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State of the Art of Independent Living Workshop

LIST OF PARTICIPANTS

Achtenberg, Jack
Professor of Law
University of San Fernando Valley
College of Law
Sepulveda, CA 91343
(213) 894-7002

Berrol, Sheldon, M.D.
Santa Clara Valley Medical Center
751 South Bascom
San Jose, CA 94128
(408) 293-0262

Berkowitz, Monroe
Professor of Economics
Bureau of Economic Research
165 College Ave.
New Brunswick, N.J. 08901
(201) 846-1057

Baird, Ralph
Director of Special Education
Tacoma Public Schools
P.O. Box 1357
Tacoma, Washington
(206) 383-1811

Brean, Edna, R.N.
Center for Independent Living
2539 Telegraph Ave.
Berkeley, CA 94704
(415) 841-4776

Collignon, Fredrick
President
Berkeley Planning Associates
2320 Channing Way
Berkeley, CA 94704
(415) 549-3492

Cole, Charles
Consultant
University of California
2515 Hillegass
Berkeley, CA 94704
(415) 642-1711

Donald, James
Deputy Attorney General
Attorney General's Office
Sacramento, CA

Duncan, Barbara
Rehabilitation International
122 East 23rd St., 2nd Floor
New York, New York 10010
(212) 674-4340

Dugan, Cathy
Independent Living Skills Specialist
Center for Independent Living
2539 Telegraph Ave.
Berkeley, CA 94704
(415) 841-4776

Fay, Fred
The Urban Institute
2100 M St., NW
Washington, D.C. 20037
(202) 223-1950

Ferguson, Allen, Jr.
Center for Independent Living
2539 Telegraph Ave.
Berkeley, CA 94704
(415) 841-4776

Frieden, Lex
9667 Meadowvale
Houston, Texas 77042
(713) 781-8949

Galloway, Don
Center for Independent Living
2539 Telegraph Ave.
Berkeley, CA 94704
(415) 841-4776

Galvin, Don
Director
Department of Rehabilitation
Box 1016
Lansing, Michigan 48904
(517) 373-3390

Gentile, Frank
Vice President
Abilities Incorporated
Albertson, N.Y.
(516) 747-5400

Goldheimer, Michael
Research Assistant
Regional Rehabilitation Research
Institute
Portland State University
Portland, Oregon
(503) 229-4040

Harveston, Dominic
Center for Independent Living
2539 Telegraph Ave.
Berkeley, CA 94704
(415) 841-4776

Hessler, John
Director
Physically Disabled Students' Program
2532 Durant #2
Berkeley, CA 94704
(415) 642-0518

Heumann, Judy
Research Assistant
Office of Senator Harrison Williams
U.S. Capitol
Washington, D.C.
(202) 224-9161

Hodgkis, Ralph
Center for Concerned Engineering
1707 Q St., NW
Washington, D.C. 20009
(202) 232-2721

Inkster, Douglas
Director
Center for Independent Living
310 E. 15th St.
New York, N.Y.
(212) 674-7580

Jacobson, Neil
C.I.L. Computer Project
2020 Milvia
Berkeley, CA 94704
(415) 849-2911

Kaplan, Debbie
1472 University Ave.
Berkeley, CA
(415) 849-0373

Kimberlin, Gregory
Director, Mental Health Services
for the Deaf
Rusthaven Psychiatric Hospital
765 College St.
Los Angeles, CA 90012
(213) 626-8241

Kloepping, Kent
Special Services Office
College of Education
University of Arizona
Tucson, Arizona 85721
(602) 884-3268

Kruger, Irving
Chief,
Vocational Rehabilitation Services
New Jersey Commission for the Blind
1100 Raymond Blvd.
Newark, New Jersey 07102
(201) 648-2324

Lauder, Francis
3515 H.E.W. South
Office for Handicapped Individuals
Washington, D.C. 20201
(202) 245-0447

Leech, Peter, M.S.W.
Center for Independent Living
2539 Telegraph Ave.
Berkeley, CA 94704
(415) 841-4776

Leon, Joan
Center for Independent Living
2539 Telegraph Ave.
Berkeley, CA 94704
(415) 841-4776

Leibowitz, Herb, Ph.D.
ORS, H.E.W.
50 Fulton Street
San Francisco, CA
(415) 556-0251

Matlock, Wallace
Rehabilitation Engineering Center
Children's Hospital
Stanford University
Palo Alto, CA

Moyers, Jeff
Center for Independent Living
2539 Telegraph Ave.
Berkeley, CA 94704
(415) 841-4776

O'Brian, Thomas
15 Welsley Road
Danvers, Massachusetts
(617) 722-6163

Orchard, Harry
Manager of Customer Relations
Office Products Division
I.B.M.
411 Borel Ave.
San Mateo, CA
(415) 573-3000

Poling, Dan
United Cerebral Palsy of New York
1430 Broadway
New York, N.Y. 10018
(212) 869-3317

Randals, Richard
Federal Systems Division
I.B.M.
18100 Fredrick Pike
Gaithersburg, MD. 20760
(301) 840-0111

Ed Roberts
Director
Center for Independent Living
2539 Telegraph Ave.
Berkeley, CA 94704
(415) 841-4776

Ryan, Barry
Center for Independent Living
2539 Telegraph Ave.
Berkeley, CA 94704
(415) 841-4776

Smith, Jack
Executive Director
White House Conference on the Handicapped
Room 5715
New North Office Bldg.
330 Independence Ave., S.W.
Washington, D.C. 20201

Soderberg, Richard
Chief Deputy Director
State Department of Rehabilitation
Capitol Mall
Sacramento, CA

Stubbs, Miriam
Office of Rehabilitation Services
Program Division
Department of H.E.W.
Washington, D.C. 20201
(202) 245-0629

Teormina, Betty
Executive Secretary
State Department of Rehabilitation
Capitol Mall
Sacramento, CA
(916) 445-3971

Topp, Karen
Counselor
State Department of Rehabilitation
1111 Jackson St.
Oakland, CA
(415) 464-0835

Ursin, Kathleen
National Center for Law and the
Handicapped
1235 North Eddy St.
South Bend, Indiana 46617

Vash, Carolyn
Deputy Director
State Department of Rehabilitation
107 S. Broadway, Room 7106
Los Angeles, CA 90012
(213) 620-3353

Williamson, Dale
Director
Region IX-Office of Rehabilitation
Services
Department of H.E.W.
50 Fulton Street
San Francisco, CA

Zukas, Hale
Center for Independent Living
2539 Telegraph Ave.
Berkeley, CA 94704
(415) 841-4776

Michael Cole
Instructor
Living Skills Center
San Pablo, CA

William Gerrey
Engineer-Technician
Smith-Kettlwell Institute of
Visual Sciences
2232 Webster St.
San Francisco, CA 94115
(415) 563-2323



Center for Independent Living, Inc.

2539 Telegraph Ave • BERKELEY, CALIFORNIA 94704
SERVICES (415) 841-4776 • ADMINISTRATION (415) 841-3900

July 7, 1975

Mr. Lex Frieden
9667 Meadowvale
Houston, Texas 77042

Dear Mr. Frieden:

Because of your interest and expertise in the area of housing for the severely disabled, we are inviting you to be one of a small and select group of rehabilitation professionals and consumers from across the country who will contribute papers to form the basis of a multi-volume "state of the art" document on independent living of the severely disabled. This document will be distributed to major rehabilitation centers in this country and abroad. Contributors will also be asked to participate in an intensive workshop-seminar this fall to exchange ideas and shape future strategies and programs.

C.I.L. has received a grant from Region IX of the Office of Rehabilitation Services, Department of Health, Education and Welfare which permits us to pay an honorarium of \$100 for the writing of each paper and to pay for transportation and per diem expenses for the author to attend a national workshop to be held in the Bay Area in October. (See enclosed Schedule and Information Sheet.)

Participants in this project will include people from the central office of O.R.S. in Washington, people at the state director of rehabilitation level, and other consumers and professionals (both disabled and non-disabled) from across the country who have special expertise in areas of the independent living movement. The basic purpose of the seminar-workshop and the "state of the art" document will be to bring together the most advanced thinking and experience in this historic movement which is drastically changing the traditional roles of disabled people and the nature of the rehabilitation world.

We are working under severe time constraints in order to produce a finished document by the end of the year and therefore must ask you to respond by filling out the enclosed post card and sending it back to us by July 18 at the latest.

After receiving your card, one of us will be in touch with you to discuss the specific content and form of your paper. In the mean time, if you have any questions or suggestions about the project, please call either Allen Ferguson or Joan Leon at (415) 841-4776.

We We sincerely hope that you will join us in this important and exciting project.

Sincerely yours,

Edward V. Roberts

Edward Roberts
Executive Director

Allen Ferguson, Jr.

Allen Ferguson, Jr.
Project Coordinator

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STATE OF THE ART OF
INDEPENDENT LIVING FOR THE SEVERELY DISABLED
PROJECT SCHEDULE

July 18--Post cards indicating willingness to participate must be returned to C.I.L.

August 8--Outlines of papers to be finished and sent to C.I.L.

September 1--Drafts of papers to be finished.

September 20-- Editing of original papers to be finished by project staff and papers to be sent out to all workshop participants.

October 21-23-- Seminar in the Bay Area to discuss and review papers and to exchange and develop ideas and programs. Seminar date is tentative.)

December 31--Publication date for state of the art document based on the original papers with input from the seminar.

STATE OF THE ART OF
INDEPENDENT LIVING OF THE SEVERELY DISABLED
PROJECT INFORMATION SHEET

General Expectations for the Papers

We are planning to have written approximately 15 papers on different aspects of the independent living movement. Tentatively, the list of topics includes the following:

- transportation
- housing
- employment
- legal rights
- technology and equipment
- health and medical aspects
- training (both of rehabilitation professionals and of disabled consumers)
- education (disabled students programs and the role of public schools)
- the role of sheltered workshops
- the role of private industry
- a model service program
- the psychology of disability
- the role of the state agencies
- the federal outlook
- concepts of and organizing for independent living

Most papers are expected to be approximately 5000 words in length, though this will vary to some extent from one paper to another. The content, of course, will vary greatly, but in general, we are looking for papers which do the following three things: (1) give an overview of current issues in the area; (2) describe particularly successful or promising programs or projects; and (3) point the way to the future by critically describing policy decisions and social and political issues which must be addressed in order to achieve independent living and full participation in society of the severely disabled. Technical language should be avoided in so far as possible so as to make the papers readable to a broad spectrum of professionals and consumers.

In order to cover some of the topics in the space desired (approximately 5,000) words, it will be necessary to condense and summarize much material. While this may involve some sacrifices in content, it is necessary in order to produce a broad state of the art overview of reasonable length.

A project staff person will be in touch with each author within a few weeks to discuss the form and content of his or her individual paper.

Nature of the Seminar

The seminar (tentatively scheduled for October 21 to 23) will include as participants the authors of the various papers and a select group of other consumers and professionals (disabled and non-disabled) who are particularly active and interested in some phase of the independent living movement. It will be a two-and-a-half day meeting, beginning after lunch on Tuesday (the 21st) and ending before dinner on Thursday (the 23rd). The seminar will be held at an accessible location in the San Francisco Bay Area--probably in Berkeley. (The exact location has not yet been determined.)

Seminar participants will have received each of the papers approximately a month in advance, so as to have a chance to become thoroughly familiar with the topics and issues to be discussed.

The purpose of the seminar will be two-fold, first to exchange ideas and information, to discuss and plan the future of the independent living movement, and, second, to review and refine the material for the state of the art document. Formal presentation of papers will not be necessary. Instead, a moderately structured discussion format will be used.

Nature of the "State of the Art" Document

The document is expected to be a multi-volume monograph, published in sufficient quantity to be distributed to major rehabilitation programs and other interested groups and individuals in the U.S. and other countries. We hope to make it visually attractive through the use of graphics and illustrations.

The content will basically cover the area suggested by the list of topics above. The basis of the document will be the papers written on those topics, with input from the seminar. In cooperation with the authors, the project staff will edit and, where necessary, condense or revise individual papers to produce a final document that is well written, covers the field, and is not repetitious.



Center for Independent Living, Inc.

2539 Telegraph Avenue
SERVICES (415) 841-4776

BERKELEY, CALIFORNIA 94704

ADMINISTRATION (415) 841-3900

August 14, 1975

Mr. Lexington Frieden
9667 Meadowvale
Houston, Texas 77042

Dear Mr. Frieden:

This letter is to fill you in about progress on the "state of the art of independent living" project, and to request your assistance in furthering its goals.

Response to the project has been overwhelmingly positive. With only one exception, everyone we originally asked to participate has agreed to do so. Furthermore, many people have strongly urged us to include other individuals who have special expertise and interest in some area of independent living of the blind or severely disabled. We have attempted to accomodate these requests, when it seemed worthwhile for the project as a whole, by inviting additional people.

One result of the unexpectedly strong response is that we are in danger of overextending our very limited resources. We have already had to tell several people who have special ideas and experience to contribute that we may not be able to pay for their transportation or expenses. As a result, we would like all prospective participants who are able to do so to contribute from their own budgets to their transportation and/or living expenses so that we will be able to include a few more participants. We are convinced that this will benefit the project as a whole and enhance the breadth and quality of the final publication. Enclosed is a post card on which to state the extent to which you may be able to contribute to your expenses.

Other information on the progress of the project is as follows:

- The tentative dates of October 21-23 are now firm.
- The workshop will be held at the Claremont Hotel, Ashby and Domingo, Berkeley, CA, Phone: (415) 843-8000.
- The workshop will begin Tuesday, October 21 at 1:30 p.m.
- The list of topics to be covered in the papers has been expanded to include tentatively:

The role of the state agency for the blind

A model service program for the blind

A model service program for the elderly blind

National organizing of disabled consumers and the development of a national publication

The role of private industry

Sexuality and the severely disabled

The federal legislative outlook

If you have not yet sent us an outline of your paper, please do so, if doing so would not interfere with your getting a draft of your paper to us on time. In any case, please make all appropriate efforts to finish a draft of your paper and mail it to us by September first. If you have any questions, either write or call as soon as possible.

Again, please fill out and mail the enclosed post card as quickly as possible so that we will be able to make a final determination of topics, authors and workshop participants soon. Your cooperation is very much appreciated!

Ed and I look forward to reading your papers and meeting you at the workshop.

Sincerely,

A handwritten signature in blue ink that reads "Allen Ferguson, Jr." with a stylized flourish at the end.

Allen Ferguson, Jr.
Project Coordinator



Center for Independent Living, Inc.

2539 TELEGRAPH AVENUE • BERKELEY, CALIFORNIA 94704 • (415) 841-4776

November 12, 1975

Dear Workshop Participants:

Exactly three weeks have passed since the close of the State of the Art of Independent Living Workshop. Although we have returned to our own communities and jobs, the events of the workshop remain fresh in our minds; and although those events put many of us on a high, so to speak, about the great potential of the "independent living movement," we should not let matters rest there. Now is the time, it seems to us, consciously and critically to juxtapose the experience of what was learned at the workshop with the reality of the institutions and environments in which we work and live. The results of this kind of examination should prove fruitful both in gaining a clearer understanding of the challenges which face us in the struggle to achieve full participation of the severely disabled in society and in suggesting new avenues and methods of effecting change in that direction. In any case, we should like to hear the results of this kind of examination on your part and perhaps to add some notes about it to the upcoming publication.

With regard to the publication, we are busy editing the papers and the transcripts of the meeting, as well as making printing arrangements. We fully expect to have the material ready to go to press by the end of the year, though the printing itself will probably not be complete until some time after that. As we edit the papers and transcripts, we are planning to condense the material into a synthesis which will do justice to the thoughts and work of each participant as well as to the ideas which were generated collectively at the workshop. In addition, copies of the individual papers will be made available and will be listed in the publication. We are certainly open to having participants review portions of the transcript in which they were substantially involved before submitting the material to the printer. Please let us know if you wish to do so.

(2)

We look forward to receiving some of your thoughts vis a vis ideas developed at the workshop and their implications with respect to the real world, as well as any suggestions you may have about the papers or the publication.

Sincerely,

Edward V Roberts

Edward V. Roberts

Director

California Department of Rehabilitation

Allen R. Ferguson, Jr.

Allen R. Ferguson, Jr.

Project Coordinator

*P.S. We have submitted
your statement of expenses to
our accounting department.
You should receive reimbursement
and the honorarium soon.*



Center for Independent Living, Inc.

2539 Telegraph Ave. Berkeley, CA 94704

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STATE OF THE ART OF INDEPENDENT LIVING WORKSHOP INFORMATION SHEET

Time: The workshop will begin at 1:30 p.m., Tuesday, October 21, and end sometime in the late afternoon on Thursday, October 23rd.

Place: Claremont Hotel, Ashby Avenue, Berkeley, California. (The Claremont is a landmark. It is located at the foot of the Berkeley Hills and is impossible to miss.)

Transportation Information: Participants flying in should arrive, if possible, on the morning of the 21st and schedule departure for the late afternoon or early evening of the 23rd.

If possible, you should fly into Oakland, rather than San Francisco, since the Oakland airport is much closer to the conference site than is the San Francisco airport. If you do have to fly into San Francisco, the quickest way (and one of the cheapest) to get to the East Bay is to take a helicopter to Oakland. However, the choppers are inaccessible to people in wheel chairs, so if you're in a chair, don't try this route. If you do take the helicopter (walkies only), have your airline or travel agent reserve a space for you in advance. (It's cheaper that way, and surer.)

If you are in a chair or have any other mobility limitation, we will try to meet you at whichever airport you fly into. It is your responsibility to send us your flight information so that we'll be able to meet you.

People flying from the East coast: If you are flying from Boston, New York or Washington, you can leave in the early a.m. of the 21st on United Air Lines flights to Chicago, changing there to U.A.L. flight No. 221, departing Chicago at 10:15 a.m. and arriving in Oakland at 12:30 p.m.

INFORMATION SHEET

page 2

Proceedure for paying transportation and per diem costs:

Some participants have indicated ability to cover some or all of these costs from their own budgets. For participants whose transportation and expenses we are paying, in whole or in part, the following will be the proceedure: (1) Rooms - We are handling the bill for hotel rooms directly. Participants staying at the Claremont, therefore, need not worry about the charge for their sleeping accommodations. (Of course, if you make long distance calls, use room service, etc., you will be expected to cover these extra expenses.) (2) Meals - We will reimburse you for meals, up to \$12 per day. (3) Transportation - The normal proceedure will be for us to reimburse you for air and/or reasonable ground transportation. If you need us to advance this money to you, please let us know right away.

Honoraria: A \$100 honorarium will be paid for the writing of each paper. Where there are co-authors, this amount will be split between them. The honoraria will be mailed out following the workshop.



Center for Independent Living, Inc.

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STATE of the ART of INDEPENDENT LIVING SEMINAR

OCTOBER 21 - 23, 1975

CLAREMONT HOTEL, BERKELEY, CALIFORNIA

SCHEDULE

TUESDAY, OCTOBER 21

10:30a.m. - 1:30p.m.

Registration: Claremont Hotel Lobby

1:30

Welcome and Introductory Remarks

Edward V. Roberts, Executive Director,
Center for Independent Living

Dale Williamson, Regional Director, Office
of Rehabilitation Services, Region IX, DHEW

Herbert H. Leibowitz, Research and Demon-
stration Specialist, Office of Rehabilitation
Services, DHEW

2:00

"Transportation, Housing and Architectural
Barriers"

Barbara Duncan, Rehabilitation International
staff

Lex Frieden, Consumer Expert on Housing

John Hessler, Director, Physically Disabled
Students Program, U.C. Berkeley

Thomas O'Brien, Transportation Expert
Boston, Massachusetts

Barry Ryan, Consultant on Architectural matters
Center for Independent Living

Hale Zukas, Director of Community Affairs,
Center for Independent Living

State of the Art of Independent Living Seminar
Schedule page 2

TUESDAY, OCTOBER 21 (cont.)

- 3:45 "Health and Medical Aspects of Disability"
Sheldon Berrol, M.D. Psychiatrist, Santa Clara Valley Medical Center
Edna Breen, R.N., Center for Independent Living
- 5:00 "Role of Research in Rehabilitation"
Monroe Berkowitz, Professor of Economics, Rutgers University
Frederick Collignon, Berkeley Planning Associates
Susan Pflueger, Research Evaluator, Research and Demonstration Project, Center for Independent Living
Carolyn Vash, Deputy Director of Rehabilitation, State of California
- 8:15 Reception - Panorama Room, Claremont Hotel

WEDNESDAY, OCTOBER 22

- 9:00a.m. "Psychology and Sexuality of Disability"
Neil Jacobson, Instructor, Center for Independent Living, Computer Training Project
Debby Kaplan, Center for Independent Living Board member, student of law
Peter Leech, Director of Training Project for Rehabilitation Professionals, Center for Independent Living
Carlyn Vash, Deputy Director of Rehabilitation, State of California
- 10:45 "Educational and Training Aspects of Independent Living"
Ralph Baird, Director of Special Education, Takoma, Washington Public Schools
Dominic Haverston and Hal Kirshbaum, Degree-Granting Program, Center for Independent Living
John Hessler, Director, Physically Disabled Students Program, U.C. Berkeley

State of the Art of Independent Living Seminar
Schedule page 3

WEDNESDAY, OCTOBER 22 (cont.)

Judy Heumann, Office of Senator Harrison
Williams, U.S. Senate

Kent Kloepping, Director, Disabled Students
Program, University of Arizona

Peter Leech, Director of Training Project for
Rehabilitation Professionals, Center for
Independent Living

12:15

Lunch, Claremont Dining Room

1:15p.m.

"Services, Model Service Programs, and
Consumer Organizing"

Michael Cole, Blind Living Skills Center,
San Pablo, California

Edward V. Roberts, Executive Director,
Center for Independent Living

Cathy Dugan, Independent Living Skills
Specialist, Center for Independent Living

Donald Galloway, Director of Research and
Demonstration Project, Center for Independent
Living

Douglas Inkster, Director, Center for
Independent Living, New York

Dan Polling, United Cerebral Palsy of New
York City, Polling Magazine

Karen Topp, Rehabilitation Counselor,
California State Department of Rehabilitation

2:45

"Legal Issues and Services"

Jack Achtenberg, Professor of Law, San
Fernando Valley College of Law

Debby Kaplan, Disabled People's Legal
Resource Center, Berkeley, California

Kathleen Ursin, Educational Director,
National Center for Law and the Handicapped,
South Bend, Indiana

4:00

Visit to Center for Independent Living

State of the Art of Independent Living Seminar
Schedule page 4

WEDNESDAY, OCTOBER 22 (cont.)

5:15

"Presentation on Technology and Equipment"
(at Center for Independent Living)

William Gerrey, Engineer-Technician, Smith-
Kettelwood Institute of Visual Sciences

Ralph Hodgkis, Center for Concerned Engineering,
Washington, D.C.

Wallace Matlock, Engineering Rehabilitation
Center, Stanford University

THURSDAY, OCTOBER 23

9:00a.m.

"Employment"

Monroe Berkowitz, Professor of Economics,
Rutgers University

Frederick Collignon, Berkeley Planning Associates

Allen Ferguson, Jr., Project Coordinator,
Center for Independent Living

Michael Goldheimer, Regional Rehabilitation
Research Institute, Portland, Oregon

Frank Gentile, Vice President, Abilities, Inc.,
Albertson, New York

Richard Randals, I.B.M., Gaithersburg, Md.

10:45

"The Role of State Agencies"

Donald Galvin, Director of Rehabilitation
Michigan

Irving Kruger, Chief, Vocational Rehabilitation
Services, New Jersey Commission for the Blind

Edward V. Roberts, Executive Director, Center
for Independent Living

Carolyn Vash, Deputy Director, California
Department of Rehabilitation

12:15

Lunch, Claremont Dining Room

State of the Art of Independent Living
Schedule page 5

THURSDAY, OCTOBER 23 (cont.)

1:30

"Federal and Congressional Outlook"

Fred Fay, The Urban Institute, Washington, D.C.

Judy Heumann, Office of Senator Harrison
Williams, U.S. Senate

Miriam Stubbs, Director of the Division of
Planning and Management Assistance, R.S.A.,
DHEW, Washington, D.C.

Dale Williamson, Regional Director, Region IX,
Office of Rehabilitation Services, DHEW

3:00

Wrap up: Group discussion to draw together
ideas and strategies generated during the
course of the workshop.

PEOPLE AND NUMBERS TO CALL IN CASE OF EMERGENCY:

Ron Roberts, emergency attendant, Claremont Hotel, Room 138
(Hotel number - 843-3000)

Allen Ferguson, Project Coordinator, Claremont Hotel, Room 139

Carol Fewell, Project Assistant, 548-6546

Center for Independent Living, 2539 Telegraph Ave. 841-4776 or 841-3900

Workshop Participants
Page 2

small (about 40 people), and most of the "audience" will also be panel members at some point. We hope that new ideas and new syntheses of old ideas will emerge. This is why we are calling the meeting a workshop, and why we wish participants to read the papers in advance.

We at C.I.L. look forward to seeing you shortly.

Sincerely,

A handwritten signature in dark ink, appearing to read "Allen".

Allen Ferguson, Jr.
Project Coordinator



Center for Independent Living, Inc.

2539 TELEGRAPH AVENUE • BERKELEY, CALIFORNIA 94704 • (415) 841-4776

STATE of the ART of INDEPENDENT LIVING WORKSHOP PROPOSED AGENDA With Panel Assignments

Tuesday, October 21, 1975

Morning - Participants arrive

- 1:30 - Workshop begins
 - Welcome and Introductory Remarks
 - Discussion of traveling to the workshop
 - First Panel -- Transportation, Housing and Architectural Barriers: Barbara Duncan, Lex Frieden, Tom O'Brien, Barry Ryan, Pam Dinkel
- 3:30 - Break
- 3:45 - Second Panel-- Health and Medical Aspects: Edna Brean, Sheldon Berrol
- 5:00 - End of Day

Wednesday, October 22, 1975

- 9:00 - Third Panel -- Legal Issues and Services: Jack Achtenberg, Debbie Kaplan, Kathleen Ursin
- 10:30 - Break
- 10:45 - Fourth Panel -- Services and Model Service Programs: Don Galloway, Phillip Hatlin, Doug Inkster, Greg Kimberlin, Hale Zukas
- 12:15 - Lunch
- 1:15 - Fifth Panel -- Education and Training: Ralph Baird, John Hessler, Judy Heumann, Kent Kloepping, Peter Leech
- 2:45 - Sixth Panel -- Employment: Allen Ferguson, Frank Gentile, Richard Randals, Karen Topp
- 4:00 - Visit to CIL
- 7:30 - Seventh Panel -- Research: Monroe Berkowitz, Fred Collignon, Carolyn Vasch
- 8:45 - Eighth Panel (Media Presentation) -- Technology and Equipment: Ralph Hodgkis, Wally Matlock

Thursday, October 23, 1975

- 9:00 - Ninth Panel -- Psychology and Sexuality: Greg Kimberlin, Carolyn Vasch, Neil Jacobson, Peter Leech
- 10:30 - Break
- 10:45 - Tenth Panel -- The Role of State Agencies: Don Galvin, Irving Kruger, Carolyn Vasch, Ed Roberts
- 12:15 - Lunch
- 1:15 - Eleventh Panel -- Federal and Congressional Outlook:

AGENDA page 2

Jack Duncan, Fred Fay, Judy Heumann, Herb Leibowitz,
possibly others.

2:30 - Twelfth Panel -- Consumer Organizing: Dan Poling, Hale
Zukas, Ed Roberts

4:00 - Wrap-up



Center for Independent Living, Inc.

2539 TELEGRAPH AVENUE • BERKELEY, CALIFORNIA 94704 • (415) 841-4776

October 6, 1975

To: Participants in the "State of the Art of Independent Living" Workshop

From: Allen Ferguson, Jr., Project Coordinator

Re: Papers for the workshop

Enclosed you will find drafts of thirteen papers prepared in preparation for the "State of the Art" workshop. Please try to read them before the workshop, and bring them with you to it. The purpose of all participants reading the papers beforehand is to become familiar enough with the authors' ideas and the information in the papers to facilitate lively discussion and exchange of ideas at the workshop. The papers will not be read at the workshop; instead, panel and group discussion will be the basic format.

Please keep in mind that the papers in present form are drafts only and that they will be edited and may be substantially revised following the workshop and before the State of the Art publication comes out at the end of the year. To protect the authors, please do not reproduce these drafts.

Unfortunately, we have been unable to reproduce all of the papers in advance of the workshop (in many cases, because of receiving them late). Consequently, about ten more papers will be distributed at the beginning of the workshop itself.

*Meeting
stand in
set for*



Center for Independent Living, Inc.

2539 Telegraph Ave. • BERKELEY, CALIFORNIA 94704
SERVICES (415) 841-4776 • ADMINISTRATION (415) 841-3900

October 2, 1975

Dear Workshop Participants:

The date of the "State of the Art of Independent Living" Workshop is fast approaching. This letter, with enclosures, is to give you final information about the workshop. Enclosed are (1) an "Information Sheet", stating time, place and travel information, and (2) a tentative agenda. If the time at which you are scheduled to be on a panel (or, in a few cases, to make an individual presentation) is for some reason inconvenient, or if you have other questions about the agenda, please let me know right away.

We are attempting to make arrangements with the hotel to be able to set up displays. Consequently, if you have any material that you would like to display for the other workshop participants, please let me know that right away also. In addition, one or two participants wish to make film and/or slide presentations. We encourage the use of these media, and if you have films or slides that you would like to show, again let me know.

For the publication, which is to be put together from the papers and the workshop discussion and will come out toward the end of the year, we are looking for good photographs and art work illustrating various phases of independent living. If you have anything that might be good, please bring it with you.

Drafts of most of the papers are being sent to you under separate cover. Please read them before the workshop, so that we will all have a basic familiarity with the material in advance. Because of receiving some papers late and occasional editing delays, a few of the papers will be distributed at the beginning of the workshop rather than in advance.

I would like to emphasize one final point about the workshop. It will not be like a professional organization meeting at which formal presentation of papers is made. Instead, panels (and in a few cases, individuals) will discuss their topics with co-panel members and with the audience. The group will be fairly