Young Carers

Referrals Guidelines

Prepared By

University of Oxford – Department of Social Policy and Intervention

Revision 02

SPI-003

December 2017

Contents

1 Initial information 1
1.1 Codes 2
1.2 First Steps for Any Referral 3
1.3 Initial Assessment 3
2 "Types" of Referrals and Next Steps 6
2.1 Code RED Sexual/Code A Physical Abuse (ongoing/in home or community) 6
2.2 Code BLACK: Suicidality/Mental Health 9
2.3 Code F: Food Insecurity 10
2.4 Code T: TB Test or TB Treatment 10
2.5 Code M (Meerkat): Cognitive delay/ Child Disability 11
3 Other referral actions 13
3.1 Pregnancy 13
3.2 HIV Test 13
3.3 Special School 15
3.4 School Uniform 16
3.5 Substance Abuse 16
3.6 Child Mortality 16
4 Grants (South Africa relevant – for other countries please see information leaflets) 1
5 An Important Note about Feelings and Vicarious Trauma 2
6 Appendix A – Referral Case Studies 3
6.1 Case Study 1: Sexual Abuse 3
6.2 Case Study 2: Health/Failing school/Family issues/Abuse/Forced sex 8
6.3 Case Study 3: Suicidality/Rape/Mental Health/Removal 9
6.4 Case Study 4: School uniform/family issues/physical abuse/rape 10

Revision Summary

Document Revision	Revision Summary
01	Issued November 2016
02	December 2017 added section 1.1, 2.3, 2.5, 4.5, 4.6

1 Initial information

The resource-constrained setting of our studies means that our participants lead difficult lives and many of them have been victims of criminal acts. It is not uncommon for our participants to break down in tears during an interview or to disclose traumatic events to the Research Assistant (RA). As researchers, we have a legal obligation to help participants in imminent danger; additionally, we feel a moral obligation to assist participants in the direst circumstances. However, we are a research project and not an NGO; this means that we do not provide services and that we cannot help everyone who may need help. When the project does provide assistance to the participant or their family, we call it a referral case since it usually entails referring the participant to a relevant government agency or service organisation, and helping them access those services. We distinguish between Emergency Referrals and regular Referrals.

As always, it is very important to remain aware of the cultural context in which the projects operate. Local team members will usually be the most knowledgeable about the best methods for seeking out help for participants and their families. We want to make sure that we do not make the situation worse, especially as we may be considered as 'outsiders' who are interfering in a culturally insensitive way. Always include local team members in planning next steps in referrals.

There are five main ways that referrals come to us:

1. The participant discloses something to the RA during or after the interview
2. The participant is visibly upset but does not want to speak about it or has visible traces of physical abuse and the RAs investigate further
3. The participant does the interview his or herself and we find the information during data checking
4. The parent or caregiver discloses during the consent process
5. The participant doesn't disclose anything, but when an incident happens, they phone their RA (eg. They live with an abusive parent and were doing the interview in that parent's home. They didn't say anything during the interview, but the next time their parent beats them, they call.)

If a referral comes during the interview, the RA should decide with the child whether the child wants to continue the interview or stop and discuss the referral. The child should be reminded that they can stop the interview or take a break at any point in time. Generally, the RA and participant choose to finish the interview and then discuss the referral. If the participant becomes distressed, pause the interview and talk to the participant to see what is going on. Sometimes they will want to continue and sometimes they will want to stop. Before continuing with the interview, the RA should contact a fieldwork coordinator or PM right away, especially if there is any threat of danger (a violent person in the house).

RAs should be trained to know that if a participant discloses a referral, they do NOT need to finish the interview that day. They can, if the participant wants to.

1.1 Codes

Codes or "referral flags" will appear throughout the questionnaire based on responses from participants to specific questions. The meaning of each code is consistent across all forms and each code requires different follow-up action. Below is an overview of all codes (updated to November 2017).

EMERGENCY REFERRALS CODES:

- **Code Black (Suicidality):** This appears if participant has tried to kill themselves yesterday, in the last week or in the last month. Emergency referral if this happened in the last 24 hours.
- **Code Red 1 (Sexual abuse):** Participant has been forced to have sex at least once this year, monthly or weekly. Emergency referral if this happened in the last 72 hours.
- **Code Red 2 (Emergency contraception):** Following on from the Code Red 1, the participant has been asked if they want help to access emergency contraception and have answered yes. Emergency referral if this happened in the last 72 hours.
- **Code Red 3 (Sexual abuse)**: Participant has had their private parts looked or touched or been forced to look or touch someone else's private parts when they didn't want to in the at least once this year, monthly or weekly. Emergency referral if this happened in the last 72 hours.
- **Code Red 4 (Sexual abuse)**: Participant had sex with partner when they didn't want to (they were afraid of the consequences) at least once this year, monthly or weekly. Emergency referral if this happened in the last 72 hours.

Other Codes:

- **Code A (Emotional Abuse)**: Participant has experienced any of the 10 emotional abuse items on a weekly basis.
- **Code A (Physical Abuse):** Participant has been hit hard with a hard item or hit hard enough to leave marks on a weekly basis.
- **Code D (Defaulter, down-low):** This appears if the participant has indicated they are defaulting on their ARVs in S4 ACASI but not directly to the research team (hence the 'down-low'). Will need to be handled sensitively.
- **Code D (Defaulter, open)**: This appears if the participant has indicated they are defaulting on their ARVs to the RA directly (hence the 'open').
- **Code F (Food insecurity)**: The participant has gone more than 3 days without enough food in the house in the past week. Situation gauged by RA to see if food parcel or social services appropriate next steps.
- **Code M (Meerkat)**: This appears if participant has scored less than 10.5 in the neurocognitive test and may be disabled, cognitively delayed or a slow learner and might be in need of more support from RA to complete interview.
- **Code T (Tuberculosis)**: This appears if participant has answered often to coughing up blood or that they have been tested and are still sick. This is more for the RA to stay safe e.g. positioning, make sure there is good ventilation by opening a window or going outside. Depending on severity, the RA may advice the participants to get tested.

1.2 First Steps for Any Referral

RAPE

If a child discloses having been raped in the past 72 hours you need to act fast!

- Assess if the child has accessed emergency contraception (if a girl) and post-exposure prophylaxis (PEP) for HIV prevention
- If NOT, take them to the nearest rape clinic or hospital
- NOTE: Every rape victim has the right to PEP and contraception within a 72hr period after the rape whether or not they open a case with the police
- Make sure to follow the steps outlined below – see Section 7.4.1 CODE RED

SUICIDE

If a child discloses having attempted suicide in the past 24 hours you need to act fast!

- Assess if the child has accessed clinical care and what the outcome was
- Assess if they are still feeling suicidal
- If you have any doubts, take them to the nearest hospital and ask for them to be admitted – see Section 7.4.2 CODE BLACK

1.3 Initial Assessment

An adolescent has just disclosed their experience (of suicide, rape, abuse, illness, etc.) to you. Now what?

1.3.1 Step 1: Safety first

Assess whether anyone is in immediate danger. Use the following questions as a guide.

- Is there a violent person in this home who may be angered that I am speaking to their teen?
- Is it safe for me/a team member/the teen to be in the home right now?
- Is the teen at risk today or tomorrow?
- Is the teen at a different type of risk in this moment than they have been previously?
- Is the teen in a different kind of risk given that they have spoken to you?

If there are safety concerns for you (the research team), leave. We can figure this out from a safe place. Make sure the participant has a phone number to reach you at and reassure them that you are going to get in touch very soon.

1.3.2 Step 2: Reassurance

You're not in immediate danger, and neither is the teen you are speaking to. Excellent! Your job now is to reassure the teen that it is okay, that they did the right thing by telling you, and that absolutely nothing about this situation is their fault. It is crucial that the teen knows that you heard and believed them. There is a lot of research from a lot of countries that shows that victims need to feel you believe them. When this is not the case, victims often develop significantly higher levels of trauma, suicidal thoughts, and sometimes psychosis.

1.3.3 The Golden Reminder

Absolutely nothing about what has happened to the teen or their family is the teen's fault. Say this as many times as you can, and mean it. Say it in different ways. In many cases, the teen will have been blamed for their own abuse or situation, and even where this is not the case, they are likely to be carrying a lot of internalized shame. Remind them that terrible things happen to lots and lots of people. They did nothing to deserve this, and they couldn't have done anything to prevent it. It is also important to emphasize that it was not their fault and that nobody has the right to hurt them or pressure them into something they don't want to do or say.

Thank and praise the teen for disclosing this hard piece of information to you.

- I really appreciate that you told me about that. I know it can be really hard to share difficult things that have happened. Thank you so much for trusting me enough to tell me. You were really brave to go through that and to share it with me.

There will be a number of questions that a teen might ask following disclosure, which research teams should be prepared for.

This may include:

- Will I be punished?
- Will I have to stay in that house?
- Will I feel better soon?
- Will I be taken away?

Don't make any promises. The teen is in a vulnerable space now, and your job is to listen, believe, and reassure. As you already know, we can't guarantee any outcome because we don't offer any services!

1.3.4 Step 3: Pace yourself

Remind yourself to take it slow. Be aware of your own response to this situation as an 'outsider'. Remember that the incident that you are dealing with is traumatic because you are hearing about it for the first time. Most likely, this teen has been dealing with the situation for much of their lives. Don't offer a "quick fix" or referral right now. It is more helpful to wait before taking action and consult everybody you need to consult in order to devise a long-term 'solution'. This is especially the case with rape and abuse situations, unless we are talking about a CODE RED emergency referral.

1.3.5 Step 4: Information gathering

If the teen is calm and able to talk to you, ask questions to get a clearer picture of what is going on and what ideas, steps, or solutions the teen and family are open to. Some example questions are below, depending on the type of referral.

If the teen is traumatized, it may take some relationship building before they are ready to open up. Things we have done in the past to encourage adolescents to share difficult experiences include offering that they go to counselling at Lifeline or another trusted place. You can offer them something safe like support around going to school or just that most teens like to talk to someone from time to time. You can also take them to lunch and chat with them there. Once you and the teen are comfortable together, you can try to steer the conversation toward the referral situation.

Remember that it is easy for a teen who has survived abuse or rape to feel like they are being put on trial when being asked questions, so do your best to ensure that questions are asked in a supportive way.

- "Would it be okay if I ask you a few questions about what happened that will help us figure out the best way to support you?
- You don't have to tell us anything that you don't want to, but some more information will help us figure out the best way to keep you safe and get you help."

1.3.6 The story will inevitably expand and change as you proceed

Every family member will have a different take on what is going on, and the teen is likely to change his or her story over time (especially if the teen is young and sexual abuse or rape is involved). This is okay. Even if you have reported the case to other agencies or authorities, they will be used to this too.

2 "Types" of Referrals and Next Steps

Different types of referrals will call for different courses of action. Some will be emergency referrals, while most others will be less urgent, but still a cause for concern.

2.1 Code RED Sexual/Code A Physical Abuse (ongoing/in home or community)

2.1.1 Step 1: Assessment of type of referral

If the **Code RED** happened within the last 72 hours, it is an **EMERGENCY REFERRAL**. If this is the case the teen is eligible for emergency contraception (if a girl) and post-exposure prophylaxis (PEP) for HIV prevention. Both can only be given within **72 hours** of the occurrence of unprotected intercourse. It is very important to be aware of this and to offer help accessing that service. Any rape survivor has the right to access PEP following an HIV-test at their local clinic to determine whether they are already HIV-positive.

2.1.2 Step 2: Moving forward

If it is not an emergency referral, talk to the teen and family and find out what the teen wants. Sometimes the family already has a solution that they are trying to implement, like having the teen move out of town to live with relatives or taking the rapist to court. If this is the case, you can try to support the participant and the family in line with their proposed solution. For example, if they want to move the teen, our Emergency Fund can cover the transport costs. If they want to go to court or the police, we can accompany them and help them seek out supportive/sympathetic people there.

Go to the local police to see if you can get information about what happens with reported rape cases: Is the perpetrator held in jail upon allegation of the abuse or is it reported, and the perpetrator released home pending investigation? Are the jails full? Gauge attitude of the people you are speaking to, and try to speak to a variety of people to see if you can find someone who is knowledgeable or sympathetic about cases involving violence against women, adolescents or children. If there is a victim safety centre within the community, prioritise speaking to that centre.

This information, along with the desire of the teen, will inform your next steps. In many places, perpetrators are given very light sentences or are let out on affordable bails. It's a hard conversation, but the teen needs to be told when this is the case. Perpetrators can be really angry if they are arrested and then released and can take that out on the teen, which can put the teen's wellbeing or life at risk. Sometimes the teen wants to go ahead with a case anyway, but often a teen's motivation for wanting to go to the police is to get the perpetrator away from them. In this case, other solutions are often more effective. Check in with the teen frequently to gauge what they want, what they are scared of, and whether there are changes in what they want. Make sure they know that we will support them in whatever solution feels best to them.

2.1.3 Step 3: Call Lucie

With the available information, call Lucie for advice. There are often risks and complications involved in an abuse case that you may not have thought of, even with experience.

2.1.4 Step 4: Evidence

If the teen is intent on opening a case with the police, support them in going to the clinic to access post-rape services and a rape kit applied by the local nurses. Prepare the teen that the nurses will have to take a swab of DNA and that they may have to take pictures of any present injuries. Make sure to use the rape crisis centres available in many larger towns.

2.1.5 Step 5: Relocation

Best solution is often moving the teen out of town. Do they have relatives elsewhere? If so, try to get in touch with them and assess whether the teen can be relocated. We have successfully relocated several teens to different locations within the family to get them away from a rapist or abuser when the police or court systems couldn't help. If you are doing this, make sure to take their ID/birth certificate, their medication, and a transfer letter from their school and their clinic, otherwise they will not be able to access schooling or treatment in the new place.

*For cases of Abuse (Code A), gather information from the interview as well as the RA. Often, getting hit/spanked at home is considered a common form of discipline. Discuss with the RA whether there were any signs of abuse in the household. Ensure that the RAs are trained to ask general/round-about questions on how the participant is doing and about their home lives, in the case that a 'Code A' pops up at the end of the interview (keeping in mind that abuse questions are part of the independent ACASI section and are meant to remain confidential even from the RA). Carefully review interview answers while data checking to note whether different types of abuse accumulates (combination of weekly spanking, withholding meals, feeling unwanted at home, etc.).

Case study

*****See Case Study 1: Sexual Abuse & more – in appendix A**
*****See Case Study 2: Sexual Abuse, Domestic Abuse & more – in appendix A**

Some local notes for Eastern Cape, South Africa: **We have experienced extremely unprofessional and damaging accusations from the sexual assault specialist (Sister Matikane) at Bhisho trauma unit. She is <u>not</u> the only counsellor there. Keep in mind to compare the services and responses of survivors using different counsellors (i.e. Bhisho vs. Lifeline).

**In cases of sexual assault, the Thuthuzela Care Centre, located in Cecilia Makiwane Hospital (CMH) in Mdantsane, and Grey Hospital in King William's Town can provide rape care. Services include: medical examinations (if the rape occurred within 72 hours of the reported incident, then DNA testing is done and PEP is administered); counselling, and referral letters for long-term counselling; nurses can arrange follow up visits for treatment and medication for STIs and HIV/AIDS; liaison with police and consultations with a specialist prosecutor and victim assistant officers in preparation for court proceedings.

**We had at least one teen survivor denied PEP because he didn't want to report his rape to the police. This is not acceptable but is a common practice among nurses. I would say if this happens, throw an absolute fit, demand to speak to the person in charge, and threaten to write a formal letter of complaint against the person denying the PEP. I realize that this is very aggressive, but it is the tactic that we've had the most success with in the past. Throwing a fit is also a tall demand and something you should assess whether or not you feel capable doing. Supporting the teen in reporting to the police, explaining why this is often a prerequisite, and asking your line manager for guidance with any of these options are also points to keep in mind. In any case, being aware of your outsider status here is important in deciding how to act, and how you feel comfortable acting.

2.1.6 Documentation

Regardless of circumstances, you will need a series of documents in order to successfully relocate a teen.

**Note: We have had experiences of social workers being either "too busy" to handle a removal or refuse to do a removal within a family, e.g. if the teen is being abused in their mom's house and wants to move in with grandma in another city or province. These steps are helpful to know even if the social worker is doing a removal, so that you can check in and make sure all these pieces are taken care of. You can also speed up the relocation process and support social workers by getting the below documents. We've had really mixed experiences in terms of social worker competency.

1) Go to the school for the teen's school report. Usually they will not give you the report for this year, so the teen will have to repeat a year. You will also need a transfer letter. It should say:

'[Name of teen, ID number] has completed up to [X year] at [School name]. They will be moving to [Location], please consider them for admission to your school.'

- Important to include stamp of the school on this letter.

2) If taking treatment or medication, the teen will need their Road to Health Card (RtoH) or similar for the country in which fieldwork is taking place. The teens will know whether they have one of these. This can be tricky because often the caregiver will keep this card. It's very important to get this card as clinics will not administer medication without it, which can result in dangerous changes in ART regimen.

- Ask teen for assistance with this. Brief the teen that this is very important to get, and that they should look for the card when their caregiver is out and not tell the caregiver (if the caregiver is the abuser). If there is a sympathetic adult in the household who can assist without putting the teen at risk, that is obviously the better course of action.
- If the teen is not going to be able to do this, arrange a police escort to escort teen back into their house to retrieve the card.

3) Transfer letter from the clinic: Every clinic will know what to do for this, and this will also need to be stamped. Clinics are usually good with this. Do check with the teen whether they are taking any medication. Ensure that all medications are listed in the letter that the clinic writes.

4) If grant transfers are required: Go to social services or similar organisation and they will conduct an investigation. Bring the RtoH card and transfer letters, as this will speed everything up. You will not have any power to sort out grants. Most offices will have somebody whose job is specifically to sort out foster care grants. Speak to this person if possible.

FYI for South Africa:

- Child support grant: Up to age 18.
    - *Note from LC: if you apply for a child support grant for your *own* child, even if <18, you and your family would lose the child support grant they get for you. Another reason why young moms may not be claiming grant directly but through their own parent/ caregiver/ guardian.*
- Foster care grant: Up to 18 or up to 21 if still in school

2.2 Code BLACK: Suicidality/Mental Health

2.2.1 Step 1: Assessing whether there is a threat of suicide or actual attempt

Cut-off point can be whether or not they have actually thought of a way to kill themselves. 'Is there an indication that someone is making plans for this?' If they are thinking of ways to kill themselves, treat it as an attempt. If they are vaguely contemplating suicide, assess – but this is probably OK. Many teens respond that they have thought about killing themselves because no one has ever asked them that before, and it has crossed their minds. It is always worthwhile to ask the teen if they would like to speak to someone about their experiences and explain how kind and helpful the people at Lifeline are.

If making plans or have actually tried to kill themselves, get the person to counselling as soon as you can. We have had the experience of not taking seriously enough a teen making plans to kill herself, and then she did attempt suicide, which led to an emergency situation.

Case study

***See Case Study 3: Suicidality, Rape & more – in appendix A

2.2.2 Step 2: Overnight Hospital Stays

If the person is in immediate danger of hurting or killing themselves, you can have them admitted overnight in the hospitals. Most hospitals will not have a psych ward, so they will end up hospitalizing survivors. This is not always the best option, but sometimes it is the only option. This is also an option for 24-hour watch when you are concerned about someone. It helps a lot to have relationships with hospital staff who can advocate for the teen being hospitalized even though they are not "sick." Ask the doctors or staff that you work most closely with if this is something that they have heard of happening at the hospital or if they would be willing to try it BEFORE you have an emergency situation.

In South Africa Lifeline is an excellent resource; Lifeline will deal with any type of case. However, they have transport issues. The King office has had success with having a regular (weekly) visit from a Lifeline counsellor to the office and scheduling participants to come in to the office for counselling.

For other countries, see local resource sheets that each project will have, and consult with local NGO partners.

2.3 Code F: Food Insecurity

2.3.1 Adolescent/adult/household food insecurity

Code F will be flagged if there is household food poverty for more than 3 days in the last week. Providing food parcels is not a sustainable solution and should be avoided. Preferred follow-up is listed below.

First choice: Get them a grant. Check with the family which grants they are currently receiving and then discuss with the management which additional ones they can apply for.

Second choice: Get them access to an ongoing food parcel through their ward councillor, clinic, or any local soup kitchen or programme. These are hard to find and pretty variable, but some clinics do offer food parcels or supplements to their ART patients, and some wards do have food parcels for at least part of the year. Community gardens should also be explored. If they express interest in a personal garden and just need help getting this started, that is also an option.

Third choice: Get them a one-off food parcel through the emergency fund. This is especially a good thing to do if the RA is distressed about the family's situation. Food parcels can be a useful tool to tide over a family while they are waiting for a grant to be sorted out. Otherwise, their main purpose is to raise team morale or soothe a worried team member. However, food parcels are a contentious issue within the communities and the projects must refrain from setting precedents or giving regular food parcels to families. Food parcels should not replace grants, and we should ensure that families claim for all the grants they are entitled to rather than distribute food parcels. Ideally, if it is not an emergency food parcel, try to deliver it in line with grants day.

**A note about morale: Delivering a round of food parcels can be a pretty healing thing to do when encountering a lot of poverty. It feels good to be able to have the instant relief of shopping for food, delivering it, and knowing that a family won't be hungry TODAY. However, food parcels should be a last resort and are not a sustainable solution to poverty.

2.3.2 Child food insecurity

When asking about food security of younger participants, Code F will be flagged after 1 or more days of food insecurity in the last week. In other words, this flag is more sensitive when asking about younger children.

The RA should assess the severity of the situation and investigate the extent of food insecurity. Depending on the situation it may be appropriate to provide a smaller food parcel to support feeding the child. This should be decided case-by-case with the PM.

A similar response should be followed as for household or adolescent food insecurity. Team should facilitate access to an ongoing food parcel through their ward councillor, clinic, or any local soup kitchen or programme as above.

2.4 Code T: TB Test or TB Treatment

TB testing and TB treatment at a healthcare site can and should be supported by an RA. In cases of RAs escorting participants to receive a TB test or treatment, RAs (and everyone else!) should be trained to

remember that sitting in waiting rooms is a great time for bonding with teens and giving them space to open up about other aspects of their lives.

During high risk of exposure to TB it is important to note the following:

- RA and participant should stay in well-ventilated areas. If you are inside then make sure all the windows are open and that the RA sits at the open door
- TB can be really dangerous so if the team member is HIV-positive they should prioritise themselves and ask another team member to support with the referral.
- Research participants who have been on treatment for 2 weeks are no longer infectious.
- See more information in the Health & Safety Manual.

In South Africa Parental consent is required to get a TB test – legally, teens can make their own medical decisions from age 16, but we don't want to overstep boundaries with parents. We've never had a parent refuse this, as far as we know.

The RA should:

- ask the teen if they know what is going to happen to them, and explain how a TB test works even if the teen says yes (cough into a cup, mucus goes to the lab; it doesn't hurt, nothing to be scared of, etc.)
- ask the teen if they'd like to be accompanied in to see the doctor, and while doing the TB test
- bring colouring books, games, etc. **It is important to use this time to bond with the participant.** Even our best team members have struggled with this; they are used to spending a lot of time in waiting rooms, and people just switch off. Unfortunately, our teens have complicated lives, and **many of our most difficult referrals have been disclosed while in waiting rooms for TB tests or treatment**. Emphasize this to the team and explain why it's important.
- technically, all members of the household should be tested if a test comes back positive. Call the family and explain this, then call once to follow up. Accept that it almost never happens.
- remind RAs that if a participant says they have TB and are not on treatment, the interview should be postponed or done outside. Many RAs feel uncomfortable stopping an interview, so this is worth role-playing and providing support around this during training.

2.5 Code M (Meerkat): Cognitive delay/ Child Disability

Code M may be flagged after cognitive tool or when participant responds to questions about disability. RA should assess which questions lead to Code M and follow respective steps.

2.5.1 Cognitive delay

If Code M is flagged after the cognitive tool, this may mean that participant is a slow learner and have difficulty using the tablet or responding to questions. The RA should provide additional support to help the participant understand and answer questions

2.5.2 Child disability

Code M has also been programmed to come up when participants report their younger children have difficult with hearing, sight, speech, or has difficult walking (i.e. physical disability). For

these cases, the RA should find out what help caregivers have done in response this. It may be that caregivers are not aware of these issues until they have been asked about it or may not know what services are available for their children.

Suggested referral response: If the caregivers would like more support we can refer the children to the hospital where they be assessed by an occupational therapist, speech therapists or Ear Nose & Throat specialist. The team may decide the family needs assistance to ensure the child accessed the appropriate services.

3 Other referral actions

3.1 Pregnancy

Not every pregnant teen is a referral case. Pregnancy referrals can and should be handled by an RA; such a referral most commonly involves a pregnant teen who is not receiving antenatal care. The most important thing in this case is to link the participant to medical care. We do not comment on or get involved in pregnancy disclosure unless the teen asks for our help with this. It does not matter whether the participant is HIV+ or HIV-; they should be getting antenatal care regardless. RAs can accompany teens to the clinics for their first appointment should teens be scared to go by themselves. Teenage pregnancy can lead to exclusion from school, being disowned and thrown out of the home, and being married against the teen's will. It is therefore important to remain non-judgmental of the pregnant teenager and link her to the appropriate services.

If the teen is interested in a termination of the pregnancy, she should be referred to a clinic that offers these services. The teen will receive counselling there from qualified nurses who will help them make the difficult decision of whether they should carry to term or not. Only team members who will be able to support a pregnant teen and her decisions for or against termination should be assigned to these cases.

3.2 HIV Test

A referral case for an HIV test can be supported by RAs or by management. In cases of RAs escorting participants to receive an HIV test or treatment, RAs (and everyone else!) should be trained to remember that sitting in waiting rooms is a great time for bonding with teens and giving them space to open up about other aspects of their lives.

In South Africa, parental consent for an HIV test is not required for adolescents aged 12 and older. However, where we can, we do not want to overstep boundaries with parents and more importantly, we have to make sure that the adolescent has a support network available to them should they test positive. We have in the past had parents refuse HIV-tests even though their adolescent's health was deteriorating very quickly. It is then important to find people within the adolescent's environment who could offer the emotional and treatment support, should the adolescent test positive.

Whoever accompanies the adolescent should:

- ask the teen if they know what is going to happen to them, and even if the teen says yes, explain how an HIV-test works (a tiny stick will be used to prick their finger, then one single drop of blood will be squeezed out of the finger and put on a strip, the strip will then react with the blood, and indicators on the strip will show you in 5 minutes whether your test is HIV+, HIV- or invalid)
- ask the teen if they'd like to be accompanied in to see the counsellor, and while doing the HIV test

- if you feel comfortable, you can get tested first to show the teen that there is nothing to be afraid of
- bring colouring books, games, etc. **It is important to use this time to bond with the participant.** Even our best team members have struggled with this; they are used to spending a lot of time in waiting rooms, and people just switch off. Unfortunately, our teens have complicated lives, and **many of our most difficult referrals have been disclosed while in waiting rooms for HIV tests or treatment.** Emphasize this to the team and explain why it's important. Furthermore, this is a really stressful situation for anyone, and it is a very brave decision to want to test for HIV. Reinforce this and use your time in the waiting room to redirect the teen's worries.
- If the teen tests positive, the counsellor will be there to support them and tell them about next steps. Be calm, do not cry, or freak out. What the teen now needs is for multiple adults to tell them that many people have HIV, live good lives, and are very much loved, that it is not the end of his/her world as he/she knows it, that free treatment is available to them as well as counselling and support, and that you will support them if they need somebody to speak with during the initial phase.

3.2.1 ART Help

If the participant is defaulting, it is important that the RAs gather as much information as possible to understand the cause. For example, in some instances, the participants were afraid of their nurses and asked the RAs to escort them to the clinics. Other teens didn't take their medication regularly while living with a parent who wasn't taking meds or took them inconsistently, but then started taking them properly when they moved to a more supportive environment.

ART help can come from getting counselling at the local clinic or from the prescribing doctor. Occasionally, there are ART support groups at clinics. Sometimes once-off counselling can be really helpful, for example, if the teen has been taking meds since they were very young and was never really told why taking them properly is important. Sometimes a teen just needs a reminder of why their meds are essential. And sometimes counselling doesn't really help because there is a root cause to why the teen is defaulting that has nothing to do with knowledge.

**Note: A lot of teen boys go to circumcision school for several weeks in July or Nov/Dec. Different circumcision school leaders ('ikhankatha' in iXhosa) have different attitudes about ART during circumcision school. There are leaders (ikhankathas) who work with doctors to make sure that the teen is able to continue taking ART without disclosing his status to everyone at the camp. CMH has a doctor who works specifically on leaders (ikhankatha) outreach and can advise about which circumcision schools are best for teens on ART.

Case study

3.2.1.1 Case Study: Defaulting on ART (successful outcome)

We visited a 16-year-old girl who approached us about defaulting on treatment and wanting support around how to take her pills better. We sat with her and helped her think through why she wasn't taking the pills and what her barriers were. She determined that she didn't have a good way to remember and was usually rushing to school in the mornings, so she just forgot.

Together, we came up with a whole bunch of different approaches that might work for her, and we landed on a 3-fold approach – she would take her pills at 8 in the evenings because that is when the TV show Generations began and that would help her remember. In the mornings she would take her pills at 7 so that she could take them before school at the same time as her older sister. Her sister would remind her in the morning and they would take their pills together. She would also put a note for herself on the back of the door out of the house so that she would see it on her way out if she had forgotten.

These strategies worked well for the girl, and we suspect that this is because she herself felt ready to get back on treatment and adhere and the decision was driven by her.

3.2.2 Disclosure of HIV-status to an adolescent

It is important to be cautious not to get overly involved in providing support for disclosure. The RAs must be reminded they are not lay counsellors. You must also remind yourself of this. Disclosure is best to be discussed with a caregiver or participant according to their best wishes and then referred to a clinic counsellor.

However, in some cases you or your manager may be well placed to moderate a group debrief after a particularly difficult disclosure or referral. This is a particular skill that you should ask for guidance in leading. It involves creating a non-judgmental space, for a determined period of time, in which people can 'check-in' and share how an incident has affected them. It's important to reiterate that the best solutions to difficult referrals are often sustainable ones that are embedded in existing services – however, poor they may be – and acknowledge that feeling upset is an understandable response to the situation.

3.3 Special School

Several of our participants have requested to attend special schools. There are only a handful of them available, but most are full and have long waiting lists.

1. Find out why they think they need a special school. Is the teen performing badly in school? Do they clearly have a learning disability like Down's syndrome? Did they receive a letter at their current school?

2. What steps has the family taken already to try to improve school success for the teen? This can include extra homework help, tutoring, or exploring other schooling options.

3. Talking to a teacher is often really helpful because they will have a better sense of whether the teen really does need a special school or whether there are other options available that would be better suited to the teen. We have had teachers explain that sometimes teens whose parents think they need special schools are really just struggling with a particular subject or concept.

4. When possible, explore other areas of life that may be taking the teen's focus off during school. Often, teens are failing school because of trauma or abuse in the home or at the school. Frequently, when their situation changes, they begin to thrive in school.

**The project should have a list of special schools in the area. The next step is to assess the quality of the schools (if this has not already been done), mark the schools based on the assessment, and pass it out to families who have requested a special school placement.

3.4 School Uniform

We have encountered a lot of participants living in extreme poverty who have dropped out of school because they didn't have a school uniform and were told that they could not come to school without one. Most towns or cities have a big store that has all of the school lists and colours. Again, this is not a sustainable method to decrease poverty and we need to be careful in setting precedent.

Case study

***See Case Study 4: School uniform – in appendix A

3.5 Substance Abuse

Substance abuse may be identified by RA and/or disclosed by a participant or caregiver. It can be extremely hard to get any sort of rehabilitation program or substance abuse-specific support in East London or King Williams Town. Lucie recommends that in cases where there are no services at all, the best (although limited) option is that the teen is sent away to a rural relative – the more rural, the better. Since there are no support services around this, she has seen the best success in just removing the teen from substance-using friends or access to substances. It is also worthwhile to enrol the teen in general counselling with Lifeline, if the teen is willing.

Step 1: Substance abuse identified/disclosed, find out more about the situation

If substance abuse is identified by RA and/or disclosed by a participant, the RA should find out more about the situation (reasons for substance abuse and how teen accesses harmful substances). If the teen requests support we can refer them to Lifeline Masithethe (in South Africa) and also suggest that they relocate to a more rural area, away from access to substances.

Step 2: Referral action

Lifeline support: the team can set-up and appointment for Lifeline Masithethe and provide the participant with means of transport to get to the appointment. The before appointment the RA, with whom the participant has most contact with, should contact the participant to remind them about the appointment. Especially with substance abuse, teens may face more barriers to exercise control and actually go to the appointment so the teen may need to be **picked up and taken to lifeline by the team.** A follow-up call is also needed to make sure the teen went to the appointment and if they may need support to schedule follow-up appointments.

Note: These referrals have historically been challenging and time consuming as they require finding participants (older boys - out of school) who have moved around a lot and whose lives are precarious.

3.6 Child Mortality

When finding out about adolescent parent's child's death, this should be handled very sensitively and carefully. It is of upmost importance that the RA interact sensitively with the family and participant without asking too many questions, especially after finding out. This very difficult situation not only

hard for the participant but also difficult for the RA and team who have a relationship with this participant.

Note: vicarious trauma to the team. Being exposed to these circumstances can remind individuals of when they have experienced similar events in their life. It is important the managers are aware that exposure to this may bring up trauma in the team. To support RAs going through this, managers should check in with the RA and find out about how they are doing. If the RA would like to access counselling then the manager can facilitate this (see section 5).

3.6.1 Step 1: assess situation and plan next steps with RA

The family mourning the loss of a young child may appreciate the RAs presence or may not. The RA should assess the situation and discuss with PMs how best to support the adolescent parent and their family. Steps be taken should respect what the participant shares with the RA and what needs are expressed.

3.6.2 Step 2: Arrangement of food parcel and/or counselling for parent

The project would like to offer both counselling and a food parcel to the participants in the case of child mortality. Discussion of such provisions should be undertaken sensitively and at a suitable time deemed by the RA.

- Condolences for the family
- Counselling for the parent
- R500 food parcel, or whatever else is appropriate in the individual situation

3.6.3 Follow-up and information gathering

Lucie and Elona advice that we follow-up with the parent only after a couple of months have passed. Although it is important for us to understand the cause of the child's death, this should be handled very carefully and avoid causing any further trauma.

This would be to check-in on the participant and to find out a bit more about the circumstances of the child's passing. This should only be done after **a few months** following initial disclosure of child death. Before returning to contact a participant whose child has passed away, the RA and referral lead should consult on a plan.

4 Grants (South Africa relevant – for other countries please see information leaflets)

South African Social Security Agency (SASSA) provides various types of grants including:

- Social Relief of Distress
- Grants-in-aid
- Child Support Grant
- Foster Care Grant
- Care Dependency Grant
- War Veteran's Grant
- Disability Grant
- Grants for Older Persons

SASSA grant pamphlets are available in the office in English and in Xhosa. Ensure that RAs pack the pamphlets and provide proper information to participants on grants. Many participants are eligible for grants; however, they may lack the resources and information to access them.

Please visit http://www.sassa.gov.za/index.php/social-grants for more information on grants. With the SASSA office, it often helps to have a professional accompany the family to the SASSA office who can advocate for them. We have experienced a lot of cases of families being turned away from grants that they qualify for until they were accompanied by someone from the project. In challenging cases, it can help to have a white or foreign person go too due of the power dynamics still prevalent in South Africa from apartheid. Once you've established a name for the project(s) at that particular office, any team member should be able to advocate. Know which grants the person qualifies for and why, and speak up about it.

The Social Relief of Distress grant is supposed to be available to anyone for short-term assistance at any time after an emergency or life change (like losing a job or a change in household income) and can be used in the meantime while any of the other grants is being processed. Most people don't know to ask about this, and you should ask for it specifically. At some offices it is in the form of food parcels and they run out.

Case study

***See Case Study 4: Grants, working with DSD & more – in appendix A**

5 An Important Note about Feelings and Vicarious Trauma

This stuff is really hard! It is emotional to work every day with teens in such dire situations and to know that it's not going away any time soon. It's important that you acknowledge that having a response to these situations is normal and expected. Go to therapy. Take days off. Take a vacation. Talk to each other. Figure out what you need to do to care for yourself. This is not just for you, but you are also modelling for your team what space they have available to grieve and care of themselves during referrals and in the workplace.

We sometimes have similar responses to situations; other times foreign team members have different responses to local team members. Something may be shocking to an 'outsider' that is not as surprising to a local. It is important not to impose your own personal response to a situation. Remember, too, that each case can be even more emotionally draining on the RAs, who usually live in areas where they are surrounded by these types of situations in their own families and communities. They are the ones doing most of the hard work of trust building and communicating with the teen, and they are the ones understanding every word and comforting tears. You probably get to go home to a safer place that is away from the trauma of referrals at the end of the day – they probably don't. Make sure that RAs know that you know this is hard for them and are concerned for their wellbeing. We are working in a place where people have generations of family members who were fired on the spot for missing a day of work or doing something imperfectly. RAs will often be understandably hesitant to express that something is hard on them or not working for them and may push themselves to be okay. This is not useful – we are in it for the long haul, and it is not possible to really show up for the teens when we are exhausted or traumatized ourselves.

The projects pay for counselling sessions for all team members. Skype sessions are available through CCPD Counselling in London for counselling via Skype; Lifeline is available for those who want to access counselling locally. Please make use of these resources and make sure everyone understands that these are available to support them. Time off should be given to those who need to access these services.

***Doing something fun or unusual as a team when morale is low can be really helpful. Something as simple as getting a surprise cake can be good. Remember different things work for different people and no one solution fits all. Have regular team-building days away from the office to mitigate some of the work-related stress.

6 Appendix A – Referral Case Studies

6.1 Case Study 1: Sexual Abuse

We interviewed a 17-year-old girl in Dimbaza who reported that she was caring for her 9-year-old sister after they had moved to their grandmother's house because the 9-year-old was being routinely raped at gunpoint by her uncle (please note that in South Africa, the terms 'uncle' and 'aunt' are understood in their wider meaning; 'aunts' and uncles' may be individuals related by blood or family connection, but they may also be friends of the family, etc.). We were told that the uncle came to the grandmother's house to rape her every weekend and no one could stop him because he had a gun. Previously, they had been living with their mother and uncle.

Below is an email exchange between Lucie and the project manager, outlining their plan and the thinking behind the chosen steps, as well as important questions and information.

Hi Lucie and team,

Today we visited a 9-year-old who is being raped at gunpoint by her uncle every weekend. The uncle obviously has a gun, so we want some advice about what to do so as not to put anyone's lives or safety in danger (our team or the teen and their family)

- *Mother and uncle live together and drink together on weekends*
- *teen was living there, but is now living nearby with her grandmother, who loves her and wants her to be safe. There are several other teens living with the grandmother -- 17-year old girl (who we interviewed), 10-year-old girl, 8-year-old boy, and 7-year-old boy*
- *mother is not happy with this arrangement and wants the teen back, but grandmother knows that teen isn't safe at home and wants to keep her*
- *mother comes around on weekends to take the teen back, and has brought the uncle, who has threatened the grandmother and teen with a gun*
- *don't know how long she has been being raped*
- *don't know when she moved to grandma's*
- *older sister (who we interviewed) noticed a lot of discharge on the teen's panties and asked her about it. teen started crying and told her what was happening.*
- *teen was taken to clinic, where doctor verified that she was being raped*
- *neighbour also heard the teen crying and the sound of someone being raped, then saw the teen behind a wall wiping herself off with her t-shirt and crying*
- *teen wasn't born HIV+ but now is, family thinks because of rapes*
- *so far, police haven't been approached and nothing has been done*
- *grandmother and sister are scared that if they do anything, uncle will come shoot them or will shoot the teen*
- *they all live in a rural-ish area 10 minutes outside of Mdantsane*
- *we have searched for emergency shelters for women and children in immediate danger in east london and found none*
- *could consider hospitalizing her on weekends if possible?*

- *obviously, we would like the uncle to be imprisoned, but are unsure of how to take action without putting anyone at risk*
- *What should we do?*

Dear J

OK. Firstly, I'm sorry this is such an awful situation. We need to prioritise keeping the child safe this weekend and then give ourselves a bit of time to make a longer-term plan that is safe for everyone.

SHORT-TERM: Can you arrange for grandmother and 9-year-old and rest of children to go away somewhere this weekend? Emergency fund can pay for this. Is there someone they could visit? Or a place we could rent for just the weekend? This is of course not a long-term plan but it is now Tuesday, and we'll need more time to get our act together for more considered planning. We can also do this next weekend if necessary.

LONG-TERM: We are going to need to contact the police or some kind of justice measure, but we need to think about this very carefully first. Do you know any of the community leaders in this area? Ward councillor, chieftain (if it is rural enough)? Ask Granny first, and also find out does any of the team know people or come from this area? We need to find out if the uncle is well-connected in the area (and whether a formal police complaint will end up like the girl in Mpumalanga--we want to avoid this). Can you get some information first and then we can think through approaches.

LONG-TERM: does Granny have any relatives living far away that we could help them move to?

RIGHT NOW: Julia and team are you OK? It's 9.30 pm where you are so probably too late, but I can chat if needed early my time tomorrow morning.

So sorry how awful but we can help.

LC

Thanks, Lucie, very helpful. We can visit them tomorrow to see if they can visit someone. I am just a bit scared that we are going to put them (or ourselves, possibly) in danger if we take them all away for the weekend and then they come back. Should I be worried about this, or does the girl's safety this weekend trump that?

We are also considering asking Doctor Goldswain if she can hospitalize the girl for the weekend so as to be discrete. But I will check with the grandmother tomorrow if they ever visit anyone and what a plausible story might be.

I will also ask granny about the area and connections -- ward councillor and community guides here have not been that helpful, and we haven't had a face-to-face meeting with ward councillor.

We are ok. Thanks for the good advice and steps!

Dear J

Good careful thinking.

Does granny have a phone? Can you call before and check uncle doesn't come round during the week? (does he work?). Your safety MUST be priority here so if any risk of him being there do NOT go. You can arrange to meet kid at school or clinic or granny elsewhere.

Yes, very good idea to hospitalise girl for this weekend if possible. We can pay for transport from emergency fund.

You are right to see if there can be a plausible story. If not then could we say it is part of a project for children and leave them with a word doc flyer saying weekend away for children (just adapt a quals weekend one). So yes, we don't want to alert uncle to the fact that he's been noticed, but equally we should be able to think of good excuses to avert suspicion.

I'll be up from 6am NYC time (12 noon SA time) and can chat if needed.

Best wishes, LC

Notes from J and Lucie call today:

1 - TODAY: Call and make sure uncle has never visited during week. Check if uncle has a car. Visit home or meet family somewhere if yes to ever visited in the week.

2 - TODAY: Also to clarify with family – how long after a rape did they take child for rape kit testing? See if any documentation from doctor re: rape. Also check how connected Uncle is–does he have friends in police, in local ANC, ward councillor, chieftain. Ask if they can go for longer if need to. Check if granny needs to physically pick up pension or similar. Appointments at doctor.

3 - Ask team if any family or contacts in that area. Find out if there's a chieftain.

4 - Call Tshiamo and ask for one of their volunteers for a couple of days to help with this – better to have woman, so Nash

5 - IMMEDIATE TODAY this weekend plans: 1) ask if there's a relative who lives somewhere further away that they can visit for weekend – support them financially to do this/take them; 2) call Magda in Hamburg and Carol Hofmeyr at Keiskamma and ask if there's anywhere there we could put up the family

for the weekend or somewhere we could rent (either Elona or Julia to just call them) and then help them get there, with 'deflecting' information to the mother so not suspecting; 3) explore same in King Williams Town with Isibindi (get Tshiamo and Sbo involved); 4) Julia to call OVC woman in Berea re alternative care 5) last option call Gerry Boon and ask if we can get child hospitalised at Frere for weekend (not ideal as other children in home who may be at risk)

6 - LONGER-TERM plans: 1) Call Cindy at Childline and ask to meet her today or tomorrow to get a sense of how much experience they have with court and justice system. Can she actually help to get family through process of reporting to police? 2) find out from family where getting rape kit results from and call the clinic/hospital to ask when we can come to pick them up. 3) Whilst waiting for these, Julia and Cindy if possible go to police station (depending on how well-connected Uncle is) and explain story – see what they're like, see if they do actually have a family liaison officer. **Ask if they've ever managed to successfully prosecute a child-rape case?** Ask them if uncle is arrested, will he be staying in prison till sentencing, or will he be released to home? 4) talk to Cindy and see if anyone good in Department of Social Development (DSD) we can talk to.

7 - For next week, see if we can get some counselling from Lifeline for child.

8 - Lucie, Julia, and Nash to speak tomorrow. Lucie on cell all day 0044 7980 856 651

Below is some information from today's visit.

- uncle has "no friends", is drunk, unpopular, and rarely leaves home, according to family. Is not politically connected and doesn't have friends in police or courts that family knows of.
- sister at clinic wrote a letter on 18 Aug referring them to CMH, where she was swabbed by a doctor in paediatrics. The swab was for a bad smelling discharge, so probably an sti test, not a rape kit. We will accompany them tomorrow to her next appt to get results and see what we can learn/discuss with doctor first thing in the morning about documentation.
- family is scared to all leave home together because that will be very unusual and suspicious and want just the child and her 18-year-old sister to go, as sometimes they go and stay with their father in Amalinda for weekends. They could actually go to the father (in Amalinda, not far away) or say they are and go where we arrange them to.
- we will talk to father tomorrow also, at grandma's insistence, uncle doesn't have a car or job and is usually drunk
- slightly different story today: uncle and mom haven't come round for some time now, but they came last week saying they are going to come this weekend to take the child to church. Child became hysterical crying that she didn't want to go.
- uncle usually asks for money from the mother and when she doesn't give him money, he pulls out the gun and rapes child at gunpoint
- unclear which of these versions is more accurate, or where in the middle the truth is?

We then contacted Ulutho Child Services, who work in child social work and child protection. Below is an email to the social worker there from Lucie. The social worker asserted that we needed to involve DSD and the police.

Nomvuyo – thank you for this and for your sensitivity to the potentially volatile situation. We agree that police and social services will need to be involved, but have had experiences in the past when social services or police have come very fast into a situation, but have then been unable to follow-up with any services, and have left children in very high-risk situations. You are clearly also very aware of this risk and we hugely appreciate your help and your consultation of the legal advisor.

Some brief thoughts:

1. I agree that it would be a good idea for the child and sister to visit the father this weekend (we can help with money for transport, etc). If not the father then we could arrange something else as discussed, but very important to get her away this weekend.

2. Is there any way we could make sure that the other children in the family are safe if the uncle comes around? Is there a man who could be there when he comes there so that he can't take another of the children?

3. Nomvuyo – this is important – do you have any experience of this area and the DSD and justice services? Do we know anything about conviction rates, about the police and the magistrate's court in this area? We have had many instances of perpetrators being released, not being charged, and being released after conviction due to 'full prisons' or other excuses. These are likely to put the child at greater risk, and we need to consider this carefully to try to get the best outcome.

4. When you speak to the father, Julia – could you ask him about whether there's any ways we could provide more safety for the child? She is clearly well cared-for by grandma. Be aware that father may not know about this situation at all. I am very happy to talk it through with you if needed first or during.

Best wishes and thank you both for great work in this very difficult situation.

Lucie

The above pages of correspondence are included for you to see examples of the kinds of questions we were asking in an attempt to think through the safest possible plan for the girl and her family in both the short and long term, as well as the sort of lateral thinking involved when police or DSD are not immediately helpful or not available. Below are the next steps that were taken in this case:

- For the weekend, we arranged an emergency homestay for the child and her older sister through DSD. This was not a really formal process – the social worker took her home to her (the social worker's) sister, who sometimes fosters children and has a spare bed for them. We transported her there ourselves so that we could check out the place, meet the people, and

get a feel for what this arrangement was. This worked well but required a lot of effort on our part, including transporting the girls in both directions.

- We called every organization we could think of to ask for advice about how to handle this. They advised us to tell DSD and report to the police.
- We took her to speak with Sister Matikane at Bisho, who told us, in front of her and her sister, that she "must have enjoyed what was happening to her, because she was protecting the man." There, she told us that she hadn't been raped; she was just having consensual sex with a 9-year-old boy. This did not go well, and we then found a different counsellor.
- We took her to be examined at CMH because she was having discharge that smelled bad and was painful. Our goal was her health and safety, but the examiner spent several hours with her on the table and carefully documented the scarring there. This person informed us that the rape was done by an older person who had a fully developed penis and that it was highly unlikely that anything she was doing with another 9-year-old could have caused that extent of damage. The child did access needed STI treatment through this, and the nurse examining her was loving and kind.
- We arranged ongoing counselling for her and her older sister at Lifeline, who we have a good relationship with.
- Eventually, we did involve DSD, who returned her to her mother's custody, thereby putting her back in the house that the uncle also lives in. This did not go well, as the child was ultimately living with her rapist again.

6.2 Case Study 2: Health/Failing school/Family issues/Abuse/Forced sex

15-year-old girl was flagged during data checking because of a physical disability, forced sex, and TB symptoms. The RA who had interviewed the girl said that she hadn't said anything about forced sex during the interview but that she seemed jumpy and distracted, had nervous body language, and wouldn't make eye contact when asked about rape.

We tried to visit her at home, but she wasn't there, so we spent some time speaking with her caregiver. Her caregiver didn't seem interested and kept changing the subject away from the girl and her history, health, and wellbeing, even while telling us a lot of grim stuff. She shared that

- the girl was raped repeatedly by a man who used to drive her home from school as a young child. She never said anything to anyone about it, but the doctor told the caregiver after a time that she was hurt so badly by rape that she couldn't walk. The caregiver never noticed the rapes – the girl's younger brother was present at the doctor and announced that a man comes and takes her away every week.
- when she found out about the rapes, the caregiver took her to the clinic to have an IUD inserted so that she wouldn't become pregnant
- caregiver said that doctor reported that child had been re-infected with another strain of HIV and that "no medication would help her now" and so took her off of ARVs

- girl has trouble hearing. She has ear infections in which "green stuff" comes out of her ears. Caregiver used to take her to the clinic for this but stopped because it wasn't making a difference. At another point, the caregiver said that the girl doesn't like taking her ARVs and so doesn't take them well.
- Neighbours have reported the grandmother for child abuse and DSD came to take the child away, but the grandmother physically beat up the social worker, and they never came back after that.
- girl is failing school repeatedly.

Next steps taken:

Because of the strange story about the ARVs and because the girl seemed to be defaulting one way or another, we spoke with the primary care (HIV) doctor at the girl's care provider. It turned out that the girl has been attending teen support group at the hospital for years and the doctor knew the whole history. She informed us that the girl was taken off of treatment by a different doctor because she is resistant to the first line of treatment and was seriously defaulting on the second line. So, they had her stop taking ART until she is ready to take it more consistently [NB: not taking ARVs consistently increases the chances of developing a drug resistance to them]. The girl has not been taking ART for years but is somehow still OK.

The doctor said that the grandmother is psychologically unstable, and is definitely not a safe caregiver for the child, and that she has been meaning to refer the girl to child welfare but hasn't had the capacity. We were all clear that the girl would be better off living somewhere else, but an assessment by DSD could put the girl at risk by triggering a violent response in the caregiver.

We decided together that we would compile a report for DSD about our experiences with this family, including a warning that the grandmother has been violent in the past. The doctor was going to write up her history with the family and send it to Julia [the PM] to include in letter to DSD.

Then, the doctor realized that she couldn't include confidential information in writing to us, so asked us to list her contact information in the report. We compiled a letter and gave it to the doctor to pass on to DSD. DSD refused to visit the house because of the threats the grandmother had made previously. The team then had to withdraw because the grandmother was too aggressive. However, a few months later we saw the child and she said she had re-started treatment and was attending the support group.

So while there are limits of how far we can go with our involvement in some of these cases, family trajectories move up and down and there may be some improvement without intervention from the outside.

6.3 Case Study 3: Suicidality/Rape/Mental Health/Removal

We interviewed a 16-year-old girl who had been raped by her neighbour in the past. She still had to walk past this neighbour every day to get to school, and this was traumatic for her. She described it as "he is raping me over and over again every day". Sometimes he harassed and threatened her when he

saw her, and she went out of her way to avoid seeing him, taking alternate routes home from school and hiding in the bushes when she saw that he was in his yard.

We established that she didn't want to go to court or approach the police because the ordeal would be too traumatic for her and her goal was to get away from the man and not to have to see him.

She answered yes that she had thought of a way to kill herself, and we made her a psychologist appointment for the following week. By the time she got to the appointment, it turned out that she had tried to kill herself the previous night and had not been successful. After her appointment, the psychologist accompanied her to emergency, where she was admitted for the next two days in order to be in a safe place under 24-hour watch. This experience was fairly traumatic, as the girl was profoundly depressed and had to wait among a lot of disturbing scenes for more than 12 hours while we waited for a bed to open up, but once she was admitted it gave us a chance to find a better home placement for her and remove her from the man's threats.

We were working with a women's shelter at the time, and they gave her a bed in a shared room because of our relationship with them. This was a temporary solution because there were no permanent beds at the shelter, so we had to agree that she would stay there temporarily while we arranged another solution. At the shelter intake, they asked her more about what was going on and gave her some motivational counselling.

Meanwhile, we asked her and her aunt, who she lived with and who cared for her, if there were any other family members that she might be able to live with in order to be farther from the man who raped her. Her aunt recommended that the girl move in with a different aunt who lived farther away in a deep rural area. We moved the girl there (following the steps for a removal), and it went fine. She started doing better in school and feeling less suicidal and terrified.

6.4 Case Study 4: School uniform/family issues/physical abuse/rape

14-year-old male participant and his sister saw our car go by in the morning before school and called us to ask if we could advocate for them being allowed to write their school exams without wearing their school uniforms. They then told us they had been kicked out of their home by their mother the previous night and had slept on the street, so they didn't have their uniforms. The teens had been living with their aunt, who was severely physically and emotionally abusive. She once stabbed the girl in the abdomen, and she had to go to hospital. The girl was raped while sleeping on the street after the aunt locked her out, and the aunt told her that she deserved it and she hopes it happens again.

The teens asked us to phone their two older sisters, who are married and live outside of the home. The sisters said that they were willing to take the teens in and care for them, but they needed the foster care grant to be transferred from the aunt to them.

The teens really wanted to write exams because they had been studying for them, so we accompanied them to school and explained the situation, and they were allowed to write. While there, we asked the teachers if they knew what was going on in the home. They said that they did but wouldn't disclose any information to us because we were not from DSD.

We went to the local DSD office, but only the social worker who worked with seniors in the area was there. Luckily, she was a committed person and wrote a letter on official DSD paper asking the teachers to work with us and referred us to DSD's Child Protection Services.

We took the letter to DSD in downtown, where we brought the children and their older siblings. We met several social workers before finding the one who worked in the area where the teens lived and was willing to take the case. The teens and their older sisters explained the details of the situation, and the social worker arranged to do a home visit the following day to do the assessment needed to move the foster care grant. We arranged to meet him in the village.

The social worker actually did go and do the assessment, and the foster care grant was moved to the sisters. We followed up with the social worker every few days during this process.

Finally, we went to the police so that they could escort the teens to their home to get their ARVs, school books, uniforms, and other necessities. The police were confused and resistant about why they were needed to accompany us to the home and referred us to the victim support centre, where we did an intake. The victim support centre advocated for the police to accompany the teens into their home, and the teens were able to get their things safely.

We also arranged for the girl to get counselling at Masimanyane for the rape and abuse.

Some notes about working with DSD:

- to do any kind of removal that requires the moving of grants that not all members of a family agree with, you'll have to work with DSD. Their process involves doing a home visit where ostensibly they interview family members and neighbours to find out what is going on in the home and assess the home and whether it is decent for teens to be living in, then decide what to do with a child who is living in an abusive situation.
- the above case study was a dream in terms of working with DSD: we were assigned a social worker who wanted to make things happen, who had access to a work car and time he needed to do the visit, and everything moved very swiftly. This is often not the case. Depending on the office and year, DSD social workers either work by physical area (one per neighbourhood, roughly), or by jurisdiction (one for child protection, one for foster care grants, one for seniors, etc). Who you can work with will be constrained by this, and in our experience they usually aren't very flexible about it. It can still be useful to identify which social workers seem most knowledgeable and proactive. While they may not be able to actively take the case, they can offer advice and can advocate for you if things are moving slowly.
- your methods for working with social workers (and other gatekeepers) who are challenging to work with will be your own (we once had a PM shout, "God will hate you if you let this child die" – as a very last resort). Here are a few things we have done in the past:

    - start by being very humble and grateful. Thank them SO MUCH for the brilliant work they do. Tell them you are so very grateful that you have found them, etc.
    - mollify the office with cake! If something goes really well, also bring cake to the supervisor and tell them what a brilliant job the social worker did. (Only do this if

things are really good, or it can backfire. The supervisor knows which social workers generally get things done and which don't.)

- if someone is really not working and a child is at risk, let them know that if this continues, you will have to write a formal complaint. Explain that obviously you don't want to do this, but you job is to keep the children in your care as safe and well as possible. We have written several letters of complaint to supervising social workers and to the regional office, when the supervisor also wasn't helpful, and this has been the single most effective thing we've done to get our cases addressed by DSD. You can also write a formal complaint to the Social Service Professions Council – their website http://www.sacssp.co.za/Public/Lodge has a complaint section.