

A Look at Pathways to Hope

How to not only survive but thrive while raising or serving individuals with Fetal Alcohol Spectrum Disorder through understanding, hands-on techniques, and a system

An overview

Developed by
HaysKids

clipboard

The purpose of this teaching

- To educate everyone living and working with FASD
- To make changes to everyone's way of thinking about FASD and the individuals who are living with it.
- To create a light bulb moment

Who we are

- Janice Goudy – the step-grandmother/adoptive mother of a teen-age boy who has a diagnosis of ARND (previously FAE). I have retired after 31 years as a school speech/language and was a family resource coordinator for the Minnesota Organization on Fetal Alcohol Syndrome for two years. I am currently a PCA and board member of HaysKids working as a FASD educator and advocate.
- John Hays – the adoptive father of 15 children, all who have been prenatally exposed to alcohol. He currently serves as a parent liaison for the Adoption Support Network, taking crisis calls from adoptive parents. As founder of HaysKids he is the executive director and a FASD educator and advocate.
- 2nd time we met

Why prevalence matters

- Prevalence is much higher than currently recognized
- 50% of women who are of child bearing age drink. Of those, 50% have unplanned pregnancies
- In some communities, the percentage for exposure is much higher
- The range of disability for this spectrum disorder is from very little effect with few characteristics to drastic physical, mental, and emotional disability even to the point of death.

Beginning the diagnostic process

- Any time I see a child or adult with either unusual, unexplainable, behavioral or emotional problems, or someone who is deeply struggling, I ask myself if these are because of an organic, emotional or traumatic problem. I also ask the same question when I see a person with multiple diagnoses who also struggle with the areas cited in the following statistics related to individuals diagnosed with FASD
 - 90% have other mental health diagnoses
 - 80% cannot keep a job
 - 70% will be locked up for alcohol and drug rehab (they are genetically predisposed), mental health reasons, or, number 1, for crime. Their largest crime is their vulnerability—brain shift—impulsivity—not learning from their mistakes—the choice of friends—part-time conscience—confusion—always seeming to be in trouble and their lack of the ability to stay out of jail.
 - 60% will have trouble finishing school
 - over 50% will do things sexually which could get them into legal trouble

Difficult to obtain an accurate diagnosis

- FASD is greatly under diagnosed for several reasons:
- not enough diagnostic capacity
- socially not acceptable diagnosis
- lack of reliable proof that the mother was drinking
- adult diagnostics can be even harder to get
- no one suspected it or even thought it was a possibility
- a general misunderstanding of the range of affects caused by prenatal exposure to alcohol

A new model for diagnosing

- FASD - the result of organic brain damage. The suspicion of any other physical condition is immediately investigated and a diagnosis is made. If your physician suspects you have cancer he does not tell you that the cancer clinic is very good and meets once a month on Tuesday afternoon and the next available appointment is in 6 months.
- Clinic without walls – the coordination of service providers within a community who are FASD trained, physician, psychologist, speech, OT, and PT evaluate in their own work setting. The professionals with the assistance of a FASD coordinator combine their findings into a single report and determine the diagnosis. This model allows any community to provide a FASD diagnosis
- A more detailed description is available at www.hayskids.org

The Early Years

- Through a seminar we learned enough about FASD to suspect it was a problem for some of our children
- We started getting them evaluated
- This helped, because we started to understand that they had organic brain damage and that was the reason for their behaviors. These behaviors were not going to be corrected by normal parenting techniques
- We received services based on their behaviors, developmental delays, and their diagnoses
- We started learning about fetal alcohol (what causes it, statistics, and how to prevent it. As one teacher said, “There is no silver bullet,” meaning there is no pill, therapy, or special parenting technique that will heal them. Realizing at times nothing works. (DBT Story)
- We started learning new parenting techniques (some of which I now disagree with)

NEXT

- We started talking to our children about fetal alcohol
- We started teaching our children about Fetal Alcohol, just as you would teach a person with diabetes about their disease
- We started developing parenting techniques specific to fetal alcohol (through trial and error). We were realizing that normal parenting techniques usually did not work
- We started experimenting with diet

PRESENT

- We continue to develop more parenting techniques
- Our goal is to not only survive but to thrive in raising children and adults with fetal alcohol
- We must get beyond blaming the birth mother
- We are teaching forgiveness to everyone for everyone
- We are teaching them at new level about fetal alcohol
- We are creating programs for helping the brain develop

The Future

- Working towards revamping the diagnostic process
- More teaching and program developing to especially include
 - brain development
 - relationship parenting
- Emphasis of the radical approach
- Help individuals to recognize their disability and to accept help
- Achieve a much deeper understanding of the disability and the prevalence of it
- Realizing a small percentage of individuals affected by prenatal exposure will actually get a diagnosis
- As a society realizing the effects of prenatal exposure
- Working on strategies to help individuals both diagnosed and undiagnosed to deal with the secondary disabilities—an important part of this is people recognizing they have a problem, for them to stop blaming others or life for their problem, and to accept the help then need

The Future cont.

- Having an honest conversation about prenatal exposure and the effects it is having on our society
- Stop blaming and shaming the birth mother who gave their fetus alcohol. Continue working hard to stop the next generation from being affected
- Stop blaming and shaming the individuals who are having trouble (both diagnosed and undiagnosed), but instead work to help them
- A realization that sometimes it is not prenatal exposure but another problem which may still be caused by organic brain damage
- Teaching young girls the importance of their lifestyle for the next generation
 - not only not to drink but not hanging out with people who do
 - having purpose in life
- Teaching about and having incredible prenatal care
- Conferences that teach brain development, etc.
- Teaching professionals to a whole new level

Wheel to success

Made up of 5 parts

the following 4 areas are equal on the wheel

- the Body—nutrition, exercise, and hygiene
- Relationships—friends, relatives, recreation, and relationship parenting
- Executive Functioning Skills—goes way beyond organizing both thinking and their day. It affects impulsivity, abstract thinking, controlling one's behaviors and emotions, and much more.
- Academics—both what we think of as traditional education (maybe done a little differently) and life skills.

over the top of the wheel is an arc

- Values—laws, manners, purpose in life, faith, forgiveness, accepting help, friends, alcohol and drugs, sexuality, finances, and much more

Radical Approach

- Charts can work when they are linked to more than collecting stars.
- At HaysKids we use a Radical chart which includes the use of a chore chart. The use of these charts with adult support, when needed, help the development of executive functioning skills
- Activities which target executive functioning skills
- Racquetball story

To understand the depth of the disability understand these Common Characteristics

- Concrete Thinking
- Poor Executive Functioning Skills
- Impulsivity/Lack of self-control
- Incredible sense of what is fair and unfair for themselves and others even when the perception is incorrect
- Slow processing and short term memory problems
- Not learning from their mistakes – transferring cause and effect
- Confusion/Unreasonableness
- Negativity/Discouragement
- Denial of disability/Refusing help
- Vulnerability – the #1 thing that keeps them vulnerable is the denial of the disability and their refusal to accept help
- Example of several of these in one story, “Grand Theft Auto,” a story to learn by

Parent/Professional Mindset

- Trying to understand the depth of the disability – this will take years
- Realize that often improvements in behaviors and attitudes for individuals with FASD is more often related to the change of thinking and approach by those living and working with them
- The “Brain Shift,” changes the behavior and thinking which can affect their behavior and knowledge temporarily. Causes can include nervousness, stress, new situations or challenges, old memories, or be unknown. It can create a “part time conscience”
- Because a child knew it before does not mean they know it now. Later they may be able to do it again. This can be extremely confusing for them and anyone else involved.
- A strategy may not work even if it is done properly or consistently
- Outcome based programs – seldom work in the long run – to change behaviors use consistency, repetition, patience, and understand that at times nothing will work
- Lack of drive or negative behavior may not be willful
- Functional IQ vs Intellectual IQ – understand the difference
- Can’t vs Won’t – won’t is a heart condition, can’t is a lack of ability

Relationship Parenting Techniques that Professionals should also use and teach

- Consequences vs Supports – a whole new way of looking at parenting – focus on what you want them to do, not what they did
- No shaming and blaming – it does not work and can only make things worse
- Delayed Parenting – not only does it work, it can deescalate the situation, create both calmness and truthfulness and it is convenient.
- Calm– less said and calmer more effective
- Re-runs – doing it over, role playing to teach correct responses
- “Just the Facts” – the reason doesn’t matter because the strategy will be the same
- Teach them to be nice – accept help - ask for help
- Structure and programming - helps develop executive function skills, redirecting, support for change
- Life skills and chores – Teach to work
- Teach about FASD and Adolescence - Getting them to understand that they have organic brain damage

Talk To Them About

- Talk to them about:

Friends – can get them into trouble or encourage them

School – often the source of frustration, hardships, and bullying

Goals – normal desires but abnormal skills and drive

Non-Socially Acceptable Behaviors – must be addressed

The statistics cited previously – not be beat them up but to equip them

Forgiveness – to forgive others, themselves, and their biological mother

Tools for Success

a system for helping individuals with FASD and their family

1. evaluate based on in-take
If diagnosed go to step 2.
If not, consider doing
BeST (screening tool)
2. while doing your job consider:
3. other resources
4. using a team approach
5. offering FASD advocate for both
family and team members
6. listening to the parent and try to
use your experience, expertise,
and education to think outside
of the box and come up with a
plan

Teach the individual and
family about FASD using:

- Pathways to Hope – 3 parts
or Preparing for Their
Future (not FASD specific)
- FASD Workbook for transition
years and beyond or
Preparing for Their Future
Workbook (not FASD specific)

Physical exercise

Me Moves

Brain games

Diet

Community Resources

Diagnostic Clinic

Medical

Primary Care

OT/PT/Speech

Social Services

Public Health

Case Manager

DD

Mental Health

School

Justice System

Employment

FASD Advocate

MOFAS

HaysKids

NOFAS

NACAC – ASN

(Adoption and
Kinship Care)

Support Groups

Respite/PCA

Assisted Living

Residential Care

Chemical Dependency

Churches

Not False Hope

How to thrive not just survive

Hope is

- Parenting and professional techniques specific to FASD
- Understanding brain shifts
- Long term consistency and structure
- Realizing at times nothing works
- Trying
- Not shaming and blaming nor judging their heart
- Unconditional love
- Forgiveness
- Protection
- Being calm
- Teaching and learning about FASD
- Pushing them to help their brain develop

Work together using your knowledge, expertise, and experience to think outside of the box to find solutions to behavior and other problems. Then take your gifts of patience, calmness, forgiveness, knowledge, and unconditional love and go forth and live a good life together.

www.hayskids.org

resources that have been mentioned in this presentation

www.hayskids.org – click on “A Look at Pathways to Hope - A PowerPoint Presentation”

- Pathways to Hope – an FASD teaching for everyone
- Preparing for Their Future – a non FASD teaching for everyone with disabilities and behavioral concerns
- A Fetal Alcohol Workbook – for transitions from adolescence to adulthood and beyond
- Preparing for Your Future Workbook – for transitions from adolescence to adulthood and beyond for individuals with disabilities and behavioral concerns
- BeST – behavior screening tool for FASD
- Brain Health – teachings to help you understand the impact of FASD
- Wheel to Success – values, body, relationships, academics, and executive functioning skills
- Radical Approach to Success – a program to help develop optimal functioning using the Wheel to Success, OT/PT exercises, computerized brain exercises, relationship parenting, teaching about the disability and chores and charts.
- “Why Won’t You Just” – working with the person who can’t get it together
- Steps to Deal with Bad Behaviors
- Handout – Tools and Community Resources
- A Look at Pathways to Hope – A 30 minute PowerPoint presentation

Questions and Answers

Real Life Scenarios

- From the participants

- From the presenters

Real Life Stories To Learn By

- Criminal justice story
- Need for secure
- Need for security
- Gas station theft
- 1st drink
- Bowl of soup
- Locked cupboard
- Matches
- Shower
- Tashianna's black bean brownies