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

FAS DPN Clinical Model
Manual

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Table of Contents

I. Introduction ...................................................................................................................................1
   A. The Interdisciplinary Clinical Team .................................................................1
   B. The Clinic Format ...............................................................................................1
   C. Purpose of the Manual ......................................................................................2

II. The Clinic Process ....................................................................................................................2
   A. Phase 0: Preparatory Activities: Review of Data ..............................................2
      1. Purpose ........................................................................................................2
      2. Preparatory tasks conducted prior to the clinic visit ....................................2
      3. Preparatory tasks conducted on the day of the clinic visit .......................4
   B. Phase 1: Clinical Assessments ............................................................................5
      1. Purpose ........................................................................................................5
      2. Clinical interview with the caregiver(s) and the patient ................................5
      3. Patient assessments ......................................................................................6
      4. Patient physical exam ..................................................................................7
   C. Phase 2: Case Conference: Diagnosis and Treatment Planning ......................7
      1. Purpose ........................................................................................................7
      2. Case conference to establish the diagnosis and treatment plan ..................7
      3. Presenting the diagnosis and plan to the client ..........................................8
   D. Phase 3: Caregiver Debriefing ...........................................................................9
      1. Purpose ........................................................................................................9
      2. Provide opportunity for caregiver to emotionally debrief .........................9
      3. Provide brief overview of diagnosis and recommendations .....................10
      4. Share diagnosis with patient .....................................................................11
      5. Closure ......................................................................................................12
   E. Phase 4: Staff Closure .......................................................................................12
      1. Purpose .......................................................................................................12
      2. Completion of forms ..................................................................................12
      3. Develop follow-up plan ............................................................................12
      4. Staff debriefing and emotional closure ......................................................12

III. Additional FAS DPN Materials .......................................................................................13
I. Introduction

A. The Interdisciplinary Clinical Team

Individuals exposed prenatally to alcohol often have complex, challenging problems and issues. At the University of Washington (UW) Fetal Alcohol Syndrome Diagnostic and Prevention Network (FAS DPN) clinic we have learned that making accurate diagnoses and intervention plans for alcohol affected clients requires an interdisciplinary team approach, involving the expertise of physicians, psychologists, language specialists, social workers, public health nurses, family advocates, and others.

Some of the most important requirements of team membership in our setting include: 1) ability to work collaboratively, 2) ability to apply one's knowledge to issues germane to FASD across a patient's life span, and 3) the capacity to formulate interventions for the patient, his/her caregivers, and the community.

In this manual we will share our thoughts about our process of evaluation of patients at the UW FAS DPN Clinic.

B. The Clinic Format

The UW FAS DPN Clinic model involves five phases:

Phase 0: Review of data: Preparation for patient visit
Phase 1: Clinical assessments
Phase 2: Case conference: Diagnosis and treatment planning
Phase 3: Caregiver debriefing
Phase 4: Staff closure

Each phase involves many concrete tasks that are related to a variety of conceptual issues.

In Phase 0 (the preparation phase or passive data collection) the referrals of prospective patients are obtained, background information is collected and team members review the records provided by the various sources such as hospitals, schools, and the justice system. Initial assessments and interview planning are conducted.

In Phase 1 (the clinical assessment phase or active data collection) a physician and psychologist interview the caregiver and client; a variety of formal and informal assessments may occur.

In Phase 2 (the case conference phase) the team discusses the patient's issues, establishes the diagnosis, and develops a treatment plan. The team then shares the diagnosis and recommendations with the caregivers.

In Phase 3 (the debriefing phase or data analysis and interpretation) the psychologist offers the caregivers an opportunity to begin emotionally processing the experiences of the clinic day. The team psychologist provides limited counseling to the caregivers so the caregivers can express initial feelings about the diagnosis and its meaning. Upon completion of the therapeutic phase, other appropriate team members, such as the social worker, family advocate or public health nurse enter the Phase 3 room to review the diagnosis and recommendations one more time with an emphasis on providing more specific information such as names and phone numbers for service referrals, etc. Specific feedback is also given to patients usually with the caregivers present.
In Phase 4 (the staff closure phase or data re-interpretation) the team members complete necessary paper work, make referrals and discuss issues with other staff members. In addition, team members make "sense" of the case, and emotionally debrief among themselves.

I. C. Purpose of this Manual

This manual describes our ideas, our patterns of operation, and the tasks we carry out throughout the clinic process. We see this manual as a work in progress. We are attempting to share our thoughts about the concepts that have guided our work and to specifically describe the tasks we have performed at the UW FAS DPN Clinic. Your own clinic will evolve over time, but we offer this initial structure and process as a model. Some of you will find these detailed suggestions useful while others of you may have your own ideas about how to proceed based on years of interviewing and counseling experience. Please use the information that is helpful and also inform us of needed changes and additions. We share our approach only as a guide to your own creative work in providing help and understanding to patients prenatally exposed to alcohol.

II. The Clinic Process

A. Phase 0: Preparatory Activities: Review of Data

1. Purpose
   The purpose of Phase 0 is to respond to requests for appointments and assist the patient in completing the New Patient Information Form (NPIF) and gathering background records. The team members (clinic coordinator, psychologist, physician, etc.) who will see the patient for assessment review each case prior to the clinic visit. With such preparation, the team can effectively discuss the case and prepare for diagnosis and treatment planning.

   Prior to 1996, funding restrictions prevented our clinic staff from carrying out our own assessments prior to the day of the clinic visit; however, in the network clinics, such specific psychological, speech, occupational and physical therapy assessments may be planned and carried out in advance of the case conference day. The information from such assessments can be used to guide diagnosis and recommendations.

2. Preparatory tasks conducted prior to the clinic visit

   a. Preliminary tasks: The tasks of requesting an appointment, collecting the necessary background information, and filling out the clinic NPIF are the initial steps in preparing for the clinic visit.

      We have found that the clinic coordinator, parent advocate and social worker are essential to many families in understanding the complex set of organizational tasks that are necessary in obtaining the patient's background records. Often the support of our parent advocates or family support people in the community, as well as people currently working with the family, such as teachers, public health nurses and case workers can help complete the forms and do the various tasks needed like requesting, copying, organizing and mailing the data. Often too, there are many emotional issues for the caregivers and possibly for the patients about coming to clinic for a diagnosis. During this time of possible emotional turmoil the caregiver's support people will often be important to give encouragement and support.
Washington State FAS Diagnostic and Prevention Network Clinical Model

b. The completed NPIFs are returned to the clinic coordinator and sent to a clinic member for initial review and screening.

Screening serves two purposes:

i. It allows one to triage inappropriate referrals to more appropriate clinics. For example a referral, in which the primary concern is attention deficit and prenatal alcohol exposure is unknown, would be more appropriately referred to an ADHD clinic.

ii. It also allows one to pre-review the request and prioritize appointments to accommodate deadlines and crises.

c. The clinic coordinator schedules the appointments and makes contact with the family helping them with the specific details of finding the clinic, registration, and parking.

d. The clinic coordinator prepares the clinic list well in advance of clinic appointments and then checks on all patients' intention to comply with appointments a day or two before the visit.

e. The psychologist and physician review the list of scheduled cases prior to the day of clinic and begin the process of reviewing the records.

The psychologist's first task is to begin to understand the cases by reviewing the written records. In the UW FAS DPN Clinic, psychologists are responsible for a review of the psychosocial, behavioral, and educational issues in each case. The physician completes a similar review with emphasis on the medical record reviewing previous medical reports and prior diagnoses.

Strategies: If two or more physicians or psychologists work in your clinic, you may want to assign individual cases to individual physicians and psychologists before the clinic day. Issues such as client and caregiver characteristics and possible needs, appointment times, experience with different age groups, etc. may be factors in making case assignments.

As we review case materials examples of areas we tend to initially check are:

● Is the New Patient Information Form complete?
● Who completed the NPIF and when?
● How valid does the information appear to be?
● Is essential information (legal, medical, school records, etc.) missing?
● Does this patient need a psychometric or educational assessment in order to make the diagnosis? When and where can the assessment be obtained?

f. Completion of the Psychosocial Summary Form (PSF) by the psychologists

The psychologist succinctly summarizes all psychosocial information from the NPIF, previous assessments, and other past records supplied by the caregiver on the Psychosocial Summary Form (PSF). This written outline facilitates staffing on clinic day and helps the physician incorporate pertinent information into the dictated medical summary note. The information is organized by category in chronological order. Emphasis is on summarizing pertinent dates and assessment outcomes.
g. The psychologist or another member of the team may need to make a follow-up call to the caregiver to request that missing essential information be forwarded. As is the experience of many clinics, despite our efforts to inform families of the importance of sending these records, school records, special education assessments, and psychological reports are often not sent before the day of clinic. Most caregivers have preferred to bring such information with them to the clinic appointment. We are often faced with the task of last minute record review.

h. If pertinent assessments have not been conducted in the past, arrangements are made to conduct on-site testing. See the Psychometric Training Guide for suggestions of assessment tools we have found useful.

We try to obtain current observational information about adaptive functioning. It would be optimum to make observations in the client's home or school. This could be the job of a public health nurse.

3. Preparatory tasks conducted on the day of the clinic visit

a. Register patient and introduce them to the clinic format.

b. Request HIPAA compliant consent for inclusion of their non-identifiable data into the Network Research Clinical Database.

c. Obtain consent for obtaining a clinical facial photograph and take the photographs if consent is obtained.

d. Obtain the patient's weight, height and OFC.

e. Assist professional visitors who are attending the clinic.

Professionals routinely visit our clinics. Visitor orientation is a necessary role that we have undertaken. A single team member is assigned to explain the clinic process and answer questions about roles, diagnoses, etc. This individual makes sure that all introductions are made and confidentiality explained. Confidentiality Agreement forms are signed by each visitor.

f. Prior to the interview, the team reviews all information at hand.

The team decides what new information needs to be obtained and what other information needs to be reviewed in the interview. In this pre-interview session we try to consider the following issues:

General issues:
- What are the important referral questions?
- What is the reported family structure- biological parent(s), adoptive parents, foster caregivers?

Specific issues:
- What information is missing on the NPIF and other records?
- Are there any important etiological factors other than alcohol exposure?
- What interventions have been tried?
Washington State FAS Diagnostic and Prevention Network Clinical Model


Issues on how to conduct the interview
- Which interviewer plans to take the lead?
- What information should each of the interviewers gather?
- What portions of the case information need to be supplemented or highlighted?

Issues of interview structuring
- Will the interviewers work together for all or part of the time in the interview?
- Is this a teenage patient who needs a private interview?
- Is there a case manager or other professional who needs a separate interview or feedback session?
- Are there several children that might need to be observed?
- Is there a child or teenager who needs company, supervision, or caregiving?

II. B. Phase 1: Clinical Assessments

1. Purpose
   In the intake interview, we try to get an understanding for the patient, the caregivers, and their world as they presently experience it, as well as learning and reviewing pertinent factual information about the case.

2. Clinical interview with the caregiver(s) and the patient.  The results of this interview are documented on page 6 of the FASD Diagnostic Form in the FASD Diagnostic Guide.

   a. How to begin the interview.

   Examples of opening questions include:

   * We've read through all the forms you filled out and the information you brought in, but we always like to ask: What did you hope to learn today?
   * What are your most important questions and concerns about the patient?
   * How can we help you today?

   b. Factual information to collect pertaining to the patient’s functioning

   - Behavioral control/ modulation
   - Language expression and understanding (especially social language usage)
   - Thinking skills, judgment
   - Ability to plan
   - Developmental tasks - when they occurred and how they were demonstrated
   - Free time activities
   - School experiences
   - Social interaction patterns with family members, peers, adults
   - Self help skills
   - The nature of a day with this child
   - The amount of supervision/ protection required to maintain safety

   c. Also we try to determine the caregiver's feelings and understandings and assess the nonverbal information:
Examples of information to determine include:

- What is the reason the informants say they have come to clinic, and how does this fit with your intuition about why they are there?
- What is the attitude and feelings about coming to clinic for caregiver and patient?
- What do caregiver and patient know about an FASD diagnosis?
- Does the caregiver appear to understand the child?
- How accurate and aware are the informant(s)?
- How valid do you think the information is?
- What strengths do the informant and patient have?
- What is the context from which they speak (e.g., do they have other children to compare this child to)?
- What does the family like about the child?
- What does the caregiver feel they need most in terms of support?
- What are additional significant stresses for the caregivers?
- What is the caregiver's sense of the future with this patient?
- What does the caregiver believe will help this patient?

Observation suggestions:

- Watch for behavior and interactions when the patient enters the room and joins the caregivers.
- Attend to the child's pacing, modulation, attention, vocabulary?
- If you are interviewing two or more caregivers, who takes the lead and does the lead vary as different ideas are discussed?
- What are the interactions of the informants- parents, case worker, child(ren) and parents?

d. Interviewing the patient

The psychologist may want to spend individual time with the patient on the day of diagnosis. The need for an individual interview will vary depending on the age of the patient and the prior experience team members have had testing the patient.

In our setting at the UW FAS DPN Clinic we directly interact with the patient by sitting with the family in the waiting room, taking the patient on a short walk or informally talking with the older patient, observing testing by another professional, or directly testing and interviewing the patient.

3. Patients Assessments

At the UW FAS DPN Clinic we have had a variety of professionals available to see the patient on the day of clinic. Audiologists, speech and language pathologists, dentists, and occupational therapists have intermittently organized and provided short assessments. We have found that information on the patient's understanding of sophisticated language forms and their ability to tell stories and express themselves in complex formats as well as information on the patient's visual spatial drawing and writing and gross motor skills have been very important in understanding cognitive functioning related to organic brain damage.
4. Patient physical examination

The physician calls the patient into the room typically after the interview with the caregivers and conducts a brief physical examination looking principally for minor dysmorphic features and neurologic status. In our clinic height, weight, head circumference and a photograph of the patient’s face, frontal and side, are taken prior to the physician's exam.

During the examination we involve the patient in informal conversation. We also see how they respond to an open-ended question that requires divergent reasoning. The physician solicits this response by telling the patient he would like to play a game with them. In this game he tells them that “You will be granted a ‘perfect’ day. You can be anywhere, do anything, with anyone. What would you do on such a day?”

II. C. Phase 2: Case Conference: Diagnosis and Treatment Planning

1. Purpose

In Phase 2 the interdisciplinary team is involved in a comprehensive sharing of factual and emotional information. The team discusses the diagnosis, the client’s and caregiver's potential understanding of and reaction to the diagnosis, the priorities for information sharing with the client, and the recommendations.

2. Case conference to establish the diagnosis and treatment plan

The physician, in discussion with the team, determines the medical diagnosis using FAD 4-Digit Diagnostic Code described in the FASD Diagnostic Guide (Astley, 2004). The team members clearly state their observations and share relevant information as it applies to determination of the diagnosis. We encourage other team members to ask questions if the diagnosis is unclear.

After the diagnosis has been established, we develop general and specific recommendations for intervention using a problem solving approach. The team discusses what they perceive to be the most crucial needs for the patient and family, and make recommendations based on the individual's age, current program, strengths and weaknesses, and functioning.

The physician and psychologists facilitate obtaining specific referrals and programmatic ideas by asking for the other team members' ideas. Attempts are made to make realistic, achievable, appropriate recommendations that are at a level that the family can understand in their current situation and psychological state.

We develop a plan for talking with caregivers and clients. The team decides how to present the diagnosis and recommendations to the client. If several caregivers other than the parents are involved with the patient’s care and present at the clinic visit, it is necessary to decide if all people who came (e.g. case workers, foster, biological parents, adult patient) should be present in the feedback. What sub-group should be seen? How much information and at what level of sophistication should the diagnosis and recommendations be shared at the case conference in phase two?

The psychologist then organizes printed handouts for the client that will be distributed in phase three.
Washington State FAS Diagnostic and Prevention Network Clinical Model

These handouts are available in a "Patient Resource Box", provided by the Network to each clinic. These handouts cover a range of topics helpful to caregivers, families, and teachers, and others in the community that work with the clients. Examples of topics include: FASD, other birth defect syndromes, SSI funding, DDD services, classroom interventions, etc.

The team members can begin the process of completing the Preliminary Summary and Recommendations Form. This form can be found in the FASD Diagnostic Guide. The primary recommendations are documented on this form. All team members who saw the patient add their findings and recommendations to the form. One copy is given to the family upon leaving the clinic; the other copy is retained for the patient's file. This allows the family to go home with preliminary written documentation of recommendations as they wait for the final medical summary note to be sent to them.

3. Presenting the diagnosis and plan to the client

a. Preparation of the client for feedback
   i. Room preparation - We arrange the room configuration so those staff members who are "at the table" have been directly involved in the case. We seat visitors or those staff members who have not been directly involved as unobtrusively as possible around the edge of the room.
   
   ii. Team and visitor preparation - We try to be conscious of the time and plan for who will talk to the client about various issues. Usually the physician and psychologist do the majority of speaking during the feedback, but other team members (including all those who assessed patient and the parent advocate) are valuable participants.

   iii. One of the team members who has already had contact with the caregiver invites and accompanies them to the conference room:

   1.) During this transition the interviewer who accompanies the caregiver has an opportunity to talk with the caregiver, set them at ease, and prepare them for meeting the rest of the staff

   2.) We welcome the caregiver and make introductions to the team members and visitors who they have not yet met.

   One might imagine that the large group setting would at first be rather intimidating for the caregivers, but we have found that most people are pleased to find that so many people have been involved in considering their case and see the group as highly supportive. During this phase the team members focus on giving clear information and on providing emotional support to caregiver during the diagnosis and discussion both verbally and non-verbally.

b. Feedback to the caregivers: Diagnosis and recommendations presented

   i. Diagnosis: The physician generally begins the discussion and presents the medical diagnosis. We have found that patients have difficulty with the anticipatory stress of the diagnosis, so we offer the final diagnosis first, let the patient react to the terms and then begin a process of explanation that we gear to their apparent level of understanding. Each team member shares their specific findings in order to make the diagnosis more understandable. At times the pattern of testing results can help the caregivers understand "organic brain deficits". For example, in the UW FAS DPN Clinic, the occupational
therapist may present behavioral observations, neurological screening data, or motor skills test results that are indicative of atypical neurological functioning. Also, the language specialist may provide concrete examples of child's problems in reasoning and verbal expression that can be related to the patient's behavioral difficulties.

ii. We congratulate the parent for doing a good job (when praise is appropriate). We make an effort to enumerate the many positive actions and attempts the family has made on child's behalf. Positive acknowledgment is very important. Parents usually get negative feedback from their families and communities, as problems of the patient may be attributed to lack of parental effort, poor parenting, or inherent "badness" in the child.

iii. We also try to be aware of the nonverbal information related to the caregiver's understanding and acceptance of the diagnosis and recommendations.

During the time spent sharing diagnostic information with the caregiver, it is important to track the caregiver's reaction and understanding of the diagnosis. "Where" is the caregiver in the process of understanding and acceptance of the diagnosis? The psychologist in particular should try to monitor the caregiver's apparent understanding, emotions, behavior, apparent agreement or disagreement, fatigue, or anxiety as well as cognitive and emotional understanding and address the emotional issues in phase three.

We share our recommendations in terms of broad generalizations. The psychologist may present a brief summary of education, family, and the support issues we want to address and then relate a broad recommendation to each issue.

At the UW FAS DPN Clinic because of time constraints we tend to save the specifics of implementation of recommendation for Phase 3.

II. D. Phase 3: Caregiver Debriefing

1. The purpose of Phase 3 is to provide quiet, private time for the caregiver and patient to review the emotional and cognitive experiences of the clinic day. This final phase with the caregiver is divided into two segments. First, there is therapeutic segment, a time for emotional debriefing. Second, there is a cognitive segment to review the diagnosis, recommendations, and specific referrals. The first segment is best done with only the psychologist and caregivers present. This time may not need to be more than 5 to 15 minutes, but it is time for expression of feeling before the focus again returns to more cognitive matters. In the first part of Phase 3 the psychologists are primarily following the client's agenda and pace and let them express their feelings.

The cognitive segment may involve the psychologist, caregivers, others who come from the community such as caseworker, parent advocate in a discussion of specific information and recommendations. With a patient over 10 years of age, individual time is given to review their experience in clinic, the diagnosis and broad recommendations.

2. Provide therapeutic processing and an opportunity for the caregivers to emotionally debrief.

The psychologist's role is to follow the client's lead: create a time for feelings and emotional expression, and support for the caregivers and patient. There are limitations on how much any person can absorb cognitively in the midst of an emotionally intense experience.
We try to provide appropriate pacing and match the caregiver's speech and body positioning. Be protective and gentle. Allow for tears, rambling talk, anger, appreciation, etc. Listening may be much of what we do.

Examples of questions we often use at the beginning of the session include: "Did the diagnosis make sense to you?" "How do you feel??" "What can I do for you now?"

The psychologist then listens for the caregivers to elaborate on such questions. We try to allow for silence, processing, sorting out. This time has been very beneficial because it helps the caregiver process the diagnosis on an emotional level. We have found if we put the emphasis on the client, and listen to them, we don't go wrong. We simply need to encourage the caregivers to discuss what their issues are, help them prioritize these issues and find out what they want to do next, facilitate their goals, and assist in their growth related to new information.

3. Share the basic ideas about prenatal alcohol exposure, discuss recommendations and planning, for follow-up.

This is the cognitive portion of Phase 3. We provide time for others involved in the case to enter the discussion (such as the caseworker, counselor, school personnel, etc.).

a. We read the Preliminary Summary and Recommendations aloud to the caregiver to make sure it is clear, legible, and includes sufficient information so that it is usable. Add written clarification statements as needed.

b. We clarify that the client understands diagnostic labels such as "FAS", "ADHD" or "static encephalopathy". We try to provide a clear, direct, concise explanation of terms. We often write on the chalkboard, draw pictures, and present previously constructed visuals. We explain what occurs with prenatal alcohol exposure and how the patient's diagnosis is like or dissimilar from the full Fetal Alcohol Syndrome diagnosis.

c. Next we focus on the recommendations and try to make specific referrals and a plan to carry out the recommendations. In this part of the planning process, we are finding out what makes sense and is possible for the caregiver to do next.

This time can be used for brainstorming what is needed to implement the recommendations. It is very helpful to have the team from the community available to suggest how best to implement the interventions.

We have found it is important to be specific and yet be aware of limitations of understanding for caregivers and patients. It is very difficult for them to hear and comprehend so much information at one time. We always err on the side of letting go of recommendations made by the team, and going with what the client really wants to do (if it seems appropriate). It is important to acknowledge that the family may be in a hard place, and offer what help can be realistically given. We listen to what the client needs to share or knows at this point in time.

d. Provide concrete specific suggestions, telephone numbers. Identify potential referrals and agencies.

e. Sign extra forms such as the Mutual Exchange of Information Form.

f. We share materials from the "Patient Resource Box" such as handouts of articles on FASD, copies of the most recent newsletters and books and information for teachers.
When the caregivers appear emotionally acclimated and understand the diagnosis and recommendations, we turn to issues of feedback for the patient.

4. Share the diagnosis with the patient

a. Planning of patient feedback

Together the caregivers and psychologist plan the feedback for the patient. We almost always give direct feedback to any patient over twelve years of age, the decision to give direct feedback to children between the ages of 5 and 11 will vary based on their level of comprehension and their caregivers desires.

We assess from the caregiver what the patient already knows about FASD and how they feel about coming to clinic. We plan with the parent what feedback to give to the child and how best to state the explanations. Tell the parent: "While I am talking to (the child), listen, so that you can repeat it over and over and over, until it makes some sense. I'll just do the explanation one time, but what is really important is what you do in explaining it repeatedly."

Usually it is best to give feedback to the patient in the presence of the caregiver. This is important because then the caregiver and patient hear the same explanation and this conversation can reduce potential secrets or different messages to different family members.

b. Provide clear, understandable information that is geared to the cognitive level and the emotional needs of the patient.

Examples of initial clarifying questions: Do you know why you are here? Do you have any questions? Is there anything that you want to say?

Be sure to keep advice to teens straightforward, reinforce (when appropriate) the teen's strengths, and reinforce what people in the teenager's life are already saying.

Talk about feelings the patient may have, especially about their biological mother's role in their current difficulties.

An example of a starter for such a discussion: We are sure that your mother did not intentionally mean to hurt you.

Address the client's problems in learning, behavior, and growth. Make sure that the child understands that having fetal alcohol effects does NOT mean they aren't good and capable people, but that it does mean they have a learning problem, and that they need a plan to help them learn (if the latter is a point they will understand).

Usually we try to indicate that we know the patient tries, has had difficulties, and over the years may have been misunderstood. Their diagnosis gives an explanation of why learning and acting calmly has been difficult for them. It is not that they haven't been trying, but rather they have had some difficulties. Also, give them hope that they can do positive things, but they may need extra time, help, etc. With support they can do a better job and live a reasonable life. Explain that the patient needs to act their best and try to learn what is necessary to do a good job in school and work with friends and family.

Address the child's risk of becoming alcoholic and encourage abstinence.
You might say: "As you probably already know, if you come from a family with a problem with alcohol, you are likely to have a problem with alcohol too. Sometimes other kids will pressure you to drink, but just tell them you are at risk of becoming an alcoholic because of your family history.

5. Closure
   a. It is important to provide clear closure. Say good-bye and voice your appreciation to the caregivers and patients. Thank the family and discuss the courage it took to come to clinic (especially with biological parents). We try to take time to say good-bye to children to whom we did not give feedback and thank them for coming to clinic.
   b. Clarify with caregivers if there will be future involvement with the clinic. Be clear about the scope of the clinic follow-up.

II. E. Phase 4: Staff Closure

1. Purpose
   The purpose of Phase 4 is to complete all the paperwork and details in the case. Also staff closure involves the team to task to each other and share their own feelings about the case they have seen in the clinic day.

2. Completion of Forms
   We review personal notes, write up impressions, and add any new information obtained in the third phase or modified recommendations. The psychologist gives these notes, permissions, and other information to the team members who need them. It is helpful to check and update the PSF after the client leaves, to make sure the form remains accurate once additional information has been obtained.

3. Develop follow-up plan
   We make a list of things needed to do as follow-up regarding each case. Also we clarify which team members will continue work with each patient and on what specific issues.

4. Staff debriefing and emotional closure
   Finally, we provide ourselves with a chance to debrief about the cases. A chance to talk with another clinic member about what has happened can help each of us come to terms with our work and the issues we have shared.
III Additional FAS DPN Materials


