



# Metro DC Collaborative for Women with HIV/AIDS

Center for Women Policy Studies

in collaboration with

**PROTOTYPES**

The Measurement Group

Metro DC Collaborative: CWPS, 1996



# Metro DC Collaborative

Health Resources and Services  
Administration

Special Projects of National  
Significance

Metro DC Collaborative: CWPS, 1996

# Metro DC Collaborative

- Center for Women Policy Studies
  - in collaboration with
- PROTOTYPES
- Evaluation by The Measurement Group

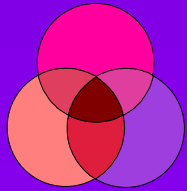


Metro DC Collaborative: CWPS, 1996

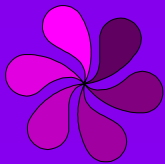
# Slides in This Presentation are Coded



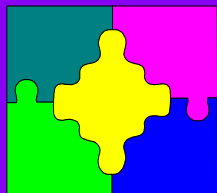
- About the Collaborative



- Using observations of CWPS staff



- Using focus group results from women with HIV



- Special projects of Collaborative members

# Metro DC Collaborative: Project Goals

- Comprehensive assessment of local barriers to services for women with HIV
- Policy development to reduce barriers
- Capacity building to overcome barriers
- Information dissemination to reduce barriers



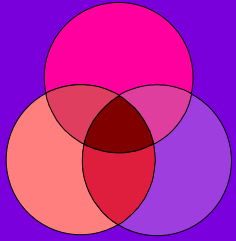
Metro DC Collaborative: CWPS, 1996

# Purpose of This Presentation

- Results of CWPS staff group interview about Year 1 activities
- Preliminary results of focus groups with women with HIV

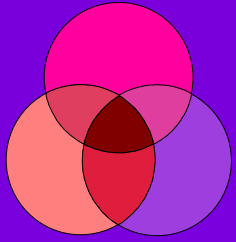


Metro DC Collaborative: CWPS, 1996



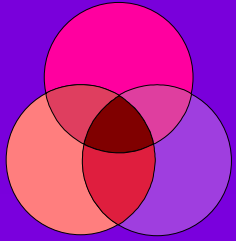
# Year 1: Staff Group Interview

Center for Women Policy Studies

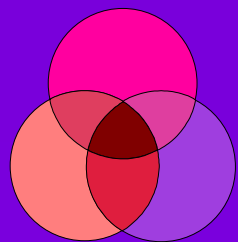


# Staff Group Interview

- AIDS Team
  - Belinda Rochelle
  - Edna Viruell
  - Irene Snow
  - Jennifer Smith
- Interview conducted by The Measurement Group
- Interview questions were developed by The Measurement Group in collaboration with CWPS staff

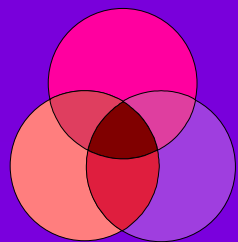


What Changes Have There Been in  
the Collaborative Over the Last 12  
Months?



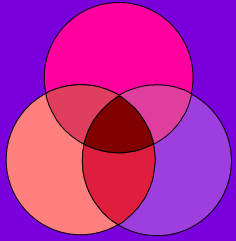
# First Year Changes in the Collaborative

- Focused on gathering information from women with HIV to determine unmet needs, advocacy issues, and policy planning
- Shifted focus from Steering Committee meetings to community outreach to organizations and individuals in Metro DC
- Established relationships with local advocacy organizations and direct service providers

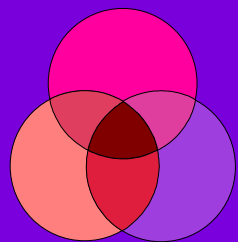


# First Year Changes in the Collaborative

- Facilitated linkages among HIV/AIDS service organizations in the community while maintaining a neutral role
- Focused on permanency planning, case management, Medicaid, and managed care policy issues during the first 12 months

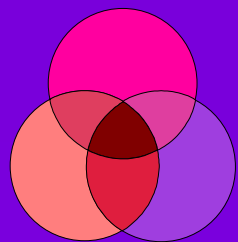


# What is the Vision of the Metro DC Collaborative?



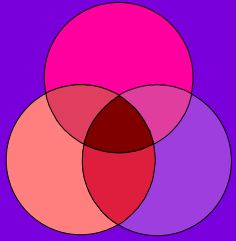
# Staff Vision of the Metro DC Collaborative

- Support women with HIV in the community
- Facilitate involvement of women with HIV in the Collaborative's advocacy and local policy development efforts
- Examine barriers women with HIV face, identify policy issues, and advocate for policy change
- Conduct policy development activities
- Document the Collaborative's implementation process

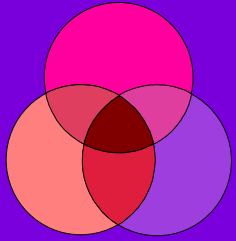


# Staff Vision of the Metro DC Collaborative

- Develop and nurture leadership of women with HIV by including them in all aspects of planning and development
- Educate policy makers about issues facing women with HIV
- Create a model demonstrating how to mobilize communities in an effort to advocate for the needs of women with HIV

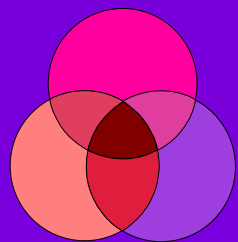


# What Has Been the Role of CWPS Staff in the Collaborative Process?



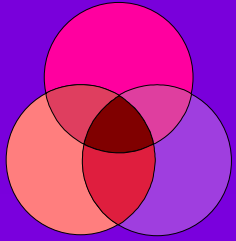
# Role of CWPS Staff in the Collaborative Process

- Organize communities involving...
  - women with HIV
  - local and federal health departments and other government agencies
  - policy makers, community leaders, advocates
  - service providers and other professionals
- Plan, schedule and facilitate working groups and information sharing meetings to address issues faced by women with HIV

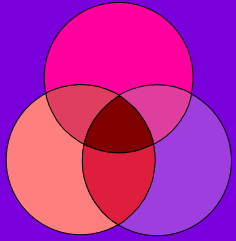


# Role of CWPS Staff in the Collaborative Process

- Identify policy issues based on experiences of women with HIV
- Communicate with individuals and agencies regarding the experiences and needs of women with HIV
- Maintain connections with the community and collaboration with other agencies
- Design-implement policy advocacy activities
- Work closely with women with HIV as consultants to the Collaborative

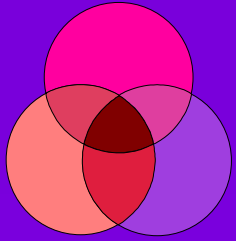


# How Do the Collaborative's Activities Inform the Work of CWPS with the National Resource Center on Women and AIDS (NRCWA)?

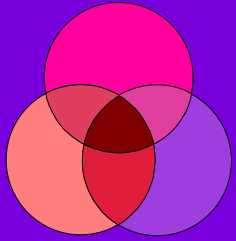


# How Collaborative Activities Feed Back into the NRCWA

- The Collaborative is the centerpiece of the work of NRCWA
- Through the Collaborative, CWPS staff learn from women with HIV, their advocates and providers about emerging national policy issues
- CWPS staff feed their knowledge from other CWPS research into the Collaborative and local issues

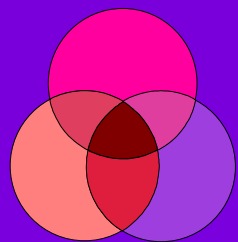


# What Issues Affected the Building of Relationships with Participating Agencies in the Collaborative?




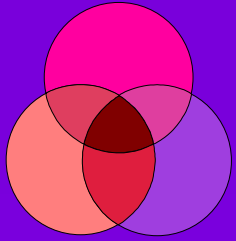
## Issues Affecting Development of Relationships Among Agencies

- Some organizations are hesitant to participate in the Collaborative since they feel that their highest priority is direct care services
- Some agencies folded due to lack of funding
  - they must focus on survival rather than collaboration due to uncertain future funding

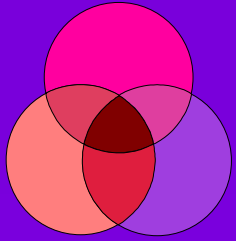


## Issues Affecting Development of Relationships Among Agencies

- Information sharing meetings on case management, Medicaid, and permanency planning positively affect relationships with agencies
- The CWPS team is multi-ethnic and all women, which positively affected outreach and development of relationships with agencies and women with HIV
- Service providers lack knowledge and commitment to address the needs of women with HIV

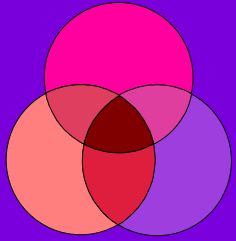


Have There Been Issues That Have  
Either Made It Easier or More  
Difficult for Agencies to Participate in  
the Metro DC Collaborative?



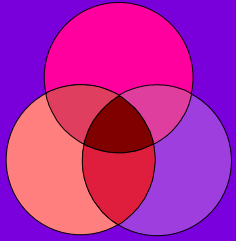
# Local Issues that Affected the Metro DC Collaborative

- The DC financial crisis
- Some HIV-service organizations have folded due to the local fiscal crisis
- Women with HIV are unable to access services due to problems with Medicaid and are being forced into managed care
- Limited number of out-stationed Medicaid benefits specialists in DC
- Collaborative efforts needed to establish linkages for women with HIV in different states in metro area (DC, MD, VA, WV)

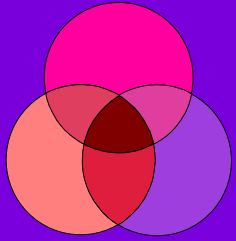


# National Issues that Affected the Metro DC Collaborative

- Agencies are vulnerable to the national budget crisis as there is no government or state legislature to advocate for DC, which directly depends on the federal budget appropriations

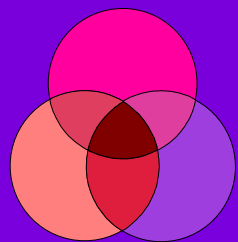


Have There Been Any Barriers to Accomplishing Project Activities?



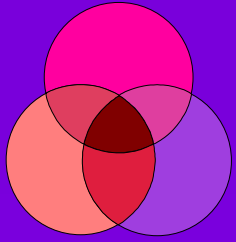
## How Barriers Affected Collaborative and Actions Taken to Reduce Them

- **Barrier:** difficulties recruiting women with HIV to attend focus groups
- **Effect:** focus groups for Latinas and Caucasian women did not occur as scheduled
- **Action:** generated alternative strategies to reach Latinas and white women with HIV
  - Conduct outreach to key CBOs and case workers
  - Tap into networks of women with HIV
  - Conduct family focus groups for Latinas



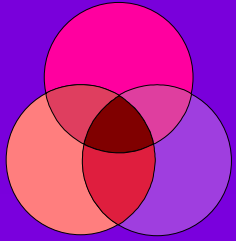
## How Barriers Affected Collaborative and Actions Taken to Reduce Them

- **Barrier:** distrust among government agencies and CBOs
- **Effect:** initial lack of community participation in the Collaborative
- **Action:** CWPS became involved in other organization and coalition meetings to support their efforts rather than “reinventing the wheel,” which resulted in established relationships with agencies in the community

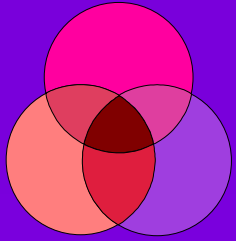


## How Barriers Affected Collaborative and Actions Taken to Reduce Them

- **Barrier:** organizations which have not participated in the Steering Committee were unaware of its existence or unfamiliar with the purpose of the Collaborative
- **Effect:** limited community participation
- **Action:** policy and information briefings were held for CBOs
  - Develop a “Woman CARE Newsletter” to maintain connection with contacts in the community

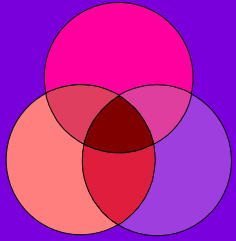


# The Role of the Steering Committee

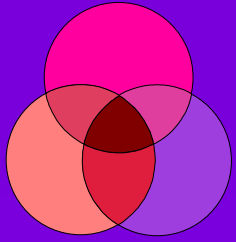


# Steering Committee

- For year 1, CWPS staff provided a forum for information sharing and networking to establish connections among agencies in the Steering Committee
- For year 2, the Steering Committee will develop their coalition-building skills, and have mini-conferences and additional information sharing meetings

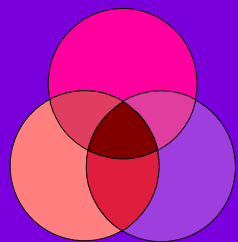


# The Process of Identifying Policy Issues Relevant to Women with HIV



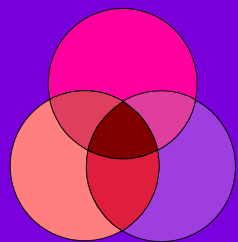
## Policy Issues Relevant to Women with HIV Chosen by:

- Involving women with HIV as:
  - Steering Committee members
  - hired consultants
  - focus group participants
- Drawing from the expertise of women with HIV
- Focusing on issues related to access to services and continuity of care (Medicaid/managed care) through CWPS participation in other coalitions and working groups



## Policy Issues Relevant to Women with HIV Chosen by:

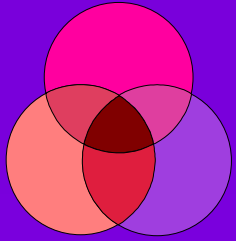
- Assessing what impacts the availability of services and the day-to-day struggles of women with HIV
- Listening to women with HIV about what they say are top issues



# Policy Issues Chosen in Year 1

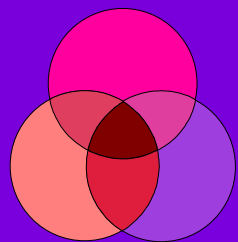


- Permanency Planning
- Medicaid
- Case Management



# How Have Women with HIV Participated in the Metro DC Collaborative?

Metro DC Collaborative: CWPS, 1996



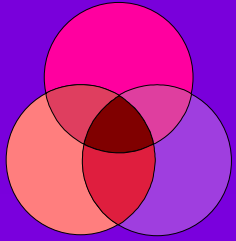
## How Women with HIV Participated in the Collaborative

### ■ Year 1

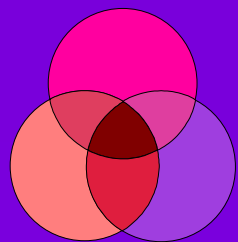
- 5 women participated in the steering committee
- 15 women participated in focus groups
- 15 women participated in information sharing meetings
- 3 women served as consultants in conducting outreach and recruitment of women with HIV

### ■ Year 2

- CWPS plans to conduct more focus groups and in-depth interviews with women with HIV

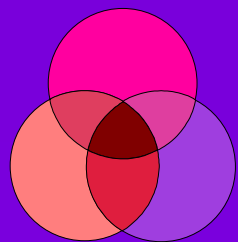


# First Year Policy Accomplishments of the Collaborative



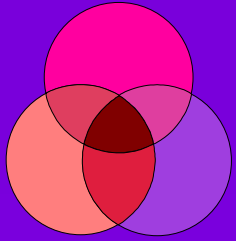
# First Year Policy Accomplishments

- Included women with HIV of diverse racial/ethnic backgrounds in the Collaborative in accordance with CWPS philosophy
- Team work by staff resulted in effective communication and problem-solving
- The Steering Committee brought together a multi-ethnic group of researchers, policy analysts, local service providers, and women with HIV

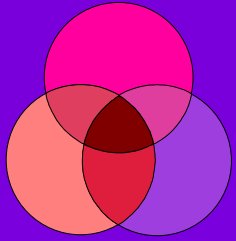


# First Year Policy Accomplishments

- Sponsored information sharing meetings for local service providers and women with HIV
  - permanency planning
  - medical manifestations of HIV/AIDS in women
- Established network of federal and local contacts and policy makers to work with Medicaid
- Identified top priority policy issues for women with HIV
  - Medicaid, case management, permanency planning

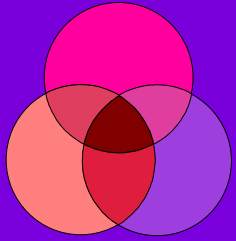


# Considerations for Year 2



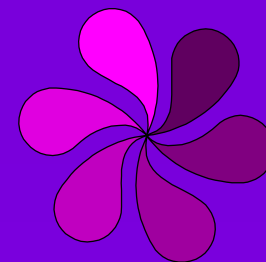
## Policy Plans for Year 2

- Distributing newsletters to community contacts
- Continue involving women with HIV as consultants
- Continue holding quarterly meetings with the Steering Committee
- Developing a flow chart of policy issues as they emerge
- Creating or updating a list of referrals for women with HIV



## Policy Plans for Year 2

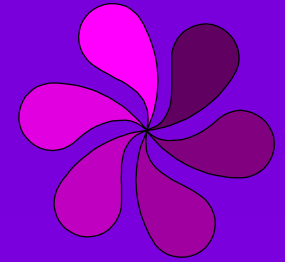
- Continue disseminating information through information sharing meetings
- Convene a second set of focus groups and conduct individual interviews with women with HIV



# Focus Groups of Women with HIV

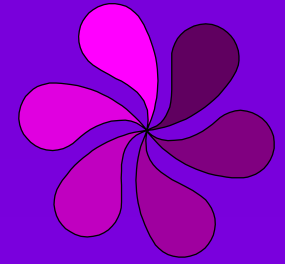
Metro DC Collaborative: CWPS, 1996

# Focus Groups of Women with HIV



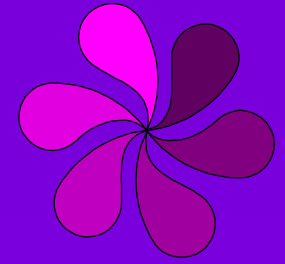
- Focus groups were held in community-based organizations that were easily accessible by participants (e.g., in their community)
- Two focus groups were held in August and September, 1995
- Focus groups were scheduled for early evening, the most convenient time for participants to attend
- Stipends were given to participants

# Focus Group 1 Participants

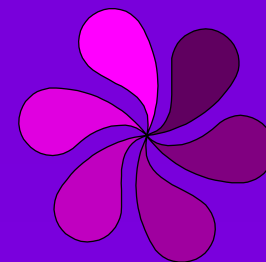


- 10 African American women with HIV
- Ages ranged from mid-20s to early 60s
- Two participants recently learned of their HIV status while others knew for a couple of years
- Participants worked full- or part-time outside of the home, unable to work due to the advanced stage of the disease, or were primary caretakers of their children
- Participants' visible symptoms ranged from none to severe

# Focus Group 2 Participants

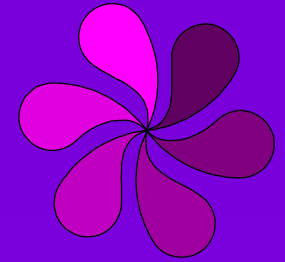


- 5 African American women with HIV
- Ages ranged from mid-30s to mid-40s
- HIV status was known from 2 to 9 years
- All participants were recovering from alcohol and other drug abuse
- Participants worked full time outside of the home, attended school, or were unable to work due to physical problems and depression
- Each participant obtained medical services from the same provider since her diagnosis



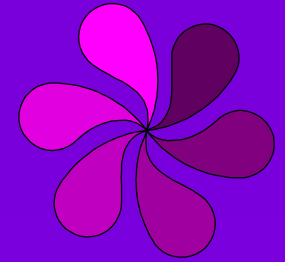
# Where Do You Go to Get Health Care?

# Focus Group Participants Used the Following Resources

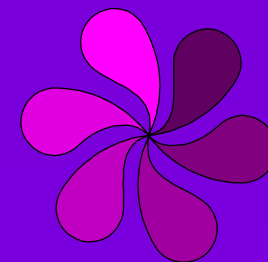


- AIDS Hotline - resource information
- Case Manager assigned through an agency
- Damien Ministries
- Georgetown University Hospital
- George Washington Hospital
- HIV Community Coalition
- Howard University clinical trials (WIHS study)
- INOVA

# Focus Group Participants Used the Following Resources

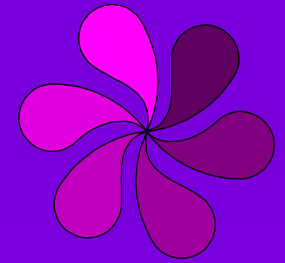


- Informal networking with other persons living with HIV/AIDS Metro Teen AIDS
- Montgomery County Health Department
- Prince George County Health Department
- Support groups (informal and structured)
- Us Helping Us
- Whitman Walker Clinic



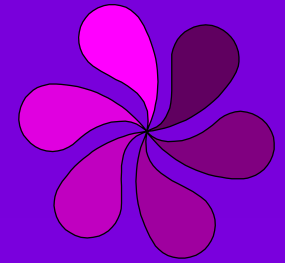
# Barriers to Care for Women

# Barriers to Care for Women

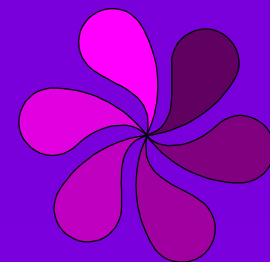


- Lack of physician education on HIV/AIDS diagnosis
- Lack of compassion from physicians when interacting with women patients
- Fear of being recognized, stigmatized, rejected and left alone due to HIV status
- Setting the needs of children, significant others, jobs, and housing issues over own health care
- Long waiting lists for medical appointments

# Barriers to Care for Women

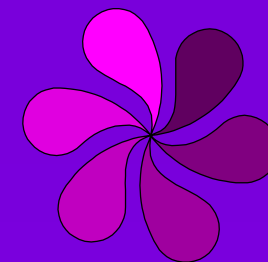


- HIV status of some women determined the type of service they received
- Medications prescribed without presenting options or discussing side effects with women with HIV
- Difficulty in adjusting to new physicians
- Stringent requirements and bureaucracy when trying to receive disability (SSI)



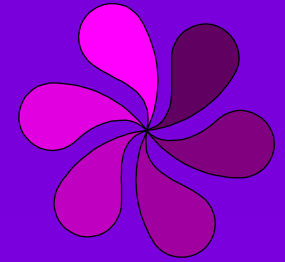
# How Can the Delivery of Services Be Changed to Meet the Needs of Women with HIV?

# How Service Delivery Can Accommodate Women's Needs

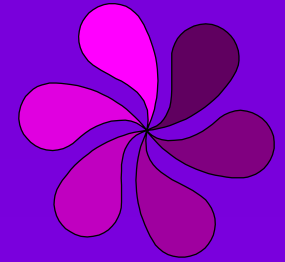


- Hire persons with HIV as case managers to assist women's relationships with service providers and to facilitate rapport
- Provide more support groups specifically for women with HIV
- Provide home health care to prevent onset of symptoms and to assist the women's ability to care for her illness

# How Service Delivery Can Accommodate Women's Needs

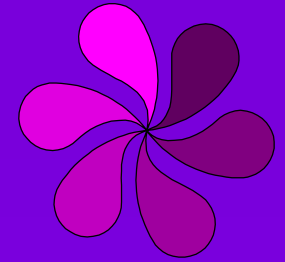


- Incorporate effective communication and involve women with HIV in the treatment plan and medication regimen
- Provide compassionate care
- Increase HIV/AIDS service providers in the Metro DC area
- Ensure that all women with HIV have access to services



# Involvement of Women in Policy Development

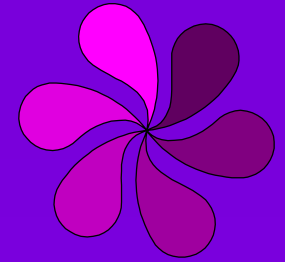
Metro DC Collaborative: CWPS, 1996



# Focus Group Participants' Perceptions on Policy-making Opportunities for Women

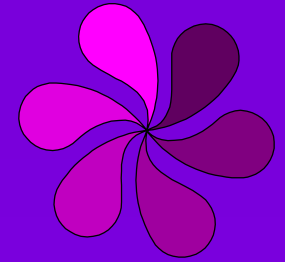
Metro DC Collaborative: CWPS, 1996

# Women's Perceptions on Policy-making Opportunities

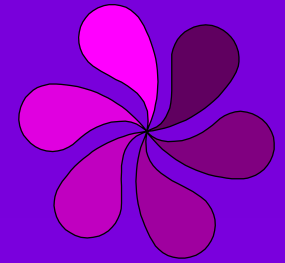


- Participants expressed interest in participating in policy-making bodies
- Most services are identified as being gender-biased toward men
- Lack of HIV-related services for women of color
- Society “punishes” women with HIV by taking away their self-confidence and self-esteem when accessing services

# Women's Perceptions on Policy-making Opportunities

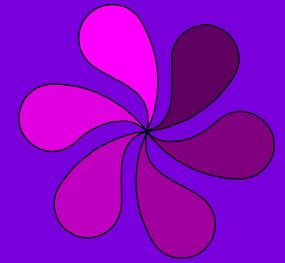


- Lack of awareness of opportunities for women to participate in setting policies for HIV-related services
- Most women are afraid to come forward to be involved
- Need for more support groups relevant to women's issues
- Need to assist women in developing self-confidence and self-esteem



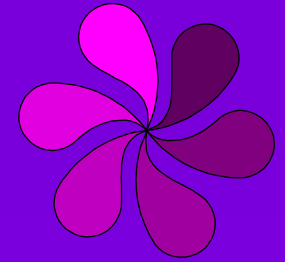
# Needs Expressed by Focus Group Participants

# Women's Needs



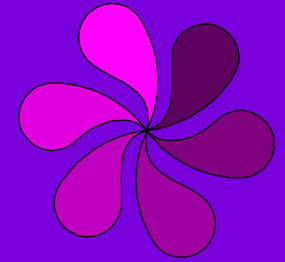
- Information on how to talk to children regarding HIV, including therapy for children
- How to disclose HIV status
- Support groups to deal with pressures and challenges of the disease
- Day care facilities
- Training for service providers (sensitivity, communication, confidentiality)
- Provision of home health services for women with HIV

# Women's Needs

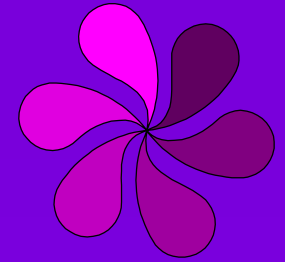


- Hiring women with HIV to assist in communicating HIV information
- Networking and information sharing
- Facilitating women to have a stronger voice in the Metro DC area
- Cultivating an environment of trust so that more women can come forward to participate
- Therapy for families
- Retreats
- Enrollment in clinical trials

# Women's Needs



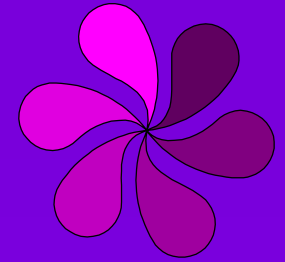
- Outreach to women with HIV
- Education about HIV disease
- Woman-centered AIDS care
- Information
  - nutrition
  - alternative medicine
  - continuum of care
  - credit problems
  - social security and related benefits
- Assertiveness training




# Policy Issues Discussed by Focus Group Participants

Metro DC Collaborative: CWPS, 1996

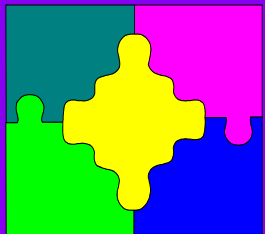
# Policy Issues



- Mandatory testing of all pregnant women
- Equal access to services and clinical trials
- Child care
- Decentralizing services to increase access
- Food stamp distribution
- Providing list of service providers to clients at intake
- Providing clients with ongoing education regarding self-care



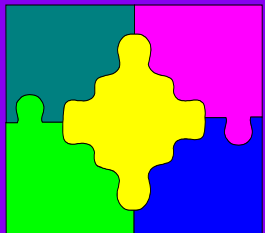
# Additional Activities of the Metro DC Collaborative



Metro DC Collaborative: CWPS, 1996

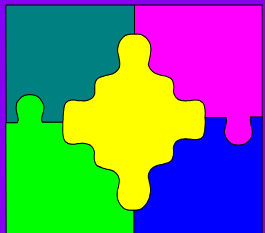
# PROTOTYPES

- Training of Trainers for staff from agencies in the metropolitan area
- Topics include: Women and HIV/AIDS, Drugs and Addiction, Violence against Women, and Case Management
- Needs assessment of local service needs and provider practices



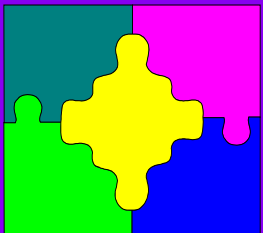
# PROTOTYPES

- Agency action plans and technical assistance to service agencies in the metropolitan area
- Agency action plans include development of agency goals and needs assessments
- Technical assistance has been provided to agencies who request this service



# The Measurement Group

- Developing methods to measure new programs by CWPS and PROTOTYPES
- Developing measures of empowerment and self efficacy
- Continuing to assess changes in individuals and service agencies as a result of the activities of the Collaborative



# Authors of This Presentation

- Program results from the Center for Women Policy Studies
  - Leslie R. Wolfe, Ph.D.
  - Belinda Rochelle
  - Edna Viruell, M.P.H.
  - Irene Snow
  - Jennifer Smith
- Evaluation results from The Measurement Group
  - Grace Lee, M.P.H.
  - George J. Huba, Ph.D.
  - Lisa A. Melchior, Ph.D.





# The End



Metro DC Collaborative: CWPS, 1996