ANNEX 5 : DISCLOSURE OF HIV/AIDS DIAGNOSIS TO CHILDREN

1/ INTRODUCTION

To learn that your child is HIV positive can create an emotional shock for the parents or the care takers. Their reactions will be influenced by the knowledge and personal experience they have with HIV/Aids. After this reaction, it's typical that the parents want to ask questions and receive answers about the disease and the treatment. But they will also wonder if it's necessary to announce the diagnostic to the child? If yes, how to announce it? How is the child going to react? Etc.

This is the reason why it's very important, when working with HIV + children, to support the parents and the care takers as much as possible.

Disclosing HIV/Aids status to a child includes two questions:
disclosure to **the caretaker** & disclosure **to the child**.

This annex helps us to reflect on :

- Why : the reluctance to disclose ? the importance/need of disclosure ?
- When : during post-test, later on, at what age, ... ?
- How : progressively or straightly, by parents or with the support of counselors, ... ? content of our messages ?
- What : what means disclosure ?

In any case, keep the best interest of the child as a guiding principle!

2/ COUNSELING AND TESTING OF CHILDREN FOR HIV/AIDS

The testing of children for HIV can be done in a voluntary form (VCT), or to confirm a clinical observation (PICT) or in the frame of the medical care provided after a rape. In any case, it implies from the beginning a reflection on disclosure: what should the child be told about the test, what should he know about the result...

2.1 Key issues when testing children

HIV counseling and testing of children brings up complex issues as the point of view of the child and the caretakers have to be taken into consideration and may not always coincide.

- According to most national laws, minors of age should only be tested within the presence and consent of a confirmed adult care-taker.
- In case of adolescents who come alone to be tested (either because he doesn't have any family or because he doesn't want to inform his parents/care-takers about it), we could accept to do the test (according to his life situation and maturity) but will recommend the adolescent to bring a support person (confident), being an another adult or an older friend.
- If testing a baby with DNA-PCR, the test result may only come after a few days. Therefore, the counsellor should include social identification (with agreement of the care-taker), in order to be able to trace the mother and the baby if they do not come to get the result.

- Health promotion group sessions prior to testing could be done with care-takers to give them more information on HIV/AIDS. Avoid to do it with children as not all of them, depending on their age, their maturity, their family situation, is at a stage where he can understand.
- It is recommended to conduct the pre-test counselling and post-test counselling individually as it allows to assess better the knowledge and readiness of the caretakers and children to be confronted to the subject of HIV/AIDS. Different steps will be adopted, depending on the child's age, development level and care-taker's attitude towards HIV and disclosure, seeing the caretaker alone, then with the child, then eventually the child alone....
- With children, the information on HIV/AIDS (adapted to their developmental level) needs mostly to be given at the post –test level if the result is positive. At the level of the pre-test counselling it is more a need of the caretaker to know about HIV. There is no need to overload a young child with information (even partial) on HIV/AIDS if he is not HIV+ .
- Pre-test and post-test counselling should always be done by the same counsellor, being it on the same day or another day.
- In case you doubt about the care-takers relation to the child or possible mistreatment, don't hesitate to discuss with the child alone. This will avoid being confronted to badly intentioned persons.
- Testing counselling can end up with a total disclosure of the diagnostic to the child or be the beginning of a progressive disclosure process.
- For children whose HIV+ result is not disclosed during post-test counselling (because of young age or non readiness of caretakers), progressive disclosure sessions should be organised later on, on an individual or group form.
- The child has the right to be involved in all decisions affecting his life and to make his views known according to his maturity level and developmental stage.

2.2 How to organize the PRE TEST counselling of a child?

In most situations, the child is brought by his caretaker. In this case, you'll start your counseling session with the care-taker alone if possible and arrange the child to be welcomed and occupied in the children's area.

Step 1

Besides the classical introduction - to welcome the parent, to introduce yourself – counseling caretakers of children who will be tested has it's particularities, especially when it is not voluntary :

1) Check first if the caretaker knows why he/she has been send to the counselor. Find out if he/she came by reference or voluntarily. Explain your role. Explain the necessity of the test for diagnostic purpose (if it's a PICT).
2) Explain the procedure of counseling and testing, explain principle of confidentiality, explain why you asked to see the caretaker alone first, before the child.
3) Find out what is his/her relation towards the child: Is he/she the primary care-taker of the child, if not which relationship and legal status ? Does he/she has the authority of consent to test the child
4) Assess the family situation : Has the care-taker been tested (+ possibility to be tested), HIV+ members of the family, family members who died from HIV/Aids, attitude towards PHA in the family… ?
5) Ask what the child knows about the reason of his visit : What information did the care-takers give to the child beforehand ? Does the child know he comes for an HIV test ? What does the child knows about HIV ? Does he know about other family members being HIV+ ... ?
6) Check what is the developmental level and emotional maturity of the child : through simple conversation about his age, his school level, how the family speaks about health at home, the child's reactions when being sick, the interest he shows, emotional maturity, …
7) In case of adolescents, you will straightly discuss with the caretaker on the importance to discuss openly with the adolescent about the disease and the result of the testing

→ This will help you to decide what option to take to continue the pre-test counselling.

Together with the caretaker, you will decide :

1) whether you continue the counselling with both the care-taker and the child (e.g. a 9 years old boy whose mother is openly HIV+ and who knows already he is coming for an HIV test) or if you need to go on with the care-taker alone before the child enters (e.g. a care-taker who has few knowledge about HIV/Aids and is not ready to tell his/her child of 9 years that they came for an HIV test)
2) how much information can be given to the child. Can you talk to him about HIV/AIDS or only about blood, general health... (especially during the post test counselling if result is +)? The parent or care-taker should feel confident that you'll not disclose the status to the child if the care-taker is not ready for it.

> We often assume too fast that children are too young to participate to the HIV counseling. It's actually more the readiness of the parents and the maturity of the child that will determine how far you will go into the counseling with the child.

2.3 Possible scenarios of counselling at the pre-test of the child

2.3.1 Case 1 : The child doesn't know the reason of his visit & the care-taker(s) is(are) not ready to fully disclose a possible HIV+ result to the child

1) Step 2 : Continue with the care-taker alone

- Establish what the care-taker knows about HIV/Aids
- Clarify misconceptions
- Complete information about transmission modes & non-transmission modes
- Go deeper into the risk analysis
- Explain the testing procedure and the possible results
- Let caretaker express emotional feelings towards possible results
- Explain the benefit of testing the child and the possibility of treatment if result is +
- Evaluate readiness of the care-taker to get the results
- Discuss possible support to the care-taker
- Provide opportunities for questions
- Take enough time for emotional support
- Discuss together what can be said to the child when he will enter

2) Step 3 : Let the child join the care-taker & the counselor

- Welcoming and establishing confidence
- Present yourself to the child in general terms
- Give some basic information on the test, just to involve the child : it can be just saying you are taking some blood for looking why he is sick or if he has an illness... or explaining how the body works, how blood goes everywhere in the body, that you are taking blood in the finger or in the arm to check if everything is ok, …
- Never lie by saying blood taking will not hurt. Rather tell he/she will feel it but it will go very fast and if he helps by keeping his hand/arm properly it will be easier and go faster.
- Take time after having taken the blood to reassure the child
- While waiting for the test result, let the child go back to the children space to play and discuss with the caretaker alone how to announce to the child that he is sick
- Make an appointment for the post-test counselling if the result is not given at the same moment

2.3.2 Case 2 : The care-taker(s) accept to disclose to the child his HIV status if result +

1) Step 2 : Continue with care-taker alone, before letting the child joining, if you feel it is still necessary : discuss same topics as in Case 1, including what can be said according to the age or developmental level of the child.
   If this is not necessary (ex. Care-taker already in the program and accepting open discussion with the child), you can let the child join and go on for step 3

2) Step 3 : Let the child join the care-taker & the counselor, adapt the counseling to the developmental level of the child, using appropriate communication skills

- Welcoming and establishing confidence
- Present yourself to the child in general terms
- Establish what the child know about the reasons of his visit/test
- If the child knows it's for an HIV test, clarify misconceptions & complete general information about HIV/Aids (depending the developmental level of the child, you'll decide how far to go into details)

- If the child doesn't know it's for an HIV test, give some basic information on what you will do: it can be just saying you are taking some blood for looking why he is sick or if he has an illness... or explaining how the body works, how blood goes everywhere in the body, that you are taking blood in the finger or in the arm to check if everything is ok.…
- Explain the testing procedure
- Provide opportunities for questions
- Never lie by saying blood taking will not hurt. Rather tell he/she will feel it but it will go very fast and if he helps by keeping his hand/arm properly it will be easier and go faster.
- Take time after having taken the blood to reassure the child
- While waiting for the test result, let the child go back to the children space to play and discuss with the caretaker alone on the strategy to announce the result.
- Make an appointment for the post-test counselling if the result is not given at the same moment

2.3.3 Case 3 : If the child is an adolescent

When speaking about adolescence, we will generally refer to Piaget's stages but you still need to adapt it to the cultural context you are working in. In most of MSF missions, we can consider the age of around 12 years old enough to address the child directly in HIV testing and to go for total disclosure.

In case the adolescent is accompanied by his care-takers

1) Step 2 : continue with the care-taker & the adolescent together

- Welcoming and establishing confidence
- Present yourself to the adolescent
- Establish what he/she knows about HIV/Aids
- Clarify misconceptions & complete general information about HIV/Aids (depending the developmental level of the adolescent, you'll decide how far to go in details)
- Explain the testing procedure and the possible results
- Explain the benefit of testing and the possibility of treatment if result is +
- Explain that you would like to discuss with the adolescent alone for a while

2) Step 3 : continue with the adolescent alone

- Insure confidentiality of what will be said here except if adolescent wants otherwise
- Deepen the risk evaluation
- Explore the adolescent's feelings about being tested and address any fears he might have
- Discuss the familial and social support (parents or other reliable family-members or friends) the adolescent can have in case of HIV+ result
- Prepare for how to cope if positive result
- Evaluate readiness of the adolescent for a possible positive result
- Present possible MSF support (adolescent alone and/or with care-taker) in case of positive result

3) Step 4 : continue with the care-taker & the adolescent together

- Do the test
- Rapid test : wait for the result, adolescent and care-taker together
- Make an appointment for the post-test counselling

Remark : If the care-taker doesn't feel ready to explain to the adolescent the reason of his visit, take time with him to assess the reasons of being reluctant, discuss the risks of the non disclosure and the advantages of explaining the test to the adolescent. If care-taker is still not ready after this part of the counseling, don't insist and go further as in case 1. You will take more time to work on disclosure process after the post-test in case of positive result.

In case the adolescent comes alone

National law will probably say children under 18 or 16 years need to get consent of the care-takers for being tested. But adolescents may not be ready to tell their care-takers about their willingness to make an HIV test as they would have to uncover a part of their affective life. There is a high risk for them, if we refuse to see them alone, not to come back with their care-takers, not to be tested and not to get access to treatment if they would have needed it.
That's why you should find a compromise between country rule, children's rights and our medical ethics to facilitate access to those adolescents. Discuss this with the medical coordinator of your program in order to establish specific criteria for adolescent according to the context.
Our recommendations will be :

Step 1 : Adolescent alone

- Same steps as for adults but communication and tools adapted to adolescent : welcome the adolescent, introduce yourself and your role, explain procedure of counseling and testing, find out if the adolescent came by reference or voluntarily, explain principle of confidentiality, ...
- Assess the reasons for requesting the HIV test and make a risk evaluation
- Discuss why the adolescent came alone and assess possibilities to come for another appointment with a care-taker If adolescent agrees to bring his care-taker and you are trustful he will come back, fix a next appointment
- If the adolescent doesn't feel comfortable to come back with his care-taker, assess who else can provide support, any other reliable adult, or friend if no other possibility, who can be there when getting the result

Step 2 & 3 :

- If adolescent comes back with a care-taker : cfr. "In case the adolescent is accompanied by his care-takers" : step 2 & 3
- If not possible, step 2 & 3 will be done with the adolescent alone

2.3.4 In case of sexual abuse

Within the medical protocol of care of victims of rape, an HIV test is foreseen. You may therefore receive referrals from the practitioner who took care of the victim.
As the child is already affected by the rape, HIV counseling can be heavy to support. The HIV counseling part may therefore be split into different sessions.
Here as well, it will be important to have some parts of the counseling with both child & care-taker together, other parts separately.

NB: If the child has been brought or presented himself for an HIV test after a rape, insure first that he has access to medical care.

2.4/ Possible scenarios at the post-test of the child

The way to handle the post-test will be slightly different in case you are using the rapid test method, where you give the result right after the pre-test, or in case the lab results come out later, on the same day or another day.

The present chapter gives the main steps to follow in case of positive result, referring again to the same scenarios described in the pre-test section.
In case of negative result, follow the same steps but with an adapted content.

2.4.1 Case 1 : The child doesn't know the reason of his visit & the care-taker(s) is(are) not ready to fully disclose a possible HIV+ result

1) Step 1 : Start with the care-taker alone

- Briefly asses the emotional situation of the care-taker, waiting for the result
- Is anybody available to support the care-taker (refer to the pre-test) ?
- Give the result in a clear, calm manner
- Let the care-taker express his/her emotional feelings towards the results
- Assure immediate emotional support (shock, denial, anger, guilt, sadness,…)
- Ask the care-takers their main concerns and support the care-takers according to these concerns
- Discuss the first medical issues : the doctor will see the child the same day, further exams, ... and reassure on availability of treatment even if no cure
- Explain the different services of the project : medical and support services.
- Discuss about the care-taker’s plan for the day and what support he would like to get, from where, what to do for it
- Clarify how much information the care-taker feels comfortable telling the child. Reassure you won’t use the words HIV/Aids and you will help the care-taker later on to communicate with the child.
- Some of the counselling cards can be showed to the care- taker to reassure him on what you will say to the child and how.

You won’t be able to answer all of the questions and fears of the care-taker, just be enough supportive for him to feel confident you will provide care and support and to feel ready and strong enough to support his/her child. The role of the counselor doesn’t stop after post-test !!!
Emphasize that ongoing counseling and support will be proposed beside the medical care.

2) Step 2 : Let the child join the care-taker(s) and the counsellor

- Welcome the child and discuss how he feels
- Re-assess which topics discussed in the pre-test have retained the attention of the child
- Depending on the decision taken with the care-taker, decide how far to go with the child. For sure you won’t use the words HIV/Aids. With small children, you will just say that he will need to go to see the doctor and to take some drugs and reinforce the child by complimenting him of being brave and courageous, ... For older ones, you can use the counselling cards (as long as the words HIV and Aids don’t appear) and explain that you send the blood sample to the lab and they found out there is a germ in

his/her blood and that the doctor will have to give him drugs, ... Again reinforce the child positively.

- Always reassure the care-taker about your support.
- End the session by referring yourself the care-taker and the child to the doctor or the reception or any other person going to take over.

2.4.2 Case 2 : the care-taker(s) is (are) ready to disclose a possible HIV+ result to the child

1) <u>Step 1 : Care-taker(s) alone</u>

- Briefly assess the emotional situation of the care-taker, waiting for the results
- Is anybody available to support the care-taker (refer to the pre-test) ?
- Give the result in a clear, calm manner
- Let the care-taker express his/her emotional feelings towards the results
- Assure immediate emotional support (shock, denial, anger, guilt, sadness,…)
- Ask the care-takers main immediate concerns and support the care-taker according to these concerns
- Discuss the first medical issues : the doctor will see the child the same day, further exams, ... and reassure on availability of treatment even if no cure
- Explain the different services of the project : medical and support services.
- Discuss about the care-taker's plan for the day and what support he would like to get, from whom, what to do for it
- Clarify again if the care-taker agrees the child to know about his diagnostic (for children above 6 years). Discuss if the care-taker prefers to announce himself or if he/she prefers the counsellors to announce the result. Don't forget the emotional state of the care-taker after having got a bad news ! Never force them telling they should say it themselves. Anyway, even if they decide to announce it themselves, it will be difficult for them to explain the disease in an adapted way. You are there to support them.
- Show the counselling cards you can use to support the explanations of the care-taker or to explain by yourself.
- Be sure the care-taker feels a bit reassured and ready before letting the child join.

2) <u>Step 2 : Let the child join the care-taker(s) and the counsellor</u>

- Welcome the child and discuss how he feels
- Re-assess which topics discussed in the pre-test have retained the attention of the child
- With children above 6 years old, explain the result in a clear, calm manner. This can be done either by the care-taker first, and ongoing by the counsellor, either by the counsellor and eventually completed by the care-taker. Try to be complementary with the care-taker. It will reassure the care-taker to see you are collaborating well and the child to see he can get support from both care-taker and counsellor.
- For children below 6 years, general information on the fact that he is sick will be given (without naming the disease), the info on HIV/AIDS will only be discussed with the caretaker as well as the necessity to disclose progressively the status of the child as he grows up.
- Use the counselling cards when disclosing the status. The explanations should be given in a simple, natural way. Don't worry if the information doesn't come over completely. The child will have lots of other opportunities to get more detailed

information. The objective is for him to understand you want to involve him in taking care of his disease, you respect him, you show he has the right to get information, ...
- Always reassure the child about your support and the presence of his care-taker.
- End the session by referring the care-taker and the child yourself to the doctor or the reception or any other person going to take over.

2.4.3 Case 3 : If the child is an adolescent

In case the adolescent is accompanied by his care-taker(s)

- Welcome the adolescent and discuss how he feels, waiting for the results
- Re-assess which topics discussed in the pre-test have retained his/her
- Briefly assess the emotional situation and readiness for getting the result
- Give the result in a clear, calm manner
- Let the adolescent and the care-taker express their emotional feelings towards the results
- Assure immediate emotional support (shock, denial, anger, guilt, sadness,…)
- Ask the adolescent's and care-taker's main immediate concerns and support them according to these concerns
- Discuss the first medical issues : the doctor will see the adolescent the same day, further exams, ... and reassure on availability of treatment even if no cure
- Explain the different services of the project : medical and support services.
- Discuss about what the adolescent is going to do the rest of the day and how his care-takers or other people can support him
- Always reassure the adolescent and his/her care-taker(s) about MSF support
- End the session by referring the adolescent to the doctor or the reception or any other person going to take over.

In some situations and depending on the discussions and/or decisions taken in the pre-test :

It can be useful to see the care-taker alone : to announce the result to the care-taker first before announcing it to the adolescent when you are afraid of the care-taker's reactions towards the adolescent or when you want the care-taker to assume the shock first and to be available and supportive when announcing to the adolescent.

It can be necessary to see the adolescent alone : to re-discuss some difficult topics the adolescent raised in the pre-test and/or to reassure him about your confidentiality and the possibility to be seen individually in consultation and/or counselling sessions.

In case the adolescent came alone

- Welcome the adolescent and discuss how he feels, waiting for the results
- Re-assess which topics discussed in the pre-test have retained his/her
- If there has been some time between pre- and post-test, assess if the adolescent had thought about anybody in his environment being able to support him.
- Give the result in a clear, calm manner
- Let the adolescent express his/her emotional feelings towards the results
- Assure immediate emotional support (shock, denial, anger, guilt, sadness,…)
- Ask his/her main immediate concerns and support him/her according to these concerns

- Discuss the first medical issues : the doctor will see the child the same day, further exams, ... Explain basics on HIV treatment, just for him/her to know about the existence of ARV, no need to now yet details on when, why, how to taker ARV's ...
- Discuss about what the adolescent is going to do the rest of the day, is there anybody he wants to see, how he will do at home, ... ?
- Always reassure the child about your confidentiality and support.
- Present him the different services of the project. Refer him for first medical consultation and social support. Be sure to see the adolescent again after those consultations and next day.

General note :
In case of positive result for young children after Provider Initiated Counselling and Testing, the counsellor should suggest the care-takers and brothers and sisters to be tested as well (if this is not yet done). As learning an HIV+ result of the child is already traumatizing for the care-takers, those tests will preferably be done another day.

3/ WHY ADULTS CAN BE RELUCTANT TO DISCLOSE ?

3.1/ Why care-takers can be reluctant to disclose ?

3.1.1 Educational reasons

- Care-takers don't see the need and/or benefit of speaking about the disease, especially at the first stages on the infection, if the child has few symptoms.
- Belief that the child is "too young" and won't understand.
- Belief that if the child doesn't ask questions it means he doesn't realize what's going on or that he doesn't want to know
- General education and communication habits within the family, as poor communication with the children in general, overprotection of the children, ...
- Not knowing how and what to say to the child. Fear to tell too much or not to find the right words.
- Cultural habit of not considering the child as a responsible person and actor of his life

3.1.2 Emotional reasons

- Fear about the immediate reactions of the child. Will the child be able to cope with the information ? Care-takers are willing to "protect" the child from bad news, being afraid to hurt him.
- Fear about the emotional impact on the longer term : frightening, sadness, depression, ...
- Fear that the child won't love them anymore, will reject them
- Isolation and lack of support to help the care-taker to take the decision
- Difficulty to cope with their own illness (in case of HIV+ care-takers)
- Fear of having to disclose his own status (in case of HIV+ care-takers)
- Feeling of shame and guilt of having transmitted the disease and having to account for the transmission (in case of HIV+ care-takers)
- Mourning process of a partner still ongoing

- Sense of abandoning the child. If the child understands the care-taker(s) is HIV+, he/she could be frightened about the possible future death of the care-taker and himself/herself remaining orphan.
- Denial strategy from the care-takers : the child represents hope and future, non-disclosure keeps the illness away.

3.1.3 Family related and social reasons

- Familial or cultural taboos, especially around sex, death, …
- Fear of sensitive and embarrassing questions the child could raise or questions that are difficult to answer.
- Beliefs about the origin of the HIV/Aids : eg. witchcraft, punishment, ...
- Fear that the child won't keep the secret and will disclose to other people (voluntary or inadvertent disclosure) and the possible consequences : stigma, social exclusion

3.2/ Why health-staff can be reluctant to disclose ?

- As health-staff are often parents as well or at least know some children around them, they generally have the same reasons to be reluctant for disclosure as care-takers have.
- Very often, the main reasons for care-takers to be reluctant or to postpone disclosure is because they don't know themselves how to go for it, due to a lack of training or experience
- The lack of adequate tools and means is also playing a role
- The fear and guilt of hurting a child is an unconscious barrier as well as the discomfort of being the one who brings the bad news
- When care-takers are not open or collaborating, health-staff are in a difficult position

Note :

1) If health-staff are not convinced themselves about the importance to communicate about the illness and disclose the HIV status to the child, they won't be able to support the care-takers to go for it.
2) As health-staff is responsible for the child's long-term adherence to treatment, supporting the care-taker in evolving and progressing towards disclosure is an important part the job !

4/ WHY TO COMMUNICATE / WHY TO DISCLOSE ?

4.1 Risks and consequences of keeping the HIV status of the child hidden

The concept of « secret »
All previously mentioned reasons make some care-takers reluctant to speak with the child about his illness, to tell the child's diagnostic and drive them to keep it a secret or even to lie by inventing other arguments.

Keeping a secret is sometimes necessary in life and not always negative.

But a secret can also become a danger for a child, an adult or a family. A secret becomes dangerous when it hamper the development of trustful relationships in between people.
Especially, when the person who carries the secret would like to speak about it but is afraid to hurt others or herself by telling it, the person who carries the secret feels torn apart. It then often happens that the person's attitudes will once in a while involuntarily and partially disclose the secret. The child is then disturbed by an incoherent care-taker and will be more attentive to all what's seems unusual, abnormal for him and will try to understand in his own way what is happening.

As Tisseron[1] said « A secret stops being normal and becomes pathological when we stop being the guardian of the secret and feel the prisoner of the secret ».

The more the secret lasts, the more difficult it will be to break the silence, the more the consequences can be important, especially with teenagers, as trust and confidence in the adults will be broken.

Secret about HIV/AIDS and the unanswered questions
A sick child asks himself questions, according to his age and cognitive development : Why do I have to go to the hospital ? Is it going to hurt ? Why do I take medicines if I'm not sick ? I often missed school, what will happen ? I'm loosing weight, am I going to die ?...

In front of these questions, the child can adopt two kind of attitudes :
- Either he/she will ask his/her questions to the adults around him but as they want to keep the secret about the illness, the child won't get answers to his/her questions.
- Either he/she doesn't dare to ask his/her questions because he feels it's a taboo, and he knows he won't get an answer.

Consequences of not receiving answer to those questions

1) When the child understands there is a secret without knowing what it is about, he will develop his fantasy and imaginary to develop hypotheses and build an explanation about the illness or the secret, to find a meaning. Those imaginary hypotheses are often worse than the initial secret. Smaller children can for example explain the secret or the illness as a punishment because he hasn't been good, because he is not appreciated. These feelings of guilt or self-depreciation can lead to detachment, keeping silent or aggressiveness...

   Be aware, child imagination and fantasy can be worse than reality !

2) The sickness cannot always be kept unnoticed and the child will eventually know about his disease:
   - There is a risk that the child will be informed of his disease by someone external, voluntary or by accident. For example: a friend who has heard something and repeat it, a conversation heard amongst adults...

[1] Psychiatrist and psychoanalyst, specialised in family secrets analysis

- Or the child will suspect his/her status by himself trough the symptoms he is having and the knowledge he gathers from different sources. For example: he observes he has infections more often, he has regular medical check ups, he watches a TV show on HIV, he receives an HIV sensitization at school …

Even when the child will intuitively know or effectively get to know his diagnostic, he will keep the secret, waiting for the parents to tell him. Caretakers will remain thinking the child doesn't know his status and this situation of keeping the truth from each others can become really awkward..

> Children hear a lot of things around them. They understand more than we imagine and feel when something is going wrong, when something is hided from them.

3) Physical symptoms can give the child the feeling of being different from the others, a feeling of inferiority, of low self-esteem.

4) Some children get anxious at the idea of having to take drugs every morning, going to the doctor that could use on them a needle, fear the pain, fear the loneliness if hospitalized, fear to be abandoned ...
As long as the disease is kept secret from him, impeding everyone to talk about it, this anxiety cannot be expressed and the child will suffer in silence, alone.

5) The child can feel isolated, keep by himself, as well at home as at school, being sad going towards depression.

6) When children feel they should hide their thoughts, their emotions and accept the secret, they may act them out in their behaviours For example trough bedwetting, psychosomatic complaints, aggressive behaviour, isolation, regression behaviours...

7) The fear of death (his own or the death of one of his parents) can be a great source of anguish, sometimes unbearable for a child, especially if he has been already confronted to the death of a close person.

8) As the child understands things are hidden from him, or worse that adults are lying to him, he doesn't feel respected and will not rely on, have confidence and/or respect his care-takers anymore, neither the heath staff who didn't tell him the truth.

9) The secret, the un-said are also difficult for the parents who have to permanently hide things from the child or even lie to him. Some studies have shown a level of depression higher within parents who live with a secret than with parents who talk about the disease to their child.

10) The child feels when an adult is sad, preoccupied, not feeling well. The sadness and the pain that he observes in his parents (and that cannot be discussed because of the silence kept around the disease) can create in him a feeling of guilt or other psychosocial perturbations.

The secret excludes any opportunity of expression and listening !!!

The child stays ALONE, isolated with his questions, partial information, his worries, his feeling of guilt , his anguish towards the disease, pain, death... Even if the parents support him

Possible consequences

- Behavioural perturbations : aggressiveness, change in behaviours...
- Emotional perturbations : depression, anxiety ...
- School difficulties : lack of concentration, of interest, drop out …
- Interpersonal and social disturbances

4.2 Advantages of communicating about the illness and/or disclosing HIV diagnostic to the child

1) Being able to talk openly and to get answers to his questions may help the child to clear up any misunderstandings he has, confusion, fantasies and nightmares as well as inadequate guilt he might feel (if I'm sick it's because I have been a bad boy).
   It will help him to stop believing he is to blame because he is sick.

2) Enables to give appropriate information to the child, adapted to his age.

   Prefer a well-done progressive disclosure (well-prepared, good conditions, appropriate person, ...) than the accidental discovery by the child through a non well informed person.

3) Thanks to open communication, there is a space for exchanging information, listening, answering the questions raised by the child, give place for expression, … The child dares to speak openly about his feelings, his suffering, his anxiety, ... Knowing about his health status helps him to understand what's going on around him and within himself, his emotions. The child will experience the relief of knowing the truth and being able to tell whenever something is difficult for him rather than being worried and stressed about the unknown or the secret to keep. Disclosure helps to cope with the disease.

4) The child will feel respected and appreciated for who he is. Children who can express themselves have a higher self esteem, develop better capacities to react and cope with difficult situations, show less depressive symptoms, manage better psychosocial difficulties.

5) The child will feel the presence of his parents, will understand they are there to help him and protect him. The adult is then perceived as a trustful person, who knows what to do. It helps the child, the care-taker and the family to live to include the illness as a normal part of daily life and adopt a positive living attitude.

6) A child who knows about his illness can be more aware about the importance of medical care and adherence to the treatment It helps the child to make sense of what is happening in his body and why to take the drugs. It helps him to gain control on his body. It makes more sense of what is happening around him and help him to cope better. He copes better with the treatment and sticks better to the medicines intake. We can request more participation, responsibility and involvement in the care. He can understand the importance of hygiene, of protection of himself and of the others.

7) Once adolescents are disclosed it is more easy to discuss in depth with them about affective life, sexuality, desire to have kids, pregnancy....

8) Caretakers will also feel more capable to deal with the child's expressions and reactions. It helps to build a constructive relationship in which caretakers can help the child to get stronger and learn to live with the disease.

9) The adherence to treatment depends also on the good relationship between the child and the different health staff from the clinic. Talking with the child about the disease and the treatment in an openly manner strengthens this relationship. It helps the child to feel comfortable of telling how he feels, where it hurts, what is worrying him, … But if the health staff is also lying about the child condition, the child will have difficulties to trust them and to follow their medical advices.

10) Being informed about his status can help the child to join a support group of peers living the same situation. Participating to a group of disclosed children is a strong tool to break isolation, to reinforce self esteem by promoting exchanges and mutual support.

11) If the community is supportive and the diagnostic can be disclosed, parents or care-takers can benefit from outside support.

Remarks : there are nevertheless difficulties inherent to disclosure

1) It is not rare to see children expressing sadness, angriness, depression, isolation, … after having learned about their HIV diagnostic. Receiving a difficult news, as being diagnosed HIV+, will necessitate an adaptative process (similar to a mourning process) as much for children as for adults.
2) Disclosure is difficult for HIV+ parents on the short term as they need to face their own positive status and the fact that they transmitted it to the child. Nevertheless, these short term difficulties are leading to benefits in the future
3) If the child is disclosed too early, when he cannot understand the reason of keeping it still secret to some people (e.g before 6 years old) or in a bad manner (he just heard he is HIV+ but doesn't know what it means), there is a risk for him to disclose his status around him without being aware of possible consequences for him and his family as stigma and social exclusion.

4) Disclosure to adolescents can provoke intense emotional reactions such as anger, rebellion, denial …. as adolescents are in a questioning phase of their life. But a secret kept too long can, when the truth is finally told, lead to reject in block their parents, the health staff and the treatment.

Remember that keeping this kind of secret brings lots of difficulties and that the benefits of communication with children about their illness, their status, are more important than the temporary difficulties of telling them.

5/ WHEN TO DISCLOSE ?

We just showed you the importance of disclosure, but now arise the questions of when and how to disclose.

Parents generally know that they won't be able to avoid for ever talking with their child about the disease but they wonder often when is the best moment to announce to the child his diagnostic. Most of them try to postpone it as much as possible. Some will wait until the secret becomes unbearable in their life to ask for help.

The disclosure to a child doesn't happen in the same way as for adults.
The disclosure to a child needs to be integrated within a permanent discussion about the health of the child and the activities related to his medical follow-up.

With children, we speak about « **Progressive disclosure** » as it is a gradual process of giving progressive information that will one day end up by revealing the full diagnostic.
The child first learns about health, having an (unnamed) infection, the necessity to take a treatment, and finally hears his HIV status. It is a compromise between the need of the child to know what is happening to him, and the fact that he, and his care-takers, might not be ready (intellectually or emotionally) yet for full disclosure.
That's why we will speak about partial or total disclosure of children, depending on the amount of information on their status they have received.

5.1 The concepts of "partial" & "total disclosure"

« **Partial disclosure** » gives information about what is happening in the body without naming the disease. It's a way to maintain an open dialogue with the child about health. It starts with simple explanations about hygiene, health and become more complex as the child grows up, according to his developmental stage and understanding of health.

«Total or full disclosure» means you declare the name of the virus and the disease. Using the words HIV and AIDS will lead to talking about transmission modes, family history, treatment, future, …

5.2 Key points of "partial disclosure"

The disclosure process will be done in a individualized step by step strategy, according to the child's development level, emotional maturity as well as the family dynamics, care-takers readiness and consent.

- We encourage the care-takers to speak with the child as soon as possible about the child's health status.
- It should at least start when the child starts asking questions about himself, his health, his regular clinic visits... In general, it's the child who will set the pace of this process by his questions. The easiest way is to follow the evolution of the questions he raises. Don't avoid them, answer the questions when they come.
- Whenever the child has to go to the clinic, be hospitalised or any other new event happens, you can give him more information or at least explain the situation.
- Partial disclosure starts already during the post test counselling when the counsellors present the result of the test. Later on, this process will mainly be done by the care-takers (at home) but can also be supported by the health staff (including counsellors) at the clinic. Care-takers and counsellors should regularly assess how much the child understands as well as what he thinks and feels in order to correct misconceptions, support his emotions and decide on what will be the next step of disclosure.
- What a child will be told depends on his developmental level and maturity. Discussion about health, illness and treatment should be part of daily life. The child should feel it's not a "taboo" topic and that he is not to blame himself for his condition.
- Never lie to your child. This doesn't mean you need to give all information at once or that you have to use directly the word HIV if he asks why he is sick. You can give him partial true information. But if he asks straightforward the care-taker if he has HIV/AIDS, it means he seems ready to hear it and needs to be disclosed. Then, you shouldn't lie or tell him he has any other kind of diseases. If you tell them something which is not true, it might be difficult for them to believe what you will say later on. Parental trust will be lost.
- Avoid using the words HIV/Aids in front of a child under 6 years. He won't understand everything that relate to it and he might not be able to keep this information to himself and not understand when to speak about it and when not and with whom.

START THE PROGRESSIVE DISCLOSURE AS EARLY AS POSSIBLE
- at the latest when the child starts asking questions
- the longer we wait, the bigger the risk to loose the child's trust
- the more the secret lasts, the more difficult it will be to break the silence

5.3 Keys points of "total disclosure"

- It is recommended that the complete disclosure takes place **between the ages of 6 - 12 years.**
- We often see that there is a tendency of the caretakers to announce the diagnostic to the child later than what health staff feels adequate. If the gap is not too big, the counsellors should follow the care-takers proposed timing.
- If the care-takers delay too much the announce, we'll have to work with the care-takers on the importance of the disclosure.

- In any case, never judge the parents if they don’t want to announce the diagnostic to their child but help them through active counseling by understanding why they are reluctant to announce and by showing the advantages of disclosure.
- If children of 10 years don’t know about their status, start working with the care-takers to insist on progressive disclosure to make sure he will have total disclosure before 12.
- Total disclosure should be achieved before adolescence.
- Waiting for the child to be a teenager, possibly in crisis, to announce him his HIV/AIDS status may bring difficult reactions from his part. A secret kept too long might also make him angry at his care-takers, or reject the treatment.
- When a habit of communicating in the family has already been instituted (notably during the whole progressive disclosure process), take the opportunities to talk when they arise naturally instead of having to start this difficult and delicate discussion from scratches. Take the opportunity of an event that happens to start the announcement : a movie about HIV/AIDS on the television, your child having got information about HIV at school and speaking about it at home, the child having new opportunistic infection or having to be hospitalized, the start of ARV treatment, when the child asks about something he heard about HIV/AIDS. ..
- Don't forget to monitor post-disclosure coping: after the diagnostic has been given, the dialogue must continue, and the child needs to receive a continuous support from the care-takers and the counsellors. Keep on talking about HIV/AIDS to let the child feel it is not a taboo subject. Encourage them to ask questions and to confide in you whenever they want. This support doesn’t need absolutely to be given by a professional, it will depend on the confidence the parents/caretakers have on their own capacity to do it. They may need some help at the beginning.

6/ WHO IS IN CHARGE OF “TOTAL DISCLOSURE” ?

For children whose HIV status has not been disclosed at post-test because they were too young and/or care-takers were not ready for it, counsellors will continue to work with care-takers to evolve towards a decision of disclosure.

Support staff may help by listening to their concerns regarding disclosure and by helping them analysing the advantages of appropriate disclosure and taking the decision to go for total disclosure.

Once care-takers are ready for total disclosure, they may still need your support to find the best strategy to go for it and maybe even need your support at the moment of disclosing itself. Start by explaining the different possibilities for total disclosure to the care-takers and ask them how they would like it to happen ?

6.1/ Care-takers are disclosing at home

As the child knows his parents/care-takers and as they are supposed to be trustful references for him/her, they should ideally be the ones to announce the HIV diagnostic to the child.

If care-takers feel ready and strong enough to disclose the status to the child at home, help them by discussing about the content of the message to pass, the information the child should need to know about the disease and the treatment. Also explain the normal character of child's reactions as sadness, angriness, … and how to deal with them.

As mentioned in the previous chapter, disclosure at home can be done naturally when any opportunity arises or more formal if the care-takers prefer to sit down with the child for an open discussion.

In any case, reassure the care-takers about your possible support if needed and the support which can be given later on to the child when coming at the MSF health structure. Support staff will then use counselling cards or other tools to go deeper into adapted explanations and emotional support.

6.2/ Care-takers & counsellors are disclosing together

Even if care-takers decided to go for total disclosure, they might not feel strong enough to do it by themselves. They often don't know how to do it and fear the child's possible reactions.

In this case, there is a high risk for care-takers announcing the child he is HIV+ without giving appropriate information and support. They will say you the child knows his status even if he actually just heard the terms HIV or AIDS. This gives the child's creativity too much place for inappropriate representation of the disease and development of psychosocial troubles.

Care-takers are generally more equipped and experience in how to use the right words and appropriate tools. They are more able to remain professional and not to be submerged by the emotional situation.

That’s why care-takers may request the help of the counselor or the counsellor may suggest his help if he feels the care-takers need it.

We will recommend to opt for individual disclosure sessions. Practically, either the care-takers will announce the diagnostic to the child and the counsellor will go on by emotional support and basic explanations to reassure the child (based on disclosure tools). Either teh counsellor gives the diagnostic and provide emotional support and explanations while the care-taker intervenes whenever he/she feels comfortable.

In any case, the presence of the care-takers shows to the child that he is open for discussion on this topic. It is important for the care-takers to hear the way you explain the diagnostic to the child in order for them to be able to continue the discussion later on in the same way. It will also help to cope on emotional side, both for the child and for the care-taker.

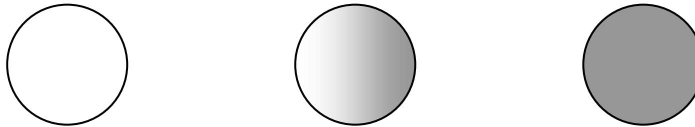
Exceptionally, disclosure can be done in group sessions, (for example in missions with huge number of child-patients) for children who are integrated in the program since a while and participate already in some groups activities. In this case, you will mix children and their care-takers, as we just mentioned the importance of care-takers being present. Be sure to mix children of same age-categories and level of understanding, preferably who know each others already.

6.3 All health staff should know whether the child knows his status or not

All health staff should know where the child is situated regarding disclosure ! Neither a doctor, nor a nurse, nor a counsellor, ... can work properly and openly if he doesn't know what's the child's knowledge regarding his visit at the hospital and treatment.

This doesn't mean they all have to know details about how the disclosure took place, who explained the diagnostic, ... but they should at least know if the child is "not" – "partially" – or "totally" disclosed.

This should appear in the child's file, available to everyone.
Example by filling the circle of the child's knowledge about the disease.



Empty	Half shaded	Fully shaded
no disclosure at all	partial disclosure	total disclosure
No information about the disease	Basic information about the disease but no use of the terms HIV/Aids	open naming of HIV/Aids

7/ SCHEMATIC PRESENTATION OF A DISCLOSURE PLAN

When going for disclosure, the counsellor should always start by evaluating the child's knowledge and understanding of his condition, the disease, why he comes to the clinic, why he take drugs, ... Gradually you will move from basic explanations, to more detailed information. Usually, the child himself will guide the process, by asking questions.

Please, find here a sample of a disclosure plan[2]:

- information about hygiene
- information about being sick
- information about going to the doctor
- information about the body and the blood circulation
- information about germs and getting sick
- information about our defences (immune system)
- information about immune system needing assistance from drugs
- information about the specific virus the child has
- naming the virus and the illness : HIV / Aids
- discuss with the child with whom the secret should be shared
- information about CD4 count (and/or viral load if available)
- information about transmission & non-transmission of HIV/Aids
- information about sexual relations and condom use

Partial disclosure

Full/Total disclosure

7.1 Examples of tools[3]

Amongst support tools for HIV+ children, counselling cards and books will be the most appropriate ones for disclosure counselling. Disclosure tools can be used either for partial, or for total disclosure.

Concerning "partial disclosure tools", fairy-tales as "Bekhi" or "Thanks ARV" are easy and nice to use with children. Counselling cards can also be used if you select only one part of the whole counselling set (The terms HIV/Aids shouldn't appear on your counselling cards !!!)

Concerning "total disclosure tools", story-books can be used as well but counselling cards will be more appropriate as they include educational information about the disease and the treatment. They are also adapted for emotional support. If counselling cards are easy to use and helpful, it is not compulsory to use them. Many care-takers will disclose the diagnostic of the child at home without any tools. In that case, the counselling cards can be used later on with the disclosed child in order to give him more detailed information about the disease and the treatment.

If you want to see how to use counselling cards, see the nice video made by Jean-Chris Banange, CNLS-NACC Rwanda, TRAC Plus (Centre for Infectious Disease Control) & Lux-development : "Tell the children the truth" (available on DVD "Patient support for HIV infected children)".

[2] Based on Dr. A. Peltier (2007) Annonce du diagnostic d'infection par le VIH/Sida chez l'enfant : un enjeu majeur de l'éducation thérapeutique. In Développement et Santé, n°187

[3] refer to the DVD to see all the tools available