

# Managing Scarcity

Report on a Statewide  
Initiative to Build Skills and  
Enhance Collaboration Among  
Ryan White HIV Planning  
Councils in California

February 2008

Prepared by

**CompassPoint**  
NONPROFIT SERVICES

## A C K N O W L E D G M E N T S

This report chronicles a three-year initiative that benefited from the involvement of many individuals and groups.

Almost 100 members of various HIV community planning bodies participated in the series of conferences, the leadership retreats, and the advocacy activities as a part of the Managing Scarcity Initiative. Their participation was phenomenal in the feedback that strengthened each conference, the openness in sharing struggles and successes, and in their day-to-day work in making the critical decisions for future care and services.

The Planning Committee for the five conferences worked incredibly hard to push the traditional boundaries of large meetings so they could be places of learning, provide deeper connection, and be a catalyst for regional and statewide change. Susan Strong provided instrumental leadership in developing and facilitating the conference agendas and proceedings, Laura Thomas and Jeff Byers provided critical planning in the design of each gathering. John Mortimer, in his former role as Director of AIDS Partnership California, provided the initial concept and impetus for the Managing Scarcity Initiative, artfully managed all the moving parts, and saw the project to its successful implementation. Steve Lew, Michelle Gislason, and many other CompassPoint staff created the leadership learning cohorts and managed the evaluation activities of the initiative. Laura Thomas and Steve Lew were the primary writers for this report and the regional case studies.

AIDS Partnership California gratefully acknowledges these contributions, as well as the generous support of the members of AIDS Partnership California. Over the course of the initiative our funding members included The Evelyn & Walter Haas, Jr. Fund, The California Endowment, The California Wellness Foundation, and Kaiser Permanente. We are appreciative of the specific support from Sutter Health and a grant from The California Endowment which made the final year of the initiative and this report possible.

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About AIDS Partnership California

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# I. Introduction

Between January 2005 and December 2007, AIDS Partnership California (APC) – a collaboration of private funders in California – organized and directed the **Managing Scarcity Initiative** (MSI). The goal of the Managing Scarcity Initiative was to strengthen Ryan White community planning groups and their deliberations in relation to their management of increasingly scarce health resources for people living with HIV in California. Managing Scarcity was conceived by John Mortimer, in his former role as Director of Collaborative Enterprises at Northern California Grantmakers and AIDS Partnership California<sup>1</sup>.

The Managing Scarcity Initiative centered on a series of programs to support the state's nine community planning entities located in Ryan White CARE Act Title I-funded areas at an important turning point in California's HIV epidemic. Beginning in 2001, new funding for Ryan White had stalled in California, while the number of people living with HIV/AIDS in the state had continued to climb. Planning councils that had been charged with the legal mandate of setting priorities for the funding of HIV health and social services, along with the local health departments that administered those funds, were struggling as processes that had worked well for allocating new funds in the past no longer worked in a period of diminishing funds. New skills and orientations were needed, it was felt, to help planning council members and local health agencies conduct meaningful planning and effective service and resource allocation in a climate of shrinking resources and more complex demand.

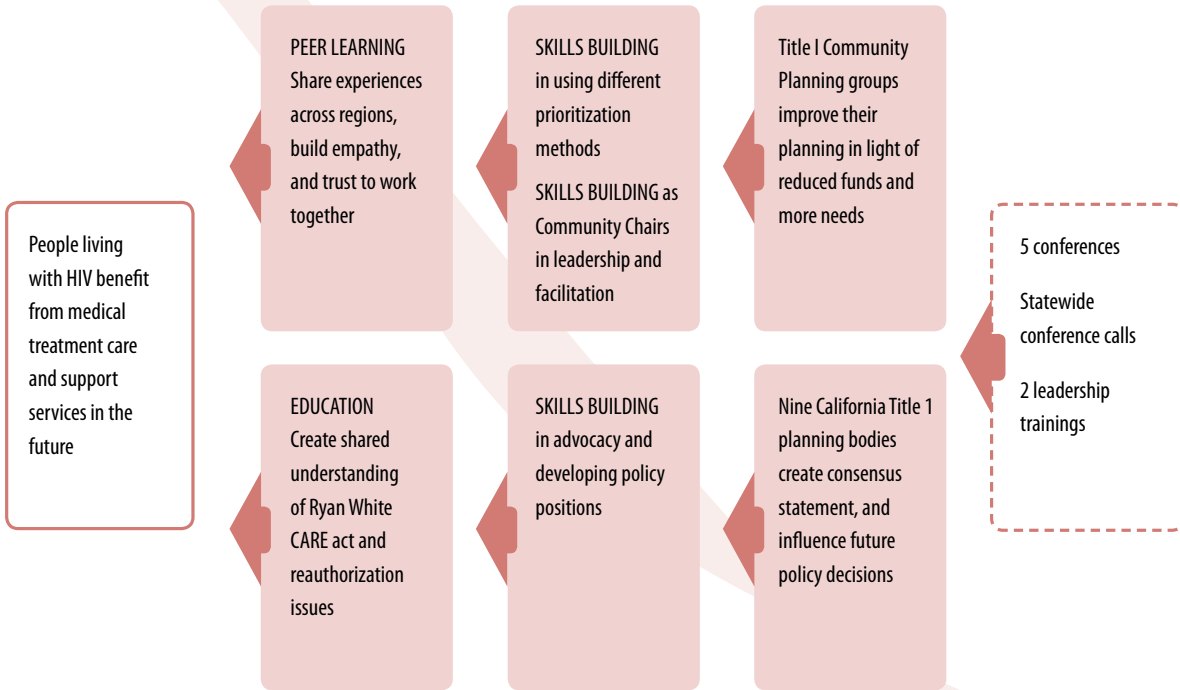
The core of the Managing Scarcity Initiative involved a series of **five statewide planning, coordination, and skills-building conferences** held over three years, each of which involved an average of between 60 and 80 participants from each of California's nine Eligible Metropolitan Areas (EMAs)<sup>2</sup>. Each conference had a different theme or focus, addressing aspects of the work of both community planning councils and grantees. Managing Scarcity also included ongoing support to facilitate conference calls on public policy strategies, and coaching and leadership training to two targeted groups of council members: community co-chairs and women living with HIV.

The Managing Scarcity Initiative aimed to create an entirely new structure aimed at bringing together Ryan White Title I stakeholders and decision makers to enable them to learn from each other and better prepare for changes in the political, economic, and scientific landscape that would affect people living with HIV over the third decade of the epidemic. The following report describes the evolution of the three-year initiative, the outcomes realized by planning council participants, and their community planning efforts during this time. These descriptions are interspersed with three specific case studies detailing some of the ways in which Managing Scarcity was able to help local jurisdictions use the tools they had gained to confront problems related to declining resources and expanding and increasingly complex HIV-infected and affected populations. The report provides basic information and guidelines on the project to help encourage and support similar efforts in other states and regions to bring members of HIV-related planning groups together to collaboratively address critical issues in HIV planning and delivery.

*1 AIDS Partnership California grew out of a regional grantmaking fund sponsored by Northern California Grantmakers. Over the course of the Managing Scarcity Initiative, APC funding members included The Evelyn & Walter Haas, Jr. Fund, The California Endowment, The California Wellness Foundation, and Kaiser Permanente. Sutter Health also made a substantial contribution to MSI.*

*2 This terminology changed in reauthorized 2008 Ryan White legislation to Transitional Grant Area (TGA) for the smaller metropolitan areas in California, and continued with EMA for the larger areas. "EMA" is used for both types of regions in this document.*

## Managing Scarcity Initiative Logic Model



## II. Summary of Project Outcomes

The Managing Scarcity Initiative was thoroughly evaluated throughout the project period to track participant satisfaction and the specific benefits accruing from the statewide meetings and related activities. The evaluations found that Managing Scarcity consistently met its objectives and that participants were able to apply the lessons learned from the process to strengthen their own local planning and decision-making skills. The great many of the tools and approaches presented at the conference are still in use today, from Los Angeles' adoption of the value paradigms for priority setting, to Orange County's continued engagement in policy discussion. 38.6% of participants stated they used one to two tools and 40.9% said they used three to four

tools. After the five conferences concluded, 87% of the participants said that the tools and strategies presented would still be useful for their EMA's planning. 79% were also likely to very likely to use these tools in their EMA. The strongest impacts of Managing Scarcity involved strengthening local and national advocacy efforts; sharing council practices; and developing planning council leadership.

*"I think these conferences have been a great help. I have been a [Planning Council] member for ten years and [in these conferences] I learn new things from each and every one I have attended. New ways to approach old problems, as well as new and upcoming problems."*

Strengthening of local and national advocacy efforts meant that the Managing Scarcity Initiative was able to make an impact on the 2006 reauthorization of federal Ryan White legislation. Previous efforts to develop a statewide consensus on Ryan White in California had been marked by significant disagreements – disagreements that in turn had hampered the state's ability to

influence legislation on its own behalf. The consensus that Managing Scarcity was able to generate at the state level was remarked upon and appreciated by the California Congressional and Senate offices, and had a national policy impact. Planning council members who had been provided with training and the opportunity to advocate for themselves and their communities were not only empowered as individuals, but were able to affect policy efforts at the federal level. Participants were given access to policy makers, and were able to follow up with them and make their concerns heard beyond their individual council processes.

The development of council leadership was another intended effect of Managing Scarcity. For this reason, Managing Scarcity conferences were complemented both by the Generations Project – a multisession program designed specifically to build the leadership capacity of women living with HIV on planning councils – and by a focused training program conducted specifically for planning council co-chairs from throughout the state. Over the course of Managing Scarcity, a number of council members and staff stepped forward as leaders both in their communities and on a statewide basis, including women with HIV, young gay men, people who had lived with HIV/AIDS for many years, and individuals new to the system of care.

AIDS Partnership California believes that many of the processes, practices, and products that have grown out of the Managing Scarcity Initiative are highly replicable for other states, regions, and jurisdictions of the US. For populous states that contain several different Ryan White Part A planning regions, the model offers an opportunity to create better cohesion and information sharing, and to build collaborative approaches and partnerships that enhance quality of care and manage better responses to diminishing resources. Managing Scarcity may also provide a model that can help states and regions that contain different HIV planning and coordinating bodies bring participants in those bodies together to discuss mutual needs and issues, share knowledge and perspectives, and formulate new approaches to collaboration that may also have important policy and advocacy outcomes. Managing Scarcity also includes lessons on building planning, leadership, and decision-making capacity among planning council members, consumers, and co-chairs that may help strengthen the capacity of local planning bodies to better manage and make tough decisions regarding scarce resources.

AIDS Partnership California encourages other jurisdictions and planning groups throughout the nation to consider increased intergroup networking, planning, and consensus building as a way to increase the effectiveness of all of our efforts to serve the neediest HIV-infected and affected populations using the limited pools of public resources at our disposal.



## III. Background of the Initiative

### The Ryan White Community Planning Process

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act is a federal legislative program that was first enacted in 1990 to improve the quality and availability of care for low income, uninsured, and underinsured individuals and families affected by HIV disease. The program is named after Ryan White, an Indiana teenager whose courageous struggle with HIV/AIDS and against AIDS-related discrimination helped educate the nation. Reauthorized three times since its inception – in 1996, 2000, and 2006 – the Ryan White program delivers HIV/AIDS care to over 500,000 people each year. During its most recent reallocation, in December of 2006, the Act was renamed the Ryan White HIV/AIDS Treatment Modernization Act (RWHTMA), and featured a number of changes in terms and definitions.

Ryan White legislation allocates federal funds to US urban areas hardest hit by HIV/AIDS through Title I – renamed Part A in 2006. California has nine areas receiving such aid:

- Inland Empire (Riverside and San Bernardino Counties)
- Los Angeles (LA) County
- Oakland (Alameda and Contra Costa Counties)
- Orange County
- Sacramento (Sacramento, Placer, and El Dorado Counties)
- San Diego County
- San Francisco (Marin, San Francisco, and San Mateo Counties)
- San Jose (Santa Clara County)
- Sonoma County

With federal Ryan White funding comes a number of obligations, including the requirement to have a community planning process responsible for prioritizing and allocating funds across a number of service categories, such as primary medical care, mental health care, housing, and transportation. The community planning process is designed to ensure that local needs and priorities are taken into account, and that the funds are used effectively to build a continuum of care for low income, uninsured people living with HIV/AIDS. Local community planning councils must include both consumers and providers of services, and are required to reflect the demographics of the local epidemic. At the present time, at least one-third of planning council members must be people living with HIV/AIDS. Each council determines its own process for accomplishing its tasks within the parameters set by the legislation and by the federal Health Resources and Services Administration (HRSA), a division of the Health and Human Services Department. HRSA provides a list of allowable services, and councils choose which services to support and by how much. Councils are required to take into consideration a number of criteria, including the demonstrated need for services, the priorities of the affected communities, and the availability of other resources.

In addition to the Part A funds for urban areas, Ryan White Part B (formerly Title II) funds are allocated directly to the states, including California, for distribution to local jurisdictions in support of essential HIV medical and supportive services. Part C funds support the provision of direct HIV health services by medical clinics, while Part D funds support programs providing tailored services for women, children, and youth infected and affected with HIV. Finally, Ryan White Part F funds support a number of programs, including dental schools, demonstration projects, and training for medical professionals.

Over the three years of the Managing Scarcity Initiative, a number of changes took place in the funding and legislative environment for California's nine Part A/Title I areas. The most significant involved the reauthorization of Ryan White legislation in the fall of 2006. The previous Act expired in 2005, and much of the work of MSI between early 2005 and the final conference in 2007 was focused on advocating for and then interpreting the new legislation. In addition to the revised legislation, funding levels changed over the years of MSI. Overall, appropriations for Part A/Title I services decreased from Fiscal Year (FY) 2003 to 2007, with funds for Part A/Title I areas in California declining along with reductions in total appropriations.

## Context of the Managing Scarcity Initiative

Since 2003, the federal appropriations for Ryan White Part A/Title I have decreased, even though the number of people living with HIV/AIDS in the US has continued to increase. Each of the California EMAs has struggled with the question of how to meet increasing needs with no significant increases in resources, and in some cases large reductions. In many respects, it had begun to seem that the job of planning councils had changed from identifying and meeting new service needs to choosing which programs to cut. Planning councils were facing a new challenge that many of them were unprepared for, as the experience and training they had received did not always translate into the task of managing fewer resources and making difficult decisions regarding how to eliminate needed services. The problem did not seem to have an easy solution, nor any end in sight, as federal funds were increasingly scarce.

John Mortimer identified this problem, and decided to use the resources of AIDS Partnership California to do something about it. By mobilizing the private foundation membership of APC, John was able to generate significant support for Managing Scarcity from The California Endowment, the Evelyn & Walter Haas, Jr. Fund, The California Wellness Foundation, Kaiser Permanente, and Sutter Health. These funders remained active throughout the MSI process, and in many cases attended and served as active participants in Managing Scarcity conferences and gatherings. The integrated support of funders through MSI typifies the uniquely collaborative relationship that AIDS Partnership California has been able to facilitate between private funders and HIV planners, providers, and consumers throughout California.



## Planning Council Dynamics

The inclusion of multiple perspectives on planning councils, while leading to stronger decisions, can also create tension among the various interests and needs of consumers, nonprofit providers, community members, and public health departments. Table 1 summarizes some of the competing interests, needs, and opportunities to meet those needs for each group. Other factors that affect council dynamics include the balance of power between local government and the council; the strength of working relationships among council members; the capacity of grantees to support the planning process; and the quality of council leadership.

**TABLE 1: Factors Influencing Planning Council Dynamics**

GROUPS	DISTINCT PLANNING INTERESTS	COMMON PLANNING NEEDS
<b>CONSUMERS</b>	<ul style="list-style-type: none"> <li>Find ways for specific services to be improved, maintained for self and groups of consumers.</li> <li>Specific health and service needs are addressed in plan</li> <li>Services and money are transparent, “accounted for”</li> <li>Equal or dominant voice in the discussions</li> </ul>	<ul style="list-style-type: none"> <li>Information and process that builds trust in services needs assessment</li> <li>Tools to analyze service categories</li> <li>Credible metrics of service access, quality, and cost</li> <li>Common framework for considering future needs and resources</li> <li>Common framework for making personal and group values explicit</li> </ul>
<b>PROVIDERS</b>	<ul style="list-style-type: none"> <li>Service contracts protected</li> <li>Fair measures for setting service standards and evaluative metrics</li> <li>Organizational services provided are adequately reimbursed</li> </ul>	<p><b>COMMON ADVOCACY NEEDS</b></p> <ul style="list-style-type: none"> <li>Up-to-date analysis of public policy changes, and implications upon planning</li> <li>Advocacy skills building</li> </ul>
<b>GRANTEE</b>	<ul style="list-style-type: none"> <li>Plan serves public health mandates – safety net</li> <li>Plan can be implemented</li> <li>Public health agency contracts protected</li> </ul>	<p><b>COMMON OPERATING NEEDS</b></p> <ul style="list-style-type: none"> <li>Member recruitment, orientation</li> <li>Facilitation skills development</li> </ul>



## IV. Goals, Objectives, and Key Activities

### Goals and Objectives

The Managing Scarcity Initiative worked to attain the same set of goals throughout the program, with specific objectives and themes developed for each individual conference. This section lists the three overarching goals for the program itself, and includes a partial list of the objectives for each of the five conferences, with overlapping or repetitive objectives removed. From the outset, the Managing Scarcity Initiative has been designed to focus on adding to the tools, skills, and abilities that local community planners – including Ryan White Title I Planning Councils, grantees, and support staff – can use to respond actively and innovatively to the changes required by declining resources and an altered legislative focus.

#### Overarching Managing Scarcity Initiative Goals:



1. To increase capacity within key Title I EMA leadership to respond creatively, with depth and breadth, to financial challenges as they present, whether they result from reduced fund allocations, changes in client mix, increased demand for services, or other issues.
2. To increase capacity within key Title I EMA leadership to respond skillfully, creatively, and strategically to leadership challenges as they present, whether they result from reduced fund allocations, changes in client mix, increased demand for services, or other issues.
3. To provide opportunities for interaction among EMA leadership with an eye to building coalitions, strengthening networks, and improving communication.

#### Objectives of Managing Scarcity Conferences:

1. Develop an understanding of the status of consumer services and program funding, as well as participant concerns about managing scarcity in the upcoming environment in EMAs in California.
2. Develop a shared understanding of various topics surrounding resource reduction, including services rationing, commonly used definitions, ethical, and legal issues.
3. Develop increased understanding of leadership and leadership challenges in times of scarcity.
4. Develop greater knowledge of other EMA participants, identifying potential partnerships for dialogue and support as the environment changes and EMAs are forced to respond to those changes.
5. Present opportunities to exchange ideas, compare solutions, and develop working relationships with colleagues from other EMAs.
6. Increase participant awareness of the issues and context surrounding RWCA reauthorization and the current status of the legislation.
7. Develop effective advocacy skills and help participants feel more confident in their ability to advocate for RWCA reauthorization and appropriations.

8. Deepen participant understanding of the known and anticipated impacts of the Ryan White HIV/AIDS Treatment Modernization Act of 2006 (RWTMA) on Title I EMAs.
9. Share strategies to implement the RWTMA at the local level relative to the delivery of care and support services and managing scarcity.
10. Consider the ramifications of any new federal legislation following sunset of the RWTMA in 2009.
11. Explore potential points of consensus around federal legislation and other policy development that impact people living with HIV/AIDS in California.

## Conferences

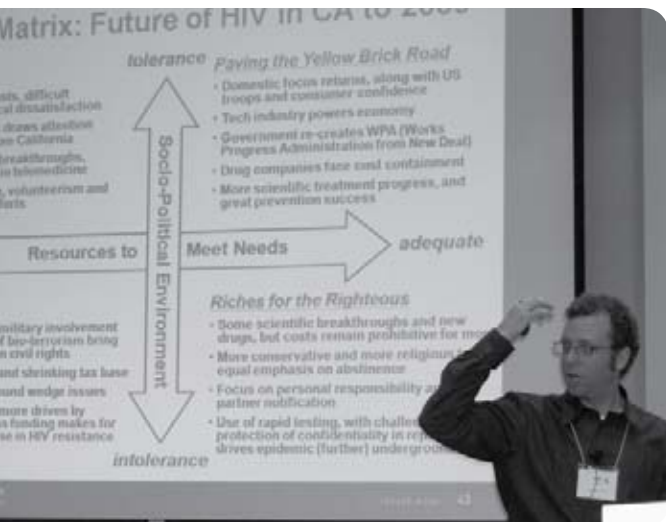
As noted, a total of five two-day conferences were held at various locations in Northern and Southern California during the MSI process. Attendees included planning council/commission officers and members, including co-chairs, prioritization and allocation committee chairs, membership committee chairs, policy committee chairs, consumer committee chairs, local health jurisdiction grantees, planning council support staff, and key staff of the California Department of Health Services Office of AIDS.

*“These conferences help me to realize why I do this work — and be sustained by the work itself. Also the information I can bring back to the board. I have been happy to be able to attend regardless of my own scarcity. [I] learned more about the process of funds and how much I have to learn. I have valuable information to share as a consumer.”*

In addition to developing formal goals and objectives, the planning team designed the meetings to address group learning needs and to build a peer learning environment. As a counterpoint to the dire nature of “managing scarcity,” fun activities and social time were considered a critical component of each conference, and were built into each day’s activities. Through the leadership of Sue Strong, each conference had a theme, with activities and table decorations to match. The “Ryan White Jeopardy Game,” modeled after the television show, proved so successful that it was re-done with new questions for more than one conference. Social time was also included on one evening for each conference. Those activities were popular, but were also designed to meet the objectives of building trust among conference participants while strengthening ties and effective working relationships throughout the state.

The planning team also designed agendas to include a mix of activities, from didactic lectures to small group discussions to exercises that required participants to move around the room.

Agendas also included a mix of presentations from content experts and from conference participants themselves. All conferences were set up with tables seating eight to ten participants, and the seating charts were created with care. The planning team intentionally mixed participants for some agenda segments to promote inter-EMA information sharing and trust building. The planning team’s knowledge of the personalities and experiences of most of the participants was very helpful in assigning individuals to tables. Balancing tables by EMA, gender, race/ethnicity, and role (e.g., grantee, council member) was important to the final assignments. For other activities, participants were seated by EMA.



*“What I liked best about this conference? Meeting with and interacting with people in different areas (EMAs) and learning how similar our challenges are in spite of the differences in demographics.”*

Following is a short summary of the focus of each of the five Managing Scarcity conferences. A full set of documentation materials is available from AIDS Partnership California describing each conference, including agendas, participant lists, the full evaluation write-up, and a summary of the discussions and notes.

- *Pathways to Decisions* was held in Oakland, CA, June 15-16, 2004. The focus of this inaugural Managing Scarcity gathering was on managing reduced resources through the use of clear decision-making frameworks, including values-based justice paradigms. It was attended by 58 participants. The core of the conference was a series of presentation from John Golenski on ethics-based tools for addressing scarcity.

- *Decisions and Leadership* was held on December 7-8, 2004, in Costa Mesa, California. Designed specifically for the leadership of Title I EMA Planning Councils across the State, the conference focused on long-term leadership challenges through scenario planning and justice paradigms. The conference was attended by 61 total participants.

*“Each conference has had an impact on my role on the planning council. Justice Paradigms impacted the way we make decisions in setting priorities and allocations. Scenario planning helped us think regarding the application of paradigms; and the Advocacy training impacted the way we advocate for policy and understand that we need to educate our partnerships.”*

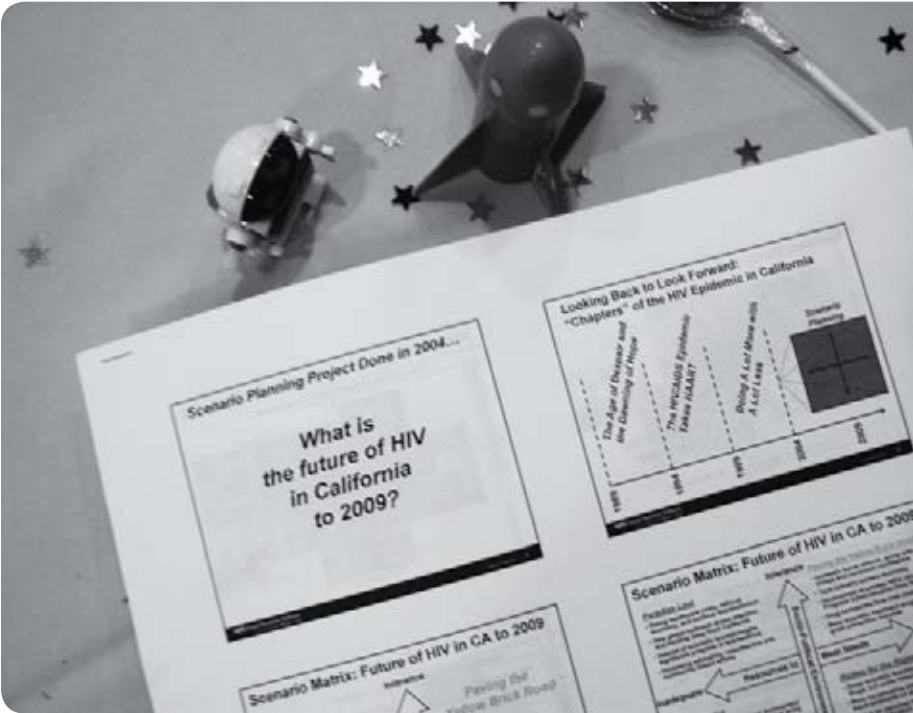
- *Leadership and Advocacy* was held in Sacramento on March 14 and 15, 2005, with 75 participants. This conference gave attendees training in how to participate in the legislative process, including information and skills required to successfully advocate on behalf of persons with HIV. A highlight of the conference was a session with California State Assemblymember John Laird and State Senator Carole Migden, and a staff person for Assemblymember Paul Koretz. Most specifically, the conference focused on reauthorization and appropriation issues related to the Ryan White CARE Act. After the conference, local advocacy organizations made appointments for participants to meet with their Congressional representatives in their district offices, receiving hands-on experience in the advocacy process.

*“The first conference inspired our [Planning Council] to document and refine its decision-making process. The third conference had the greatest impact on our Planning Council in terms of initiating its advocacy efforts.”*

- *Today and Tomorrow* was held on December 6-7, 2005, in West Hollywood. It focused on Ryan White reauthorization, policy analysis, sustaining council leadership over time, and learning from other EMAs. The Consolidated Statement was a key topic of discussion. This was the largest of the Managing Scarcity conferences, with 78 total participants from the nine EMAs in California.

- *Into the Future*, the final Managing Scarcity conference, was held on May 14-16, 2007, in San Francisco for 76 individuals. With the passage of the Ryan White legislation complete, the conference was closely focused on the impact of the new legislation and efforts to advocate for better programs in the future. A highlight was a conference call with Connie Garner from US Senator Edward Kennedy’s office, enabling participants to convey their concerns and ask questions of a key staffer involved in the Ryan White reauthorization process. In keeping with the “future” theme, much of the agenda was spent on identifying key concerns, proposals, and activities to carry forward as next steps for California.

Two smaller programs focused upon people living with HIV who serve as consumer members on planning councils. The Generations Project brought together 26 women over two annual leadership retreats and provided group coaching sessions by phone to build the leadership and advocacy skills of these women (see text box on page 16). A two-day retreat for planning council co-chairs was also held in 2007 to help these leaders fully step into their co-chair role, and to reinforce the skills needed to approach difficult group decision-making processes. Each of these programs was designed to catalyze peer learning among participants along with introducing group leadership skills.



## CASE STUDY #1 – LOS ANGELES COUNTY COMMISSION ON HIV

# Applying a Values-Based Framework to the Prioritization Process

### CONTRIBUTORS:

*Carla Bailey (Co-Chair), Robert Butler, (Executive Committee member and Co-Chair of the Diversity Committee), and Craig Vincent-Jones (Executive Director, Commission on HIV).*

The Los Angeles Eligible Metropolitan Area (EMA) is the largest in California, with an estimated 60,500 residents living with HIV/AIDS. Persons living with AIDS (PLWA) in Los Angeles County represent about 5% of all AIDS cases nationally and more than a third of California's AIDS cases, according to the 2007 Ryan White CARE Act FY 2007 Title I Application. The Los Angeles Part A/ Title I budget for FY 2007 is \$35,263,560, an increase of \$368,183 from FY 2006.

The Los Angeles County Commission on HIV is a fairly large planning council with 50 members and alternates who represent the breadth and diversity of LA County. The original council was created in 1990, and its operating and planning processes were well developed by 2004. On the whole, the commission's discussions on key issues have gone well throughout its history. The commission underwent a major restructuring in 2005 that resulted in more independence for the commission which now reports to the County Board of Supervisors rather than the Los Angeles County Health Department. There was significant membership turnover at that time. The LA Commission seems to have emerged from these changes as a stronger organization, with a good relationship with the grantee.

Several aspects of the Managing Scarcity Initiative and its conferences were able to build upon and enhance the existing strengths of the Los Angeles County Commission on HIV, including developing the commission's decision-making processes, advocacy efforts, and leadership development efforts. The largest impact on Los Angeles probably grew out of the first MSI conference, which offered the LA Commission some powerful tools at the right time. When this conference was held in June 2004, the Los Angeles Commission was only two months away from its scheduled prioritization process. A presentation made by John Golenski on justice paradigms, values-based decisions, and the notion of operating values resonated with several of the participants from Los Angeles (see page 12). A fairly large portion (8 of the 42 members) of the commission was able to consider the usefulness of the values framework at the Managing Scarcity Conference before they made a presentation to the full council on this framework. Robert Butler said, "We've had comprehensive plans, but this paradigm and using operating values gave us a stronger base to affirm and stand on the plan itself."



"This was a pretty mature council that has dealt with many issues together. Bringing a values-based framework to the prioritization process was not difficult to embrace, and yet it made a difference" said Craig Vincent-Jones, commission staff to the process. During the actual priority-setting process, Robert Butler said the values framework helped the group get through one of the most difficult decisions. He said, "It helped us with the low scenario (10-15% reduction) decision making. Everybody could understand that this was a common framework the council was using, and after discussions, we adopted a utilitarian value – 'the greatest good for the greatest number of people.' We looked to our needs assessment and service utilization data to inform that value." As a result, this led to decision making that kept intact the services which had the highest priority for the greatest number of people. Transportation services and peer support programs were cut as a result of this prioritization.

By exploring the values of the group, the commission was also able to adopt a social justice value affirming that certain individuals and communities needed to be addressed as a part of this prioritization, including newly diagnosed women and the disproportionately affected transgender



community. Los Angeles has continued to use these paradigms as a way to organize its priority setting process, as documented in their most recent application for Part A/Title I funds (see column at right.)

While the Los Angeles County Commission on HIV had a wealth of experience with priorities and allocations, the group took full advantage of the opportunities to share and learn from other EMAs at the series of MSI conferences. They adopted planning tools from other EMAs and learned from others' successes and failures. "About 60% of the things we do now are based on learning from other EMAs through the MSI gathering," Robert said. "Things we have changed or enhanced." They produce a version of the service category summary sheets first developed in San Francisco as documented in their application. "Our process is totally improved. People are making it their business to understand what is going on," added Carla Bailey. "There are contentious discussions but they are healthy...to get to what is valid and real for people and their communities."

Advocacy was another important area in which Managing Scarcity had an impact, according to Craig Vincent-Jones: "LA has been pretty far out on advocacy and the conference validated our approach, since we have been criticized in the past for being so out there." The commission has used its new status under the LA Board of Supervisors to address more policy issues, and has encouraged other planning councils to do so as well. "It was an important tool to help the nine planning councils together to speak consensually for the state," said Vincent-Jones.

Los Angeles has been able to use the statewide network of planning councils developed through MSI to become more involved in policy and advocacy issues. When HIV name reporting was proposed, for example, the Los Angeles Commission strongly supported it, and asked planning councils across the state to endorse it as well. Commissioners visited San Jose and Alameda to make presentations to their councils. "This wouldn't have happened without the APC meetings and facilitating interpersonal relations [among councils]," Vincent-Jones said.

The MSI conferences also had an impact on the individuals involved. Carla Bailey attended all of the conferences except the first one, and now serves as Co-Chair of the LA Commission. The conferences taught her leadership skills and gave her the support to speak up. She said, "I sat on the council for three years and didn't open my mouth. Going to these (MSI) gatherings I stopped being quiet. I let others weigh in first...but I make sure now that I have my say." She serves as a mentor to others on the commission, sharing her skills with them and encouraging them to speak up, too.

The Los Angeles Commission on HIV is a large planning council with an independent staff, many years of experience in prioritizing and allocating funds, and they gained some very concrete benefits from MSI. Participants from Los Angeles were actively engaged in all of the conferences, and presented on topics such as HIV name reporting. The timing worked well with other changes in their structure and leadership, so they were able to take full advantage of the tools MSI introduced.

## **Some Impacts of the Managing Scarcity Initiative on the Los Angeles County FY 2007 Priority and Allocation-Setting Process**

"The process continued in February 2006 with the selection of paradigms that described the model, perspective, and context within which the commission would make its decisions (equity, utilitarianism, retributive justice) as well as the operating values that guide the process, dialogue, and decision making (quality of data, beneficence, access, efficiency), culminating in the delineation of three funding scenarios (contingency plans).

"At the next stage (March 2006), the P&P Committee prioritized – and the commission subsequently approved – all of the services in the continuum of care (CARE Act-funded or other) based on expressed and documented needs, documented demands for the service, and other relevant data. The final needs assessment report and the Service Category Summary Sheets (SCSS) were developed, a provider survey was distributed, and the results compiled, and provider focus forums were conducted in each of the EMA's eight Service Planning Areas (SPAs) for further input."

*~ From the Los Angeles 2007 Ryan White CARE Act FY 2007 Title I Application*

## Prioritizing Values: Tools to Respond to Diminishing Resources and Increased HIV Service Demand

Over the first two conferences, John Golenski, EdD, a leading medical ethicist and Executive Director of the Institute for Ethics and Health Policy, made a series of presentations and conducted interactive exercises with MSI participants to introduce social justice frameworks for decision making and discussion tools for surfacing group operating values. These frameworks were explored during conference sessions and participants were encouraged to adapt some of these discussion tools within their service prioritization processes.

*“Explicit values clarification is often not discussed or poorly stated. It was a good discussion and exercise.”*

*“Our commission culture is changing and although adversity and diversity are on-going challenges, the paradigms are helping us to understand we do have/share common values and the trust in setting allocations as we rotate an entire process established trust with new people and audience understanding.”*

### Potential Justice / Resource Allocation Paradigms:

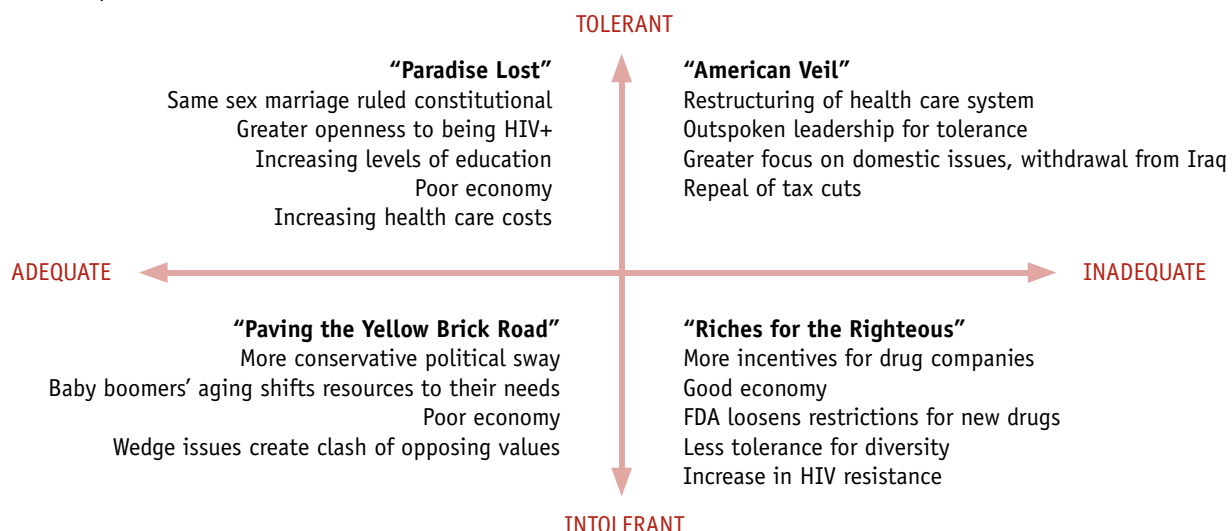
- **Equality:** Equal portions to each or equal cuts
- **Equity:** Relatively equal portions with attention paid to severe need
- **Fairness:** Similar cases treated in a similar fashion
- **Altruism:** Volunteering to take a cut or go without
- **Compassion:** Rescuing those who cannot support themselves
- **Chance:** Fate decides through random choice
- **Coercion:** Enforced decision by authority
- **Utilitarianism:** Greatest good for the greatest number
- **Rights & Duties:** Community participation recognizes reciprocal rights and duties

### Operating Values:

- **Openness or Transparency:** Decision processes are not secret but open for all to witness and for all interested parties to input
- **Good Citizenship:** A focus on an individual’s or an agency’s responsibilities as a participant in the larger community
- **Efficiency:** Accomplishing the desired operational outcomes with the least possible use of resources
- **Organizational Integrity:** Most frequently misunderstood, this is not a “moral” value in the sense of personal integrity but rather a state of economic and structural stability

Dr. Erik Smith from Global Business Networks also worked with conference participants to incorporate scenario planning as a part of service planning and decision making. For many groups this approach added a richer context to service planning, taking into account the social, political, technological, and cultural trends that would influence or determine financial scenarios. Several groups had struggled with using financial scenarios previously and this type of scenario building (also conducted with the California State Office of AIDS) deepened participant analysis and compelled many to consider the external factors that positively and negatively affect resources for people living with HIV.

The following scenarios were developed and fleshed out by participants using one axis that reflects different sociopolitical futures, from a tolerant to intolerant environment, and another axis that reflects resources to meet needs that are adequate to inadequate.



## V. Implementing Managing Scarcity

### Managing Scarcity Planning Team

John Mortimer assembled the original planning team for the Managing Scarcity Initiative. This team included Jeff Byers from the State Office of AIDS (OA); Susan (Sue) Strong, a consultant with a strong background in HIV services and meeting facilitation; and Laura Thomas, a long-time member of the San Francisco HIV Health Services Planning Council, and the Director of Policy and Grants at Continuum HIV Day Services in San Francisco. The team members represented a variety of perspectives on Ryan White and community planning, and had many years of experience with planning councils. Jeff Byers had represented the State Office of AIDS on many councils across the state, and had served on nearly all of them at one point. His participation also reinforced the coordination with OA which was essential to the success of Managing Scarcity. Sue Strong served on the Sacramento Planning Council, and has continued to be involved in statewide projects such as the California HIV Planning Group. She is familiar with the individuals and issues relevant to HIV services across California. Her consulting work focuses on conference and meeting planning, facilitation, and evaluation. Laura Thomas, in addition to her many years working with the San Francisco HIV Planning Council, is on the Executive Committee for Communities Advocating Emergency AIDS Relief (CAEAR) Coalition, a national policy and advocacy group, and was able to provide frequent updates on the status of federal legislative efforts.

In 2005, CompassPoint Nonprofit Services was engaged to evaluate the Managing Scarcity Initiative. This brought Steve Lew onto the planning team. In addition to many years of experience in HIV services, consulting, and evaluation, Steve is a former co-chair of the San Francisco HIV Health Services Planning Council.



### Funding

Managing Scarcity began as one conference, but the success of that conference led the planners to envision a series of conferences to address the multiple needs identified at the initial gathering. Managing Scarcity was funded through AIDS Partnership California, a project of Northern California Grantmakers. In 2005, APC applied for and received funding from The California Endowment to support the Managing Scarcity conferences. The California Endowment grant enabled the initiative to continue to support planning councils through a key time period while the legislation was being reauthorized. Additional support for the initiative came from the State Office of AIDS and Sutter Health, a private, nonprofit, statewide hospital and health care system, and was coordinated through Northern California Grantmakers. The fifth conference was also partially funded by the Universitywide AIDS Research Program (UARP).

### Transition to UARP / CHRP

In 2007, in consideration of John Mortimer's impending departure from APC, Northern California Grantmakers transitioned AIDS Partnership California to the University of California's Universitywide AIDS Research Program, a program of the University of California Office of the President that is now known as the California HIV/AIDS Research Program (CHRP). Established in 1983 by an act of the California Legislature, CHRP provides state funding to support merit-reviewed AIDS research at nonprofit research institutions and community-based organizations. APC will function as a self-governing entity within CHRP, creating a unique private/public partnership which has the potential to serve as a national model for HIV/AIDS investments.

In order to effectively oversee the Managing Scarcity Initiative's transition to CHRP, key CHRP staff took responsibility for directing the work of APC, including the agency's Executive Director, George Lemp, and Associate Director, Bart Aoki. Robert Whirry, an independent program development consultant, was also added to the Managing Scarcity team, with responsibility for helping generate new foundation funding for the initiative.



## CASE STUDY #2 – SONOMA COUNTY “PROJECT RE-CONNECT”

# Using the Planning Process to Transform the Service Model

### CONTRIBUTORS:

*Lisa Albertson, Steve Bromer, Rick Dean, Harold Lackey, Bill Musick, Allen Nishikawa, and Ellen Swedberg.*

The Sonoma County Commission on AIDS, the planning council for the EMA, had already been considering some sort of “re-invention” of its planning process when it began participating in the Managing Scarcity Conference in 2004. A county with mixed rural and urban populations north of San Francisco, the Sonoma County Title I area had a significant aging population of consumers – long-term survivors who had relocated from urban centers. Even with newer infections in the county, the AIDS Commission was aware that as an “older epidemic,” its Ryan White Care Act (RWCA) funds were more vulnerable in coming years.

There were many reasons for the commission to consider a fresh approach to the manner in which HIV funds were prioritized and allocated. Many long-term clients of HIV services were living fairly active lives, and with more emphasis upon patient self-management, a significant portion of service consumers no longer needed traditional case management services. “The challenge for everyone was to recognize the positive movement of people to move forward in their lives, and not see the shifts in funding as a discreet way to cut services in a deficit-focused model of services,” noted Allen Nishikawa, a long-time staff member to the commission. Allen

saw parallels with other population-based services such as refugee resettlement efforts in the late ‘70s and immigrant services that needed to be responsive to new populations, and recognize the positive changes that clients were making in their lives. Nishikawa drafted a concept paper for the commission that suggested how some aspects of the HIV care system should support people who were now aiming to re-connect with school, work, and other activities outside of the HIV community while remaining connected to the HIV health services.

This discussion was in progress when the first Managing Scarcity conference was held in March 2004, and the commission had just finished what everyone had considered a contentious decision-making process. After initially being asked to make recommendations to the commission based on five levels of funding availability, the Funding Allocations Work Group (composed of both unaffiliated and affiliated consumers) undertook a very challenging process and made tough decisions to develop its recommendations. However, when the commission reviewed these recommendations and realized how limited the funds were across the range of services, it adopted only the higher fund scenarios, ignoring the lowest two. The experience was frustrating to many people, but it also highlighted the need expressed by several consumers and commission members to look at the framework for services in light of the changing needs of people living with HIV.

By attending the Managing Scarcity conference and discussing financial scenario decision making with other EMAs, Sonoma County participants realized that several other councils were also struggling with how to make decisions in relation to lower funding level scenarios. For commission member Lisa Albertson, “Learning and being with other EMAs was huge. Seeing how others would go back to the drawing table with their prioritization processes was very insightful.” The scenario-planning model presented by Global Business Networks and the exercises practiced by conference participants did not focus solely upon financial scenarios, but explored the most likely social, political, and economic scenarios that would impact the lives of people living with HIV. This approach to analyzing various “socioeconomic” scenarios added a helpful dimension to the planning approach for many of the participants, since it allowed people to recognize opportunities and strengths that existed alongside the threats of reduced or more restricted funding. According to Bill Musick, Vice Chair of the AIDS Commission, “There was a high amount of learning for our team at that conference that later helped us to critique our decision-making process.”



The Sonoma attendees used both the scenario-planning framework and the Life Boat exercise on personal and group values in a commission retreat held soon after that conference. According to Commission Chairperson Rick Dean, "Coming back from the MSI conference, the commission retreat took on a 'makeover' theme – looking at our external/internal values, what to keep/not keep, choosing paradigms and values." Bill Musick noted that as a result of this work, the Commission sharpened its 2005 process. "We put a lot less emphasis on the higher funding scenarios; they were more fine-tuned to the current reauthorization drafts and recognition of local and national realities."

Over the following two years the AIDS Commission and staff sought to engage consumers through a series of community forums called "Project Re-Connect." These forums encouraged consumers to consider what their current service needs are, and for those whose health is stable, how to re-engage with work, volunteering, or continuing education. The discussions in these forums also educated consumers about the likelihood of less service funding in the future, and encouraged participation in the planning process. "The commission saw even more than before, the importance of having unaffiliated consumers informed and involved in our planning. It was helpful hearing from several other EMAs (at the conferences) about the importance of doing this."

By having consumers more engaged in the process, the service model is beginning to change. According to Allen Nishikawa, "There was initial resistance at the provider agency level, and with some consumers. But there was also a practical realization that the trend to re-connect beyond the HIV community was a good reflection of their lives. Several consumers, including those on the commission were back in school, trying to be active in the broader community."

The AIDS Commission and staff have continued to explore new opportunities for consumers while making the difficult planning decisions of working with less funding overall. They also became more engaged in public policy advocacy, joining with other EMAs in the statewide consensus policy statement on CARE reauthorization. "The MSI conferences brought us together and increased our commitment to what needed to happen locally" stated Bill Musick.

A new paradigm has emerged from this work. At its 2006 planning retreat, the commission revised its mission to "Helping Persons with HIV Disease to Live Healthy and Independent Lives" and revised the role of the commission to "Advocate for Change." It also adopted the following rationale:

"The HIV Service System was established at a time when medical treatment options for HIV were limited. With client life spans estimated to be five years or less, there was an assumption of increasing client dependency and the need to provide services to the end of life. Given current realities, this model is neither accurate, financially sustainable, nor helpful for people. 'Stabilization and maintenance' should be the starting point, not the end goal, for persons with HIV disease. We must invest in and support independence wherever possible."

While changes to the services model are just beginning to take hold, the Sonoma County AIDS Commission has identified directions for the future transition of each service area. Along with refocusing psychosocial services such as case management and benefits counseling, there are positive examples of medical services also incorporating the "Re-Connect" Philosophy.

Steve Bromer, a commission member who is also a medical provider noted, "There are many instances of patients who see their lives defined by HIV and HIV treatment yet want to find ways to go beyond this. One aspect of supporting this as their medical provider is taking the time in a visit to help set goals that are not just about adhering to treatment. Like creativity or taking a new course of education."

To fully adopt this paradigm, the AIDS Commission will continue to engage consumers and the broader community in policy advocacy, along with setting new policies for HIV services in the county. The Managing Scarcity conferences and activities helped keep the momentum going for a more creative and proactive approach to funding reductions, and introduced a more hopeful model of services to other California Part A/Title I Area planning councils.



## Fostering Leadership:

### The GENERATIONS Training for HIV-Positive Women Serving on California HIV Planning Councils

#### Main Findings:

- HIV+ women, with training and support from other HIV+ women, can be effective leaders on Planning Councils.
- For HIV+ women, competing concerns of family, home, jobs, and managing HIV can take priority over Planning Council duties.
- Likewise, Planning Council duties can sometimes take priority over personal concerns.
- This intervention helped six women move up to leadership positions within California Planning Councils.

#### Background

The Women's Leadership and Community Planning project is an expansion of AIDS Partnership California's (APC) Managing Scarcity Initiative, which was launched in 2004. Run by CompassPoint Non-profit Services in San Francisco, CA, the project offered a two-day leadership training reinforced by six months of facilitated group support. This project empowered 26 women with HIV with increased leadership competency and prepared them to undertake leadership roles in the California Title I Ryan White CARE Planning Councils. Through a pilot project approach, five of the women also received individualized leadership coaching. The project was funded through the GENERATIONS: Strengthening Women and Families Affected by HIV/AIDS initiative with support from Johnson & Johnson and the National AIDS Fund in collaboration with APC.

#### Why this project?

Female consumer leadership has been virtually absent among Planning Councils. Care and treatment needs of women with HIV are best served when women with HIV are in leadership roles in Planning Councils. The goal of our project was to train and support women with HIV to be more effective leaders and decision makers in order to ensure health care access for the most vulnerable women and families living with HIV.

#### Intervention

The Women's Leadership and Community Planning project had four components:

- Two-day leadership training
- On-going listserv
- Six months of facilitated support
- Individualized leadership coaching

#### Leadership Training

In September of 2005 and 2006, we convened two cohorts of women for a two-day training in San Francisco, CA. Thirteen HIV+ women attended each training. With both Year 1 and Year 2 cohorts, the group bonded quickly, which resulted in organic organizing and various opportunities for the women to improve their public speaking, communication, and decision-making skills. Based on recommendations from Year 1, CompassPoint invited two 2005 alumnae to join the group as alumnae/mentors. Their participation helped participants better understand planning council politics and activities such as Robert's Rules of Order.

*"Together, we have a more powerful voice than if added up separately. I'm now understanding better than I ever had how policy and advocacy and community planning can become more effective. We also have great support from the program and from each other in taking care of ourselves physically, mentally and spiritually. If we have a question or a problem, help is just a phone call away. It is such a relief to finally feel that we have some control over our destinies."*

*"This program has been the most valuable event that has happened for me since my diagnosis 11 years ago. As a member of the planning council, I feel much stronger and more confident in my participation with other council members and in other relationships in my life."*



## Demographics

Our project reached 27 women over two years: 13 African Americans, 8 Caucasians, 6 Latinas, 1 Native American, and 1 Asian American. Most (13 women) were aged 51+, 12 were aged 40-50, and 4 were aged 29-39.

## Leadership roles

Six out of thirteen women moved into leadership positions within the first six months: three became Chairs, two became Co-Chairs, and one woman became a Subcommittee Chair.

Several of the participating women from Year 1 have taken on a stronger leadership or participatory role on their planning councils, advisory boards, or in their communities.

- **Catherine Newell** was appointed Chair of the San Mateo County Advisory Board and was also elected to the Board of Directors of AIDS Community Research Consortium
- **Carla Bailey** was appointed Co-Chair of the LA County Commission (first consumer and woman of color to be appointed to this position)
- **Cinnamen Kubricky** was appointed Co-Chair of the San Diego HIV Health Services Planning Council (first consumer to be appointed to this position)
- **Lisa Albertson** was asked to chair the Membership Committee for Sonoma County Commission on AIDS
- **Alicia Sanchez** was appointed to the Planning Council as a member

## CASE STUDY #3 – ORANGE COUNTY Improving Advocacy Efforts

### INTERVIEWED:

*Tucker Baldwin, Jerry Lail, and Tamarra Jones.*



Orange County sits between the Los Angeles, San Diego, and Inland Empire Eligible Metropolitan Areas (EMAs) in Southern California, and is one of the medium-sized Part A/ Title I funded areas in California. With the new Ryan White legislation in 2006, it is now categorized as a Transitional Grant Area (TGA), rather than its previous designation as an Eligible Metropolitan Area (EMA). Orange County reports 7,127 total AIDS cases and 3,657 people living with AIDS as of July 2007, and another 1,024 living with HIV counted so far in the very incomplete HIV reporting system. Orange County has almost five percent of the state's AIDS cases. Orange County itself covers nearly 800 square miles and is home to over three million people in 34 cities. It is facing continued population growth and demographic shifts towards a majority people of color population in recent years. Its proximity to the Mexican border provides opportunities and challenges, particularly in reaching a transient population.

Orange County has been a Title I EMA/TGA since 1992. It received \$4,966,678 in Ryan White funding for FY 2007 including Minority AIDS Initiative funds, a small increase of \$108,099 over FY 2006 levels. The Orange County Healthcare Agency (HCA) serves as the grantee and the Orange County HIV Planning Council (HPC) is the council. They oversee both care and prevention services, and are staffed by the HCA. The HPC has seen a great deal of turnover in members and staff in the past four years, and was represented at MSI by a changing cast of participants.

The Managing Scarcity Initiative had its largest impact on the Orange County HIV Planning Council in the areas of consumer support, advocacy, and networking. One of the challenges for Orange County involved figuring out how to transfer the information from the conferences to the council members, in part because of the turnover in participants.

According to Jerry Lail, "The biggest impact of MSI has been the consolidated statement and ongoing coordination of advocacy efforts." He says this would not have happened without the trust building and group learning that happened through the conferences. The Orange County HIV Planning Council was not able to endorse the Consolidated Statement on its own; all endorsements of that nature must go through the Board of Supervisors. As a result, the Orange County Council organized the effort to work with its Board of Supervisors. It was able to use the MSI network to demonstrate statewide support for the statement. "The California EMA working group Consolidated Statement leveraged the council's advocacy with the local Board of Supervisors; they got behind the position shared by all the other EMAs and authorized the county to lobby for positions" in support of the Consolidated Statement, said Lail.

Tucker Baldwin added that "MSI prompted cooperative local advocacy" and public policy work. The HPC went from feeling that it was prohibited from taking policy positions or advocating on behalf of people living with HIV/AIDS in Orange County to knowing how to take items to the Board of Supervisors, and building relationships with key staff to the Board. MSI provided both specific advocacy skills training and the network of supportive peers across the state to help make that happen.

Jerry feels that this coordinated work has heightened council member awareness of the stakes in having a well articulated and effective planning process. He hopes it will make the decisions impact how people are served, and how Orange County is able to compete for funds in future applications to HRSA. As Tucker said, "When people are able to share experiences common to their work, everyone gains practical benefit. By getting wisdom from the collective together you improve the information and help them gain the bigger picture of what they all struggle with."



## Involvement of PLWH in the Priority-Setting and Allocation Process

“The mission and vision statement of the Planning Council (Council) places PLWH at the forefront of decision and policymaking. The Council ensures participation of unaffiliated consumer members in all of its priority-setting and allocation processes. The Council and Grantee are aware that consumers may consider participation in the planning process overwhelming due to the complexity of the system and use of technical information to convey trends in the disease. To encourage greater consumer participation and to familiarize interested members with the process, the Grantee provided an orientation and training prior to starting the FY 2006 priority-setting and allocation process. The Grantee also provided a tutorial session to help members of the Priority Setting and Allocation Task Force (Task Force) better understand the epidemiological and utilization data presented so that they could more fully and actively participate in the priority-setting and allocation process.”

~ From the Orange County 2006  
Ryan White CARE Act FY 2006  
Title I Application

## Leading in a Time of Change: Training for California Planning Council Co-Chairs

The Planning Council Co-Chair Training conducted in April 2007 was designed to build the leadership, planning, and consensus-building skills of a key group of individuals involved in state HIV planning: co-chairs of community Ryan White planning groups. The training for co-chairs was designed to complement the skills targeted through the Managing Scarcity Initiative, and to explore the effectiveness of a training aimed specifically at planning council leaders. Specific objectives of the training included

- Fostering leadership development including increased self-awareness, communication skills, and effective decision making;
- Fostering a deeper understanding of effective group process during council meetings and the role that facilitation plays;
- Exploring strategies for dealing with resistance, debate, and private agendas;
- Discussing values and how they influence decisions about where money is allocated; and
- Facilitating exchange of diverse experiences and expertise and encouraging the creation of a network of peers across the State of California.

Group exercises were intended to increase skills that had special relevance to the task of prioritizing and allocating limited HIV resources in the face of increasingly complex demand. Among the specific topics covered in the two-day training were the following:

**Models of Group Effectiveness:** What does effective group process look like when it's working? What's going right? How are people engaging? Are there clear goals? Are there agreements on how to work together? What factors might members say contribute to group ineffectiveness? Is there undiscussed conflict? Are people not motivated by tasks? Is the group missing certain expertise? Are there ground rules?

**The Role of the Facilitator:** What are the hats you must wear as a facilitator? What facilitative skills are most useful? What do you need to call on most often? How do you get in your own way?

**Behind the Scenes Planning:** Agenda building, focusing on desired outcomes, discovering personal agendas, building alliances

**Building Agreement:** Gathering diverse points of view; building a shared framework of understanding; finding inclusive solutions; reaching closure

**Values-Based Decision Making:** How values affect decisions and prioritize allocations; how to surface values.

**Conflict & Resistance:** Behaviors that enhance or hinder group effectiveness; dealing with emotions; when to intervene; mindsets for solving problems.

# W. Evaluation and Key Findings

## Evaluation

The Managing Scarcity Initiative was evaluated throughout the conference series, which formed the core of the project. Evaluation methodology included evaluation forms filled out by participants after each conference, key informant interviews, and the review of selected EMA documentation. The results of the conference evaluation process are summarized in Table 2.

The planning team relied heavily on the meeting evaluations in planning each subsequent conference, and worked to tailor the conferences to meet participant preferences established through feedback. For example, participants consistently praised the fact that they were able to hear about other EMA activities in the evaluations, so additional time was built in to the conferences for networking and presentations from EMAs.

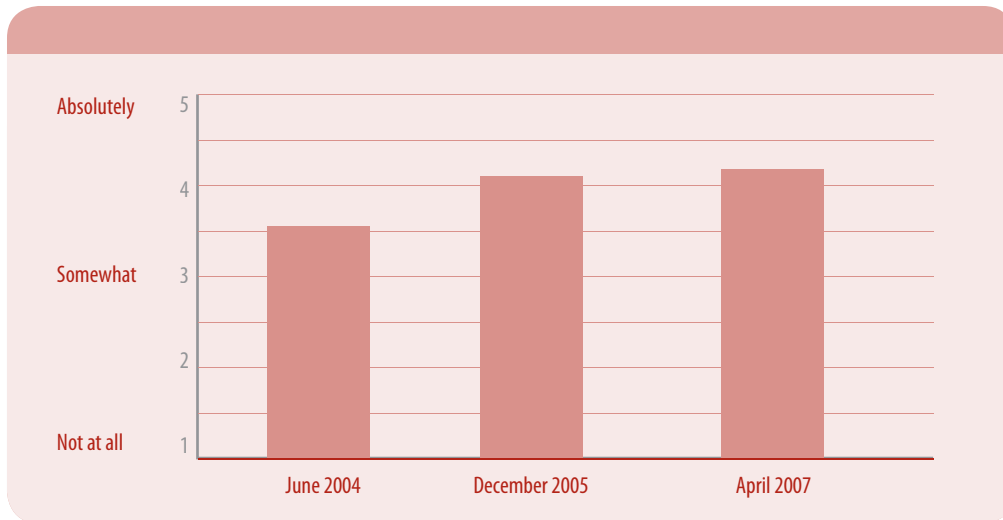
**TABLE 2 : Summary of Evaluation Activities and Results**

EVALUATED	METHOD	FINDINGS (BY AVERAGE RATING)
June 15-16, 2004 <b>Conference: Pathways to Decisions</b>	Written meeting evaluation by participants (n=45 of 58).  Method: Survey with scale rating, comments. 5 point scale with 5 as highest agreement.	<ul style="list-style-type: none"> <li>• Better understanding of what other EMAs are doing (4.25).</li> <li>• Plan to use these planning tools in your EMA (3.7).</li> <li>• Better prepared to make difficult decisions (3.5).</li> </ul>
November 15, 2004 <b>Phone Interviews</b>	Phone interviews to assess how information from June 15-16, 2004 conference was utilized in local planning process.  Method: One-on-one phone interviews of 13 participants, co-chairs, and grantee staff.	<ul style="list-style-type: none"> <li>• Increased awareness of different paradigms and approaches for reduction decision making. Most groups could not apply any new approaches to their current process due to timing, and some implementation of new approaches (using values and scenario frameworks) fell short.</li> <li>• Some benefited from adapting planning documents/forms from other EMAs.</li> <li>• Many identified ongoing training needs for council members.</li> </ul>
December 7-8, 2004 <b>Conference: Decisions and Leadership</b>	Written meeting evaluation by participants (n=50 of 61).  Method: Survey with scale ranking and open comments. 5 point scale with 5 as highest agreement.	<ul style="list-style-type: none"> <li>• Better understanding of what other EMAs are doing and how they are responding to funding and other challenges ranked high (4.25).</li> <li>• Better understanding of group decision-making frameworks (3.5).</li> <li>• Better prepared to make difficult decisions (4.25).</li> </ul>
October 2005 – March 2007 <b>Generations: Women's Leadership Retreat and Group Coaching Calls</b>	16 out of 26 participants completed pre- and post-surveys, and 2 women from each cohort were interviewed.	<ul style="list-style-type: none"> <li>• Participating women reported that their ability to exercise council leadership skills increased 30-45%, especially in leadership issues that were challenging and in getting planning goals accomplished.</li> <li>• Skills that these women felt they would sustain included public speaking, conflict resolution, prioritization, and self care.</li> <li>• 8 of the 26 women reported taking on new council leadership responsibilities including co-chairs, chair of membership, and full council members.</li> </ul>

EVALUATED	METHOD	FINDINGS (BY AVERAGE RATING)
March 2005 <b>Conference: Leadership &amp; Advocacy</b>	Meeting evaluation by participants (n=48 of 75).  Methods: Survey with scale rankings and open comments. 5 point scale with 5 as highest agreement.	<ul style="list-style-type: none"> <li>• High level of learning about RWCA and reauthorization issues (4.6); level of confidence in ability to advocate (3.95); and high level of sharing strategies (4).</li> <li>• Role-playing legislative visits and actual visits to legislative offices were greatly appreciated and supported participant advocacy skills.</li> </ul>
December 6-7, 2005 <b>Conference: Today and Tomorrow</b> <i>West Hollywood</i>	Meeting evaluation by participants (n=54 out of 78).  Methods: Survey with 5 point scale rankings and open comments.	<ul style="list-style-type: none"> <li>• Participants rated the panel on RWCA reauthorization as very helpful to their understanding of the potential changes in new legislation (4.1); and what advocacy was needed in their EMA.</li> <li>• There was a high level of learning related to Medicare Part D (4.0).</li> <li>• 71% stated they would use what they learned at the conference, and the majority of participants continued to benefit from the sharing of experience across EMAS.</li> </ul>
April 16-17, 2007 <b>Community Co-Chair Leadership Training</b> <i>San Francisco</i>	Participant evaluation (n=8 of 10).  Method: Survey with 5 point scale rankings and open comments.	<ul style="list-style-type: none"> <li>• The participants rated each of the seven sessions highly (between 4.4 and 5) and found the content shared by peers and by the trainers as relevant information that they will bring back to their councils. While each session was rated highly, the session focusing upon the distinct roles of facilitation, consumer advocacy, and group leadership was appreciated the most.</li> </ul>
May 14-16, 2007 <b>Conference: Into the Future</b> <i>San Francisco</i>	Meeting evaluated by participants (n=38 out of 76).  Methods: Survey with 5 point scale rankings and open comments.	<ul style="list-style-type: none"> <li>• High level of learning among participants regarding the impact of RWTMA on Title I areas in CA (4.0).</li> <li>• Participants gained a better understanding of how other Title I areas were coping (4.0) and felt that these strategies will be useful to their own area (4.0).</li> <li>• Understand implications of state health policy changes (3.5).</li> <li>• Able to explore points of consensus for statewide position (3.7).</li> <li>• The conference continued to promote a high level of interest and motivation to strengthen working relationships among Title I areas (4.16), and to use what was learned in their local area (4.16).</li> </ul>

A number of key questions were repeatedly asked in the evaluations of multiple conferences. Participants were asked if the right mix of participants had been invited for the first three conferences, and the ratings increased over time from an average of 3.8 following the first one to 4.2 after the third. Chart 1 shows the average response regarding using the information learned at the conference, which was asked in three of the five conference evaluations. Participants also consistently ranked the ability to participate in small group discussions very highly.

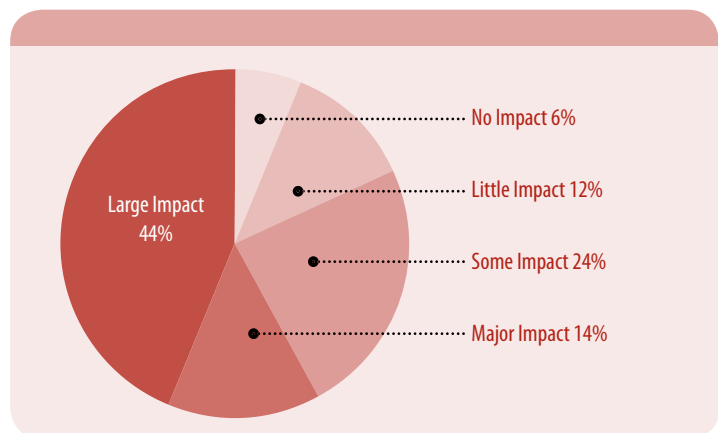
**CHART 1: Do you plan to use what you learned here in your EMA?**



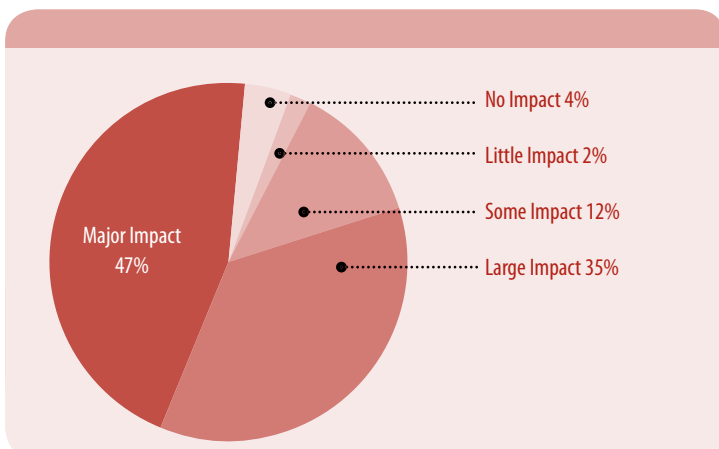
In addition to the evaluation forms filled out at each conference, participants were interviewed in 2005 about the impact of MSI on their EMA. Respondents indicated that the areas where MSI had had the largest impact on their EMA were in the areas of awareness of what other EMAs were doing and how they approached decision making, and in their understanding of the impact of Ryan White reauthorization. The conferences also had a large to major impact on developing council leadership. The areas that showed the lowest impact were related to council functioning and improving the working relationship between the grantee and council leadership. (See Charts 2 through 5 on pages 21 and 22).

**CHART 2: Developed council leadership**

*“Some of the ideas we gained in ‘reduction decision making’ proved helpful when we started are prioritizing and allocation process. It went much smoother this year than in previous years because the task force started an idea brought back from this conference.”*

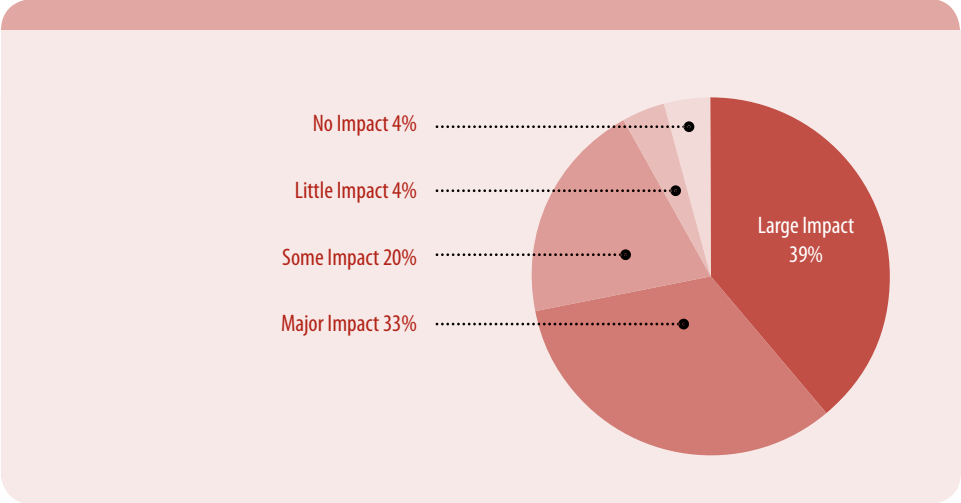


**CHART 3: Awareness of other EMA approaches and activities**

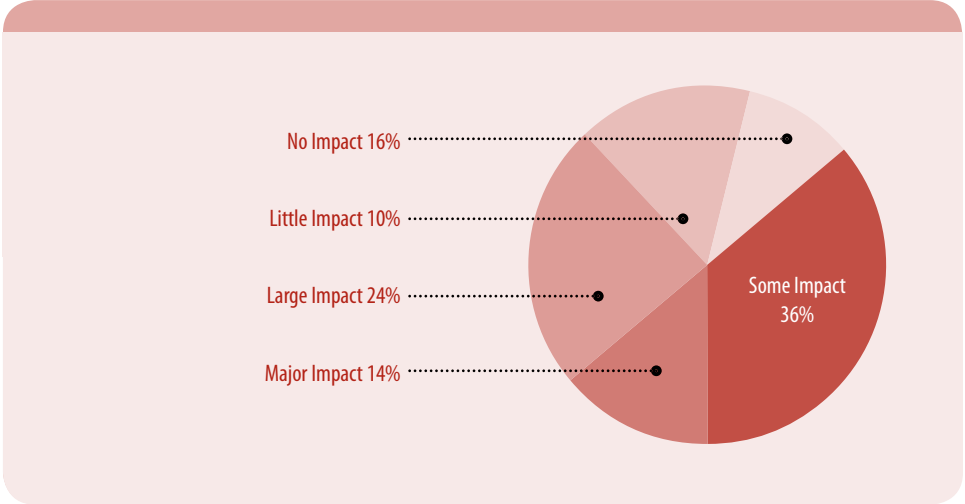




**CHART 4: Strengthened understanding of the impact of CARE Act reauthorization**



**CHART 5: Improved the working relationship between grantee and council leadership**



## Successes and Lessons Learned

The following were among the major outcomes and lessons learned through the three years of the Managing Scarcity Initiative:

1. Through Managing Scarcity, planning council members were able to move from a more internally-focused process to a more externally-focused one. With advocacy training and support, they were able to see themselves as advocates and participants in the larger political process. They became **more engaged in reauthorization**, and were able to be active, rather than just waiting for new legislation to be passed. Feedback from participants showed that they felt better informed about the national legislative process, and better able to be a part of it. This had an impact in Washington, DC, where Congressional offices were more aware of the importance of CARE because constituents trained through Managing Scarcity had visited their district office here in California. There was a strong interest on the part of council members, especially people living with HIV/AIDS, to be more actively involved in advocacy efforts, but many felt that they didn't have the skills or training to do so. Participants in the Sacramento conference gave an average ranking of 4 out of 5 points to the question "Do you feel more confident of your ability to advocate for RWCA reauthorization and appropriations as a result of this conference?" By providing them with the skills and giving them the opportunity to meet directly with elected officials and their staff, Managing Scarcity was able to support them as advocates and leaders for their community.

*"The discovery process was useful in identifying the way we actually conduct business vs. the way we'd like to conduct business."*

2. Conference participants **developed a level of trust** and unity over the first three conferences that led to the development of a statewide consensus statement responding to the Administration's reauthorization principles. The consensus statement was an unanticipated action that flowed from the policy input and advocacy training provided through the conferences. EMAs wanted to be able to respond and take action, and AIDS Partnership California was able to provide support through conference calls and emails for the group to develop the consolidated statement, secure buy-in from all EMAs, and then gather sign-ons from planning councils and health departments. The consensus statement addressed the needs of people with HIV in California and was distributed to the California Congressional delegation. This policy stance was possible because of the connections and trust built over the series of Managing Scarcity Initiative meetings. The disagreements and animosity among councils from different parts of the state created during previous reauthorizations was noticeably absent this time. In addition, some of the smaller areas such as Orange County and Sonoma participated in reauthorization discussions, which have often been dominated by the larger cities of Los Angeles and San Francisco. For a complete version of the Consolidated Statement, please see <http://chrp.ucop.edu/APC/APC1.html>.

*"The fellowship was the best thing about this conference."*

3. Conferences and leadership trainings **filled a vacuum**. Prior to Managing Scarcity, there had been little technical assistance provided to planning councils on how to do their work, and participants were eager for information on what other areas were doing, and hungry for concrete tools that they could use to improve their decision making, especially in an atmosphere of increased need and decreasing resources. The information provided to grantees and councils by the Health Resources and Services Administration is quite generic, and does not address the most challenging decisions – where to cut funding in a fiscal crunch. With overall reductions in

funds, more and more EMAs are facing very tough decisions, and community members rarely have the background in health care economics or ethics that would prepare them to make those sorts of decisions. The justice paradigms, for example, provided a framework for decision making that was very helpful and immediately adopted by some EMAs. Los Angeles is still using the justice paradigms in their process.

4. Many of the EMAs had already developed useful tools to support their decision making, and the conference process provided an opportunity for EMAs to showcase what was working for them and to adopt solutions from other areas. Tools such as San Francisco's service category summary sheets and the Inland Empire's data summit are now in use across the state. **Peer learning** formed an essential component of the project's success, as participants found they faced the same set of challenges, and recognized the utility of what their peers had developed. Buy-in from grantees (local health jurisdictions) was also helpful in incorporating some skills and tools into local decision-making processes. The conference segments on sharing EMA activities and successes were routinely identified as a highlight of the conferences.

*"I love coming together and hearing how other EMAs are dealing with difficult times of cuts. It helps me see if our EMA is on a similar track and the possibility to modify our system, even though I am very proud of how much consumer involvement we have."*

**5. Inconsistent participation and turnover in council and grantee staff was a barrier** to institutionalizing some of the learnings from MSI, and led to the uneven use of tools presented. Council leadership tends to change from year to year, and consequently some EMAs were represented by many different people over the three years of MSI. This made it somewhat more difficult to build on skills and learning from conference to conference. The extent to which EMAs were able to incorporate all of the tools presented at each conference was dependent on the enthusiasm of the participants and their ability to share what they learned with their fellow council members and staff. As Chart 6 shows, only seven percent of the participants surveyed said that their EMA was able to use five or more tools. Most areas were able to incorporate some of the decision-making and priority-setting tools presented, and not all tools were relevant to all areas, but more consistent representation may have enabled EMAs to adopt and institutionalize more of the MSI learnings.

6. It was important to have the California State Office of AIDS (OA) involved. Through Jeff Byers, the **Office of AIDS became a consistent part of the planning process**. Having OA staff at the table and as participants in the conferences was essential to ensuring that meeting presentations were accurate, that activities were coordinated, and the conferences were complementary rather than duplicative of the OA summits. OA held periodic meetings for Title I grantees across the state. The MSI conferences differed from the OA summits in that there was more of a focus on peer learning, building a network, and advocacy. OA's perspective as the Title II grantee for the state of California was also helpful in the discussions of the impact of potential reauthorization proposals.

**7. Limits on advocacy activities** at the local level may prevent some community members from being able to take positions. Several planning councils function under their county Boards of Supervisors, and operate within county limitations on advocacy activities. This meant that these jurisdictions had to bring the consensus statement to their Board of Supervisors for sign-on. Ultimately, this meant that several counties signed on, which made for a stronger statement, but it took much longer to get those counties on board. This was an unanticipated challenge to the collective action proposed by the conference participants. Each EMA had a different process for approval, and a different set of bureaucratic hurdles.

*“MSI was an important tool to help the nine planning councils together to speak consensually for the state.”*

For example, Orange County thought they would not be able to sign on, but were able to engage their Board of Supervisors in a fruitful policy discussion on HIV and were able to get approval to put the county’s name on the document.

8. The planning group put a great deal of thought into details such as who sat at which table. Those details turned out to be critical to the success of the project. **Intention and thoughtfulness in organizing the opportunities for interaction supported the building of trust, networking, peer learning, and participant satisfaction.** Participants were mixed for some sessions, and grouped by EMA for other sessions to reinforce conference messages and provide opportunities to practice the skills learned. The amount of time put into planning details such as seating charts paid off in successful conference experiences. The agendas combined didactic presentations with small group activities. The planning group paid close attention to the evaluations from the previous conferences, and were able to address issues raised at one conference at the next one. Participants ranked the social activities highly on evaluations, and generally felt that they were able to be heard in the small groups. Social time was built into the schedule to encourage additional bonding among participants. Sue Strong’s insistence on including fun activities, such as the several rounds of Ryan White Jeopardy, made the conferences more enjoyable for the participants and contributed to their success.

## VII. Conclusions

The conferences and trainings made possible through Managing Scarcity were consistently well received by project participants, who appreciated the project's information-sharing opportunities as well as the introduction of new approaches and decision-making paradigms. The great majority of participants found this learning highly applicable to their local council work, and many of the tools and approaches presented at the conferences are still in use today, from Los Angeles' adoption of the value paradigms for priority setting, to Orange County's continued engagement in policy discussions. The two leadership training and coaching programs included in Managing Scarcity allowed 36 women and men living with HIV/AIDS to lead and facilitate council discussions and actions more effectively. One of the greatest successes of the program – the development of the consolidated Ryan White statement – was a participant-generated activity that grew directly out of the new statewide network generated by the Managing Scarcity conference. The last MSI conference ended with a long list of future activities and issues which we hope will be put into action over the coming months and years.

One of the most important immediate outcomes of Managing Scarcity has been the development of a new statewide initiative which directly builds upon the program's success in creating consensus and building a collaborative dialogue among California HIV planners and providers called **Visioning Change**. Visioning Change is a new three-year, collaborative, multidisciplinary statewide planning and decision-making process designed to create new channels for communication and decision making involving key HIV planners, policymakers, and providers across California. The process is designed to help formulate and implement significant and groundbreaking enhancements in the way in which HIV care, prevention, and research are organized, delivered, and financed in the state. Visioning Change will center on monthly meetings of a Core Planning Group comprised of key HIV leaders from throughout the state, augmented by a series of focused, high-level Work Groups which will explore and develop responses to critical HIV care, prevention, and research issues. The process will also incorporate an annual planning and decision-making retreat attended by representatives of care and prevention planning councils across California, along with staff and consumer representatives from both urban and rural regions. Visioning Change will fill an urgent and unmet need for a high-level statewide planning process that can enhance statewide HIV planning and decision making; shape new local and statewide responses to the epidemic; increase planning and coordination with non-HIV-specific entities; and expand and enhance California's national HIV leadership role. This process would not have been possible without the initial groundwork laid by the Managing Scarcity Initiative in creating the foundation for a stronger consensus-building process in the state.

AIDS Partnership California believes that many of the processes, practices, and products that have grown out of the Managing Scarcity Initiative are highly replicable for other states, regions, and jurisdictions of the US. For populous states that contain several different Ryan White Part A planning regions, the model offers an opportunity to create better cohesion and information sharing, and to build collaborative approaches and partnerships that enhance quality of care and manage better responses to diminishing resources. Managing Scarcity may also provide a model that can help states and regions that contain different HIV planning and coordinating bodies bring participants in those bodies together to discuss mutual needs and issues, share knowledge and perspectives, and formulate new approaches to collaboration that may also have important policy and advocacy outcomes. Managing Scarcity also includes lessons on building planning, leadership, and decision-making capacity among planning council members, consumers, and co-chairs that may help strengthen the capacity of local planning bodies to better manage and make tough decisions regarding scarce resources.

AIDS Partnership California encourages other jurisdictions and planning groups throughout the nation to consider increased intergroup networking, planning, and consensus building as a way to increase the effectiveness of all of our efforts to serve the neediest HIV-infected and affected populations using the limited pools of public resources at our disposal.

## ABOUT AIDS PARTNERSHIP CALIFORNIA

AIDS Partnership California (APC) is a coalition of private foundation funders that has played a unique and important role in the history of the foundation response to HIV/AIDS in California. APC operates as a statewide public/private collaboration whose purpose is to slow the rate of HIV infection in California, inform sound policy decisions, and strengthen systems of HIV prevention, care, and treatment. AIDS Partnership California began its life as the AIDS Task Force – a San Francisco Bay Area regional funding collaborative that awarded over \$7 million in HIV/AIDS funding between 1988 and 2000 for a range of HIV programs and services addressing critical gaps in the epidemic. In July 2000, Northern California Grantmakers – the coordinating entity for the Task Force – re-christened the collaborative as AIDS Partnership California, an initiative jointly supported by foundations, corporations, and the California State Office of AIDS. The immediate goal of APC was to address the crisis of HIV/AIDS within California communities of color.

In 2007, AIDS Partnership California completed a formal merger with the California HIV Research Program (CHRP) – California’s unique, publicly supported HIV care, prevention, and policy research organization, formerly known as the University-wide AIDS Research Program (UARP). APC fully preserves its autonomous structure through this merger, and is able to receive foundation gifts through CHRP’s nonprofit, 501 (c)(3) status. The merger also provides important resource-sharing and collaborative opportunities for both organizations. Meanwhile, the APC Advisory Committee – composed primarily of representatives of APC funding agencies – continues to oversee the activities of APC, and provides direction on grantmaking strategies while reviewing and recommending approval of all grants awarded by the organization.

With its roots in the earliest years of the AIDS epidemic, the California HIV Research Program (CHRP) has a proud history of providing proactive, research-based responses to California’s HIV/AIDS crisis. Established in 1983 by an act of the California Legislature, CHRP provides state funding to support merit-reviewed AIDS research at nonprofit research institutions and community-based organizations in California. CHRP is both the oldest and largest state-sponsored HIV research entity in the United States. The mission of CHRP is to fund innovative basic, clinical, social, behavioral, and policy research, and to provide scientific leadership by convening California stakeholders from diverse backgrounds with expertise in ending the human suffering caused by HIV disease.

Since 1983, CHRP has awarded nearly 2,000 research grants to more than 50 California institutions, and in the 2007-2008 fiscal year will make a total of approximately \$11 million in disbursements through at least 15 separate priority areas. One of the most important objectives of CHRP funding is to help leverage additional public and private funding to support new research and interventions. A 2002 survey of California investigators found that nearly \$7 in federal and other grant support was generated for every \$1 invested by CHRP in California-based start-up research. During the five-year period between 1995 and 2000, \$17 million in CHRP investments in California-based pilot research projects directly yielded more than \$115 million in subsequent federal and private grant funds.

By linking the private foundation funding partnership of APC with the public care, prevention, and policy research capacity of CHRP, our new merged public/private partnership – the first of its kind in the US – has the potential to significantly enhance the way in which HIV prevention and care are organized, funded, and delivered in our state.

# Managing Scarcity

Report on a Statewide Initiative to Build Skills  
and Enhance Collaboration Among Ryan White  
HIV Planning Councils in California

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