative  
Nicole Turman, Program Manager, ADEPT  
Anthony Chan, Assistant Program Manager, ADEPT  
Shirley Keith Knox, Editor, PA Message

# Executive Director's Message

## Maureen Cronin

### FASD IS PREVENTABLE!



We recently recognized the month of September as Fetal Alcohol Spectrum Disorder (FASD) Awareness Month. The Arc of PA and Governor Wolf had a joint press conference. I had the pleasure of representing The Arc of PA at the press event with the Department of Human Services Acting Secretary Teresa Miller and Drug and Alcohol Programs Acting Secretary Jennifer Smith. During September, numerous organizations engaged in events to educate expectant mothers and the public on the dangers of consuming alcohol while pregnant. For The Arc of PA, this is an important issue, not just during the month of September, but throughout the year.

Fetal alcohol spectrum disorders (FASDs) are a group of conditions that can occur in a person whose mother drank alcohol during pregnancy. FASDs are completely preventable if a woman does not drink alcohol during pregnancy.

In fact, The Arc has a long history of promoting fetal alcohol spectrum disorder awareness. Over the years, many campaigns have included the message that if you are pregnant or planning to become pregnant, DON' T DRINK.

Our work is not done. We need to make sure that everyone knows the harm of alcohol on the developing fetus. We all see the warning labels on alcoholic beverages. Yet, over time, we can get desensitized to the importance of this message. Women can get desensitized to this information, all along thinking "If I don't know I'm pregnant, the alcohol doesn't count." But it does. The first trimester, especially the first weeks, is a time of early development of the brain and central nervous system. It is never too late to stop drinking and get treatment in order to help your baby have the best chance for a healthy life.

We must educate women and men about the secondary conditions of FASD that often occur throughout life. For a person with FASD, secondary conditions may include the inability to live independently or to hold down a job. It may result in mental health conditions or drug and alcohol addictions. For some individuals, this may involve the legal system as a result of unlawful activities.

We must make sure physicians and other clinicians can recognize the very distinctive characteristics of some children born with FASD, recognizing that most children born with FASD do not have the typical facial features associated with FASD. Healthcare providers, human service professionals, and early childhood teachers must know to refer to early intervention. I know firsthand how an early diagnosis leads to better outcomes for the child and the family.

To educate and to advocate: this is the ongoing work of The Arc of Pennsylvania. We must continue our efforts to:


1. Increase awareness of the dangers of alcohol use during pregnancy.
2. Know the resources in your community and make sure others know how to seek evaluation and treatment early on and when secondary conditions emerge.
3. Outreach to health care providers, human service professionals, and early childhood educators so they recognize the physical, cognitive, and behavioral characteristics of children with FASD and refer to early intervention.

What can you do?

A handwritten signature in black ink that reads "Maureen Cronin".

Maureen Cronin

***“To whom much is given, much is required –  
not expected, but required.”***  
– Andrew Young

 Find Us on Facebook

 & Connect with Us on Twitter

***Achieve with us.***

## A FAMILY'S JOURNEY: ETERNALLY HOPEFUL

My husband, Rich and I have two boys: Noah (14yo) and Kiel (10yo). Our family wasn't created the old-fashioned way. Noah came to us via international adoption from Russia and Kiel after years of fertility treatments. In many ways, we are like so many other busy American families juggling sports, music lessons, homework, and friends. Yet with therapy appointments, IEP (Individualized Education Program) and other school meetings, we are very busy. Part of our energy is focused on keeping our world small for Noah. So, we often feel like we straddle the line between "normal" and "other."



Sports is a big deal in our family. Both boys play soccer and basketball. Noah excels at soccer. It is the first place where, as parents, we could just sit back and enjoy watching him interact like all the other kids. On the soccer field, you would never know that Noah struggles with a number of disabilities. This fall Noah played on his 9th grade school team, our community team, and was chosen for his community select team.

In addition to sports we stay busy trying to keep up with homework, listening to the beginning sounds of Kiel playing his violin, and running to and from therapy appointments for Noah.

Our family also has two cats, Thor and Sera, and a year ago, we added Hercules Mulligan, a sheepadoodle puppy. The unconditional love from all of them, especially Hercules, plus their silly antics, have been a tonic for all of us.

Noah received a PDD-NOS (pervasive developmental disorder - not otherwise specified) diagnosis when he was 5. Having a diagnosis has been a blessing and a curse. A blessing because it gave us the "label" we needed to get additional services. A curse because his teachers and therapists wanted to treat him as a child with autism and use interventions that would be used with a child on the autism spectrum. These rarely worked with Noah, leaving all of us increasingly frustrated.

I first suspected Noah had a fetal alcohol spectrum disorder (FASD) after attending a retreat for mom's parenting kids with

issues related to early childhood trauma. Noah was 7 at the time. When we first adopted Noah, we had doctors in Russia and in the United States evaluate him. They ruled out FASD because he didn't show any of the facial features. But after talking with other moms at the retreat, I realized that Noah's behaviors sounded a lot like the kids with FASD that some of them were parenting.

I went home from that retreat overwhelmed, but also feeling as if I had new hope. I thought, "Maybe this would help us make sense of Noah and his behaviors." I did a lot of reading. I talked with the team of therapists and doctors with whom we were already working. Our developmental pediatrician sent us for an MRI (magnetic resonance imaging) of Noah's brain. The results of this test showed damage in the cerebellum. Eventually, we ended up at St. Christopher's Hospital and their special health care needs program, where Noah was evaluated for FASD. Certain criteria need to be met to receive an FASD diagnosis. One of those is proof that the birth mother drank alcohol while pregnant or that the child has specific facial features that have been linked to fetal alcohol exposure. Noah does not have the facial features and due to the circumstances surrounding his birth, we have no way to confirm positively or negatively if his birth mother drank alcohol while pregnant. There is an assumption however, given the rate of alcoholism in Russia, that many children adopted from there were exposed.

We had mixed feelings about the results of Noah's evaluation. In one way, we were frustrated because the diagnosis he was given was Static Encephalopathy, Alcohol Exposure Unknown. Just short of an actual FASD diagnosis. We wanted a definitive FASD diagnosis so we could start educating the people working with him. In some ways, it is easier to help other people gain understanding when you can give the disorder a label, just like the PDD-NOS label Noah received a couple years earlier.

Over the years I've come to realize that it is more important that I know. Very few professionals have knowledge of FASD, so I'm generally the one leading their education. While it is often "bang-your-head-against-the-wall frustrating" because it is almost impossible to find people to work with my son that have experience with this, I have been fortunate enough to find wonderful professionals in the FASD community. They have been helpful in pointing me in the right direction for research and resources to pass on to Noah's team.

There are a number of things that have helped me over the years help Noah. I share these with you in no particular order:

### 1. Finally understanding that Noah's brain was different.

It wasn't his fault. No child wants to be in trouble all the time. While this seems very simple to understand, it often isn't. Especially when you are dealing with your

[continued on page 5](#)

5th meltdown of the day and have already cleaned up honey from your piano keys, or found a hole in your wall that your child created. It isn't always that easy.

**2. Don't waste time working with professionals that aren't willing to learn.**

Or tell you they have all the answers. It took a long time for me to learn that it's ok to say, "This isn't working" and to move on to someone new. I spent too much time with professionals that made ME feel bad because THEY weren't helping. Instead, I found people that proved they cared about Noah and our family and were willing to educate themselves. Or most importantly, listen to us.

**3. I will never, ever, do another sticker chart or token economy again.**

Just saying that several years ago was incredibly freeing. Perhaps because it was one of the first times I really took charge of what we were doing to help Noah.

**4. Finding my "tribe."**

I found a group of women that parent kids like Noah. They have been my safe space and my rock. I know I always have someone I can talk to that gets it, or probably has dealt with worse. The retreat I went on when Noah was 7 saved me. Since then I have gone every year. Now I am an officer on the board of directors of the organization and in a position to give back to other moms that are where I was years ago: desperate and feeling very alone.

**5. Self-care.**

I used to hate this term. How could you possibly take the time to do something for yourself when your child and family were falling apart around you? Wasn't that the definition of selfishness? Recently I learned however, that NO, it isn't selfish. I had to reach bottom before I finally accepted that I needed to spend some time helping myself. There are many ways to define self-care, and they may be different for everyone. The important thing is that you do it. Don't lose yourself in the process of helping your child.

Right now, Noah is doing very well. We've seen some great growth and maturity in

him, and it's amazing how hopeful we feel for his future. A year ago, we weren't sure he could safely continue to live with us. We've been through the good, the bad, and the funny I like to say.

Resources that I've found invaluable:

**Beyond Trauma and Attachment (BeTA)**

<http://momsfindhealing.com/>  
<https://www.facebook.com/beyondtraumaandattachment/>

**Attachment and Bonding Center of Pennsylvania**

<http://www.abcofpa.net/>

**St. Christopher's Hospital**

[Center for Children and Youth with Special Health Care Needs](#)

*Kristine Needleman and her family live in Furlong, PA. She serves as board secretary for Beyond Trauma and Attachment (BeTA). BeTA is a non-profit organization run by moms of kids that have experienced early childhood trauma. Our mission is to support families who are raising children who have complex trauma and attachment issues by networking, offering support, and educating others. In addition, she is a parent member of the FASD task force for the state of PA.*

# SUMMARY OF PENNSYLVANIA FASD TASK FORCE

Gordon R. Hodas, MD

The Pennsylvania FASD Task Force consists of representatives of various statewide departments as well as community stakeholders including physicians, psychologists, social workers, and family advocates. The Task Force seeks to improve the identification and treatment for individuals across the lifespan with FASD, and also to promote FASD prevention.

Among the specific objectives of the FASD Task Force are the following:

- ✓ Development of a statewide FASD family advocacy organization.
- ✓ Ensuring that providers in all human service, legal, and educational systems are familiar with FASD, and their workforce is trained to work effectively with persons with an FASD.
- ✓ Continued FASD prevention, with the goal of engaging all relevant Commonwealth Departments in a unified approach to address FASD in PA.
- ✓ Identification of brief FASD screening tools for different age groups for use in Pennsylvania, useful approaches to FASD assessment, and support for the formal mental health diagnosis of "neurodevelopmental disorder associated with prenatal alcohol exposure, "when present."

Individuals seeking membership to or additional information about the PA FASD Task Force can contact Shaye Erhard at [eserhard@pa.gov](mailto:eserhard@pa.gov).

**GO GREEN**

**The Pennsylvania Message is now available via email. Please send your full name, local chapter, and email address to:**

**[ahouser@thearcpcpa.org](mailto:ahouser@thearcpcpa.org)**

**to receive your electronic copy.**

LEARN MORE / DO MORE

Stay Informed with PIE - The Policy Information Exchange (PIE) covers policy issues for Pennsylvanians with disabilities, their families, and advocates. The Arc Pennsylvania manages PIE for the PA Developmental Disabilities Council.

Email us at [pie@thearcpcpa.org](mailto:pie@thearcpcpa.org) to receive electronic alerts and the quarterly newsletter.

# FETAL ALCOHOL SPECTRUM DISORDER AND SYSTEMS OF CARE: INTERVENTION AT A HIGHER LEVEL

By Gordon R. Hodas MD

It is not just services that may be in silos - ideas can be separated by silos as well. For many people familiar with “systems of care” for children and their families, the presumed target population is youth with what is referred to as a “serious emotional disturbance” - e.g., bipolar disorder, conduct disorder, post-traumatic stress disorder, etc. While a system of care approach is indeed appropriate for such conditions, it is also appropriate to address fetal alcohol spectrum disorders (FASD), a developmental disorder that may result from maternal use of alcohol during pregnancy. I wrote the article below, “Fetal Alcohol Spectrum Disorder and Systems of Care: Intervention at a Higher Level,” in order to link FASD with systems of care, so that interventions addressing FASD will be more effective. The article was initially published on the Parecovery.org website, as part of the *Children’s Mental Health Matters* series (Number 52, October 2016).

## Introduction

Effective intervention for fetal alcohol spectrum disorders (FASD) is inextricably tied to systems of care (SOC) - both the use of a SOC perspective and its effective implementation. In this article, I provide a synopsis of FASD, followed by discussion of the SOC approach and its relevance to FASD intervention.

## Fetal Alcohol Spectrum Disorder (FASD)

FASD (fetal alcohol spectrum disorder) is an umbrella term for preventable neurodevelopmental disorders that result from in-utero exposure of a fetus to alcohol during any part of the pregnancy (National Organization on Fetal Alcohol Syndrome website, National Institute on Alcohol Abuse and Alcoholism website). Given that alcohol is toxic to a developing fetus, alcohol exposure can lead to irreversible, brain-based consequences and physical health problems. Thus, it is urgent that women of child-bearing years refrain from any alcohol use while pregnant. In addition, early FASD identification and intervention can lead to helpful interventions that improve an affected child’s functioning and overall prognosis (PA Call to Action, 2011).

Many children with an FASD do not have identifying physical characteristics that facilitate early identification and treatment. For this reason, FASD is often referred to as an “invisible disability.” In reality, children with an FASD, most with normal intellectual ability, have many emotional, behavioral, and cognitive challenges. These challenges can lead to academic failure and to difficulty with relationships, community functioning, understanding and processing of information, and learning from experience. Common outcomes for children when FASD is not identified and addressed may include interrupted education, use of intensive mental health services, legal problems, extreme frustration, and inappropriate blaming of the child and/or family. In contrast, early identification and intervention can make a significant difference. FASD should be

recognized as both a highly challenging clinical disorder and a significant public health challenge in society.

## A System of Care (SOC) Perspective

The SOC perspective begins with recognition that challenging clinical problems are multi-faceted - involving the child, family, multiple child-serving systems, other social systems, and the community (Pumariega and Winters, 2003). Given this complexity, there is need for common understanding and a cohesive effort that is collaborative and strengths-based. Child and family need to be encouraged to participate actively, with their “lived experience” recognized as a valuable source of expertise. A collaborative approach is team-driven, meaning that the involved stakeholders - professionals, family, and others - create and maintain an active team. A team-based approach is also family-driven and youth-guided, and incorporates use of natural supports in the community.

## System of Care Implementation

Implementation of an effective SOC involves creation of an infrastructure, through structure, policy, funding, clinical expertise, and a commitment to quality at multiple levels. This enables the complex needs of children and families to be constructively addressed through the use of needed services and supports. Also important are efforts to maximize family self-management and independent functioning as much as possible.

In Pennsylvania, federal grants fund what is known as the System of Care Partnership (PA System of Care Partnership website). This initiative involves partnerships among the following entities: the state, specific counties, behavioral health managed care plans, mental health providers, specific school districts, other involved child-serving systems, children, families, and communities. Through this initiative, the needs of both individual children and their families and the larger community can be effectively addressed.

## The Critical Interface of FASD and SOC

Families that have a child with an FASD face many challenges. Involved systems typically include education and special education, mental health, physical health, and at times child welfare, juvenile justice, and drug and alcohol. Involved professionals may include teachers, counselors, psychologists, social workers, child psychiatrists, pediatricians, case workers, specialists, and others. Given these multiple stakeholders as well as the challenges created by FASD itself, intervention efforts can be greatly compromised when they are fragmented and disjointed.

continued on page 7

In contrast, the prognosis for a child with an FASD is greatly enhanced when early intervention involves the use of a cohesive team guided by systems of care practices. This values-based approach is holistic, strengths-based, and attentive to social context. It is also trauma-informed, prioritizing safety, supportive interactions, and shared decision-making. Whenever possible, the use of High Fidelity Wraparound (HFW) as a planning process helps the team maintain a unified focus and break down change into manageable pieces (PA Youth and Family Training Institute website). HFW also helps child and family identify and access community supports. If, in addition, a parent is also found to have an FASD, appropriate adaptations can help increase the functioning of both parent and child.

It can be said that the greater the challenge facing a child and family, the greater the need for a systems approach. The same applies to resources - the more limited the resources, the greater the need for systems of care. FASD involves significant challenges to children and families, with limited resources all-too common. Intervention needs to be at a higher level. The use of a SOC approach can help families with FASD face the challenges, maximize their efforts, and persevere.

*Gordon R. Hodas, M.D. is the statewide child psychiatric consultant to the Pennsylvania Office of Mental Health and Substance Abuse Services (OMHSAS) and its Children's Bureau. He is also a member of the Statewide Fetal Alcohol Spectrum Disorder (FASD) Task Force, and of the Systems of Care Workgroup of the American Academy of Child and Adolescent Psychiatry (AACAP).*

## HELPFUL RESOURCES

- National Organization on Fetal Alcohol Syndrome  
[www.NOFAS.org](http://www.NOFAS.org)
- National Institute on Alcohol Abuse and Alcoholism  
[www.niaa.nih.gov](http://www.niaa.nih.gov)
- Pennsylvania Children's Bureau's 2011 "Call to Action: FASD Awareness, Identification, and Intervention for Children in Pennsylvania"  
[www.parecovery.org/services\\_fasd.shtml](http://www.parecovery.org/services_fasd.shtml)
- Pennsylvania System of Care Partnership  
[www.pasocpartnership.org](http://www.pasocpartnership.org)
- Pennsylvania Youth and Family Institute  
[www.yftipa.org/high-fidelity-wraparound](http://www.yftipa.org/high-fidelity-wraparound)
- Pumariega, A. and Winters, N. (eds.) (2003). *Handbook of Child and Adolescent Systems of Care: The New Community Psychiatry*. San Francisco: Jossey-Bass.

## RECOGNIZING FASD CHARACTERISTICS

### FASD in Infants

- Irritable, not responding to holding, rocking, or soothing
- Poor sucking reflex
- Decreased muscle tone/appears floppy
- Jittery, tremors, increased startle response
- Problems eating & sleeping
- Hypersensitivity and hyper-reactivity to stimuli - noise, light, activity, touch, & taste
- Problems bonding
- Difficulty grasping objects, sitting up, crawling, & walking
- Difficulty with language, talking comprehension, & following instructions
- Problems with vision and/or hearing
- Lack of stranger anxiety



### FASD in Toddlers

- Hyperactivity
- Attention deficit, easily distracted
- Low frustration & low tolerance
- Cannot organize own play
- Poor motor coordination
- Language problems of various types
- Lack of physical boundaries - may touch others in inappropriate ways
- Overly friendly behavior - lack of stranger awareness
- Cannot follow instructions
- Temper tantrums
- Toilet training delays
- Thumb sucking and other persisting infant behaviors



### FASD in School Age Children

- (Often not diagnosed until elementary school, or not at all; especially those with a normal or higher IQ and normal physical appearance)
- Uneven development
  - Cognitive deficits & learning difficulties
  - Short term memory problems
  - Tendency to follow others, seeking to belong to social group
  - Language deficits, especially comprehension
  - Inability to tell you what they want or need
  - Difficulty following instructions
  - Does not understand personal boundaries



continued on page 8

# PENNSYLVANIA JOINS WITH THE ARC OF PENNSYLVANIA TO PREVENT FASD

“The Arc has a long history of promoting awareness regarding the impacts of alcohol use during pregnancy. FASD Awareness Month is an opportunity to broadcast the message that there really is no known safe amount of alcohol during pregnancy,” said Maureen Cronin, Executive Director, The Arc of PA. “Let’s give our babies their best chance at life.”

Alcohol disrupts proper development of fetal organs, even at very early stages of pregnancy - before a woman may know she is pregnant. Alcohol passes from the mother’s bloodstream into the developing baby’s blood stream. Damage to a baby’s brain caused by the mother’s alcohol use can result in problems throughout a person’s lifetime: impaired memory, learning disabilities, inability to think and reason properly, deficits in sensory processing, impaired ability to interact or socialize with others, and disruptive or otherwise inappropriate behaviors.

The Centers for Disease Control and Prevention estimates that between 2.4 to 4.8 per 100 children have FASD. The damage of FASD caused by a mother’s drinking during pregnancy is permanent and 100 percent preventable. The impact on children born with FASD is staggering:

- About 80% enter the foster care system or adoptive care system.
- Over 60% will have a disrupted school experience of suspension, expulsion, or drop out.
- 95% will develop depression and often other mental health issues.
- 70-80% will not be able to maintain employment and will not be able to live independently as adults.
- More than 50% of males and 70% of females will have substance use disorders.
- 60% will encounter problems with law enforcement, with most of them spending time in a juvenile and/or adult correctional facility.

“The lifelong impact of this from a physical and mental health perspective is overwhelming, but the financial impacts are just as severe,” said Teresa Miller. “The

lifetime cost of care for one individual with FASD can reach \$2 million.” “It’s not all doom and gloom,” said Miller. “People with FASD are people with special needs, but first and foremost, they are people. And like most people, they have positive attributes, talents and abilities, and some become very skilled in a profession.” In spite of all of the adversities that they face, people with FASD can graduate from college, own a business, become employed skilled craftsmen and craftswomen, and live independently.

While there is no cure for this condition, early intervention can improve a child’s development and enable them to live an everyday life. “With early identification and diagnosis, children can receive services that can help maximize their potential. The commonwealth provides early intervention services to infants, toddlers, and preschoolers with a diagnosis of FASD and ongoing support and treatment throughout the life span,” said Miller. “Local early intervention programs work closely with pediatricians, hospitals, and children and youth agencies so that children at risk for FASD are referred to early intervention for a developmental evaluation.”

Many people with FASD benefit from the support of one-on-one counseling. In addition, they often require intensive service coordination if they do not have someone who can coordinate the many services they need (such as ongoing individual therapy, job coaching, housing, and transportation). “The Wolf Administration wants to spread the word to all Pennsylvanians - if you are pregnant or trying to get pregnant, don’t drink alcohol,” Jennifer Smith said.

*Source: Excerpts from September 2017 press release. Department of Human Services Acting Secretary Teresa Miller and Drug and Alcohol Programs Acting Secretary Jennifer Smith were joined by The Arc’s Executive Director Maureen Cronin, individuals impacted by Fetal Alcohol Spectrum Disorder (FASD), and advocates to raise awareness and discuss prevention of the disorder.*

FASD Characteristics continued from page 7

- Unable to tolerate over stimulation (noise, motion, bright lights, too many people)
- Clumsy & disorganized
- Hyperactive
- Poor peer relationships, socially inept, cannot make and keep friends
- Does not understand cause and effect
- Sleep disorders
- Disobedience, defiance of authority
- Lack of understanding social norms and rules
- Visual and perceptual problems which may not be identified earlier
- Hearing problems, if not identified earlier
- Poor sense of time and direction
- Drama queens and kings, attention seeking behavior, create chaos

## **Most Important - Positive Attributes in Children, Teens, & Adults**

- Cuddly, affectionate & cheerful
- Fun
- Loving, caring, concerned about others when not focused on self
- Determined & persistent
- Spontaneous & curious
- Creative, artistic (music, visual arts, dancing)
- Kind and caring towards younger children & animals
- Will help when asked
- Highly verbal - a chatterbox
- Mechanically inclined & likes repetitive tasks
- Good gardeners, plant keepers, animal keepers
- Energetic, hardworking when conditions are right
- Athletic

Contributor: Lyn Becker, MBA, RMA, FASD Parent Advocate, Educator & Activist



## A SISTER'S PLEA



Today I will attend a meeting at one of our 25 State Correctional Institutions as part of my work assignment. I accepted the assignment because I believe I am more prepared than my coworker who was originally assigned. My coworker has never set foot in a prison. To the contrary, I have been a prison visitor off and on for two decades. This is information that I have not shared in my work environment because others believe that going into a prison would be like going to Mars; it just isn't going to happen. I used to think that too.

My brother's birth mother drank alcohol while she was pregnant. He was given up for adoption at birth; absolving her of future responsibility. Her consumption of alcohol affected her unborn child's neurological development.

She never knew about Daniel's delayed development; his poor coordination and memory; his poor judgment and impulse control; and his constant struggle with logical, verbal, social, and emotional connections. Physically, Daniel appears fine. Socially, he's eight or sometimes a young teen. He's polite, kind, interested, and curious. I see Daniel as a child living in an adult body: in a cage (cell) amongst an adult prison population because his brain cannot pair consequences with actions.

Everyday family life was borderline manageable for Daniel. His IQ was "70ish" so he bounced between special education and mainstream classrooms. I remember my mom describing Daniel's hyperactivity as "He's hanging from the chandelier." I remember how cruel kids can be. No one understood fetal alcohol spectrum disorder (FASD). There's no mercy for holes in one's brain and no comprehension of the inability to multitask. You see,

information processing for Daniel wasn't teachable as it was for other kids. His language, reading, and writing skills were severely delayed - hardly a foundation for future adult success.

Daniel's short attention span, stubbornness, and inability to follow directions were harshly punished by my Dad. He must have thought, "How else would you get your son (the prodigal adopted child) on "the right path?" He would yell, threaten, and eventually he used the belt. Thinking about it now, this was probably more damaging to me and it was certainly ineffective for Daniel. I protected and consoled my brother, hence my decades of human service employment.

Somewhere in the fog, my weekly or biweekly calls with Daniel stopped and I accepted a collect call from a county jail. The charges against Daniel were horrendous. I believed in his innocence and posted bail. I told no one. He then lived under my watch until the charges were dismissed.

The next few prison stints, all for less severe charges, were always 'someone else's fault'. I eventually realized I could not rescue him. But, I continued to accept the collect calls and filled his commissary account with money that I begged/borrowed from my Dad who really couldn't be bothered. Saturdays were spent driving 3 hours for a 30-minute phone visit. Twenty-two years ago, I had promised my mom, on her deathbed, that I would 'take care' of Daniel. By my own standards, I have failed, or at least I fail periodically.

I did have Daniel evaluated and it was the result we already knew - FASD! The diagnosis opened the door to treatment and adult services. I wish we had done this sooner. Through a non-profit agency, Daniel received service coordination, culinary training, and GED (General Equivalency Diploma - a high school equivalency diploma) prep instruction. We were exceptionally grateful for the day programming, vocational support, and the accountability it required of Daniel. It was a starting point. However, when Daniel was unable to obtain the

Safety Serve Certification or pass the GED, it tipped the failure scorecard. Nevertheless, major kudos for the ongoing and selfless dedication of Daniel's supports coordinator; unfortunately, his missed appointments understandably severed that resource.

From Daniel's perspective, more than a job and stability, he wanted 'family.' My father had moved on with his life and sadly, Daniel would have done anything for a relationship with him. In fact, just prior to my dad's passing, Daniel sped from Pennsylvania to Hilton Head, South Carolina and into the Hospital's intensive care unit to see my Dad alive one last time. Yet, because he bypassed the general visitor sign-in and Central Disease Control guard outside my Dad's room, my dad's wife called the police. She deemed my brother "a dangerous monster". During the time he was fleeing the police, my father died. Daniel believes my Dad's wife caused his death. Even my sister is not an ally. She bowed out of family dysfunction decades ago and although she and I have a relationship, I know never to speak of my brother, as he is dead in her world.

Daniel is now fifty years old and living in prison. He is awaiting sentencing for new (unrelated) charges. I've upheld some boundaries for my own health and now that my children are adults, I've shared some details with them. I have talked to Daniel about FASD at nauseam, but he'd rather talk about electric cars, life in Denmark, or my Mom's old recipes ..... that's just how his brain is wired.

Regardless of the subject, I want a conversation with my brother that doesn't require me to empty my pockets and walk through a metal detector; but I worry about that too. Without services; his freedom is temporary. As a family member, I am sad and exhausted. As a professional and public servant, I am encouraged and optimistic. There is now an active platform for FASD to be recognized statewide. And it includes education that treatment is available. It provides hope to families and sisters. And we must remind people that this can all be prevented. Don't Drink!

*The author of this article has requested anonymity. The author lives in Central Pennsylvania.*

# STRATEGIES FOR LIVING

These tips are here to help make your daily life easier. Whether worried about an infant, struggling raising an adolescent, encountering challenges working with an adult, or as an educator having difficulty with a student with an FASD, you might find the following strategies and suggestions useful. With each stage of life providing a new challenge, simple, practical solutions can be invaluable.



## FOR INFANTS

CONCERNS	STRATEGIES
Poor sleep-wake cycles/irritability	Play soft music and sing to your baby. Rocking, frequent holding, low lights, automatic swings and wrapping them snugly in a soft blanket also can be helpful.
Poor weight gain	Consult a nutritionist to develop a food plan or discuss supplement use.
Chronic ear infections	Speak to a specialist about evaluating your child's hearing and effectively treating infections.
Delays in rolling over, crawling, walking	See an occupational therapist for assistance. Also help your baby in crawling, grabbing and pulling.
Speech Delays	Consult a speech therapist and purchase tapes or toys that are specifically designed for children with delays. Speak and read aloud expressively to your baby.

## TODDLERS

CONCERNS	STRATEGIES
Continued motor skill delays	Work with an occupational or physical therapist. Use toys that focus on manipulating joints and muscles.
Distracted easily	Establish a routine and use structure. Simplify rooms in the home and reduce noise and other stimulation.
Dental problems	Consult a pediatric dentist. Your child may not be able to sit still, so be sure to prepare your child for the exam and allow more time for the appointment.
Small appetites or sensitivity to food texture	Serve small portions that are lukewarm or cool and have some texture. Allow plenty of time during meals and decrease distractions such as television, radio or multiple conversations.

## SCHOOL AGE

CONCERNS	STRATEGIES
Bedtime	If your child cannot sleep at night, shorten naps or cut them out completely.
Making and keeping friends	Pair your child with another who is one or two years younger. Provide activities that are short and fun.
Boundary issues	Create a stable, structured home with clear routines and plenty of repetition.
Attention problems	Medication may be helpful. Keep the child's environment as simple as possible, and structure time with brief activities.
Easily frustrated/tantrums	Remove your child from the situation and use calming techniques such as sitting in a rocker, giving a warm bath or playing quiet music.
Difficulty understanding cause and effect	Repetition, consistency and clear consequences for behavior are important.

## ADOLESCENCE

CONCERNS	STRATEGIES
Anxiety and depression	Medication may be helpful, as well as counseling or encouraging your child to participate in sports, clubs or other structured activities.
Victimization	Monitor the activities of your child and discuss dealings with strangers.
Lying, stealing or anti-social behavior	Family counseling is helpful, as well as setting simple and consistent rules with immediate consequences.

continued on page 11

## ADULTHOOD

CONCERNS	STRATEGIES
Housing	Finding appropriate housing for adults affected by FAS/FASD is extremely challenging. Contact your state’s department of disabilities to pursue residential funding and get on every waiting list you can find that offers housing options.
Poor peer or social relations	Enroll your child in classes or social clubs for adults with disabilities
Mental health issues	Provide structure, routine, and plenty of activities. Investigate medication options and counseling
Handling Money	Many FAS adults need the family to handle all financial matters.
Difficulty obtaining or keeping jobs	Investigate trade schools, job training programs or job coaches. Be sure to select jobs that offer structured, routine activities that won’t cause overload or stress.

**Routine:**

- Keep your family’s routine as consistent as possible.
- If the family’s routine or schedule changes, remind your child about changes.

**Behavior:**

- Learn how to tell when your child is getting frustrated, and help out early.
- Make sure your child understands the rules at home.
- Tell your child about what will happen if he or she has good behavior or bad behavior at home.
- Let your child know when he or she has good behavior.
- Teach self-talk to help your child develop self-control. Use specific, short phrases such as “stop and think.”

- Repeat everything you say and give your child many chances to do what you ask.
- Be patient.
- Give directions one step at a time. Wait for your child to do the first step in the directions before telling your child the second step.
- Tell your child before you touch him or her.
- Be sure your child understands your rules, and be firm and consistent with them.

Source: *National Organization on Fetal Alcohol Syndrome - (800) 66-NOFAS; <https://www.nofas.org/>*  
 Check out all the resources that are available for parents and professionals at this website.

## AT YEAR IN REVIEW

by Sandi McNally & Kim Singleton from Pennsylvania’s Initiative on Assistive Technology

Since we work in the field of assistive technology (AT), we often hear, “What’s new in AT?” The answer is... a lot!

The lines between mainstream and specialized technology are fuzzy. Items that are everyday tools for many of us meet a real-life need for someone with a disability. In past issues, we have talked about Amazon Echo and Google Home. In December, 2017, Apple will release the HomePod. Many of us use these “digital assistants” as convenience items. They can solve real problems for people with disabilities. We can command them to play music, add to our shopping lists, answer questions, etc. For a person with a disability, these devices, automate tasks in their home. The digital assistant can combine with other “smart home” devices to control lights, thermostats, ceiling fans, locks, vacuums, and more.

Other examples of using digital assistants as AT: setting alarms, setting timers, checking daily schedule, or adding to a shopping list. We talk...the device listens. If the person has difficulty speaking, digital assistants can recognize computer voices from speech generating devices and apps.

Another handy service is Ask My Buddy - a free service that works with Amazon Echo, Google Home, and Cortana (the Windows digital assistant). After setting up a free account [www.askmybuddy.net](http://www.askmybuddy.net), you can create an emergency contact list, or “Personal Alert Network”. Then, when you need help, use the Ask My Buddy voice command. The device will send an email, text message, and voice message to their Personal Alert Network. It



is not a substitute for 911, but can give people peace of mind when living on their own. You know that you can contact someone quickly if needed, without using the phone.

People everywhere are getting involved with the “Makers Movement.” People come together in community spaces to develop unique products. The Internet and modern technology has made it easy for people to create tools without expensive companies. This trend continues to gain momentum. It has implications for people with disabilities because it can meet our specific personal needs, it also can create jobs for people with disabilities.

Not all tools need to be fancy or complicated. Did you know that we have a project in Pennsylvania that makes unique, personalized adaptive tools for people with disabilities? We are making these strong and beautiful items out of common materials like cardboard, glue, and paint. People make everything from chairs to bed trays and more!

If you want to find out more about technology and tools for Pennsylvanians with disabilities, please contact us at [ATinfo@temple.edu](mailto:ATinfo@temple.edu), 800-204-7428, or visit <http://disabilities.temple.edu/piat>. Like us on Facebook: [www.facebook.com/PIATTempleU](http://www.facebook.com/PIATTempleU).

Non-Profit Org.  
US POSTAGE  
PAID  
Harrisburg, PA  
Permit No. 649



# The Arc™

## Pennsylvania

The Arc Pennsylvania  
301 Chestnut Street  
Suite 403, Pennsylvania Place  
Harrisburg, PA 17101  
717.234.2621  
www.thearcpa.org

The Pennsylvania Message is published by The Arc Pennsylvania.

The Arc Pennsylvania is affiliated with The Arc of the U.S. and 33 local chapters serving 57 counties and 8,000 members.

## THE ARC OF PA'S WORK IS RECOGNIZED

*Photo 1 (left)*

Rita Cheskiewicz and Nicole Turman attended the PEAL Center's annual Inclusion Awards dinner at LeMont in Pittsburgh. Rita and Nicole accepted the PEAL Center's Advocacy in Inclusive Education Award on behalf of The Arc of PA's Include Me program.

*Photo 2 (right)*

Rita Cheskiewicz, Nicole Turman, and Anthony Chan participated in the Marc Gold & Associates retreat in Ocean Springs, MS. They joined colleagues from all over the United States at the 9th Annual Retreat at the Gulf Coast Research Lab at the University of Southern Mississippi. The retreat provided clarity and consistency for those who have hands-on experience with the strategy of Discovery. The intent of the retreat was to develop a common understanding of the



powerful concept of Discovery and to establish a cadre of stewards who can share the approach with others. Mike Callahan, President of Marc Gold & Associates, invited Rita, Nicole, and Anthony to provide an overview of The Arc of PA's work in PA to serve as a model for other states.

### MISSION STATEMENT

*The Arc Pennsylvania promotes the human rights of people with intellectual and development disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.*