GETTING COMFORTABLE

UNDERSTANDING THE RYAN WHITE CARE ACT PLANNING BODIES
Through education, training and advocacy, AIDS Alliance for Children, Youth & Families addresses the needs of children, youth and families living with, affected by, or at risk for HIV and AIDS.

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Dear Friends,

Ever since we first learned about AIDS, people living with the virus have been strong leaders in the fight to find medical treatments and develop support services for people with HIV. Their advocacy mobilized the nation’s fight against AIDS and led to creation of the Ryan White CARE Act in 1990, which provides money for HIV-related services in communities all across the country. The legislation also requires that people most affected by the epidemic — people just like you — participate in planning and evaluating HIV/AIDS programs at the local and state level.

When CARE Act planning bodies were first developed most of the “consumer representatives” were gay men, the people most affected during the early years of the HIV epidemic. Very often they were experienced community advocates who had been long-time leaders in the fight against AIDS. Today HIV affects many other groups. Women, young people, family members of children with HIV, heterosexual men, people with substance abuse histories, and gay men (particularly men of color) are now serving in important leadership positions on Ryan White planning bodies.

This is a very important change. It means that a much more diverse group of consumers is now involved in making decisions about care and services for people living with HIV/AIDS. And, it has created opportunities for consumers like you to have a role in planning these services.

Because we think this change is so important, we wanted to hear from these “new” consumer representatives and learn about their experiences. In the spring of 1999 the AIDS Alliance for Children, Youth, and Families sent a questionnaire to a group of women, young people, and families of children with HIV who were serving on Ryan White planning bodies.

1 In preparing this book we surveyed consumers who are serving on Ryan White Title I and II planning councils and consortia. We think that what they told us is important for consumers serving on all kinds of advisory and planning groups. Throughout this manual, we will use the term “planning body” to mean any kind of advisory group in which consumers have a role. These include planning councils, consortia, and community advisory boards.
bodies. We asked them about their experience. What was hard about it? What was rewarding? What advice would they give to other people living with HIV (PLWH) about becoming involved in a planning council or consortium? What kinds of information and training would have been helpful when they were new council members? We received answers from 75 consumers. What they told us was fascinating. This guide is based on what we learned.

The most important thing the consumers told us is that working on a planning body is a rewarding experience. But, they also told us it could be very challenging. It demands a lot of time, a lot of hard work, and sometimes, a lot of new skills. Many of the people who answered the survey said that at first they felt unprepared for the job they were asked to do. Some even questioned whether they had anything to offer. Others said they lacked information about the Ryan White CARE Act and other policy and legislative issues. Quite a few told us they hadn’t had any prior experience serving on a board or committee. They were confused by the formal way that meetings were conducted and they found it intimidating to speak up at meetings. Almost every person who answered our survey wished that there had been more training and information available to help build their confidence and skills when they were new planning body members.

We’ve written this manual in response to what consumers told us. It’s organized as a kind of “personal training guide” with information and activities that focus on the areas the survey identified. You can complete all the exercises in the manual, or select only those that are of particular interest to you.
Section 1, Mastering the Basics provides background information on the Ryan White CARE Act. It explains the CARE Act and identifies the ways consumers are involved in planning and evaluation.

Section 2, Can I Really Do This? helps you learn more about yourself – as an individual and as a spokesperson for others. It will also help you identify the kind of practical and emotional supports you may need to participate fully on a planning body.

In Section 3, The Nuts and Bolts of the Job you’ll have a chance to work on some of the skills required for effective planning body work.

Section 4, The Art of Communication offers a variety of activities to help you become a better communicator.

We conclude in Section 5 with advice from two consumers who have become effective advocates in their own communities. Also, throughout the book you’ll get tips and encouragement from other consumers, In Their Own Words.

We hope this guide will help you feel more comfortable about serving on a Ryan White CARE Act planning body. It is essential that your voice, and the voices of other women, families, and youth, be counted in the important discussions occurring all across the country. Do get involved. You have so much to offer!
In this section we present some basic information about the Ryan White CARE Act. We consider it the first step in your education about the CARE Act. There is a brief description of each part of the CARE Act, a glossary of terms, and even a quiz to test your knowledge. After you have absorbed what is presented here, you can move on to the many excellent and more comprehensive materials available through your planning group.

It is the responsibility of planning bodies to provide information to their members. They are also required to provide that information in useful and understandable ways. When you are ready for more information, ask the chair of your group, your contact person, or your mentor to provide it. Ask them, as well, about any training or orientation programs they may provide for members. If nothing exists, ask if something can be developed.

Listed below are some excellent resources that your planning group should be able to provide for you. They include up-to-date information about the Ryan White CARE Act, information about how planning bodies function, and glossaries of frequently used words and terms. Take time to read them. They will help make you a more effective group member.

- Training Guide: A Resource for Orienting and Training Planning Council and Consortium Members from HRSA/HAB
- Title I Manual from HRSA/HAB
- Title II Manual from HRSA/HAB
- Title III Manual from HRSA/HAB
- Title IV Manual HRSA/HAB
- PLWH Sourcebook from HRSA/HAB
- The Challenge Ahead: Renewing the Ryan White CARE Act in 2000

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2 These materials are also available on the Internet at www.hab.hrsa.gov or the HRSA Information Clearinghouse at 1-888-ASK-HRSA.
Section 1: Mastering the Basics

THE RYAN WHITE CARE ACT

The Ryan White CARE Act (CARE stands for Comprehensive AIDS Resources Emergency) provides federal funding to improve care for individuals with HIV and their families. It provides a “safety net” for hundreds of thousands of people who are unable to pay for health care or other basic needs. CARE Act funds are used for medical care, drugs, and support services that improve access to care and the quality of life for people with HIV. The CARE Act is sometimes called the “payer of last resort.” This means that CARE Act money pays for services that other programs, like Medicaid, do not cover.

Historical Background
Congress enacted the Ryan White CARE Act in 1990 to help communities and states provide care to people with HIV/AIDS. Since that time, the CARE Act has provided money to communities across the country to deliver HIV-related services. In 1996 and again, in 2000, Congress “reauthorized” (renewed) the CARE Act and made some changes. The President signed the most recently reauthorized CARE Act into law on October 20, 2000.

What does the CARE Act do?
The Ryan White CARE Act provides funding for a range of HIV-related services. These include medical care for people living with HIV disease, supportive services for individuals affected by HIV and their families, training for health care providers who treat people with HIV, and assistance to organizations providing HIV-related services.

Ryan White CARE Act money comes from the Federal government in Washington, DC and goes to cities, counties, states, and community-based programs. The “streams” of money that flow from Washington to states and communities are referred to as:

- Title I
- Title II
- Title III
- Title IV
- Part F

The Ryan White CARE Act is named in honor of Ryan White, a young man who was diagnosed with HIV when he was 13. Ryan, with his mother and rest of his family, fought to overcome the fear and ignorance of his neighbors in a small-town in Indiana and became a symbol of bravery and integrity. Ryan died in 1990 at the age of 18.
Each of these titles, or sections, has a different focus. However, all programs funded by the CARE Act are required to work together at the state and local levels to maximize coordination of services.

At the federal level, all Ryan White CARE Act programs are administered by the HIV/AIDS Bureau of the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services in Washington, DC.

**Consumer Involvement**

The CARE Act requires that people living with HIV be part of the planning and decision-making process. There are many ways that consumers can be involved in CARE Act activities. They can help to identify unmet service needs in the community, make decisions about how CARE Act funds are spent, and evaluate the quality of existing programs.

Table 1 lists the ways that consumers can participate in each section of the CARE Act.

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Consumer Participation in the CARE Act</th>
</tr>
</thead>
</table>
| **Title I** | Planning council members  
| | Subcommittee members  
| | Participants in council meetings  
| | Help in needs assessments  
| | Focus group participants or facilitators  
| | Outreach to other PLWH (People Living with HIV/AIDS) |
| **Title II** | Consortia members  
| | Help in needs assessments  
| | Focus group participants or facilitators  
| | Outreach to other PLWH (People Living with HIV/AIDS) |
| **Title III** | Community advisory board members  
| | Paid staff and volunteers |
| **Title IV** | Advisory board members  
| | Paid staff and volunteers  
| | Outreach to other women, families and youth |
What is Title I of the Ryan White CARE Act?
Title I of the Ryan White CARE Act provides funding to the areas (sometimes several cities or counties in one state) that have felt the greatest impact of the HIV epidemic. These areas are called Eligible Metropolitan Areas or EMAs. In order to be an EMA, communities must have reported over 2,000 AIDS cases during the most recent five-year period. EMAs must also have a population of at least 500,000 (this does not apply to EMAs funded prior to 1997). In fiscal year 2000, 51 EMAs received Title I funding. Approximately three-quarters of people with AIDS in the United States live in an EMA.

How is funding determined under Title I?
EMAs are eligible to receive both formula and supplemental funding through Title I. Formula funding is based on the estimated number of people living with AIDS in each EMA. In fiscal year 2005, formula funding for EMAs will be based on HIV cases and not just people diagnosed with full-blown AIDS.

Supplemental funding is awarded on a competitive basis to EMAs that have the most severe need. EMAs may request this funding in addition to the formula amount they receive. Staff at the Health Resources and Services Administration (HRSA) review the requests to determine which EMAs receive additional money.

How are Title I funds used?
EMAs may use Title I funds to meet needs for medical and support services that are not met by any other program. These could include, for example, primary medical care, home health and hospice care, dental services, case management, mental health care, substance abuse treatment, housing assistance, transportation, nutrition services, early intervention services, and day care. EMAs are required to spend Title I funds in accordance with the local demographics of AIDS, including proportional allocations for infants, children, youth, and women.
EMAs fund services according to priorities set by a local HIV Health Services Planning Council. This planning council must include public health professionals, housing or homeless service providers, providers of services to prisoners or former prisoners, health care providers, people living with HIV, and others. Thirty-three percent of membership must be consumers of Title I services.

Planning councils are also required to include a representative from a Title IV program (the Ryan White Title that provides care to women, children, and families). If there is no Title IV program operating in the area, representatives of organizations with a history of serving children, youth, and families living with HIV are asked to serve on the planning council.

**TITLE II**

What is Title II?
Title II of the CARE Act provides funds to all the states, the District of Columbia, Puerto Rico, and U.S. territories. The purpose of Title II is to improve the quality, availability and organization of HIV-related care and services. Typically, Title II money is administered by state health departments. Title II is designed to assure that all people living with HIV have access to adequate care, whether they live in rural, suburban, or urban areas.

How is funding determined under Title II?
The amount of Title II money a state receives is based on:
- the estimated number of people living with AIDS in the state as a whole, and,
- the estimated number of people living with AIDS in the state outside of the Title I EMAs.

States with fewer than 90 people living with AIDS receive a minimum of $200,000; those with more than 90 cases receive a minimum amount of $500,000. In Fiscal Year 2005, HIV data will be integrated with AIDS data to determine funding.
In addition, new funding is now available for “emerging communities” that are affected by the HIV/AIDS epidemic, for reducing HIV perinatal transmission, for HIV counseling, testing, and outreach to pregnant women, and for partner notification, counseling and referral services in states with partner notification programs.

**How are Title II funds used?**
States may direct Title II funds toward a range of primary medical care and support services (the same support services that Title I may fund). Title II funds may also be used to pay for health insurance programs which enable people with HIV to continue their private health insurance coverage if they can no longer afford their premiums, or to buy health insurance. Title II also contains funds for states to reduce mother-to-child (perinatal) HIV transmission.

As in Title I, Title II funds are required to be spent in accordance with the local demographics of AIDS, including proportional spending on infants, children, youth, and women.

**Title II and ADAP**
The AIDS Drug Assistance Program (ADAP) is a special part of Title II. ADAP helps people with HIV who are uninsured or underinsured pay for HIV-related medications. ADAP has enabled many people with HIV to afford treatments, including powerful antiviral drugs and other medications to treat HIV disease.
Section 1: Mastering the Basics

TITLE III

What is Title III?
The Title III of the CARE Act provides grants (funding) to public and private community-based clinics to provide primary care and support services for people with HIV with very low incomes.

Title III grantees include, for example, community and migrant health centers, hospital and university-based medical centers, and city and county health services. Many Title III programs are targeted at people in historically under-served and/or geographically remote communities. In 1997, Title III programs provided primary health care services to more than 96,400 people with HIV.

How are Title III funds used?
Title III funds may be used for a range of activities, including HIV counseling and testing, primary medical care, medications, dental services, case management, mental health care, nutrition services, and treatment of tuberculosis and substance abuse.

TITLE IV

What is Title IV?
The Title IV of the CARE Act provides funding for HIV-related care and services for children, youth, women, and families. The money is awarded through a competitive process to public and private nonprofit institutions and organizations. Although Congress first authorized the Ryan White CARE Act in 1990, the Title IV program was not funded until 1994.

Title IV funds 66 grantees in 33 states, the District of Columbia and Puerto Rico. These grantees provide and/or arrange for direct HIV services at several hundred clinical sites. Title IV grant amounts range from $200,000 to $2 million.

How are Title IV funds used?
Title IV funds are used to develop and sustain comprehensive systems of care and support and may include primary medical care, social services such as case management, and access to research. In addition, Title IV funds have also been used to develop HIV-testing and prenatal care programs for women, as well as comprehensive care to HIV-positive pregnant women. Title IV money has also gone to support innovative model programs for adolescents in selected cities.
**PART F**

**What is Part F?**

Part F of the Ryan White CARE Act is often referred to as Title V. It authorizes three separate programs.

The HIV/AIDS Dental Reimbursement Program. This program provides reimbursement to dental schools, programs, and community-based providers who work with them, for oral health care to uninsured and indigent people with HIV. In 1997, the program served over 70,000 people at more than 100 dental schools.

The AIDS Education and Training Centers (AETC). This network of 14 centers throughout the United States and its territories—along with several national provider resource centers—provides multidisciplinary education and training programs for health care providers. The AETC program helps to ensure that health care and social service providers, including those in rural areas, have the necessary skills and knowledge to provide state-of-the-art HIV care. More than 700,000 providers have been trained by AETCs since 1991.

Special Projects of National Significance (SPNS). This competitive grant program supports the development and evaluation of innovative models of HIV care. A percentage of the funds appropriated for Titles I, II, III, and IV is given to the SPNS program. SPNS projects usually target traditionally under-served groups, including adolescents, residents of rural areas, people in prison, and Native Americans.
## Table 2
The CARE Act at a Glance

<table>
<thead>
<tr>
<th>TITLE</th>
<th>DESCRIPTION/PURPOSE</th>
<th>2001 FUNDING</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Title I</strong></td>
<td>Provides funding to metropolitan areas (EMAs) that have felt the greatest impact of the HIV epidemic.</td>
<td>$604,200,000</td>
</tr>
<tr>
<td><strong>Title II</strong></td>
<td>Provides funds to all states and territories to improve HIV-related care and services.</td>
<td>$322,000,000</td>
</tr>
<tr>
<td><strong>Title II – ADAP</strong></td>
<td>AIDS Drug Assistance Program (ADAP), helps people with HIV who are uninsured or under-insured pay for medications.</td>
<td>$589,000,000</td>
</tr>
<tr>
<td><strong>Title III</strong></td>
<td>Provides funds to community-based clinics to provide early intervention and outpatient health services to people with HIV.</td>
<td>$185,900,000</td>
</tr>
<tr>
<td><strong>Title IV</strong></td>
<td>Provides funding for HIV-related care and services for women, children, youth, and families.</td>
<td>$65,000,000</td>
</tr>
<tr>
<td><strong>AETC</strong></td>
<td>Network of centers providing education and training on HIV care for health care professionals.</td>
<td>$31,600,000</td>
</tr>
<tr>
<td><strong>SPNS</strong></td>
<td>Provides money (through a competitive process) for development and evaluation of innovative models of HIV care.</td>
<td>$25,000,000</td>
</tr>
<tr>
<td><strong>Dental Program</strong></td>
<td>Provides reimbursement to dental schools and programs, and community-based providers, working with them, for oral health care to uninsured people with HIV.</td>
<td>$10,000,000</td>
</tr>
</tbody>
</table>
A GLOSSARY OF CARE ACT TERMS

This glossary explains a few of the words that were used in this section to describe the Ryan White CARE Act. For a more comprehensive list of words, you can review the glossaries in the various Ryan White CARE Act Manuals and at www.hab.hrsa.gov.

**ADAP** — AIDS Drug Assistance Program helps eligible people pay for HIV-related medications.

**AETC (AIDS Education and Training Centers)** — Network of centers providing education and training programs on HIV-related issues for health care providers.

**Consortium** — A planning group established by states to plan and sometimes administer Title II funds. Consortia members usually include health care providers, support service providers, and consumers.

**Eligible Metropolitan Areas (EMAs)** — Communities that are eligible to receive funding under Title I of the CARE Act because of the impact of the HIV epidemic on their population. These communities are usually large metropolitan areas.

**Formula grant** — The process by which EMAs and states apply for and receive funding determined by a formula based on the number of reported AIDS cases in their area.

**HIV/AIDS Bureau** — The department (called a bureau) within HRSA that administers the Ryan White CARE Act.

**HRSA** — Health Resources Services Administration. The federal agency in the U.S. Department of Health and Human Services that administers the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act.

**Needs assessment** — A process used to determine the needs of particular populations, the extent of the need, the services that are available and the gaps that exist.

**Planning council** — The planning body that is appointed to develop a plan for the delivery of HIV services in the EMA and to establish priorities for the use of Title I funds that the EMA receives.

**SPNS (Special Projects of National Significance)** — A program funded under Part F of the CARE Act that provides grants for demonstration, research, and evaluation.
Quiz

THE RYAN WHITE CARE ACT

Okay. You have read about the Ryan White CARE Act. Now it’s time to test your knowledge. Read the questions below and pick the answer you think is correct.

If you find you need to study some more, go back to the beginning of this section and read the material again. Remember it takes a while to fully understand the information. Give yourself plenty of time to learn this important background information.

1. What year was the CARE Act first enacted by Congress?
   - 1990
   - 1996
   - 1995

2. Which Title of the CARE Act focuses on services for women, children, and youth?
   - Title I
   - Title IV
   - SPNS

3. EMA stands for:
   - Emergency management action
   - Eligible metropolitan area
   - Every means available

4. Which of these services are not specified under Title II funds?
   - home and community-based care
   - continuation of health insurance benefits
   - day care and transportation
   - advocacy training

5. Most EMAs receive two different kinds of grants. What are they?
   - formula and supplemental
   - equation and formula
   - supplemental and required
6. The HIV/AIDS Dental Reimbursement Program is funded under which Title of the Care Act?
   - Title I
   - Title XIII
   - Title V (Part F)

7. All states receive a certain amount of money under Title II, regardless of the number of PLWH living there. What is that amount?
   - $150,000
   - $61,000
   - $200,000

8. What are Title IV grants called?
   - competitive
   - formula
   - supplemental

9. Which answer is not correct? The ADAP program:
   - helps people pay for HIV-related medications
   - enables people to afford the available, powerful but expensive, HIV treatments
   - funds transportation to dental appointments

10. What is the Federal agency that administers all titles of the Ryan White CARE Act?
    - the HIV/AIDS Bureau of the Health Resources and Services Administration (HRSA)
    - the Maternal and Child Health Bureau of the Health Resources and Services Administration (HRSA)
    - the Centers for Disease Control and Prevention (CDC)

11. Consumers can get involved in the CARE Act by:
    - serving on planning bodies
    - joining a focus group to give ideas about improving HIV care
    - being interviewed or surveyed about gaps in services
    - all of the above
This section includes five exercises to help you think about becoming involved in a CARE Act planning body. They are fun to do and we hope you will complete them all. This booklet is yours to write in — so grab your pencil and get started. Remember, this booklet is just for you, so write down whatever comes to mind. There are no right or wrong ideas! Be honest, be expansive, enjoy yourself!

**Activity 1:** The Rewards of Participation

**Activity 2:** Identifying My Strengths

**Activity 3:** Secrecy, Disclosure, and My Participation

**Activity 4:** Partnership: Working with Others

**Activity 5:** Getting the Support I Need: My Action Plan

**In Their Own Words...**

“Don’t feel afraid, intimidated, or like you are not as educated or important as other people who are in the group— you are very important!”
Section 2: Can I Really Do This?

Activity 1

THE REWARDS OF PARTICIPATION

Many people told us how glad they were to be involved with a planning body. They offered lots of reasons. For some it was because it felt good to “have a voice.” Others enjoyed doing something totally different, and “feeling like I really make a difference.” Several liked participating because they could speak for others — especially other women “who can’t or won’t because they are afraid.”

Just like the consumers who answered our survey, you can probably think of many reasons why being a member of a planning body would be rewarding. On the next page is an activity that helps you think more deeply about those reasons. The activity encourages you to identify the benefits and rewards that you and others can gain when PLWH participate on planning bodies.

Grab your pencil and write down your ideas! There are no right or wrong answers and you’re sure to learn a lot about what your participation can mean.

IN THEIR OWN WORDS...

“It’s great to be part of the solution.”

“The rewarding thing is to make known the needs of the people.”
The Rewards of Participation: My Worksheet

In the left-hand column, make a list of all the ways you think you can benefit from participating on a planning body. In the middle column, list the ways that your participation might help other people affected by HIV. Finally, in the right-hand column, describe how your participation can benefit the HIV-related programs in your community.

<table>
<thead>
<tr>
<th>The Ways My Participation in a Planning Body Can . . .</th>
</tr>
</thead>
<tbody>
<tr>
<td>help me</td>
</tr>
<tr>
<td>help other consumers</td>
</tr>
<tr>
<td>help programs</td>
</tr>
</tbody>
</table>
Review the list of possible rewards and benefits of your participation on a planning body. Have you listed things that are important to you? Is it worth your time and effort to be involved? If you said yes, then you probably have decided to get involved. Remember to reread this list in the future as you think about your ongoing involvement.

**Table 3** lists the benefits of participation that other consumers have identified. See how many are the same as yours.

**NOTES**

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**IN THEIR OWN WORDS...**

“My involvement means a woman’s point of view is expressed.”

“My involvement means I’m doing something totally different, meeting new people, learning, and every now and then feeling like I really make a difference.”
**Table 3**

**What Other Consumers Have Said...**

We asked consumers, “What are the most rewarding things about being a consumer on the planning council or consortium?” Here’s a sample of what people said. Do you agree?

### Benefits for Me and for Other Consumers

- It means I have a voice
- It helps me understand where the funding comes from and where it goes
- It means I am part of the decision making
- It increases my involvement in my own health care — I’m not just a bystander
- It feels good knowing that my decisions will help people with HIV
- It helps me to feel like I’m not alone
- It helps me to make contacts with other consumers
- It gives me information that I can use
- It gives me a sense of inner peace, goodwill, self-esteem, and pride
- It means I can speak for the young who can’t speak for themselves

### Benefits for the Programs and the Providers

- It makes the system more responsive to consumer needs
- It directs funds where they are most needed
- It makes the programs more real
- It brings about change and improves conditions
- It increases the providers’ knowledge of consumer needs
- It improves relationships between providers and clients
- It develops a group of consumers who can advocate for the program
- It helps save money
Activity 2
IDENTIFYING MY STRENGTHS

Some consumers have told us that they question what they have to offer their planning bodies. Some worry that they do not have enough education or the right kinds of skills to be effective. You may also be wondering why you were asked to get involved. Most probably, you’ve been asked because someone saw leadership skills in you. Or maybe they thought you could bring fresh ideas and experience to the group.

Listed below on the chart Strengths Inventory are some of the personal qualities that consumers have said are important when serving on a planning body. Look at the chart and follow these steps:

❖ First, read the list of strengths and underline the ones that are most like you. Then find someone you trust—your husband or wife, a friend, or your partner—and discuss them. Talk about how these qualities help you understand what it is like for people with HIV/AIDS and how you can use your strengths to help other PLWH.

❖ Now, look at the list again. This time circle the qualities you feel you need to work on to improve. Again, talk with someone you trust about the qualities you circled.

❖ Finally, write each one of the qualities you circled on the worksheet, Building My Skills. Write them in the column marked “Skills I Want to Develop.” Then think of at least three ideas for improving your skills. Write them in the next column. Talk with your friend about these ideas and then do them! Table 4 presents a sample worksheet if you need some ideas.

IN THEIR OWN WORDS...

“The hardest thing for me was to understand how I could contribute.”

“Do not be intimidated by the providers—speak your mind—you know what consumers need, many times more than they do.”
Strengths Inventory

Read the list of strengths and underline the ones that are most like you. Then find someone you trust — your husband or wife, a friend, or your partner — and discuss them. Talk about how these qualities help you understand what it is like for people with HIV/AIDS and how you can use your strengths to help other PLWH.

Now, look at the list again. This time circle the qualities you feel you need to work on to improve. Again, talk with someone you trust about the qualities you circled.

<table>
<thead>
<tr>
<th>I am able to communicate well</th>
<th>I am willing to share my life's experiences</th>
</tr>
</thead>
<tbody>
<tr>
<td>I understand my own health care needs</td>
<td>I am accepting of myself and others</td>
</tr>
<tr>
<td>I am committed to improving services</td>
<td>I am an outgoing person</td>
</tr>
<tr>
<td>I am able to listen well</td>
<td>I want to help others</td>
</tr>
<tr>
<td>I am organized</td>
<td>I can speak comfortably about my own situation</td>
</tr>
<tr>
<td>I can work well with others</td>
<td>I am willing to learn</td>
</tr>
<tr>
<td>I am able to network with other consumers and providers</td>
<td>I can ask for help</td>
</tr>
<tr>
<td>I am optimistic</td>
<td>I am able to share</td>
</tr>
<tr>
<td>I am a caring person</td>
<td>I am able to interact with many different kinds of people</td>
</tr>
<tr>
<td>I am confident</td>
<td>I understand the needs of PLWH beyond my own and my family's needs</td>
</tr>
<tr>
<td>I have experience working with other PLWH</td>
<td>I am an honest person</td>
</tr>
<tr>
<td>I am comfortable talking about my HIV status</td>
<td>I have an attitude of partnership</td>
</tr>
<tr>
<td>I am not judgmental</td>
<td>I am able to provide and receive support</td>
</tr>
<tr>
<td>I have a sense of humor</td>
<td></td>
</tr>
</tbody>
</table>

Activity: Identifying My Strengths
### Building My Skills

Write each one of the qualities you circled on the Strengths Inventory in the column marked “Skills I Want to Develop.” Then think of at least three ideas for improving your skills. Write them in the next column. Talk with your friend about these ideas and then do them! A sample worksheet is presented in Table 4 if you need some ideas.

<table>
<thead>
<tr>
<th>Skills I Want to Develop</th>
<th>Ways to improve my skills</th>
</tr>
</thead>
<tbody>
<tr>
<td>A)</td>
<td>1)</td>
</tr>
<tr>
<td></td>
<td>2)</td>
</tr>
<tr>
<td></td>
<td>3)</td>
</tr>
<tr>
<td>B)</td>
<td>1)</td>
</tr>
<tr>
<td></td>
<td>2)</td>
</tr>
<tr>
<td></td>
<td>3)</td>
</tr>
<tr>
<td>C)</td>
<td>1)</td>
</tr>
<tr>
<td></td>
<td>2)</td>
</tr>
<tr>
<td></td>
<td>3)</td>
</tr>
</tbody>
</table>
### Table 4
Building My Skills

#### SAMPLE Worksheet

<table>
<thead>
<tr>
<th>Skills I Want to Develop</th>
<th>Ways to improve my skills</th>
</tr>
</thead>
</table>
| A) I am able to communicate well. | 1) I can practice saying what I want to before the meetings  
(Sometimes I get nervous when I speak in front of a group of people. I am worried I won’t be able to speak up during meetings)  
2) I can talk to someone I trust about my fears  
3) I can prepare by reading all the materials so I’ll feel that I know what I am talking about. |
| B) I can work well with others. | 1) I can count to 10 before I respond  
(Sometimes I get upset when people say things I don’t agree with, or that I think are incorrect)  
2) I can talk to the person who upset me after the meeting to tell them how I feel.  
3) I can think of two or three reasons why that person might see things differently from me. |

You’ve probably discovered that you already have lots of strengths to bring to a planning body. And you have made a plan for enhancing your skills even more. Over time your inventory of strengths will grow — so will your confidence in yourself!
Activity 3

SECRET, DISCLOSURE, AND MY PARTICIPATION

Telling other people that you or someone in your family is HIV positive is a very personal decision. And, people deal with it in many different ways. Some don’t find an HIV diagnosis to be an issue requiring secrecy. They share the information with family or friends almost immediately. Others decide to keep the information private. They may fear being rejected, or losing their job or health insurance. Many people spend months or sometimes years keeping HIV a secret part of their lives — even from their closest loved ones.

Over time most people living with HIV decide to let others know. They choose to disclose their HIV status to family, to neighbors, and even to members of their broader community.

Some consumers told us that it was very important to be able to talk about being HIV positive at planning body meetings. In fact, they said that when people knew they were HIV positive, it helped their effectiveness. A few people, who had not disclosed their HIV status in the community, said they sometimes worried about their participation in the planning body. They were especially worried because they could not control the level of confidentiality at the meetings.

If you decide to serve on a planning body, you may or may not be asked to tell anyone else in the group about your HIV status. For your own comfort, though, you should think carefully about how your work with such a group might affect your decisions about disclosure.

If you have not shared information about being HIV positive before, ask yourself the following questions. Use the space on the next page to jot down your answers.

IN THEIR OWN WORDS...

“I fear the loss of privacy and possible repercussions because of going public.”

“I’m speaking for women who can’t and for those who are afraid.”
Secrecy and Disclosure: My Thoughts

❖ How will I feel if someone I know (but who doesn’t know about my HIV status) is at a meeting?

❖ What will I say if someone asks me why I am a member of a CARE Act planning body?

❖ What will I do if there is media coverage of planning body activities?

❖ What will I do if someone makes an offensive comment about people with HIV/AIDS?

❖ Will there be consequences to me and/or my family if my participation in the planning body becomes known?

❖ Is serving on a planning body the best way for me to be an advocate for PLWH?
After thinking about these questions you may decide that you are ready to participate in a planning group. Or, you may decide that, for the time being, you are more comfortable working in a less public way to improve services for people with HIV. If so, there are many ways you can let your voice be heard. Here are some ideas.

❖ You can participate on a sub-committee of the planning body. These meetings are less public and yet you can make a real contribution.

❖ You can agree to speak at meetings or conferences in distant communities. You’ll get your message out, but it is unlikely that someone in the audience will know you.

❖ You can meet with or write to one of the consumer members of the planning body to offer your input and perspective. If you meet with them regularly, you can keep informed about important issues as well as contribute your ideas.

❖ You can use a “pen name” and write an article for your community newspaper about your or your family’s experiences living with HIV. You will reach a broad group of people, and can affect the way they think about issues that are important to you and other PLWH.

❖ You can participate in support group activities.

❖ You can volunteer to participate in focus groups and one-on-one interviews. These sessions are held by the planning body to get community member input on HIV-related needs. They provide a wonderful opportunity to share your perspective and offer advice. The names of participants are usually kept confidential.

❖ You can respond to consumer surveys. You’ll have important input, but your identity will be protected.
Do you have other ideas? Write them below.

MY IDEAS

_________________________________________________________________________________

_________________________________________________________________________________

_________________________________________________________________________________

_________________________________________________________________________________

_________________________________________________________________________________

_________________________________________________________________________________

_________________________________________________________________________________

_________________________________________________________________________________
Activity 4

PARTNERSHIP: WORKING WITH OTHERS

Planning bodies have from 10–50 or more members. Some of them may be professionals — doctors or social workers — and some may be other people living with HIV. One of the things you will have to do if you agree to serve on a CARE Act planning body is to work closely with all kinds of people.

Some of the consumers who answered the survey said that at first they felt unsure about how to form these new relationships, and how to work in partnership with people who were very different from them.

This exercise will help you think about what it means to be a “partner” and evaluate your own experience working side-by-side with others. The exercise has three parts.

❖ First, think about a time when you were in a good partnership with someone else. Your example could be a personal one or a work-related one. It could be about your marriage or a close friendship. It could be about creating a quilt with your support group or organizing a community supper at your church. It could be a bake sale at your child’s school. Or it could be about getting something accomplished at your job.

❖ Now, write your example down on the Partnership Worksheet. If you think of more than one example, write it down too!

❖ Finally, ask yourself, “Why was that partnership a good one? Why were we successful?” Jot down some of your reasons on the Partnership Worksheet.
My Partnership Worksheet

My example(s) of a good partnership:

My partnership worked because:
Following are some of the reasons you may have written down about good partnerships:
❖ we really communicated well
❖ we trusted each other
❖ we shared a common goal
❖ we each brought different skills and abilities to the task

Have you thought of more reasons? Add them to your list.

After you complete this exercise, you’ll realize that you already know what it’s like to be in a successful partnership. And, you’ll have identified some of the reasons that contributed to your success. A summary of these reasons is presented in Table 5. It has been shown that these reasons are present in every kind of partnership – one that is informal such as planting a community garden, or one that is formal, such as serving on an advisory board or committee.

Keep these reasons in mind as you build new relationships with the other members of a planning group. They will help you be a great partner!

### Table 5

**Our Partnership Works Because...**

- We respect each other’s skills and knowledge
- We are clear and honest when we talk to each other
- We try to understand each other’s point of view
- We work toward the same goals
- We develop plans and make decisions together
- We share our information with each other
- We stay in touch
- We ask each other, “How is our partnership working?” and “How can we make it better?”
- We try to think the very best about each other
- We work hard to understand and appreciate our differences.

Adapted from: Focal Point, (1987), Vol. 2, No. 2, Research and Training Center, Regional Research Institute for Human Services, Portland State University, Portland, OR.
Activity 5

GETTING THE SUPPORT I NEED: MY ACTION PLAN

Now that you’ve completed the first four exercises, you have a pretty good idea about whether or not to get involved with your Ryan White CARE Act planning body.

You’ve identified some of the benefits of participating. You’ve thought about the strengths that you bring to this role, as well as the things that you might find especially challenging. You’ve also reviewed what it takes to be a good partner. Now you must think carefully about the kind of support — both practical and emotional — you may need so that you can be an effective consumer representative.

Listed on the following page are some of the resources and supports that other consumers have found to be helpful. Check off the ones that are the most important to you.

IN THEIR OWN WORDS...

“It helped me a lot to get things explained in advance of meetings.”

“I needed childcare and money for my meals and mileage.”

“Just getting to meetings is hard!”
### My Support Checklist

- Childcare
- Transportation
- Money for meals
- Information I can understand
- Information in my language
- Meetings close to my home
- Meetings scheduled at a time when I can attend
- A mentor or buddy to help me
- Confidentiality about my HIV status
- Training about the planning body and my role
- Materials delivered in time to review them before meetings
- A phone call to ask if I need anything to help me attend the meeting

Other supports I need:

- 
- 
- 
- 
- 

On the next page, write an action plan for getting the supports you need to be an effective member of your planning body. If you need some ideas, take a look at the sample action plan presented in **Table 6**.

Remember, it’s important to plan ahead. If you know what you need, and make a plan to get it, you’ll increase your effectiveness and your comfort as a planning body member!
My Action Plan

These are the supports I need to participate effectively on my planning body. Here’s my plan for getting them.

What I need:

Who can help me?

What do I need to do?
### Table 6
Sample Action Plan

<table>
<thead>
<tr>
<th>What I need:</th>
<th>I need childcare for Isaiah for every meeting from 3 to 6 PM.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who can help me?</td>
<td>My mother or my sister. My neighbor but I will need to pay her.</td>
</tr>
<tr>
<td>What do I need to do?</td>
<td>1. Call each of them to find out who is available.</td>
</tr>
<tr>
<td></td>
<td>2. Call the planning body contact person to ask how I get funding for childcare before the meetings.</td>
</tr>
<tr>
<td></td>
<td>3. Fill out the reimbursement forms they send me.</td>
</tr>
<tr>
<td></td>
<td>4. Be sure that I have childcare arranged for each meeting by giving my babysitters a schedule of the meetings.</td>
</tr>
<tr>
<td></td>
<td>5. Write on my calendar the name of the person taking care of my child on the meeting dates.</td>
</tr>
<tr>
<td></td>
<td>6. Give each babysitter information on how to reach me during the meetings.</td>
</tr>
</tbody>
</table>
In this section we present tools to help you participate in meetings more effectively. The material is designed to increase your confidence. You’ll find background information to help you understand the process that groups use to get their business done. And you’ll find practical strategies and tips for being an informed participant. Most of the information presented in this section comes from the experiences of other consumers. They told us what helped them, and we’re passing it along to you!

**Activity 6:** Meetings by the “Rules”: A Guide to Parliamentary Procedure

**Activity 7:** Be Informed

**Activity 8:** Getting the Most out of Meetings: Tips for Success

**Activity 9:** There’s So Much to Read!

---

**In Their Own Words...**

I worry about being on a planning group because...

“I’m not good at speaking up and being assertive.”

“I’m not able to keep up with all the reading.”

“I fear I can’t always say the right thing, or express options to solve a problem.”
Activity 6
MEETINGS BY THE "RULES": A GUIDE TO PARLIAMENTARY PROCEDURE

Formal meetings, such as the Ryan White CARE Act planning body meetings, are usually organized by a set of procedures called Robert’s Rules of Order. These “rules” establish the ways that things get accomplished at meetings. They ensure that meetings are conducted in an organized way.

Robert’s Rules of Order are based on three important principles, or “rights”:
❖ the right of the majority to rule
❖ the right of the minority to be heard, and
❖ the right of the individual to have a voice in the decision-making process

Robert’s Rules of Order are sometimes referred to as parliamentary procedure. Under this system, business is conducted by acting on motions—ideas or actions that committee members suggest.

IN THEIR OWN WORDS...

“The structure of the meeting can make it hard to keep consumers involved.”

---

1 In this section we explain the process by which planning groups make decisions using Roberts Rules of Order. We decided to use a light-hearted example – serving ice cream and cake at meetings – because we wanted to emphasize the process of making motions and amendments, rather than the content of the subject under discussion.
This is what happens:

A member of the planning group introduces a main **motion**.
- “I move that we have ice cream and cake at all meetings.”

Another member then **seconds the motion** (supports it).
- “I second the motion.”

The person in charge of the meeting then **restates the motion**.
- “It has been moved that ice cream and cake be served at meetings.”

And opens the meeting to **discussion** about the motion.
- “Is there any discussion?”

Discussion takes place.
- “I think it is a really good idea. I’m always hungry when I come to these meetings, and it would be great to have ice cream and cake to look forward to.”
- “I’m not so sure about this. Ice cream and cake are not healthy foods. I think we should have carrot sticks instead.”
- “I’m in favor of the motion. These meetings are so long. It would be great to have a break and have ice cream and cake at each one.”

After a while, when discussion is finished, or when it is time to stop the discussion, the person in charge of the meeting asks if participants are ready to **vote** on the motion. If there is general agreement (consensus), the person in charge restates the motion and takes a vote.
- “All those in favor of the motion?” (People can vote with their voices or by raising their hands.)
- “All those opposed?” (Again, people can vote verbally or by raising their hands.)

In the case of the ice cream and cake motion, all the members of the committee voted “Aye!” They were in favor of the motion and it passed unanimously! In the future, ice cream and cake will be served at meetings.
Sometimes, though, the process is not so simple. For example:

During discussion one committee member was concerned about the expense of having refreshments served at meetings.

- “I don’t think our committee can afford to have ice cream and cake at every meeting. I would like to amend the motion to have ice cream and cake at every other meeting.”

There are various rules about whether the original motion can be amended (changed).

❖ Sometimes the person who made the original motion is asked to accept a friendly amendment. In this case, to change the wording of the original motion to have ice cream and cake at every other meeting.

❖ In more formal meetings, the person in charge may ask that the original motion be withdrawn, and then restated to include the proposed changes.

❖ Or the person in charge may require that the original motion be voted on. If it is defeated, a new motion, which includes the proposed changes, can then be introduced.

In our example, the friendly amendment was not accepted. The original motion was put to a vote, and it passed. Ice cream and cake will be served at all meetings!

Here’s another example:

There were many concerns about the cost of ice cream and cake at committee meetings. Discussion continued. Finally, someone suggested that the matter be referred to a sub-committee.

- “We have so many questions about this issue. I propose that we refer the motion to a sub-committee to find out exactly what it will cost.”

If there is general agreement, the person in charge of the meeting refers the motion to a subcommittee.

- “Please gather the necessary information and report back to the full committee at next month’s meeting.”
And one more example:

Discussion about ice cream and cake dragged on and on and on. Some people were concerned about the cost; others worried about the nutritional value. Many, however, thought it was a splendid idea. No one could agree. After quite a long time, someone acts to end the discussion and require the members to vote on the motion to have ice cream and cake at all meetings.

- “I move the previous question.” (make a motion to end discussion and take a vote)

Someone else supports the idea to end discussion.
- “I second the motion.”

The person in charge then asks for a vote. Two-thirds of the people vote to end the discussion. They then take a vote on the original motion. And, finally, it is agreed that ice cream and cake will be served at all meetings!

Remember, Robert’s Rules of Order are intended to provide a fair decision-making structure. They are not meant to stop important discussions or to take up lots of valuable time. They are meant to help groups work toward consensus in the fairest and most efficient way possible. Table 7 presents the terms you are most likely to hear during meetings. Keep it as a handy reference on parliamentary procedure.
Table 7
Robert’s Rules of Order: A Glossary of Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motion</td>
<td>an idea or action that a planning body member suggests or recommends</td>
</tr>
<tr>
<td>Second the motion</td>
<td>support a suggestion or recommendation that has been made</td>
</tr>
<tr>
<td>Amend the motion</td>
<td>offer a change or addition to a motion</td>
</tr>
<tr>
<td>Amendment</td>
<td>a proposed change to a motion</td>
</tr>
<tr>
<td>Refer the motion</td>
<td>ask a subcommittee to gather additional information about a motion</td>
</tr>
<tr>
<td>Postpone the motion</td>
<td>delay a motion until a stated future time</td>
</tr>
<tr>
<td>Move the question</td>
<td>bring an end to discussion and take a vote on the motion</td>
</tr>
<tr>
<td>Point of order</td>
<td>suggest that a “rule” of parliamentary procedure has been broken</td>
</tr>
</tbody>
</table>

WHO IS ROBERT?
Henry Martyn Robert was an officer in the United States Army. One day, without any warning, he was asked to run a meeting at his church. It was a disaster! People wouldn’t listen to each other; they wouldn’t take turns speaking. He was very embarrassed, and he vowed never to attend another meeting until he understood proper meeting procedures. He studied many books on British parliamentary procedure and in 1876 published the first edition of Robert’s Rules of Order.

Adapted in part from 10 Minutes to Better Board Meetings by Norah Holmgren (1997), Planned Parenthood Federation of America
Activity 7
**BE INFORMED**

We said before that information is an essential resource for your success. This checklist was created by consumers. It presents the specific kinds of information and training that will help you be more effective in your role.

Read through this checklist. Identify the items that are important to you, and then ask your planning body leaders to provide them!

### My Information Checklist

- Information in my own language
- An orientation to my role and responsibilities on the planning body
- Training on how to be an effective planning body member
- Basic information on the Ryan White CARE Act
- Definitions and a glossary of frequently-used words and acronyms
- Information about current medical treatments and medications
- A list of names and phone numbers of other planning body members
- Opportunities to meet with experienced planning body members
- Information about consumer groups in my community and state
- Minutes from past planning body meetings
- Other information I need:
Activity 8

GETTING THE MOST OUT OF MEETINGS: TIPS FOR SUCCESS

As a member of a Ryan White CARE Act planning body, one of your primary responsibilities will be to attend regular meetings. That's where the important discussions take place and decisions are made. Sometimes though these meetings may seem overwhelming — especially when you are new to the group.

Consumers gave us many great suggestions for ways to make participation in meetings easier and more productive. They offered ideas on how to prepare for meetings as well as what to do during meetings. Here is their advice.

Before you go to the meeting...

- Ask for directions to the meeting and if parking is available.
- Get a phone number to leave with your family or sitter.
- Find out who is in charge in case concerns arise.
- Read the materials you've received ahead of time.
- Seek out a buddy in the group and don't go to meetings alone, especially the first few times.

In their own words...

“Ask immediately how the group works and how you can be a fully functioning member.”

“Ask questions if something is being said that you don't understand. Don't let the conversation go on to the next topic until you understand.”
At the meeting...

- Introduce yourself and ask people to introduce themselves if they haven’t.
- Take notes — they will help you remember later.
- Remember, it’s okay not to know. It takes time to feel comfortable. Listen carefully.
- Ask questions — there is no such thing as a dumb question. Someone else probably has the same question and feels too shy to ask.
- Ask for a list of commonly used terms and initials. Don’t hesitate to ask what something means.
- Observe body language — you’ll pick up a lot of clues about how people are feeling.
- Attend regularly. It will help you understand the issues, and understand the group’s dynamics.
- Learn the subtle rules that make a difference — where to sit, what is done about lunch and breaks, and the best time to arrive and leave.
- Know yourself — be clear about your values and priorities.
- Be open to the perspectives of others in the group.

Between meetings...

- Think through the best way to handle the sharing of family or personal information so you can make your points most effectively.
- Get to know the other members. Learn about their perspectives.
- Talk with other consumers in your community to learn their perspectives on issues.
- Read, read, read.

In their own words...

“Find allies and buddies on the council who will help you.”

“Attending every meeting is important if you want to know what is going on.”
Activity 9

There’s So Much to Read!

We heard two very important things about preparing for Ryan White CARE Act planning body meetings. The first was how crucial it is to be well prepared for meetings. The second was how difficult it was to read and understand the many pages of information provided before each meeting!

On the Reading Worksheet we have listed some of the common problems people face when they encounter difficult or confusing written information. We have also listed some foolproof strategies for getting through all that reading material. Can you think of a few more? Jot them down in the space provided.

Remember to consult this worksheet from time to time. It’s full of good ideas you can use to be a well-informed planning body member!

In Their Own Words...

“Be well enough informed to be able to ‘think on your feet’ as the discussion unfolds.”

“Plan on an extensive time commitment. There’s lots of reading to do!”
<table>
<thead>
<tr>
<th>PROBLEM</th>
<th>STRATEGIES</th>
<th>MY THOUGHTS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Concentration:</strong></td>
<td>• Everyone learns better at certain times of the day. Be aware of your peak learning time and schedule difficult readings during this time.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Take breaks to check on your understanding. If your ability to understand the information is declining, take a break.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Choose a comfortable place for reading that will allow you to concentrate.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Read a small amount each day — that way you won’t have to read everything in one sitting, right before the meeting.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• When your concentration wanders, try reading aloud.</td>
<td></td>
</tr>
</tbody>
</table>

**Vocabulary:**

While I am reading I run into words that are difficult and that I don’t understand.

• Skim the material for unfamiliar words before you begin reading. Then look them up in a dictionary before you start reading.

• When you spot an unfamiliar word, read the whole sentence. Use the meaning of the sentence to help you define the word.
### My Reading Worksheet (cont.)

<table>
<thead>
<tr>
<th>PROBLEM</th>
<th>STRATEGIES</th>
<th>MY THOUGHTS</th>
</tr>
</thead>
</table>
| **Sentence structure:** Many of the sentences are long and confusing. | • Break the sentence down into shorter sections to get to the main point.  
• Read the sentence aloud.  
• Restate the concept or idea, using your own words. | |
| **Comprehension:** The concepts covered are just too hard and too complicated to understand. | • Take notes as you read.  
• Highlight areas that you want to come back to later.  
• Look for other reading materials that may explain the concept in simpler terms.  
• Make a list of concepts you don’t understand and ask another group member to explain them to you. | |
| **I need the basic information:** The material is written for someone who is already an expert on the subject. I’m new at this, and I have no idea what the author is writing about. | • Read the introduction to the material. Basic information is often included there.  
• Ask your contact person on the planning body for background reading materials that will help you understand the information being covered. | |
### My Reading Worksheet (cont.)

<table>
<thead>
<tr>
<th>PROBLEM</th>
<th>STRATEGIES</th>
<th>MY THOUGHTS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disorganized material:</strong></td>
<td>• Pay particular attention to section headings or any bolded or italicized information.</td>
<td></td>
</tr>
<tr>
<td>The reading material is</td>
<td>• Use the opening and closing paragraphs as organizational tools.</td>
<td></td>
</tr>
<tr>
<td>presented in a confusing</td>
<td>• Create an outline of the material as a guide for your own understanding.</td>
<td></td>
</tr>
<tr>
<td>way. There is no organized</td>
<td></td>
<td></td>
</tr>
<tr>
<td>structure.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>What's the point?</strong></td>
<td>• Scan the whole piece for an overview of what is covered.</td>
<td></td>
</tr>
<tr>
<td>I can't tell what is and is</td>
<td>• As you read, ask yourself questions to increase your understanding.</td>
<td></td>
</tr>
<tr>
<td>not important.</td>
<td>• Use a highlighter to mark the parts you think are most important.</td>
<td></td>
</tr>
</tbody>
</table>
Communication is at the heart of your job on the planning body. Just think about it:

- You **listen** to the concerns of people affected by HIV in your community.
- You **share** those concerns, as well as your own perspectives and experiences.
- You **ask questions** so that you will have complete information and an understanding of the issues.
- You **discuss** ideas and options with other members of the group.

Good communication skills are the key to effectiveness. And yet, we know that many consumers felt their own communication skills were inadequate. Some felt shy about speaking up in public. Some were uncomfortable expressing differences of opinion, especially with service providers and program administrators. Some even worried about how to maintain contact with other people with HIV in their communities.

Following are activities to help you think about your communication style and develop new skills as an effective communicator. Here's what you will find:

- **Activity 10:** Connections with Other Consumers: Ideas for Staying in Touch
- **Activity 11:** Learning to Listen
- **Activity 12:** Speaking Up: Tips for Success
- **Activity 13:** Questions: The Keys to Understanding
- **Activity 14:** Guidelines for Giving Reports
- **Activity 15:** “You Just Don’t Understand!”
- **Activity 16:** My Communication Worksheet

These exercises contain information and ideas that you can use in your work on the planning group. They can help you sharpen your communication skills. Get started now. It’s fun!
Activity 10

CONNECTIONS WITH OTHER CONSUMERS: IDEAS FOR STAYING IN TOUCH

Talking with other women, young people, and family members about their concerns will help you know what the current and important issues are. This will also make you a more credible advocate. Remember, your voice speaks for the voices of many others in your community. Here are some ideas for staying in touch with other consumers.

❖ Ask your support group members for their ideas and concerns.

❖ Develop a flyer that asks PLWH to contact you with their ideas and concerns.

❖ Distribute the flyer to AIDS organizations and support groups in your community.

❖ Ask local AIDS organizations to host “Consumer Coffees” so you can meet informally with others in your community to learn about their issues.

❖ When important or controversial issues are slated for committee discussion, telephone a representative group of consumers before the meeting to learn their perspectives.

❖ Write a “Consumer Column” for AIDS-focused newsletters on issues that come before the planning group.

In their own words...

“I needed help and assistance to maintain communication with other parents.”

“It is so important to get the opinions of other women with HIV before participating in discussions at the meetings.”
Do you have more ideas about ways to keep in contact with other consumers? Jot them down here.

**MY IDEAS**

Be sure to stay in touch with other people in the community who are affected by HIV. It's an important part of your job as a planning body member.
Activity 11
LEARNING TO LISTEN

A good communicator knows how to listen. She offers her undivided attention to the speaker — even when the subject is complex, painful, or controversial. You will need to listen carefully to other consumers to understand what is on their minds. You will also need to listen to the other members of the planning group. Pay attention to the “way” you listen. Sometimes it can interfere with your ability to hear.

The following “listening styles” really get in the way of hearing others. Watch out for them!

The mind reader. If you are trying to guess what someone is thinking or feeling, you won’t hear anything they are saying.

The rehearser. When you’re thinking about, “here’s what I’ll say next” you won’t hear what is being said.

The screener. Some call this selective listening — you only hear what you want to hear.

The dreamer. If your attention drifts off, you’ll be forced to ask, “What did you say?” or “Could you repeat that?” People will know you weren’t listening.

The know-it-all. If you relate everything you hear to your own experience, you probably won’t really hear what is being said.

The critic. When your attention is focused on judging the “messenger,” you’re sure to miss the message.

The goody-goody. Agreeing with everything you hear just to be agreeable or to avoid conflict does not mean that you’re a good listener!
What kind of listener am I? What can I do to improve my listening skills?

**My Ideas**

_In Their Own Words..._

“It takes a long time to understand, but stay, listen to what’s said, and keep coming.”

“It really helps to be a good listener.”
Activity 12
SPEAKING UP: TIPS FOR SUCCESS

As a planning body member, you will have to speak up before the group to discuss ideas, make statements about what you think should be done, or comment on actions being proposed. Many people feel nervous or shy about speaking up at meetings. However, that’s why you are there. Here are some tips for controlling your nervousness so that you can be an effective participant.

- **Know what you are talking about.** If you don’t know the issue or are not familiar with the topic being discussed, your nervousness will probably increase. Read your materials before the meeting so that you can participate in a meaningful way.

- **Think about what you want to say before the meeting.** Talk to your friends, your family, or your partner about the issues you’d like to raise. Write down your thoughts using words that are “natural” for you. Stand in front of a mirror and speak as if you are in the meeting.

- **Visualize yourself speaking to the group.** Imagine yourself speaking, your voice loud, clear, and confident. When you visualize yourself as successful, you will be successful.

- **Realize that people want to hear what you have to say.** You bring a unique perspective to the discussion. People want to hear about it. They want to know about your experiences, and they want you to be successful.

- **Focus on your message – not your nervousness.** Focus your attention away from your own anxieties. Instead focus on your message and the people you are talking to. Your nervousness will go away.

- **Use notes.** If you have important points you want to be sure to cover, jot them down on an index card or notepad. They will help you stay focused on your message.

- **Don’t apologize.** It’s okay if you are a little nervous, but you don’t need to share that feeling with the group.

- **Relax.** Take a deep breath to ease your tension. Remember, you have important information and insights to share. Be as natural as you can.

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**In their own words...**

“Sometimes it’s hard to speak up — even when I know that our needs aren’t being met!”

“Be as honest as possible. And don’t be afraid.”
Activity 13

QUESTIONS: 
THE KEYS TO UNDERSTANDING

Ask questions! That’s something we heard again and again from consumers. There is so much to learn, especially when you are a brand new member of a planning body. And the only way to be a productive member is to understand what is being said.

But many people feel shy about asking questions. They think, “Oh, that’s a silly question.” Or, “Everyone else seems to understand. I must be the only one who doesn’t.” Or even, “If I ask that question they will think I’m stupid.”

The number one thing to remember: There are no stupid questions! In fact, it’s a pretty good bet that if you have a question, someone else in the group has the same one but is too shy to speak out.

Questions can serve a number of purposes. And there are different kinds of questions. For example specific, closed-ended questions enable you to gather the exact information you need to participate in the discussion and in the decision-making process. The following are examples of closed-ended questions:

❖ What do those initials stand for?
❖ What is a funding formula?
❖ Can you please explain what Title II is?

Questions can also give you a deeper understanding of the planning group’s history and process, especially if you ask more open-ended questions such as:

❖ How did the planning group first become interested in this agency?
❖ Can you give me a little background?
❖ Are you able to tell me some more about the history of this issue?
You can also use questions to open up new ways to think about an issue. Consider these questions:

❖ Are there some other ways to look at this issue?
❖ What would be our ideal outcome?
❖ What would happen if we changed the way that we distribute these funds?

Finally, questions can be used to bring all participants into the discussion. For example:

❖ What are your thoughts on this issue, Dorothy?
❖ Do you have something to say about this, Rosa?
❖ Are there other issues or concerns that our group should be thinking about?

Questions are tools to help you gain information and understanding — about issues and about people. Use them wisely and use them often!
Activity 14
GUIDELINES FOR GIVING REPORTS

One of the best ways to take an active role in your planning body is to serve on a subcommittee. These smaller committees tackle such issues as community outreach, by-laws, and clinical advances. Reports and recommendations from subcommittees are presented to the full planning body for discussion and final decision-making.

If you serve on one of these subcommittees you may be asked to give a report to the full planning council. Or, you might report on an important issue that affects your community. If so, here are nine easy steps to follow. We’ve included an example to illustrate each step.

1) **Keep it Simple.** Begin with a simple statement of the issue. Briefly describe the work the committee has done on the issue. For example:
   • “Our committee was asked to find ways to provide childcare for members during planning body meetings. We interviewed members about their childcare needs and developed a list of ways we could meet those needs.”

2) **Present the key information your committee discovered about the issue.** Don’t offer your personal opinion. For example:
   • “Twenty percent of the people we interviewed said lack of childcare was a barrier to attending meetings. We identified three ways to overcome that barrier:
     • hire childcare workers during meetings;
     • find community volunteers to provide childcare during meetings; or,
     • provide money to group members to pay their own childcare expenses.”

3) **Explain what is important about the findings.** For example:
   • “Quite a few of our group members have a problem coming to meetings because of childcare. These members are all consumers — and we know how important it is to have consumers present at meetings. So, we must deal with this issue. We have looked at three ways to address this issue...(here you would describe the pros and cons of each approach to meeting the childcare need)...and we’ve decided that giving individual members money for childcare is the best approach.”
4) **If necessary, give a clear example to make your point concrete.**
   - You could describe one consumer’s struggle to find babysitters for her children while she attends monthly meetings. You could report that she would prefer to pay a babysitter she already knows in her own community, rather than having to bring her kids with her to the meeting.

5) **Ask for questions.** Be thorough, objective, and non-defensive in your answers.

6) **If your report calls for action, make a proposal.** For example:
   - “We recommend that our group pay childcare expenses for members. We also recommend that the money be given to members at the time of each meeting, rather than in the form of a reimbursement.”

7) **Explain what would be changed or improved if the committee’s proposal is accepted.** For example:
   - “If we pay for childcare for our consumer members we will make it much easier for them to attend meetings. It will also show how much we value their input by helping to overcome this barrier to their attendance.”

8) **Describe what the proposal would cost, who would need to be involved, and how it would be administered.**

9) **If appropriate, make a resolution for action.** Draft the resolution ahead of time. For example:
   - “I move that the child care expenses of consumer members be paid for by the planning council. Money for childcare expenses will be given to consumers at the time of each meeting.”

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**NOTES**

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Adapted in part from 10 Minutes to Better Board Meetings by Norah Holmgren (1997), Planned Parenthood Federation of America.
Activity 15

“YOU JUST DON’T UNDERSTAND!”

One of the greatest communication challenges facing consumers is dealing with anger and frustration during meetings. It is completely normal to feel upset from time to time, but an effective advocate must be able to communicate calmly and clearly under these difficult circumstances.

Conflict and disagreements are part of all human interactions. And committees of all kinds deal with differences of opinion among committee members. Just realizing that these differences are “normal” can relieve your worry.

Here are some common causes of disagreements.

❖ Differences in values, philosophy, or goals
❖ Differences in perception
❖ Simple misunderstandings
❖ Poor communication
❖ Inaccurate or insufficient communication
❖ Limited resources
❖ Fights for power, turf, or control

Differences of opinion will almost always occur. Your job is to increase the skills you need to deal with those differences. Learning to communicate respectfully and openly with other members will increase your effectiveness and make you a valued member of the group.

“… it’s hard not knowing how to critique decisions without feeling like an ‘ingrate.’”

“… I had trouble learning to voice my needs without anger or blaming.”
Activity 16

MY COMMUNICATION WORKSHEET

Now that you’ve learned more about the communication skills you’ll need to be an effective planning body member, it’s time to assess your own style and abilities.

On the next page you’ll find a Communication Worksheet. This worksheet is a tool to help you think about how you communicate with others. Here’s how to use it:

❖ First, read the statements and rate yourself on each one.

❖ Then, when you identify an area of weakness, think about how you could improve and write down your ideas. Talk them over with a trusted family member or friend. Try to put your ideas into practice.

Be sure to refer to the Worksheet regularly to see how your communication skills have improved. You’ll be proud of your progress!

IN THEIR OWN WORDS...

“Stay open minded and willing to learn.”
### My Communication Worksheet

#### My Beliefs & Behavior

<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>So-So</th>
<th>Yes</th>
<th>How Can I Improve</th>
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</thead>
<tbody>
<tr>
<td>• I believe that the perspectives and opinions of all group members are important.</td>
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<td>• I am patient and courteous towards other group members.</td>
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<tr>
<td>• I put aside my emotions and preconceived ideas.</td>
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<tr>
<td>• I limit comments and conversation with those sitting near me so I don’t distract others.</td>
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#### When I Listen

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<tr>
<th></th>
<th>No</th>
<th>So-So</th>
<th>Yes</th>
<th>How Can I Improve?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• I am an active listener.</td>
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<tr>
<td>• I focus on understanding what is being said.</td>
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<tr>
<td>• I concentrate on being present by not thinking about other issues.</td>
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<tr>
<td>• I ask myself, “Do I understand what that means?” If not, I ask for clarification.</td>
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<tr>
<td>• To make sure that I understand someone’s point of view, I restate their message in my own words and ask for confirmation.</td>
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<tr>
<td>• I try to be objective in evaluating what others are saying.</td>
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<tr>
<td>When I speak</td>
<td>No</td>
<td>So-So</td>
<td>Yes</td>
<td>How Can I Improve?</td>
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<td>--------------</td>
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<tr>
<td>I express what I want in a positive way.</td>
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<tr>
<td>I state my ideas clearly and concisely with an appropriate level of feeling.</td>
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<tr>
<td>I participate actively in the discussion, and support my points with evidence and examples.</td>
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<tr>
<td>I aim to create a shared understanding of issues and ideas.</td>
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<tr>
<td>I answer other member’s questions and challenges seriously and diplomatically.</td>
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<tr>
<td>I speak for no more than five minutes at a time.</td>
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<table>
<thead>
<tr>
<th>When I Disagree</th>
<th>No</th>
<th>So-So</th>
<th>Yes</th>
<th>How Can I Improve?</th>
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</thead>
<tbody>
<tr>
<td>I express my ideas and feelings without being critical of others.</td>
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<tr>
<td>I accept that other points of view will differ from my own and that we are all “right.”</td>
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<tr>
<td>I am receptive to opposing viewpoints.</td>
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<tr>
<td>I count to 10 before speaking when I’m angry.</td>
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<tr>
<td>I use “I” statements that represent my thoughts and feelings without blaming others for seeing things differently.</td>
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Throughout this book you’ve read comments from some of the consumers who completed our survey. In this final section, we’d like to introduce you to two women who have served on Ryan White CARE Act planning bodies — Linda Horton-St. Hubert and Gigi Nicks.

**Linda Horton-St. Hubert** is the Director of AIDS Programs at the Parents’ Place of Maryland, a family advocacy organization. She is a well-known trainer and speaker on women’s issues, consumer involvement, and consumer/provider collaboration. Linda is a co-author of *Making Connections: Building Support Networks for Families Living with HIV*. She serves on many boards and councils in her community and nationally.

**Gigi Nicks** has been an active consumer advocate for many years. She is the Director of Consumer Advocacy at the CORE Center in Chicago, a Ryan White Title IV program. She has served on her EMA’s planning council and helped to create a training program for new consumer members of the planning council. Gigi is a member of the Board of Directors of the AIDS Alliance for Children, Youth, and Families.

We asked Linda and Gigi what advice they had for you. Here’s what they told us — in their own words.
LINDA HORTON-ST. HUBERT

Linda, please tell us about your experience as a consumer on your planning council.

“My experience on our local planning council in 1993 was very different than it is today for consumers. At that time, there were really only two sides of the table – them and us. The only ones of “us” who had any power were the ones who could scream and fight. Those of us who acted differently – peacefully – had no power.

“I was on the PLWH subcommittee. We began to realize that if we wanted things to be different we would need to join together. We started inviting other consumers to attend meetings even if they couldn’t vote — just their physical presence made a statement. It was a big support to have them in the audience.

“And then, the chair of our PLWH committee died. He was a long-time advocate and the Friday night before he died, he was at the council meeting acting out, speaking for an important issue. We were grief stricken that he had fought so hard and yet nothing had changed when he died. For a long time we had kept ourselves separate – gay, women, mothers. But no more — the impact of his death brought us together.”

In what kinds of ways did you come together?

“Well, first we began to talk to each other more. And then we began to ask ourselves what we as consumers could do to make things better. We were determined to become more vocal. We would no longer allow other council members to talk about things we didn’t understand. We demanded explanations. We would stop the conversation when we didn’t understand what was being said. We kept interrupting to ask questions. Finally they decided that we needed orientation and training. That was the beginning of the major changes on our planning council.”
Linda, what was it like for you on a personal level? Did you go through any changes because of your experience on the planning council?

“One of the hardest things for me was that there was a roomful of white people deciding what services people of color needed. There were no African American providers, no Executive Directors of color at the table. I was forced to come to grips with my own prejudice. It became very important to me to figure out how to help the providers understand who we were as people. I felt they were only looking at the dollars and the numbers. They had forgotten that this whole fight was about people.

“I also struggled with my own set of class issues. There were people from different backgrounds and social classes among the consumers – IV drug users, street workers, lesbians, transgenders, and me, an African American middle class Christian woman. These were people my friends and I used to talk about – people I had been taught not to like or understand. I had to ask myself, “How can I work with these people? How can I sit at the table and be part of this group?” It took a major adjustment of my attitudes. I learned how important it was to deal with my own prejudices and how much I could learn from these people who were struggling with the same illness.

“Finally, I learned how to sit at the table and be true to myself. Some of the other consumers would scream, fight, and act out. That's not me. I wanted to sit at the table in peace. I was determined to behave in the way of Martin Luther King. I called it my ‘Martin Luther King Stand for Peace.’ The Peaceful Rebel, that's me!”
Linda, can you sum up your advice to other consumers?

“Yes. I call these my **10 Steps to Success**”

1. **Begin with yourself.** You can’t participate effectively until you have your own self together. Think about how you present yourself. Develop an understanding of how you come across to others.

2. **Learn about the community.** Learn who the people and programs are. Learn about the needs.

3. **Develop the big picture.** Educate yourself about the issues that concern all people affected by the service system. Think beyond your own situation.

4. **Develop new skills.** Attend conferences (especially the free ones). Learn about computers, about public speaking, about how organizations work.

5. **Assume the best about people.** The other members of the planning group are not the enemy.

6. **Learn to collaborate** — with policy makers, with service providers and with other consumers.

7. **Be prepared.** Do your homework. Read what they send you. Ask questions.

8. **Learn to say “no.”** Don’t let yourself take on too much. Know when you need a break.

9. **Share the spotlight.** Suggest other consumers who can also participate in leadership activities. Provide encouragement to them.

10. **Go to the dump-yard.** Get rid of old prejudices and stereotypes. Keep an open mind and an open heart.

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Gigi Nicks

Gigi, what is the most important advice you have for consumers about serving on planning bodies?

“The number one thing I would tell new consumers is take your time! Before I became a council member, I attended meetings as an observer. I did that for about a year. That experience helped me learn how the council functioned, who had the power on the council, and how decisions were made. Over time, when I felt comfortable, I put in an application to become a member. By then, I understood how things worked and was able to participate very effectively.

“These days I do training for consumers who are interested in taking on a leadership role in the fight against HIV. And I strongly advise them to do the same thing — to go to council meetings and spend some time watching and listening. When you attend as an observer, you are not vulnerable and you are not as accountable as when you are a member. It gives you time to get experience and learn about the issues. The consumers who have taken my advice tell me they feel much more comfortable participating once they become council members. It is very painful to be thrown into a situation where you can’t be an effective participant.

“One woman I trained recently was noticed by the council because she came to meetings, spoke out when it was important, and gained valuable experience. Now she has submitted an application, and she’s sure to be selected. She has become known as a reliable person who can speak with understanding and passion.”

What other advice would you offer?

“My second piece of advice is to look for training opportunities. We have a consumer-run group in Chicago that provides training to any consumer who is interested in learning about the Ryan White CARE Act and how planning bodies function. We hold retreats for consumer members of the council to fill in the gaps in their knowledge and understanding. We also offer ongoing training and support to make sure that
people feel comfortable to participate in meetings. Finally, we have a buddy program that matches new council members with experienced ones. At first, if the new consumer member feels uncomfortable speaking out or asking questions, the veteran “buddy” can do it for them.”

**Gigi, will you sum up your advice, please?**

“Of course. Let me sum up by saying that the steps to effectiveness are not that steep. But they do require commitment. As consumers, we have to take responsibility for ourselves — it’s our job! Remember:

- Don’t feel intimidated. Go to meetings, sit and listen, learn.
- Learn about all the resources out there to help you. Thse HRSA HIV/AIDS Bureau’s PLWH Sourcebook is especially helpful.
- Stay connected with other consumers. Get together with them before meetings to talk over issues that will be addressed by the council — especially when voting on important issues. Get their feedback, information, and support.
- If you don’t feel you can ask a question sit next to a buddy who can ask the question for you.
- Finally, don’t let yourself feel alone. Many of us had few resources and knew very few people when we started. If that’s your situation, change it!”

**IN THEIR OWN WORDS...**

“You may think you don’t have what it takes to do this seemingly huge job — but you do!”
Through education, training and advocacy, AIDS Alliance for Children, Youth & Families addresses the needs of children, youth, women & families living with, affected by, or at risk for HIV and AIDS.