

Fetal Alcohol Spectrum Disorder: Moving Beyond Prevention to Practical Supports

**The Arc's National Convention
Bellevue, Washington
Sunday, August 4th, 2013**

***Presenters: Jim Stream, Executive Director, The Arc of Riverside County
Leigh Ann Davis, Project and Information Specialist, The Arc***

Overview of Today's Two-Part Session

PART ONE (9:00 – 10:30 am)

Collaborating for greater success: Obtaining/providing supports from and within disability and educational systems; obstacles in eligibility for services

PART TWO (11:00 – 12:15 pm)

Digging deeper: Importance of providing quality psychiatric supports; “In the trenches” forensic perspective , and educating the legal system about FASD – It’s not just an excuse

FASD Advocacy at The Arc: Where We've Been, Where We're Going

- 1977 – The Arc supported research by Dr. Ken Jones to continue work originally supported by March of Dimes
- 1988 – Provided several FAS-prevention publications for chapters (teacher's manual, brochures, cartoon booklet)
- 1990 – Provided input via CDC's advisory board for national conference on FAS
- 1992 – Identified FAS as one of three main objectives for strategic plan
- 1998 – Advocated for FAS Prevention and Education Act, The Arc invited to be on national advisory board

FASD Advocacy at The Arc: Where We've Been, Where We're Going

- 1998 – “Think Before You Drink” and “*10 FAS Prevention Projects: A How-To Booklet from Chapters of The Arc*”
- 2004 – Created CDC-funded curriculum “*Sharing Stories, Finding Hope*” shifting focus from prevention to providing supports and services (addressing secondary conditions)
- 2008 – The Arc invited to serve on SAMHSA’s FASD Expert Advisory Committee (four years)
- 2011 – The Arc receives funding from SAMHSA to create and support The SAFA Network (on-going)
- 2011 – Staff invited to co-author publication on victim’s issues in *Journal of Psychiatry & Law*

FASD Advocacy: Where We're Going

“Understanding the system, how to access the system in the appropriate way, how to affect positive policy changes – this knowledge will better prepare parents to properly make system changes and improve the quality of the lives of our children.”

- Mother from Montana

“Parent support is so important. Talking with other parents who may be raising a child with fetal alcohol syndrome is very helpful.”

- Missouri mother of 22- year old son with FAS

“In a perfect world everyone would know all those things that would really help those children (with FASD), because even if you say they need support, I know my teaching staff does not have the knowledge it needs to do what should be done for these children.”

- Special Educator and mother of a daughter with FAS

SELF-ADVOCATES WITH FASD IN ACTION (SAFA)



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FASD Advocacy at The Arc: Chapter Programs/Activities

- The Arc St. Louis – Go the whole 9 campaign:
https://www.slarc.org/site/456/fasd_prevention.aspx
- ***The Arc of Riverside County (CA) – NineZero campaign:***
<http://arcriversideca.org/ninezero/index.html>
- The Arc Northland (MN) – FASD Training Program:
<http://www.arcnorthland.org/fasdtraining.htm>
- The Arc Mecklenburg (NC) – FASD Committee of Mecklenburg
<http://www.arcmeck.org/FASD.html>

FASD Advocacy at The Arc: Upcoming Events

- The Arc of New Jersey – FASD 40th Anniversary Summit
Sept 26 – 27, 2013
Atlantic City Convention Center, New Jersey
Presenters include Ken Jones and Natalie Novick-Brown
<http://bit.ly/FASDanniversarysummit>
- The Arc Arkansas FASD Summit
Sept 22 – 25, 2013
Presenters include Tom Donaldson, Billy Edwards, Stephen Greenspan, Susan Rich, Monica Leinberger and others
Contact: Cynthia Stone: cstone@arcark.org

The Arc of Riverside County's Early FASD Experiences

- The Arc US materials in early 1990s
- Encounters with FASD adoptive moms who needed services
- Employee with family member with In-laws with FASD

Breakthrough in Our Understanding of FASD Issue

- The Broken Cord
- Criminal Justice reports
- Ann Striessguth presentation at National TASH Convention

Prevention Efforts of our local Arc

- First FASD Curriculum for HS
- FASTRAC use of peer instructors in HS (grant funded)
- NineZero initiative
- Eva Carner and Ricky Nelson
- Eva Carner article in “Exceptional Parent” magazine
- NOFAS participation

The Arc of CA involvement

- Local board member with step-son with FASD
- Connected with Key FASD professionals in state
- Board member with step-son had son in state Assembly
- Legislative Briefing on FASD issues in CA
- FASD State Taskforce
- National Conference on FASD in Riverside

Recent FASD Developments for our local chapter

- Billy Edwards Involvement
- FASD Support Group
- Treatment for a Documentary on FASD
- Under Development – Facebook page – “The CA Regional Center Eligibility Project”
- Outreach to key Legislator

What Local Chapters Can Do to Support individuals with FASD

- Support and advocate for State Chapter Involvement
- Locate and join FASD Support Groups in State (State NOFAS chapters)
- Find one state legislator who will champion the cause
- Highlight taxpayer cost of FASD w/out services vs. benefits of services
- Participate in local and state FASD awareness efforts
- Support legislation that increases FASD awareness, prevention or services
- Participate in a state FASD stakeholder Taskforce (begin thru state Arc if not yet 1 in your state)
- Find a prominent person affected by FASD to speak on its behalf (mimic Autism)
- Support The Arc US on this issue (and push from grassroots up)
- Become a clearinghouse for FASD resources

What Needs to be Done to Move FASD Advocacy Forward – A local chapter perspective (California specific)

- Educate elected officials on the high cost of FASD and the benefits of providing services
- Advocate for acknowledgement of FASD as a developmental Disability by State and Fed legislative bodies
- Publish and circulate creditable cost data on FASD
- Mandate Regional Centers to use 5th category of eligibility to qualify individuals w/FASD
- Develop quality (and quantity) FASD services and supports
- Advocate for alternatives to incarceration
- Train as appropriate all public officials and professionals that encounter individuals w/FASD in social services and criminal justice systems
- Advocate for identification of FASD at earliest possible age (schools and social services)
- Collaboration between The Arc US and NOFAS



Riverside County

Achieve with us.

Top Ten Reasons Why FASD Advocacy is Difficult

- Often is an invisible disability
- Stigmatization of birth moms
- Prevalence and cost data on FASD difficult to collect
- Our culture's love affair with alcohol
- No celebrity family members pushing the envelope (compared to Autism)
- Misdiagnoses are common (mental health, ADHD, etc.)
- Lack of professionals trained to look for FASD (social workers, nurses, doctors)
- Foster Care, CJ and school systems untrained, apathetic, and overburdened
- Mixed messages from medical profession
- State social service systems and legislatures reluctant to fund