

Project to Increase Participation of HCH Clients: Report and Recommendations

Paul Boden
Western Regional Advocacy Project
2940 16th Street
San Francisco CA 94103
pboden@copper.net

John Lozier
National Health Care for the Homeless Council
PO Box 60427
Nashville TN 37206
jlozier@nhhc.org

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ABSTRACT

In early 2005, the National Health Care for the Homeless Council launched a project to “increase the capacity of HCH consumer bodies to effectively determine and represent to HCH project administrators and policy makers the health care needs of homeless persons.” A pilot program of outreach to Health Care for the Homeless clients in six cities indicated a high level of satisfaction with HCH services, demonstrated a significant base of support for enhanced consumer involvement in HCH, and provided an initial model for increasing consumer involvement. This report recommends continuing the program of outreach and incorporating its findings into HCH practice at local and national levels, and clarifying and strengthening the role of Consumer Advisory Boards and/or other mechanisms for consumer involvement in HCH governance.

INTRODUCTION

From March through June, 2005, the National Health Care for the Homeless Council piloted a project intended to increase the capacity of Consumer Advisory Boards and other consumer groups to participate effectively in the governance of Health Care for the Homeless (HCH) projects. The project was designed and implemented by the Western Regional Advocacy Project and was overseen by the National Consumer Advisory Board, a component of the National HCH Council. The project was supported by a grant from the Health Resources and Services Administration (HRSA).

BACKGROUND

HCH projects are funded by HRSA under the authority of Section 330(h) of the Public Health Services Act, as part of the Consolidated Health Center funding stream. A provision of this legislation requires that Consolidated Health Centers be governed by Boards of Directors that include 51% or more consumers (clients) of the Health Centers’ services. However, in the case of HCH grantees, HRSA is authorized to grant waivers allowing less than majority consumer composition on the Board, provided that other mechanisms are implemented to assure meaningful client input into the governance of the Health Center (see Appendix I). Consumer Advisory Boards (CABs), which provide advice to program administrators and Boards of Directors, have emerged as a common mechanism for consumer input. Throughout this document, use of the term “CAB” or “Consumer Advisory Board” is meant to embrace a variety of models used by HCH projects to obtain consumer input and participation in project governance.

The National Health Care for the Homeless Council is a membership organization comprised of HCH agencies, individual HCH clinicians, and clients of HCH programs.

The National Consumer Advisory Board (NCAB) is comprised of HCH clients who meet annually during the National HCH Conference and elect an Executive Committee that functions throughout the year. The Executive Committee functions as a Standing

Committee of the National HCH Council, with its Chairperson serving on both the Governing Membership and the Board of Directors.

The Western Regional Advocacy Project (WRAP) is committed to organizing people who have experienced homelessness to achieve their own goals. WRAP's Coordinator, Paul Boden, the former Executive Director of the Coalition on Homelessness in San Francisco, designed and carried out this project under contract to the National Council.

METHODS

Working with the NCAB Executive Committee, local CABs, HCH program staff, homeless coalitions, National HCH Conference participants and the National Council staff and board members, WRAP developed and then tested in 6 communities across the country a pilot project of consumer based outreach. The six pilot communities were Boston MA, Kalamazoo MI, Los Angeles CA, San Francisco CA, Oakland CA, and Fort Lauderdale FL. Using a standard form for the collection of information, local CAB members at 13 program sites performed outreach to and documented the input of 249 HCH clients on issues relevant to both local HCH programs and the National Council. By design, these HCH clients were not necessarily involved in local CABs or otherwise identified with the HCH project; the clients were selected as outreach contacts because of their presence at an HCH site.

Four open-ended questions were asked:

- (1) Have you found the services to be effective in addressing and treating your healthcare needs? If yes, in what way(s)? If no, why not?
- (2) How would you describe your interactions with staff and providers? Do you feel comfortable here? Are you treated with dignity and respect?
- (3) What would you say is the best part of the program?
- (4) What are your suggestions for improvement?

The input from these outreach contacts was compiled by WRAP; aggregate national data is reported below, and program-specific data was provided to the appropriate local HCH project.

Beyond the project's interest in HCH clients' responses to the four questions, the project intended to assess the infrastructure needs of local CABs to maintain ongoing outreach, document its results, and create responses to the issues raised. This was accomplished through WRAP's observation of and interaction with CABs, together with conversation with the NCAB Executive Committee and National Council staff.

RESULTS

A very large percentage of clients report feeling they are treated with respect at HCH programs. This is not a common trend at many homelessness and poverty programs and

shows a strong foundation from which to build. The aggregate data presented in Appendix 2 also reveals client concerns (e.g., waiting time for HCH services) that are appropriately identified and resolved through an outreach approach.

RECOMMENDATIONS AND DISCUSSION

Recommendation #1: Local CABs should conduct ongoing documented outreach to consumers at HCH sites as part of their role as consumer representatives.

The outreach should rely on personal contact, should utilize open-ended questions and discussion to elicit complete responses, and should be recorded on simple standard forms to facilitate compilation and analysis of responses.

CAB members are well suited for this role because of their personal legitimacy among other clients, having experienced homelessness themselves, and because of their responsibility to understand and represent client perspectives.

Outreach responses should be brought to local HCH project staff to be compiled, collated and returned to the CAB for follow up. Lessons learned regarding compilation of responses are presented in Appendix 4, "Compiling the Outreach Input."

The outreach method generates information for CABs as to what other clients are thinking. Based on their legitimate experiences as clients, CAB members can work with their local HCH projects to how identified issues might be best addressed. Please see Appendix 3 for a more detailed description of the approach and its benefits to CABs and HCH projects.

Outreach to HCH clients should be systematic and on-going.

A next round of outreach should be designed to include questions that will promote on-going dialogue between CABs and HCH clients by following up on issues identified in the first round. For example, the outreach could note the waiting time concern expressed in the first round and ask for clients' ideas about how to remedy that. Each round should also provide opportunity for clients to react to and influence elements of the National Council's policy agenda. A next round could be conducted by a small number of HCH projects. However, the National Council should consider whether it is appropriate to stimulate further outreach when resources for supporting the activity are not in place (see Recommendation #3).

Recommendation #2: Findings from local outreach should be compiled at the national levels to determine common themes, issues, and appropriate follow-up.

Findings should be compiled by staff of the National HCH Council and reviewed by first by NCAB and then by the Policy Committee.

NCAB and the Policy Committee must then come up with an action plan for the organization, which is then returned to local HCH projects and their CABs *and incorporated into on-going outreach efforts*. This feedback to clients is critical to the legitimacy of the undertaking, and should include a description of opportunities for clients to take action on identified issues.

Client perspectives identified through outreach should be incorporated into every aspect of the National Council's work.

Recommendation #3: The National Council should budget to provide on-going support for increasing client involvement in outreach and HCH Governance.

Creating and funding this pilot project shows a strong commitment by the National Council to incorporate systemic approaches to solidifying the connection amongst the clients, local staff and national staff and Board.

The National Council budget should provide for staff time at the national level, and for at least part-time regional staff to encourage and assist local CABs in their outreach.

The National Council should examine its policies for reimbursing costs incurred by clients in outreach and in participating in NCAB meetings, seeking ways to provide support according to individual need while respecting the dignity of clients.

The national materials and office should be multi-lingual.

Recommendation #4: The role and functions of local CABs should be clarified.

There is no consistent set of expectations regarding the role of CABs in the governance of HCH projects, or of their potential role in the larger issues of community involvement in the delivery of health care services and the resolution of homelessness generally. This could be clarified through revision of the NCAB by-laws or other National Council documents, and through policy guidance from HRSA. Forthcoming publication of HRSA's proposed revision of its Policy Information Notice on governance may provide an opportunity.

The role that CABs play should be respected and incorporated into the "lifeblood" of HCH at every level.

The vision of majority consumer Boards of Directors is feasible and should be vigorously pursued within HCH projects. HCH staffs are stretched thin to provide support to both a Board and an Advisory Committee.

The organizational structure and policies of the National Council should be adjusted to address the requirements for community organizing.

Recommendation #5: Local HCH staff should be supported in organizing and advocacy efforts.

Local HCH staff wish to do more community work and would be very effective at it. They would support and participate with the national office and at the local level in taking on the issues harmful to their clients. Many feel they don't work in an environment that encourages this or affords them the time to do it.

At a minimum, input from local staff should be sought on the same outreach basis as input from clients, and should be incorporated into analysis of outreach findings.

Appendix 1

NATIONAL CONSUMER ADVISORY BOARD

SUMMARY OF HEALTH CARE FOR THE HOMELESS
CONSUMER GOVERNANCE REQUIREMENTS

Many Health Care for the Homeless (HCH) projects receive federal funding as part of the Consolidated Health Center program. Other projects such as Community Health Centers and Migrant Health Centers also receive this funding, often called “Section 330” funding for the section of the Public Health Service Act that establishes the program.

As a condition of its federal funding, a Consolidated Health Center must be governed by a Board of Directors which represents the community served by the project. Under the law, a Board must:

- Be comprised of a majority (at least 51%) of individuals (“consumers”) who are being served by the health center and who, as a group, represent the individuals being served by the health center.
- Meet at least once a month.
- Select the services to be provided by the health center.
- Schedule the hours during which such services will be provided.
- Approve the health center’s annual budget.
- Approve the selection of a director (Program Director or CEO) for the health center.
- Establish general policies for the health center, except in the case of a governing board of a public center.
- Approve applications for subsequent grants for the health center.

The law allows an HCH project to obtain a waiver of these requirements *if* it is not part of a Community Health Center. About half of the HCH projects qualify for a waiver, which exempts them from one or more of the requirements listed above.

Waivers are available because the circumstances of many homeless persons’ lives make active participation on a Board of Directors very difficult. In applying for a waiver, however, an HCH project must establish plans for obtaining guidance from the homeless people it is intended to serve. Under their waivers, HCH projects

have created a number of ways for consumers to influence decisions by HCH projects. These include:

- Including some consumers on the Board of Directors (even if not a majority).
- Establishing a Consumer Advisory Board (CAB), made up of consumers, which provides advice to the Board of Directors in a regular, formal way.
- Conducting regular focus groups to learn from consumers about how the program is meeting -or not meeting- their needs.
- Distributing questionnaires or “patient satisfaction surveys” to HCH patients.
- Asking consumers to do regular outreach to other homeless persons, inquiring about their health care needs and experiences, and compiling this information.

Community Health Centers with HCH funding are required to have at least one homeless consumer on their Board of Directors, and should use additional approaches like those described above to help assure that they are getting broad-based input from homeless consumers.

Some HCH projects are working toward the creation of majority consumer Boards of Directors, a development that we encourage.

A fuller description of these matters is available in our *Consumer Advisory Board Manual*, available at http://www.nhchc.org/Publications/CA06E_CAB_Manual.pdf.

Outreach forms, in English and Spanish, have been created for Consumer Advisory Boards to use in inquiring about the health care needs and issues of other homeless people, and are available from the National Consumer Advisory Board.

Section 330 of the Public Health Service Act is available at <http://www.nhchc.org/Publications/REAUTHORIZATION.pdf>.

For assistance with consumer governance at an HCH project, including trainings for consumers, staff and Board members, contact the National Health Care for the Homeless Council and the National Consumer Advisory Board, at ncab@nhchc.org.

Please visit our website at www.nhchc.org.

National Consumer Advisory Board
National Health Care for the Homeless Council
PO Box 60427
Nashville TN 37206-0427

615/226-2292

APPENDIX 2**HealthCare for the Homeless
Program Site Outreach Results**

7/6/05

Locations:

Boston, Mass. Kalamazoo, Mich. Los Angeles, CA. San Francisco, CA.
Oakland, CA. Ft. Lauderdale, Fla.

13-Sites Input Total: 249

(1) Have you found the services to be effective in addressing and treating your healthcare needs? If yes, in what way(s)? If no, why not?

Yes	125	Excellent	38	No	21	All right	4	Unhappy	3
No Answer	4	Very Good	3	Yes/No	3	Good	3	Not all time	1
No Problems	1	Best they can do	1	Haven't had services	1	Every time	1	OK	3

Positive Aspects:

Diagnosed	13	Saved Lives	5	Medical Treatment	30	Helpful	5	RX.	10
Dental	1	Good Staff	3	Personal Perspective	1	Timely	4	Food	3
Personal Needs	2	Quick Attention	5	Maintain Health	2	Testing	1	Rx. Dr.	1
Good Services	1	Mental Health	1	So Far/So Good	1	Respectful	1	Caring	3
Comparative	1	Help Uninsured	1	Concerned w/ Health	1	Counseling	1	Accurate	1
Psychiatrist	2	Life Altering	1	Good Program	4	Friendly	7	Low Cost	2
Dr.'s Invested	1	Prosthetics Parts	1	Personal Treatment	1	Treatment	1		
Professional	6	No Complaints	1	Polite/ Pleasant	2				
Informative	11	Knowledgeable	4	Health Benefit	1				
		Flexible	1	Referred/Follow-up	1				
		Schedule							
				Staff invested in clients	1				
				Somewhere to go	1				

Negative Aspects

Long Wait	6	No Staff	2	No/Wrong RX	2	Funding	1	Pain RX	1
Bureaucracy	1	Not on Route	2	ID Problems	1	OTC Meds	1	Dental	3
Denied Respite	1	No Health Care	3	Wrong Treatment	1	No MRI's	1	Rx Glasses	1
Dr. Refuses Rx	1			Personal Treatment	1	Counseling	1		
Overworked/underpaid	1			Economic Classes	1	Acceptance	1		

Psych Dr too short	1	Medical Marijuana	1
Vocational Services	1	Legislative Rulings	1
Court Internments	1	Outpatient Clinic	1
Peer Pressure w/in Staff	1	Services updated	1

(2) How would you describe your interactions with staff and providers?

No Answer	53	Excellent	3	Helpful & Caring	3	Good	18	Yes	10
Respectful	2	Asked Needs	2	Very Professional	3	Very Good	6	OK	6
Friendly	2	Courteous	3	Not treatment effective	2	Pleasing	5	Great	5
Sometimes	2	Understanding	1	Wonderful	1	Not Bad	1	All right	2
All's Well	1	Well Organized	1	Helpful	1	Fair	1	Fine	2
Informative	1	Subjectable	1	Positive	1	Super	1	Exactly	1
Stressed	1	Very Comfortable	1	Satisfied & Blessed	1	Equals	1	Kind	1
Simple	1	Value	1			Rude	1	Nice	1

(2.2) Do you feel comfortable here?

No Answer	30	Very Well	2	Good Services	1	Adequate	1	Yes	53
No Body Rude	1	Most of Time	2	Very Much	5	No	1	OK	3

(2.3) Are you treated with dignity and respect?

No Answer	47	Very Well	2	Very Respectful	1	No	1	Well
Yes (sometimes)	1	Accordingly	1	Overwhelmingly	1	Respected	1	OK

95%

Positive Aspects

Personal Preference	1	Good Staff	2	Polite	1
Understand Patience	1	Comfortable	3	Good Food	1
		Feel Important	1		

Negative Aspects

No Case managers	1	Staff Turnover	1	More Help	1	No Help	1
Negative Staff Attitude	1	Too Many Rules	1	Rudeness	1	Lost Dr.	1
		Uncomfortable	1	Inaccuracy	1		
		Work with Client	1				

(3) What would you say is the best part of the program?

No Answer	7	Free Medicine	2	Availability	1	Timely	3	Service
Respite Care	44	Location	2	Serving Homeless	1	HIV Clinic	6	Everything
Professional	4	Helping Ill	1	Care/options	1	Good Job	1	Staff
Excellent	1	Needs a Must	1	Homeless Program	1	Yes	1	Cost
Recovery	1	Commitment	1	HIV Drop-in	1	To Help	1	None
Confidential	1	Undetermined	1	Gender Specific	1	HIV Class	1	Doctors
Knowledgeable	1	Personalization	1	Native Nurses	1	Timely	1	Triage
Caring	8	Kind Services	1	Native Staff	1	Helpful	1	Dental
I.C. Group	5	Unknown	6	Talking Circle	1	Results	7	Food
Education	3	Help Homeless	5	Progress Group	8	Follow-up	3	Formats
Graduation	3	Employment	1	Learning Self	3	Coffee	1	OK
Cleanliness	1	Sober/Clean	2	Outside Meetings	3	Restrooms	1	Bed rest
People Potential	2	Friendly	1	Community	1	Free Space	3	Stay Dry
Information	2	Addiction Cvr.	1	Most Needs Met	1	Proper Drs	1	
General Mtg.	2	Med Help	1	Understand Needs	1	Staff Mtg.	1	
Stay out of trouble	1			Primary Counseling	2			
Ability to problem solve	1			Anger Management Grp	1			
Family/children Programs	1			Prog./Mtgs. Benefits	2			
Personal Treatment	6			Treatment Group	1			
Personal Attention	5			Better Life for Everyone	1			
Personal Perception	1			Good coming/ short goings	1			
Personal Concerned	1							

(4) What are your suggestions for improvement?

Keep up the Good Work	3	No Answer	17	Good So Far	1	None	49
Waiting Time/Appoint. Clinic	26	Water Cooler	1	Comfortable	1	Rx Glasses	4
Waiting Time/Drop-in	14	Reminder Calls	1	Invested Drs	1	Funding	6
Waiting Time/RX	11	Food/Snacks	2	New Scales	1	Dental	7
Faster Waiting Lines	14	Longer Hours	1	Extermination	1	O.T.C.'s	4
Appointment Schedule	1	Add van to Route	1	No Change	4	Don't Know	1
Give what required	1	More Staff	16	Recreation	6	No Thanks	2
Drop in System	1	More Doctors	1	Better Food	6	More Work	2
Printable Information	1	Traffic Control	1	Amenities	3	PM Meds	1
More Info/services	1	More outside Mtgs.	2	Orthopedics	1	Respect	1
More Money for Dental	1	Heath Care	4	Pharmacy	1	Clinic	1
More Money for Staff	1	Better Medical	3	Peer Group	1	Clothing	1
Dispute Resolution	1	More IC Group	1	Veteran Svs.	1	Less Class	1
Sober Workgroup	1	Economic Svs.	1	Rehab Svs.	1	More	1
More Progressive Group	1	Mental Health Grp.	1	Online Comp.	1	Rest Day	1
Stop Repetitive Questions	1	More AA Mtgs	1	Patient Beepers	1	Separating	1
Board Involvement	1	Better Organized	1	Monitor System	1	More Housing	1
More Treatment Videos	1	Bridging Recovery	1	Split Large Groups	1		
Improved/Bigger Building	3	Rss. Peer Leader	1				
More Self Help Books	1	More Grp. Privileges	1				
Efficient Follow-ups	1						
More Comfortable	1						

Appendix 3

BENEFITS OF OUTREACH TO HCH AND CAB's

- With so many HCH sites, we need to develop an accurate method of gathering input from clients and front line staff about what is working within the HCH service system and what changes need to be made.
- Utilizing an outreach approach with a feedback questionnaire allows us to gather a broad perspective from populations of homeless people who would not normally have a mechanism for providing critical feedback on the services of HCH. Homeless people often have competing time conflicts (food, shelter, childcare, other volunteer commitments) or a disability that would prevent attending meetings. We must be able to gather their feedback regardless, and a questionnaire with direct input will allow this to happen.
- Using the anonymous outreach questionnaire allows the CAB members almost all of whom deeply appreciate HCH, due to their personal interactions, to provide critical judgments of the program without worrying that they will be seen as attacking HCH.
- Doing outreach provides an active opportunity for CAB members to engage in a process that will help shape the work that is directly connected to their life and passion. Through outreach and trainings, many volunteer outreach workers have become paid frontline staff in the programs they have met through outreach.
- Outreach provides an opportunity for HCH staff and clients to work together on a project that lifts both groups out of the separation that is inherent in their roles in the service system. It provides training on the interconnectedness of systemic poverty issues that both staff and clients identify as being extremely frustrating, on a daily basis. It also allows both groups to find common bonds and work jointly towards developing a better system of care.
- Policy: Outreach provides a format for developing priorities that become the advocacy platform of the organization. It also creates personal investment among CAB members, clients and staff in continuing to build and carry out the policy advocacy agenda, as they have been an intrinsic part of developing the priorities that shape the agenda. This provides a context for developing relationships among staff, clients, volunteers and donors that is based in common goals, not personal experience or charity.
- Research: Outreach questionnaires create a mechanism for gathering data on the needs of homeless people and staff training without professional/clinical or researcher bias.

- Program: Outreach can identify sites where there is a strong mutual respect between staff, clients and program administrators. Sites with strong mutual respect are better able to focus on the overall NHCHC policy and advocacy agenda building work. When we identify sites that lack this trust and respect, we can better focus our assistance on program development at those sites. An organizing agenda builds a mechanism for developing trust based in identification with broader issues. It allows a dynamic shift from confinement in job roles or client/staff roles to the more equalizing role of people carrying an agenda larger than any one person, with responsibility for and accountability to a collective process representing the real needs of people who use the program, not just the opinions of individual clients/staff/administrators.

- Public Education: The public education work of both the local HCH programs and the NHCHC is greatly enhanced with this methodology. When you are able to produce reports and position papers that can be backed up by homeless people randomly interviewed in the street your positions are accepted as being representative of homeless and poor people and families as a whole. Your spokespeople can still tell their stories or speak to the broader issues but when reporters, bureaucrats or community groups check your data with a homeless person or service provider they are meeting with the chance have “your” positions confirmed by their experiences or their knowledge of people having the same experiences are greatly increased and lend more legitimacy to your claims.

Appendix 4

COMPILING THE OUTREACH INPUT:

Lessons learned:

- should not have three part questions
- when you develop the outreach questions create your template for compiling the input
- Date your drafts
- Hang on to the original outreach responses
- Seems better to do a small number of open ended questions than a large number of really specific ones. While it is a little harder to compile the input, the answers you're getting are much better defined. (i.e. 15 people can say "no, this program is not helping me but they could be saying so for 10 different reasons)
- This system does not just tell you if something is working or not it all so tells you why and what people would recommend be done about it. The open ended format gives a sense of the programs organizational environment.
- In general: it seems the answers are a little more thought out when people fill the forms out themselves but the overall gist of what is being said by people doesn't seem to change based on the style of outreach conducted.
- CAB meeting agendas should be based on responses from the outreach with follow up outreach asking about ideas for solutions to any problems or how to duplicate or expand on positive issues.

Compiling the data:

- Before you document anything read through all the forms you have
- Get a sense of how the responses are flowing and how that fits with the documentation form you have.
- If you run into a response sheet you can not understand put it to the side until you have compiled all the input from the other forms and then bring it back out and look to see where it might "fit in"
- Track how many response sheets are coming in but don't worry about the numbers of responses adding up. Some people give more then one answer while some leave certain questions blank.
- After you have read through the responses go back over them question by question. Look at all the question #1 responses. Tally when the answer is simple (yes/no) and begin to create categories for the "yes, but or no, but" answers. We placed them in a negative and positive categories format on the pilot outreach form.
- The positive or negative reasons given through this style of outreach will begin to add up and truly begin to "paint a picture" for you as to how people are experiencing what they are talking about. "Yes, this program is helping me but you have to wait a really long time for services" was a common example in the pilot outreach effort we just did. "No, but the staff tried..." is another.
- Start a check off tally of the more common answers and begin documenting the individualized ones.

- After the tally section is completed go through the individualized answers and categorize them by common theme or areas of concern. Staff comments in one section. Service modality in another, hours of operation, etc. etc.

On the national scale this opened ended format gives you a very broad range of input regarding positive and negative perceptions but not an infinite number of answers as eventually the common tallies start to go up and the individual perspectives decrease.

READING THE OUTREACH RESULTS:

In order to ensure that the input from your outreach is “painting the picture” for the group it is important to consider these points as you are reading your local and national results sheets. Examples listed below are from the national results sheet but both should be read the same way:

- The final results sheets lists answers that are similar yet stated differently as separate responses, i.e. (Q1.) Have you found the services to be.....Yes-125: Excellent-38. As the group discusses these responses you will begin to coalesce these answers into one statement from consumers. It is important to wait until the group discussion stage before coalescing similar answers into one answer so as to prevent the assumptions of the one or two people compiling the outreach results influencing the answers.
- The goal when creating a national agenda is to identify those issues most relevant to people in all the HCH communities, while the local agenda is the issues most relevant to people in the immediate community. Therefore when working with the national results it is important to have the local outreach results available for reference. This will ensure that no single community’s outreach effort will dictate the national perspective.
- Look to match areas of strengths and weaknesses. The national results can assist the NCAB/NHCHC in connecting CABs and programs in communities that are achieving positive results with a program or policy with communities that are looking for some help with similar program or policy issues.
- As your discussing and consolidating the input and identifying areas of strengths and weaknesses you should start developing the next set of questions for your outreach. In this way, some if not most, of your next set of questions will relate back to the previous questions you asked. This creates an ongoing dialogue and increases the follow up amongst the consumers, CABs and agencies.
- At this point you begin to develop recommendations for next steps to be taken. Some will fall within the purview of the CABs or NCAB and steps can be taken with the results reported back to the consumers (i.e. recommended trainings or the acknowledgement of a staff person etc.). While others will create the basis for the

follow up questions in next months outreach (i.e. program or policy changes, direct actions, etc)