

FASD News and Views



A Michigan Coalition for Fetal Alcohol Resources, Education and Support (MCFARES) Newsletter






Established in 2003

Questions We Are Asked

Question: *We are going to visit family during the Christmas break this year. Our first destination is a 6-hour drive from our home. We'll stay there for about 3 days then drive another 3 hours to our second destination where we'll stay for four days. The ride home will be about 7 hours. Both children struggle with adapting to new environments, are easily overstimulated and have significant sensory challenges. How do we prepare our children, ages 6 and 4, who are both on the fetal alcohol spectrum?*

Answer: Is it possible Andy Williams was wrong and it's not the "Most Wonderful Time of the Year?" Our families may have a bit more of a challenge "With the kids jingle belling and everyone telling you be of good cheer" but with a plan we can make it "the hap- happiest season of all." First, consider your plan. Is it realistic and must you accomplish the whole plan as it is laid out? Perhaps a longer visit at only one location or rethinking the plan and staying home for a quiet Christmas break would work for your family.

Before leaving for the trip, prepare the children. Show them pictures of the people they will meet and the places they will stay during your visit. Talk about the activities that you will do. Put pictures of the people, places and events into a book that you can

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review with them during the car ride and before each event.

Think about the car ride, how well do your children travel? Plan for breaks to stretch, use the restrooms and run around. Don't force them to sit still and quietly for longer than they can handle. If possible, drive during their normal sleeping/napping times. Plan activities for them to do while you are in the car.

Perhaps they like watching videos or they'd like to play some driving games (for example, <http://www.momsmivan.com/>). Bring their favorite comfort items such as a blanket,

pillow and/or a stuffed animal. If feasible, plan to stay at a hotel near family so that the children have a quiet place to unwind and relax.

Once at your destination, or preferably even before, plan for a quiet space for you and your children to go to when they're overwhelmed. Educate your family about the needs of your children prior to your arrival and how they can help to support your family. Re-think taking the trip if your family is unwilling to support your family or is unwilling to adjust their expectations and plans. Put your children's needs first and let their needs and behaviors direct the activities you choose to participate in. Know your child's clues that they're getting

overwhelmed and overstimulated and make changes before the situation gets out-of-control.

Prepare your children for meals and for experiencing foods that may be different than what you regularly eat at home. If you think they may not eat what is served at meals, plan for them to eat before the meal is served or prepare a special plate for them to enjoy while everyone is eating together.

Remember that due to all the changes in their schedule, your children may be more anxious and may need more rest. Allow for time to nap or for other quiet activities.

If you have any FASD-related questions, please send them to Charisse at charisse@mcfares.org

FASDay Summary

MCFARES and Project SAFE families recognized International Fetal Alcohol Spectrum Disorders Awareness Day on Saturday, September 12th at Fellowship Chapel in Sterling Heights, MI. Twenty-six supporters enjoyed a pot-luck dinner, playtime in the gym for the children and a trivia game for all. Everyone learned ways to support affected individuals and agreed to help spread the word about the dangers of pre-natal alcohol exposure.



Paradigm Shift

By Karen Tarr

Since beginning a Master's Degree program I have learned many new things and my world view has been challenged and changed in radical ways. It has been an exciting year. I have gained a new understanding of how and why teachers teach the way they do. I have also changed my mindset, my perspectives, and my opinions about almost everything to do with teaching and students. The agents of these changes have been professors, students, textbooks, videos, assignments and experiences in the classroom.

I used to have a fixed mindset. I thought that some students would succeed because they possessed the intelligence and motivation to do so, and others simply did not have the innate ability to do well in school or life. I believed that some people are smart and others just aren't. My way of thinking began to change when I read the book *Mindset* by Carol Dweck. The book was full of stories about children whose mindset was changed from a fixed to a growth perspective and as a result, their achievement and performance went from failure to success and attitudes went from defeat to determination. Reading this book created a sense of hope in me as I accepted the premise that every child has potential. I realized that when a child fails to learn it is due to a lack of belief not a lack of ability. I have decided to believe that I can change and I now choose to have a growth mindset.

One day a few years back, before I had children of my own, I criticized my sister's method of disciplining her two-year-old son. My Dad told me not to worry. He said, "Once people are grown up, it is really hard to tell the difference between the ones who were naughty as children and the ones who weren't." My father's point was that almost all children will mature into responsible adults. Pondering this and thinking about the adults I know, I realized that it is true. But it was not until recently that I realized just how profound his words were.

In September, when I read Carol Dweck's *Mindset*, my lifelong assumption that "people do not change" was challenged. Dweck says, "All brains have the ability to change and get stronger when they are used." Her research on conditioning people to switch from a fixed mindset to a growth mindset convinced me that people can and will change when they have the desire to change. This realization was a truly paradigm shift in my way of thinking about human potential. As a teacher it is my responsibility to recognize and help students to believe in their own potential.

Another change in perspective was set in motion when I received an invitation. A group called SAFE invited me to attend a meeting. SAFE is a support group for families of children affected by Fetal Alcohol Spectrum Disorder (FASD). The meetings are usually closed and serve as a time when families can relax and discuss the stresses they experience raising children with FASD, free from the critical eyes of those ignorant about the disorder. Once a year they hold an

open meeting in hopes of increasing awareness of FASD. I am so glad I accepted that invitation, it led to a revolution in my heart toward individuals with FASD.

That night I picked up some informational material on FASD that amazed and dismayed me. I learned that people affected by FASD may exhibit any or all of the symptoms of all the following disorders combined: Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder, Sensory Integration Disorder, Autism, Bi-Polar, Reactive Attachment Disorder, Depression, Oppositional Defiant Disorder, Trauma and Poverty. Sometimes Fetal Alcohol Spectrum Disorder is called the invisible disability because there may not be any outward visible signs of the disorder. Signs of FASD are: not paying attention, daydreaming, poorly motivated, lazy, defiant, or distractible. People affected by FASD may be overly sensitive to noise, light, texture, or pain. They may focus on little things, seem picky, or avoid eye contact. Students with FASD may need more re-teaching or seem to be starting from scratch, because they have memory deficits. FASD students tend to hide their issues because they do not want to seem different. They may become disoriented by change and have trouble with organization, anxiety, irritability, stubbornness or repetitive behavior. It is often difficult for them to see patterns or identify cause and effect and they may need prompts and cues in spite of trying to be self-sufficient. I felt overwhelmed and discouraged by what I read,

However, I already knew that difficult as this disorder is, it is not without hope. One of the presenters at the SAFE meeting was a remarkable young lady named Ana. Ana is affected by FASD. As Ana spoke, I was able to hear from the student's perspective about the difficulties, stresses, and anxieties experienced by an individual with FASD. Ana and her mother told the group about, Barkley, her service dog. Ana was able to recognize that a service animal would be the ideal solution to help her cope with the anxiety she experiences as a normal part of her day at school. Ana's family got a dog for her and she eventually convinced them that she was capable of taking her dog through the training program to be a FASD Service Animal. After successfully completing the training, Ana and her dog appeared at a hearing before the school board for her school district. Ana was granted permission to bring her service animal to school. I was so impressed by what this determined young woman has accomplished and I began to see that because she has hope, there is hope for her.

As I watched Ana I realized that I have met other children who are very much like her. In my work as a substitute teacher I have encountered children with the characteristic facial features of FASD and many children who wrestle with social and academic difficulties. I remember one such student; an eighth grader named Patty. She was very vocal with very high energy; it felt like she was demanding my attention. That day after lunch several of the students I had seen for computer lab in the morning were also part of my fifth hour social studies class, including Patty. The group was noisy, and active. I explained the assignment and told them to get to work but the students did not settle down. I spent the class period circulating around the room prompting students to stay on task and managing disruptive behavior. Patty was one of the students who had been out of her seat repeatedly. She was talking to some other girls when

suddenly the situation erupted. One of the girls stood up and shoved Patty with so much force that she fell down. I saw the girl turn around and give a satisfied smile to her friends as Patty went down. When I spoke to her, the girl seemed to feel her attack was completely justified because Patty had refused to stop bothering her. It was a very strange situation and seemed stranger still when I learned later that although I had referred both girls to the Principal's office, Patty had been punished and Sydney had not. It was not until the SAFE group meeting that I started to understand what had happened.

During that evening with the SAFE group I found myself thinking about Patty and I realized that she has some of the characteristic facial features associated with FASD and it dawned on me that Patty may be affected by FASD. Looking at the situation with that possibility in mind I conjectured about what happened. I suppose Patty was blamed for the fight that day because she frequently has trouble getting along with other students. If Patty is FASD, she may be unable to recognize social norms or interpret signals; because of this, other children may become annoyed with her. She has probably been told to leave others alone and stop provoking behaviors. But an individual with FASD may not be capable of changing her behavior. Her teachers and counselors are probably frustrated with her inability to change her behavior; they very likely assume she doesn't care and chooses to continue the behaviors that are causing problems. My eyes were really opened that night to the difficult situations faced by students affected by FASD. I realized that greater understanding of what is behind a student's behavior could lead to very different outcomes.

Because of everything that I have learned this year, I now view the behavior of students from a different perspective. I used to find some students annoying, or disobedient or badly behaved. Now I realize that many times they are just trying to survive in a world they don't understand. I recognize that my role as a teacher is not to manage and endure the behaviors that make teaching difficult; rather my responsibility is to understand the challenges faced by many students and to manage the learning environment and adapt my teaching methods to help them to succeed socially and academically. I believe that if teachers and counselors understand their students better they will be better able to help them cope with the stresses of school while coaching them toward better relationships with their peers. If we strive to do that, any student can succeed. I can truthfully say that I have changed my thinking in a revolutionary way and I have undergone a complete transformation in my expectations and hopes for every student.

Karen's major is Master of Arts in Elementary Education from Oakland University. She hopes to teach 5th or 6 grade and will graduate in April of 2016.

Free Book

Addressing Fetal Alcohol Spectrum Disorders is available for free from SAMHSA, and may be downloaded. See <http://store.samhsa.gov/product/TIP-58-Addressing-Fetal-Alcohol-Spectrum-Disorders-FASD-/SMA13-4803>

Are We Home Yet? Can I Release My Frustration?

By Laurel Smith

Our daughter has multiple diagnoses, FAS, ADHD, probable PTSD, early trauma, Hashimoto's Disease are the current ones. She's outgrown CAS (Childhood Apraxia of Speech--hard to understand her speak), FTT (failure to thrive--she was the size of a thin American 4 month old at adoption...she was 25 months old), and a few more. Our son seems to be headed for another diagnosis now. He also had early trauma (orphanage life) and has ADHD. Yes, our house can be very lively, very loud!

One of the things that happens with my kids is that they 'hold it together' in school, at church, at most social events until we get home. Then it all breaks loose. It's usually not screaming rages anymore, it's more like a building anger. If I give them time to 'decompress' before asking questions or requiring homework to be finished, things usually go better. The anger that used to be directed at me is now usually directed at each other--mean words, slaps, kicks, punches when I'm not watching, hurting the animals in little ways: a small pinch, an ear tug, pulling a paw a bit too hard.

Lately, we have not been taking our daughter back to church for middle school group time. This was a choice I made because of a number of issues. While she would have a GREAT time there, there are hundreds of kids and she's among the smallest. Three times, she had the wires knocked off her braces while kids were trying to grab candy that was thrown. (I don't think anyone should need a mouth guard for youth group time! LOL!) She doesn't understand the messages. She loves the music and the social aspect but the messages are way over her level. Lastly, the fallout at home became extreme. She wouldn't go to bed, she was too hyped up. She would stay awake till midnight and be angry the next morning when I got her up for school. It just wasn't worth it.

We run into similar problems going on vacation. If we stay with relatives, both kids will act pretty good for the 3-7 days we are there. Usually around day 3, we have building anger and nerves. By day 5 or 6, I'm spending lots of 'time in' with them. (Time out means they are alone in a room & who knows what they'll do--rip things to shreds, hurt themselves, even worse?) I usually dread vacation times because I know I will be "ON" 24/7 for the next 'x' number of days. I am thankful for their medication but that only goes so far. They certainly don't become zombies on it!

When we have 'time in', I try to remember to pray aloud with the kids. To ask God to forgive me for being harsh and help me have a loving spirit. I also mention the reason for the 'time in'. Parents of 'typical' kids might say this happens with all kids. I know it does, just not to the extent, the constant extent it does here. Parenting 2 kids is hard, parenting 2 kids with multiple needs multiplies everything.

I am thankful for friends who cheer me on from near and far. Social media has helped with support groups, so I know I'm not going crazy. (or not completely so--just a little off kilter!) I am thankful for God putting these people in my life. I am thankful I know Jesus and I can pray to Him ALL THE TIME. I am thankful for seeing the small miracles everyday. I am thankful God gave me a husband to balance out my wacko moods when things get to me.

Fallout is hard. VERY, VERY hard. Teachers don't understand how the perfectly great kids at school could go home and 'flip out'. Church leaders don't understand how having a fun time can cause problems at home. It's very real. We make choices to keep schedules and routines so we don't get very much fallout at home. If I tell you we can't make it to a function, please be kind. We aren't shunning you, we are trying to manage our kids and our home life.

For now, we need a calm, scheduled routine. Maybe someday my kids will be able to go to fun youth group meetings, come home and just talk about it, not try to hurt the animals and stay up till midnight. Thank you for understanding our choices.

Macomb Daily – Program helps children who experienced trauma – 1 Oct 2015

<http://www.macombdaily.com/health/20151001/program-helps-children-who-experienced-trauma>

Braggs

Gabby...



...turned 13, and received 80 cards from friends and family. It took her two hours to open them all.

Cindy...



... age 18, applied for her first job, and will attend Michigan Career and Technical Institute in February.

Joshua...



... age 21, is participating in a work experience in the kitchens of Henry Ford Hospital.

Things Our Kids Say

- I had to show a 6th grade boy how to use the push button phone in the lobby. 'It doesn't have a SEND button...' I dialed the number for him, told him to watch & keep the phone up at his ear. "Oh! It has sounds for the numbers!" Thumbs up with a grin when it connected & he heard ringing.
- “Mom, your daughter is talking to her shoes,” said by the 18-year-old about her 14-year-old sister who was treating them just like a baby as she washed them.
- Me (while loading the dishwasher): Do you have any bowls in your room?
Him (21 years old): Nope.
Me: What about the salad bowl you were just using?
Him: Yeah, that’s in there.

GoodSearch

Please consider helping MCFARES to raise funds to support individuals and families who are affected by pre-natal exposure to alcohol. Each time you conduct a search at <http://www.goodsearch.com/>, a donation is made to MCFARES. Please designate MCFARES as your charity of choice. You can also use GoodShop for your on-line shopping needs. A percentage of your on-line purchases will be donated to MCFARES.



Kroger Community Rewards

Please consider registering MCFARES as the beneficiary of rewards using your Kroger Plus card. The MCFARES organization number is 91150. We thank you for your support. Funds raised will assist MCFARES in providing support to individuals and families affected by pre-natal exposure to alcohol.

Project S.A.F.E. (Supportive Activities for Everyone)

Project S.A.F.E. is a monthly pot-luck activity for families who are living with FASD. Our families come together for a meal, play time for the children and time for support for adults. Project S.A.F.E. is held at Fellowship Chapel at 12875 14 Mile Road, Sterling Heights, MI 48312. We usually meet on the 2nd Saturday of each month. If you're able to join us, please contact Charisse at charisse@mcfares.org to RSVP and confirm that the activity will be held as scheduled. Note: Unless other arrangements are made, these meetings are reserved for family members only.



Donate Time – Work with Us!

Do you have a few hours to spare? We have several different opportunities to help you put your spare time to good use. Do you like kids? Maybe you can enjoy Project S.A.F.E. with us and supervise the children after dinner so that parents have some time to talk. Do you have website-building skills? We'd love your help re-designing and updating the MCFARES website. Do you have newsletter-designing skills? We could use your help putting the quarterly MCFARES FASD News and Views newsletter together (we'll develop the content and you can organize it into the newsletter).

Pure Michigan



The Dossin Great Lakes Museum on Belle Isle and the Detroit Historical Museum in Midtown are great Detroit-area destinations when cooler winds blow.



Support Groups for FASD in Michigan

(not all groups are specifically for FASD support)

(Please phone or email contact person prior to attending to ensure that group is still meeting. If information has changed, please email Charisse at Charisse@mcfares.org).

Alpena County

FASD Family Support Group, Meets 3rd Wednesday of each month; 6:30 – 8 p.m., Thunder Bay Transportation Authority, 3022 US23 S, Alpena. Contact Mary Schalk at maryschalk@frontier.com 989-734-2877 for more information.

Eaton County

Eaton County Foster Adopt Support Group, Meets 1st Thursday monthly, 6 – 8:30 p.m. Pot-luck dinner at 6:00 p.m. Group/training at 6:30 p.m. Childcare available. Eaton Intermediate School District, 1790 Packard Highway, Charlotte, MI 48813. Located right next door to Walmart. Contact Michelle for more information at besa_93@yahoo.com.

Kent County

West Michigan FASD Support Group, Meets 3rd Tuesday of each month, 7 – 8:30 p.m., Westminster Presbyterian Church, 47 Jefferson Avenue, Grand Rapids, MI 49503. Contact Sandy Kezenius, 616-874-9522; Corry Tait, 616-550-4273; or Barbara Wybrecht, 616-241-9126 or bmwybrecht@gmail.com for more information.

Self-Advocates with and FASD in Action (SAFA), generally meets on the 3rd Tuesday of each month. The meeting is for adults age 18 and up who have an official FASD diagnosis. Contact Rob Wybrecht for more information, rob1195@yahoo.com.

Adoptive Families Support Group, Meets 3rd Tuesday of each month, 6 – 8 p.m., Holy Family Catholic Church, 9669 Kraft Avenue SE, Caledonia, MI 49316-9723. Contact Shelley Garcia, 1-855-MICH-P2P, x705 or sgarcia@afsn.com for more information.

Macomb County

Project SAFE (Supportive Activities for Everyone), Generally on a Friday or Saturday evening from 5:30 – 8:30 p.m. at various locations in Macomb County. Families meet for pot-luck dinner followed by supervised play for the children and support group time for adults. Contact Charisse at Charisse@mcfares.org or 586-329-6722.

Brunch Bunch, Monthly, 2nd Tuesday, 9 a.m. – 11 a.m., In Clinton Township, Contact Charisse at Charisse@mcfares.org or 586-329-6722 for location details.

Muskegon County

Support group for foster/adoptive/kinship families. Very active group meets weekly for various activities. Contact Janice Hilleary at Bjhilleary@comcast.net or 231-286-7892 (cell phone).

Washtenaw County

Ann Arbor Support Group, Meets 4th Wednesday of each month except November (meets 3rd Wednesday) and December (no meeting), 7 -9 p.m. St. Joseph Mercy Hospital, Education Center, Classroom #5, 5305 East Huron Drive. Contact Betsy for more information, betsysoden@juno.com.

On-line Support

Families and Supports Affected by FASD: <http://groups.yahoo.com/group/FaSAFASD>

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MCFARES is the Michigan NOFAS Affiliate

MCFARES Member Agencies

Arc Services of Macomb
(fiduciary)

Macomb County Office of
Substance Abuse

Family members of affected
individuals

Oakland University School of
Nursing

Macomb Intermediate School
District, Early On

Macomb County Community
Mental Health

Fraser Public Schools

Macomb Family Services

Macomb County Health
Department

Madonna University



***MCFARES needs you.
Call us at 586-329-6722
to find out how you can
help.***

MCFARES

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Clinton Township, MI 48036

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Address Line 1

Address Line 2

Address Line 3

Address Line 4
