

# Unlocking the Secret to the Ideal System of Care for Individuals with FASD




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# What is the Key to Success in Building a System of Care?

- ◆ How do we define success for FASD?
- ◆ Success = achieving potential with decent quality of life in a healthy, safe environment
- ◆ Preventing the secondary disabilities defined by Streissguth's research
  - Mental health issues
  - Suspension, expulsion, school drop out
  - Trouble with the law
  - Addiction
  - Homelessness, joblessness
  - Alcohol exposed pregnancies



# Protective Factors

- ◆ Early diagnosis
- ◆ Eligibility for disability services
- ◆ Appropriate intervention supports
- ◆ No domestic violence
- ◆ Stable home environment

Streissguth 1996



# Systems of Care for John

- ◆ From 8 weeks old to 28 years old
- ◆ Diagnosis
- ◆ Medical/health care
- ◆ Foster care
- ◆ Education
- ◆ Developmental disabilities
- ◆ Mental health
- ◆ Criminal justice system
- ◆ Substance abuse prevention



# Diagnosed at birth

- ◆ All diagnostic criteria present
- ◆ Birth mom inebriated
- ◆ Amniotic fluid reeked of alcohol
- ◆ Doctors recently trained to diagnose FAS







# Medical/Health Care

- ◆ Open heart surgery
- ◆ Failure to thrive
- ◆ Genetics clinic
- ◆ Physical therapy
- ◆ Occupational therapy
- ◆ Speech therapy
- ◆ Birth control





# Foster Care

- ◆ Training in child development
- ◆ Training in attachment issues





# Education System

- ◆ Early intervention preschool
- ◆ Special education classes
- ◆ Individualized education plan
- ◆ Transition plan
- ◆ Vocational training





# Mental Health System

- ◆ Axis I diagnosis:
  - ADHD (Attention Deficit Disorder)
  - Impulse Control Disorder (adulthood)
- ◆ Quarterly med review
- ◆ Psychotropic medications
  - Adderall
  - Paxil



# Developmental Disabilities

- ◆ Borderline IQ
- ◆ Case manager
- ◆ SSI, SSDI
- ◆ Respite care
- ◆ Residential services





# Criminal Justice System

- ◆ DD training for new police officers
- ◆ Fact sheet for law enforcement personnel
- ◆ Court system trainings
  - Drug Court
  - Family Court
  - Wellness Court
- ◆ Tools for Success training



# Substance Abuse Prevention

- ◆ Risk assessment
- ◆ Awareness education
- ◆ Streissguth study: Protective factor
- ◆ Substance abuse treatment programs



# SAMHSA: System of Care

- ◆ **Center for Mental Health Services**  
**Division of Service and Systems Improvement**  
**Child, Adolescent, and Family Branch**
- ◆ A system of care is about partnership—a partnership made up of service providers, families, teachers, and others who care for a child. Together, the team develops an individualized service plan that builds on the unique strengths of each child and each family. This customized plan is always implemented in a way that is consistent with the family's culture and language.



# SAMHSA: System of Care

- ◆ In a system of care, mental health, education, child welfare, juvenile justice, and other agencies work together to ensure that children with mental, emotional, and behavioral problems and their families have access to the services and supports they need to succeed. These services and supports may include diagnostic and evaluation services, outpatient treatment, emergency services (24 hours a day, 7 days a week), case management, intensive home-based services, day treatment, respite care, therapeutic foster care, and services that will help young people make the transition to adult systems of care.





# SAMHSA: System of Care

- ◆ Systems of care are developed on the premise that the mental health needs of children, adolescents, and their families can be met within their home, school, and community environments. These systems are also developed around the principles of being child-centered, family-driven, strength-based, and culturally competent and involving interagency collaboration. The Child, Adolescent, and Family Branch embrace and promote these core principles of systems of care.
- ◆ The goal of systems of care programs is to build innovative community treatment programs for children with serious emotional disturbances and their families.



# Community Partnership of Southern Arizona

- ◆ **PROJECT MATCH** (Multi-Agency Team for Children) builds on the existing managed-care base, supporting mental health and substance abuse services, and existing collaborative efforts to develop a coordinated service delivery process at the most local level: the community. PROJECT MATCH staff shares pooled resources to develop a single, family-centered, individualized case plan; expand and implement wraparound services; render operational a strength-based model of care; and deliver culturally sensitive services to the target population. The staff from the Behavioral Health Agency, the State Child Welfare and Developmental Disabilities Agency, the courts, and the Juvenile Corrections Agency will be co-located and cross-trained, and will have access to the pool of resources for service provision.



# What Works

- ◆ Team process
- ◆ Interagency collaboration
- ◆ Communication
- ◆ Educate everyone
- ◆ Parents can become part of the system
- ◆ Professionals can become part of the family
- ◆ Understanding the true nature of FASD

# Array of Abilities

- ◆ Many different levels of development
- ◆ High verbal expressive language skills
- ◆ Low comprehension, social skills





# Many Developmental Levels

## FAS Development Array of Abilities

Age level

21

Physical maturity

Actual age: 21 ◀

18

Verbal skills

15

Information

12

Reading skills

IQ score: 70-75 ◀

9

Abstract reasoning

6

Writing, math skills

Vineland score: 35 ◀

3

Life skills, social skills





# Invisible Gap

- ◆ Difference between *apparent* ability to function and *actual* ability to function
- ◆ John Kellerman: “Sometimes I function at the level of a 4 year old, sometimes I function at the level of a 14 year old, and sometimes I function at the level of a 24 year old. I can’t predict or control my level of function, and that is scary.”





# Invisible Gap

## FAS Development Array of Abilities

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➔ **Apparent Ability**

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➔ **Actual Ability**

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# Cracks in the System

- ◆ Diagnostic criteria
- ◆ Medical schools
- ◆ Foster care, child welfare
- ◆ Teachers, job coaches
- ◆ DD respite, residential
- ◆ Mental health team
- ◆ Criminal justice system
- ◆ Substance abuse risk



# Cracks in the System

## ◆ Diagnostic criteria

- Only 11% receive diagnosis before age 6
- Some diagnostic clinics (AZ genetics team) only diagnose full FAS
- Different doctors make different diagnoses
- Confusion about use of term “FASD”
- Diagnosis of ARND not taken seriously



# Cracks in the System

## ◆ Medical schools

- Only 17% current medical textbooks include correct info on alcohol during pregnancy
- Only 1-in-4 new books calls for abstinence

*[2002 American Journal of Preventive Medicine]*

## ◆ Medications

- Too many, too few, none at all

## ◆ Medical professionals

- Only 8% of doctors have diagnosed FAS



# Cracks in the System

- ◆ Foster care, child welfare
  - 90% of children removed from homes where parents abuse alcohol
  - 75% of children in foster/adopt homes may be alcohol affected
  - Child Protective Services may be first contact with the system where parent and child could get appropriate help, *if* FASD were recognized



# Cracks in the System

## ◆ Teachers

- Inclusion almost never works
- Special Ed teachers treat FASD like all other disabilities
- Regular teachers are not trained or prepared

## ◆ Job coaches

- Vocational Rehabilitation most often provides only short-term skills training





# Cracks in the System

## ◆ DD respite, residential

- In most states, only 16% qualify for services for developmental disabilities
- Even harder to qualify for long term services like residential placement
- DD workers are undervalued, underqualified, undertrained, underpaid



# Cracks in the System

## ◆ Mental health team

- Med review: Room full of professionals who don't know FASD, don't know individual, discuss critical and very personal issues
- More than 50% have clinical depression
- 43% have made suicide threats
- 23% have made suicide attempts
- 29% have symptoms of psychosis
- Don't get help until crisis, hospitalization



# Cracks in the System

## ◆ Criminal justice system

70% of adults  
with ARND have  
been in trouble  
with the law.

Most have been  
victims of crime.

70% of those with  
FASD are victims  
of sexual abuse.



# Cracks in the System

- ◆ Substance abuse risk
  - 50% of men with ARND
  - 70% of women with ARND
  - Less than half received treatment
  - Alcohol industry



# There Is No Ideal System of Care

- ◆ Even with the best services in place, the system fails individuals with FASD and their families again and again.
- ◆ Instead of one comprehensive system of care for FASD, we need all existing systems of care to become aware and educated about FASD and working together to provide services for prevention, treatment, and care.



# The Master Key

- ◆ Vision: Every person in every system is trained in FASD issues and understands the nature of FASD as neurological impairment, can recognize the symptoms of invisible forms of FASD, can see the Invisible Gap
- ◆ Invisible Gap: Difference between apparent ability to function (chronological age) and actual ability to function (much younger)





# Successful Outcomes

- ◆ Depend on strong family, parenting
- ◆ Reality based awareness on part of individual with FASD
- ◆ Acceptance of limitations imposed by FASD and need for protective environment
- ◆ Develop talents and natural gifts
- ◆ Lifelong circle of support for individual
- ◆ Strong support system for parents



# Success Story

John's success is fragile and depends on a chain of support with no weak links





# What Can You Do?

- ◆ What can you do to fill the cracks and bridge the gaps?
- ◆ Educate one system at a time, one person at a time, one day at a time
- ◆ Arizona Division of Developmental Disabilities: Project FASD Train will provide full FASD training to every case manager in the state, will begin screening individuals with DD for possible FASD.



# Damaged Angels

By Bonnie Buxton

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