

“... And then it Becomes Complete”

## ORAL HISTORY The Process, The Product



*When you look at a photograph, you see how a person looks. When you read their quotations, you see the heart of the person, and then it becomes complete.*

Bernard K. Punikai'a, IDEA, Hawaii

Produced by the Oral History Project  
a division of The International Leprosy Association  
Global Project on the History of Leprosy

in association with

The IDEA Center for the Voices of Humanity

The Nippon Foundation



Cover Photo:

Bernard K. Punikai'a, with schoolchildren at the *Quest for Dignity Exhibit*, on display at Honolulu City Hall, Hawaii, in 1997. This Exhibit is almost entirely made up of quotations from oral history interviews, poetry and writings of individuals who have personally faced the challenges of leprosy or experienced other deep personal tragedy or loss. *Photo by Pamela Parlapiano*

All photographers retain their own copyright.

## **A History Built Around People**

*Oral history is a history built around people. It thrusts life into history itself and it widens its scope. It allows heroes not just from the leaders but from the unknown majority of the people. It helps the less privileged and especially the old, towards dignity and self-confidence. It makes for contact and thence understanding between social classes and between generations . . .*

-- Paul Thompson, *Oral History: The Voice of the Past*

*. . . . the most distinctive contribution of oral history has been to include within the historical record the experiences and perspectives of groups of people who might otherwise have been 'hidden from history' . . .*

-- Robert Perks & Alistair Thomson, *The Oral History Reader*



Guo Hua listens to the life experiences of Chen Su, age 93, the oldest resident of Taihe Hospital, P.R. China, 2003. *Photo by Pamela Parla-*

## **Introduction**

*Oral history should be a way to get a better history, a more critical history, a more conscious history which involves members of the public in the creation of their own history.*

-- Ronald J. Grele, *Envelopes of Sound: The Art of Oral History*

IDEA, the International Association for Integration, Dignity & Economic Advancement, is an international advocacy organization and network of support for individuals who have personally faced the challenges of leprosy. Members of IDEA have conducted more than 300 hours of oral history with individuals who have personally faced the challenges of leprosy from around the world over the last 25 years. Extensive interviews have also been conducted with family members, health professionals and others who have worked in the field of leprosy.

These guidelines for conducting oral history have not been designed as a step-by-step process on how to conduct oral history. Numerous websites and publications already exist that provide basic instructions, examples of which are listed at the back of this publication. Instead, these guidelines have been developed as an approach to be considered when conducting interviews with people who, because they have had leprosy, have faced deep personal loss, social exclusion, and the denial of basic human rights. Since these voices have been largely neglected in conventional histories, oral

history is not only a means of adding new information and personal perspectives to documented history, but becomes a process through which people are empowered and enabled to assume their rightful place in history.

These guidelines reflect insights based on IDEA's experience in the process of conducting interviews, the importance of how the interviews are used, as well as a firm commitment to developing concrete ways in which history can be used as a powerful tool to effect social change.

*All history depends ultimately upon its social purpose.*

-- Paul Thompson, *The Voice of the Past: Oral History*

## **The Process**

Oral history involves interviewing eye-witness participants in the events of the past in order that a fuller, more inclusive, history may be compiled. Oral history provides the opportunity for people to speak about their own lives and feelings, rather than having them summarized and interpreted by others.

**Who Can do Oral History?** The most important characteristics needed to conduct a good interview are to simply be interested and be a good listener. IDEA also

encourages members of the younger generation of people affected by leprosy to interview members of the older generation who have experienced this disease. This can result in more in-depth, personal interviews since there is often an inherent sense of trust already in place. At the same time, the interview process creates a network of support. Recording the experiences and wisdom of the older generation assures these individuals that their lives have had value and will be remembered.



Francisco Guerrero, a resident of Fontilles, Spain, is interviewed in 2003 by Jose Ramirez, Jr., as part of the Oral History Project.  
*Photo by Magdalena Ramirez*

**Who Should Be Interviewed?** It is always important to first interview those individuals who are elderly or at risk for health problems, that may prevent them from being interviewed at a later date. However, it is also important to record the experiences of people from all generations in order to better understand the social implications of having leprosy in the past and in modern times. Interviews should also be conducted with family members, including children of individuals who have had leprosy, to learn about their experiences with regard to how the disease has affected their lives.

## What Format Should be Used? Video? Audio? Other?

Opinions differ greatly as to what is the best format to use to record interviews. IDEA strongly recommends that video be used whenever possible. Video enables the viewer to understand more of the personality of the person being interviewed. Video enables us to see the person's surroundings, which also reflect personality.

Recording on videotape enables us to record people's talents, such as singing, artwork, poetry and dance. All of these things encourage us to see the whole person, rather than simply a person who has had leprosy.

The process of enabling people to feel comfortable with the video format is an important one that has implications



Antonio Moreno's skill in typesetting (left) and his extensive keychain collection are recorded on videotape by Jose Ramirez, Jr., as part of an interview conducted at Fontilles, Spain, for the Oral History Project. *Photos by M. Ramirez*

for self-confidence that go beyond the interview itself. IDEA discourages videotaping people from behind or in the shadows because this perpetuates a sense of anonymity and stigma in the process as well as the product.

If someone is opposed to being on video, the video camera can be directed away from them towards something in their home or outside. We have often found that a person is reluctant to be videotaped because they think emphasis will be on any disabilities they may have. If it is clear that focus is on their personality and talents, we have seen that those initially reluctant to be videotaped will often agree.

An important part of encouraging people to be comfortable with the video process is to show them portions of their video interview so that they are agreeable as to how they are being portrayed by the camera. This can be done simply by rewinding the tape and replaying it on the video camera itself, if other means are not available.



Artur C.M. De Sousa, IDEA, Brazil, shares the videotape he has recorded at Sian Hospital with Wu Jia Feng, P.R. China. *Photo by Valerie Monson*

If it is impossible to videotape the interviews, audio tapes can be used. If neither format is available and it is only possible to write down what people say, it is important to write down quotes and later read them back to the person for accuracy.

*It is hard to forget the wisdom of the elderly, these little things that stay forever in our minds. They are like photographs generated in the studio of our brains.*

-- Antonio Borges, Jr., IDEA, Brazil

## **Names & Identity**

IDEA encourages people to use their full names as part of the process of eliminating the stigma. Rejecting anonymity results in people being restored to their rightful places in their own history. IDEA has seen that if people are assured that their words will be used in a dignified way that educates people, and if they are included in the process of developing forums for the use of their words, they will often choose to be fully identified.

*I started to use my real name again, which is Michihiro Koh. I am 63 years old. I feel like I was reborn as a real human being. It seems to be very simple, but it is the joy that I am feeling now.*

-- Michihiro Koh, Japan, who used the name Masao Kozaki throughout most of his life to protect his family.

## Language & Interpreters

Whenever possible, people should be interviewed in their own language, the language they are most comfortable with. If this is not possible, it is important to find a translator who has some familiarity and sensitivity with regard to issues faced by people with leprosy. In addition, it is extremely important that the translator understands how important it is to translate the person's words in full, rather than summarizing them. The interview must reflect the person's own words and feelings as fully as possible.

*. . . there have been telling criticisms of a relationship with informants in which a middle-class professional determines who is to be interviewed and what is to be discussed and then disappears with a tape of somebody's life which they never hear about again – and if they did, might be indignant at the unintended meanings imposed on their words.*

-- Paul Thompson, *Oral History: The Voice of the Past*

*Our lives are really about the concept of taking our insides and turning them out, to show the world that we have emotions, that our hearts beat, our heads turn and our spirits tick, just like everyone else.*

-- Ymelda Beauchamp, *IDEA, USA*

## **Preparing for the Interview**

1. Learn the proper manner in which to request an interview. For example, in Spanish, one would ask for permission to engage in a “platica”, which literally translates into a “conversation”, but the term is a non-intrusive one. Additionally, as a matter of respect, ask the person how they prefer to be addressed, for example “Mr.” “Mrs.”, first name, etc. An incorrect salutation may mean the difference between an informative and engaging interview, and one which turns into simply a formal “yes” and “no” session.
2. The interviewer can contribute greatly to the success of the interview by becoming familiar with the history of the disease and some of its effects on individuals prior to the interview.
3. Develop a list of questions prior to the interview, but be flexible in terms of using this list.
4. Make sure you are familiar with any equipment you will be using prior to the interview.

## **Permission Form**

It is important to develop a permission form so that the person knows that they are in a position to say “yes” or “no” to being interviewed, and that we respect them enough to ask for their permission. It is important for people to understand and agree to how their interview will be used.

## Oral History Permission Form (sample)

Date \_\_\_\_\_

I hereby grant permission for the ILA Global Project on the History of Leprosy, IDEA, and others interested in promoting a better understanding of the lives of individuals who have had leprosy, to use interviews conducted with me for historical and educational purposes, including publications, website and documentaries. Any use of my interview should be consistent with the guidelines developed by IDEA, the International Association for Integration, Dignity & Economic Advancement, which is an international network of support and advocacy organization for people who have personally faced the challenges of leprosy.

\_\_\_\_\_

Signed

Name in block letters \_\_\_\_\_

Address \_\_\_\_\_

Name of Interviewer \_\_\_\_\_

Notes: [Here you can indicate if there are any restrictions or special instructions regarding use of the interview]

## **The Interview**

*... the material recorded in an oral history interview should be as much as possible the creation of the narrator.*

--The General Commission on Archives and History

1. Approach the interview with the recognition that *the person being interviewed is the expert*. Let them guide the direction of the interview, for this will reveal what they feel is important in life, and what they feel we need to know, rather than what we feel we need to know.

2. At the beginning of the interview, ask the person to remember as far back as they can, back to their earliest memory. This is an important way to see what is important to the individual and lets them initially direct the interview. People are sometimes very surprised at this question, but there is also an instant recognition that we are interested in their whole life and in them as a person, not just as someone who has had leprosy.

Some people will start talking about their experience with leprosy. Others won't mention it for some time. For example, one individual in Brazil talked for 25 minutes without even mentioning leprosy. It was just one of many things that had affected her life. This also lets us know what people's lives were like before they developed the disease. And, it gives people a chance to tell us things that we might never know about if we just did an interview filled with our own questions.

3. Allow for the natural flow of the conversation that will most likely reveal information that would not have been covered in your questions. Review your list of questions at the end of the interview and see if there are any that have not been covered in the interview.

4. Try to do the interview in the person's home or in a place that is most comfortable for them. Someone's home will also reveal a great deal about the person. Sometimes it is a good idea to interview someone at work. For example, women who are doing embroidery might be more comfortable talking while working, and this also provides the opportunity to focus on their skills.

5. It is important to choose a setting where there is good lighting and as little background noise as possible.

6. Ask people if they have any photographs. We have seen people bring out an old family photograph or a photograph of themselves when they were young, even in the most remote places. Photographs will often trigger memories and a connection to the past. It is important to take a photo of any photographs that people have, and also record them on video, if possible.



Tokio Nishimura is interviewed in his home in Japan in 2004 as part of the Oral History Project. During the interview he shared his wedding photograph. *Photo by Henry Law*

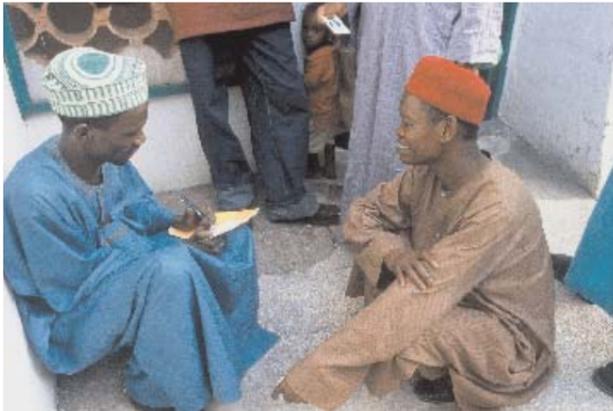


Yayesh Molla embroiders a pillowcase while being interviewed by Rosalijn Both in Ethiopia as part of the Oral History Project. *Photo by Rosalijn Both*

7. The interview can be done with more than one person at a time. For example, some people might prefer to be interviewed together with a spouse or a friend. In other instances, interviewing a small group of people together may help prompt their memories.



Carlien Bruining-Westerveld and Helene Van Pardo, friends from Suriname, are interviewed together as part of the First International Conference on Issues Facing Women Affected by Leprosy. *Photo by Marian Wester*



Alhaji Shehu Abdullahi Sarkin Fada (left), IDEA Nigeria, records the thoughts of Aminu Usman. *Photo by Pamela Parlapiano*

8. Look for people's talents. Maybe they can sing, write poetry, paint, take photographs, garden, or raise chickens. Even people in the most difficult living situations develop creative ways of expressing themselves, and it is important to try and learn about these.

*I was over 30 when I learned to write tanka and, as I reflected anew upon myself, other people and the world, I felt in my heart the beauty and the grandeur of existence. In poem after poem, I released years of bitter hardship, sometimes weeping, sometimes dancing for joy as I celebrated that spark of soul incarnate in my body.*

-- Akashi Kaijin, Poet, Japan



Kong Haobin and Chen Guanzhou, musicians, Hongwei Village, P. R. China.. IDEA Photo

## Creative Expression as a Supplement to Oral History

Poetry, music, written recollections and art are important supplements to oral history. Creative expression tells us about people, their feelings and their lives in a way that often doesn't come out in interviews or traditional

*No matter how people felt about their situation, there was always something inside them that could not be subdued and it came out through their music, their art, their poetry.*

-- Bernard K. Punikai'a, IDEA, Hawaii



Calligraphy/Painting by Chen Shi Yun, on his 75<sup>th</sup> birthday, P.R. China,

*When I look back at my past, my soul is beckoned to the poems I wrote of my father. There are times when I think it would be more natural for me to write about my life as a leprosy sufferer, but my attitude of mind as a poet is inclined more to write about my existence as a “human being.”*

-- Haruko Tsuda, Poet, Japan

## Oral History: A Personal Experience

Zilda Borges, Coordinator, IDEA Latin America,  
who interviewed residents of Rovisco Pais Hospital  
as part of the Oral History Project

*It was night when I got off the bus in front of the big gate of the Rovisco Pais Hospital in Portugal. It was the 12th February, 2004. It was necessary to walk a certain distance from the gate to reach the big hospital wings. I thought that **distance is the landmark** of the people who lived in these old leprosaria. I walked alone entering that soil marked by so many hidden lives.*

*The next day, I went to meet the people who had lived there for a long time. When they saw me, they asked if I was a journalist and quickly said that **they didn't want any photos taken or to give any interviews**. "I am not a journalist," I replied. I am Zilda Borges, a member of IDEA – an organization of people affected by Hansen's Disease. I came here just to give each one of you a hug and bring news of and greetings from a lot of people all over the world who have had Hansen's Disease.*

*A timid smile on a few faces, a wider smile on others and some even risked a hug. Very little was said during the first meeting, marked by embraces. I visited them at various times during the day, to help them at meal times and bring them around in the wheelchairs to visit each other.*

*It was necessary to build up a new form of relating to them. They were tired of being interviewed, said that they didn't like reading the articles or seeing their photographs. They didn't want any more of it.*

*I spent eight days circulating between their lives and histories that were revealed a little more with each passing day.*

## **The Product**

*My idea is always one of fighting the stigma and communicating with people is the best way to do this. I don't like to be a "poor me" type person . . . I like to remember what I went through and explain it to others, but not have them feel sorry for me.*

-- Antonio Borges, Jr., IDEA, Brazil

The product of any oral history project should always include transcripts of the interviews. This is the most permanent format, one that can be passed down from generation to generation, regardless of changing technology.

If interviews are done on digital video, they can be edited on a computer and utilized quickly and cost-effectively as a part of educational and historical projects. Quotations from oral history interviews can be utilized in any number

of ways, such as in articles, books, documentaries, exhibits, websites and newsletters. Many creative uses for oral history interviews can be found on the internet by searching “oral history”.

Before transcribing, make a copy of the tape or videotape and work from this copy so that the original tape isn't worn down or ruined in other ways during the transcribing process.

It is a person's right to know how their interviews will be used. Any products created from oral history interviews will be much better if the person interviewed is actively involved in the creation of any product that uses their interviews. The product should reflect, as much as possible, the complete words of the individual rather than summaries by the interviewer. In this way, the person continues to be the one telling the story, rather than having it told by someone else.

*We human beings are the most valuable and perfect species on earth, in the whole universe as we know it. We are able to walk, speak, sing, think, love -- with no need to use batteries or a computer. All of these qualities are found in the rich and in the poor; in the millionaire and in the person who begs; in our son and in the street child. Nothing is comparable in value, in beauty, in complexity.*

*-- Francisco A.V. Nunes, Brazil, IDEA's First President for Advocacy*

## **Examples of Use of Oral History**

Survivors of the Shoah: Visual History Foundation [www.vhf.org](http://www.vhf.org) -- provides numerous examples of how oral history can be used based on the Foundation's experience with conducting 52,000 visual history interviews in 32 languages in 56 countries with Holocaust survivors and witnesses.

Mahatma Gandhi Research & Media Service: Oral history interviews on India's Independence Movement are available online.

[http://www.gandhiserve.org/activities/research/oral\\_history.html](http://www.gandhiserve.org/activities/research/oral_history.html)

IDEA website: [www.idealeprosydignity.org](http://www.idealeprosydignity.org)

AIFO website: [www.aifo.it/english/resources/online/exhibitions/ideabook/ideal.htm](http://www.aifo.it/english/resources/online/exhibitions/ideabook/ideal.htm)

Telling Their Stories, Oral History Archives Project,  
The Urban School of San Francisco  
[www.tellingstories.org](http://www.tellingstories.org)

IDEA publications: *Freeing Ourselves of Prejudice;*  
*The Texture of Our Souls; Peace: The Fruit of Justice.*

*People From Our Side. A Life Story and Oral Biography.*  
<http://www.collectionscanada.ca/2/16/h16-6202-e.html>

## **References and Resources**

Thompson, Paul. *The Voice of the Past: Oral History*. Oxford University Press, 3<sup>rd</sup> edition, May, 2000.

Perks, Robert and Thomson, Alistair. *The Oral History Reader*. London: Routledge, 1998.

Grele, Ronald J. *Envelopes of Sound: The Art of Oral History*.

<http://www.ischool.utexas.edu/~loriene/SpectrumFiles/oralq.html>

Ritchie, Donald A. *Doing Oral History*. New York: Twayne Publishers, 1995.

Oral History Society [www.oralhistory.org.uk](http://www.oralhistory.org.uk)

The General Commission on Archives & History (GCAH)  
of The United Methodist Church  
[www.gc ah.org/oral.html](http://www.gc ah.org/oral.html)

For more information or assistance, please contact:

IDEA Center for the Voices of Humanity  
32 Fall Street, P. O. Box 651  
Seneca Falls, New York 13148

Phone: 315-568-5838; FAX: 315-568-5891  
email: [info@idealeprosodydignity.org](mailto:info@idealeprosodydignity.org)



Mrs. Nevis Mary's speech at India's First Conference for Women Affected by Leprosy is videotaped as part of the Oral History Project. A panel with oral history quotations is displayed behind her. *IDEA Photo*



John Cambra, forcibly isolated on the Kalaupapa peninsula in Hawaii as a young man in 1924, shares his memories as part of the Kalaupapa Oral History Project. *Photo by Henry Law*