

2008-2009 FASD Parent Network Plan

Mission of the Parent Network

To increase awareness of Fetal Alcohol Spectrum Disorder (FASD) among the residents of Ohio; provide information and resources to organizations serving individuals affected by FASD; and provide information, resources and support to families and caregivers.

With this mission in mind, the FASD Parent Network has set the following goals for the year 2008-2009:

1. To continue developing and building a statewide FASD parent network through the regional meetings which began during the month of April 2008. The activities to accomplish this include:
 - updating the parent address and list serve documents to ensure communications are reaching parents,
 - having follow-up regional meetings as requested by regional attendees,
 - providing suggestions and requests from parents to the steering committee for consideration and inclusion in agency plans (these suggestions/requests appear as the last section of this plan),
 - targeting top three parent requests for action,
 - providing parents with information about FASD education opportunities through the steering committee, OPEC, Double ARC, etc.
2. To develop a Birth Mothers Network (BMN) within the Parent Network to provide a strong basis of support for them and their families. The activities to accomplish this include:
 - Octavia Gray will take lead role in planning and development,
 - BMN information will be obtained from Kathleen Mitchell at NOFAS,
3. To plan some social events for FASD children and siblings to get together and meet each other. The activities to accomplish this include:
 - determine interest at Regional Parent meetings,
 - brainstorm ideas for social event such as crafts, bowling outing, picnic, etc.
 - see what youth programs may have to offer special needs kids through Ohio Partnership for Youth
4. To determine a NAMI Parent Advocate connection in each region through the Mental Health system
5. To connect with the Ohio Coalition for the Education of Children with Disabilities
 - see about FASD article for the group's *Forum* publication

- see about opportunities to provide FASD information workshops at coalition conferences
- see about coalition presenting at a steering meeting
- see how coalition resources can help FASD parents with education issues.

Regional Parent Network Requests, Recommendations, and Suggestions

**Central/Southeast Region
FASD Parent Network Meeting
OSU Center for Learning Excellence
Friday, April 4, 2008
Phil Petrosky, Facilitator**

Suggestions

1. When FASD diagnosis is determined at Genetics Clinic, have staff provide information about FASD to family and information about or referral to pediatricians and physicians who are knowledgeable about FASD.
2. Would like to understand available state and local services better. It would be helpful to have flow charts posted on the website that do this which provide the income, assets, etc. tests; information that is needed to accompany applications; what services are provided, who will follow-up on the application, and time frames.
3. Wisconsin is having a state FASD conference with many interesting topics and speakers. Is it possible to obtain Wisconsin conference information, possibly DVD of speakers and/or materials.
4. Filling out paperwork for various programs is cumbersome. Assistance with paperwork is needed. Also needed is accountability for returning telephone calls and responding to questions.
5. Participants would be interested in a late summer event similar to the family picnic last September.
6. A next meeting was requested and is set for Thursday, June 5 from 5-7 at the Drug Free Action Alliance at 6185 Huntley Road in Worthington, Ohio 43229
7. Families asked to share email addresses and all are OK with sharing. The email addresses follow:

Southwest Region Report
Place: Forest Park Public Library
Date and Time: April 29, 2008 6 pm
Facilitators: Octavia Gray and Marge Schaim

Attendance: 13 Number of parents who could not attend: 7

Our meeting was very informative, those who attended shared their experiences of raising a child or grandchildren with FASD and shared resources with the group. Some of the participants were professionals, facilitators of their own support groups and professional grandmother. Several of the parents had attended the Town Meeting and both state FASD conferences.

Time was spent discussing how our group could address concerns that would benefit not only our area and the state of Ohio.

Some of the concerns the group would like the Steering Committee to address are:

- ⇒ Universities and colleges to include FASD training as a part of the curriculum for future doctors, nurses, teachers, counselors, criminal justice and social workers.
- ⇒ Provide parent advocates for parents when attending meetings.
- ⇒ Build a data base of services for adults with FASD (jobs, independent living, supports, etc.)
- ⇒ Develop a list of attorneys who will address FASD adult rights.
- ⇒ Support from the AMA to consider FASD as a disability because Social Security respects their opinion. Difficult for children to receive SSI.
- ⇒ Develop a uniform tool for assessing FASD.
- ⇒ Have places across the state that can due full assessment.
- ⇒ Develop a list of Institutional settings that is knowledgeable to handle our children.
- ⇒ Develop a data base of support groups and individuals across the state that addresses FASD.

Topics and events the group would like our meetings to address:

- ⇒ To develop a list of groups and parents in our area to address FASD

- ⇒ Have an event to honor Judges, Attorneys, Law Enforcers, etc. who are supporters of families with FASD children.
- ⇒ Develop a list of professionals serving families with FASD children.
- ⇒ During our sessions have topics to address our needs [Bridge with Transition, chemical dependence, DSMS, GLATTC, Porch Light Program, the Brain, Guardianship, etc.]
- ⇒ Develop a support group for sibs living with a love one with FASD This was a very productive and enjoyable evening. The intent is to meet more than quarterly.

Next meeting: June 10, 2008 at 6:30 pm.

Submitted by: Octavia Gray

**Northeast Region
Friday, April 11, 2008
Akron Main Library
Facilitators: Lynette Blasiman and Deb Klinessmith**

- People had an opportunity to introduce themselves and explain a little background on why they are interested in FASD and how they have been effected
- Each family/individual was provided with a folder which contained information and handouts
- The CD that was developed for the education forum was shown
- The participates were asked to list their goals and needs for future meetings (below)
- Those attending agreed to share their information
- There was an interest expressed in future meetings
- No future meeting date has been set at this time
- We will look at a different meeting site and possibly a better day or time to include more people

Interests expressed by participates

- Seminars and trainings to increase personal knowledge about FASD
- IEP training
- Provide information to pediatricians to increase awareness and knowledge
- JFS personnel becoming aware of FASD and have a basic understanding
- Increase awareness of gatekeepers across systems including juvenile courts

- Increase screening for FASD children to be identified earlier and therefore managed more appropriately and effectively

The two priorities that were clear from the meeting were trainings on Fetal Alcohol and IEP information. The participants want an overview of FASD and to understand the IEP process and their child's rights, along with understanding the school system's responsibility concerning educating their child.

Northwest Region
April 25 and June 27, 2008
Owens Corning Conference Center; Room - Commons 2, Toledo, Ohio
Facilitator: Cheryl Kyser

- Educate the people at the juvenile justice system, other agencies that work with our children (MRDD, BVR, summer day camp programs, assisted living support personnel, i.e.)
- Build a way to provide out kids friendships between each other, i.e. social/support group.
- Meet once a month as parent group,
- Meet for social interaction as a kids group – maybe link in to the inclusion group from MRDD.
- Running public awareness announcements
- Publicize Double Arc Classes for teachers, social workers, etc for CEU credits

Action Plans:

- Provide PSA CD to television stations – check with Kim == Cheryl
- Follow up with MRDD Inclusion to start a young adult, high functioning, social group == Cheryl
- Start reviewing the possibility of organizing a Ohio FASD Conference for individuals and caregivers (cont. of Michigan conference) == Karen, Kathy
- Provide a copy of everyone's info == Cheryl (done)

Meetings

- Start once a month, see how that goes, 12:30 – 2:30pm maybe alternate with evenings
 - 30 min support, sharing
 - Report out on action items

Review new needs or actions