

Club COSTA: How to Start a Local Self-Advocates Group

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We have only just begun. But just like a baby right after she is born, our idea for Club COSTA has had a lot of time and energy go into the development of our program. Let's take it from conception to birth

It all started with an idea.

I had this idea a few years ago, made some notes, designed a logo, put it into a file, then got busy on another project that needed my attention right away, and kind of forgot about it. A good idea isn't much good if it never gets plugged in.

Over time we have met several families like ourselves, struggling with the challenges of living with FASDs. The younger kids have lots of behavior problems. The older kids have difficulties in school. As adults, some have had success, and some have fallen into the cracks.

What do we mean by success?

Finishing school, getting a degree

Finding a job, and keeping it, doing something we enjoy

Becoming as independent as possible in a safe environment that will ensure continued success

What do we mean by falling into the cracks?

Running away, living on the streets, with the "wrong" crowd

Getting arrested, going to jail or prison, losing independence

Getting fired from a job, evicted from a home, not being able to be self-supporting

We want to help our youth find self-sufficiency and independence, as much as they are able, to stay safe, to make good decisions, to be healthy and happy. We want to help our self-advocates avoid the serious secondary disabilities Ann Streissguth explained in her research report. We want to avoid:

- Depression and suicide attempts
- Dropping out or getting kicked out of school
- Getting in trouble with the law
- Inappropriate sexual behaviors
- Substance abuse
- Ending up in an institution (prison, mental health facility)

We know that having a strong circle of support is crucial to finding success if we live with FASD, or even if we don't have any disabilities. We all need others to help guide us, to support us, to help us get what we need to survive and thrive. We are interdependent. We can share resources.

What resources do our self-advocates have?

Parents and friends, faith community

Books and Internet

Mail lists and support groups

Is that enough?

We saw a need for more than just what can be taken from a support group or mail list. We saw a need for frequent meetings to discuss ongoing problems and to find solutions that will work. We saw a need for acceptance and understanding. We saw a need for friendships to be nurtured. We saw a need for these young adults to learn more about their disability, to work through the grief they feel, to learn how to explain FASD to others, how to speak up and ask for what they need in an effective manner. We saw a need for a bigger, better, stronger Circle of Support. So John and I decided, after many years of just thinking about it, to form Club COSTA, a Circle of Support for Teens and Adults with FASD.

First step – get connected

We have been connecting with other groups for many, many years. The Arc – join national group, find local chapter, attend events, become a member

Disability community – local advisory council, governor’s council

Legal advocacy – Arizona Center for Disability Law – Can you find yours? Attend classes

Community forums – Three local legislators held a monthly forum at the library

Faith community – St. Paul’s United Methodist Church

What kind of groups can you connect with?

NAMI

Post adoption groups

Second step – get involved

Volunteered on board of Pima Council on Developmental Disabilities

Attended classes through county and state programs

John became a drummer in the band, I am a volunteer at church

I volunteered to be a parent mentor with local advocacy group, became a board member

Third step – get noticed

Gave talks in schools, for civic groups and at community events

Gave presentations at conferences (for no pay)

Put materials on tables at events

Write articles for local organizations

Fourth step – identify your resources

Can one of these organizations provide a place to meet?

Can these organizations get the word out for you on their mailing lists?

Are there local businesses that will make a donation?

Can one of these agencies act as a fiduciary for collecting donations?

Articles and ideas from www.fasdlane.com and from Club COSTA CD

Fifth step - put it all together

Find a few other families to help you get started

Find a place that will allow you to hold meetings

Reserve the same time for once a month for a year

Use our logo and flyer as a template

Send an email invitation out about a month ahead of time, reminder a week ahead of time

Step back, take a deep breath, exhale, and watch what happens!