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19/2/6/1

Datum
Date
Umhla

30 July 2002

Oepartement van Gesondheld
Department of Health
iSebe lezeMpilo

The Head of Health
DDG: Special Health Projects and Transversal Programmes
DDG: Operations
DDG: Administration
Chief-Director: Rural Regions and Mental Health
Chief-Director: Metropole Region
Regional Directors
Director: Programme Development
FAS Provincial Reference Group Members
Relevant Stakeholders

Dear Colleagues

FETAL ALCOHOL SYNDROME: PROVINCIAL STANDARDISED TRAINING MANUAL

In April 2001 we had a provincial workshop were it was decided that we should motivate for funding for FAS prevention and management projects. Another recommendation of this workshop was that a FAS Training Task Team should be established to develop a standardised training manual.

As you are aware a conditional grant (R500, 000) was released for this programme. The bulk of the money was allocated to the regions and a small amount was retained for the provincial programme, managed by the MCWH sub-directorate. (A progress report of this program was recently distributed, should you be interested in a copy please contact this office at the above-mentioned telephone number or 021-4834216.)

A Training Task Team was established and produced a draft-training manual. Attached please find a copy of this document for your perusal and comments. Sections of this document have already been piloted in the rural and metropolitan regions. It would be highly appreciated if you could please forward your comments to Leana Olivier at Fax: 021-4834345/2682 or e-mail: lolivier@pawc.wcape.gov.za before 23 August **2002.**

We are planning to finalise the training manual in September 2002 and after final circulation for comments it will then be printed and distributed for implementation.

Training Manual

Management of Fetal Alcohol Syndrome at a Primary Health Care Level

Western Cape:
Provincial FAS Reference Group:
Training Task Team

Dr C Adnams (Developmental Paediatrician, UCT); Dr G de Jong (Human Geneticist: US); Ms R du Plessis (Regional MCWH Manager, Boland/Overberg Region); **Ms AS** Marais (Researcher: FARR); **Ms** L Olivier (MCWH Provincial Manager, PAWC); Thobeka Moletsane (HRD & Training Officer, Metropole Region)

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How to use this Training Manual

1. Welcome.
2. Request the workshop participants to complete the Attendance List.
3. Hand out student workbooks and evaluation forms.
4. Discuss assignment to **be** handed in.
5. Put posters to enable discussion on wall.
6. Sign and post attendance certificate to student.

importance to the provincial office not to "re-invent the wheel', but to built on these initiatives and to learn from their experiences.

On 19 April 2001 delegates involved in FAS intervention/research programmes in the Western Cape province attended a provincial workshop to report on their initiatives, establish whether there is a perceived need for a Provincial Plan of Action and to decide on the content of this plan.

At this workshop a multi-disciplinary and inter-sectoral Provincial Reference Group was established and given the mandate to proceed with the development of

Standardised training about FAS and related issues
Standardised Management Guidelines
A Health Promotion and Education Programme

A conditional grant for the development of the above-mentioned and to support the regional/district intervention programmes was allocated by PAWC for *200213.*

3. Development of the Training Programme

Members of the FAS Provincial Reference Group were nominated to develop the training programme.

Drafts of the Training Programme including manuals, were circulated for comments and inputs to the Reference Group and the Regions.

The final draft was piloted in _____ on _____

Copies of the Training Manual and material are made available to the Regional HRD, MCWH and Training Programmes for continued in-service training.

4. Aim

The aim of this training is:

To provide standardised training for primary health workers responsible for the management of individuals affected by or with Fetal Alcohol Syndrome in the Western Cape Province.

ATTENDANCE LIST

DAJE: _____ Please Print

NAME	ORGANISATION	POSTAL ADDRESS	TELEPHONE	FAX	EMAIL

MODULE I

FETAL ALCOHOL SYNDROME: AN OVERVIEW

Diagnosis

Diagnosis

- 3 – 10 years of age is the best time for diagnosis
- Cluster of symptoms
  - Growth retardation: height, weight and head circumference (below the 10th percentile)
  - Facial anomalies
  - Physical abnormalities
  - Central nervous system dysfunction

Transparency 3

NOTES TO FACILITATOR

- Best time to diagnose is between 3 – 10 years of age as signs and symptoms of FAS are most distinct during this period.
- To obtain a diagnosis of FAS a specific cluster of symptoms must be present:
  - **Pre/post natal growth retardation for height, weight and head circumference (less than the 10th percentile).**
  - A distinct pattern of facial anomalies
  - Other physical abnormalities
  - Central nervous system dysfunction.

Epidemiology

TAP AND CUP

Transparency *5*

NOTES TO FACILITATOR

- Explain concepts of prevalence and incidence to the workshop participants by using the diagram of the dripping tap and cup:
  - The dripping water symbolises the new cases that are been added (incidence) to
  - The existing number of cases in this community (prevalence) during, for example, a specific year.
- Ask the workshop participants to name two or three examples.
- Ask the participants what they think the prevalence of FAS is in:
  - the Western Cape
  - South Africa
  - the world.

See example on page 13

Risk factors

Risk factors

- Volume consumed
- Duration and timing of drinking during pregnancy
- Additional substance abuse
- Age
- Parity

Transparency 7

NOTES TO FACILITATOR

- Volume consumed
  - See Alcohol calculations.
  - Binge drinking results in intermittent extremely high blood alcohol levels even though for a short while.
  - The chronic drinker could not sustain these levels but has chronic lower blood levels.
  - Binge and chronic drinking are both dangerous to the developing fetus.

- Duration and timing of drinking during pregnancy
  - Refer to diagram **2** and indicate the possible damaging effect of alcohol in the different developmental stages of the fetus.
  - Show learners that the brain develops throughout the 40 weeks of pregnancy.
  - Damage to the brain could therefore happen any time through the 40 weeks whereas the maximum development of the heart happens over a short period (between **4** to 6 weeks). If the mother drinks between **4** to 6 weeks gestation, there is a much higher risk for the heart to be affected.

- Additional substance abuse
  - Many people who abuse substances, abuse more than one substance.
  - Multiple substance abuse will increase the harmful effects on the developing fetus. Women who smoked marijuana during pregnancy were five times more likely than non users to deliver a child with FAS features.
  - Ask learners for examples of substances that are abused.
  - For example: dagga, tobacco smoking , Mandrax, Cocaine

- Age
  - As a woman gets older and she continues to drink, the risk of serious effects to the fetus increases.

- Parity
  - Increasing parity is linked to the increasing age of the mother
  - The effects of alcohol on the developing fetus gets much worse with every consecutive pregnancy if the mother continues to drink.

Group work 1: Risk factors

Case Study

A 30-year old pregnant woman presents at your antenatal clinic for booking. On examination she is 20 weeks pregnant.

You notice that she is underweight and has a severe cold. She is married and lives with her 3 children in an informal settlement near the clinic. Her husband, an alcoholic, is unemployed and abuses her physically.

She smokes and drinks beer. She is an unemployed and sells cigarette for an income. Two of her children are under 6 years of age and receive child support grants. She mentions that the youngest child is "slow" and "very active".

Identify and list the relevant risk factors in this patient.

Transparency 9

NOTES TO FACILITATOR

- Hand a copy of the case study to learners.
- Read through the case study
- Divide the workshop participants into groups of 6-8 people per group.
- Ask each group to select
  - A facilitator
  - A scribe
  - A rapporteur
- Assign question (see below) to groups.
- Each group has to discuss the relevant question for 20 minutes and report back for 10 minutes/group.
- Provide the group with newsprint/transparencies and pens.

Characteristics of Fetal Alcohol Syndrome (FAS)

Characteristics of FAS

- Growth retardation, under the 10th percentile for:
  - Height
  - Weight
  - Head circumference (microcephaly)
- Facial abnormalities
- Physical abnormalities
- Central nervous system dysfunction

Transparency 10

NOTES TO FACILITATOR

- Refer to Diagram 2 and indicate to workshop participants that FAS can affect the fetus at any stage of development.

  POSTER OF DIAGRAM 2 (To be put on wall prior to start of workshop)

Characteristics of FAS (cont. 1)

Facial features

a) DISCRIMINATING FACIAL FEATURES
Microcephaly with:
- Short palpebral fissures
- Flat mid face
- Short up turned nose
- Indistinct philtrum
- Smooth, thin upper lip

Transparency 11

b) ASSOCIATED FACIAL FEATURES
- Epicanthic folds
- Low nasal bridge (flat mid face)
- Minor ear abnormalities
- Micrognathia (small chin)

Transparency 12

NOTES TO FACILITATOR

- Ask workshop participants to refer to Diagram 1 while indicating the characteristically facial features.
- The diagnosis is made on discriminating features, microcephaly, growth retardation, and one or more discriminating features.
- Associated features may commonly be found but do not contribute to the diagnosis.

- Definitions of features:
  - Microcephaly: a small head size due to impaired brain growth and development. The head size is measured by the head circumference.
  - Mid face: middle third of the face including the nose and cheekbones.
  - Palpebral fissures: the space between the eyelids extending from the outer to the inner canthus (canthus: either of the two angles formed by the junction of the eyelids).
  - Philtrum: the depression on the surface of the upper lip immediately below the septum of the nose.
  - Epicanthic folds: a congenital anomaly in which a fold of skin covers the inner canthus of the eye.
  - Micrognathia: abnormal smallness of the jaws, especially of the lower jaw.

Characteristics of FAS (cont.2)

Associated Physical Abnormalities

- Cardiac
- Skeletal
- Renal
- Ocular
- Auditory
- Other:
  - Cleft palate
  - Neural tube defects

Transparency 13

NOTES TO FACILITATOR

- Ask workshop participants to name other abnormalities associated with FAS that they have come across.

  Insert table 9.1 — see page 22

- Definitions:
  - **Radio-ulnar synostosis:** a union of the originally separate radius and ulna by bony material.
  - **Camptodactyly:** a condition in which one or more fingers are constantly flexed (curled) at one or both phalangeal joints.
  - **Ptosis of the eye:** drooping upper eyelids.
  - **Strabismus:** squint

Characteristics of FAS (cont. 3)

Associated Neurologicallbehavioural problems

Neonate / infant

- Irritable, poor arousal
- Cries a lot
- Sleep disturbances
- Immature motor behaviour
- General motor behaviour delay including speech and language

Transparency 14

-

NOTES TO FACILITATOR

- Discuss the above.
- Ask workshop participants to discuss possible reasons for the baby's behaviour and the effect it might have on the mother/baby relationship.

Characteristics of FAS (cont. 5)

Associated Neurologicallbehavioural problems

Toddler/Pre School Child

- Developmental delays, including
  - Language delay
  - fine motor co-ordination delay
- Hyperactivity
- Sleeping problems

Transparency 15

NOTES TO FACILITATOR

- Discuss the above.
- Ask workshop participants to discuss the effect that these problems might have on the child's further development and hislher relationship with significant others in his/her life.
- How would this child present to the Primary Health Care facility?

  Behaviour problems presenting, as for example, hyperactivity, may be responses to other causes such as anxiety, depression in the child or caregiver, as a response to a poor external environment.

Characteristics of FAS (cont. 7)

Associated Neurological & Behavioural Problems

Adolescents

- Hyperactivity
- Attention and Learning problems
- Emotional and Mental Health problems
- Social Skills problems
- Conduct disorders
- Repetitive stereotypic behaviour
- Impaired
  - Problem solving
  - Memory

All of the above lead to impaired learning

Transparency 17

NOTES TO FACILITATOR

- List conduct disorders
- Emotional and Mental Health problems, for example anxiety, depression, low self esteem
- Conduct disorders, anti social behaviour for example stealing, aggression, harming others, cheating, and crime.
- Repetitive behaviour for example persistently repeats a particular activity, repeats words.

Characteristics of FAS (cont.9)

ADULTS

Adults have life **long** problems:

- Intellectual disability and incomplete schooling
- Attention and concentration problems
- Increased dependency on others
- Employment problems
- Mental health problems:
  - anxiety
  - depression
  - substance dependency
- Poor social functioning
- Crime
- Institutionalisation secondary to crime, intellectual disability and mental health problems

Transparency 19

NOTES TO FACILITATOR

- Present the above. Do not entertain any discussions at this stage.
- Refer to group work 2.
- Poor social functioning start in adolescence and continue to adulthood.

Group work 2:
Anti-social behaviour:
Adolescents & Adults

Model answers

Group 1:

Ensure that the presentation by the group contains aspects such as:

- Easily influenced and poor judgement make then more susceptible to
  - Sexual activities and exploitation
  - delinquency
  - Involvement in crime
- More readily influenced by
  - Peers and peer pressure due to poor judgement.
- Learning and reasoning impairments influence scholastic performance, possible early drop out and unemployment.
- Poor social judgement and effect on interpersonal relationships...
- Mental health problems... (anxiety to cope with everyday life as they are constantly compared)

MODULE 2

MATERNAL INTERVIEW

FAS: The Maternal Interview

A. Why the interview with the mother?

B. When to do the interview?

C. Where to use the interview

D. Who does the interview?

Transparency 20

A. Why the interview with the mother?

Objective:

Interview an at risk woman to enable the health worker to plan an appropriate intervention and to provide the mother with the necessary information to enable her to make an informed decision about her health and behaviour and to enable health care workers to use the information obtained, in their daily work and activities.

Transparency 21

B. When to **do** the interview?

At any opportunity where you are in contact with women at risk.

AT RISK WOMEN ARE:

ALL WOMEN OF CHILD BEARING AGE WITH EMPHASIS ON AND ESPECIALLY:

- women who you know drink
- high risk communities where alcohol drinking and abuse are prevalent
- when husband/ partner drinks/abuses alcohol
- when the household is known to drink/abuse alcohol
- previous child with **FAS**
- high index of suspicion of drinking of any of the above

Transparency 22

INCLUDE SPOUSES / PARTNERS WHERE RELEVANT AND WHENEVER AVAILABLE

Transparency *25*

Group work 3:
Maternal Interview
"Setting the scene"

Possible pitfalls of an interview.

- The opposite of any factors mentioned in the prerequisites for a good maternal interview.
- Any additional factors such as
- Personal bias, for example language, cultural, religious and social-economic bias
- Poor communication/interviewing skills
- Aggression or any other defence mechanism
- Language barrier
- Disturbances and Interruptions: noise, telephone, crying child, others entering the room.

THE INTERVIEW

History of alcohol intake

History of alcohol intake

- Specific order of questioning
- Open-ended questions
- Appropriate questions to situation
- Avoid suggesting/helping
- Probe inconsistency
- Be non-judgmental about volumes of intake

Transparency 26

NOTES TO FACILITATOR

- Discuss the above-mentioned.
- Ask workshop participants to demonstrate or to pose examples of questions.
- Ensure that workshop participants understand the importance of a non-judgmental attitude about volumes of intake. If the woman finds it difficult to recall amount, suggest a high volume (e.g. 8 beers a day).

Alcohol Intake (cont.)

VOLUME OF ALCOHOL

- Beer 300 ml = 1 drink

- Wine 150 ml = 1 drink

- Spirits 50 ml = 1 drink
  Spirits is also called "Strong Wine"

Home brewed alcohol = Alcohol content varies

One Drink equals:

Beer 300 ml
Wine 150 ml
Spirits 50 ml

Transparency *2*

NOTES TO THE FACILITATOR:

- Different types of drink contain different amounts of alcohol, i.e.: some are stronger than others. Therefore 1 drink of beer (300ml) = **1** drink of spirits (50ml).
- This means both have the same amount of alcohol.
- Alcohol consumption is measured in number of drinks. (See transparency on volume)
- Each type of alcoholic drink comes in different volumes and containers:
- Wine: 750 ml, **2** litres, 5 litres
- Beer: 340 ml, 750 ml.

Alcohol Intake (cont.)

Alcohol Calculations

Definition of a drink: **15ml AA** (Absolute Alcohol)

Heavy Drinking in pregnancy is defined as: -

- 2 or more drinks per day
- >5 drinks per week taken on a single occasion (binge)
- >45 drinks per month

Light Drinking in pregnancy is defined as: -

- Up to 2 drinks per day

Moderate Drinking in pregnancy is defined as: -

- More than 2 drinks and up to 5 per day taken in one sitting

DRINKS:

BEER: 350ml = 1 drink

600ml = 2 drinks

750ml = 2.5 drinks

1500ml = 5 drinks

WINE: Calculated at 100ml **of** wine having 10ml **AA.** 100ml wine may have 12ml **AA**

150ml = 1drink

300ml = 2 drinks

600ml = **4** drinks

750ml = 5 drinks

900ml = 6 drinks

1500ml = 7 drinks

SPIRITS: 50ml = **1** drink (for 30% absolute alcohol. Less if 40%)

Alcohol Intake (cont.)

NOTES TO FACILITATOR

Tell workshop participants to:

1. Return to page on alcohol calculations.

2. Turn to page of examples of alcohol consumption.

3. The facilitator should work through the examples with the workshop participants.

4. These tables enable the workshop participants to do calculations of the amount of alcohol consumed.

Counselling of Index families

Counselling of the Index family

Objective

Transparency 32

NOTES TO FACILITATOR

- Ask the workshop participants if they have experience in counselling women.
- Share the objectives with the workshop participants
  Add to the objectives.
- This will allow those that had experience to share knowledge.

Group work 4:
Maternal Interview

Group work (Role-play)

Case study

A 30-year old pregnant woman presents at your antenatal clinic for booking. On examination she is 20 weeks pregnant.
You notice that she is underweight and has a severe cold. She is married and lives with her 3 children in an informal settlement near the clinic. Her husband, an alcoholic, is unemplpyed and abuses her physically. She smokes and drinks beer. She drinks 4 X 750 ml beer on a Friday night and she drinks *6* X 750 ml beer on a Saturday. She is unemployed and sells cigarettes for an income. Two of her children are under 6 years of age and receive child support grants. She mentions that the youngest child is "slow" and "very active".

Task:
You are going to conduct a role-play whereby the "At risk" mother will be interviewed by a "health worker" whilst 2 observers observe the interview in order to provide the "actors" with feedback.

You are allowed 20 minutes to complete the groupwork. After 10 minutes the participants will be requested to exchange roles: observers become "health worker" and "at risk mother" and vice versa.

After 20 minutes (10 + 10 minutes) the 2 pairs of observers will be given the opportunity to give feedback to the "actors".

The facilitator will ask you to share some of your experience with the rest of the workshop participants in plenary. This is however voluntary.

MODULE 3

INTERVENTION STRATEGIES

Intervention Strateaies

1. Identify resources in the area, e.g. Churches, social services, Schools.

2. Identify people as resources.

3. Intervention is a combined effort of EVERYBODY in the community. Everybody in the community has an important role to play in intervention and prevention. Community role players include employers, businesses, schools, private health sectors, etc.

Transparency 33

What can be done **by** the Primary Health Care Worker?

- Identify resources in the community.
- Discuss resources with colleagues.
- Use the knowledge from the workshop and training manual to address problems of the community you work in.

1. support
   - Especially to women who try to stop the abuse of alcohol
   - Never condemn the woman as a person
2. Information

2.1 Guidelines for training to enable intervention:
   - invite guest speakers involved in FAS or alcohol prevention
   - programs, e.g. community workers, NGO's.
   - show video's
   - identify resources in your community

2.2 Start:
   - Support groups
   - Programs
   - Information campaigns
   - Open days
   - Awareness campaigns

3. Referrals and linking to appropriate services and resources, e.g.
   - Church groups.
   - Support groups.

NOTES TO THE FACILITATOR

1. Who should intervene?
   - At national level?
   - At community level?
   - At family level
2. Intervention is the responsibility of everybody in the community.
3. Health care workers play a small but important role in intervention and prevention.
4. Churches and the community should be involved.

PAWC:DEPARTMENT OF HEALTH

Maternal, Child and Women's Health
Student Workbook

Management of Fetal Alcohol Syndrome at a Primary Health Care Level

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Dr C Adnams (Developmental Paediatrician, UCT); Dr G de Jong (Human Geneticist: US); Ms R du Plessis (Regional MCWH Manager, Boland/Overberg Region); Ms AS Marais (Researcher: FARR); Ms L Olivier (MCWH Provincial Manager, PAWC); Thobeka Moletsane (HRD & Training Officer, Metropole Region]

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6. Group work 2: Anti-social behaviour (Adolescents) &
7. Life long problems (Adults)

8. Diagram 3: In utero alcohol damage

9. Group work 3: Maternal Interview "Setting the scene"

10. Diagram 4: CAGE test

11. Group work 4: Maternal Interview

12. Certificate of Attendance

13. Evaluation Form

14. Notes

How to use this workbook

1.

2.

3.

4.

5.

6.

Do at final draft

Group work 2: Anti-social behaviour (Adolescents) & Life long problems (Adults)

Questions for Group work

- Group **1:** Adolescents
  What are the possible implications of the anti-social behaviour that adolescents, affected by FAS, present with? In your discussion you should keep in mind that these adolescents are being exposed to the same challenges as their peers.

- Group **2:** Adults
  Prenatal alcohol exposure has a severe detrimental effect on an individual's life, from before birth until adulthood. As adults these individuals often are parents themselves. Discuss the public health implications of an adult affected by FAS.

Task:

1. Select
   - A facilitator
   - A scribe
   - Arapporteur

2. Discuss the question that was assigned to your group. In your discussion refer to Diagram 3: In utero damage. (20 minutes)

3. Record the above on newsprint/transparencies.

4. The rapporteur will be requested to give feedback.

Group work 4: Maternal Interview

Role-play: Case Study

A 30-year old pregnant woman presents at your antenatal clinic for booking. On examination she is 20 weeks pregnant. You notice that she is underweight and has a severe cold. She is married and lives with her 3 children in an informal settlement near the clinic. Her husband, an alcoholic, is unemployed and abuses her physically. She smokes and drinks beer. She is unemployed and sells cigarettes for an income. Two of her children are under 6 years of age and receive child support grants. She mentions that the youngest child is "slow" and "very active".

Task:

1. You are going to conduct a role-play whereby the "At risk mother will be interviewed by a "health worker" whilst 2 observers observe the interview in order to provide the "actors" with feedback/critique.

2. Decide who would be
   - The "at risk mother
   - The "health worker"
   - Two observers

2. You are allowed 20 minutes to complete the interview. After 10 minutes you will be requested to exchange roles: observers become "health worker" and "at risk mother" and vice versa.

3. After 20 minutes (10 + 10 minutes) the 2 pairs of observers will be given the opportunity to give feedback to the "actors".

4. The facilitator will ask you to share some of your experience with the rest of the workshop participants in plenary. This is however voluntary.

Certificate of Attendance

Notes