

---

**Washington State  
Fetal Alcohol Syndrome  
Diagnostic and Prevention Network  
(FAS DPN)**

**Community Development of an FAS DPN  
Manual**

**Third Edition  
2004**

**University of Washington  
Seattle, Washington**

---

Authors:

Sterling K. Clarren, M.D., Aldrich Professor of Pediatrics  
Susan J. Astley, Ph.D., Professor of Epidemiology

Revised 2004

Susan J. Astley, Ph.D., Professor of Epidemiology

Copyright © 1999, 2004  
University of Washington  
Seattle, WA 98195, U.S.A.

All rights reserved. This guide is protected by copyright. No part of this guide may be reproduced in any format or by any means, including photocopying, or utilized by any information storage and retrieval system without written permission from the copyright owner.

To obtain additional copies of this manual please contact:

Fetal Alcohol Syndrome Diagnostic and Prevention Network  
Center on Human Development and Disability  
University of Washington  
Seattle WA 98195  
[www.fasdpn.org](http://www.fasdpn.org)

# Procedures Manual for the Washington State FAS Diagnostic and Prevention Network

## Table of Contents

I.	Community Development.....	1
	A. Purpose.....	1
	B. Needs assessment.....	1
	C. Partner/stakeholders identification .....	1
	D. Partner/stakeholder interest assessment.....	2
	E. Development of informal alliances .....	2
	F. Development of formal partnerships .....	2
	G. Regular meetings/communication .....	2
	H. Resource development.....	2
	I. Community recognition/Public relations .....	3
II.	Referral and response process.....	4
	A. Purpose.....	4
	B. Establishment of phone referral infrastructure .....	4
	C. Referral/appointment package and response .....	4
III.	Clinic Operation.....	5
	A. Purpose.....	5
	B. Role of clinic manager .....	5
	C. Billing .....	5
	D. Patient assessment.....	6
IV.	Clinical staff qualifications.....	7
	A. Purpose.....	7
	B. Clinical staff descriptions .....	7
V.	Medical documentation.....	10
VI.	Family referral process .....	10
VII.	Follow-up procedures .....	10
VIII.	Patient Confidentiality .....	11
IX.	Volunteers.....	11
X.	Additional FAS DPN Materials.....	13

## **I. Community Development**

### **A. Purpose**

The FAS Diagnostic & Prevention Network (FAS DPN) is a collaborative model requiring support and resources from many sources. To achieve site permanency, community development is essential. This includes utilizing existing partnerships and coalitions, formation of new alliances, tapping traditional and non-traditional resources and developing communications and recognition mechanisms to keep the processes moving forward. The initial community development plan should include the following:

- Needs assessment
- Identification of all possible stakeholders and partners
- Identification of stakeholder/partner interest and potential resources for the site
- Development of information alliances for exploration and initial planning
- Development of formalized partnerships with written agreements
- Regular meetings or processes for communication
- Development of ongoing resource development processes
- Mechanism for mutual recognition and public relations in the community

### **B. Needs Assessment**

A needs assessment can provide a base of information to draw partners, resources, and community support for a Network clinic site. The assessment can draw on existing state and county assessments, as well as add local data and anecdotal information, especially from families and concerned professionals. The assessment could include:

- Needs of families affected by fetal alcohol (educational, medical, social services, respite, long-term placement, vocational, etc.)
- Substance abuse treatment capacity for women, especially women with children
- Number/type of professionals currently serving families affected by fetal alcohol and serving women who abuse alcohol
- Fetal alcohol prevention efforts (school, community and targeted to high risk, alcohol abusing women)
- Existing fetal alcohol services and/or capacity from public and private providers

### **C. Partner/Stakeholder Identification**

Possible partners can include groups of people across two spectrums: prevention and services/intervention. Partners could include:

- Schools
- Health departments
- Substance abuse treatment professionals and facilities
- OB/GYN providers and related services
- Insurers, hospitals, managed care providers (prevention saves money)
- Health organizations (e.g., ARC, March of Dimes)

- Advocacy groups (especially children's advocacy groups like PAVE)
- Disability groups
- Mental health agencies or departments
- Family support organizations or unaffiliated families
- Group homes
- Criminal justice/juvenile justice groups and organizations
- Local community groups (geographic, cultural, religious, etc.)

#### **D. Partner/Stakeholder Interest Assessment**

Potential stakeholders and partners should be brought together and provided an explanation of the FAS DPN. Possible roles (including responsibilities and benefits to participants) should be highlighted. Then a survey or follow-up call/visit should be scheduled to explore interest and potential areas of contribution.

#### **E. Development of Informal Alliances**

All interested potential partners should meet to explore as a group how the pieces might fit together in their community to support a network site. Potential partners may be eager to offer, or may hold back, waiting to see what others have to offer. A skilled facilitator, trusted in the community, can greatly enhance this process. Outsiders should be limited to a few "experts" providing technical assistance, not telling a community what to do or how to do it.

#### **F. Development of Formal Partnerships**

The final partnership development phase is the identification of formal relationships, which outline what each partner will contribute and what, if anything, they will receive from pooled resources. These partnerships should be documented in writing and are greatly strengthened by signed contracts or statements of work to avoid the "I thought you were doing that" syndrome.

#### **G. Regular Meetings/Communications**

Once a site is ready for operation, timelines should be established which include regular group meetings to identify what is going well and what needs improvement. Both clinic content and process issues should be explored and addressed. Minutes should be taken and distributed with action items clearly delineated. Team building is critical not only for the clinic diagnostic team, but all the support arms in the community, be they paid or volunteer.

#### **H. Resource Development**

An inherent weakness in the FAS DPN model is a lack of identified, stable funding. There are two ways to address this weakness: build the model within an existing system (avoiding duplication and utilizing existing strengths), and develop funding streams that flow across all the stakeholder borders.

Examples of building within existing systems includes planning the clinic in an existing facility or organization such as a genetics clinic, neurodevelopmental clinic, public health clinic, substance abuse treatment facility, or even a school. These organizations have infrastructure that provide space, support systems, billing mechanisms and natural linkages to other needed services.

Development of varied funding streams includes both cash and in-kind contributions. Cash contributions could be from private or government grants, fee-for-service contractual relationships for screening or diagnosis from a system who needs such services (juvenile justice, corrections, courts, schools), and support from insurers and managed care providers who do not wish to fully gear up to provide ARBD diagnostic services themselves.

In-kind support could include coverage of salaries for any of the clinic staff (especially MD, PHNs, psychologists and school personnel) who serve the client population as part of their existing job. In-kind support can also include secretarial support and volunteers. (See volunteer development plan)

### **I. Community Recognition / Public Relations**

The recognition of the contributions of each participant and supporter is the key to future support. It is simply appropriate to recognize people and organizations. In addition, such public recognition propels many of the on-going fundraising needs of contributing organizations - they are willing to be part of a coalition, but in turn often require some distinct recognition.

Public relations are also important in gaining community support and buy-in for a clinic site. These activities should highlight the benefits of the clinic with specific examples of how the services helped someone in the community. This type of publicity will bring a continued flow of clients, raise awareness of and enhance FASD prevention efforts and possibly even attract supporters unknown heretofore to the clinic group.

These communications functions can be implemented by the host organization, or by local volunteers and communications professionals.

## II. Referral and Response Process

### A. Purpose

Each clinic requires a referral process for potential clinic clients. The process needs to be simple enough so as not to burden the host facility while providing helpful and timely assistance to callers. The following process has been developed to initiate the referral and response process.

### B. Establishment of Phone Referral Infrastructure

- Establish a phone number or voice mailbox.
- Link the phone number to an answering machine or voice mailbox.
- Anticipate three types of calls:
  1. Definite interest in an appointment.
  2. Inquiry about appropriateness of an appointment.
  3. Specific questions about the clinic or patients already seen that require triage.
- Assign an individual (the facility receptionist) to retrieve the messages and follow-up within 24 hours with one of the following actions:
  1. Send out a referral/appointment package.
  2. Answer inquiries directly.
  3. Direct caller to appropriate staff member for further assistance.

### C. Referral/Appointment Package and Response

- The referral/appointment package sent to prospective clients should include:
  1. New Patient Information Form (NPIF).
  2. Information about the clinic.
  3. Clinic costs.
  4. Who to call for assistance with the NPIF.
- Upon receipt of the completed NPIF, the designated clinic member reviews and determines if the referral is appropriate and processes it in one of three ways:
  1. If the referral is appropriate, the NPIF is sent to the clinic scheduler who:
    - A. Contacts family and assigns an appointment date and time.
    - B. Sends the family the clinic instructions packet which contains:
      - i. A list of information to be collected by the family before clinic.
      - ii. A map to clinic/parking.
      - iii. An explanation of costs.
      - iv. Information regarding childcare during the clinic evaluation.
  2. If the referral is inappropriate, clinic staff member or triage clinic staff member sends letter explaining the situation and suggesting alternative referrals, if known.
  3. If the referral is appropriate, but volumes and prioritizing place the patient on a waiting list, a letter is sent explaining that situation.

### **III. Clinic Operation**

#### **A. Purpose**

Each clinic will vary with local resources and needs. The basic functions may be executed by various types of people. An outline of basic clinic operations follows.

#### **B. Role of Clinic Manager**

The clinic manager's role is to ensure the patient and his/her family is scheduled, seen, and that appropriate notes and referrals are created.

Prior to clinic:

1. Prepare the clinic schedule including:
  - A. The names and ages of the patients.
  - B. The primary and secondary staff members attending the session.
  - C. The names of visitors/observers.
  
2. Call the families to confirm the appointment, answer any questions about the clinic and facilitate the collection of supporting information which may include:
  - A. patient photos
  - B. school records/assessments
  - C. psychological test data
  - D. medical records
  - E. social system reports.

On clinic day:

1. Greet families and direct them to appropriate locations.
2. Make staff aware of patient flow and any potential problems.

After clinic day:

1. Collect reports and mail them to all appropriate recipients.
2. File the reports.
3. Complete billing.

#### **C. Billing**

A system for sending bills, collecting funds, depositing funds, working with insurance companies, managed care organizations, collection agencies, and families needs to be developed.



#### **D. Patient Assessment**

Patient assessment consists of five phases labeled Phase 0 through Phase 4, noted below. Different programs can organize the five phases of patient assessment in different ways and along variable time lines, but all issues noted in the patient assessment need to be covered. In our experience, appropriate care cannot be provided without a reasonable time consideration to all of the issues in each Phase. It is estimated that Phases 2 and 3 each take about one hour. Phase 1 will vary in length depending on the test battery that is given. A more detailed description is provided in the FAS DPN Clinical Model Manual.

Phase 0: Review of previous records (Passive data collection):

1. Collection of data previously obtained and presented by family, reviewed by primary clinical staff.

Phase 1: Clinical assessments: (Active data collection)

1. Completion of patient history with family.
2. Completion of physical exam.
3. Completion of other assessments (i.e. speech, education, psychological, medical).
4. Completion of any other additional testing that is suggested by Phase 0 or Phase 1.

Phase 2: Case conference to establish and share the diagnosis and treatment plan:

Staff meeting to consolidate and organize information listed above.

1. List of etiologies involved in the case.
2. List of all pertinent diagnoses.
3. Development of treatment plan.
4. Discussion of above with family/patient.

Phase 3: Caregiver/patient debriefing: (Data interpretation)

1. Avenues for dealing with feelings and emotions associated with the diagnosis.
2. Clarification of the diagnosis.
3. Strategies for implementation of the recommended treatment plan.

Phase 4: Clinical staff closure:

1. Records completion.
2. Post clinic discussion of cases and emotional impact on staff.
3. Planning for further clinical involvement with the patient.

## **IV. Clinical Staff Qualifications**

### **A. Purpose**

The primary interdisciplinary team is ideally composed of six staff members. Some of the specific work assignments of one team member could be performed by an alternate team member under some unique or specific circumstances. Further, it is recommended that more than one individual be recruited to share each team role. Sharing responsibility helps with clinic staff in times of individual illness or vacation and allows for individuals with diverse expertise to share their knowledge and experience.

### **B. Clinical Staff Descriptions**

#### **Physician**

Qualifications:

1. The team physician should be a pediatrician, a family physician, or possibly a pediatric nurse practitioner.
2. The physician must be capable of conducting the semi-structured interview and efficiently assessing the birth history, drug and alcohol history, and family history of social and behavioral concerns.
3. The physician must be capable of a skilled exam for dysmorphic features, especially of the face and hands, and a comprehensive neurologic exam as well as a routine physical examination.

Duties:

1. The physician is responsible for participating in the Phase 0 chart review, the Phase 1 family interview, and in conducting the physical examination.
2. The physician participates in the Phase 2 case review by helping to establish: 1) the list of potential etiologic factors; 2) the diagnosis; and 3) the treatment plan.
3. The physician is responsible in whole or in part for the clinical summary note.

#### **Psychologist**

Qualifications:

1. The team psychologist (clinical, developmental, educational, etc.) should have a M.S. or Ph.D.
2. Since many psychologists have expertise with specific age populations (early development, school age, adolescent or young adult), finding psychologists with experience across different age groups will greatly help the clinic to see clients across the age range.

Duties:

1. The psychologist is responsible for participating in the Phase 0 chart review and in abstracting and interpreting previously obtained psychological reports and records.
2. The psychologist participates with the physician in the Phase 1 historical interview and is often responsible for collecting the educational history and participates in the collection of the social and behavioral histories.

3. The psychologist has the task of helping the clients to become comfortable with the examination setting and to support the family through the experience by establishing rapport.
4. The psychologist may also participate in Phase 1 by conducting some or all of the psychological testing that is needed.
5. The psychologist participates in Phase 2 and helps to develop the treatment plan.
6. The psychologist conducts Phase 3 and helps the family to emotionally debrief from the clinic experience.
7. The psychologist may be partly responsible for the clinical summary note.

### **Speech and Language Specialist**

#### Qualifications:

1. The speech and language specialist should be a Speech and Language Pathologist at the M.S. or Ph.D. level with training in assessment and implementation of speech and language issues.
2. This team member will need to be trained in the administration of the Special Language Battery designed by Truman Coggins, Ph.D. at the University of Washington.

#### Duties:

1. Conduct speech and language assessments with all patients in Phase 1.
2. Participate in Phase 2 and help develop the treatment plan.

### **Occupational Therapist**

#### Qualifications:

1. The occupational therapist should be at the O.T.R./L level with training in assessment of motor and sensory issues.

#### Duties:

1. Conduct motor and sensory assessment with all patients in Phase 1.
2. Participate in Phase 2 and help develop the treatment plan.

### **Social Worker**

#### Qualifications:

1. The social worker should have a Master's degree (M.S.W.) with psycho-social expertise.
2. The social worker will support families emotionally, as well as have knowledge of local social systems in areas that clients are likely to need services and access.

#### Duties:

1. The social worker will participate in Phase 2 and help to develop the treatment plan.
2. The social worker will participate in Phase 3 and Phase 4 in helping the family come to terms with the diagnosis and to develop an implementation strategy, especially in the areas of accessing financial resources by appropriately qualifying for aid, working with social agencies (adoption, adoption support, etc.), triage to alcohol treatment, counseling and vocational programs, etc.

### **Public Health Nurse**

Qualifications:

1. The public health nurse should have a degree in public health nursing.
2. The PHN should have skills in supporting the family with the emotional issues related to the diagnosis.

Duties:

1. This team member's role may overlap with that of the social worker in some settings.
2. The PHN participates in Phase 2 to develop the treatment plan.
3. The PHN may lead the Phase 3 discussion of team implementation.
4. The PHN is the member most responsible for actively supporting the family in their efforts to carry out the plan and for triage back to other team members for specific help with implementation issues.

**Family Advocate**

Qualifications:

1. Be the parent (birth, foster, or adoptive) of a child with FASD.
2. May be a member of an appropriate family advocacy program (e.g. FAS Family Resource Institute, PAVE, ARC)

Duties:

1. Help identify appropriate referrals in the community.
2. Help explain the clinic process and “prepare” uncertain families for their appointments.
3. Work with families after the clinic appointment to help implement the treatment plan by identifying human and financial resources.

**Team Leader**

Qualifications:

1. One member of the primary team is designated "team leader".
2. This job can be given to one person, be incorporated into the assignment of one of the groups described above (i.e. it is always the physician, or it is always a PHN, etc.) or the job can be rotated. Most sites, to date, have selected a specific individual as the single team leader. Generally, but not always, the assignment has gone to the team physician.

Duties:

1. The team leader keeps the team on task and on time as it proceeds through an evaluation.
2. The team leader assures that all documentation is accurate and complete.

**Other Team Members**

Other members of the interdisciplinary team may include psychiatrists, neuropsychologists, geneticists, dysmorphologists, mental health counselors, etc.

## **V. Medical Documentation**

The clinical team completes the FASD Diagnostic Form during the diagnostic evaluation. This form is in the Diagnostic Guide for FASD 3<sup>rd</sup> Edition (Astley, 2004).

In the FAS DPN, the medical summary is composed throughout the diagnostic evaluation by the members of the clinical team using a computerized template. An example of the form is presented in the training materials. This medical summary is signed by the FAS DPN physician, and sent to the patient's legal guardian. A copy is also submitted to the patient's medical record. The FASD Diagnostic Form is not sent to the patient or submitted to the medical record. This is a research form that remains on file at the FAS DPN.

## **VI. Family Referral Process**

Once a diagnosis has been made, one of the most valuable parts of the process for the patient and the family is the appropriate referral to services.

Based on the implementation plan, families should be offered referrals at one of two times. Optimally, referrals will be provided in Phase 3. Sometimes the team will need to consult directories or make inquiries to find referrals and these will then be included in the final dictated summary note.

Accessing referral resources, if available, is often contingent on application and funding. It is generally assumed that families will be responsible for making the appointments and travel arrangements and finding funding. With the population served in these clinics, these assumptions may not always be true.

It is the role of the team, especially the PHN, social worker, or family advocate, to help the family understand clearly the route they must follow to get help. It may be necessary in some cases to be considerably more pro-active. Helping the families in this way needs to be carefully assessed in terms of time commitment and cost to provide this support.

Coordination of referral resources is often not available unless the family can motivate and coordinate these interactions. It would be optimal if team members could assure that the community resources are conferring with each other on a regular basis in situations in which this is necessary.

## **VII Follow-up Procedures**

Follow-up evaluations are either necessary or helpful under the following circumstances:

1. Further medical or psychometric tests are needed before a final diagnosis can be rendered.
2. The patient was diagnosed two or more years ago and their needs have changed over time.

Occasionally, a diagnosis cannot be made because further medical or psychometric information is needed and was not available on the day of diagnosis. The team should be available to re-assess the situation after this missing information becomes available. Generally, such a follow-up will not require the full four-phase process. The team leader can generally decide how to modify the evaluation so that follow-up can be completed.

Generally, the needs of this patient population change over time. Many patients may benefit from reassessment of their psychological profile and treatment plan every two to four years. For very young children (less than five years of age), the diagnosis may also change with age. The ability to identify organic brain damage in a young child is very limited. As they get older, the diagnostic reliability of psychometric assessments increases. It would be appropriate to develop a mechanism for reassessment to meet this need. Generally, the assessment would require a full four-phase evaluation, but the session could be modified and shortened in some cases.

## **VIII Patient Confidentiality**

### Confidentiality in the Clinical Setting

The clinical team must abide by the standards of confidentiality established in each respective discipline in discussing the clinical information and distributing records and reports. In general, this means the entire team will need to obey the strictest set of rules among the clinical standards brought to the program by the participants. These are usually Mental Health standards. All procedures should be HIPAA compliant.

### Confidentiality in the Research Setting

Data from the New Patient Information Form and the FASD Diagnostic Form are entered into the FAS DPN clinical database. Use of this data for research purposes is approved through the University of Washington Human Subjects Review Board. Patients must sign a FAS DPN Research Consent Form before their data may be used for research purposes. The consent is voluntary, confidential and is independent of receipt of clinical services.

## **IX Volunteers**

The FAS Diagnostic & Prevention Network requires a number of supports, some of which must come from the professional community (diagnosticians, follow-up professionals) and some of which can come from the community in the form of volunteers. These volunteers can provide system enhancements that can improve the experience for families and professionals in the diagnostic process and help build awareness of FASD issues in the community for further diagnostic, prevention or resource development activities.

Currently, four areas have been potentially identified for volunteer support:

- Provision of childcare during the clinic process.
- Providing appointment phone confirmation calls to families.
- Family advocacy.
- Developing community support for a clinic site and its activities.

### Provision of Childcare

There are two reasons for child care at the clinics: 1) few sites have broad resources to keep any child occupied during the 2-3 hour diagnostic process, and 2) children referred to the clinic are generally referred due to behavioral problems which may need close supervision.

Childcare is needed for unsupervised siblings and patients while their parent(s) or guardian(s) is interacting with the diagnostic team.

Provision of childcare at the sites required the following components:

- Recruitment of volunteers
- Reference check/clearance procedures/use of waivers
- Job descriptions
- Training
- Supervision
- Debriefing
- Volunteer recognition/appreciation

### Recruitment of Volunteers

- Must be available during the day for shifts of 4-8 hours.
- Can be recruited through FASD parent support groups.
- Can be recruited through existing social service agencies that have volunteers experienced in working with special needs children.

### Reference Check/Clearance Procedures

- Specific host-agency volunteer procedures must be researched and adhered to.
- State Patrol fingerprint and background checks should be required.
- A volunteer form should be used which includes: volunteer assessment of FASD knowledge, and three references, particularly if the volunteer is not known to the project.
- References should be verified.
- Volunteer waiver (part of volunteer form) should be signed by volunteer.

### Job Description

- A job description with volunteer and organization expectations should be given to each volunteer and reviewed for understanding.
- Any variations from the job description should be put in writing to confirm understanding by all parties.

### Volunteer Training

- Volunteers should be given a basic didactic introduction to FASD.
- Volunteers should be given hands-on training at clinic with an experienced volunteer or staff person. The training should include a briefing on the clinic process as well as the special needs of children with this type of organic brain damage.
- Volunteers should be briefed on basic childcare protocols (Campfire Boys & Girls Club has a good model program that also includes special needs children).

### Volunteer Supervision

- Volunteers should have direct supervision and be periodically monitored by clinic staff (see if they need a break, assistance, etc.).
- Volunteers sitting in on the staffing phase should be directly asked for their input. Some volunteers may be intimidated and will not speak up unless invited to offer their observations of the child's behavior during the baby-sitting period.

### Volunteer Debriefing

- The volunteer coordinator should call the volunteer after their first few experiences to debrief the volunteer and identify any outstanding questions, challenges, or new ideas that could be shared with other volunteers.
- After a volunteer has been working for a few months, the volunteer coordinator should touch base on a regular basis (monthly) to ensure things are going smoothly for the volunteer. Feedback should also be sought from the clinic diagnostic team.

### Volunteer Recognition

- As with any volunteer program, all volunteers should be thanked for their time spent. Thank you cards, letters of recognition to the volunteer's employer, or notices in local papers can be forms of recognition.
- Personal feedback can also greatly strengthen volunteer commitment. A phone call of thanks or to get feedback from the volunteer demonstrates that the individual is worth your time.

## **X Additional FAS DPN Materials**

1. *Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code*, 3<sup>rd</sup> Edition, Astley SJ, 2004.
2. *FAS Facial Photographic Analysis Software*. Version 1.0.0. Astley SJ. University of Washington, Seattle WA. 2003.
3. *FAS DPN Clinical Model: Manual*. Washington State FAS Diagnostic and Prevention Network, 3<sup>rd</sup> Edition, Clarren SGB, Olson HC, Beck S, Clarren SK and Astley SJ, University of Washington, Seattle WA, 1999, 2004.
4. *Psychometric Training Guide: Washington State FAS Diagnostic and Prevention Network*, Olson HC, Clarren SGB, Beck S, Lewis & Jirikowic T, 1999.
5. *Fetal Alcohol Syndrome TUTOR<sup>TM</sup> Medical Training Software* (CD-ROM), Astley SJ, Clarren SK, Gratzner M, Orkand A, Astion M., National March of Dimes / University of Washington, 1999.