

Originally Processed With FOIA(s):

S

FOIA Number:

S

FOIA MARKER

**This is not a textual record. This is used as an
administrative marker by the George Bush Presidential
Library Staff.**

Record Group/Collection:	Donated Historical Materials
Collection/Office of Origin:	Frieden, Lex, Collection
Series:	Printed Materials
Subseries:	Miscellaneous

OA/ID Number:	52165
Folder ID Number:	52165-009

Folder Title:
9-23-98 Read [Independent Living, Travel, Personal Assistance Services - 1998]

Stack:

Row:

Section:

Shelf:

Position:

Presentation by Lex Frieden

John Dalrymple introduced Lex Frieden.

Mr. Frieden began his presentation by stating, "What is past is past, the important things are what we are going to do tomorrow and the day after that."

The rest of his comments are as follows:

"I was not always an advocate. Mike Phillips was an advocate in Tulsa when I was a student. At that time, the only interest I had was working on schoolwork so VR would pay for my books. That was my whole interest in life.

My father came home one night from work and had a newspaper article about a group meeting to discuss issues for persons with disabilities. My father was interested, and I wasn't. He took me to the meeting that night anyway.

I gave a lot of reasons not to go. My father said it was a year since I had broken my neck, and it's important that I take an interest in public events. This is an opportunity I needed to face. I said I had plenty of opportunities. My father said that did not suit him. He compelled me to go to the meeting. It was something he wanted to go to, not me. I got tears in my eyes, he lifted me from my wheelchair and took me to the meeting. I was angry (because) he took me there like a child. I've never forgotten it.

He got me there, and took me into the meeting. I remember going in and there were five or six people in wheelchairs, a man without arms, a young woman who couldn't talk to me. It was like a movie, being in a weird place, a surreal experience. All of these emotions came out. It was a time when I was trying to come to terms with a permanent impairment, and in the space of an hour all of these feelings came out. I'm where I don't want to be with these people I don't want to be with.

I smiled and shook hands with people. I met the Phillips'. Mike was speaking and a disabled businessman was there selling seat cushions. There was a "para" selling wheelchairs. Then Mike Phillips said he was teaching kids and tutoring. I was thinking get me out of here, just take me back to Tulsa University where there were only two people with wheelchairs and a blind woman who did not even want to talk with me.

I went home and cried myself to sleep that night. The next day, the sun came up and things were back to normal. Three days later, I was thinking about studying when I got a phone call from Mike Phillips. He asked me to write an article for their newsletter about life on campus in a wheelchair. I tried to get out of writing it. He insisted. To get the man off the telephone, I said I would write it and send it to him.

A week later, Mike called back. I told him I was still working on the article. He said he would come by my house and pick it up Sunday afternoon.

I was looking out my bedroom window the next Sunday and saw a van pull into my driveway with a side lift, and Mike came out of the van and Judy and their kids were with them. I was beside myself.

My mother greeted them at the door just like you would anybody else. I was hoping she would tell them I was away from home. I wanted my parents to tell them anything to get them to go away. My dad was angry and urged me to go greet them. I did, and it was the nicest afternoon I ever had. It was good for all of us. It was important for my parents to see someone with a disability who was successful and had a family and was independent.

It was a life altering experience. About a week later, my parents and I visited their home. We learned a lot about access and adaptations.

I owe Mike and Judy a lot of what I am today because they reached out when nobody else thought about that. Inadvertently they forced me to face a conflict I was willing to live with the rest of my life.

Today, Christopher Reeves is an example of someone who is not facing the face that he is someone with a disability. We are not simply someone with a disability or a disfigurement. We are people with disabilities and we are people. We all have to come to grips with that in our lives, and we have to deal with that if we want to succeed.

That is the role of IL. To give people the opportunity to meet themselves. We must provide opportunities for those already well aware of themselves. If we don't realize our job to bring more people into the effort, we are missing not only an opportunity but a responsibility!

Some of us can do it better than others. And we each do it in different ways. You have the ability to do things in your own community and own state.

The participants in the whole IL milieu have the ability to do more than we give them the opportunity to do. This has been a good experience to be here in NC.

Twenty years ago, four guys from Charlotte called me to come to NC to see how they could live outside their parents' homes independently. They started the Metrolina IL Center and ended up helping more folks than just the four of them who called me that day.

NC has a lot of people who have taken the responsibility of doing things for themselves and others that the system just would not do for them.

I've met a lot of staff during the last few days. NC is doing things other states aren't doing. You are fortunate to have the people here to do things that persons with disabilities can deal with. Unfortunately, you do have some rules that get in the way of doing business. But, you have people who are willing to work within those rules to help.

We met with the Commission on the Blind about their mini-centers for persons with visual impairments who are discovering their disabilities and their needs.

I had the opportunity to visit folks with the IL agencies and the CILs representatives. I heard about Sylva, Greenville and Winston-Salem. I was looking forward to hearing things that I could feedback to you and tell you what you are doing wrong.

But, you folks are taking the initiative and are doing things other states are not doing. You are not basing your view of IL on what the folks in Washington or some national organization think should be done, and that won't help the people living in Rocky Mount or Charlotte, because these cities are different from other areas of the country and different from each other.

When this concept of IL began, we tried to define IL. It involves making decisions that involve your lives. We have to be involved in making decisions. We lived through a patronizing approach to people. Now IL, which was perceived to be is being shaped by government regulations or group membership criteria. This is wrong. The only way to right the wrong is to do it right. I am inspired that some of you in NC see guidelines as just that, guidelines. Where we need to end up is where the people in our communities want to be.

Some communities already may have peer networks. Why should IL spend for that when the peer network is already there? It all goes back to what the people in the community need.

It is generally true in all states that in order for this program to survive, at least for federal dollars to be available, we really have to demonstrate that the agencies don't own IL, the people do. This is a challenge.

This program can't survive unless the people served by it believe that it is their program. That expands to VR as well. VR will not last unless the people served by it are vested and believe in it.

This requires a partnership. Not a standing outside, not like an owner, but like a customer.

We can stand on the outside of IL and VR to discuss why our needs aren't being met, or we can go inside and change the structure of the program so all who are served are members of the organization that owns the program. We can make friends with the people in charge of the programs.

Mike and Judy Phillips reached out to me, bribed me if you will, and thank God for them. We need to be involved with the people we are serving. We must encourage them to be a part of the program. We may have to confront them to be a part of the program.

I didn't want to come into the program at first. I had more excuses not to come in. I couldn't hold out. I think everyone has a contribution to make to the IL programs. Anyone should be and could be an owner of this program. Owners expect a voice in the program. We can't bring them in as tokens. People see through this real fast.

We have a history in VR of Texas with the Commissioner and the staff understanding the importance of having consumers involved, and have had a consumer advisory task force.

When the task force first came up, a lot of us were excited about this concept. We found out that they had in mind bringing us up to Austin, showing us how hard they worked, buying us some coffee and sending us home to tell others how hard they work. This changed when they realized we had some real ideas to help make things better.

Anytime we needed someone to dig down deep to support other advocacy efforts nationwide, we have been able to call on Claude Myer, Bob Philbeck and John Dalrymple to help. They are willing to help. The NC leadership has for the last 25 years, without question, used their connections to help advocacy efforts.

Here are people who really care. Within those of us who really care, we must use our imaginations to do even more. We have a responsibility not to let someone else do it. Through a partnership process we can do more.

In 1984, I was chairman of the National Council on Disabilities. My goal was to accomplish something tangible as long as I served on that job. I went up to Washington with the idea we would accomplish something. We were to produce a report on what people with disabilities need. We all know by experience what we needed. In 1985, the issues were discrimination, transportation, health care, etc. In 1977 at the White House Conference, the issues were the same.

We worked on the report for about a year. We vowed to turn the report in on time. I thought we would make history by getting it done on time. The President would call us to the Oval Office, we would be on the Nightly News for getting this report done before the deadline.

Around the end of 1985, we went down to the office over the Christmas holidays to get this finished. We hired the Federal Prison Industries to print our report so it would get done on time. It was supposed to be given to the President. We had 10,000 copies stored in my office. We decided to show it to the White House before it was presented to the public so we wouldn't catch them by surprise. We took it to the President's liaison staff.

At six the next morning, the White House called. Bob Sweet was on the phone asking what we had done. He asked us if we knew the President's point of view, and said Ted Kennedy would not support the proposals we had outlined in our report they were so out of line.

I argued it was just a report, and we were told (by Sweet) not to issue it. I said I was sorry he felt that way, but the law tells the council to do this. He called me back two minutes later to meet at 10 am with Bill Roper, head of domestic affairs for the White House.

I contacted my cousin, who works at CNN, to find out about Bill Roper. He found out Mr. Roper was a doctor in Alabama who had worked at a rehab center near Birmingham.

I went into the meeting with Mr. Sweet and he had the report torn up and laying around his office. Dr. Roper then came in. Mr. Sweet said the report was the problem and was not consistent with administration policies.

Dr. Roper asked for specifics from the report...he noted it called for no discrimination on basis of disabilities. Dr. Roper asked me what I had to say. I said we went all over the US to find the major barrier to independence and to work. Nearly all of the respondents said discrimination. Then I said it seems to me in your experience you have helped a lot of people, you've studied and practiced medicine and understand rehab. You understand how much we spend in this country to keep people alive following trauma. You know how much we do to help people get work through VR. It seems to me a person with your background would have difficulty backing a policy that would waste the time, money and tears it takes to make people with disabilities full members of this society. We should have the opportunity to use the benefits of all this rehabilitation and love.

Dr. Roper looked at me and said, 'You are saying it is illegal to discriminate against any person with a disability.' He then told Bob Sweet he had a problem with him. Dr. Roper said our council will meet with the president and deliver its report.

Bob Sweet learned that treatment of people with disabilities is not based on philosophy, race, gender, political views, but on morality. A lot of people learned during advocating for the ADA that persons with disabilities are whole, and can make an impact on the lives of our families and others. This experience we had of coming together on ADA is one we have to draw upon again. We have to recognize that our lives have completely turned around just because of the ADA. We have to work together now to represent VR and IL. We have to have a national personal assistance plan. We have to make assistive technology available to all. We have to demonstrate leadership. We can demonstrate to people with little means, who are left out of our society how they can gain control of their lives, not by complaining about what they don't have but working to find the things they need.

People with disabilities in rehab have been treated as though they know less about their disability than somebody who has been to school four or eight years. Don't tell me to take these pills till the bottle runs out. Work with me.

This applies to the whole society when it comes to health care. That was the original philosophy dealing with managed care. Profiteers within the insurance industry focused on the bottom line and their own health. They understand that managed care means managing someone else's care, not allowing people to manage their care.

We have a great opportunity with the advent of the Internet to advocate. This is not like observing with a VCR, or a news station on the FM band. The communication potential for the whole society is enormous. Those of us who know about working together and organization (the Internet) gives us a quantum leap.

Motivated by love, passion, and the moral and ethical right, we can use the Internet to make ourselves, our families, our friends, and others in our community better. I want to thank each of you for listening to me.

In comparison to other states, NC has advantages you need to take more advantage of.

In the past two days, the lack of transportation is the issue I heard the most. If NC has a fault, it is not reaching out on the issue of transportation. The Internet should not be an excuse for not allowing people to visit their folks (or) going to the store. The virtual world is not a replacement for traveling in the real world.

I met with the agency for the Blind the other day. Transportation is an issue which cuts across all disability groups. It affects poor people, too. You need some solutions to offer when the time is right. This gives you a chance to work together.

Thank you for listening to me. Now we will have some discussion."

Dollie Smith commented, "What he (Frieden) has done, is what we can all do, especially from this council. The enforcement of the ADA is imperative. When you find barriers in your community. You need to bring it to the attention of someone who is responsible. If they do not correct the problem, you go to the media. They are usually ready to help. Transportation in my city is handled by special vans for disabled. There is a rule that says we have to live within 3/4 miles of an existing bus route. That is a rule by city council that no one ever challenged. Now, with changes on the council, I will be working to get this changed. "

Mr. Frieden remarked, "Rules are made to be changed. And I believed they can be."

Mike Phillips stated, "One problem we noticed in dealing with paratransit in Winston-Salem is confusion in the regulations. Some people qualify to ride under ADA, and others under Medicaid and arrangements with health care organizations. Each group has different regulations which the transit authority must operate under...they are confused."

Mr. Frieden remarked, "In Texas, we went to the Attorney General and asked him to look at the situation. He made a ruling for the state that accepts any transit agency from the state to sort through the rules and carry people as people, not members of a group."

Mike Phillips asked, "Would you leave with Roger (Goble) a couple of states (names) we can model some solutions off of?"

Mr. Frieden remarked, "I will tell you some people to call."

Mr. Frieden commented, "For reasons I can't explain, the fact I've been places at some times when I was given the right answer. But there have been lots of frustrations. There are some people who are going to have to do things I can't do.

The disability movement does not have Martin Luther King. We don't have an evident leader. We don't have anyone to nominate for the Nobel Peace Prize. But that is the strength of the

movement. We cannot delegate leadership to somebody. We all have to lead when the time comes. We have the power to speak individually for ourselves and be leaders when the time comes.

I happen to be the one called on to do it, and had to do some things the best way I could. We all need to do that - to do our best, to listen to our heart and if we intend to make things better, we will all excel in this leadership role."

Vennetta Baker commented, "It just dawned on me, I work at Western Carolina Center. I have a problem because the Human Rights Committee is only concerned with the rights of people on our campus. But, human rights is much more than that. They need to call it something different than that."

Mr. Frieden remarked, "I would definitely confront them about that."

Venetta Baker stated, "There are some people so respectful to our residents, but not the people who work there. That is not fair."

Mr. Frieden commented, "Maybe they need to call themselves the Residents Advocacy Council instead of the Human Rights Committee. It sounds like they are a residents advocacy council."

Mr. Frieden then stated, "I think the SILC needs to practice being authentic. You need to get down to it. There are some issues beneath the surface with the SILC and programs, and you will be more effective. If you promise not to hurt others feelings, there are some issues that need to be brought to the surface. We need to set aside interpersonal barriers and get down to gut level issues.

We need to say, let's all put our feelings aside and agree we will leave as friends. But, let's go ahead and discuss these issues. Either we do that, or we don't need to come together. We need to address our views in an open manner and don't bring with them hidden agendas. That helps us to understand each other better, even if we don't agree with each other."

Mike Phillips commented, "Thank you for your comments on our meeting. I want to say I am happy to hear so much of what you say based on morality and feelings, and not just getting mixed up with politics and power struggles. That is the salvation of any effort. The problem with movements come up when people worry about what camp they are going to be in. We have the moral right on our side. I am glad to hear you have come through all of this in Washington with that still shining out."

Mr. Frieden remarked, "What goes on in Washington or city hall?; a lot of the politics are games, they are nice distractions that can be manipulated. But, that is not life and that is what we are dealing with. If we focus our real initiatives on what is life, if we focus on that, we will be able to accomplish much more.

Dollie Smith commented, "We need to find the games that are being played, and what the rules are."

Mr. Frieden remarked, "The first time I went before an appropriations committee of Congress, we had a million dollars to run the National Council on Disabilities. I thought that was a lot of money. Being from Texas, I believed taxes were too high, and government was spending too much money. I continued to borrow paper and typewriters and get tickets for free for flights, just like when I was working with a non-profit with no budget.

I thought I would get the medal of honor for saving 200-thousand dollars from our budget. Then one congressman said, 'If all you need is 800-thousand dollars, then that's what you are going to

get, not the 1.2 million you asked for.' Then I determined that (government work) was not something I wanted to do long term."

Dollie Smith stated, "In NC, money not spent goes back into the general fund and go to some other agency at the end of the fiscal year. At the state or federal level, they do not reward you for tightening your budget."

Mr. Frieden stated, "I want to raise the issue of diversity in Independent Living. This appears to be a diverse group. We need to be consistent with our convictions when it comes down to equality. Unfortunately, CILs nationally, VR and IL nationally underrepresent persons of color. I do not believe it is intentional. I believe it comes from not understanding the needs of all communities.

It is not fair for the poor people to come across town to the middle class side of town to the CIL. Maybe it makes better sense to have the center where the people are, who can't travel across town. We have to fix our programs to meet the needs of people.

If your IL center does not have a person with multiple disabilities that serves people with cognitive disabilities, mental illness, HIV and AIDS, or sensory disabilities, it should. You must deal with the diversity of your community.

If we don't demonstrate leadership on the issue of diversity, no one else will. You must be diverse in the work that you do."

*Chairman Goble and Butch Cooke thanked Mr. Frieden and his attendant Mac Brodie for coming to NC and meeting with the SILC and various independent living organizations.



1333 Moursund
Houston, Texas 77030-3405
In the Texas Medical Center
(713)799-5000

Official Procedure

SUBJECT:

TRAVEL

DISTRIBUTION:

Program Physicians and
Management Council

REVISED:

July 1995

PROCEDURE

NO. F-2

REVISION NO.:

APPROVED:

L. M. Adelman

PAGE

4

OF

POLICY

TIRR Hospital is committed to providing travel necessary for the support of its clinical, research, and educational programs. Any or all reasonable costs incurred by employees or non-employees who travel at the request of, or on behalf of, the Hospital may be considered as allowable. All travel is subject to approval by management. Approval will be based upon the particular situation and its relevance to the on-going business of the Hospital.

PROCEDURES

1. Approvals

- A. All travel must have advance approval of a member of Management at least one level above the individual making the request. For example, staff travel must be approved by an appropriate department head, service manager, or program administrator; department heads, service managers, and program administrators by their Executive Director or Vice President; Executive Directors and Vice Presidents by the Chief Operating Officer, etc. Approvals for amounts to be spent are the responsibility of each department head and must be within the departmental budget. Appropriate departmental documentation must be completed prior to departure.

2. Airline Tickets

- A. Airline tickets must be ordered from either Apple Travel or Travel Unlimited. Both of these agencies guarantee lowest available fares.
- B. Each department/program should appoint at least one travel coordinator to be responsible for ordering airline tickets.
- C. The travel coordinator must provide the following information to the travel agent when ordering airline tickets:
 - (1) Cost center number of appropriate department/program/grant
 - (2) Name of the travel coordinator requesting airline ticket

TRAVEL

F-2

Program Physicians and
Management Council

July 1995

Louisa Adelman

2

4

(3) Brief description of purpose of travel (i.e., seminar name)

- D. Only economy or coach class airfare may be purchased for Hospital business. Exceptions may be granted in certain cases (Reference 3.C.).
- E. The cost of canceling or changing non-refundable tickets will be borne by the department/program/grant or by the employee, depending upon the specific circumstances.

3. Allowable Travel Expenses

A. The following may be treated as allowable travel expenses:

- (1) Seminar/Conference registration fees
- (2) Airfare
- (3) Lodging (check on availability of group rates for seminars)
- (4) Meals, meal-related tips, and incidental tips (i.e., bellman, etc.) not to exceed a daily maximum amount established annually or as allowed by the particular grant under which travel is paid
- (5) Mileage for personal vehicle (i.e., home to airport) at per-mile rate established annually
- (6) Parking fees/Road tolls
- (7) Rental of compact or mid-size automobile (only if necessary and justified; also, includes related gasoline usage)
- (8) Taxi or shuttle services
- (9) Business-related telephone calls

B. Expenses for companions, family members, etc., are not allowed, unless such persons are required by reason of disability to perform personal care assistance.

C. Additional expenses may be allowed for travelers with disabilities who require and receive pre-approval for reasonable accommodations.

D. If a meal is furnished as part of a meeting or by an airline at no cost to the employee, no reimbursement will be made for that meal. Meals will be reimbursed for the

 Official Procedure	1333 Moursund Houston, Texas 77030-3405 In the Texas Medical Center (713)799-5000		SUBJECT: TRAVEL		PROCEDURE NO.: F-2
	DISTRIBUTION: Program Physicians and Management Council		REVISED: July 1995		REVISION NO.:
	APPROVED: <i>Luisa Schumacher</i>		PAGE 3 OF 4		

day departing or the day returning depending on which meals would be necessary due to travel schedule.

4. Business Development Expenses

- A. In certain instances, the Hospital will reimburse employees for the cost of business development. A valid business purpose must exist for the expenditure. Prior approval must be received for these expenditures in accordance with Section 1.A. of this policy.
- B. Business development expenses must be documented on the business expense form in accordance with IRS requirements. The following must be documented:
 - (1) Specific business purpose
 - (2) Names of all persons and organizations represented
 - (3) Date
 - (4) Place
 - (5) Type of expense (i.e., lunch, dinner, theater, sporting event, etc.)

5. Reporting Travel Expenses

- A. Travelers are expected to keep receipts for all allowable expenses in order to receive reimbursement. The only exclusion would be mileage incurred on personal vehicle and incidentals (i.e., miscellaneous tips). Unsupported expenses will not be reimbursed. The traveler will be personally responsible for any expenses deemed excessive or unreasonable.
- B. Within 30 days of return from travel, employees should prepare the appropriate business expense report (with all receipts attached) and submit to the appropriate level of management for review. Receipts smaller than 1/2 page must be taped to an 8 1/2" x 11" sheet of paper and attached to the expense report. Once approved, the business expense report and receipts should be forwarded to Accounting with a properly documented and approved check request.
- C. Reimbursable expenses in excess of \$50 will be repaid by check and will be processed within five working days of

TRAVEL

F-2

Program Physicians and
Management Council

July 1995

Louis Adelman

4

4

receipt. Amounts less than or equal to \$50 should be reimbursed from petty cash through the Cashier's office.

- D. It is imperative that the last page of an airline ticket be submitted as a receipt, even if paid in advance by the Hospital. A copy will be accepted in limited circumstances, and only if approved in advance by the traveler's appropriate level of Management. The employee will be expected to reimburse the Hospital for the full amount of unsupported airfare paid in advance.

6. Travel Advances

- A. The employee will be expected to incur all allowable travel expenses (except those paid by the Hospital in advance) using personal resources (i.e., personal credit card). Travel advances will not be made to employees except under extraordinary conditions approved in writing by the Chief Operating Officer. In certain circumstances involving externally-sponsored, non-employee travel for education or research purposes, approval may be given by the appropriate Vice President or Executive Director.
- B. In the event an advance is issued, it must be reported on the business expense report form and included in determining the amount due to/from the employee. If the amount of the advance exceeds actual expenses, the employee should submit to Accounting a personal check made out to TIRR along with the expense report and receipts within 30 days of end of travel.

**Draft Interim Recommendations of the
National Blue Ribbon Panel on Personal Assistance Services
September 10, 1998**

Recommendation 1: Technical Assistance to Assist States in Reaching the Goal of "Most Integrated Setting"

The Department of Health and Human Services, in conjunction with ASPE, HCFA, and other federal agencies, as appropriate, should conduct a nationwide program of technical assistance designed to assist states in reaching the goal of "most integrated setting" and community-based placement for people with disabilities who require routine, on-going assistance with activities of daily living.

The recommended technical assistance program should be designed and conducted with substantial input from people with disabilities and organizations representing people with disabilities. Such individuals and groups should be employed by the program as advisors, consultants, program designers, and trainers. Preference should be given to individuals with disabilities and organizations of individuals with disabilities, including centers for independent living, in the process of awarding grants and contracts which may be associated with this initiative.

The recommended technical assistance program should include multiple components, including on-site training of regional Health and Human Services staff and state Medicaid personnel; on-going meetings with consumer groups; on-site consultation; remote consultation via telephone and Internet; one or more regional and or national training programs; and support materials and information necessary to carry out the program effectively.

The technical assistance program should assist states with program design, including the development of service delivery options. It should also assist states in addressing liability issues, particularly with respect to health-related personal assistance service activities. Additionally, it should assist states with issues pertaining to personnel development, personal assistant recruitment programming, and personal assistant training. In general, the technical assistance program should address all issues pertinent to the development and operation of a state-

wide infrastructure designed to support the provision of personal assistance services and other related services necessary to reach the goal of "most integrated setting." In each state, this program should be guided by a technical assistance advisory committee which includes consumers, state agency personnel, and representatives of public and private service providers.

The technical assistance program should make demonstration grants available to states for the following purposes:

- a. Demonstration funds will be available to assist states with minimal experience to develop necessary skills and infrastructure to achieve the goal of "most integrated setting," and
- b. Demonstration funds will be available to facilitate the transfer of "best practices" in relation to the goal of "most integrated setting," from state to state.

The goal of this technical assistance program should be to insure that every state develop policies and programs that achieve the goal of "most integrated setting" for each eligible program participant in that state.

Recommendation 2: Public Consultation to Facilitate Planning and Implementation of Programs Within States to Achieve the Goal of "Most Integrated Setting"

The Department of Health and Human Services, in conjunction with ASPE, HCFA, and other federal agencies as appropriate, should conduct a series of public discussions on the subject of "most integrated settings." At least one such discussion should be held in each federal region. These meetings should be designed to:

- a. Promote understanding of the concept of "most integrated setting;"
- b. Receive recommendations related to the elimination of institutional

bias in HCFA-sponsored and other public programs, as appropriate;

- c. Receive reports and recommendations about progress toward reaching the goal of "most integrated setting;" and
- d. Facilitate the process of planning to achieve the goal of "most integrated setting" within states by providing an appropriate forum for consumers and advocates, including representatives from the aging community, the developmental disabilities community, independent living centers, and other interested parties to work together with state Medicaid officials and others, as appropriate, to develop implementation plans for their respective states.

The format for these public discussions should include:

- a. Plenary style presentations by federal and regional officials, and by consumers and their representatives relative to the public goal of "most integrated setting;"
- b. Small group working sessions to include representatives of consumers and state agency personnel from each state within the region designed to facilitate planning and implementation of activities within states aimed at the goal of achieving "most integrated setting" placement for all eligible program participants; and
- c. An open forum for public discussion, particularly including invited input from representatives of the aging community, the developmental disabilities community, and centers for independent living.

The above recommendations were generated by Blue Ribbon Panel project staff based on directions given by the Blue Ribbon Panel at a meeting of the Panel on August 29, 1998. These are consensus recommendations of the

panel. However, the final wording of the recommendations has not been formally approved by the full panel. For further information, please contact Lex Frieden at (713) 797-5283 or Pamela Dautel at (713) 520-0232.

The National Blue Ribbon Panel on Personal Assistance Services is staffed by ILRU (the Independent Living Research Utilization program at TIRR). Project support is provided, in part, by a grant from the Robert Wood Johnson Foundation. Recommendations and other products of the Blue Ribbon Panel do not necessarily reflect the views or opinions of the Robert Wood Johnson Foundation, ILRU, or any of the groups or organizations whose representatives or members serve on the Panel.