University of Cape Town

CENTRE FOR
SOCIAL SCIENCE RESEARCH

MAPPING WORKSHOP MANUAL
FINDING YOUR WAY THROUGH LIFE, SOCIETY AND HIV

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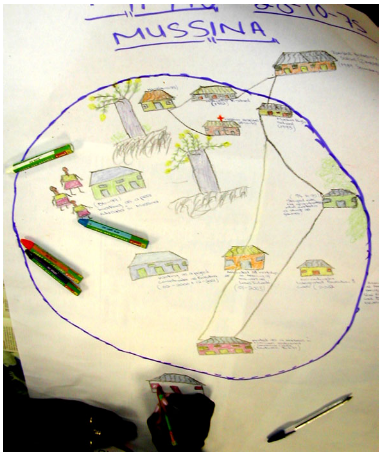
Mapping Workshop Manual



Finding your way through Life, Society and HIV

ASRU

AIDS and Society Research Unit
Centre for Social Science Research

UNIVERSITY OF CAPE TOWN

Disclaimer

The photos that feature in this workshop manual reflect a wide range of people in different contexts and their inclusion does not infer anything about HIV status.

Acknowledgements

This version of the manual was rewritten and redesigned primarily by: Colin Almeleh, March 2004

This manual is based on previous innovative work done by Jonathan Morgan, Lindsay Rabinowitz, Beatrice Were, Anya Subotsky, Kylie Thomas, Lisa Stratton and Colin Almeleh. The body mapping exercise draws on work done by Jane Solomon. Contributions have been made by Nicoli Nattrass, Lauren Kahn, Jo Stein, Jolene Skordis-Worrall, Margo Russell, Nondumiso Hlwele and the Bambanani Women's Group.

The Mapping Workshop Manual is a working document. It changes according to relevant research, and experiences running workshops in support groups.

Our work is supported by the Ford Foundation and Absolute Return for Kids.

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http://www.cssr.uct.ac.za/asru.html

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Introduction

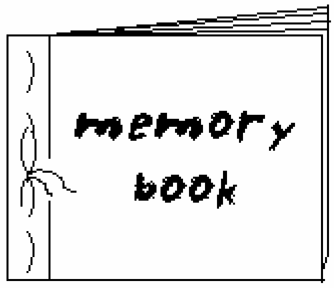
The tools described in this manual have been developed within the Memory Box Project, which is part of the Aids and Society Research Unit (ASRU), Centre for Social Science Research (CSSR) at the University of Cape Town. The manual is a working document which changes as our experience grows from working with HIV-positive support groups. It summarises the main "intervention tools" used by a group of Xhosa-speaking peer educators know as the A-team in ASRU. This *Mapping our Lives* initiative is designed to help people address the social challenges posed by HIV/AIDS.

Some of the tools in this manual draw on the tradition of "memory work". Memory work was begun by Carol Lindsay-Smith and a group of HIV positive mothers in Uganda who used Memory Books and boxes to help them disclose their positive status to their children, as well as to begin the process of future planning together.

The original direction of memory work in the HIV context pointed towards bereavement work and succession planning. This approach was and still is very pertinent to many social issues created by the HIV pandemic. However, this approach was developed in a situation where anti-retroviral treatment was just a fantasy, something that one could not imagine in the foreseeable future. The social context of the HIV pandemic is now quite different. Even though logistical problems continue to affect the roll-out of ARV treatment, more and more people *are* getting treatment every day.

The memory work of the past has now taken on a different spin. People living with HIV now have the opportunity to live increasingly productive lives. However, these opportunities are not straight forward. Rather, they are dependant on an enabling environment in which empowered and informed life choices can be made. The *Mapping our Lives* initiative in ASRU helps people in HIV-positive support groups grapple with the social constraints and possibilities which shape their lives. The various 'mapping' exercises are designed to encourage critical reflection, promote understanding, and lead to new insights about living positively.

The mapping tools are constantly being updated as we learn more about the social dimensions of the AIDS epidemic from our work in support groups. We thus particularly welcome criticism and advice from others using these tools. Please email us at membox@commerce.uct.ac.za with your comments and suggestions.



The Value of Peer Education[1]

The *Mapping our Lives* intervention is a form of peer education. Peer education settings, like our work in support groups, provide the space where individual opinions can be integrated into a social context, and therefore individuals can benefit from “an evolving group process”.[2] In this social setting, individuals contribute their own opinions whilst learning from the experience of others and listening to their opinions on similar topics. They can feel empowered to share their experiences, knowing that others are listening to learn.

> “Ideally, the peer education setting should be a microcosm of the ‘thinking society’, a term that refers to the way in which social identities and their associated recipes for living are collectively shaped through a combination of debate and argument in everyday-life contexts” (Campbell 2003: 48)

Behaviour change is a major focus of the *Mapping our Lives* intervention. Living positively with HIV is not easy, and people have to make concrete life decisions about how they are going to manage the virus and not let it determine their identities and control their lives. People living with HIV need to be empowered to make life choices that will support them to regain their health and become active members of society. They need proper nutrition, to manage their stress properly, to adhere to their treatment regimens and generally to take an active role in managing their health. However this is not so easy in disadvantaged socio-economic environments. People do not necessarily have control over important aspects of their lives. They are less able to make decisions that concern managing their health. As a result they are less likely to engage in health-enhancing behaviours.[3]

The peer educational setting, like the support group in which we work, provides a comfortable and supportive framework in which individuals can bounce their ideas, opinions and experiences off one another, can together analyse the pros and cons of particular behaviours, can develop substitute behaviours and partake in a decision

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[1] Written by Colin Almeleh
[2] Campbell (2002: 333).
[3] Bandura (1996).

making process whose discourse is created by the members of that particular group.[4] In this way, it can help people negotiate and shape (where possible) the social context which confronts them.

Narrative Therapy[5]

Story-telling is an important part of *Mapping our Lives*. In this regard, we have been influenced by a school of thought called Narrative Therapy. This way of working with people and their stories was pioneered by Michael White and David Epston and is common within disciplines such as social work, nursing, psychology, psychiatry etc. A story is a series of events linked across time by a theme or a narrative. This work tries to help people find empowering themes or "plots" in their own lives.

Each of the different aspects of the Journey Map, Body Map and Social Map allows participants to think about different part of their lives and to make sense of these in story form. Some people use all of the events depicted on the different maps or choose the most influential and important few to consider. Others have linked the distant past; beginning with a particular ancestor, to the present and others have included their hopes and fears about the future as part of the story.

In a similar way the memory exercises can be seen as projective instruments, a kind of blank screen onto which people project their inner worlds and minds. This might be interesting to them as well as to others, for example other people in a support group going through similar challenges, and to outsiders like researchers. Most importantly the exercise gives people a starting point to begin to plan their Body Map (i.e., how they want to represent themselves).

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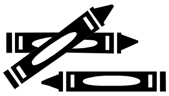
[4] Campbell (2002).
[5] This narrative therapy explanation draws on previous work by Jonathan Morgan.

Materials:

Below is a complete list of the materials that you will need for a workshop. If you are unable to get some of the materials you can improvise i.e. if you can not get large sheets of cardboard, you can stick old posters together and create the Body Map on this. Remember…**BE CREATIVE**

	Material	**Description**	**Quantity**	**Supplier**
1	Cardboard for book covers	2 pieces of cardboard for each book cover	1 per Person	Refuse bins, shops
2	Paper	Blank paper, or if your organisation has lots of paper that has been printed on one side, bring lots of it	Bring the equivalent of 2 reams of A4 Paper	Stationary Shops
4	Wax Crayons	Buy Crayola brand if you can, they are brighter colours and not much more expensive	1 small box of 10 for every 3 participants	Stationary Shops
5	Food colouring	A set of red, green, yellow and blue	Set of 4 for every 3 participants	Supermarket
6	Paint brushes	Very thin small ones that fit into food colouring bottles	4 for every 3 participants	Hardware shop
7	Pens	Cheapest pens	1 each	Stationary shops
8	Scissors	Small	1 for every 3 participants	Stationary shops
9	Sponges	Ordinary dish washing sponges with one rough side	5	Supermarket
10	Nails	10 cm nails	5 for every 3 participants	Hardware shop
11	Hammers	Cheapest hammers	1 for every 5 participants	Hardware shop
12	Paper clips	Regular without plastic coating preferably, any will do	1 packet	Stationary shops
13	String	Not too thick	1 ball per 20 participants	Stationary shops
14	Refuse bags		1 roll	Supermarket

15	Bottles of water to wash paint brushes and sponges			
16	Glue	Any glue that can stick to paper, you can even make it with flour and water	1 litre per 20 participants	
17	Name tags	A self adhesive sticker to write each person's name on	1 per participant	
18	Stanley knives	Those blades with a handle to cut book covers	1 for every 5 participants	Hardware shop
19	Lots of old newspapers	To work on so that participants don't make a mess		
20	Thick marker pens		1 per 3 participants	Stationary shops
21	Flip Chart		1	Stationary shops
22	Press Stick		1 packet	Supermarket
23	Body-sized sheets of paper or cardboard	For Body Mapping	1 per participant	Stationary shops Cardboard/paper suppliers



Workshop Planning

This manual contains a range of different intervention tools that can be used independently or, if time permits, can be used as the basis for a 15 – 20 session workshop. The decision as to which parts of the manual are needed, lies within the specific organisation that is employing the mapping workshop idea. Therefore the facilitator has a responsibility to get to know the community and support group participants, what are their issues and complexities, what is the social environment that precipitated the need for the intervention. This should be done prior to running a workshop. Through adequate and well-informed knowledge of a community and its people, the facilitator will be able to choose which techniques are the most beneficial for their specific context. For example, Body Maps focus heavily on the 'body as a museum of one's life' and therefore Body Mapping might be the most useful in a context such as HIV or violence, where the body has directly been affected by the experiences of the individual. If there is a need for the telling of stories and the recording of such, Memory Books and Journey Maps would be appropriate. If the facilitator is working in people's homes and space is limited, Memory Books would be appropriate.

This manual contains five modules:

- Journey Maps – 2 sessions
- Body Maps – 7 sessions
- Memory Books – 7 sessions
- Social Maps – 2 sessions
- Sexual and Reproductive Maps – 2 sessions

The facilitator must be totally aware of the social environment in which they work.

Thinking About Why? [6]

Facilitator: This activity aims to begin the process of getting the participants to reflect on their own lives and social environments. This idea is central to the mapping workshop. You as the facilitator need to encourage the workshop participants to engage with the social issues that shape their identities and possible life choices. That is why even before we are getting people to tell their life stories; we are encouraging them to think about the significance of story telling in the context of their social lives.

You need to listen carefully to what the participants say when discussing the questions below, as you need to refer back to their answers. That is why you are recording as much as possible on the flip chart. The questions in this activity are based on the participant's experiences regarding their cultural context and the people they are generally closest to i.e. the members of their families and/or households. The participants must feel a sense of ownership over the process they will be going through as well as the product they will be creating. You need to encourage them constantly to reflect and discuss relevant social issues and how they influence personal issues.

- Why do you think storytelling is important?
- Is storytelling an important part of your culture?
- Did your parents or grandparents tell you stories about their lives?
- Do you feel the need to tell your story? Why or why not?
- Can others learn from your life experiences?
- When you make a record of your own history (Memory Book, Body Map or Journey Map), what do you want to do with it?
- Are you going to show it to other people, your family, friends, or do you want to keep it a secret, like a personal diary?

Facilitator: You can use the responses on the flip-chart paper to get to know the group and their ideas better.

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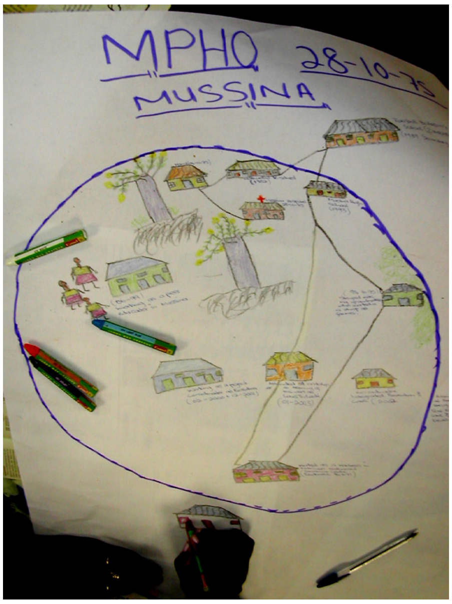
[6] Colin Almeleh

Journey Mapping[7]



The Journey Map encourages individuals to externalise their life stories and look at the key aspects of their lives in visual form. The mapping concept corresponds with the individual's life journey through time and space and the ways in which they, as individuals and part of the broader society, have grown and changed over the course of their lives.

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[7] This work draws from an original idea piloted by Jonathan Morgan and Jane Solomon with the !Xhun San people in Schmidsdrift, Kimberley, South Africa. It has subsequently been rewritten by Colin Almeleh, Anya Subotsky and Nondumiso Hlwele.

Materials**:**

- Pens
- Coloured pens, cokies, pencils, crayons
- A2/A3 paper (flipchart paper recommended)

Instructions:

Facilitator: Write these questions on the flipchart in front of the participants:

THINGS TO THINK ABOUT WHEN LOOKING AT THE DIFFERENT STAGES OF YOUR LIFE:

- What did you do in these places?
- How old were you?
- Who lived with you at this time and how are you related to each of them?
- What about this place or this time in your life has made you remember it?

On the large piece of paper you are now going to map out your life journey.

1. Start off by recording the place where you were born, and the date.
2. Mark the different places you have lived and where you have moved. Put a date to each place. Write why you moved to these places.
3. Where did you go to school? What kind of education have you received? Mark this on the Journey Map.
4. Where have you worked? Where have you looked for jobs? When did this take place? Mark this on your Journey Map.
5. What other travels or movement have you made? Have you been for a holiday somewhere? Did you do travelling for your work? Do you visit family or relatives somewhere? Mark this on the Journey Map.
6. Think about the different stages of your life. Which stages were happy and which were times of struggle and difficult.
7. Think of symbols to represent each phase. For example, a tree might represent a time in which you felt strong and full of growth. A storm cloud

might symbolise a time of struggle, and a medicine bottle might speak of illness or wellness.

8. When on your Journey Map did HIV come into your life? How did you find out? Try remembering the first thing that came into your mind when you found out your HIV status. Mark this place with the date and a description of what happened.
9. When you look at your journey map, how has HIV affected your life?
10. What things have you changed in your life because of HIV?
11. What have you done to live positively with HIV?
12. Think about how you feel at the moment. Look at the journey you have made to get to where you are today. Draw a picture representing how you feel about your life today.
13. You have made a long journey through many places and through times of struggle, triumph, happiness and sadness. Thinking about where you have come from and where you are now, draw a picture representing your future.
14. When you think about your life and look at it represented here, what stands out as the most shining moment or highlight for you? Mark this in the right place and right time. Draw a picture that represents this amazing time in your life.
15. What has been the most painful experience of your life? What steps did you take to overcome the painful experience? Mark this in the right place and right time. Try drawing a picture where you describe this experience.

Once you have finished all the instructions, add anything you want onto your Journey Map.

Facilitator: **Instruct the workshop participants to get into groups of 5. Everybody can have 5 – 10 minutes to share their Journey Map. Remember to encourage listening, support, confidentiality and caring so that people will feel comfortable to share their stories. You, as the workshop facilitator, must also listen carefully and give support to the storyteller.**

Body Mapping[8]

The Body Mapping exercise aims to assist participants to recognise and understand how their life story and HIV have affected their body: *within* and *without*. The body is like a museum of one's life. It records the life story through injuries, scars, birthmarks, illnesses, operations etc. Through a creative and visual process, the Body Mapping exercise aims to let people see how their body is affected by their world.

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[8] The basic Body Mapping activity was originally run by artist Jane Solomon with the Bambanani Women's Group for the Long Life Project in association with Medecins Sans Frontiers. This culminated in a book by Jonathan Morgan and the Bambanani Women's Group called "Long Life: Positive HIV Stories" (Double Storey, 2003). Since then it has evolved into its current form through learning from our workshop experiences in many different support groups. The version in this manual draws on experiences from Colin Almeleh, Anya Subotsky, Jonathan Morgan, Nondumiso Hlwele and the Bambanani Women's Group.

Facilitator: **Just remember: give the participants time to do all the activities. You as the facilitator must provide the framework for the participants to express their inner and outer selves onto the bodymaps.**

Instructions

1. Choose a partner.
2. Draw carefully around your partner's body with a black khoki on a big piece of cardboard.
3. Ask your partner to draw around your body on the same piece of cardboard.
4. Repeat the exercise on another piece of cardboard so your partner has his/her own Body Map to work on with you as the shadow.
5. Write your name and where and when you were born on the cardboard. Write this nice and big in a place outside of your outline.
6. Choose a colour to represent you and paint around the outline of your body.
7. Choose another colour and shade your partner everywhere they are outside the outline of your body.

Facilitator: **Ask the group these questions:**

- What is the significance of the shadow?
- Has there ever been somebody in your life that has consistently given you support through happy and sad times?
- Which of you ancestors might this shadow be?
- Write their name somewhere next to the shadow and write something about this person and how they influence your life.

Discuss this ancestor or person with the group.

8. Ink up/paint your hands and feet and stamp them where your hands and feet would be.
9. When you are feeling down or depressed where on your body do you feel your emotional pain? What part of your body gives you strength to overcome times

of struggle and strife? Feel where your place of personal power in your body is. Mark this place.

10. Choose a symbol to represent you. The symbol should represent your strengths and weaknesses. It could be a plant, and animal, an object, anything… It could also be a combination of a few symbols. Some people have drawn Table Mountain representing their ties to Southern Africa, others have drawn a fruit or vegetable, and some have drawn farm animals symbolising how their strength lies in the Eastern Cape. Sketch the symbol in rough on a piece of paper and thereafter paint or draw it onto your Body Map where you marked your place of personal power.
11. Draw the symbol of your clan, and write the name next to the drawing.

Everybody in the workshop can now share their symbols of power. They can share answers to the following questions:

- What have you drawn?
- Why did you choose that particular symbol?
- How does that symbol represent who you are?

Share a story from some time in your life, which gives meaning to the symbol you have chosen.

12. Using a mirror draw a small, five-minute self-portrait on a piece of paper.
13. Enlarge your drawing to life size in black ink or colours onto your face/body outline.
14. Close your eyes for one minute and try remembering your first memory. Somewhere on your Body Map paint/draw a picture of your first memory and describe it in a few words next to the picture.
15. Similarly to the Journey Map, now close your eyes and imagine your future. Draw/paint this future somewhere on the Body Map.
16. You must now think about your physical body and specifically your skin. Your body is like a museum, containing the all the marks that represent stories that have happened in your life. Notice all marks, birthmarks, beauty marks, scars, stretch marks, moles, pimples, rashes and wrinkles, wisdom lines, on your

body. Draw these marks onto your body in the correct places. Next to the mark write something about how it came to be there.

17. Feel where else in your body, underneath the skin you feel strong emotion, joy or pain. Maybe you have had an operation or some of your organs have been damaged for some reason. Mark these places using colours and patterns.
18. Have you had TB in your lungs? Do you have heart or liver problems? Which of the organs in your body tell a story? Find an anatomical drawing to use for reference if you don't know what the organ looks like. Write next to your body outline what happened there and when.
19. You can also show emotion on your Body Maps. A broken or joyful heart cannot be seen but it can be felt.

Facilitator: **We now take a break from painting to have a discussion about illness, wellness and HIV. The discussion will take up a full session. You must know the discussion guide well in order that you can facilitate a productive discussion. The rest of the Body Mapping process focuses on HIV and the discussion session will bring the issues concerning HIV into people's minds so that they can really express themselves on their Body Maps.**

Go to Appendix A at the end of the manual for the Discussion Guide

Carry on with the following instructions after the discussion session

20. Ask yourself how HIV has affected your body? Has HIV left scars? What has happened to your skin? What opportunistic infections have you experienced and what did you do to heal yourself?
    Discuss amongst the entire group how you think HIV is working in your body. What is it doing? How is the HIV interacting with your blood?

21. Locate the organs and parts of your body that have been affected by HIV related illnesses the most. Mark these on your Body Map using a picture and a description. Draw these in their correct places on your Body Map.

Facilitator: Draw this table on the flip chart for the participants to see:

Stage 2	**Stage 3**	**Stage 4**
Weight loss	Chronic diarrhoea	Severe disease
Coughs	Lasting fevers	AIDS
Flu	Thrush	Meningitis
Colds	TB (tuberculosis)	Pneumonia
		Kaposi’s Sarcoma

22. Write next to each illness, side-effect or opportunistic infection what you did to control the symptoms or heal yourself.

23. This is your Body Map so feel free to add any other details, colours or patterns that have special meaning to you.

24. For the last activity, you must create a key that explains what you have drawn/painted/written on your Body Map.

The key should include:

- Your symbol of personal power.
- How and why you represented HIV on the Body Map.
- The opportunistic infections that you drew.
- Why you think you got HIV.
- Any other important areas on the Body Map that you would like to explain.

How do you feel about your Body Map self?
When you look at your Body Map, what kind of person do you see?

Prepare a 5-10 minute presentation of your Body Map. Remember that everybody in your group is sharing their stories, and they will appreciate your listening carefully and giving them support while they tell their stories.

Memory Books[9]

The Memory Book has proved to be a popular and important tool. The facilitator needs to stress once again that the participant who creates the book or any other product has the choice over what happens to the end product. Deciding what to do with the book is in itself a good discussion to have with the participants. Issues around stigma, secrecy and disclosure might come up in the discussion. This is exactly what the workshops are about: engaging with people's thoughts, feelings, opinions, experiences and ideas about life. Workshop participants are able to take their books home and work on them with their family and friends, or hide them under their beds if they choose to.

The difference between the Journey Map and the Memory Book is that the Memory Book is more focussed on the entire experiences of the person. As you will see in the Memory Book, the participants choose the 6 most important events, periods, people or places in their lives, and they write down and record the entire stories. All the extra pieces of paper that are written on during exercises involving Body Maps, Journey Maps, Social Maps and discussions, can be stuck in the Memory Book

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[9] The Memory Book and specifically the windows exercise originates from previous work completed by Morgan, J. and the Great African Spider Writers, 1999, *Finding Mr. Madini,* David Phillip Publishers: Cape Town. Kylie Thomas contributed to the original ideas when she worked at ASRU in 2001. The Memory Book activity as described in this manual is largely based on Morgan's work while he was the director of the Memory Box Project (2001 – 2003).

Exercise 1: How to make a Memory Book

Materials:

- 2 pieces of cardboard for the back and front covers
- A4 paper for the pages
- piece of string or wool
- paper clip
- 4/5 long thick nails
- hammer.

Facilitator:

Making the book:

You need to have made at least one Memory Book prior to the workshop, so you can bring the book as an example. You can introduce yourself through your Memory Book. This demonstrates the trust the facilitator has in the group, which can have positive benefits for the level of confidentiality the group feels towards the other participants in the group.

The facilitator needs to make one book with the group as a demonstration and this can be used as an evaluation book for the workshop. After each day, the participants can write a small evaluation of the day, and this can be stuck in to the group book.

1. Decide on the size of your book and cut out a cover using two pieces of cardboard.
2. Decide how many pages you want and put them in between the covers.
3. The next step is bookbinding. Square up the pages and the cover. Take a nail, and hammer it through both covers and all the pages about 3cm from the edge.
4. Leave that nail in and make about 4 or 5 holes in line with the first hole.
5. Take the paper clip and bend it into a needle and then thread the string through the holes till the book is bound. Tie a knot in the string.

Exercise 2: Drawing Techniques

Materials:

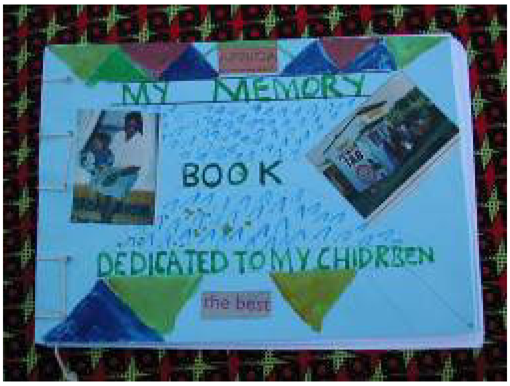
- wax crayons
- liquid food colouring
- paintbrushes.

Facilitator:

Writing in the book:

You need to demonstrate the drawing technique so that the participants are clear and can ask questions if they need help.

1. Draw or write pressing quite hard with the wax crayon.
2. Paint over your drawing with the food colouring.
3. See how the wax doesn't allow the food colouring to be absorbed into the paper and the great effect this creates. Experiment with different colours.
4. This technique can be used on other pages. Writing with a white crayon and then painting over the words with food colouring works really well.
5. You can write your name on the cover of your book if you want to or you can just draw an image to decorate the cover and front page.



Facilitator:

Dedicating the book:

You need to explain what a dedication is. In the case of Memory Books, the dedication gives social meaning to the book. The author is not just making the book for him/herself, but has other people in mind, even if the author decides not to show the book to anybody. It is symbolic of the author getting their story out into the open.

The facilitator might say:

If you go to a library and open up a few books, you might see something like this,

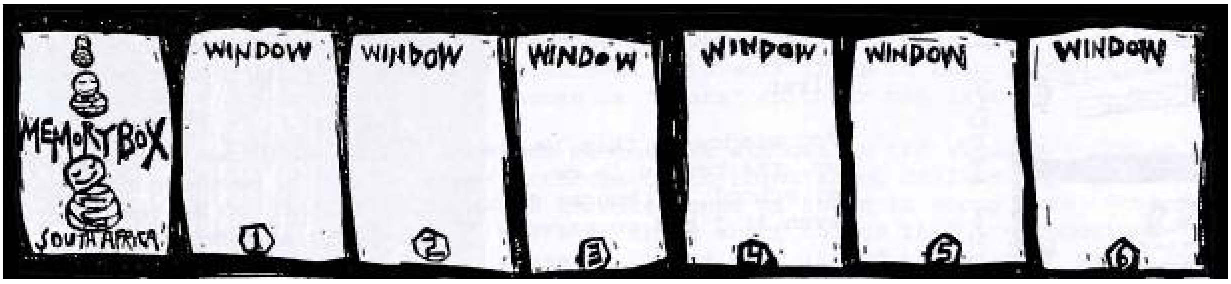
- “This book is dedicated to my mother and my father, may they rest in peace.”
- “This book is dedicated to my children, may they be safe and happy forever.”
- “This book is dedicated to me, myself and I. May we achieve great things”

Facilitator:

Give the participants some time to decorate their dedication. You may ask whether they would like to share their dedications with the group.

Exercise 3: Windows

Facilitator: When making a book, these windows can help the participant decide which stories and parts of your life they want to draw and write about. Just like a book has a contents page that shows all the main sections of the book, so the WINDOWS are like a contents page of life.



This is one way for the facilitator to introduce the windows exercise: READ OUT

"Your life is big but your book is small. You cannot fit your whole story into it. Which stories or parts of your life do you want to begin with? These windows might help you decide. Each window is a story about you or a part of your life. Maybe you want to begin with NOW or maybe you want to look at your HISTORY. You can write a heading, or draw a small picture in each of the six windows."

Below is an example of somebody's windows from their Memory Book:

Busi explained her windows as follows:

PLOT/ THE FIGHTING SPIRIT EVEN WHEN THINGS ARE MORE TOUGH.

- For window 1, I drew when I was 5 years old, as you can see the person looks sad, it was when my troubles started.
- For window 2, I drew a book, it symbolises when I started school, I was so excited, the family who adopted me bought me a uniform and the mother of the house accompanied me to school, I was good at school and in Standard 5 I started to come first.
- For window 3, this is a step ladder with the arrows going up, the person is me, I was starting to make good progress at school, I thought I would get to the top of the ladder, even if I had no parents I would have an education.
- For window 4, the arrows are going down, I draw myself the day I had to leave school, the family was not treating me well, like a slave in fact, I went to Gauteng to someone I thought would be kind to me but she was not, but I really wanted to go to school, so I explained my condition to a principal and a teacher offered to pay my fees for standard 7 and 8. For standard 9 she couldn't so I went to Cape Town and worked in a restaurant, and in '94 I went back to school paying my own fees.
- For window 5, I have drawn a shadow, I got diagnosed and when I heard that me and my child were positive I just sat down and said maybe I should just give up and wait for my dying day, I was confused I was studying for a better life then this HIV thing came in.
- For window 6, when I joined TAC, my life changed, I became a hopeful person, that's why my arms are like that, the confusion and the shadow went away.

Exercise 4: The Plot

Facilitator: Below is an easy and clear explanation of the Plot. Explain this to the participants.

“The plot is something like a common thread or a story line that runs through all the windows. Often, when we think about our lives, we think about what a battle it is. It is also easy to feel like we are losing that battle or that struggle. In Narrative Therapy and Memory work, we try to help people to recognise ways in which they are not only losing and not only victims, but also survivors and winners and heroes in their own special way. Looking for these kinds of stories in their windows is called ‘finding empowering plots’. There are different ways you can get to the plot”. (Jonathan Morgan)

Instructions:

1. Look at all of your windows; think about a theme that runs through them. Write it down or say it out loud to yourself.
2. Ask yourself why you chose the windows you chose. The answer might be a kind of plot.
3. Share your windows with another person, then ask them to write or say what plot they think runs through your story. Compare the two plots and discuss. Remember we all have multi-storied and multi-plotted lives.
4. For example, somebody might look at the six windows and say, “I chose these because they all remind me of my courage.”

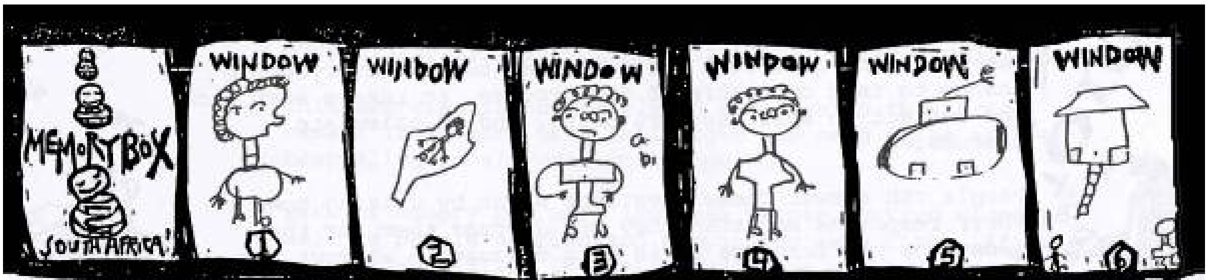
Another good way to get to the plot is to look at the windows and begin with the words,

This is a story about ……………

Here are some examples:

- *… a boy who always had hope, and who could see light even when it seemed very dark.*
- *… courage and a girl who had lots of it.*
- *… a family who supported each other so much.*
- *… me and my family and how we respect one another.*
- *… a woman who never likes to give up.*

Here are Victoria’s windows as well as the **plot** she identified for herself:



PLOT/ In My Life I always fight what ever there's a good things and, up with fight But I survive with fighting.

For window 1, I drew when I was pregnant in 1995.

For window 2, I drew a coffin box for my first child who passed away in 1996.

For window 3, I drew myself going back to school after that.

For window 4, I drew myself when I was in Cape Town.

For window 5, I drew a radio; I love to listen to Gospel music.

For window 6, I drew me and my child in my house, we are playing outside.

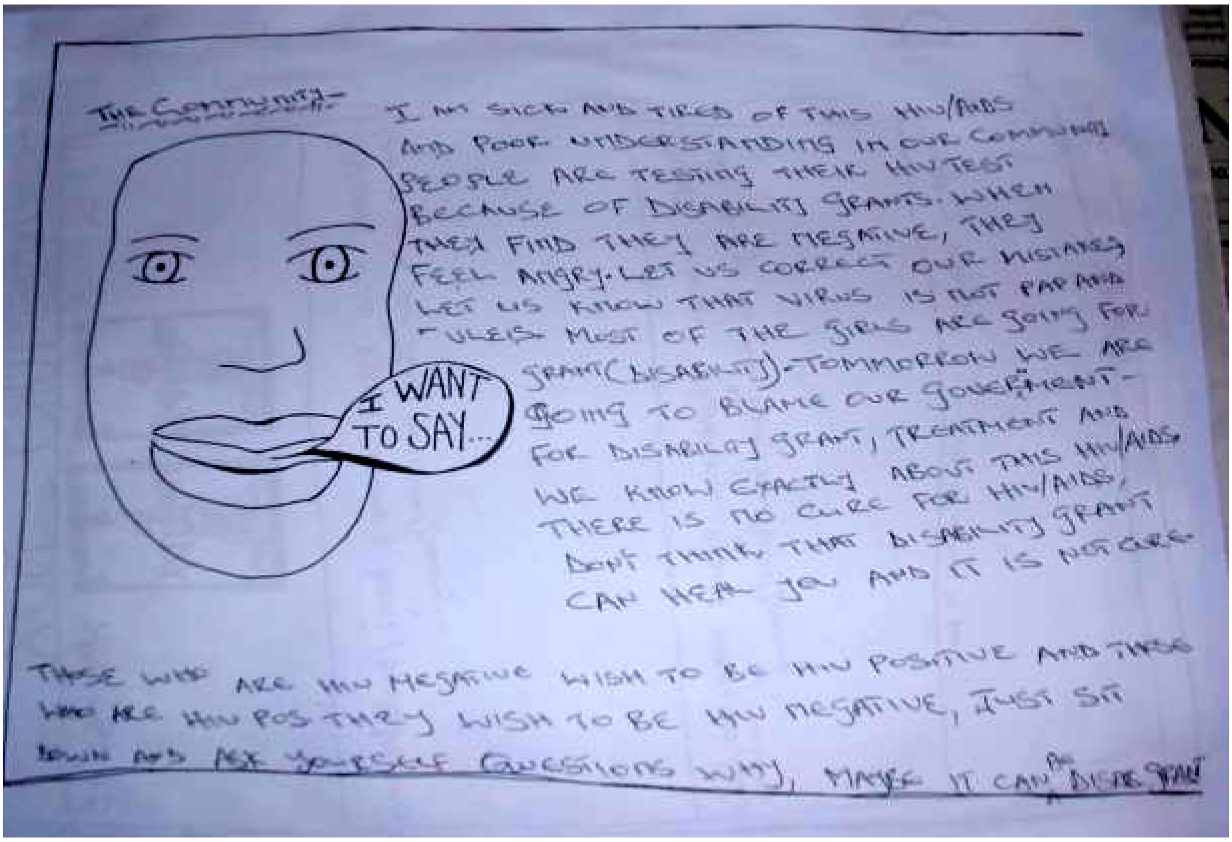
Exercise 5: Zooming a Window

This exercise gives people the opportunity to really tell the whole story that is represented by a picture, symbol or a few words in the windows. ZOOMING a window means expanding that symbol or key word into a larger picture or story. This exercise is important because it gives people a chance to think about their life experiences in more depth. The story from just one window might grow to be many pages long. Encourage the workshop participants to expand each of the windows. They may not have time during the workshop, so they can take their Memory Books home and work on them there.

Exercise 6: I want to say…

Facilitator: This is a good open prompt that allows the participant to express what is important for them. The facilitator should encourage the participants to really ‘speak their minds’ and to feel free to say anything that they feel strongly about.

Somebody in Pretoria wrote the following in response to this prompt:



THE COMMUNITY

I AM SICK AND TIRED OF THIS HIV/AIDS
AND POOR UNDERSTANDING IN OUR COMMUNITY
PEOPLE ARE TESTING THEIR HIV TEST
BECAUSE OF DISABILITY GRANTS. WHEN
THEY FIND THEY ARE NEGATIVE, THEY
FEEL ANGRY. LET US CORRECT OUR MISTAKES
LET US KNOW THAT VIRUS IS NOT FAR AND
-ULEIS. MOST OF THE GIRLS ARE GOING FOR
GRANT (DISABILITY). TOMMORROW WE ARE
GOING TO BLAME OUR GOVERNMENT -
FOR DISABILITY GRANT, TREATMENT AND
WE KNOW EXACTLY ABOUT THIS HIV/AIDS,
THERE IS NO CURE FOR HIV/AIDS,
DON'T THINK THAT DISABILITY GRANT
CAN HEAL YOU AND IT IS NOT CURE

THOSE WHO ARE HIV NEGATIVE WISH TO BE HIV POSITIVE AND THOSE
WHO ARE HIV POS THEY WISH TO BE HIV NEGATIVE, JUST SIT
DOWN AND ASK YOURSELF QUESTIONS WHY, MAYBE IT CAN BE DISAB GRANT

Disclosure and Social Maps[10]

The disclosure and Social Mapping activity encourages people to engage with the issues surrounding disclosure of their HIV status and their experiences of stigma. Disclosure is an extremely complex issue that is not very well understood. Every individual's social environment is different and people's identity and actions change according to any given context. Therefore facilitators of interventions cannot be sure that encouraging or discouraging disclosure is the correct way forward. One can never predict the consequences of disclosing one's HIV status as there are other people involved in the situation and they might react in diverse ways.

The disclosure and Social Mapping activity aims to get people to make their own informed and thought-out decisions on whether to disclose or not. We hope to do this through a collective process of thinking about the possible different kinds of support available; emotional, financial, psychological, material, social, and health-related support. The activity encourages discussion about people's experiences of stigmatising behaviour towards them and how this might affect their possibilities of disclosure.

We do not just want the negative experiences of disclosure to be the focus of the discussion, as in many cases people have received excellent support, and have found it easier to live positively with HIV. People get help with treatment, looking after their children, children understand the health of their parents, sexual partners know that they need to use condoms etc. We want people to decide for themselves why or why not they should disclose, knowing that there is no given solution. There are many benefits and risks when disclosing one's HIV status and it is important that the workshop participants learn from each other's different experiences.

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[10] The disclosure and social maps were conceived by Colin Almeleh, Nicoli Nattrass, Lauren Kahn, Nondumiso Hlwele and Margo Russell, with contributions from participants at a workshop for Voluntary Services Overseas.

Instructions for the Disclosure and Social Mapping Session

1. Ask participants to draw 3 concentric circles on a piece of flip chart paper (A2). See **APPENDIX B**
2. Ask participants to fill in their name in the inner-most circle.
3. Ask the participants to fill in their date of diagnosis next to their names.
4. Then, on a piece of A4 paper, ask them to fill in the names of at least 15 people that play a role in their lives. Then, next to the person's name, they should rank the person on a scale of 1 – 3: 1 very important, 2 important, 3 not so important.
5. They should then fill in these peoples names on the sheet of flip chart paper within the appropriate circle.
6. Instruct them to write a brief description of the person i.e. nurse, policeman, husband, boyfriend, girlfriend, mother, brother, sister, neighbour, cousin, work colleague etc.
7. They should then write where these people are located i.e. in their household, in Cape Town, in the Eastern Cape etc.
8. Instruct the participants to fill in on the paper the names of places that play a role in their lives, e.g. clinic, police station, work, support group, home in Eastern Cape etc.
9. Ask the participants to draw small red circles around the people they have disclosed to and the places where they have disclosed.
10. Fill in the dates when disclosure took place with the different people.
11. In a different colour ask the participants to draw circles around the people they would like to disclose to.

Facilitator: Divide the group into smaller groups of 3. Then initiate a discussion around **disclosure.** Below is a list of questions that should be asked to the participants while they are in the smaller groups. Give everybody a few minutes to answer each question. At the end of each section, ask if anybody wants to talk about their discussions with the bigger group. You must encourage openness and support. You need to be aware of the individuals that are finding the activity emotional or difficult.

Discussion Questions:

1. Begin the discussion by asking the group to look carefully at their Social Maps.
2. Who have they put as the most important people or places in their lives?
3. Have they disclosed to the most important people or the least important people?
4. Why have they disclosed to these people?
5. What were the benefits or negative consequences of disclosing?
6. Who on the chart have they not disclosed to?
7. Why have they not disclosed to these people?
8. Have they disclosed to their partners?
9. Why or why not?
10. Who do they want to disclose to in the future?
11. Why do they want to disclose to these people?
12. What kind of support do they feel they will receive if they disclose?
13. What kind of environment would they feel comfortable to disclose in?
14. Where can they find that environment or how can they create it?

Facilitator:

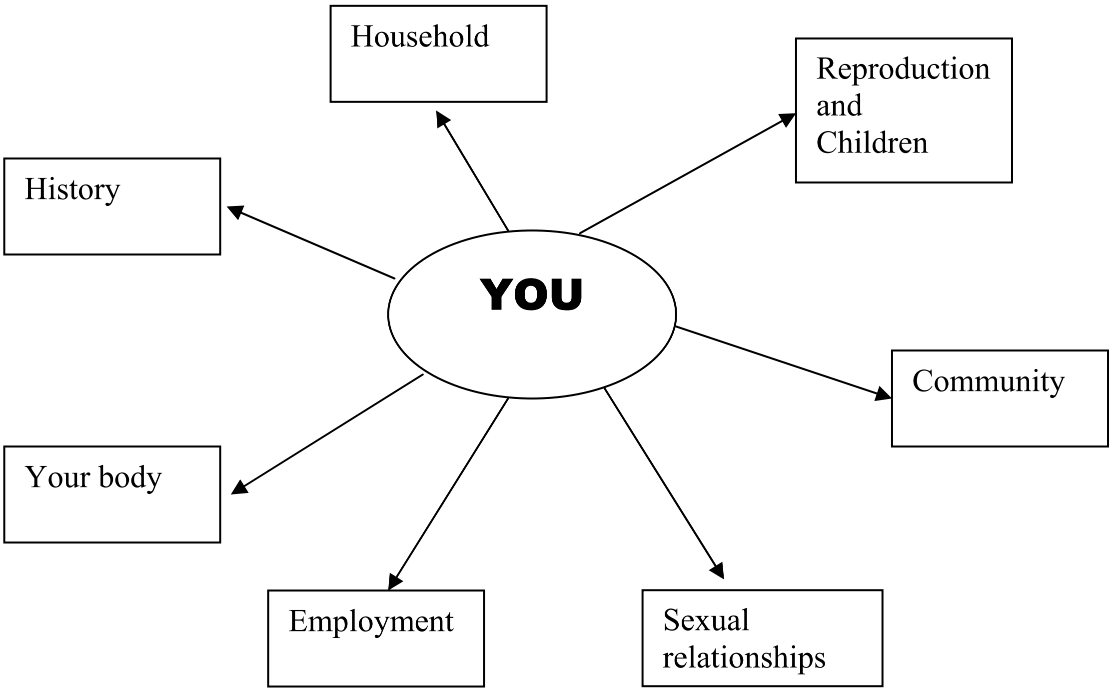
Writing in the book:

When the participants have finished the discussion, they should be encouraged to keep a section of the Memory Book that is dedicated to disclosure. They should write in the book some of their experiences of disclosure. They should also write whether they have experienced some form of stigma or discrimination because they are HIV positive.

You should encourage the participants to write how they felt about listening to other people’s experiences of disclosure and stigma, and what this means to them.

Sexual and Reproductive Journey[11]

In our lives, we move between and are shaped by a variety of social contexts:



Each of these different contexts and factors contribute to the experiences that you have been through during your life. They are all important and that is why we do Body Maps, Journey Maps, Memory Books, Social Maps and sexual and reproductive maps.

However, within each context, we do not exist alone: we are always positioned in relation to others. How we come to be who we are, how we see and experience the world around us, and how we experience ourselves can be shaped profoundly by the relationships in which we are positioned.

Even certain aspects of ourselves that we seem to have in common with others – for example, being a woman, a mother, having an HIV positive status – may be

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[11] Written by Lauren Kahn and Colin Almeleh with valuable input from the Bambanani Women's Group. This tool is currently being piloted and developed. There will be changes as we learn from our experience in support groups, and the manual will be updated on our website.

experienced very differently simply because of how we stand in relation to those around us.

Our **sexual relationships** seem to be one of the most complex relationships in which we stand, and influence a variety of **important aspects** of our lives. Our sexual partners can often serve to EMPOWER or, alternatively, DISEMPOWER us on personal [psychological and physical], social and economic levels, depending on what role they play in the spheres of our lives in which our sexual relationships play out.

Facilitator:
We need participants to start thinking about how their sexual relationships influence their lives, and many important life decisions that they may need to make. In order to start this process of thought, do the following exercise with the group:

Draw a diagram that shows all the aspects of their lives that the group feel are affected by their sexual relationships / affect their sexual relationships. [See **Appendix D** at the end of the manual for an example of the diagram that can be used as a guide if the group is lacking in ideas / uncertain of task]

Discussion Guide:

In each aspect of their lives identified by the group, the participants are positioned in a relationship of power with their sexual partner. Sometimes we share power equally, but sometimes we have more or less power than our partner in certain contexts.

- Look at each aspect of their lives that the group has identified, and try to draw out what issues come up with respect to their sexual relationships.

- Try to get the participants to discuss, in general and from their own experiences, how the group feel they stand in relation to their sexual partner in each context *in terms of how power is shared:*

- Who has power? [to make important decisions and choices / to take important actions]
- Who does not?
- How does this affect them? [positively / negatively on psychological/physical/social/material/economic levels]
- This can be done by using the guiding questions in each box if there is difficulty or confusion. Note that sometimes the issues in one aspect of life will overlap with issues in other contexts.

A good way to start the discussion is to draw attention to issues of power between a MAN and a WOMAN in sexual relationships:

- Try to get the participants to discuss how power is shared between men and women in sexual relationships. Participants should be encouraged to talk about how they think sexual relationships play out in their community IN GENERAL, and the types of roles and responsibilities that men and women are expected to hold
- In each box above, think about how men and women share power, stand in certain roles and hold certain responsibilities / expectations of each other.
- NOTE: It is not necessary for participants to talk about their own personal experiences yet. The discussion is aimed at making the group feel comfortable with the topic and to start ideas flowing.

This is important, as it will draw attention to aspects of our daily personal lives that often go by unnoticed – BUT also often have a great effect upon our power to make life decisions. If we can get people to think about these issues, they may become aware of aspects of their [sexual] relationships that are actually taking away personal freedom, rights and power to make decisions that benefit them – in terms of their physical health, access to material and social resources and emotional well-being.

After doing this exercise:

Try to get an idea of how the participants felt about the topic itself by asking the following questions:

- Do you feel that sexual relationships are an important part of people's lives?
- Why?
- Do you feel that it is important to give attention to aspects of sexual relationships that we have just discussed?
- Why?

Try to bring HIV into the discussion:

The majority of infection with HIV in South Africa is caused by unsafe sexual intercourse. Many people become infected within a sexual relationship. Thinking about where they stand in their sexual relationships may lead participants to start thinking about how and why they came to be infected, and also about how their status is affecting their current sexual relationships, and feelings about these relationships. In order to get these sorts of ideas flowing, which will be useful when participants map their private/personal sexual journeys:

- Do people come to be infected with HIV because of the power at play in our sexual relationships?
- Does a positive diagnosis change a relationship?
- Many people say that they are scared to get into sexual relationships because they have HIV. How do you feel about this?

Appendix A[12]

Discussion Guide

Facilitator: Please ensure that the participants feel comfortable, and understand that there are no right or wrong answers. We are only interested in their opinions etc.

1. Health status (10 min)

Facilitator: We would like to understand how people stay healthy and which elements of their lifestyle might put them at risk of disease.

Please read:

We all get sick now and again but some times are worse than others. There are some things in our lives that increase our chance of getting sick and there are some things that help us to stay well. I would like you to think about your lives for a minute and think about these things.

Facilitator: Please divide a page on the flip chart into two columns, one for 'Makes us unhealthy/sick' and another for 'Keeps us healthy'. Record the following discussion on this page.

Discuss:

- What might make you sick
- What might stop you from getting sick

Probe HOW these things make us sick/well

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[12] The HIV discussion guide was adapted from a discussion guide used by Jolene Skordis-Worrall for her health-economics research on tuberculosis.

2. Personal health-seeking behaviour (15 min)

Facilitator: We need participants to talk through their last illness experience step by step. Some illnesses may be of a personal nature and participants need to be reassured that if they are uncomfortable, they do not need to name the problem.

Probe:

I would like you to think about the last time you were ill…

- How long ago was this?
- How did you know you were ill?
- Did you tell anyone that you were not feeling well?
- How did they react?
- Were you able to carry on with your normal responsibilities while you were sick?
- Did anyone inside your household help you with your job or your chores while you were sick? **Probe whether this is 'normal' or exceptional behaviour.**
- Did anyone outside your household help you with your job or your chores while you were sick? **Probe for NGOs and broader community organisations**

Facilitator: We are aware that people may try different things to feel better and we need to understand this process step by step.

Discuss:

Sometimes when we are sick, we have to try different things before we feel better. I would like you to think about all the things you did to feel better the last time you were sick.

- What was the first thing you did? And next? And next? Why? **NB NB NB This process is very important!!**
- How did you know what to do?
- Did you take any medicine? Where did it come from?
- Did you have to pay any money to get well? Where did this money come from?
- Do you think you should have done anything differently?

3. Perceptions of illness (15 min)

Facilitator: Please take care; someone in the group may have suffered from an illness that another member considers ‘distasteful’ you need to be on the lookout for these sorts of tensions.

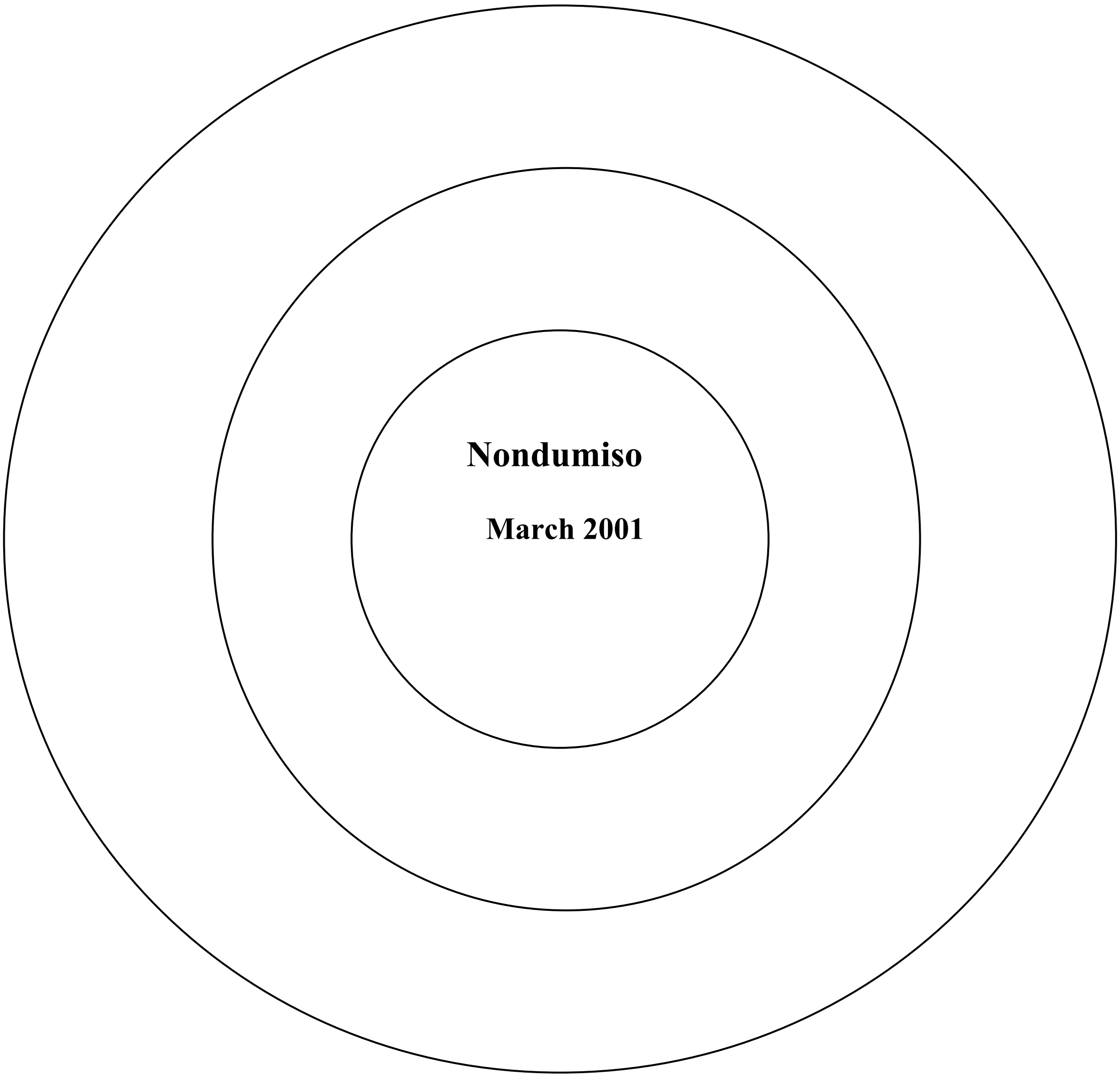
Discuss:

Some sicknesses are very common and some sicknesses are very rare. Thinking now about yourself, your family and your community;

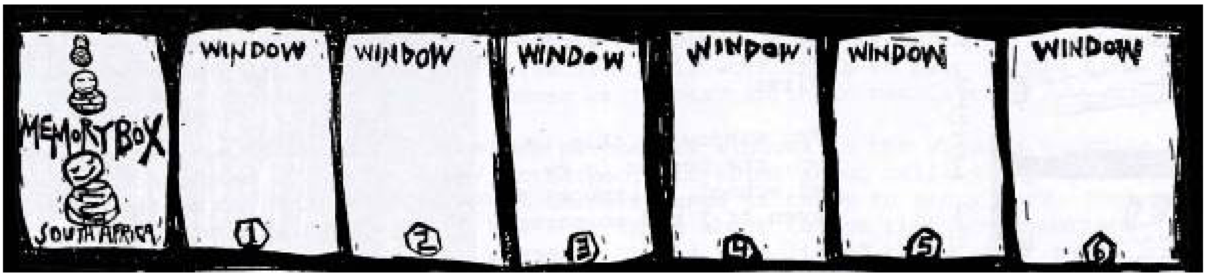
- Which illnesses would you say are very common? **Record on flip chart**
- Which illnesses would you say are very rare? **Record on flip chart**
- What illnesses do you and your family fear most? **Why?**
- What illness do you and your family fear least? **Why?**
- Would you be to blame if you caught any of these illnesses? **Which? Why?**
- Would any of these illnesses prevent people from speaking to you or treating you normally? **Which? Why? How?**

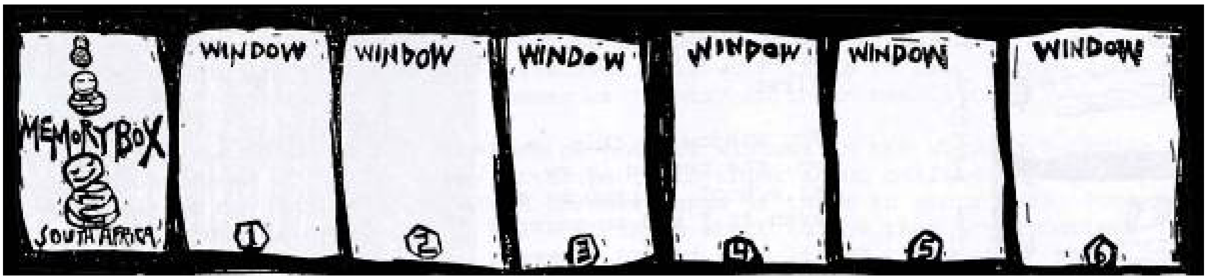
Facilitator: Once you have finished the discussion and all the information has been recorded on the flipchart, encourage the participants to ask any questions and make any comments.

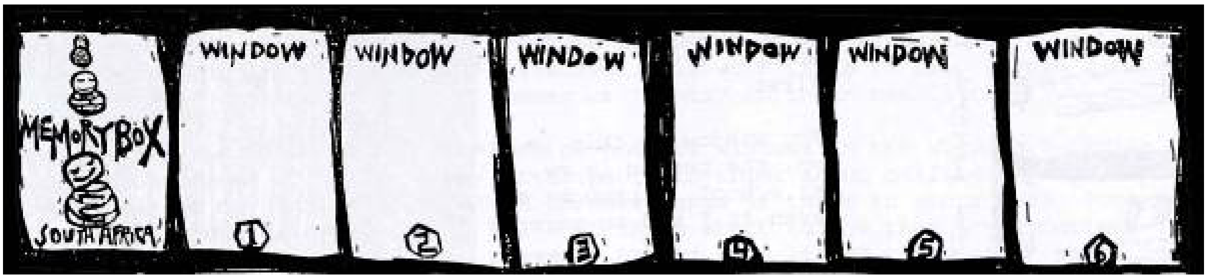
Appendix B



Appendix C


MEMORY BOX
SOUTH AFRICA
WINDOW 1
WINDOW 2
WINDOW 3
WINDOW 4
WINDOW 5
WINDOW 6


MEMORY BOX
SOUTH AFRICA
WINDOW 1
WINDOW 2
WINDOW 3
WINDOW 4
WINDOW 5
WINDOW 6


MEMORY BOX
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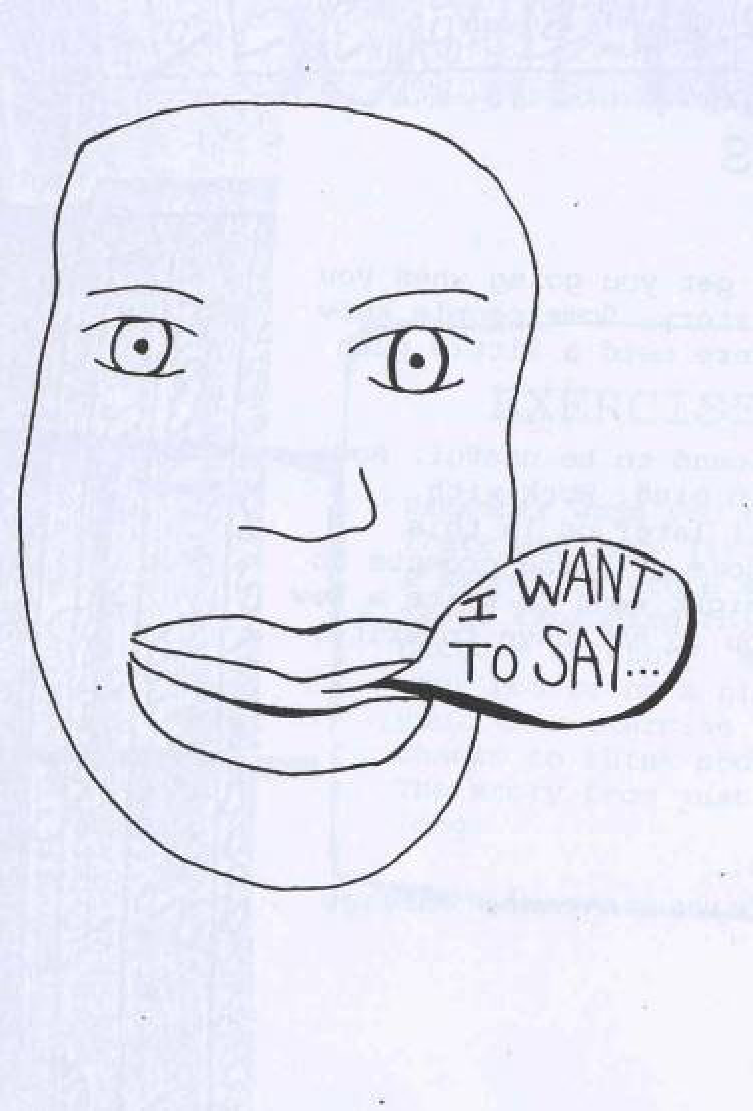
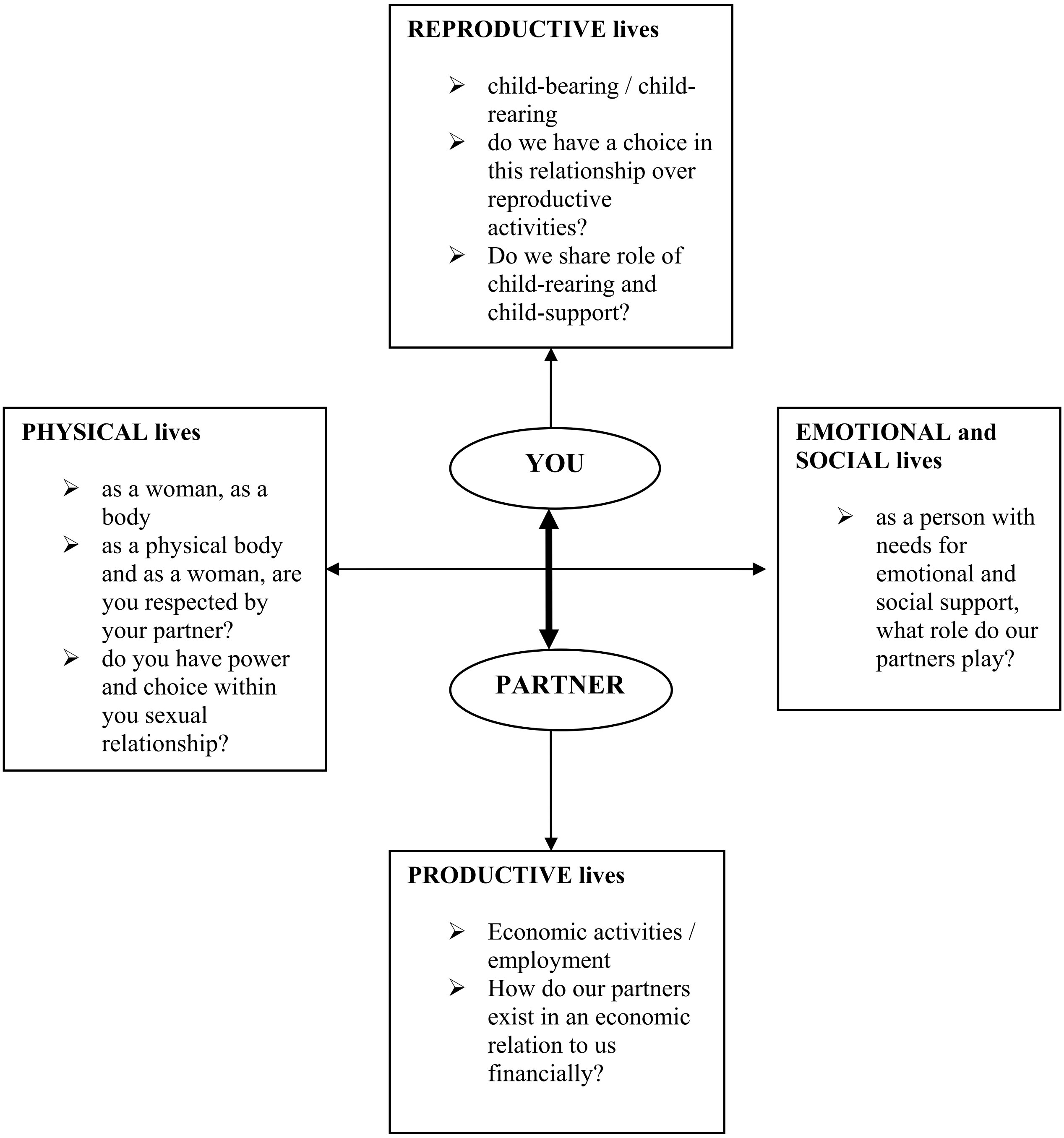
WINDOW 1
WINDOW 2
WINDOW 3
WINDOW 4
WINDOW 5
WINDOW 6


I WANT TO SAY...

Appendix D



REPRODUCTIVE lives

- child-bearing / child-rearing
- do we have a choice in this relationship over reproductive activities?
- Do we share role of child-rearing and child-support?

PHYSICAL lives

- as a woman, as a body
- as a physical body and as a woman, are you respected by your partner?
- do you have power and choice within you sexual relationship?

YOU

PARTNER

EMOTIONAL and SOCIAL lives

- as a person with needs for emotional and social support, what role do our partners play?

PRODUCTIVE lives

- Economic activities / employment
- How do our partners exist in an economic relation to us financially?

The Centre for Social Science Research

The CSSR is an umbrella organisation comprising five units:

The Aids and Society Research Unit (ASRU) supports quantitative and qualitative research into the social and economic impact of the HIV pandemic in Southern Africa. Focus areas include: the economics of reducing mother to child transmission of HIV, the impact of HIV on firms and households; and psychological aspects of HIV infection and prevention. ASRU operates an outreach programme in Khayelitsha (the Memory Box Project) which provides training and counselling for HIV positive people

The Data First Resource Unit ('Data First') provides training and resources for research. Its main functions are: 1) to provide access to digital data resources and specialised published material; 2) to facilitate the collection, exchange and use of data sets on a collaborative basis; 3) to provide basic and advanced training in data analysis; 4) the ongoing development of a web site to disseminate data and research output.

The Democracy in Africa Research Unit (DARU) supports students and scholars who conduct systematic research in the following three areas: 1) public opinion and political culture in Africa and its role in democratisation and consolidation; 2) elections and voting in Africa; and 3) the impact of the HIV/AIDS pandemic on democratisation in Southern Africa. DARU has developed close working relationships with projects such as the Afrobarometer (a cross national survey of public opinion in fifteen African countries), the Comparative National Elections Project, and the Health Economics and AIDS Research Unit at the University of Natal.

The Social Surveys Unit (SSU) promotes critical analysis of the methodology, ethics and results of South African social science research. One core activity is the Cape Area Panel Study of young adults in Cape Town. This study follows 4800 young people as they move from school into the labour market and adulthood. The SSU is also planning a survey for 2004 on aspects of social capital, crime, and attitudes toward inequality.

The Southern Africa Labour and Development Research Unit (SALDRU) was established in 1975 as part of the School of Economics and joined the CSSR in 2002. SALDRU conducted the first national household survey in 1993 (the Project for Statistics on Living Standards and Development). More recently, SALDRU ran the Langeberg Integrated Family survey (1999) and the Khayelitsha/Mitchell's Plain Survey (2000). Current projects include research on public works programmes, poverty and inequality.