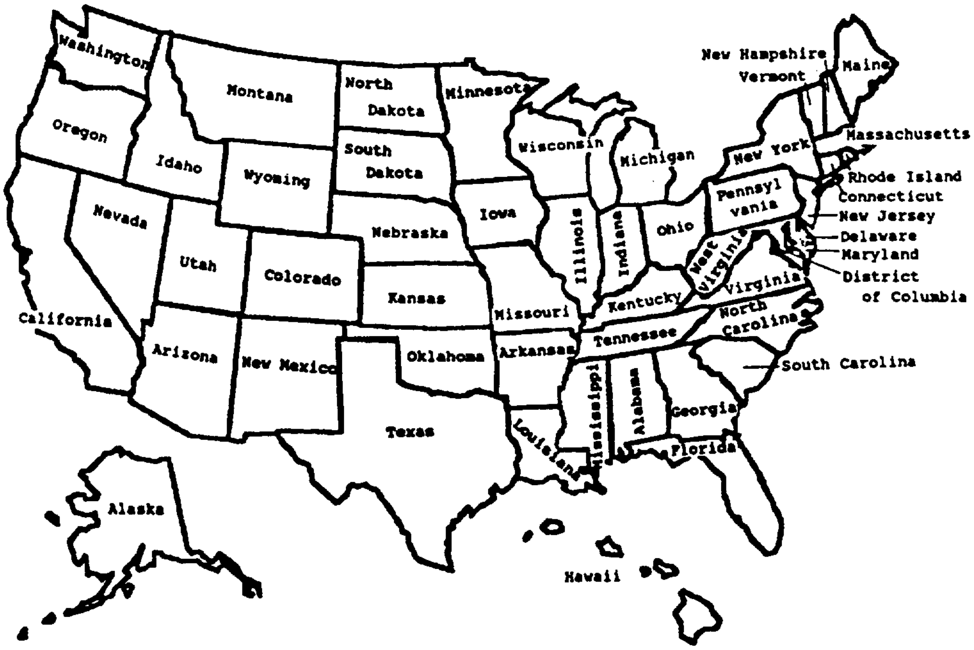
PARTNERS IN POLICYMAKING

NATIONAL ACADEMY

May 15-16, 1992

Doubletree Hotel
at Lincoln Centre
5410 LBJ Freeway
Dallas, Texas



Sponsored by:

Texas Developmental Disabilities Planning Council
World Institute on Disability
Minnesota Governor's Planning Council
on Developmental Disabilities

DEPARTMENT OF HEALTH & HUMAN SERVICES

ADMINISTRATION FOR CHILDREN AND FAMILIES
370 L'Enfant Promenade, S.W.
Washington, D.C. 20447

May 15, 1992

Dear Friends:

Welcome to Texas and the 1992 National Academy on Partners in Policymaking.

Across the United States, Partners graduates are working to create change, to influence policymakers on the local, state, and national levels, and to educate others on why and how we must create a new way of thinking about people with disabilities. The 1992 National Academy brings together Partners and state coordinators in a unique convention where past experiences will be shared and new visions will be explored.

For that's what Partners in Policymaking are--visionaries. Visionaries who are not willing to accept the status quo but who dream about how things should be for their communities, their states, and our nation. Partners don't just dream, though. Partners are turning dreams into realities.

Partners was, in fact, endowed with vision from the very beginning. In 1987, Colleen Wieck, Executive Director of the Minnesota Governor's Planning Council on Developmental Disabilities and Ed Skarnulis of the Minnesota Department of Human Services talked together about the potential impact of individuals being educated and empowered to change public policy as it relates to people with disabilites. From that conversation, Partners in Policymaking was born. Minnesota led the way and set the standards. Eleven states followed: Alabama, California, Colorado, Connecticut, Illinois, Indiana, Iowa, Louisiana, New York, Ohio, and Texas. Twelve states are joining the efforts in 1992: Arkansas, Delaware, Florida, Georgia, Hawaii, Mississippi, New Mexico, North Carolina, Oklahoma, South Dakota, Tennessee, and West Virginia. Another twelve states are expected to begin Partners in 1993.

No other method of training has achieved the depth and the positive outcomes experienced by Partners in Policymaking. The Partners program is so successful because it places high expectations on its participants. Partners graduates have been trained in and developed competencies in specific areas that encompass today's disability issues.

I salute every state represented at the Academy this weekend, for the commitment to time, personnel, and resources necessary to operate a successful Partners program. I salute every Partner, for the dedication and devotion you bring to the cause of creating change on behalf of people with disabilities. And I salute Jopie Smith, Partners coordinator from Texas, and Colleen Wieck, whose dream of a 1992 National Academy has come true today.

My dream--my vision--is that your participation here will create a family across the United States, a family whose members support each other and learn from each other, but especially, a family who continues to dream the dream and makes the dream come true.

Best wishes,

Deborah L. McFadden
Commissioner
Administration on Developmental
Disabilities

A TEXAS SIZE

THANK YOU

TO

JOPIE SMITH

FOR COORDINATING

THE 1992 PARTNERS ACADEMY

NATIONAL ACADEMY ON PARTNERS IN POLICYMAKING
THURSDAY-SATURDAY, MAY 14-16, 1992
DOUBLETREE HOTEL AT LINCOLN CENTRE
5410 LBJ FREEWAY
DALLAS, TEXAS

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Announcements, Applications, Recruitment, Screening, Selection, Letters, Agreements.

III. RELATIONSHIPS
Individual Supports, Cultural Issues, Bonding.

IV. FORMAT
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V. LOGISTICS
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VI. EVALUATION
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VII. FUNDING SUPPORTS
Creative Ideas.

VIII. POSTGRADUATE
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IX. POTPOURRI
Good Ideas from Here and There.

X. PARTNERS GRADUATES
State Rosters.

****
* ND Means No Date on Material *
****

The Academy is funded in part through grant number 90DD0221 under provisions of the Developmental Disabilities Act of 1990 (P.L. 100-146). Content of this binder does not reflect the position or policy of the Administration on Developmental Disabilities nor the Department of Health and Human Services.

NATIONAL ACADEMY ON PARTNERS IN POLICYMAKING
MEETING OF REPLICATION STATES
FRIDAY-SATURDAY, MAY 15-16, 1992
DOUBLETREE HOTEL AT LINCOLN CENTRE
5410 LBJ FREEWAY
DALLAS, TEXAS

AGENDA

FRIDAY, MAY 15, 1992

8:00 a.m. REGISTRATION

8:15 a.m. GOOD MORNING, AMERICA
Welcome.
Roger Webb, Executive Director, and Lee Veenker, Chair,
Texas Planning Council for Developmental Disabilities.

8:30 a.m. JEOPARDY
Participant Introductions and Academy Overview.
Fran Smith

9:00 a.m. NOVA
The National Agenda.
Deborah McFadden, Commissioner, Administration
on Developmental Disabilities

9:15 a.m. THE YOUNG AND THE RESTLESS
What Is Partners in Policymaking?
Colleen Wieck and Partners Graduates

11:00 a.m. A WHACK ON THE SIDE OF THE HEAD
Lessons on Creative Thinking and Instructions.
Fran Smith

11:30 a.m. LUNCH

1:00 p.m. BRAINSTORMING BREAKOUTS 1
Group A: "The Dating Game"--Recruitment, Screening, Selection.
Group B: "Family Ties"--Individual Supports, Cultural Sensitivity, Bonding.

2:00 p.m. BRAINSTORMING BREAKOUTS 2
Group A: "Wheel of Fortune"--Training Content, Speakers, Homework.
Group B: "The Price is Right"--Budget, Staff Roles, Logisitcs.

3:00 p.m. BREAK

3:30 p.m. 30 MINUTES
Group Reports.

4:30 p.m. REFLECTIONS DU JOUR
Ed Roberts, President, World Institute on Disability

5:00 p.m. NIGHTLINE
Team Assignments, Partners Graduates Meeting Only.
Kathie Snow

5:15 p.m. CHEERS
Reception.

NATIONAL ACADEMY ON PARTNERS IN POLICYMAKING
MEETING OF REPLICATION STATES
FRIDAY-SATURDAY, MAY 15-16, 1992
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AGENDA

SATURDAY, MAY 16, 1992

8:30 a.m.	STAR TREK: THE NEXT GENERATION How Partners Are Making a Difference. Colleen Wieck and Partners Graduates
9:00 a.m.	THE PEOPLE'S COURT Evaluation Is Critical. Tom Zirpoli
10:00 a.m.	LET'S MAKE A DEAL Funding Supports. Small Groups. Fran Smith
10:45 a.m.	THE WONDER YEARS Postgraduation Issues. Small Groups Fran Smith
11:45 a.m.	LUNCH
1:15 p.m.	45 MINUTES Group Reports.
2:00 p.m.	20 QUESTIONS ABOUT PARTNERS Fran Smith and Colleen Wieck
3:00 p.m.	BREAK
3:15 p.m.	SATURDAY AFTERNOON LIVE Partners Graduates
4:30 p.m.	WINGS Closing Comments. Fran Smith

NATIONAL ACADEMY
FOR
PARTNERS IN POLICYMAKING
May 14-16, 1992

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NATIONAL ACADEMY ON PARTNERS IN POLICYMAKING
THURSDAY-SATURDAY, MAY 14-16, 1992
DOUBLETREE HOTEL AT LINCOLN CENTRE
5410 LBJ FREEWAY
DALLAS, TEXAS

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NATIONAL ACADEMY ON PARTNERS IN POLICYMAKING
THURSDAY-SATURDAY, MAY 14-16, 1992
DOUBLETREE HOTEL AT LINCOLN CENTRE
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DALLAS, TEXAS

THE PROCESS BEGINS

CONTENTS

PARTNERS
IN
POLICYMAKING
ALABAMA

444 South Decatur Street
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265-0245

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****************************************
*        ALABAMA PIP ANNOUNCEMENT      *
*                                      *
* N.D. - Received prior to 1992 Academy *
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June 11, 1990

Dear Potential Applicants:

The Alabama Governor's Planning Council on Developmental Disabilities and the Association for Retarded Citizens of Alabama are currently seeking applications from interested parents of young children with developmental disabilities, and persons with a disability to participate in an exciting, innovative leadership training program - Partners in Policymaking. Partners in Policymaking of Alabama is a one-year training program designed to provide its participants information, training & skill building so that they may obtain state of the art services for themselves and others and consequently change the quality of life for people with disabilities.

Partners in Policymaking of Alabama will afford 30 participants the opportunity of training provided by national speakers addressing a variety of disability issues and empower them with competencies to make an impact on state & local policymaking.

Our search actively seeks both males and females, members of minority communities, people who represent individuals with all types of disabilities and representation from rural, urban and suburban communities throughout Alabama. Because we are seeking a broad participation base, we will not be selecting husband-wife teams but certainly encourage individual applications.

Applications for PIPA are due on August 10, 1990. Final selection of participants will be made by August 24, 1990.

If you have any questions concerning this project please feel free to contact me at the above address.

Sincerely,

Betsy Prince

Betsy Prince,
Director

BP:mdt

1-800-237-0665
A Leadership Training Program

CALIFORNIA PIP APPLICATION
N.D. - Received prior to 1992 Academy

Application Deadline: 9/9/91 to
the Area IV Board, 1700 Second
Street, Suite 384, Napa CA 94559

PARTNERS IN POLICYMAKING
APPLICATION FOR PARTICIPATION

*** IF YOU NEED HELP WITH FILLING OUT THIS FORM,
PLEASE CALL THE AREA IV BOARD AT (707) 252-6644.

NAME: ______________________________

ADDRESS: ______________________________

____
City Zip Code

TELEPHONE: ( ) ______________

1. Are you:

____ An adult who has a developmental disability?
____ A parent who has a son/daughter with a developmental disability?
____ How old is your son/daughter with a developmental disability?
____

2. Describe your disability (or son's/daughter's) and how it affects your life:

____
____
____
____
____

3. What services are you receiving? (For example: school, respite, case management, independent living skills, therapy, etc.)

____
____
____

4. How did you hear about Partners in Policymaking?

____

____

____

____

____

5. Why are you interested in Partners and what do you hope to get out of the trainings?

____

____

____

____

____

6. Are you willing to make a time commitment of 2 days (Friday and Saturday) during the months of October '91, November '91, January '92, February '92, March '92, April '92, May '92, and June '92?

_____ Yes _____ No

7. Do you currently belong to any advocacy organizations? Please list them.

____

____

____

8. Please tell us about you and your family.

____

____

____

____

9. What accommodations would you need to participate in Partners?

(Check all that apply)

____ Child Care
____ Respite
____ Interpreter
____ Facilitator
____ Attendant

____ Transportation Help
____ Special Diet
____ Other:
____
____
____

10. To reflect the diversity of the North Bay, please indicate your ethnic background:

____ Caucasion
____ Asian

____ Black
____ American Indian

____ Hispanic

***If you need more space for your answers, please feel free to use the space below as well as the back side of this page.

[redacted]ERSHIP

Realizing Expectations for Positive Change

A Training Course for Individuals Who Choose to Make a Bigger Difference

"Oh dear! Oh dear! I don't want to be late."

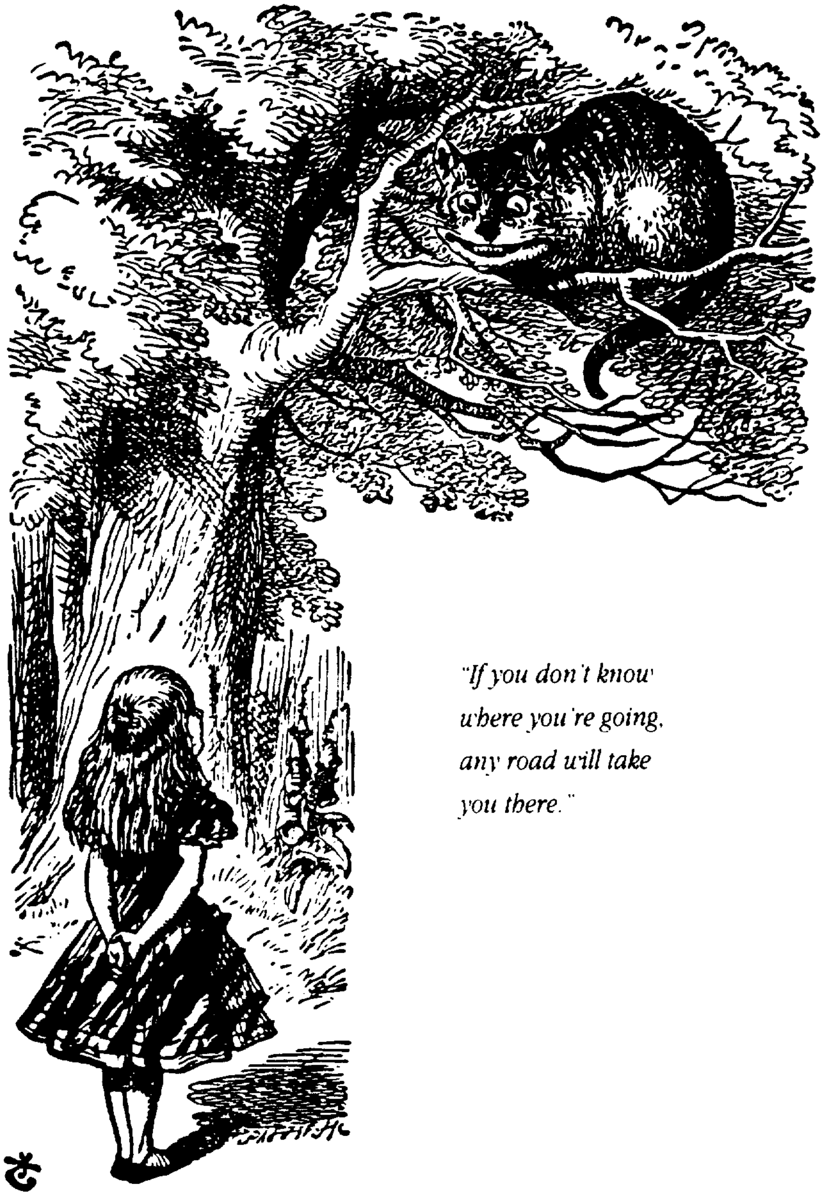
COLORADO PIP ANNOUNCEMENT/APPLICATION
N.D. - Received prior to 1991 Academy

SIX LEADERSHIP TRAINING SESSIONS

Presented by The Coalition for Leadership

♥

Sponsored by
The Colorado Interagency Coordinating Council for Public Law 99-457
The Colorado Developmental Disabilities Planning Council



"If you don't know
where you're going,
any road will take
you there."

Illustrations by John Tenniel from Alice's Adventures in Wonderland by Lewis Carroll
from the Classics Appreciation Society Condensations.

INTRODUCTION

KEEPING PACE with the changes in our lives is a challenge for most of us. Some of us also know the challenges of having a "disability" in our own lives or in our children's lives. This course is for potential leaders who care about the future and who intend to cause positive change. Partners in Leadership is geared to helping the participants see and use their own capabilities. The course will develop and expand effective communication and vision-building skills.

The course is for parents of children with disabilities (especially parents of children under age 5), consumers who use adult support services, and other self-advocates. It includes six sessions, with each session running from Friday evening through Saturday afternoon. Additional workshops will be held on selected Friday afternoons before the evening sessions. The course is free for the participants. Lodging, meals and travel expenses are reimbursed to the participants.

This course is presented by a coalition of organizations and individuals who share a common "heart" with people who have "disabilities". The Association for Community Living in Colorado, the PEAK Parent Center, and Expectations Unlimited, Inc. are working together as The Coalition For Leadership. Many of us are parents of children who have been "labeled". All of us believe that people with "disabilities" have equal rights as citizens in our society.

[illegible] THEIR EXPERIENCES

We would like to share with you some of the comments from Partners who have completed the Partners in Leadership course. We learned a great deal from them and are pleased by their growth and energy and commitment.

"I have learned that the ultimate model, the ultimate system will be to treat my daughter as a person first, as if she had no disabilities. This vision is most important."

"I am better focused and directed. My values are clarified and strong. I feel empowered to lead and look forward to doing more leading."

"My issues today are the same, only I've been empowered to write legislators, call people, make new connections and persist, persist, persist."

[illegible] ILL.

- Identify their personal values and learn to see what values influence various systems and other organizations.
- Learn to evaluate effective residential, educational and work supports, based upon the quality of the lives of the people who are in the programs.
- Learn to see how they are a part of their home communities.
- Work out a personal plan for some positive changes that they want to see and then, begin to work on getting those changes made.
- Identify what communication skills they want to improve and work with instructors to become better speakers and writers.
- Learn about how things can change and how changes affect other people.

[illegible] THIS COURSE?

The course is a must for parents of young children (under age 5) who have "disabilities" and self-advocates who would like to know what choices are possible and then decide for themselves. People from ethnically diverse backgrounds are strongly encouraged to apply.

Forty five people from diverse geographical locations will be selected for the course. Seventeen will be adults who are self-advocates or consumers of adult support services. Twenty-eight of the participants will be parents of children with disabilities.

Selection priority will be given to parents of children who are younger than five and to individuals representing minorities. The selection process will select approximately the same number of men and women, and will include a wide variety of participants who can share their experiences with different "disabilities". The course itself will stress identifying and using each person's capabilities.

[illegible]

Each participant will have the opportunity to work on communication skills, being assertive, being persuasive, negotiation skills, decision-making skills, and group facilitation. Much of the curriculum will be presented through group activities and exercises, in addition to the presentations by the faculty. Participants will have homework assignments.

Some of the course work will expect participants to expand their awareness of their local community. The state-of-the-art in service delivery systems will be covered in several sessions. Of equal importance, participants will experience their own unique abilities to cause others to join them in seeking positive changes.

[illegible]

The course includes six sessions on the dates shown below. Each session will start at 6:30 p.m., unless a different starting time is shown for that session.

- Session 1: October 25 & 26, 1991
- Session 2: November 15 (begins at 2:30 p.m.) and November 16, 1991
- Session 3: January 10 & 11, 1992
- Session 4: February 14 (begins at 2:30 p.m.) and February 15, 1992
- Session 5: March 13 & 14, 1992

Session 6: April 17 & 18, 1992

"I am so thankful for "Partners" because my son is little and I have learned so much to help us and others that I feel I'm already three years ahead."

"As I look through my notes, I'm overwhelmed by where I started and where I am now. Thank you so much for the gifts you have given me...the gifts of "ways & means"...the skills of negotiating, the assertiveness and decision-making skills you have helped to sharpen. The parameters you have helped so ably to define. Thank you for the opportunity to meet so many people, to begin the networking process."

[illegible] APPLY

> *"This course has informed me immensely on many topics."*

Interested individuals should complete and mail the application form to the address below. Individuals may also apply by making an audio or video recording (VHS format) which includes the information requested on the application form. The recordings should be mailed to the address below. Application forms and audio or video cassettes will not be returned to applicants.

Letters of support are optional. Applicants can arrange to have up to three letters of support sent to the address below, if the applicants feel that those letters would provide additional information which would be helpful to the selection committee.

APPLICATIONS SHOULD BE MAILED TO:
ACL IN COLORADO, PARTNERS IN LEADERSHIP
4155 EAST JEWELL, SUITE 916, DENVER, CO 80222

[illegible]TION STEPS

> *"I have learned so much, especially about myself. I realized that in the beginning I had my own prejudices and thoughts of limitation that I wasn't previously aware of. I have learned practical ideas and been shown new creative approaches to learning and thinking. But I think the greatest gift for me has been that I have been allowed to see the true spirit in some of the people I have met here."*

Step 1. Fill out the application form and send it in, to arrive by August 30,1991.

Step 2. Ask anyone you want to provide a letter of support for you to send a letter to the address above.

Step 3. Acceptance letters will be sent to the selected applicants by September 20, 1991.

Deadlines for Applications

Applications must be received by August 30, 1991 at the address indicated above. Letters of support should also arrive by this deadline. Applications received after this date will be considered, subject to the availability of space.

Training Location

The course will be held at the Denver Sheraton Tech Center. Participants will receive additional information upon their enrollment.

If You Have Questions...

You may call Partners in Leadership to ask questions about program details or to obtain additional application forms. If you would like assistance in filling out the application, please call us.
Our telephone number is: 303-756-7234.
Out of Town: 1-800-333-7690.

[redacted] OF PARTICIPANTS

Participants must agree to attend each of the six sessions and to work on all homework assignments between sessions.

- Participants must be highly motivated and willing to use the knowledge they acquire.
- Participants will be expected to identify personal goals to be achieved during and after the training.
- Participants will be asked to share their progress in striving for their goals.
- Participants will be expected to work on facilitating the formation of coalitions and networks, in the class and in their community.

[redacted]R PARTICIPANTS

Those participants wanting assistance with course materials or activities through readers, interpreters, physical facilitators, etc., should describe their needs on the application form. This course is intended to be available through personalized accommodations, to all qualified individuals. We will make every reasonable effort to respond to such requests.

Participants will be provided with lodging and meals from Friday at 6:30 p.m. through Saturday afternoon. Rooms will be double occupancy. Travel mileage will be reimbursed at $0.20/mile. Participants will be encouraged to travel together, when possible. Participants traveling more than 200 miles one way may be reimbursed for airfare.

Parents having childcare expenses due to attending this course will be reimbursed up to $40 per session. Arrangements can also be made for a partial lost-income allowance, in situations where participation in the course causes wages to be lost. Participants using personal care assistance may be reimbursed up to $150 per session for such services. Hotel accommodations and group meals will be offered to personal care assistants.

In summary, the curriculum for this course is intended to be personally challenging to each of the participants. We will attempt to accommodate individual needs, to enable participants to focus their efforts on the activities and assignments of the course.

"I learned about vision. 'If you can see, you can do.' It is a very powerful concept that I now can see the possibilities. I am beginning to fully appreciate the innate value of integration. I also now recognize that support is very imporant to being successful. This course has provided me with the vision, some of the tools, and the commitment of the Partnership."

[redacted] BENEFITS

"Partners has taught me that I can make a difference."

- National speakers and faculty members who know the "state-of-the-art" will share personal perspectives and visions for the future.
- Participants will learn about building coalitions.
- Participants will learn to help friends understand their concerns and how they can be of help.
- Participants can become more effective in working with the people in the "systems" they rely upon.
- Participants will learn to create and expand their own personal networks.

"There was a table set and they were all having tea."

[redacted] FORM

Please fill out the application form, detach, and return it to Partners in Leadership to arrive by August 30, 1991.

1. *Name* ____

   Address ____

   City ____

   State __________________________ *Zip Code* __________

   Telephone ____

2. *Please check appropriate boxes:*

   ☐ *Male*
   ☐ *Female*

   ☐ *Caucasian*
   ☐ *African American*
   ☐ *Hispanic*

   ☐ *Native American*
   ☐ *Asian-Pacific*
   ☐ *Other*________________

3. *If you are the parent of a child who has been identified as having "special needs" or a "disability" please indicate the child's age as of August 30, 1991.*

   ☐ *Birth through age 2*
   ☐ *Age 3 years through age 5 years*
   ☐ *Age 6 years through age 11 years*

   ☐ *Age 12 years through age 14 years*
   ☐ *Age 15 years through age 21 years*

4. *Do you feel that you are able to represent a particular "disability"? If so, please comment.*

   ____

   ____

   ____

   ____

   ____

   ____

   ____

over

5. *Do you have a need for special assistance or accommodations, personal assistance, reading, communication, special dietary needs, a translator in sign language or another language, physical accessibility needs, etc.? Please comment.*

____

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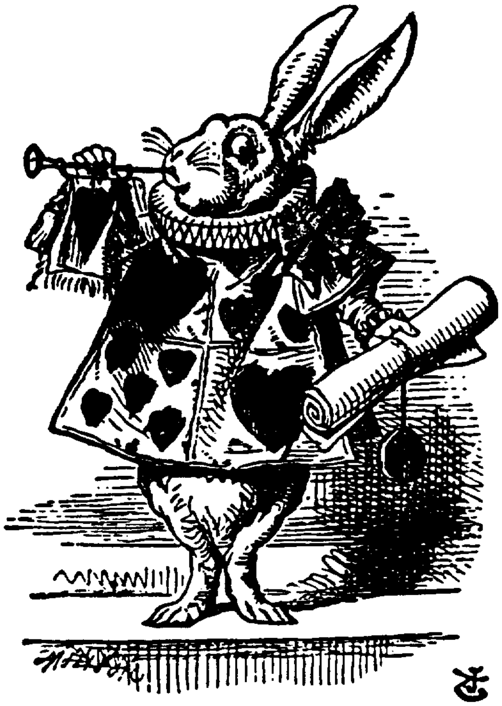
____

6. *Please attach a separate sheet of paper with your name and responses to the following questions:*
   - *a. Why do you want to attend this training program?*
   - *b. Please share additional information about yourself such as your work preferences, your recreational interests, your experiences in leadership, your experiences in causing positive change, etc.*

Optional
If you would like to provide a brief personal biography (up to 2-3 pages in length) please feel free to do so. This is not a requirement of this application process and may be done instead of answering question 6b above.

Mail completed application to:
Association for Community Living in Colorado ♥ Partners in Leadership
4155 East Jewell, Suite 916 ♥ Denver, CO 80222
Phone: 303-756-7234



The White Rabbit blew three blasts on the trumpet and then unrolled the parchment scroll..."

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*******************************************:
* ILLINOIS PIP ANNOUNCEMENT AND APPLICATION
*   N.D. - Received prior to 1992 Academy
*******************************************:
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UIC
The University of Illinois at Chicago

Illinois University Affiliated Program in Developmental Disabilities (M/C 627)
1640 West Roosevelt Road
Chicago, Illinois 60608
(312) 413-1647

June 17, 1991

Dear Interested Person.

The Illinois University Affiliated Program in Developmental Disabilities and the Association for Retarded Citizens of Illinois are currently seeking applications from interested parents of children with developmental disabilities, or persons with a disability, to participate in Partners in Policymaking. This is a one-year leadership training program designed to involve the participants in active efforts to improve the quality of life for people with developmental disabilities in Illinois. Well-informed and organized parents and individuals with disabilities have historically had a powerful influence on policymaking.

This program actively seeks both males and females, members of minority communities, people who represent individuals with all types of severe disabilities and from all areas of the state. Beacuse of our desire to have as broad a participation as possible, we do not select husband wife-teams.

Expenses are paid for travel, lodging, meals, support services or respite care. A series of eight conferences will take place at the Matteson Holiday Inn just south of metorpolitan Chicago, once a month on a Friday and Saturday. The first training session will be held on August 23rd and 24th, 1991. Attendance at all sessions is mandatory.

Selection will be made based on the quality of the applications. Applications are due on July 20th, 1991. Final selection will be made by July 31st, 1991.

Inquiries about this program can be directred to either Joyce Bertram, Program Director (312/413-1975) or Juana T. Garate, Project Coordinator (312/413-4097) at the above address.

We would appreciate your assistance in identifying qualifed applicants. Please share this information with other interested persons. Thank you in advance for your assitance in seeking qualified applicants.

Cordially,

Fabricio Balcazar
Fabricio E. Balcazar
Principal Investigator

Joyce Bertram
Joyce Bertram
Project Director

DEVELOPMENTAL DISABILITIES DEFINITION

The ternm "developmental disabilities" means a severe, chronic disability of a person which--

a. is attributed to a mental or physical impairment or combination of mental and physical impairments;
b. is manifested before the person attains age twenty-two;
c. is likely to continue indefinitely;
d. results in substantial functional limitations in three or more of the following areas of major life activity:
    i. self care
    ii. receptive and expressibe language
    iii. learning
    iv. mobility
    v. self-direction
    vi. capacity for independent living
    vii. economic self-sufficiency
e. reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

Source: Developmental Disabilities Act of 1987 (P.L. 100-146)

****
* ILLINOIS PIP ANNOUNCEMENT AND APPLICATIC
*   N.D. - Received prior to 1992 Academy
****

PARTNERS IN POLICYMAKING
APPLICATION FOR PARTICIPATION

NAME ____

ADDRESS ____

ZIP CODE __________

TELEPHONE Daytime - (   )___-____ Home - (   )___-____

****

MARITAL STATUS Married____ Single____ AGE _____ Male_____ Female_____

RACE/ETHNIC BACKGROUND __________

ANNUAL HOUSEHOLD INCOME
____ under $20,000 _____ $20,000-$50,000 ____ $50,000-$100,000

____ over 100,000

1. Are you a person with a developmental disability?

_____Yes _____No

If yes, please describe your disability:______________________________
____
____
____
____

What services (case management, supported employment, etc.) are you currently receiving?____
____
____

2. Are you a parent of a son or daughter with a developmental disability? (Please indicate if you have more than one child with a disability.)

_____Yes _____No

If yes, how old is your son/daughter? __________

Describe the disability and how it affects the ability of your son/daughter to function in at least three (3) areas of major life activity:________
____
____
____
____
____
____

What services (school, respite care, case management etc.) is s/he currently receiving? Please indicate the name of the organization(s) providing services. ______________________________

____

Describe the school placement: ______________________________

____

____

3. Do you have other children? _____ Yes _____ No

If yes, what are their ages? ____________________

4. What specific issue, area of concern or problem leads you to apply for this program? ______________________________

____

In what ways have you been actively involved in addressing this issue, concern, or problem? ______________________________

____

5. Will you make a time commitment of two days per month on a Friday and Saturday during the months of August, September, October, November, December, January, February, and March, 1990-91?

_____ Yes _____ No

Current employment: ______________________________

6. Will you travel to the metro area to attend the regularly scheduled meetings? (all expenses will be reimbursed)

_____ Yes _____ No

7. Are there any special accommodations necessary for you to participate in this program?

_____ Yes _____ No

If yes, please describe (accessibility, interpreters, respite, etc.)

____

____

____

____

____

have you been involved with any disability groups, advocacy organizations, or other agencies? If so, please list them. (Membership in other groups is not a requirement.)

9. **Please tell us a little about yourself and your family.**

10. **Please list the names, addresses & phone numbers of three** individuals who know of your interest in disability issues.

11. **Please indicate how you learned about the Partners in Policymaking project:**

****
ILLINOIS PIP ANNOUNCEMENT AND APPLICATION
* N.D. - Received prior to 1992 Academy *
****

Please note that these applications will be individually rated by a panel of screeners. Applications will be rejected if:

1. people are not able to meet at the designated times;
2. if they do not fit the definition of developmentally disabled;
3. if they are deemed too knowledgeable/active in developmental disabilities;
4. as the population of Illinois, the group will be varied by disability, geographic region, age of the person with disabilities, race & sex.

Inquiries about this program can be directed to the following individuals:

Fabricio E. Balcazar, Ph.D., Principal Investigator
Joyce Bertram, Program Director
Juana T. Garate, Project Coordinator

UAP/DD
University of Illinois, Chicago
1640 W. Roosevelt Road
Chicago, Illinois 60608

UIC
The University of Illinois at Chicago

Illinois University Affiliated Program in Developmental Disabilities (M/C 627)
1640 West Roosevelt Road
Chicago, Illinois 60608

Governor's Planning Council on Developmental Disabilities

Partners in Policymaking

Getting connected to make a difference in the lives of people with developmental disabilities

WHAT IS IT?

Partners in Policymaking teaches people to be community leaders. The program is designed to provide information, training, resources and skills building to parents of young children with disabilities and to people with disabilities so that they may obtain the best available services. The program is open to a limited number of interested people at no cost.

"The training, education and support I received has given me the tools to advocate for my son and it has opened my eyes to the needs of everyone with disabilities."

WHAT DOES IT GIVE YOU?

This program will give you the opportunity to meet and talk to international and national leaders in the field of developmental disabilities. You will learn to understand and help change public policy. It will acquaint and connect you with organizations, opportunities and possibilities. The program will educate you about current issues and state-of-the art approaches as well as how policies are made at local, state and national levels. The overall goal is to reach a productive partnership between underserved and unserved people who need and use services for developmental disabilities and those people who make public policy.

> *"This program is excellent because it empowers people with disabilities to pursue their own agenda."*

THE PROGRAM

You will attend two-day sessions, approximately eight times a year, between January and September. During each session, experts in specific areas will present up-to-date information and discuss recent breakthroughs. The sessions begin on Fridays, shortly after the noon hour and conclude on Saturdays late afternoon. There is ample time to converse with the speakers in either small groups or on a one-to-one basis. A maximum number of 35 people will be selected to attend the program. A screening process that attempts to obtain a balance of people (people of color, low income persons, single parents, person representing a variety of disabilities, gender) will be used to select participants.

All participants are paid for their travel, personal assistance services, respite care, and child care. Lodging will be provided if you live outside the metro area. Meals are also be provided.

Each session is devoted to a specific topic or level of government. you will be expected to complete assignments between sessions and to complete a major assignment (such as serve as an intern with an elected or public official) by the end of the program.

Partners in Policymaking will train and educate you in the following:

- The history of the parent movement, self-advocacy, and independent living movements
- The reasons for integrated, quality education (including post-secondary) for people with developmental disabilities
- The importance of whole life planning
- State-of-the-art technologies for people with severe physical disabilities
- How to analyze your county CSSA plan, case management and the strategies used in the county planning process
- Creating homes and family support
- The importance of employment and careers
- Critical federal/state issues and the process by which you can channel your concerns
- Necessary skills for providing testimony or meeting with public officials
- Successful techniques for advocating for services.

THE DIFFERENCE YOU CAN MAKE

There is a growing movement toward integration in public schools, an increasing demand for inclusive communities, and a greater effort for full accessibility for people with developmental disabilities all across Minnesota. Although segregation is decreasing, many people are still unserved or underserved. Partners in Policymaking needs you to help move our education systems, supported living programs, employment opportunities and technologies towards excellence. Your involvement will create solutions, and promote improvement in Minnesota's service system.

"Partners has done a remarkable job of increasing my confidence, knowledge and skills."

"I am now proactive rather than reactive. Partners has changed the way I act, look and speak on issues."

WHY YOU SHOULD FILL OUT THE APPLICATION FOR PARTICIPATION?

If you feel the need for increased skills in leadership; if you want to share and develop a collective vision for the year 2000 and beyond; if you want to meet and discuss issues with leading experts in the field of developmental disabilities; if you want the opportunity to develop grassroot efforts to affect public officials; if you want the chance to see and experience the newest technologies and practices available; if you want to understand the various social service systems and how to access needed support; if you want to be as effective as possible so that you can influence government processes and policies you should apply now!

**For more information, contact
David Hancox at 612/349-2559
or 612/296-9962 TDD**

**APPLICATIONS ARE DUE BY
DECEMBER 16, 1991**

Please send your application to:

Governor's Planning Council on
Developmental Disabilities
300 Centennial Building
658 Cedar Street, St. Paul, MN 55155

This program was funded under provisions of the Developmental Disabilities Act of 1990 (P.L. 101-496). Content of this program does not necessarily reflect the position or policy of the Governor's Planning Council on Developmental Disabilities nor that of the Department of Administration.

APPLICATIONS ARE DUE BY DECEMBER 16, 1991

APPLICATION

Name

Address

City, State, Zip

Phone (H) (W)

Are you a parent of a son or daughter who has a developmental disability?
Please indicate if you have more than one child with a disability.

Yes ☐ No ☐ Age(s)

IF YES:
Describe the disability and how it affects the ability to function in at least three of the areas of major life activity:

What services are you currently receiving (school, respite care, case management, etc.)?

Describe school placement:

Do you have other children?
Yes ☐ No ☐ How many? Age(s)

Are you a person with a disability?
Yes ☐ No ☐

Why are you interested in the program? Is there a specific issue, area of concern, or problem that encourages you to apply?

Will you make a time commitment of two days (Friday/Saturday) during the months of January, February, March, April, May, June, July and September?
Yes ☐ No ☐

Please send your application to: Governor's Planning Council on Developmental Disabilities, 300 Centennial Building, 658 Cedar Street, St. Paul, MN 55155

Current employment: ______________________________

____

____

Will you travel to the metro area to attend regularly scheduled meetings?
Yes ☐ No ☐

Are there any special accommodations necessary for you to participate?
Yes ☐ No ☐

Please describe (accessibility, interpreter, respite, etc).

____

____

____

____

Do you currently belong to any advocacy organizations?
If so, please list. Memberships are NOT a requirement.

____

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Please tell us a little about yourself and your family.

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____

List two to three references (name, address, phone).

____

____

____

Please indicate how you learned of the program.

____

____

____

____

IOWA PIP APPLICATION
N.D. - Received prior to 1992 Academy

PARTNERS IN POLICYMAKING
APPLICATION FOR PARTICIPATION

NAME ____

ADDRESS ____

ZIP CODE __________

TELEPHONE Daytime - ( ) _____-______ Home - ( ) _____-______

RACE/ETHNIC BACKGROUND _______________ AGE __________ (Optional)

* * *

1. Are you a person with a developmental disability?

   _____ Yes _____ No

   If yes, please describe your disability: ______________________

   ____

   ____

   What services (case management, supported employment etc.) are you currently receiving? ______________________

   ____

   ____

2. Are you a parent of a son or daughter with a developmental disability? (Please indicate if you have more than one child with a disability.)

   _____ Yes _____ Yes

   If yes, how old is your son/daughter? __________

   Describe the disability and how it affects the ability of your son/daughter to function in at least three (3) areas of major life activity: ______________________

   ____

   ____

   ____

   ____

What services (school, respite care, case management, etc.) is she/he currently receiving? ______________________________

____

____

Describe the school placement: ______________________________

____

____

3. Do you have other children? _____ Yes _____ No

If yes, what are their ages? ______________________________

4. Why are you interested in participating in the Partners in Policymaking project? Is there a specific issue, area of concern, or problem that encourages you to apply for this program? ______________________________

____

____

____

____

5. Will you make a time commitment of two days (Friday and Saturday) five times during the months of October, 1991 through May, 1992?

_____ Yes _____ No

Current employment: ______________________________

Do you anticipate any problems with getting time off from work?

_____ Yes _____ No

6. Will you travel to Des Moines to attend the scheduled meetings? (expenses will be reimbursed)?

_____ Yes _____ No

7. Are there any special accommodations necessary for you to participate in this program?

_____ Yes _____ No

IOWA PIP APPLICATION
N.D. - Received prior to 1992 Academy

If yes, please describe (accessibility, interpreters, respite, etc.)

8. Do you currently belong to any advocacy organization? If so, please list them and any offices. Membership in other organizations is <u>not</u> a requirement.

9. Please tell us a little about yourself and your family.

10. Please list the names, addresses and phone numbers of three references.

11. Please indicate how you learned about the Partners in Policymaking project: ______________________________

____

____

____

12. My home-town newspaper is: ______________________________
(Name) (City)

____
(Signed) (Date)

Return by September 16, 1991 to: Sylvia Piper, Project Coordinator
Iowa Protection & Advocacy
Services, Inc.
3015 Merle Hay Rd., Suite 6
Des Moines, Iowa 50310

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*************************************
*N.D. Received prior to 1992 Academy*
*************************************
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Texas Planning Council
for Developmental
Disabilities

4900 North Lamar Boulevard, Austin, Texas 78751-2316
(512) 483-4080 TDD (512) 483-4099
Roger A. Webb, Executive Director

Lee Veenker, Chairman
Shenikwa Cox, Vice Chairman

March 10, 1992

DD Council Seeks Participants for Partners in Policymaking Program

Partners in Policymaking is an innovative model of leadership training for self-advocates and parents. It provides state-of-the-art knowledge about developmental disabilities issues and builds the competencies necessary to become advocates who can effectively influence public officials.

The Texas Planning Council for Developmental Disabilities is currently seeking applications from interested people who have developmental disabilities or parents of young children with developmental disabilities to participate in Partners in Policymaking. This program is designed to provide information, training and skill building so that participants may obtain the most appropriate state-of-the-art services for themselves and others.

The program educates participants about current issues and best practices and familiarizes them with the policymaking and legislative processes at the local, state and federal levels. The overall goal is to achieve a productive partnership between people needing and using services and those in a position to make policy and law.

"Partners" attend 2-day training sessions eight times a year with each session beginning Friday at noon and concluding late Saturday afternoon. Each session is devoted to specific topics with nationally known experts as presenters. "Partners" are expected to complete assignments between sessions and also commit to one major assignment such as serving an internship, organizing a letter writing campaign, or organizing special receptions or town meetings for public officials. Attendance at all sessions is mandatory.

Session topics include:

- History - Independent Living Movement, Parent Movement, People First Movement
- Education - Inclusion and Quality
- Supported Living, Personal Futures Planning, Family Support, Supported Employment
- Assistive Technology, Seating and Positioning, Challenging Behavior
- State Legislative Issues
- Federal Policy and Legislative Issues
- Advocacy Organizations and Efforts, Community Organizing
- Parliamentary Procedure and How to Take Control of Meetings

The Council is actively seeking highly motivated men and women to participate in the Partners in Policymaking program. We are particularly eager that the members of the group represent different ethnic backgrounds, different geographic regions of the state and a variety of disabilities. Also, we are especially interested in reaching persons who are not actively involved in existing advocacy organizations. Please feel free to make copies of this packet for dissemination to interested individuals or call the DD Council to obtain additional copies. Expenses for travel, lodging, meals, respite care and attendant services for program participants will be reimbursed.

Applications must be postmarked by May 15, 1992, to be eligible. Final selection will be made by July 1, 1992. Monthly training sessions will be held from September to May, excluding December. Fax copies will not be accepted.

Applications also are available in braille, large print, ASCII and on audio cassette. To obtain alternate formats, please contact:

Jopie Smith
Texas Planning Council for Developmental Disabilities
4900 North Lamar Blvd.
Austin, Texas 78751-2316
(512) 483-4089 or (512) 483-4099 (TDD)

TEXAS PIP APPLICATION
N.D.- Received prior to 1992 Academy

Partners in Policymaking
Application for Participation

Application Deadline: May 15, 1992

Name: ______________________________

Address: ______________________________

______________________________ Zip Code: __________

Telephone: (________) ______________ Daytime Number: (________) ______________

Are you: ________Male ________Female Ethnicity: ______________

1. Are you a person with a developmental disability? (See definition on back page.)

_______ YES _______ NO Age: _______

If yes, please describe the disability (or disabilities): ______________________________

____

____

2. Are you a parent of a son or daughter with a developmental disability? (If you have more than one child with a disability, please answer for each child. See definition of "developmental disabilities" on back page.)

_______ YES _______ NO Your age: _______

If yes:

a. Describe how the disability affects the ability of your son/daughter to function in at least three (3) of the areas of major life activity (Part "D" of the definition):

____

____

____

____

____

b. How old is your son/daughter? __________

c. What is the disability (or disabilities)? ______________________________

____

____

2. *Continued:*

d. What services (school, respite care, case management, etc.) is your son/daughter currently receiving? ______________________________

____

e. Describe the school placement: ______________________________

____

____

f. Does your son/daughter live at home? _______ YES _______ NO

3. Do you have other children?

_______ YES _______ NO

If yes, what are their ages? ______________________________

4. Why are you interested in participating in the Partners in Policymaking program?

____

____

____

____

____

____

____

____

5. Is there a specific issue, area of concern, or problem that encourages you to apply for this program?

____

____

____

____

____

____

6. Will you make a commitment to attend eight 2-day sessions, held monthly from September to May, except December?

_______ YES _______ NO

7. Will you travel to Austin to attend the regularly scheduled meetings?

_______ YES _______ NO

8. Are you willing to do homework assignments (primarily reading)? _______ YES _______ NO

9. Are there any special accommodations necessary for you to participate in this program?

_______ YES _______ NO

If yes, describe accommodations needed (accessibility, interpreters, respite care, attendant services etc.): ____

____

____

10. Please list any memberships in advocacy organizations and indicate any office held. (Membership in other organizations is not a requirement):

____

____

____

____

11. What types of experience have you had in advocating for people with developmental disabilities?

____

____

____

12. Please tell us a little about yourself and your family:

____

____

____

____

____

____

____

____

____

____

____

____

____

____

____

____

13. Please list two references—names, addresses and phone numbers:

1. ____

____

____

2. ____

____

____

14. Please indicate how you learned about the Partners in Policymaking project:

____

____

____

Please mail the completed form to:

Jopie Smith
Texas Planning Council for Developmental Disabilities
4900 North Lamar Blvd.
Austin, Texas 78751-2316
(512) 483-4089 or (512) 483-4099 (TDD)

– – – – – – – – –

Developmental Disabilities Definition

The term "developmental disabilities" means a severe, chronic disability of a person 5 years of age or older which --

(A) is attributable to a mental or physical impairment or a combination of mental and physical impairments;
(B) is manifested before the person attains age twenty-two;
(C) is likely to continue indefinitely;
(D) results in substantial functional limitations in three or more of the following areas of major life activity:

- self care,
- receptive and expressive language,
- learning,
- mobility,
- self-direction,
- capacity for independent living, and
- economic self-sufficiency; and

(E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated; except that such term when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental disability or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

Source: Developmental Disabilities Assistance and Bill of Rights Act of 1990 (P.L. 101-496.)

SELECTION PROCESS RATING SHEET

App.#	Gender of App.	Age of App.	Marital Status	Ethnic Background	Income Level	Disability MR/MR+	Age & Gender of Ind. w/dis	Meets Criteria	Level of Activism	Affiliated Organizations	Narrative Rate 1-10	Rankin

ILLINOIS PIP SELECTION RATING SHEET
N.D. - Received prior to 1992 Academy

****
* IOWA PIP SELECTION PROCESS *
* N.D. - Received prior to 1992 Academy *
****

PARTNERS IN POLICYMAKING

Participant Selection Process and Criteria

The Partners in Policymaking participants will be selected using the following process:

1. Project announcements and applications will be sent out on October 15, 1989 to interested agencies, organizations, and individuals.

2. The project has been and will be announced in a number of state newsletters, and project staff will be issuing a news release to the Des Moines Register.

3. Potential applicants will complete the application and return it to the Protection & Advocacy office. Multiple copies will be sent to agencies and organizations for distribution.

4. Applications will be returned to Protection & Advocacy on or before November 15, 1989. By November 30, 1989, Partners staff and Steering Committee will meet to review and select project participants based on this criteria. By November 30, 1989, all applicants will be notified regarding the results of this selection process, and contracts will be sent to those applicants selected to be participants in Partners in Policymaking.

5. The criteria, as recommended and developed by Partners in Policymaking Steering Committee and staff persons, are in place to develop a balance within the group participants. The "requirements for participants are:

   a. The applicant is a parent of an individual with a developmental disability; or
   b. The applicant is a person with a developmental disability.
   c. The applicant will have limited or no experience with policymaking.

Beyond these participant requirements, the Steering Committee and Partners staff will be reviewing the applications of the participants to achieve a balanced group in:

1. The applicants' geographic locations.
2. Applicants' sex.
3. Applicants' race or culture.
4. Specific developmental disability which affects the applicant and/or their family.

5. Applicants' child with a developmental disability.
6. Age of the applicants' child with the disability.

In order to address the question of experience in policymaking, the application asks for three personal references, an indication of how the applicant learned about Partners in Policymaking, a statement of interest in participation in the project, issue or concern identification, list of memberships and organizations, list of other committees or task forces in which the applicant has been involved, and a listing of significant classes or workshops which the applicant has attended.

PP5 - Selection Process Rating Form

SELECTION PROCESS FORM

Applicant		Disability Group		Locale			Level of Activism			Gender		Race			Narrative 1-10	Meets Basic Criteria		Rating		
#	Type	MR	Other	S	U	R	H	?	L	M/F	Age	Min.	Maj.	?		Yes	No	Yes	?	No

NEW YORK PIP SELECTION FORM

N.D. - Received prior to 1992 Academ

KEY TO USING SELECTION PROCESS RATING FORM

Column 1 - Applicant

* = Enter number assigned to each application as it was received

Type - P for Parent

I for Individual with a Disability

FP for Foster Parent

S for Sibling

R for Relative

O for Other

Column 2 - Disability Group

MR - enter an X if applicant represents someone who is mentally retarded

Other - enter other type of disability represented

Column 3 - Local

S = enter an X if individual lives in **suburban** area

U = enter an X if individual lives in **urban** area

R = enter an X if individual lives in **rural** area

Column 4 - **Level of Activism**

Review the information provided by the applicant to determine the levels of his/her advocacy activities or involvement in related community programs. Enter an X under "H" if the individual appears to have a **high** level of activity, an X under the "L" if the individual has a low level of activity or an X under "?" if you are unable to make a determination based on the limited amount of information on the application form.

Column 5 - Gender and Age

Gender - Insert **"F"** for female or **"M"** for male of the individual making the application.

Age - Enter the age of the individual with a disability being represented, not the age of the applicant. The only time the age of the applicant is entered is if that person is also a person with a disability.

****
* NEW YORK PIP SELECTION FORM *
* N.D. - Received prior to 1992 Academy *
****

Column 6 - **Race**

Enter an X under the appropriate column to identify whether the applicant represents a minority or majority ethnic group. If this is not stated on the application put an X in the "?" column.

Column 7 - **Narrative**

After reading the narrative information provided by the applicant, it will be necessary to assign a subjective, numerical rating to its contents with "1" being the **lowest** rating and "10" being the **highest.** This rating will be based on a determination of the individual's purpose for applying, ability to fully participate in all sessions, and interest in becoming an advocate.

Column 8 - **Meets Basic Criteria**

Review all entries made on this form for the applicant and put an X in the **"Yes"** column if he/she meets the basic recruitment criteria, or an X in the "No" column if he/she does not. For example, if you had determined as one of your criteria that all participants should be parents then anyone, not a parent, would not meet the basic criteria.

Column 9 - **Rating**

In reviewing the information available on each application, an overall rating should then be assigned. If the applicant does not meet the basic criteria or received very low scores in the narrative review enter an X in the "No" column.

If the individual met all criteria and appears to be a good candidate put an X in the **"Yes"** column. Enter an X under the "?" if you are unsure at this time about the person's interest, ability, or appropriateness as a participant.

Partners in Policymaking

RATING FORM FOR APPLICATIONS

Application Number	Rating (1, 2, 3)	Comments

NEW YORK PIP RATING FORM

N.D. - Received prior to 1992 Academy

NEW YORK PIP RATING FORM
N.D. - Received prior to 1992 Academy

Recruitment Process

Overall Rating Form

Please list the serial numbers in priority order of the 50 top applicants you have identified. We will then do an analysis of all your responses to compile a Master List. Begin with our number 1 to enter the number of your top priority.

1. ____________
2. ____________
3. ____________
4. ____________
5. ____________
6. ____________
7. ____________
8. ____________
9. ____________
10. ____________
11. ____________
12. ____________
13. ____________
14. ____________
15. ____________
16. ____________
17. ____________
18. ____________
19. ____________
20. ____________
21. ____________
22. ____________
23. ____________
24. ____________
25. ____________
26. ____________
27. ____________
28. ____________
29. ____________
30. ____________
31. ____________
32. ____________
33. ____________
34. ____________
35. ____________
36. ____________
37. ____________
38. ____________
39. ____________
40. ____________
41. ____________
42. ____________
43. ____________
44. ____________
45. ____________
46. ____________
47. ____________
48. ____________
49. ____________
50. ____________

****
* *TEXAS PIP SELECTION CRITERIA* *
* *N.D. - Received prior to 1992 Academy* *
****

PARTNERS IN POLICYMAKING

Selection Criteria

o Minority representation

o Rural/Urban mix

o Good geographical representation

o Not involved in advocacy organizations/New blood

o Gender -- Male/Female mix

O Cross disability representation

o Motivated for systems change versus personal gain

o Pro-community

o Enthusiasm for learning

o Evidence of commitment to long-term advocacy efforts

o Age -- Parents of children 5 and under most preferable
-- Consumers under 35 most preferable

****
* TEXAS PIP SELECTION CRITERIA *
* N.D.. - Received prior to 1992 Academy*
****

PARTNERS IN POLICYMAKING SELECTION CRITERIA

Consumers

NAME________________________________

Best Practices

1.	Recognition of importance of Independence, Productivity, Integration. (+10)	________
2.	Understanding or willingness to learn that most services do not reflect best practices. (+10)	________

Advocacy

3.	Commitment to long-term advocacy efforts. (+10)	________
4.	Support for system change strategies versus personal gain. (+10)	________

Other

5.	Unique circumstances or personal history. (+15)	________

Personal Characteristics

6.	Minority applicant. (+8)	________
7.	Minimal prior advocacy experience. (+5)	________
	TOTAL	________

TPCDD\WORD\JS\SEL-CRIT.DOC

PARTNERS IN POLICYMAKING SELECTION CRITERIA

Parents/Family Members

NAME ______________________________

Best Practices

1.	Recognition of importance of Independence, Productivity, Integration. (+10)	______
2.	Understanding or willingness to learn that most services do not reflect best practices. (+10)	______

Advocacy

3.	Commitment to long-term advocacy efforts. (+10)	______
4.	Support for system change strategies versus personal gain. (+10)	______

Other

5.	Unique circumstances or personal history. (+15)	______

Personal Characteristics

6.	Minority applicant. (+8)	______
7.	Father of individual with disability. (+5)	______
8.	Minimal prior advocacy experience. (+5)	______
9.	Son/daughter age 0-5 years. (+6)	______
	Son/daughter age 6-10 years. (+4)	______
	TOTAL	______

TEXAS PIP SELECTION CRITERIA
N.D. - Received prior to 1992 Academy

ALABAMA PIP ACCEPTANCE LETTER
N.D. - Received prior to 1992 Academy

October 2, 1990

Dear Participant:

As you are well aware by now, you have been selected to be a participant in Partners in Policymaking of Alabama, a leadership training program sponsored by Alabama's Governor's Planning Council on Developmental Disabilities and the Association for Retarded Citizens of Alabama. As you know, P.I.P.A. is a nine month program to increase empowerment and improve the self-advocacy skills of parents of young children with developmental disabilities and adults with disabilities.

We received over 110 applications and the Candidate Selection Committee had an enormous job in narrowing the field. Each application held a compelling message and conveyed a tremendous need within Alabama for state-of-the-art information on disabilities and new opportunities that could make a significant impact in their own lives and the lives of their children. Congratulations on your selection and on having the opportunity of acquiring such valuable information and advocacy techniques.

Enclosed you will find a tentative schedule, a map and other important information. We will make arrangements for all overnight accommodations for participants traveling from outside the Montgomery area. Please allow us to make all contacts with the hotel. If you have any conflicts, please contact me as soon as possible.

I have had the opportunity of speaking with each of you on the phone and it is evident that we share enthusiasm and excitement over this new project. I hope that I addressed any questions or concerns that you may have regarding P.I.P.A. I spoke with many of you concerning accessibility to the hotel and personal accommodations that you might need in order to attend. Let's continue working together in addressing your needs and making necessary adaptations so that your trip to Montgomery will be as comfortable as possible. Please feel free to contact me if there are any questions left unanswered.

Also enclosed, you will find a list of participants. We strived to ensure a balance in terms of geography, gender, types of disabilities, parent/consumer representation, and others. If you wish to contact anyone prior to our first academy regarding travel, networking etc., please feel free to do so.

Please review all of the enclosed materials and again if you should have any questions regarding any of it's content, please call me. Again, congratulations, I look forward to meeting you and working with you on this exciting, innovative project. Together we can make a difference in the lives of individuals with developmental disabilities and their families. See you on October 19!

Sincerely,

Betsy Prince,
Director

September 6, 1990

Dear Partners in Policymaking Applicant:

Thank you for submitting your application to participate in our leadership training program, Partners in Policymaking of Alabama, sponsored by the Alabama Governor's Planning Council on Developmental Disabilities and the Association for Retarded Citizens of Alabama. Each application held a compelling message and conveyed a tremendous need within Alabama for state-of-the-art information on disablilites and new opportunities that could make a significant impact in the lives of people with disabilities and their families. We are sorry to inform you that you were not selected to be a participant in this year's project but thank you for your time and interest.

We are pleased to say that we received more than 112 applications from interested parents and individuals with disabilities. Each application shared enthusiasm and we sincerely wish we could have accepted all those who applied. It only confirmed the need for such a quality training program here in Alabama. We strived to insure a balance in terms of geography, gender, types of disabilities and parent/consumer representation. Taking all of these factors into consideration, it was a very difficult selection process.

Since we limited our number of participants to 35, our Participant Selection Committee had to make some very difficult decisions based on the above factors.

Again we thank you for your interest and time in completing our application. Our hope is that with the success of PIPA, we will be able to continue this leadership program and you may again have the opportunity of applying.

We will be disseminating P.I.P.A. information periodically, if you do not wish to remain on our mailing list, please contact me as soon as possible. If I can be of further assistance to you in the future, please feel free to contact me.

Sincerely,

Betsy Prince,
Director

BP:mdt

Texas Planning Council
for Developmental
Disabilities

4900 North Lamar Boulevard, Austin, Texas 78751-2316
(512) 483-4080 TDD (512) 483-4099
Roger A. Webb, Executive Director

Lee Veenker, Chairman
Jerijean W. Work, Vice Chairman

June 18, 1990

TEXAS PIP ACCEPTANCE LETTER
N.D. - Received prior to 1992 Academy

Kathryn Snow
4008 Clayton Road West
Fort Worth, TX 76116

Dear Ms. Snow:

Congratulations! You have been selected to be a participant in Partners in Policymaking. We received 85 applications and the task of selecting only 30 participants was extremely difficult.

As you know, Partners in Policymaking is a nine month program designed to increase empowerment and improve self-advocacy skills of individuals with disabilities and parents of children with developmental disabilities. We have enclosed information regarding the schedule of training sessions and other pertinent information. Your contract is also enclosed. Please read it carefully, sign all 3 copies and return them in the attached envelope by July 9, 1990. We will review reimbursement procedures and ground rules with you during the first session.

Our first session will be held Friday and Saturday, August 24-25, at the Stouffer Hotel, 9721 Arboretum Blvd., Austin. Registration will begin at noon on Friday and we will adjourn by 3:00 p.m. on Saturday. We will reserve rooms at the Stouffer Hotel for participants outside the Austin area and arrange to have them direct billed to our office. Please complete and return the participant information sheet attached so that we can make the appropriate arrangements. If you ever have any questions about hotel arrangements, contact our office. Please do not contact the hotel directly.

We have enclosed "A New Way of Thinking" for you to read prior to our first session. Consistent attendance is very important to a successful experience and we require that everyone be present at all sessions. Because of limited space, we will not be able to accommodate any visitors at the Partners training sessions. Please keep that in mind if you bring family members with you to Austin. You can be reimbursed for respite care services in your home community to enable you to leave your children at home. Please let us know if this causes any problems.

Please remember to return the contract and information sheet to us by **July 9.** If we don't hear from you by that time, we will assume you are no longer interested in participating in this program.

Again, congratulations on being selected for our first Partners class! We are excited about this program and think it will be an excellent opportunity for all participants. If you have any questions or concerns prior to August 24, please contact Jopie Smith at (512) 483-4089. See you in August!

Sincerely,

Roger Webb
Executive Director

ALABAMA PIP AGREEMENT
N.D. - Received prior to 1992 Academy

To Potential Applicants:

If chosen as a participant in the Partners in Policymaking of Alabama program, I must understand and agree to the following:

1. I must attend all sessions: 8 two day sessions beginning on Fridays at 1:00 p.m. through 3:00 Saturday.

2. I agree to submit forms for expense reimbursement in a timely and complete manner.

3. I will demonstrate competencies through action, i.e. letter writing and phone calls to elected officials, attendance at local & state meetings, testimony before local & state bodies, submitting news articles for print and interaction with other participants.

4. I agree to keep records and submit brief monthly reports of contacts relative to or as a result of Partners in Policymaking of Alabama.

Inturn, Partners in Policymaking of Alabama agrees to:

1. Provide, face to face, the most up-to-date information available from national experts in the field of developmental disabilities.

2. Provide reading materials, suggestions & resources to familiarize participants with a wide range of topics related to developmental disabilities and with information specific to identified areas of interest.

3. Provide both role play & direct experiences at the local, state & federal levels to assist participants in their abilities to influence public policy as related to disabilities.

4. Provide for and reimburse participant expenses generated by involvement to the fullest extent possible in return for complete participation. PIPA will provide Friday dinner and Saturday breakfast and lunch. Expenses will be paid for travel, lodging and respite care.

If you have any questions relating to these obligations, please feel free to contact PIPA at 1-800-237-0665 or 265-0245.

Betsy Prince,
Director

ALABAMA PIP AGREEMENT
N.D. - Received prior to 1992 Academy

PARTNERS IN POLICYMAKING OF ALABAMA
CONTRACT

As a participant in the Partners in Policymaking program, I understand and agree to the following:

1. I agree to attend all sessions. In the event of an emergency, I agree to contact and inform Betsy Prince- Phone - 1-800-237-0665.

2. I agree to arrive and depart from sessions at the prescribed times, i.e., arrive at 1:00 p.m. on Fridays and not leave before 3:00 on Saturdays, unless otherwise prescribed in the schedule.

3. I will not invite spouses, children, or other unexpected guests to Partners in Policymaking. Hotel accommodations are arranged on a roommate basis. If I desire to deviate from this arrangement, I will be expected to pay the additional room charges. Partners and Policymaking will not cover any of the additional costs. P.I.P.A. will also make all contacts & arrangements with the hotel.

4. Per diem rates are established for travel expenses and other costs that may be associated with participation. Participants agree to maintain these per diems:
    a. mileage reimbursement - .22 mile
    b. meal costs; and
    c. respite care costs/attendant care costs.

5. I agree to submit forms for expense reimbursement in a timely and complete manner. Meals, including tax and a reasonable gratuity, not to exceed $5.00 for breakfast provided that the person leaves home before 6:00 a.m. or is away from home overnight; $7.00 for lunch provided that the person is in travel status more than 35 miles from his/her home or is away from home overnight; and $10.00 for dinner provided that the person cannot return home until after 7:00 p.m. or is away from home overnight. Partners in Policymaking will provide Friday dinner and Saturday breakfast and lunch.

    Respite care, babysitting & personal care attendant services will be reimbursed and based upon a preapproved mutually agreeable rate that is reasonable and consistent with the norm.

6. I will demonstrate competencies through action, i.e., letter writing, phone calls, attendance at local or state meetings, testimony before local or state bodies, news articles, and interaction with other participants. I will submit a "brief" report of monthly activities related to Partners in Policymaking.

7. I will choose one major assignment from the following list:
    a. Internship with Legislator/executive branch;
    b. Monitor hearings;
    c. Organize petitions/letter campaigns;
    d. Testify;
    e. Organize meeting/receptions with members of Alabama Congressional Delegation;
    f. Other (please specify);________________________

    ____

8. I agree to keep records and submit brief written monthly reports of contacts relative to, or as a result of, Partners in Policymaking with news media, public officials, action alerts, service organizations and/or community programs, phone calls, public presentations or speeches, meetings attended, and organizations joined.

9. I agree to submit estimates of my time and out-of-pocket expenses as local match for the federal grant which sponsors Partners in Policymaking.

________________ ________________________________

Date Participant's Signature

THE PARTNERS IN POLICYMAKING PROGRAM AGREES TO:

1. Provide, face-to-face, the most up-to-date information available from national experts in the field of developmental disabilities.

2. Provide reading materials, suggestions, and resources to familiarize participants with a wide range of topics related to developmental disabilities and with information specific to identified areas of interest.

3. Provide both role play and direct experiences at the local, state and federal levels of government to assist participants in their abilities to influence public policy.

4. Provide for and reimburse expenses generated by involvement to the fullest extent possible in return for complete participation.

________________ ________________________________

Date Betsy Prince, Project Director

DEVELOPMENTAL DISABILITIES PLANNING COUNCIL

PARTNERS IN POLICYMAKING

Letter of Agreement

As a participant in the Partners in Policymaking project, I understand and agree to the following:

1. I agree to attend all sessions. In the event of an emergency, I agree to contact and inform ~~Shirley Reynolds at 1-800-395-3372.~~

2. I agree to arrive and depart from sessions at the prescribed times; i.e., arrive at 6:00 p.m. on Fridays and **not** leave before 3:30 p.m. on Saturdays unless otherwise prescribed in the schedule.

3. **I will not invite spouses, children, or other unexpected guests to Partners in Policymaking.** Hotel accommodations are arranged on a roommate basis. If I desire to deviate from this arrangement, I will be expected to pay the additional room charges. Partners in Policymaking will **not** cover any of the additional costs.

4. Per diem rates are established for travel expenses. Participants are to maintain these.

5. I agree to submit forms for expense reimbursement in a timely and complete manner. **Partners in Policymaking will provide Friday dinner and Saturday breakfast and lunch.**

6. I will demonstrate competencies through action; i.e., letter writing, phone calls, attendance at local or state meetings, testimony before local or state bodies, news articles, and interaction with other participants. I will submit a "brief" report of monthly activities related to Partners in Policymaking.

7. I agree to keep records and submit brief written monthly reports of contacts relative to, or as a result of, Partners in Policymaking with news media, public officials, action alerts, service organizations and/or community programs, phone calls, public presentations or speeches given, meetings attended, and organizations joined.

8. I agree to submit estimates of my time and out-of-pocket expenses as local match for the federal grant which sponsors Partners in Policymaking.

9. Please complete the following:

   I will need the following special meal considerations:____________

   ____

   ____

   ____

NEW YORK PIP LETTER OF AGREEMENT
N.D. - Received prior to 1992 Academy

I am willing to share the hotel room with another participant: ____Yes ___No

10. I will need the following special accommodations:

____

____

____

____

Date: ____________________

____
Signature

____
Address

____

____

____
Telephone

TEXAS PIP AGREEMENT
N.D. - Received prior to 1992 Academy

Blank Form

AGREEMENT FOR PARTNERS IN POLICYMAKING

This agreement is between the Texas Planning Council for Developmental Disabilities (the Council) and (Trainee).

1. This agreement complies with applicable federal and developmental disability laws. This agreement will provide training services that will enable people with developmental disabilities, their families, and guardians to maximize their abilities to advocate for supports and services to increase independence, productivity, and inclusion.

2. Under this agreement, the Trainee agrees to:

   A. Participate in all eight (8) two-day Partners in Policymaking training sessions (contact Jopie Smith in case of emergency) and not invite spouses or guests to attend these sessions.

   B. Arrive and depart at prescribed times, i.e., arrive by noon on Fridays and not leave before 3:00 on Saturdays.

   C. Complete homework assignments relevant to training materials provided at the training sessions and submit brief reports of activities as requested.

   D. Participate in effectiveness evaluations at the end of each training session.

   E. Participate in post-training follow-up surveys.

   F. Submit estimates of time and expenses for match requirements of the federal grant.

   G. Choose one major assignment to be completed by December 1992.

3. In consideration for providing the services listed in paragraph 5 above, the Council agrees to authorize payment to the Trainee for the following amount(s):

   A. Travel Costs to training sessions for airfare, or mileage at .25¢ per mile.

   B. Meals required during travel time. Meals will be provided during training sessions.

   C. Lodging to be provided on double occupancy basis.

   D. Respite services.

   E. Attendant/Facilitator services.

   F. Postage, telephone, and miscellaneous charges related to Partners in Policymaking activities.

Total reimbursement under this agreement may not exceed $5,000.

The Trainee will submit a reimbursement request form to the Council showing expenses incurred and will attach receipts as indicated on form. Reimbursement requests must be submitted within 20 days of training session. The balance due to the Trainee will be remitted as promptly as possible after receipt of the reimbursement request.

4. This agreement is effective on ______ and will continue in effect through ____________.

For the Council	For the Trainee
________________________	________________________
Roger A. Webb Executive Director Texas Planning Council for Developmental Disabilities	

TEXAS PIP REIMBURSEMENT INSTR.
N.D. - Received prior to 1992 Academy

INSTRUCTIONS FOR TRAVEL REIMBURSEMENT REQUEST FOR PARTNERS IN POLICYMAKING (PARTICIPANTS)

Entitled to reimbursement for:

- Expenses per day for meals and lodging as specified on your Training Agreement. (Participant's meals and lodging will be billed by hotel directly to our office)
- Actual transportation expenses such as mileage, taxi, rental car, bus, commercial airfare, parking fees.
- Attendant/Facilitator services if applicable.
- Respite services if applicable.
- Other miscellaneous expenses as specified in your Training Agreement such as postage, resource materials and telephone charges.

INSTRUCTIONS FOR COMPLETION:

Name, Address & SSN: Fill in your name, mailing address and social security number. (We must have your SSN in order to process payment)

Purpose of Travel: Indicate purpose of travel--meetings attended, purpose of meeting, etc.

Meals: Meals will be billed by hotel directly to our office. If applicable, participants may claim meals while on travel status. (e.g. lunch on Friday; dinner on Saturday.)

Lodging: Lodging will be direct billed by hotel to our office.

Car Mileage: If you travel by personal car, indicate the number of miles driven. Multiply the mileage by .24 and enter amount. Itemize mileage, i.e., home city to and from destination and any in-town mileage.

Taxi, Rent Car: If a rental car is used, receipts must be attached. A taxi should be used when more economical than a rental car. Indicate points of origin and destination when using a taxi.

Other Transportation: If other transportation is used such as bus or railroad, indicate cost and attach receipts.

Commercial Airfare: Write in the amount of airfare under miscellaneous expenses, if you traveled by commercial plane. Airline receipts must be attached. First class flight must be justified in writing.

Parking Fees: Indicate any parking expenses (airport parking, etc.) under miscellaneous expenses. No receipts necessary.

PARTICIPANTS - Page 2
Telephone: Indicate total amount of telephone expenses. Telephone calls must be TPCDD business related and need not be while in travel status. No receipts necessary.
Other Travel Expenses: List any other travel expenses under miscellaneous expenses such as attendant fees/meals, respite fees, postage, etc. No receipts necessary.
Services Provided: If applicable, give brief description of services provided.
Total Expenses: Add the total amount of expenses.
Traveler's Signature: Sign, date and return reimbursement request form to:

TX Planning Council for
Developmental Disabilities
4900 N. Lamar Blvd.
Austin, TX 78751

ALABAMA PIP SURVEY
N.D. - Received prior to 1992 Academy

I.D. Number__________

PARTNERS IN POLICYMAKING OF ALABAMA
SURVEY

This survey is an effort to measure your advocacy activities <u>prior</u> to your participation in the Partners in Policymaking program. Please answer the questions to the best of your ability providing estimates when necessary.

1. Prior to your participation in the Partners in Policymaking program, have you ever contacted local, state, or national public officials regarding your needs or the needs of a family member with a disability? (Check all that apply.)

_____Yes, National
_____Yes, State
_____Yes, Local

Specific Issue Addressed______________________________

2. If yes to Number 1, please indicate the type of contact, (letter, phone, or office visit) and estimate the number of contacts made. (Check all that apply.)

_____Letters: estimated number = _____
_____Phone Calls: estimated number = _____
_____Office Visits: estimated number = _____

3. What other opportunities have you had, prior to the Partners program, to advocate for yourself or other persons with disabilities or to educate the public regarding the rights or needs of persons with disabilities? (Check all that apply.)

_____ Testified at a public hearing
estimated number = _____
_____ Presentation to parent groups:
estimated number = _____
_____ Presentation at a conference:
estimated number = _____
_____ Service on a committee, commission, or task force
estimated number = _____
_____ TV or radio appearances:
estimated number = _____
_____ Published newspaper articles/letters:
estimated number = _____

_____ Other: ______________________________
____
Please describe specific issue addressed ______________________________
____
____

4. Please evaluate your advocacy skills, for yourself or a family member with a disability, prior to this Partners program.

______ My advocacy skills are excellent.
______ My advocacy skills are good.
______ My advocacy skills are fair.
______ My advocacy skills are poor.

5. Prior to your participation in this Partners program, have you been able to receive appropriate services for yourself or family member with a disability?

______ Yes, most of the time.
______ Yes, some of the time.
______ No, have not been able to get appropriate services.

6. Do you expect to be better able to receive appropriate services as a result of the skills and information learned from the Partner's program?

______ Definitely yes.
______ Yes, somewhat.
______ Probably not.
______ Definitely no.

Services currently receiving ______________________________

7. As a result of your participation in the Partners program, what are your general expectations?

____
____
____
____
____
____
____
____

8. Place of residence:

_____ Urban
_____ Suburban
_____ Rural

****
* ALABAMA PIP SURVEY *
* N.D. - Received prior to 1992 Academy *
****

9. Income

____Less than $12,000
____$12,000 - $19,999
____$20,000 - $29,999
____$30,000 - $39,999
____$40,000 - $49,999
____$50,000 +

10. Level of Education:

____Less than High School
____High School Graduate
____Two Years of College
____Four Years of College
____Partial Graduate Work
____Master's Degree
____Doctoral Degree

11. Type of disability: Self and/or child

12. Race/Ethnicity:

_____ Afro American
_____ Native American
_____ Hispanic
_____ Caucasian
_____ Southeast Asian
_____ Other

13. _____ Female
_____ Male

14. Age:

____ Under 20
____ 21-29
____ 30-39
____ 40-49
____ 50+

Thank you for your assistance.

OHIO PIP PARTICIPANT SURVEY
N.D. - Received prior to 1992 Academy

INITIAL INVENTORY II
11/91

Because this is an outcome based project, we need to update our assessment of where project participants are during various times during this project. Please answer the following questions. There are no wrong answers; you are right no matter what you say.

Since the last conference, how many times have you:

1. participated in a planning meeting for your family member? ______
2. addressed your school board, county MR/DD board or local mental health board ______
3. attended a city council/county/township trustee meeting? ______
4. traveled to Columbus to attend a state-level meeting? ______
5. attended a local workshop or conference? ______
6. attended a state workshop or conference? ______
7. attended a national workshop or conference? ______
8. observed an Ohio legislative hearing? ______
9. talked with your state legislator? ______
10. talked with a local legislator (city council person, mayor, etc.)? ______
11. testified at a legislative hearing? ______
12. given a talk or speech to a group of people? ______
13. participated in a local committee/task force meeting? ______
14. attended a school board, county MR/DD, mental health board meeting? ______
15. written a letter to a person in authority about an issue of concern to you? ______
16. list any other activities/accomplishments that you have done since the last conference that are the result of this project.

____

____

____

AMERICAN SOCIETY IS CHANGING

The United States is becoming a richer mix of cultures, and multicultural diversity is especially reflected among young children. NEC*TAS recognizes that this diversity presents both opportunities and challenges for people working with infants, toddlers, preschoolers and their families and would like to support their efforts.

The demographics and statistics presented here reinforce the already perceived need for a comprehensive and coordinated early childhood system. If this system is to be community and family based, as Public Law 99-457—the 1986 amendment to the Education of the Handicapped Act that mandates early intervention services for children from birth through five—is designed to be, it is vitally important for states and jurdisdictions to create culturally sensitive and appropriate programs in response to the challenge of our changing society.

We plan to publish a series of papers about cultural diversity. We hope that this paper and others in the future will generate discussion and give you some good ideas, as well as offering opportunities to create effective culturally sensitive policies and programs and to share strategies with others in the field.

Why look at cultural diversity and the new demographics?

For state and local planning and service agencies, various challenges related to cultural diversity have surfaced again and again:

- How can we, as professionals, assure representation and meaningful involvement of families from diverse cultural backgrounds in advisory groups at various levels in our states?
- "Family" and "disability" may have varying meanings in various cultures. How do we prepare professionals at all levels to understand the different meanings of "family" and "disability" among cultures, as well as differing values and other contrasts, and their implications?
- People of color are underrepresented in early childhood fields. What strategies can we use to involve more people from diverse cultural backgrounds in this work?
- Few assessment tools have been normed for specific cultural populations. Why haven't culturally sensitive assessment tools been developed? Are there other ways of measuring children's development besides normative assessment?
- Relative to their total numbers, the rising proportion of African-American, Hispanic, and other children of color in poverty is troubling. How can the needs of these children be addressed?

This paper will set the stage, providing some demographic and statistical information and offering several general strategies that have been useful in making early childhood service systems more responsive. Future papers will cover other topics. We would like your suggestions about what those topics should be (see "We Need Your Ideas!").

We recognize that issues and concerns around cultural diversity are often sensitive areas, and accordingly, we have carefully chosen ideas and words based on advice from many people and from current literature.

We also recognize the danger of generalizing. We know that there is great diversity within any group. General statements about a group of people have the potential to reinforce harmful stereotypes.

But general awareness also has the power to build respect for cultures rooted in representations of reality that unfold from conditions different from our own.

We hope that what we say will cultivate the belief that cultural differences are rightfully acknowledged, respected, and valued. We therefore welcome your comments and opinions, as well as your ideas and strategies.

As America moves to compete in a global economy, and to solve pressing problems in global frameworks, our watchword must be a new respect for the diversity of peoples, of cultures, and of interests. And while we must respond to diversity across oceans and international boundaries, a more pressing need will be to come to grips with the growing diversity of our own society right here in the United States

Lauro F. Cavazos
U.S. Secretary of Education
Glassboro State College, Glassboro, New Jersey
May 18, 1990

CHANGING DEMOGRAPHICS

Demographic statistics, by their very nature, often reflect racial trends, and this demographic analysis has been presented in a terminology of race. Race and culture, however, are not synonymous terms. For example, the many faces of Asian Americans include Japanese Americans, Chinese Americans, Filipinos, and the more recently arrived Vietnamese, Hmong, Laotian, and Cambodian peoples. Each has a different set of cultural values, beliefs, and life experiences. Ways of perceiving, believing, evaluating, and behaving (Goodenough, cited in Baca, 1986) determine culture, rather than race.

Note: We were sometimes unable to locate comparative statistics for Asian American and Native American groups. Two states have been used as examples in this section, Texas and Minnesota. While they are not intended to serve as national norms, they both represent states that have undergone significant demographic changes in the past twenty years.

A century from now, the population of the United States will be closer to the world balance: 57 percent Asian, 26 percent white, and 7 percent black. (People of Hispanic origin may be of any race, e.g., Native American, white, black, etc.). We are in the middle of a population shift, with predictions that one third of us will be "minority" persons by the year 2000 (Zeller, 1986).

Statistics supporting this trend are:

- Between 1970 and 1980, according to the U.S. Census Bureau, Hispanics increased in number by 61 percent, and it is estimated that the Hispanic population has grown another 30 percent since 1980 (*Minority Issues*, 1987).
- The white population increased only 6 percent, the black population 18 percent between 1970 and 1980 (*Minority Issues*, 1987).
- In 1982, it was predicted that the Asian-American population would more than double in fifteen years (Levy, cited in Chan, 1986).

An example of a dramatic increase in Asian-Americans in certain areas of the United States includes Minnesota:

- Demographers' estimates in Minnesota for 1980 to 1985 include a conservative estimate of an over 50 percent increase in the Asian-American population. (Population Notes, 1988).
- One of the world's largest urban concentrations of Hmong people—15,000—resides in Minneapolis/St. Paul (Spring, 1989).

Texas is an example of a state undergoing major demographic shifts. The population is growing at twice the national average due to in-migration from other states and foreign immigration as well. According to a report by the Hogg Foundation for Mental Health:

- Between 1980 and 1986, two-thirds of these immigrants were from Latin America and 22 percent from Asia.
- Children comprise almost 30 percent of the state's population, and 24 percent of these children live in poverty. Children of color are overrepresented: almost half of the poor children in Texas are Hispanic and 42 percent are black.
- Over three-fourths of these children live in female-headed families where the mother is under age twenty-five (Harris, 1988).

Children of color are the most rapidly increasing group in the U.S. population and the largest at-risk group for disabilities.

By 2010, nearly one quarter of all children in the U.S. will be children of color (U.S. Congress, 1989). Nationwide, significant enrollment changes had already occurred between 1970 and 1980: in 1970 schools were 21 percent nonwhite; by 1980 they were 27 percent nonwhite. Students of color are now the majority in the twenty-five largest school systems in the country (*Minority Issues*, 1987).

Although nationwide the overall population of children has declined, the preschool population of the United States increased by 11 percent between 1980 and 1986 and continues to grow. In a few states the preschool population has decreased, while other states, such as Alaska, Florida, Arizona, California, and Texas, have experienced dramatic increases (U.S. Congress, 1989).

Poverty, in and of itself, is not a cultural attribute. Yet due to the history of racial discrimination in the United States—in spite of strides in the past twenty years—people of color are affected disproportionately by poverty. Connections between poverty and risk for disability are linked to people of color in the United States.

Contributing factors are the:

- lack of access to health care for people of color in general;
- large porportion of children of color who are poor;
- significant percentage of at-risk, high-school dropout women of color under age thirty who are mothers of preschool children:
- direct correlation between a mother's higher education level and early identification of a child's disability or possible disability (the better educated the mother. the earlier the identification).

What is the impact of poverty on children of color?

Children of color living in poverty

The children's poverty rate for blacks is over twice that for whites, with Hispanic poverty rates falling between the two groups (U.S. Congress, 1989), as the "Percent of Children Who Are Poor" chart below indicates.

The poverty rate for children in young families is even higher. According to a Children's Defense Fund analysis for families headed by persons under thirty, the poverty rate for black children in 1987 rose to 61 percent, and for Hispanic children to 53 percent (*Closing the Gap*, 1989).

In 1987, one in five children and one in four *preschool* children lived in poverty (U.S. Congress, 1989), putting preschool children at even greater risk.

In the most recent information for poverty among young Native American children, from the 1980 census, 35 percent were poor, a poverty rate approaching those for Black and Hispanic children (National Center, 1990).

Of the 15.3 million white children under six living in the United States in 1987—70 percent of all children under six—2.1 million were poor. In contrast, in the remaining 30 percent of children of color under six, 2.9 million were poor, making the proportion of young children of color who live in poverty far higher than their white counterparts (National Center, 1990).

More and more people of color, and particularly poor children of color, are concentrated in the inner cities and poor neighborhoods of major metropolitan areas (U.S. Congress, 1989). And increasingly, families with children of all ages may be homeless, that is, have no permanent residence. Families with children of all ages represent about one-third of the homeless at any time (National Center, 1990).

Vulnerability of poor children to develop disabilities early in life

The link between poverty and disabling conditions and learning problems makes the prevalence and persistence of poverty among people of color of significant concern to early childhood professionals.

Early childhood experiences set the patterns for later development. Without early intervention services, the environment of poor young children—all too often part of a cycle of racial discrimination, poverty, and malnutrition—will continue to contribute to their high rates of school failure, dropout, delinquency, early childbearing, and adult poverty (National Center, 1990).

Poor maternal nutrition, low birthweight, and substance abuse by pregnant women have been cited as potential causes of disabilities (*Minority Issues*, 1987).

Poor women more often deliver low-birthweight babies and are more likely to have growth retardation or anemia because of poor nutrition (National Center, 1990). And children born to young and black mothers remain disproportionately likely to be of low birthweight (U.S. Congress, 1989).

Yet the WIC (Women, Infants, and Children) program serves less than 50 percent of the high-risk, low-income, eligible population. Although more money has been allotted by Congress for 1990, a 155% increase in the price of infant formula over the last ten years has forced many states to cut the number of WIC recipients drastically.

Not only is the lack of nutritional food available of concern, but also the lack of nutritional counseling, medical help, and immunizations, which are also part of the WIC program (Arnold, May 31, 1990). WIC, like Head Start, has proved to be a cost-effective program, saving many dollars in potential medical bills.

Poor children are also at more risk for accidental injury, higher doses of lead in their environments (which can cause injury to the central nervous system), and prenatal exposure to drugs and AIDS (National Center, 1990). These risk areas, as well as the increasing number of many types of drug-addicted/exposed babies, make early detection essential.

Along with other substance abuse, an area for concern is Fetal Alcohol Syndrome (FAS). Alcohol consumption by pregnant women is implicated in five percent of all cases of birth defects (Broderick, February 7, 1990).

Percent of Children Who Are Poor (1988)

Age of Child	Total	White	Black	Hispanic
Younger than 3	*23.3*	*17.3*	*50.4*	*43.6*
Younger than 18	*19.2*	*14.1*	*43.5*	*37.6*

U.S. Census Bureau October, 1989

EPSDT—Early and Periodic Screening, Diagnosis, and Treatment, a program designated by Title XIX of the Social Security Act and a component of Medicaid—was created for providing preventive and coordinated medical care to children of low-income families. Yet in 1989, according to the U.S. Department of Health & Human Services, only 34%, or about three and one-half million, of the ten and one-half million children eligible for Medicaid received EPSDT services—and the actual number may be smaller because of more than one screening per child. While recent changes in EPSDT legislation have made it possible for more children to participate in EPSDT, the full potential of the program to serve young children is not being utilized.

Preschool children are America's poorest age group.

Single mothers, poverty, and teen pregnancy

In 1987, 46 percent of female-headed families with children and approximately 60 percent of female-headed families with *preschool* children were poor (U.S. Congress, 1989). A significant factor is the increasing number of single and unwed mothers, both white and women of color, who are high-school dropouts. In 1986, 63 percent of black and 43 percent of Latina high-school dropout mothers were unmarried, and these women are often the parent of at least one preschool child (*Closing the Gap*, 1989).

- Households with children under 18 headed by black or Hispanic women are one-and-a-half times as likely to be in poverty as those headed by white women (U.S. Congress, 1989).
- About 24 percent of white families are headed by 15- to 24-year-olds who live in poverty, but the percentage jumps to 38 percent for Hispanics and 57 percent for blacks (*Closing the Gap*, 1989).
- Almost half (47 percent) of these Hispanic poor families and three-quarters (75 percent) of these black poor families are headed by single women. (*Closing the Gap, 1989*).
- Between 1980 and 1987 the median income of children living in single-parent families declined by 19 percent (U.S. Congress, 1989).

Children born outside of marriage living with single mothers are at the greatest risk of long-term poverty (National Center, 1990).

A recent study by the Children's Defense Fund, based on statistics from 1980 to 1984, showed that within Minnesota poor rural counties had the highest rates of teen pregnancy and that the majority of young mothers were white. (A sex education curriculum for kindergarten through 12th grade in one at-risk county in Minnesota was effective in reducing the birth rates for girls under age 19 from 11 percent in 1978 to 2.9 percent in 1985.) (Hopfensperger, 1990). While the results of the study showed that teen pregnancy in Minnesota is related more to poverty than to urban location and race, it does not take into account the lack of access to health-care systems that exists for people of color, or that nationally, across all education levels, white women have fewer children than women of color (U. S. Congress, 1989).

Child support

The likelihood of child support is highest when the mother is legally divorced, is white, or has a college education. Poverty rates of women receiving child support have increased since 1978. These rates are particularly high for mothers who have never been married, have little education, and have more than two children. Completing high school greatly decreases the chances of living in poverty for these mothers.

- The number of children in poverty receiving Aid to Families with Dependent Children (AFDC) declined from 73 percent in 1975 to 56 percent in 1987 (U.S. Congress, 1989).
- Child support amounts are lowest for less educated, never married, and minority women (U.S. Congress, 1989).

Health care

Although poor children in general suffer from lack of health care, white children under six were more likely than black, Hispanic, or other children of the same age to be covered by health insurance. (U.S. Congress, 1989).

The findings of the Robert Wood Johnson Foundation's Collaborative Study of Children with Special Needs strengthen conclusions drawn by others. The Johnson study analyzed the effect of Public Law 94-142 (Education for All Handicapped Children Act) in five large metropolitan school districts: Milwaukee (WI), Houston (TX), Charlotte-Mecklenburg (NC), Santa Clara County (CA), and Rochester (NY).

They concluded that gaps in access to health care in the communities they monitored often exist for poor children and children of color, who have persistent problems in obtaining health services. The impact of Public Law 94-142 is lessened in states with weak Medicaid, mental health, and child service agencies (Robert Wood Johnson, 1988). The ability of health-care agencies to provide services will also affect the implementation of Public Law 99-457, most particularly EPSDT services, since Medicaid administers EPSDT.

In 1988, 20 percent of all children had no form of public or private insurance, compared to 17 percent in 1982 (U.S. Congress, 1989).

The Johnson Study also determined that the age at which a child's problem was discovered was in direct correlation to the mother's education level—the better the education of the mother, the earlier the problem was found, yet many young mothers are high-school dropouts.

These national demographics and statistics support the perceived need for a comprehensive and coordinated community-based early childhood system. Demographics vary from state to state, so it is vital that each state look at its own demographic trends, including cultural and geographic distribution, before developing inclusion strategies.

INTERVIEWS: WHAT WE CAN DO

In order to gather ideas about strategies that have been effective in meeting the challenge of changing demographics, we decided to talk to some of you who are working each day to make your systems more responsive to a richer mix of cultural groups. In choosing people to interview, we wanted to talk to people in different positions in the early childhood system, from parents to agency representatives. We chose people from states with varied cultural groups and asked two questions of each person. Their observations and suggestions follow.

The two questions are:

- *Demographic trends indicate that the population of young children in the U.S. is becoming increasingly culturally diverse. What issues do you believe this increase raises for state early intervention and preschool planners?*
- *What are some strategies you would suggest to help these systems become more culturally responsive?*

JULIA KIRBY, TEXAS

"We, in Texas, feel we need to do much more to reach culturally diverse groups. We are doing a lot of general public awareness and information for our programs. We produce PSAs, brochures, public service campaigns, newsletters, etc. But we need to target our materials.

"Our state Part H program provides funding for services through grants to seventy-five service providers. Their grants require that each program have a plan for public awareness and Child Find. The state office provides technical assistance and materials to the programs.

"Some projects have tried innovative approaches. For example, one project has a weekly cable television program and works closely with county extension agents. Two of our programs specifically target minority communities. One is a program for children at risk in the Hispanic community. The other, now in its first year, reaches out to the Vietnamese community.

"I feel public awareness is best done locally with state office support, because the local programs know the people in their communities. The media in their communities will be more interested in local events and will be more responsive to information coming from a program in their area than from a distant state office. Local programs are involved in helping plan statewide media campaigns and brochures because they will be using the materials, and they know what will work in their local communities.

"We serve many cultures, including Vietnamese and Chinese in addition to Hispanic, and many income levels in Texas. Of course, the biggest cultural group is Hispanic and this group is growing. We have translated some brochures and posters into Spanish and our public service announcements are in English and Spanish. Before we publish anything for this group, we ask, Is this something that the people who might come to our programs will be able to read? Is it being translated into a dialect of Spanish that they understand?

"We are making efforts, but there is so much more to do. I would like to see a task force made up of people from various cultural communities. The task force could look at such questions as, What are the community's needs for information? How are we reaching and not reaching them? What materials should we produce? How should we approach the community? After all, the people from those communities should best be able to answer those questions."

Julia Kirby is the public information specialist for the Texas Early Childhood Intervention Program. She has fifteen years experience in public relations with social services and has a master's degree in journalism and mass communication.

SUMMING IT UP: STRATEGIES

Julia Kirby

- Target public awareness locally, with state office support.
- Involve local programs in planning statewide public awareness campaigns.
- Translate materials and public service announcements into languages appropriate for communities.
- Involve cultural groups in planning public awareness activities.

REFERENCES

Arnold, E. (May 31, 1990). Interview with Senator Metzenbaum on "Morning Edition," Washington D.C.: National Public Radio (NPR). (Item A1) (Available from National Public Radio, Washington, D.C. 20036 202/822-2323.)

Baca, L. Concepts: Is There A Melting Pot? (1986). In C. Moore (Ed.), *Reaching Out: Proceedings from a Special Education Symposium on Cultural Differences and Parent Programs* (pp. 32-36). Eugene, OR: Western Regional Resource Center. (ERIC Document Reproduction Service No. ED 284 408) (Available from ERIC Document Reproduction System, 3900 Wheeler Avenue, Alexandria, VA 22304.)

Broderick, R. (February 17, 1990). A Cry Unanswered. *City Pages*, pp. 8-10, 12. (Published by City Pages, Inc., 401 North Third Street, #550, Minneapolis, MN 55401.)

Chan, S. (1986). Parents of Exceptional Asian Children. In M. K. Kitano & P. C. Chinn, (Eds.), *Exceptional Asian Children and Youth* (pp. 36-53). Reston, VA: ERIC Clearinghouse on Handicapped and Gifted Children. (Stock No. B620) (Available from ERIC Clearinghouse on Handicapped and Exceptional Children, Council for Exceptional Children, 1920 Association Drive, Reston, VA 22091-1589.)

Closing the Gap for Young Latino and Black Families: A Two-Generation Approach [Special issue]. (Fall, 1989). *The Research Bulletin*, 1(3). (Published by the Hispanic Policy Development Project, 1001 Connecticut Avenue NW, Suite 310, Washington, D.C. 20036 202/822-8414.)

Harris, L.C. (1988). *Children, Choices, and Change: An Adaptation of the Darker Side of Childhood.* Austin, Texas: University of Texas, Hogg Foundation for Mental Health.

Hopfensperger, Jean. (February 22, 1990). Poor, rural counties show highest rates of teen pregnancy. Twin Cities *Star Tribune*, pp. 1A, 11A, 15A.

Minority Issues in Special Education: A Portrait of the Future [Special issue]. (1987). *News Digest*, No. 9. (Published by NICHCY, P.O. Box 1492, Washington, D.C. 20013 703/893-6061.)

National Center for Children in Poverty (NCCP). (1990). *Five Million Children: A Statistical Study of Our Poorest Young Citizens.* New York: Columbia University, School of Public Health. (Available from NCCP, Columbia University, 154 Haven Avenue, New York, NY 10032; $9.95, $3.00 postage/handling.)

Population Notes: Minnesota State Demographer. (February, 1988). St. Paul, MN: Minnesota State Planning Agency. (Available from Minnesota State Planning Agency, Room 300 Centennial Building, 658 Cedar Street, St. Paul, MN 55155.)

Robert Wood Johnson Foundation. (1988). *Serving Handicapped Children: A Special Report, Number 1.* Princeton, NJ: Author. (Available from the Robert Wood Johnson Foundation, P.O. Box 2316, Princeton, NJ 08543-2316.)

U.S. Congress, Select Committee on Children, Youth, and Families. (1989). *U.S. Children and Their Families: Current Conditions and Recent Trends, 1989, A Report together with Additional Views of the Select Committee on Children, Youth and Families, U.S. House of Representatives.* (Stock Number 052-070-06597-4). Washington, D.C: U.S. Government Printing Office. (Available from U.S. Government Printing Office, Washington, D.C. (202/783-3238; $9.50.)

Spring, M. (Fall, 1989). A Meeting of Two Worlds: Prenatal Care for Hmong Women. *WorldWomen News*, 2(1), 6. (Published by Minnesota Worldwide Women, 1929 South Fifth Street, Minneapolis, MN 55454.)

U.S. Department of Health & Human Services. (March 13, 1990). Early and Periodic Screening, Diagnosis and Treatment Program Performance Indicators -- INFORMATION (Memorandum # FPC-411). Washington, D.C.: Author.

Zeller, D. (1986). Demography: Real Numbers -- Real Changes. In C. Moore (Ed.), *Reaching Out: Proceedings from a Special Education Symposium on Cultural Differences and Parent Programs* (pp. 5-28). Eugene, OR: Western Regional Resource Center. (ERIC Document Reproduction Service Number ED 284 408) (Available from ERIC Document Reproduction System, 3900 Wheeler Avenue, Alexandria, VA 22304.)

arcfacts
Association for Retarded Citizens

April 1991

The Importance of Friendships Between People With and Without Mental Retardation

by Zana Marie Lutfiyya,
Center on Human Policy

Why are friendships between people with and without disabilities important?

Friends are important for several reasons. They support each other emotionally, are willing to see things from the other's point of view and provide assistance and feedback when needed. Friends choose each other and remain close through good times and times of crisis. They provide companionship for community and school activities and help each other enjoy new experiences and appreciate life more fully. Friendships between people with and without disabilities usually enrich the lives of both.

When should friendships begin?

If people with mental retardation are to form friendships and be a part of society as adults, these relationships must develop during childhood. Classmates and neighbors will grow into adult coworkers and friends later in life.

Therefore, integrated classrooms and recreational activities are important. In these settings children with and without disabilities get to meet each other and form relationships. Unfortunately, many parents have found that even though their children are integrated in school, they have few nondisabled friends.

What makes the development of relationships difficult?

Many individuals with disabilities interact primarily with their family, the people who take care of or provide services to them, and others in the programs in which they participate. These relationships can clearly be significant and should be encouraged. However, outside of family members, people may have no freely given and chosen relationships.

Generally, many people with disabilities face certain disadvantages in meeting and getting to know others.

Opportunity. Many people with disabilities have limited opportunities to take part in activities where they can meet peers. This may be due to physical segregation or being placed in a role as "client" or "special education student." Services may restrict people's chances to get together, through program or funder rules, curfews, transportation restrictions, and other limitations. Whatever the reason, people with disabilities frequently become cut off and isolated from others.

Support. Relationships between people with and without disabilities are not formed by simply grouping people together. Some individuals need assistance with fitting into certain settings and activities. Others may need someone to facilitate their involvement or to interpret for them. Without supports, some people with and without disabilities may never have the opportunity to know each other.

Continuity. While most people enjoy meeting new people, they are sustained by those they have known over time. The continuity of relationships over the years is an important source of security, comfort and self-worth. Many people with disabilities do not have continuous relationships. Instead, they may leave their families, be moved from one program to another and have to adjust to staff people who come and go.

What are some of the ways to facilitate personal relationships between people with and without disabilities?

It takes effort to help people establish connections. Described below are some of the ways this has been tried:

"Bridge-Building." Facilitators who initiate, support and maintain new relationships are called bridge-builders, as they "...build bridges and guide people into new relationships, new places, and new opportunities in life" (Mount, et al., 1988). Bridge-builders involve people with disabilities in existing groups or with specific individuals.

Circles of Friends or Circles of Support. Groups of people who "meet on a regular basis to help a person with a disability accomplish certain personal visions or goals" (Perske, 1988). Circle members try to open doors to new opportunities, including establishing new relationships.

Citizen Advocacy. Recruited and supported by an independent citizen advocacy office, a citizen advocate voluntarily represents the interests of a person with a disability as if the interests were the advocate's own. Citizen advocates may take on one or several roles (e.g., friend, ally, mentor, protector), and some of these may last for life.

There are different ways that personal relationships between people with and without disabilities may be encouraged. Perhaps more important than the specific method is the supporting, connecting role of one or more people (family members, staff members, friends, neighbors, etc.) who can spend time and energy for this purpose.

What are some important dimensions of friendship?

Genuine friendships between people with and without disabilities do exist. While each friendship is unique, there are some shared ideas and expectations about what friendship means. According to a recent study of pairs of friends (Lutfiyya, 1990), these meanings include:

Mutuality. The people defined their relationship as a friendship and themselves as friends. Although they acknowledge differences between themselves, they clearly found a sense of mutuality in the friendship. Mutuality was expressed in the giving and receiving of practical assistance and emotional support, and enjoyment of each other's company.

Rights, Responsibilities, and Obligations. Once a friendship is established, it is assumed that friends can make certain demands of each other and be assured of a response. Nondisabled friends talked about the obligations that they had assumed for their friend with a disability, such as teacher, mentor, caretaker, or protector. The friends with disabilities assumed certain responsibilities in maintaining the relationship such as keeping in touch or suggesting possible activities.

Feelings, from Companionship to Intimacy. All of the friends held feelings of affection for each other, expressed through their interactions with each other.

Freely Chosen and Given. Friends choose each other. It is this voluntary aspect of friendship that is regarded as the "amazing and wonderful" part of the relationship.

Private and Exclusive Nature. Within the boundaries of each friendship is a private relationship that is inaccessible to others. The friends have a history and an understanding of their connection to each other that separates this from all of their other relationships.

What can families and service providers do to enhance opportunities for friendships?

People can establish friendships with each other, but it is not possible to force friendships upon others. It is possible to create opportunities for people with and without disabilities to meet and share time with each other in ways that encourage friendships to take root and flourish. Families and service providers can do different things to make such opportunities available.

Families can:

Work for the total inclusion of their son or daughter into the regular school system. In addition to being physically present, students with disabilities need adequate supports to enable them to fully participate in classroom and school activities. Parents can also ensure that their child with a disability takes part in a variety of integrated recreation and leisure activities after school hours. A consistent physical presence in each others' lives helps lead to friendships between children with and without disabilities.

Ensure social participation. How people with disabilities are supported within integrated settings is important. Students need to be enabled to participate as much as possible, and to do so in ways acceptable to other people. People without disabilities need the opportunity to meet their counterparts with disabilities as peers, not as objects of tutoring or volunteer service.

Involve and trust others. All parents feel protective toward their children. While there may be differences in how independent people can become, parents can come to believe that there are people in the community who would, if given the opportunity, enjoy and welcome a friendship with their son or daughter.

Service providers can:

Reduce barriers to friendship. The way in which support services are provided to people with disabilities and their families can enhance or reduce the opportunities for friendships to develop. Segregated programs dramatically lessen the chances for contact between people with and without disabilities.

Even in integrated settings, students with disabilities may not be able to take part in extracurricular activities (e.g., choir, clubs, sports) because of lack of transportation from school.

When efforts are made to bring people with and without disabilities together, the people without disabilities are often treated as volunteers responsible to the teacher or program coordinator rather than as peers.

Encourage people who seem to like one another to pursue friendships. Service providers can review practices, such as curfews, lack of privacy and so on, which limit opportunities for people to meet and form friendships with each other.

With an awareness of and commitment to facilitating friendships between people with and without disabilities, all people can have the opportunity to form relationships which allow them to live life more fully.

SOURCES FOR MORE INFORMATION

Lutfiyya, Z.M. (1990). Affectionate bonds: What we can learn by listening to friends. Syracuse, NY: Center on Human Policy.

Lutfiyya, Z.M. (in press). Personal relationships and social networks: Facilitating the participation of individuals with disabilities in community life. Syracuse, NY: Center on Human Policy.

Mount, B., Beeman, P., and Ducharme, G. (1988). What are we learning about circles of support? Manchester, CT: Communitas, Inc.

Mount, B., Beeman, P., and Ducharme, G. (1988). What are we learning about bridge-building? Manchester, CT: Communitas, Inc.

O'Connell, M. (1988). The gift of hospitality: Opening the doors of community life to people with disabilities. Evanston, IL: Community Life Project.

Perske, R. (1988). Circles of friends. Nashville, TN: Abingdon Press.

Wolfensberger, W. (1975). Citizen advocacy for the impaired. In D. A. Primrose (Ed.), Proceedings of the Third Congress of the International Association for the Scientific Study of Mental Deficiency (pp. 14-19). Lorbert, Scotland: IASSMD, Royal Scottish National Hospital.

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THOUGHTS AND REFLECTIONS ON PERSONAL ASSISTANCE SERVICES: ISSUES OF CONCERN TO PEOPLE WITH MENTAL RETARDATION

by
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> *Everybody in this world today needs support of one kind or another. People need support to go ahead and do things whether this support comes from a good friend, parents, a social worker or guardian. There is no person so independent that they don't need anybody. We all need support, but with that support people don't want someone coming in and taking over their lives.*
>
> Michael J. Kennedy, 1990

As eloquently explained by Michael Kennedy, who lived over fifteen years of his life in institutions, all of us need support, which may at times, come in the form of paid services. This essay will explore several issues related to personal assistance (also known as support services), including the need for further discussions directly with people with mental retardation about their perspectives and viewpoints.

This essay draws primarily on our experiences in over 25 states in the US on how support services might be organized to better assist people with mental retardation in their efforts to lead fulfilling community lives. It particularly builds on the relatively new perspective that all adults, no matter how severe their disability, can live in typical homes in the community, if adequate support services (such as personal assistance) are made available.

What do people with mental retardation or others in the field of developmental disabilities know about personal assistance?

Generally, I have found that people associated with the field of developmental disabilities across the US, whether individuals with disabilities, family members, direct service staff, or administrators, often shared one or more of the following views regarding personal assistance:

First, many people simply had not heard the term personal assistance. Even if obtaining or using similar types of support services, these services may be described in different language (e.g., follow-along staff, come-in staff) and are often agency-controlled. Even state and local administrators in the field of mental retardation may know relatively little about the generic personal assistance system in their states.

Second, those who know about or who use personal assistance, typically view it as a service to assist people who have physical disabilities with such daily activities as going to the bathroom or eating. Most people with mental retardation do not see this concept as applying to their lives, unless they also happen to have a physical disability.

Third, the term personal care is used in some states in the field of developmental disabilities to refer to a funding stream that supports group homes (i.e., agency facilities) and traditional foster care (i.e., where a person with a disability resides in the home of another), thus bearing little resemblance to personal assistance as a user defined and determined service.

How is personal assistance defined?

In practice, personal assistance in most states appears to be defined very narrowly. Often people with mental retardation seem to be excluded from the generic options in a state, being referred back to the mental retardation/developmental disabilities service system, which is considered more appropriate to fit their needs.

A broad definition of personal assistance could include many of the types of assistance typically used by people with developmental disabilities. For example, personal assistance is:

> Whatever a person needs to live fully within the community (as defined by the individual), to ensure dignity, self-determination, respect and full participation, throughout her or his lifespan.

This could include personal services, such as assistance with dressing; assistance with self direction, safety and decision making (if desired); assistance with a variety of daily activities, including eating, cooking, shopping, working, transportation, leisure, speaking and reading, medications and health needs.

What aspects of personal assistance are particularly of relevance for people with mental retardation?

People with mental retardation have been traditionally confined to life in agency facilities, if they needed intensive support services. They are also often viewed as not being able to speak for themselves, and instead representatives, who usually hold different perspectives, have spoken for them. (This is part of my own discomfort in writing this essay.)

With both the growth in the self advocacy movement internationally, including the 1991 election of a national (US) self advocacy steering committee, and a movement toward supporting people to live in their own homes, this is beginning to change. However, organizing around personal assistance offers at least four important opportunities.

User definition and determination of services.

Personal assistance services are typically user defined and determined. In contrast, most services for people with mental retardation assume that the agency or others knows best. In fact, our review of the literature on choice, indicates that people with cognitive

disabilities are usually presumed in practice to be incompetent to make their own decisions. If making values decisions in conflict with prevailing norms, they are in particular jeopardy of social control.
Personal assistance services, including the option to hire, fire, and manage attendants (with support, if desired or legally required), can help to shift the decision-making power back to people themselves, placing agencies again in their proper supportive role. While the option must be available for people to choose to obtain assistance with coordination of personal assistance services, such an option should be available regardless of a person's disability label. A good example of an organization that is assisting people with developmental disabilities to work with their staff is Options in Community Living in Madison, Wisconsin.

The person with a disability as expert.

Users of personal assistance have strongly held that training should be done by the person with a disability, with the underlying premise that each person is unique. Since training in the field of developmental disabilities has been moving toward competency based training, irrespective of the individual, this aspect of personal assistance philosophy may help to stem the trend in this direction. People with mental retardation are not even regularly involved in prevalent group based training, and there is still resistance in some circles, to even having people participate in their own service planning meetings.

Personal determination and family empowerment.

Family empowerment has rightfully become recognized, and family support programs are now available in virtually every state. These programs, however, are typically constructed from the parental point of view (i.e., relief of the "burden" of caring), and seldom take into account the perspectives of the children. As one person I interviewed recently said,

> This is practically heretical to say at this point in this state, but I happen to know there are a substantial number of people who are probably living at home who do not want to be there...I worry that we are supporting families to the point that..we are encouraging behavior that is not fostering growth and independence in people with disabilities.

Several critical issues of concern to people with mental retardation, and I believe to all disabled people, revolve around children's rights and the rights of adults to determine their own destinies. Discussion about making personal assistance available for children, instead of thinking about the service as respite for caregivers, is still not occurring, even though the concept itself is sound and has been around for many years. The idea of helping people maintain the natural "breaks" from each other that typically occur as a child grows up is not part of the way people typically think about family support, instead taking a specialist approach (e.g., converting recreation to recreational respite).

Informal or paid services.

In the field of developmental disabilities, there is a growing interest and acknowledgement of the important role that friends, neighbors, coworkers, and other community members can play in the lives of people with disabilities. While an important development, the new assumption seems to be that it is better to use natural, informal supports and concomitantly, that services will not be provided until the informal options are exhausted.

While there are many positive aspects of this rediscovered interest in relationships (see for example, Judith Snow's account), the general trend appears to be headed in a direction opposed to the personal life experiences of people in the independent living movement. Most people with disabilities want the option in place of having paid services, and then themselves choosing whether to involve family, friends or others in personal assistance services. In the field of developmental disabilities, it is the agency that typically is doing the choosing and playing a major role in deciding how formal services can be replaced by informal supports.

What are issues that are not currently well addressed in personal assistance designs?

These issues fall under two major categories: those that apply to people across all disability groups, and those that may be of particular importance to people who need assistance with choices and decision making.

Common flaws in existing personal assistance services.

In a number of different states, we have worked with people with mental retardation and their allies to try to access generic personal assistance services to support people to live in their own homes. We experienced the following common problems, all well known to PAS users:

- limited availability of assistance compared to the needs of an individual;
- low wages and benefits (or lack of benefits) for attendants;
- inadequate or nonexistent back up systems, which leave people with disabilities stranded;
- control of some personal assistance systems by home health agencies;
- rigidity in how and where assistance is made available;
- inadequate funding within the states for this option compared to the needs;

- the medicalization of this option and the continued referral of people to options such as nursing homes, if they have need for more intense support services.

As one example of these myriad problems, Michael Kennedy explained one of his experiences in trying to keep the same work schedules as other people in his office:

> Aides' hours need to change when a person's schedule changes, which is often a problem for the aide service offices. They are not used to having someone whose schedule changes, and it can create a problem for the agency. I ended up needing to have set hours (at work) instead of changing the hours around because the aide service didn't allow for flexibility or arrange for backups when aides were sick.

Michael said while the situation in New York State was difficult, in states such as Georgia, it was practically impossible.

Personal assistance and decision-making support.

Personal assistance designs have not always taken into account the needs of people with mental retardation for support with decision making. Much greater discussion is necessary about the role of allies and supporters, and how assistive decision making can occur, still retaining the people first orientation of the independent living movement.

Choices and decision making are very complicated issues, and many people have not had opportunities to exercise even basic choices about their daily lives. The rhetoric of choice has also been used to justify neglect; and in the opposite vein, the need for support in decision making has been used to justify full guardianship and together with that, procedures such as sterilization.

Setting up a flexible personal assistance system will also be of benefit to people with mental retardation. For example, the option needs to be available to have choices to manage one's own personal assistance; to share responsibilities with an agency or other person selected by the person with a disability; and or to have another, whether an individual or organization, perform all these functions.

What about the issue of entitlement or cash subsidies for people who need assistance with decision making?

Entitlement or cash subsidies paid directly to the person with a disability are critical in a number of ways. Compared to a voucher that flows through an agency, such an approach removes some of the cost of asking for help, enables people to plan the use of financing on a long term basis, and removes some of the social control exercised through the requirement of worker involvement.

People who desire assistance with decision making should still have the option to obtain such support. Most people with mental retardation who need support with money management already have mechanisms in place or that can be put in place, such as payeeships or caseworkers. Instead of using the need for support as a rationale to force worker or agency control, entitlements and cash subsidies offer an important opportunity to rethink the current systems of case management and payeeships that typically allow for little input by people with disabilities.

What are some fears of professionals and advocates in the field of developmental disabilities?

Since discussions about personal assistance often take place with representatives of people with mental retardation, it is important to recognize some of the fears of professionals and advocates in the field of developmental disabilities.

The fight over who knows what is best for people with mental retardation.

Though this will not be publicly acknowledged, one of the deepest fears is that people with mental retardation will not have an equal voice in any coalition with groups such as people with physical disabilities. In other words, people in the developmental disabilities field view themselves in a better position to listen to, support, and encourage people with mental retardation to come into their own. Regretfully, this ends up at times, taking another form of protectionism.

However, these fears are not totally invalid. People with mental retardation have often been on the bottom of a disability "pecking order" and the wording of the Americans with Disabilities Act (ADA) itself indicates their marginality in the movement. Also, the growing self advocacy efforts have often been and are still most supported by people who are in some way connected with the developmental disabilities systems.

Integration of people with mental retardation into an inadequate service system.

Personal assistance systems have been tenuously constructed in most places, with many problems besetting stability, flexibility, security and quality. People involved in the field of developmental disabilities generally do not wish to simply see people with mental retardation participate in such inadequate systems, and yet also do not view it as their role to help with the changes that would be necessary to improve these efforts. Expanding the role of the ILCs will not be adequate to address the challenges. Systems aspects, such as having a city emergency backup aide service, are not even known as options among developmental disability agencies, who instead are moving toward developing their own specialized systems.

Rights versus mutuality.

One important area of concern in the field of developmental disabilities is that rights cannot and will not insure that people will have a good quality of life. As one ally described, "people are dying with their rights on." This is an area of mutual concern with people in the independent living movement, yet meaningful discussions about the kind of society we are hoping to achieve (e.g., a power reversal or a more mutual way of coming together) and the relationship between self-determination and mutuality, are seldom taking place.

Where can we go from here?

This essay introduces some issues for further discussion. I believe such grassroots discussions are necessary if we are going to have fundamental change at the local level as well as a political victory in creating a civil right to personal assistance. To further pursue these efforts, we can work together to:

* Create more opportunities for exchange, such as ADAPT's recent workshop on personal assistance, at the national self-advocacy conference.

* Seek opportunities to include people with mental retardation as part of national discussions on personal assistance, instead of relying on organizations with other, sometimes competing interests, to speak for people.

* Overcome the language barriers between different disability groups by describing better what we mean when we use words such as independence.

* Seek common issues to organize around. One good example is the issue of the nursing practices acts which have been problematic in several states for people to live in their own homes; another issue is the use of fire codes and requirements that may prohibit people from living in their own places.

Personal assistance, like housing, offers one visible opportunity for people to come together in creating some of the changes that can lead to better community lives for all of us.

REFERENCES

Center on Human Policy. (1989, December). In support of adults living in the community. Syracuse, NY: Author.

Heumann, J. E. (in press). A disabled woman's reflections: Myths and realities of integration. In J. A. Racino, P. Walker, S. O'Connor, & S. J. Taylor, Housing, support and community: Emerging strategies for supporting adults with disabilities. Baltimore: Paul H. Brookes Publishing Co.

Johnson, T. (1985). Belonging to the community. Madison, WI: Options in Community Living

Kennedy, M. J. (in press). "Turning the pages of life." In J. A. Racino, P. Walker, S. O'Connor, & S. J. Taylor, Housing, support and community: Emerging strategies for supporting adults with disabilities. Baltimore: Paul H. Brookes Publishing Co.

Litvak, S., Zukas, H., & Heumann, J. E. (1987). Attending to America: Personal assistance for independent living. Berkeley: World Institute on Disability.

Nosek, M. A. (1990). Personal assistance services for people with mental disabilities. Houston: Baylor College of Medicine, prepared for National Council on Disability.

Pierpoint, J. (1990). From behind the piano: The building of Judith Snow's unique circle of friends. Toronto: Inclusion Press.

Racino, J. A., O'Connor, S., Walker, P., & Taylor, S. J. (1991). Innovations in family support. Unpublished confidential research report.

Taylor, S. J., Racino, J. A., Knoll, J. A., & Lutfiyya, Z. (1987). The nonrestrictive environment: On community integration for people with the most severe disabilities. Syracuse, NY: Human Policy Press.

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Reflections on Relationships Between People with Disabilities and Typical People

> "Basically we should look at how we live--the different relationships we have, the choices we make, and so on--and aim to ensure that our friends with handicaps have the same sort of fulfilling lives we have.
>
> - Nicola Schaefer

Common Experiences of People with Disabilities

It seems trite to assert that people with disabilities possess the desire and need for relationships with other human beings. Don't we all? Yet at a recent training session with the staff from a residential program, the lack of relationships in the lives of people with disabilities was clearly pointed out. Thinking of the people they worked with, the staff determined that none had "best friends." A few of the residents could claim one or two "close friends" while two enjoyed warm ties with their families. All of the residents knew half a dozen or so "acquaintances" with whom they maintained casual contact. The majority of the people the residents knew were staff, other residents, and the people with whom they conducted the daily business of their lives; doctors, dentists, shopkeepers, and so on.

Most human service programs (schools, residences, workshops, recreation programs) effectively set up barriers between people with disabilities and most people in their community. Surrounded by paid staff and others receiving the same services, people with disabilities are made into "clients," "service users," or "program participants." Family connections may be ignored or broken. Friends may be discouraged from keeping in touch. A person's history can be lost merely by entering a residential program. Such occurrences are not infrequent. They take place so often that they form a pattern--the "normal" existence for people with disabilities.

It doesn't have to be this way. Some people with disabilities are well-loved, treated with respect and encouraged to remain connected with their families, typical peers, and people they have known in the past. However, it is important to recognize some of the other dynamics that exist in the lives of people with disabilities.

"Us and Them": Being Seen as Different

The heart of this matter lies in how most non-disabled people view their counterparts with disabilities. Over time our society defined people with disabilities as somehow different than the rest of us, and in need of specialized care. The view that individuals with disabilities are in some ways essentially different from the rest of us results in several types of experiences. People with disabilities are separated from their families and communities, cast into roles of dependency and passivity, and even when physically present in some community settings, are kept at a social distance from the other members of the community.

Separation

The pattern of the historical removal of people with disabilities from our society is well-documented. Large numbers of individuals were placed into large congregate-care facilities for the avowed purposes of education and training, medical care, family relief or social control of unwanted segments of the population (MacMillan, 1977; Scheerenberger, 1983; Wolfensberger, 1977). Some concentrated efforts were also made to sterilize certain groups to prevent their propagation and also to kill them outright (Lusthaus, 1985; Wertham, 1973).

The enforced segregation of people with disabilities from the daily life of their communities reinforced the belief that some people are so different that they cannot fit in or successfully contribute to their society. Typical community members lose the chance to meet, get to know, and be with individuals with disabilities. The opportunities for people in both groups to grow up together, and form attachments with each other are often lost.

Clienthood

By entering a program, most people with disabilities are turned into "clients." During this process, a person is cast into a dependent and passive relationship with the staff and other caregivers. When the client role becomes life-defining, the person can become lost and emphasis is placed on the person's deficits. Teachers, doctors, therapists and other workers are hired to correct the problems seen as inherent in the disabled person.

As a "client," a person learns to show the acceptable behaviours at the right times in order to get by. Consider the following incident. The author recently met two young women who shared an apartment and received support from visiting staff people. The women set up menus, bought food, and cooked the meals, all with the staff's onlooking approval. Once left to their suppers, the women would throw out these meals and prepare the food that they wanted to eat.

Given the above dynamics, it is not surprising that there is little mutual respect found in many relationships between program staff and clients. As part of their jobs, the staff attempt to control the lives of their clients, who in turn try to maintain some control over their own lives. While the staff may define the client's behaviour as manipulative, self-destructive and so on, they in turn may view that staff as capricious, inconsistent or simply out to get them (Bogdan & Taylor, 1982; Lovett, 1985).

A common part of any client's life that is under the control of staff people are the individual's contacts and relationships with others. Both children and adults with disabilities may be restricted from visiting their families or friends, from developing relationships with others.

Being a client can create barriers in the development of reciprocal and nourishing relationships with others. Through rare or a complete lack of opportunities, people with disabilities become slowly desperate for connections with others that are not governed by control (McGee, Menousek, & Hobbs, 1987). As virtually all people served by human services agencies are "clients," the area of relationships between people with disabilities and typical citizens needs to be addressed.

The People In Our Lives

Most of us take the notion that humans are social beings for granted and are surprised to learn that others may not have the same range of friends, family, and acquaintances as we do. Most of us would agree that there are degrees of closeness or intimacy across our own relationships. We acknowledge intimates or "best friends" as those few people who are closest to ourselves--at least in terms of understanding and support. They are the ones we can turn to, in any situation. Next come our friends, and then acquaintances--friends of friends, people who are not strangers. We "know" this latter group, but not well. Finally are the numerous people whom we see regularly, but for specific purposes; the postman, doctor, shopkeeper and so on.

Developing and Maintaining Relationships

Helping someone to meet people and make friends can be difficult. Formal, programmatic efforts to do so contradict our society's notion of how relationships are formed. We do not think of ourselves as reliant upon arranged marriages, strict kinship obligations, or planned introductions between people who might be "good for one another." The possible exception to the latter case are potential business associates, where purely utilitarian needs are considered appropriate.

Arranged introductions seem an artificial and heavy-handed way to establish relationships. And yet, some human service providers are attempting to do just this in order to surround people with disabilities with a number of friends and close ties. These efforts are made in order to overcome the barriers that prevent more naturally occurring relationships from taking place. Despite the obstacles, it cannot be denied that warm, reciprocal relationships between typical people and those with disabilities exist (Bogdan & Taylor, 1987b; Strully & Strully, 1985; Taylor & Bogdan, 1987). Along with the growing recognition of the importance of such relationships are human service staff hired to "build-bridges" between people with disabilities and typical people (Bogdan, 1987; Johnson, 1985; Walker & Salon, 1987).

Both popular wisdom and the literature on this subject suggest several factors that may be involved in the development and maintenance of relationships. What is still not resolved is precisely how these factors are related to each other and their impact upon individuals.

Some Qualities and Dimensions of our Relationships

It appears that at least six characteristics experienced by typical people in their efforts to meet others and develop relationships may not be as available for people with disabilities. These qualities of our relationships include opportunity, diversity, continuity, relationships that are freely chosen and given, and intimacy.

Opportunity

Typical people can take advantage of numerous opportunities to meet and get to know other people. We meet others through our families, neighbours, school/workplace, cultural, civic, and recreational events, church, synagogue. We also come into contact with innumerable individuals simply in conducting our daily affairs--buying food, getting the car fixed, taking care of our health needs, hair cut, mail received or sent. In our western culture, it requires effort to avoid meeting new people.

For many people with disabilities, such opportunities are simply lacking, and they possess extremely limited opportunities to take part in activities and events where they can meet their typical peers. We read of adults who did not know what rain was (Rothman & Rothman, 1985), or a woman who had never sat by a lighted fireplace (Bogdan & Taylor, 1982). And even when people with disabilities may be physically present in a community, a variety of circumstances conspire to keep them apart from their neighbors (for example, program rules and restrictions, transportation, poverty).

Support

Providing adequate opportunities for people with disabilities to meet and interact with valued citizens in positive ways must be the first step towards the building of meaningful relationships. Hand in hand with these opportunities must be adequate support for both the person with disabilities and the typical people involved. One woman wanted to go to church, as she had not attended since she was a child. A church of the right denomination was located, the priest contacted, and a parishioner agreed to sit with Helen during Mass and accompany her to the coffee hour afterwards. For Helen, this effort was not enough. She did not know how to behave in church, and smoked cigarettes, talked, and swore during the service. Not surprisingly, the parishioner became uncomfortable sitting next to Helen, and soon stopped coming to pick her up. Helen needed someone comfortable enough to direct her actions quietly while in church--suggest going out for a smoke, or waiting, being quiet. Initially, a staff person sensitive to Helen's need to attend church and to the limits of appropriate behaviours might have made the difference, by minimizing disruptions, allowing Helen to attend church and meet others in the congregation. This staff person could then encourage a member of the congregation to support Helen, in the hope that a friendship would develop. Enhancing relationships between people with disabilities and typical citizens is not accomplished by throwing unprepared and unsupported individuals together.

On the other hand, support, instruction, and guidance must never be confused with restricting a person's opportunities to meet and form ties with other people.

Human service programs have historically controlled and limited the opportunities available to individuals with disabilities.

Diversity

At a party once, one man suggested that even with only ten people in the room, one of us would know someone who came from, or have been ourselves, to virtually any country in the world. The first skeptic named Borneo only to learn that one woman's Malaysian secretary was born on the Island of Borneo. A coincidence perhaps, but if we stop to think about it, we know an incredibly diverse range of people with differing backgrounds, interests, jobs, education etc. Although we may not choose to associate with, or become close to everyone we meet, we have the opportunity to select our friends from a large number of very different people.

Unfortunately, the same cannot be said of many people with disabilities, especially those who were raised apart from their families and neighbourhoods. People served in both institutional and community-based settings may experience little contact with people other than fellow clients and staff people. Along with increased opportunities for people with disabilities to meet typical citizens must come the support to get to know a variety of individuals.

As we introduce people with disabilities to more people, we must also give up some of our control over their lives. The excessive control that human service staff now exercise over their clients would be socially inappropriate in the types of relationships that we wish to encourage. We must constantly discern the line between adequate support, guidance and protection and the over-protection that unnecessarily restricts a person in his/her movements and associations.

Continuity

Many of us thrive on opportunities to meet new and interesting people. But as we continue to meet new people, we are sustained by those we have known for a long time. The continuity we experience in some of our relationships over the years is an important source of security, comfort and self-worth. Human beings learn to trust each other within long-term, stable relationships (Maslow, 1954; McGee, Menousek, & Hobbs, 1987).

Many people with disabilities do not enjoy the same continuity in their relationships. Children may leave their families for foster care or residential education programs. Staff people, social workers and case managers can come and go frequently, causing disruption in a person's life. Wolfensberger (personal communication, mid 1970s) likens many people's experiences to a "relationship circus" where staff and professionals dance in and out of a person's life, each in turn demanding instantaneous trust from the person with disabilities. An observer in a supported apartment program learned that her five months observation gave her some seniority over most of the support staff (Lutfiyya, 1987).

The service providers who surround people with disabilities must learn to support and not to stand in the way of long-standing relationships of the people they serve. Assisting people to stay in touch is essential. Letters may need to be written and read, phone numbers dialed, transportation provided. Helping a person to remember birthdays, anniversaries and other important occasions are ways to maintain ties. Some people may need help to remember and cherish the history of their connections with others. Some individuals may need assistance during a visit or social event with a friend or relative; such as how to be a gracious host (or guest), how to carry on a conversation, or observe other social graces.

Freely Given and Chosen Relationships

For the most amazing reasons, others like us and love us because they want to. Our spouses, lovers, and friends all choose to be with us and we choose them. We are surrounded by people who accept, love and tolerate us and we do the same for them. When this is not the case, we think that something must be wrong somewhere, and seek to rectify the situation. Popular culture and our books of wisdom assert that this is as it should be.

Many people with disabilities enjoy few close relationships with others, and even fewer unpaid relationships (Johnson, 1985). The main source of relationships for a lot of people with disabilities are their families, program staff and other clients. Given the lack of opportunity and support to meet people in the community this should not surprise us. Yet it can be difficult to appreciate what life is like for people who know no single person who spends time with them because they want to, not because they are paid to do so or are involuntarily placed in the same setting.

Too many human service program practices prevent freely-given relationships from developing. This includes practices such as requiring someone to become an official agency volunteer, attending a training course before meeting the clients, restricting visiting times and placing the typical people in positions of control. When freely given relationships do occur, human service agencies often deny the importance of the relationship. One young woman met a three year old girl living in a children's rehabilitation hospital. Abandoned at birth, Rose lived with several debilitating physical conditions making some movement and handling painful. The woman visited Rose, read her stories, sang songs, rocked her to sleep. One week when Judy came to visit, she found another child in Rose's bed. Rose had died a few days earlier. When Judy, the woman questioned why she had not been contacted, and why no memorial service was planned, she was offered grief counselling. The staff also expressed surprise over Judy's attachment to Rose.

All of this is not to deny that some paid relationships are characterized by genuine warmth, caring and even love. But it is essential to recognize this quality in our relationships and its absence from the lives of many people with disabilities. Our goal must not simply be to introduce people to others, but to create the environment that will encourage typical members of our communities to voluntarily choose to form relationships with people whose lives have been marked by separation and loss. Human service staff hoping to support friendships between people with disabilities and typical community members can be direct in their efforts. They can ask themselves, "who seems to be interested in this person?"; "who likes this person?" and "who wants to spend time with this person?"

Intimacy

With its many meanings, the word intimacy may be confusing. It is used here as an expression of the closeness, comfort and trust that people may feel for each other. Intimates can express thoughts and feelings that they share with no one else. Despite the difficulties in determining how a person defines those s/he is "closest to", most people have (or aspire to) a few "intimates."

We are just beginning to recognize that many disabled individuals have no one with whom they share a close, intimate relationship. Some may claim such a connection with another, and find this closeness is not shared by the other person. It would be easy to interpret this "fantasy" as a result of the person's cognitive impairments. But if at least one intimate connection with another human being is vital for each of us, this "fantasy" may be necessary for the individual's functioning. There is no easy answer for those who want to support intimate relationships between people with disabilities and their typical peers. All humans struggle in their search for intimate connections with other people.

Learning from the Relationships of Others

Two themes emerge from a reading of the available literature on the development and maintenance of relationships between typical and disabled people. Often those engaged in the relationships do not see their involvement as unusual or worthy of note. They almost take the relationship for granted (Bogdan & Taylor, 1987b). Secondly, the reduction of barriers and the increase in identification between the two potential friends appears important in creating a mutually respectful relationship (O'Brien, 1987).

The Possibility of Relationships

It is important not to deny the history of any individual or of a group of people. We must never forget the generations of abuse and neglect visited upon people with disabilities, nor lose sight of the tragic pasts (and present circumstances) of the individuals with whom we work today. But we must also believe that a variety of accepting relationships between typical and disabled individuals are possible (McKnight, 1987). We must provide opportunities where people can comfortably come together to meet each other, and we must learn to recognize when we are standing in their way.

Increasing Identification

Through studying established relationships, we learn that both parties possess a mutual respect for the other. Partners also report a reciprocity in their interactions that may not be apparent to the outside observer. These feelings stem from a sense of identification between the two individuals. They come to see the "sameness" or commonalities between themselves and these serve as the basis of the relationship.

Bogdan & Taylor (1987b) suggest several bases of identification held by the non-disabled person that might account for their acceptance of people with disabilities. These include family ties, religious or humanitarian beliefs.

People involved in Citizen Advocacy (O'Brien, 1987; Wolfensberger & Zauha, 1973) attempt to create and support a variety of relationships between disabled and non-disabled individuals who live in the same community. They pay close attention to the process of increasing the identification of the two people with each other, especially when the commonalities may not be obvious.

Conclusion

A mark of real acceptance of individuals with disabilities in our communities can be found in the real relationships they enjoy with typical people. It is probably not possible to create such relationships despite the efforts of people in the human services to do so. However, the opportunities for disabled and non-disabled people to meet and interact can be increased and encouraged. The dilemma for human service workers is the recognition that their programmatic presence may in fact serve as a barrier to the development of the desired relationships.

References

Bogdan, R., & Taylor, S. J. (1982). Inside out: The social meaning of mental retardation. Toronto: University of Toronto Press.

Bogdan, R. & Taylor, S. J. (1987a). Conclusion: The next wave. In S. J. Taylor, D. Biklen, & J. Knoll (Eds.), Community integration for people with severe disabilities (pp. 209-213). New York, NY: Teachers College Press.

Bogdan, R. & Taylor, S. J. (1987b). Toward a sociology of acceptance: The other side of the study of deviance. Social Policy, Fall 1987, 34-39.

Boles, S. M., Horner, R. H., Newton, J. S., & Romer, L. (1985). The neighborhood living project: A community residential model for citizens with severe handicaps. Eugene, OR: Specialized Training Project, University of Oregon.

Forest, M., & Snow, J. (1983). The Joshua committee: An advocacy model. Leisurability, 10(1).

Johnson, T. (1985). Belonging to the community. Madison, WI: Options in Community Living and Wisconsin Council on Developmental Disabilities.

Johnson, T., & O'Brien, J. (1987). Carrying Options' story forward. Madison, WI: Options in Community Living.

Lovett, H. (1985). Cognitive counseling and persons with special needs: Adaptive approaches to the social context. New York, NY: Praeger.

Lusthaus, E. (1985). "Euthanasia" of persons with severe handicaps: Refuting the rationalizations. Journal of The Association for Persons with Severe Handicaps, 10(2).

Lutfiyya, Z. M. (1987). [Unpublished field notes]. Syracuse, NY: Author.

MacMillan, D. L. (1982). The mentally retarded in school and society. Boston, MA: Little, Brown & Company. (1st published in 1977).

Maslow, A. (1954). Motivation and personality (1st ed.). New York, NY: Harper.

McGee, J. J., Menousek, P. E. & Hobbs, D. (1984). Gentle teaching: An alternative to punishment for people with challenging behaviors. In S. J. Taylor, D. Biklen, & J. Knoll (Eds.), Community integration for people with severe disabilities. New York, NY: Teachers College Press.

O'Brien, J. (1987a). A guide to lifestyle planning. In B. Wilcox & G. T. Bellamy (Eds.), A comprehensive guide to the activities catalog. Baltimore, MD: Paul H. Brookes.

O'Brien, J. (1987b). Learning from citizen advocacy programs. Atlanta, GA: Responsive Systems Associates.

O'Brien, J., & Lyle, C. (1986). Strengthening the system. Atlanta, GA: Responsive Systems Associates.

O'Brien, J., & Lyle, C. (1987). Framework for accomplishment. Atlanta, GA: Responsive Systems Associates.

Perske, R. (1980). New life in the neighborhood: How persons with retardation and other disabilities can help make a good community better. Nashville, TN: Abingdon Press.

Perske, R. (1988). Friends circle to save a life. TASH Newsletter, 14(1).

Rothman, D. J., & Rothman, S. M. (1984). The Willowbrook wars. New York, NY: Harper & Row.

Schaefer, N. (1978). Does she know she's there? Toronto: Fitzhenry Whiteside.

Scheerenberger, R. C. (1983). A history of mental retardation. Baltimore: Paul H. Brookes.

Strully, J., & Strully, C. (1985). Friendship and our children. Journal of The Association for Persons with Severe Handicaps, 10(4).

Taylor, S. J., & Bogdan, R. (1989). On accepting relationships between people with mental retardation and nondisabled people: Towards an understanding of acceptance. Disability, Handicap & Society, 4(1), 21-36.

Taylor, S. J., Racino, J. A., Knoll, J. A., & Lutfiyya, Z. (1987). The nonrestrictive environment: On community integration for people with the most severe disabilities. Syracuse, NY: Human Policy Press.

Taylor, S. J., Biklen, D., & Knoll, J. (Eds.). (1987). Community integration for people with severe disabilities. New York, NY: Teachers College Press.

Walker, P., & Salon, R. (1987). Supporting people in the community: A case study of the residential support program--Centennial Developmental Services, Weld County, Colorado. Syracuse, NY: Center on Human Policy, Syracuse University.

Wertham, F. (1973). The German euthanasia program. Cincinnati, OH: Harps Publishing.

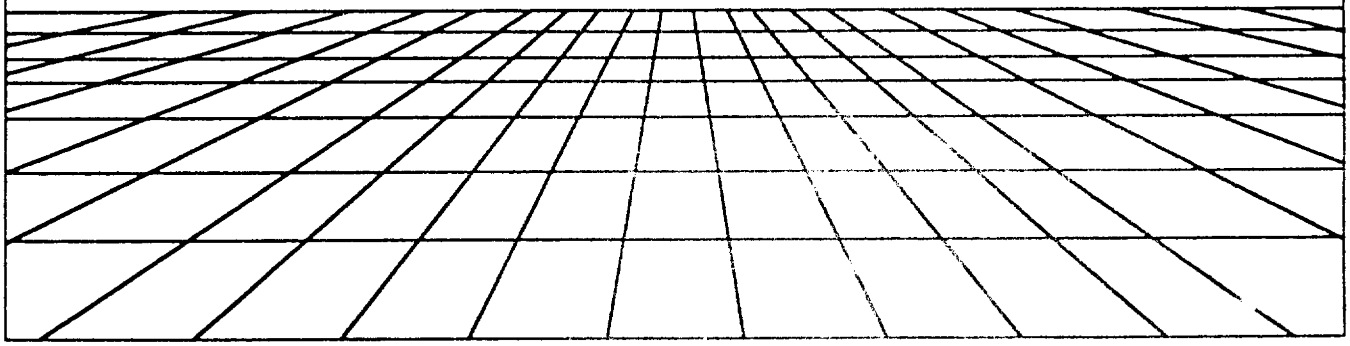
Wolfensberger, W. (1973). Program analysis of service systems, PASS (3rd ed.). Toronto: National Institute on Mental Retardation.

Wolfensberger, W. (1977). The origin and nature of our institutional models. Syracuse, NY: Human Policy Press.

Wolfensberger, W., & Thomas, S. (1983). Program analysis of service systems' implementation of normalization goals. Toronto: National Institute on Mental Retardation.

Wolfensberger, W., & Zauha, H. (Eds.). (1973). Citizen advocacy and protective services for the impaired and handicapped. Toronto: National Institute on Mental Retardation.

Beyond Awareness: Action Strategies for Promoting Cultural Diversity in the Developmental Disabilities Network



Produced by
The Multicultural Task Force in the
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RECEIVED
JAN 24 1992
Minnesota D.D.
Council

JAN 16 1992

Dear Colleague:

I am pleased to forward for your review a copy of the report entitled <u>Beyond Awareness: Strategies for Promoting Cultural Diversity in the Field of Developmental Disabilities</u> developed by the Multicultural Task Force during its September 21-24, 1991 meeting in Alexandria, Virginia.

The Task Force, sponsored by the Administration on Developmental Disabilities, was charged with designing a systemwide approach for promoting cultural diversity through the collaborative efforts of University Affiliated Programs, Developmental Disabilities Planning Councils, Protection and Advocacy Systems, and the many citizens we serve. The recommendations of the Task Force form the basis for the enclosed report.

As you are already aware, the Administration on Developmental Disabilities (ADD) has been historically committed to the promotion of cultural diversity in our field. To continue and further support this commitment, I have appointed Ray Sanchez, Director, Program Operations Division to serve as the ADD staff representative on the Task Force. In this capacity, Ray will continue to work with the Task Force to expand its membership to include consumers with developmental disabilities and to complete the tasks identified in the Report. The Task Force will serve as an advisory body to me and ADD on the progress of the Report's specific recommendations as well as on other broad issues related to cultural diversity in the field of developmental disabilities.

I enthusiastically support the report of the Task Force and I am confident that, together, we can move from awareness to action.

Sincerely,

Deborah L. McFadden
Commissioner
Administration on
Developmental Disabilities

Enclosure

PREFACE

From September 21-24, 1991, members of a task force convened by the Administration on Developmental Disabilities (ADD) worked toward the design of a systemwide blueprint for the promotion of cultural diversity among the numerous agencies, institutions, and groups supported by ADD. The Multicultural Task Force in the Field of Developmental Disabilities was broadly representative of the academicians, systems planners, and service organizations whose influence spans the universe of advocacy, education and training, clinical service, research, and technical assistance activities conducted throughout the nation. While individuals with developmental disabilities were not within the ranks of task force members, their presence was felt during the spirited debates, during small group brainstorming sessions, and during evenings spent with a note pad or word processor producing the nth draft for the morning review.

While members of the multiracial/multiethnic task force were unique in geography, professional activity, and programmatic approach, there was a shared commitment with the Administration on Developmental Disabilities that strategies must be articulated for promoting systemwide action based upon a growing awareness of the changing American demographic landscape. The recent accomplishments of model projects for the promotion of cultural diversity have generated ripples of excitement throughout the field and it was clear that the emerging paradigm of cultural diversity was rapidly maturing from Awareness to Action.

Task force members were divided into four working groups; 1) Statement of Principles; 2) Plan/Strategy for Awareness; 3) Dissemination Plan and; 4) National Conference Agenda. The Statement of Principles Working Group was charged with articulating the global statements which framed the rationale as well as the specific areas of programmatic activity to be impacted by the concept of cultural diversity. The Plan/Strategy for Awareness Working Group was assigned the task of identifying systematic steps for actively stimulating a greater commitment to cultural diversity among the agencies, institutions, and groups which comprise the ADD universe of developmental disabilities. The Dissemination Plan Working Group focused on the design of a systematic approach for identifying and transporting the tools for promoting cultural diversity (i.e., cultural awareness curricula) to those who will require the tools for implementing change in their particular environment. The National Conference Agenda Working Group was presented the challenge of developing a national forum for stimulating cross-fertilization and systemwide action among all participants in the field. An underlying premise for all Work Group activity was the shared commitment to stimulate collaboration among University Affiliated Programs, Developmental Disabilities Councils, and Protection and Advocacy Agencies.

What has emerged from those four days in September is a national plan for action, a national strategy which transcends awareness. We, the framers of this first national strategy, are graphically aware of the complexity involved in articulating a concept of cultural awareness and of the significant discussions and brave modelling efforts which must occur as we all proceed from awareness to action. But proceed we must.

John W. Mc Clain, Ph.D. & Mariellen Kuehn, Ph.D., Editors

BEYOND AWARENESS: ACTION STRATEGIES FOR PROMOTING CULTURAL DIVERSITY IN THE DEVELOPMENTAL DISABILITIES NETWORK

The Need

The reality of an American society in which racial and ethnic minorities are increasing in numbers and influence is becoming clearer each day. The message is transmitted through the media, through our crumbling education system, and within the corridors of our over-taxed and antiquated health and social service agencies. From the vantage point of the Developmental Disabilities Network, we see the consequences of poverty, of virulent to benign misunderstanding, and of apathy that are tragically concomitant with this rapid change in the new reality of the American social fabric.

The Challenge

The Developmental Disabilities Network does not reflect this new multicultural reality; not among faculty, not among our planners, not among our staffs, or our trainees, or our advocates. Part of the problem is our discomfort in disengaging with the familiar and the comfortable and our hesitancy to embrace a new paradigm in its embryonic stage. Some of us have taken a few small steps toward changing this reality and have timidly entered the realm of awareness. Our modest success have increased our commitment to spreading this awareness throughout the Developmental Disabilities Network. Yet, the urgency of the reality of a multicultural society demands that we must go beyond awareness. We must act.

Action Strategies

The purpose of this document is to provide the first of a series of blueprints for action, tools for promoting cultural diversity in the Developmental Disabilities Network (UAPs, DD Councils, P&As, etc.). It is the first step in a long new road which must be travelled aggressively but sensitively. As we gain confidence in travelling this new road, the future will become clearer and those who travel on the road will become more numerous.

The document is divided into four basic and interrelated components:

1) A Philosophy for Promoting Action;
2) A Plan/Strategy for Stimulating Action;
3) A Dissemination Plan for Identifying and Distributing Tools for Action and;
4) A Forum for Promoting Action within the Developmental Disabilities Network.

In their totality, they provide the means for collaboration among the three components of our Network (UAPs, P&As, DD Councils) as well as the impetus for going beyond awareness.

Statement of Principles

The University Affiliated Programs, the State Developmental Disabilities Planning Councils, the Protection and Advocacy Systems, and other related programs and agencies, must develop collaborative plans and service delivery systems that address the inclusion of all persons with developmental disabilities representative of all racial and ethnic minority groups. The training and service delivery system must be family-centered, community-based and culturally competent. A culturally competent training and service delivery system demonstrates honor and respect for the beliefs, interpersonal styles, attitudes, and behaviors of people with developmental disabilities and their families. It also reflects those values in policy, administration, training, and service.

1. WHEREAS, there are an estimated seven million American children and adults with developmental disabilities, including a large number who are members of racial and ethnic minority groups, and

2. WHEREAS, the Administration on Developmental Disabilities is a national leader in advocating for people with developmental disabilities and their families regardless of race, creed, color, religion, gender or national origin, and

3. WHEREAS, children and adults with developmental disabilities and their families who are members of racial and ethnic minority families have been historically and continue to be denied access to quality services, and

4. WHEREAS, members of racial and ethnic minority groups are markedly underrepresented among faculty and trainees, and the staffs of Developmental Disabilities Councils and Protection and Advocacy Agencies, and

5. WHEREAS, there is a growing commitment among all components of the ADD network to promote strategies for greater cultural diversity,

THEREFORE, BE IT RESOLVED that the ADD network, including University Affiliated Programs, Developmental Disability Councils, and Protection and Advocacy Agencies will collaborate in the design and implementation of action strategies which promote cultural diversity throughout the national ADD network.

BE IT FURTHER RESOLVED that the Administration on Developmental Disabilities will develop and implement specific plans which will promote the active participation of people of racial and ethnic minority groups currently underrepresented in the field of developmental disabilities.

A Plan/Strategy for Stimulating Action

Moving Beyond Awareness to creating an ongoing multi-cultural foundation within the Disability Network will require legislative changes, policy development and collaborative action-oriented programs. The foundation established must provide for inclusion of all persons throughout the system.

The cultural environments created must be firmly embedded through all core programs of the disability network. The ongoing impact and system outcomes from these efforts should be collaborative in nature and driven by the commitment to building a society that insures inclusion for all persons.

The following recommendations are made by the multicultural task force. These recommendations and strategies for action are based on four interrelated domains that will build the actions leading to program development to ensure participation and inclusion of all persons with multicultural backgrounds in the disability service system.

Participation and inclusion here defined refers to all aspects of the disability services system which includes consumers, councils and advocacy groups, direct service providers, interdisciplinary students and professionals and program and agency directors and administrators.

RECOMMENDATIONS

Legislation and Regulations

I. Establish coalitions with agencies and programs (eg. CCD, NADDC, P&As, UAPs, AAUAP, DD councils, AAMR, TASH, ARC, UCP, ADD, universities and other professional organizations and consumer groups) that may influence legislation and regulation affecting persons of diverse cultures and/or with disabilities in order to make changes in current legislation or initiate new legislation that assures inclusion of people of different cultures at all levels of the disability service system.

Timeline:

Ongoing -- reauthorization of each act.

Responsibility:

Lead responsibility -- AAUAP legislative coordinator and state UAP directors and administrators.

Implementation Strategies:

1. Identify disability, minority and training legislation (DD Act, Rehab. Act, Education, Health Care Professional Training, Area Health Education Consortium, Maternal and Child Health, Office of Minority Health, Health Career Opportunity Program, and Others)
2. Determine reauthorization process
3. Determine appropriations process
4. Identify and work with major constituents (eg. CCD, NADDC, P&As, UAPs, AAUAP, DD councils, AAMR, TASH, ARC, UCP, ADD, universities and other professional organizations)
5. Become familiar with multicultural lobby groups
6. Develop and present final legislative recommendations

II. Advocate for Senate hearings on the personnel training needs throughout the disability services system, assuring that specific issues and barriers confronting persons from multiple cultures are articulated and addressed.

Timeline:

FY92

Responsibility:

AAUAP, NADDC, P&A and UAP directors and administrators

Implementation Strategy:

1. Secure commitments and participation from House and Senate leadership.

Collaborative Capacity Building

I. Establish ongoing collaborative relationships with councils, P&As and other related agencies at the local, state and federal levels in order to share resources, implement policy, evaluate effectiveness of inclusion strategies, and develop long range plans to assure full inclusion throughout all levels of the services system.

Timeline:

FY92 -- Ongoing

Responsibility:

Agency and program directors and administrators

Implementation Strategies:

1. Establish interagency/multiple-agency working groups
2. Develop interagency mission statement
3. Develop and implement collaborative agreements

II. Allocate resources, reallocate existing resources and/or share new or existing resources in order to provide for participation and inclusion of all persons from different cultures in the disabilities service system. These resources must be adequate to insure commitment and quality program impact.

Timeline:

Immediate and ongoing

Responsibility:

All disability service agencies at the local, state and federal level

Implementation Strategies:

1. Identify existing resources across agencies and programs
2. Develop joint funded projects and activities
3. Implement and monitor interagency activity

Information Dissemination and Technical Assistance Clearinghouse

I. **Develop a system to support the implementation of inclusion policy and practices.**

Timeline:

Immediate and ongoing

Responsibility:

ADD, AAUAP and UAPs

Implementation Strategies:

1. Identify and evaluate effective models for inclusion.
2. Identify major initiatives and funding opportunities
3. Establish guidelines for developing outcome measures.
4. Develop a student and staff resource bank through exchange programs, mentoring programs and minority colleges and universities.

Personnel Development

I. **Establish personnel standards and implement training programs that are responsive to cultural environments and that incorporate current and emerging trends in the disability service system.**

Timeline:

FY93

Responsibility:

ADD and other state and federal agencies in collaboration with UAPs

Implementation Strategies:

1. Establish personnel training standards at the undergraduate and paraprofessional level
2. Provide opportunities for nontraditional students to enter into the system

3. Increase accessibility to interdisciplinary training at the undergraduate and paraprofessional level through nontraditional methods, such as community college programs, interactive video, etc.
4. Provide training opportunities for generic service providers.

A Dissemination Plan for Identifying and Distributing Tools for Action

Goal:

To develop a plan which includes a) the identification of target populations, b) the identification of content areas for which resources are needed to facilitate the recruitment and retention of faculty and trainees from diverse cultures and the inclusion of persons from diverse cultures in all of the planning, program, service, advocacy, and technical assistance activities of UAPs, DD Councils, and P&As, c) examples of resources available to address the identified content areas, and d) methods for dissemination of those resources through the provision of training (pre-service and in-service) and technical assistance.

Need:

The primary need to be addressed by the stated goal is the a) critical shortage of personnel at all levels of the planning, training, service, and advocacy systems designed to serve people with developmental disabilities and b) the need to create environments within the UAP, DD Council, and P&A networks that are actively responsive to the need for the inclusion of people from diverse cultures (with and without developmental disabilities) within the DD network.

Identification of Target Populations:

The target populations include: a) faculty and trainees, professionals, paraprofessionals, administrators, policymakers who are already employed within the health, education, social and advocacy service systems; b) volunteers within the DD network which includes people with developmental disabilities and their families and: c) organizations, both public and private, that have as their primary mission the provision of quality services for people with developmental disabilities and their families, organizations within the private and public sectors that provide health, education, and social services to all citizens within the U.S., and non-DD/non-service organizations, such as research institutes, institutions of higher education, and related professional associations. (See Table 1 for examples of the three types of organizations.)

Identification of Content Areas:

1) Tools to reduce prejudice and to enhance the ability of individuals to work collaboratively with people from diverse cultures at all levels of the DD planning, training, service, and advocacy systems.

2) Tools to promote the development of skills to provide direct services to people from diverse cultures.

3) Methods to recruit and retain faculty and trainees at UAPs, P&As, and other institutions of higher education that train professionals and paraprofessionals to work in fields that serve people with developmental disabilities. (See Table 2.)

4) Information that can be used to leverage resources for expanded training and research programs to address culture specific and cross-cultural issues related to the provision of services to people with developmental disabilities.

   (Note: Several bibliography lists were obtained during the meeting of the task force and with relatively minimal effort the Table 2 could be expanded to provide examples for each of the four content areas.)

Recommendations for Dissemination:

1) Identify training programs that are established to facilitate the reduction of prejudice and/or that provide knowledge about the values, beliefs, family orientation, child-rearing practices, and so forth of specific cultures and ethnicities within the U.S. These training programs would be viewed as a prerequisite to attend the regional training program discussed in recommendation #2 below.

2) Implement a regional training program for UAP, DD Council, and P&A staff on multi-cultural issues related specifically to people with developmental disabilities. It is recommended that the Multi-Cultural Education and Training Core Curriculum developed by Drs. Sam Chan and Marie Poulsen at the Children's Hospital Los Angeles UAP be the foundation for such a program.
   Such a regional training program would provide key leadership to further train professionals, paraprofessionals, administrators, policymakers, and volunteers working with people with developmental disabilities.

3) Develop a systematic method to identify resources (tools, methods, approaches) that are available not only within the AAUAP, NADDC, and NAPAS, Inc., systems, but those materials that have been developed by other organizations within the DD network, the private/public education, health, and human service agencies, and particularly those organizations that have as their aim the promotion of a specific culture, race, or ethnicity.

4) Implement a system to provide technical assistance to those organizations that are working to provide culturally-appropriate services, increase the number of faculty/staff that are available, recruit and retain trainees, develop model programs, advocate, or do state planning.

TABLE 1

EXAMPLES OF TARGET ORGANIZATIONS

	National	State
DD Organizations	AAUAP NAPAS, Inc. NADDC Epilepsy Foundation UCP ARC-USA	UAP DD Councils P & As Advocacy groups
Public/Private Provider Organizations in HHS	DEC NECTAS NABSW OSERS USPHS	Some School Districts State Public Health Depts. State Education Depts. State DD Councils or Depts. of Mental Retardation
Non-DD and Non-service Organizations	American Indians in Higher Education Cons. National Council LaRaza Maldef E-W Institute	LaRaza, etc. chapters Local Churches

TABLE 2

Examples of Practice Tools to Promote Skill Development

A. African American

Davis-Russell, E. & Long, C. (1990). Some Issues Regarding Work with African American Clients. The California Psychologist. Nov.

Randall-David, E. (1989). Black Americans. In E. Randall-David, Strategies for Working with Culturally Diverse Communities and Clients. Washington, D.C.: Association for the Care of Children's Health.

B. Asian American / Pacific Islander

Kobata, F. The Influence of Culture on Family Relations: the Asian American Experience. In The Asian American Experience.

Crystal, D. (1989). Asian Americans and the Myth of the Model Minority, Social Casework. The Journal of Contemporary Social Work.

C. Hispanic-Latino

Rogler, L. H., et. al. (1987). What Do Culturally Mental Health Services Mean? The Case of Hispanics. American Psychologist. 42 (6).

Grossman, H. (1983). What Counselors, Educators and Psychologists Should Know About the Hispanic Culture in Order to Work More Effectively with Hispanic Exceptional Students and Their Parents. (Executive Summary). San Jose State University: Department of Special Education.

D. Native American Indian

Southwest Communication Resources. (1990). Overcoming Obstacles and Improving Outcomes: Early Intervention Services for Indian Children with Special Needs.

O'Connell, J. (1987). A Study of The Special Problems and Needs of American Indians with Handicaps Both On and Off the Reservation. (Vol. 1). U.S. Department of Education: Office of Special Education and Rehabilitative Services.

E. Southeast Asian

Mueke, M. A. (1983). Commentaries: Caring for Southeast Asian Refugee Patients in the U.S.A. American Journal of Public Health. 73(4).

F. Cross-cultural Tools Related to Disciplines that work with people with Developmental Disabilities

United States Department of Agriculture and United States Department of Health and Human Services. (1986). Cross Cultural Counseling: A Guide for Nutrition and Health Counselors.

MULTICULTURAL TASK FORCE IN THE FIELD OF DEVELOPMENT DISABILITIES

Sponsored by the
Administration on Developmental Disabilities

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Supporting the Growth of the Self-Advocacy Movement:

What We Can Learn from Its History and Activists

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Abstract

The self-advocacy movement in North America among people with developmental disabilities has grown rapidly since its beginnings in the mid-1970s. This study identifies the factors that contribute most to supporting growth of self-advocacy by examining the history of self-advocacy and reporting on interviews with leaders and veteran advisors of the self-advocacy movement. It then makes specific recommendations for how agencies and professionals who work with persons with developmental disabilities can support the further growth of self-advocacy.

Supporting the Growth of the Self-Advocacy Movement: What We Can Learn from Its History and Activists

In 1974 the first self-advocacy conference in the United States was organized by persons with developmental disabilities in the state of Oregon. Since then hundreds of local self-advocacy groups have formed across the United States and Canada and around the world, helping justify the frequent use of self-advocacy movement in descriptions of this development (People First of Washington, 1985; Rhoades, Browning, & Thorin, 1986).

Many self-advocacy groups exist in relative isolation from each other, but in several states there are now either well developed networks of groups or formal statewide organizations with elected officers and paid staff. Furthermore, national self-advocacy organizations have recently formed in Canada and the United States. While it may still be accurate to describe the self-advocacy movement as fragile, it is clear that it is more than just a passing phenomenon (Brunk, 1987).

The purpose of this study is to understand why self-advocacy has grown as rapidly as it has in order to identify the factors that contribute most to supporting its growth. The study first examines the history of the development of self-advocacy in the United States. This section is based primarily on written sources, including speeches and articles by persons with developmental disabilities who have been involved in the self-advocacy movement.

The second section is based on interviews with leaders of the movement and nondisabled self-advocacy advisors. The interviews were used to draw information from the persons who are currently most directly involved in the self-advocacy movement. The third section summarizes the information from the first two sections and draws some conclusions.

Understanding the Growth of Self-Advocacy

The North American self-advocacy movement seems to have its roots in the social clubs for people with mental disabilities that existed in Sweden in the 1960s (Williams & Shoultz, 1984). Those social clubs emphasized the importance of decisionmaking by their members and supported that emphasis by providing training in parliamentary procedures and real experience in decisionmaking through the election of officers and participation in committees (Nirje, 1972).

As those clubs developed they began exchanging visits and organizing regional meetings. Those interactions culminated in a national conference in Malmo attended by 48 representatives from throughout Sweden and two guests from Denmark. The purpose of the May 1970 conference in Malmo was to discuss concerns related to leisure activities, residential living, and employment, but the real significance of the conference was that it was perhaps the first organized articulation of a desire for greater self-determination at a national level by persons with mental retardation (Nirje, 1972; Williams & Shoultz, 1984).

That desire found expression throughout the conference, as evidenced by the following excerpts from a summary of the findings of the conference:

> We all agree that we want more rights to participate in decisions, especially in planning and carrying out our leisure time activities.
>
> We all think one should decide oneself what to do during vacation. There should be student councils [in Sweden's special schools] which can take part in decisions about the curriculum, the choice of books, leisure time in school, etc.
>
> We want to choose our vocations ourselves, and have influence over our education.
>
> We think we should be present when our situation is discussed by doctors, teachers, welfare workers, foreman, etc. (Nirje, 1972)

The Malmo conference inspired conferences in Britain in 1972 and in British Columbia in 1973. Five persons from Oregon attended the conference in British Columbia. Three were residents of the Fairview Hospital and Training Center, a state institution, and the other two were staff members from Fairview. The Oregon group returned enthused about the idea of a statewide conference and organization and were able to convince other persons, both inside and outside of Fairview, of the value of organizing a conference. Their efforts led to a conference in

1974 that attracted 560 people and a second conference in 1975 that was attended by 750 people. Persons with mental disabilities were involved in all aspects of planning, organizing, and leading both conferences. While nonhandicapped persons did provide support and advice, they did so in ways that would encourage the development of skills and leaders among the persons with disabilities (Edwards, 1982; Williams & Shoultz, 1984).

Oregon continued having annual conferences, but perhaps more importantly, it became a model and source of inspiration for the formation of other self-advocacy groups across the country who contacted them or who saw a film about the second conference called *People First* (Edwards, 1982; Rhoades, et al., 1986; Williams & Shoultz, 1984). In addition to the groups that had been inspired by Oregon, there were also self-advocacy groups that began forming independent of the events in that state, as well as some that had pre-dated the Malmo conference (Williams & Shoultz, 1984).

Several hundred self-advocacy groups involving several thousand persons with mental disabilities have formed in the U.S. and Canada since the first two Oregon conferences. One study in the early 1980s identified 152 groups and estimated that those groups had a total of 5,000 members (Browning, Thorin, & Rhoades, 1984). We can make a more current estimate based on a recent directory of self-advocacy groups which lists 380 groups (Association for Retarded Citizens, 1990). If we use the same formula used by the Browning study, the estimated number of members would exceed 12,500. These numbers underestimate the real growth of self-advocacy because the ARC directory does not include groups the author has contact with in New York, Kentucky, and Kansas, and there may be other groups that are not included.

In the last decade one of the significant developments has been the growth of viable statewide self-advocacy organizations. People First of Washington was one of the early statewide organizations with the funding needed to maintain staff, offices, and communications essential to a functioning organization. Since 1981 it has opened three offices, hired a staff (over 50% are persons with developmental disabilities), and grown to 46 groups (Association for Retarded Citizens, 1990; People First of Washington, 1985 & 1986; Rhoades, et al., 1986).

Statewide organizations have formed in other areas. In New Jersey, the United Self-Advocates held their sixth annual conference in June 1990. The conference was attended by 450 people representing over 50 groups (New Jersey Self Advocate, 1990). Almost 300 people from five groups attended the Speaking for Ourselves conference in Pennsylvania in May 1990 (Speaking for Ourselves, 1990). And in New York, a new statewide organization drew 250 persons to its first self-advocacy conference in the summer of 1990 (Self-Advocacy Association of New York, undated).

More recently, self-advocates in the United States have taken steps to form a national organization. At a conference in Estes

Park, Colorado, in September 1990, 400 self-advocates voted to form a national organization and elected a steering committee to make recommendations about the mission and structure of the organization (National Steering Committee of Self Advocates, 1991). Then at a second national conference in Nashville, Tennessee, in September 1991, 700 self-advocates ratified a proposal to form a national coalition of state and local self-advocacy groups, coordinated by a Steering Committee composed of elected regional representatives (B. Carabello, personal communication, September 9, 1991).

Likewise in Canada representatives from regional organizations met in Winnipeg in March 1990 to debate a draft constitution that will lead to the formation of National People First (Laroche, 1990).

What explains the extraordinary growth in self-advocacy among people with mental retardation? I suggest that the clue to understanding this growth lies in the conflict between, on the one hand, an existing social construction of disability that relegated people with mental retardation to an inferior and segregated status and, on the other hand, a new ideology and practice of equality and integration. That conflict became particularly acute in the mid-1970s, creating in the process both motivation and a new space that encouraged the growth of self-advocacy. In what follows I will seek to elucidate my argument.

The Social Construction of Disability

The experience of disability is the result of a time and culturally specific social construct; the key elements of that social construct will vary according to the disability (Bogdan & Taylor, 1982; Gliedman & Roth, 1980; Minow, 1990; Sarason & Doris, 1979; Scheer & Groce, 1988). If we want to understand the lives of persons with disabilities we need to understand the nature of the specific construct of disability that is relevant to them.

An illuminating example of a specific social construct of disability can be found in Groce's (1985) study of persons who were deaf living in Martha's Vineyard. From the time it was first settled by Europeans in the 17th century until the early 20th century, Martha's Vineyard has had a high percentage of persons with hereditary deafness. Groce found that in their education, marital status, employment opportunities, economic standing, civic participation, and social interactions, persons who were deaf on the Vineyard did not differ from persons who were not deaf. This was a striking contrast to the situation of persons who were deaf on the mainland during that same period, who were marginalized and segregated.

Groce identifies two factors that explain the integration of persons who were deaf on the Vineyard. One was that the prevalence of deafness contributed to an attitude of acceptance because people thought that it could happen to anyone. The second factor was that virtually everybody on the island used sign language, thereby eliminating the most important barrier between persons who were and were not deaf.

The attitudes of acceptance and the lack of communication barriers were the key elements of the social construction of deafness on the Vineyard and explain why the situation was so different from the situation of persons who were deaf who lived on the mainland. That difference is forcefully highlighted in a remark made to Groce by a woman she interviewed in the course of her research, who told her, "Those people weren't handicapped. They were just deaf" (p. 5).

The Retarding Environment

In 1983 the California State Council on Developmental Disabilities contacted People First of California to conduct a needs assessment among persons with developmental disabilities. The task force that conducted the assessment consisted of six persons who were members of the Capitol People First self-advocacy group, two advisors, and a writer.

After interviewing over 150 clients and service providers in a variety of settings, the task force concluded that

> many people are better off for *not* getting services from institutionalizing and devaluing parts of the system. We also saw clear evidence that people who do get genuine *developmental* services do better than people who get traditional services. When all factors are the same, including the type and degree of biological impairment, the

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> evidence seems very strong that the ones who become able to lead the most normal lives are those who have been helped to the greatest extent *outside* of the traditional service system. In short, the task force suggests a new phrase to be used to sum up the nature and effect of . . . the traditional system of services for the mentally retarded . . .. THE RETARDING ENVIRONMENT.
>
> The retarding environment is found in state hospitals, in sheltered workshops, in segregated educational facilities, and often in integrated special education programs. It is found, tragically, in almost every type of program, and even more tragically, in the attitudes of so many of the *keepers* of the system. (People First of California, 1984, p. 10; emphasis in original)

In effect, what the People First task force describes in its report are some of the aspects of the social construction of mental retardation in the United States.

One important element of the retarding environment that the People First task force highlighted is the persistence of attitudes that devalue people with mental retardation, a reverse parallel to Groce's identification of accepting attitudes as one of the keys to understanding the situation of persons who were deaf on Martha's Vineyard.

Persons with mental retardation themselves are acutely aware of this devaluation, which they often experience as *invisibility*.

Stephen Dorsey, a leader in the self-advocacy movement in Pennsylvania, says:

> Most people look at us, *but they don't see us*. I have been in a workshop . . . for 17 years. Last month, I gave a speech to the Delaware County Association for Retarded Citizens. . . . I read some of the speech I gave in Washington on the Medicare Reform Act. After I had finished, a staff member [from my workshop] came up to me and said, 'I'm impressed, Stephen, very impressed. *I didn't even know you could read.*' That's what I mean by 'looking at us, but not seeing us.' (InterServe, undated, emphasis in original)

In a similar vein, a leader of the self-advocacy movement in Nebraska, Nancy Ward, relates this story:

> I used to work in a sheltered workshop. . . . My boss became ill. She had to quit. Before she did, she talked to me about applying for her job. I didn't have any confidence in myself. After talking to other people about it, I finally decided it wouldn't hurt to at least fill out an application. When I tried to fill out the application, the personnel department would not even let me fill it out. This made me upset, but I went back to work. A couple of weeks later, several staff members came to the workshop building with the new supervisor. After talking with them, I was told to train the new supervisor. Therefore, I quit

> and found another job. (Ward, 1989, p. 14)

These stories reflect the recurrent experience of having one's abilities ignored or underestimated, not on the basis of an objective evaluation of a person's real skills, but as the result of preconceived notions that are the result of prevailing attitudes toward people with mental retardation.

There are two noteworthy aspects of these stories. The first is that both Stephen Dorsey and Nancy Ward have rejected the validity of those devaluing attitudes. In doing so they undermine the current social construct because its continued existence depends on the passive consent of persons with mental retardation who have accepted and internalized those attitudes.

The second aspect is that they are describing experiences *within* the system of social services for people with mental retardation. As People First of California makes clear in their description of the retarding environment, a key element of the social construction of mental retardation is a service system which encourages dependency instead of independence. This is not surprising since those services are the result of a broader public policy that has in general not supported the self-determination of people with disabilities.

Berkowitz (1987), in his analysis of disability policy in the United States, notes that the funding for programs that seek to integrate people with disabilities into the economic and civic life of their communities is a small fraction of the funding for programs that simply transfer money to persons assumed to be incapable of being productive and contributing citizens.

This observation holds true if we look more specifically at public policy in the area of mental retardation. In his examination of how federal funds are used for mental retardation programs, one of Braddock's (1987) conclusions was that there was a continuing institutional bias. In FY 1985, $1.918 billion, or almost 25% of all federal funds for mental retardation and developmental disability (MR/DD) programs, went toward the maintenance of 100,000 persons in public institutions. In contrast, funds for special education and rehabilitation grants amounted to 4.8% of MR/DD expenditures. Since 38.5% of federal MR/DD funds go to income maintenance programs, that means that almost 2/3 (38.5 + 25 = 63.5%) of federal spending supports keeping people in institutions and/or out of the workplace.

What I have sketched above are some of the pieces of the social construction of mental retardation. They include the existence of widespread negative attitudes that devalue and dehumanize persons with mental retardation and that are accepted and internalized by the devalued persons. Those attitudes are reinforced by a system of services that segregate persons with mental retardation and at the same time encourage their dependence. In turn, those services are guided by a public policy that has in general not supported self-determination.

The social construct of mental retardation that relegates people with mental retardation to an inferior and segregated status was in place in the early 1970s when the self-advocacy movement began and is still largely in place today. To understand how, in spite of this social construct, the self-advocacy movement was born and continues to flourish, we need to examine briefly the growth of a countervailing set of forces and ideologies that created a space for self-advocacy.

Opening a Space for Self-Advocacy

In October 1961 President John F. Kennedy appointed the President's Panel on Mental Retardation. What perhaps differentiated this panel from previous efforts to recommend and institute broad changes in the area of mental retardation was President Kennedy's own interest in implementing reforms because of his personal connection to the issue through a sister with mental retardation. Within a year of the Panel's report, Congress passed legislation that incorporated many of its recommendations, including funds for maternal and infant care, research centers, teacher training, and demonstration projects. A significant aspect of the legislation was the emphasis on the provision of community-based services (Scheerenberger, 1987; Tyor & Bell, 1984).

President Kennedy's commitment helped focus renewed attention at the federal level on policy issues related to mental retardation, a trend that continued into the 1970s. This attention was encouraged by advocacy organization and particularly by the National Association for Retarded Children, which had been founded by parents in 1950 and experienced rapid growth throughout the 1950s (Tyor & Bell, 1984).

The social movements of the 1960s, especially the civil rights movement, also had a significant impact on developments in the MR/DD field. This impact took various paths, one of which was through the court system. The most important example of how civil rights decisions in the courts shaped disability issues was the 1954 Supreme Court decision in *Brown v. Board of Education.* The principles enunciated in *Brown* were an important basis for court decisions in the early 1970s that established the right to free, appropriate public education for children with disabilities and that culminated in the Congressional enactment of the Education for All Handicapped Children Act (P.L. 94-142) in 1975 (Turnbull, 1990).

A similar impact was felt in the legislative arena, where the key piece of civil rights legislation directly affecting people with disabilities--Section 504 of the Rehabilitation Act of 1973 (P.L. 93-112)--was patterned after the Civil Rights Act of 1964 (Scotch, 1984).

But perhaps of most importance to the development of self-advocacy was the impact of the civil rights movement on professionals and on people with disabilities. As a result of the civil rights movement, many professionals began to understand retardation as a social problem, one particularly tied to the persistence of poverty in America (Tyor & Bell, 1984). At the same time, the civil rights movement was helping some people with mental retardation gain a new perspective on themselves (Worth, 1989).

These developments gave impetus to a search among professionals for a reconceptualization of the goals of their work, and perhaps no single concept in the field of mental retardation had as much impact as the concept of normalization. Not coincidentally, the concept of normalization was born in Scandinavian countries during the period that saw the development of the Swedish social clubs noted above. It was first articulated in the United States at a conference in 1969 by the Director of the Danish Service for the Mentally Retarded and the Secretary General of the Swedish Parents Association (Scheerenberger, 1987).

In the U.S. and Canada the most influential proponent of normalization was Wolf Wolfensberger, who in an early definition of the concept wrote that normalization was the "utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible" (1972, p. 28).

While the concept was not without controversy, normalization seemed to go a long way toward responding to the desire for fresh ways of thinking about issues related to mental retardation and "became the professional ideology of the 70s" (Tyor & Bell, 1984, p. 148). Three related ideas that helped fill the conceptual void became widely accepted by professionals in that period: (a) the belief that people with mental retardation were capable of growth and development (the developmental model), (b) the legal notion of least restrictive environment, and (c) the importance of integrating children with disabilities in regular classes, or mainstreaming (Sarason & Doris, 1979; Scheerenberger, 1987; Turnbull, 1990).

These concepts found a practical expression in the growing demand among some professionals in the late 1960s and early 1970s for the deinstitutionalization of people with mental retardation, a demand that was reinforced by the occasional media exposes of truly horrifying conditions in some institutions (Rothman & Rothman, 1984; Scheerenberger, 1987; Tyor & Bell, 1984).

I briefly described above a social construct of mental retardation--the retarding environment--which, as the result of the prevalence of negative attitudes and of the nature of the programs and policies that are supposed to serve the needs of persons with mental retardation, constantly reinforces passivity and dependence. It is in the fissures of this construct that the new ideology of normalization, equality, and integration began growing in the late 1960s and early 1970s.

This ideology created the space that was needed for people with mental retardation to assert themselves as citizens, but the ideology had been articulated largely by persons who were professionals and/or advocates. If persons with mental retardation were to actually begin rejecting oppressive attitudes and institutions, they needed to be supported in those efforts. Self-advocacy groups provided that support by creating an environment where peers could learn from each other about their rights and responsibilities and where they could practice the leadership, problem-solving, and social skills that were essential to the exercise of their rights.

Washington People First, one of the early statewide self-advocacy organizations, explains self-advocacy in this way:

> When we say that People First is a 'self-advocacy' organization, we mean that the members are:
>
> - 'speaking up and speaking out' for themselves
> - solving their own problems and making their own decisions
> - knowing and exercising the full rights and responsibilities of citizenship
> - contributing to and participating in the community (1986, p. 2)

This succinct explanation reflects what persons with disabilities say when they talk about what self-advocacy means to them:

> Speaking up and speaking out is self-advocacy. Making your own decisions, being more independent. Standing on your own two feet and sticking up for our rights is self-advocacy. . . .
>
> In self-advocacy you can learn from each other, you can

> teach each other so much. In Nebraska, we have a course to teach self-advocates how to teach other self-advocates. It focuses on how to vote, civil and legal rights, and what self-advocacy is. . . . Self-advocacy is important because it makes people feel independent and as a result experience personal growth. (1985, pp. 8-9)

Self-advocacy groups support individual change and development, but self-advocacy has in turn been supported by sympathetic professionals and advocates. That support is most visible in the role of the advisor or helper, usually a person without a mental disability who assists the group while being very careful to not take control of its decisionmaking processes. While it has been argued that some self-advocacy groups may reach a point where an advisor is not needed, in practice the role of the advisor has been essential to the maintenance of many self-advocacy groups (Browning, et al., 1984; Curtis, 1984). In addition to the support provided by individual advisors, the institutional support of established advocacy organizations and government agencies has also been important. Thus, the states that witnessed the fastest growth in self-advocacy groups--New Jersey and Washington--have been the ones where financial support from other organizations was available for a central office, communications, and technical assistance.

Self-advocacy will need further support from individuals and institutions if it is to continue growing, and in the next part of this paper I explore what self-advocates and their advisors think are optimal forms of support.

The Perspective of Self-Advocates and Advisors

The first section of this paper has examined the history of the development of self-advocacy in the United States to help identify the factors that have contributed to its growth. In this section I want to draw directly from those most involved in the growth of self-advocacy, the veteran leaders and advisors of the self-advocacy movement.

I conducted phone interviews with six self-advocates and six advisors in different parts of the country. The self-advocates were all persons with developmental disabilities who are leaders in their local and state organizations and are recognized by other self-advocates as spokespersons for their groups. The advisors were all persons with long-standing involvement in self-advocacy who had experience with local groups and with state or regional self-advocacy organizations. The interviews were tape recorded and the recordings were then summarized and analyzed. One recording with an advisor was not audible, thus reducing the number of advisors used in the subsequent summary to five.

Question 1: When you reflect on the growth of self-advocacy in your state, what do you think has contributed most to supporting its growth?

The role of self-advocates. The most salient point of agreement on this question was that it was self-advocates themselves--through face to face interactions and the power of their testimony--who were most responsible for the growth of self-advocacy. Of the 11 persons interviewed, five self-advocates and three advisors emphasized the essential role self-advocates play in promoting the growth of self-advocacy.

Self-advocates said that it was important to have persons with disabilities speak to others with disabilities about self-advocacy and to share their stories and experiences. One self-advocate spoke about the need to have regular meetings and conferences where people could learn from each other.

Advisors were even more emphatic about the role self-advocates had played in promoting self-advocacy. One veteran advisor to a seven-year-old statewide project, which has helped get over 50 groups started, said that she thought that experienced self-advocates had been essential to getting those groups started. She described the function of the project as that of going around the state giving permission and information: "This is what people are doing and you can do this if you want to." But she emphasized that the success was due in large part to the fact that it was self-advocates who were giving the permission.

Another advisor also noted that permission had much more power and impact when it came from self-advocates. He spoke of how, in his experience, self-advocates were more effective than professionals in helping change low self-expectations of other persons with disabilities to high self-expectations and in helping them understand that they are allowed to want things from life.

Outside support. A second area of agreement that was mentioned by three self-advocates and four advisors was the importance of having persons outside the self-advocacy movement who understood and supported self-advocacy. One advisor talked about how in his state there had been a history of citizen activists and of key people in the service delivery system who believed in persons with developmental disabilities making their own choices and who were prepared to make resources available to support self-advocacy when it began to develop.

Advisors also spoke about the importance of specific types of outside support: (a) financial support for statewide projects for staff salaries and for holding specific events such as conferences, (b) in-kind support for copying, transportation, office space and phones, and (c) a monthly column in a parent organizations newsletter.

Self-advocates and advisors emphasized the value of educating parents and professionals about self-advocacy and about the rights and the potential of people with disabilities as a way to increase support for the self-advocacy movement. One self advocate said that having good advisors was important.

Question 2: If you were the director of a local or state program working with people with disabilities, how would you use your organization's resources to support the growth of self-advocacy?

Greater involvement in decisionmaking. Two self-advocates and two advisors said that as directors of an agency they would involve persons with disabilities in the decisionmaking process. All of them agreed that persons with disabilities should be represented on the boards of directors of agencies, and three suggested specific measures to help assure that the representation was more than token.

One advisor said that persons with disabilities should make up half of the board and that they should be paired in a buddy system with the nondisabled members who could help them understand the issues and provide them with whatever support was needed to maximize their understanding and participation.

One self-advocate had been on a statewide board and had been assisted by a translator who attended the meetings, went over agendas and minutes with him, explained the issues that were coming up, and drew pictures to communicate concepts that were otherwise difficult. He said that having a translator was very helpful and that all boards should do it. An advisor also advocated using translators and further suggested that meetings should be structured in ways that allow greater participation. As an example, he described a statewide board where people with developmental disabilities can call a break at any time they feel a need to get together to figure out what is going on.

In addition, one advisor said that he would encourage people with disabilities to become involved in decisions about the hiring, evaluating, and firing of agency staff.

Staff and board training. One self-advocate and three advisors said that as directors they would provide training about the value and philosophy of self-advocacy for their staff and board members.

The self-advocate said that he would talk to the staff about how important self-advocacy was. One advisor said that staff and boards needed to understand that day-to-day encouragement for people with disabilities to do things and make decisions for themselves was the most effective way to empower people. Another advisor said that staff needed to have a firm grounding in normalization. All three advisors agreed that persons with disabilities should have a significant role in the training; one of them said she would have persons with disabilities run her training program.

Financial support. Three self-advocates and one advisor said that as directors they would provide financial support to self-advocacy groups.

Two of the self-advocates were adamant that the financial support should only be partial so that the groups would also be involved in other forms of raising money. One of them said that he would give them half of the money they needed and would monitor how it was spent. The other self-advocate said that groups needed to raise their own money because fundraising should be a joint responsibility. The concern of the advisor was that agency's financial support should have no strings attached to it so that decisions of the groups would remain free.

Independent living. One self-advocate and two advisors said that as directors they would use their agency resources to help people with disabilities live independently in the community.

The self-advocate said that he would help people get out of institutions so they could live in the community. One advisor said that he would provide support for people to buy their own homes and to start their own businesses. He also said that it was important to pay attention to the social needs of people as they begin living in the community by helping set up friendship circles or other forms of support.

Transportation. One self-advocate and two advisors said that as directors they would help arrange for transportation to meetings of self-advocacy groups.

Conclusions

In this section I want to draw some conclusions about what factors contribute to the growth of self-advocacy, based on the review of the history of the self-advocacy movement and the interviews with self-advocates and advisors, and suggest how agencies and professionals providing services to adults with developmental disabilities could use those conclusions.

The Power of Example

One important conclusion is that the growth of self-advocacy has been greatly assisted by the power of example.

There are two kinds of exemplary activity. [illegible] is what groups do that inspires and instructs others, who then want to replicate what they observed. An important illustration of this in the history of the self-advocacy movement was the visit of five persons from Oregon to a conference in British Columbia, which gave them a vision of what people with developmental disabilities could themselves do, who then returned to Oregon to organize a statewide conference that drew 560 persons and a second one the following year that was attended by 750 persons. Those conferences, through a film of the second conference and as the result of people learning about them and contacting the Oregon self-advocates, are often credited with inspiring the formation of groups across the country.

The second kind is the power of exemplary individuals who, in relating their stories and in speaking about what self-advocacy has meant to them, open up new worlds of previously unimagined possibilities for other persons with disabilities. As noted in the interviews, those leaders help liberate others, giving them permission to speak for themselves and helping create new expectations for themselves and their lives.

Agencies and professionals could: (a) provide assistance for persons with disabilities to attend self-advocacy conferences and training sessions, (b) bring in self-advocacy leaders to speak to the persons they serve, (c) hire experienced self-advocates for their staff.

Learning by Doing

From the beginning, the self-advocacy movement has emphasized learning by doing. The members of the Swedish social clubs learned how to make decisions about their club activities by receiving training in parliamentary procedures and then practicing what they had been taught through elections and participation in committees. That practice has remained an essential activity of most self-advocacy groups, which have focused a lot of their time and energy on teaching and practicing decisionmaking, problem-solving, and social skills as part of their ongoing activities. A discussion and vote on how a group can raise money, for example, is important for the possible outcomes, but it is equally as important for the experience gained in how to present ideas, convince others, make decisions, assign responsibilities, and carry them out.

The persons interviewed who said that as directors of agencies they would involve persons with disabilities in the decisionmaking processes of their agencies and would provide support for living independently were in effect extending the practice of learning by doing beyond the relatively safe context of the self-advocacy group. Participation on boards of directors, especially when measures are taken to ensure meaningful participation--such as creation of a buddy system; provision of translators; involvement in decisions about hiring, evaluating, and firing staff; or living independently in the community--are practical ways to teach choice and decisionmaking skills.

Agencies and professionals could: (a) have a significant number of persons with disabilities on boards of directors, providing them with the support needed to ensure they are not just token participants; (b) have persons with disabilities on personnel committees; (c) train staff on methods for encouraging persons with disabilities to make choices day by day.

The Importance of the Group

Self-advocacy groups provide a supportive and safe environment where persons who have been undervalued are able to gain a new sense of confidence and possibilities.

Earlier it was noted that self-advocates such as Steve Dorsey and Nancy Ward have rejected the notion that as persons with developmental disabilities they could be routinely ignored. That act of rejection is often extremely difficult, because it is done in the face of a pervasive social construction of disability that affirms the relegation of persons with disability to the margins of society. For many persons with developmental disabilities that rejection would not be possible without the support of their self-advocacy group. That is reflected in the emphasis self-advocates give to learning from each other and teaching each other when they talk about the meaning of self-advocacy.

Agencies and professionals could: (a) assist persons with disabilities to find and participate in an appropriate self-advocacy group; (b) sponsor a self-advocacy group by helping find an advisor and providing other forms of support.

The Value of Material Support

Self-advocates and advisors interviewed for this study underscored the importance of material support for self-advocacy from groups and individuals outside the self-advocacy movement. The kinds of support mentioned included financial support and in-kind support for transportation, office space, phones and copying.

Agencies and professionals could: make available resources such as copying, transportation, and use of phones to a self-advocacy group.

The Importance of Ideological Support

In the historical review we examined how a constellation of related concepts that included normalization, the developmental model, the least restrictive environment, and mainstreaming formed the core of a new ideology that emerged in the 1970s. That ideology was adopted by some professionals and parents and helped create space within the retarding environment for the growth of self-advocacy. That ideological support remains important for several reasons. First, it helps ensure the availability of sympathetic persons who are willing to be advisors to self-advocacy groups. Second, it helps parents think about their children with developmental disabilities with enhanced expectations for independence, thus making their efforts to speak for themselves easier. Third, it increases the likelihood of material support from outside the self-advocacy movement.

Because material and ideological support are so important, the continued education of staff and parents is likewise important. The persons interviewed suggested training in normalization, the value of self-advocacy, and the importance of day-to-day encouragement of persons with disabilities to make decisions. They also suggested that self-advocates have a significant role in the training.

Agencies and professionals could: (a) use self-advocates to help train staff and board members; (b) assist self-advocates in organizing and making presentations to parent, professional, religious, government, and civic groups in the community.

Support by Those Outside Self-Advocacy

Finally, we should ask if self-advocacy is important enough that it is worth being supported by persons and institutions that are outside the self-advocacy movement. While there are many possible affirmative answers, I want to answer that question in light of the recently enacted Americans with Disabilities Act (ADA) of 1990 (P.L. 101-336).

The ADA adopts a minority model, stating in its findings that persons with disabilities are a "discrete and insular minority" who have been "relegated to a position of political powerlessness." The Act goes on to say that

> the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-

sufficiency.

In order to fulfill those goals the Act extends civil rights protections to persons with disabilities, which are designed to guarantee equality of opportunity in employment, public accommodations, transportation, state and local government services, and telecommunications. While the ADA might immensely broaden opportunities, those opportunities cannot become realities for persons with disabilities unless they are prepared to act on them, that is, unless they can shed passivity and dependence and become self-determining citizens. The law establishes the new horizon of opportunities, but only individuals acting on the basis of their own choices and preferences are in a position to make those opportunities come true.

Because the self-advocacy movement provides the supportive environment that many persons with mental retardation need in order to embrace and practice self-determination, it seems important to in turn provide the movement with the support it needs to maximize its impact.

References

Association for Retarded Citizens. (1990). *Self-advocacy programs directory.* Arlington, TX: Association for Retarded Citizens.

Berkowitz, E. (1987). *Disabled policy.* Cambridge, England: Cambridge University Press.

Braddock, D. (1987). *Federal policy toward mental retardation and developmental disabilities.* Baltimore, MD: Brooks Publishing Company.

Bogdan, R., & Taylor, S. (1982). *The social meaning of mental retardation.* Toronto, Canada: University of Toronto Press.

Browning, P., Thorin, E., & Rhoades, C. (1984). National profile of self-help/self-advocacy groups of people with mental retardation. *Mental Retardation, 22*(5), 226-230.

Brunk, G. (1987). The power of self-advocacy. *TASH Newsletter, 13*(8), 2.

Curtis, C. (1984). The changing role of the People First advisor. *American Rehabilitation, 10*(2), 6-9.

Edwards, J. (1982). *We are People First.* Portland, OR: EDNICK, Inc.

Gliedman, J., & Roth, W. (1980). *The unexpected minority.* New York: Harcourt Brace Jovanovich.

Groce, N. (1985). *Everyone here spoke sign language.* Cambridge, MA: Harvard University Press.

InterServe. (Undated). *Sharing life experiences.* New York: InterServe.

Laroche, D. (1990). The national movement: Where do we go from here. *National Organizer, 21*, July.

Minow, M. (1990). *Making all the difference.* Ithaca, NY: Cornell University Press.

New Jersey Self-Advocacy Project. (1990). *New Jersey self-advocate,* Summer.

Nirje, B. (1972). The right to self-determination. In W. Wolfensberger, (Ed.), *The principle of normalization in human services* (pp. 176-193). Toronto, Canada: National Institute on Mental Retardation.

People First of California. (1984). *Surviving in the system: Mental retardation and the retarding environment.* Sacramento, CA: State Council on Developmental Disabilities.

People First of Washington. (1985). *Speaking up and speaking out: An international self-advocacy movement.* Tacoma, WA: People First of Washington.

People First of Washington. (1986). People First of Washington. *The U.T. Quarterly,* March, 2-3.

Rhoades, C., Browning, P., & Thorin, E. (1986). Self-help advocacy movement: A promising peer-support system for people with mental disabilities. *Rehabilitation Literature, 47*(1-2), 2-7.

Rothman, D., & Rothman, S. (1984). *The Willowbrook wars.* New

York: Harper & Row.

Sarason, S., & Doris, J. (1979). *Educational handicap, public policy, and social history*. New York: The Free Press.

Scheer, J., & Groce, N. (1988). Impairment as a human constant: Cross-cultural and historical perspectives on variation. *Journal of Social Issues, 44*(1), 23-37.

Scheerenberger, R. (1987). *The history of mental retardation: A quarter century of promise*. Baltimore, MD: Brooks Publishing Company.

Scotch, R. (1984). *From good will to civil rights*. Philadelphia, PA: Temple University Press.

Self-Advocacy Association of New York. (Undated). *Newsletter*, Summer.

Speaking for Ourselves. (1990). *Speaking for ourselves, 1*(1),

Turnbull, H. R. (1990). *Free appropriate public education: The law and children with disabilities* (3rd ed.). Denver, CO: Love Publishing Company.

Tyor, P., & Bell, L. (1984). *Caring for the retarded in America: A history*. Westport, CT: Greenwood Press.

Ward, N. (1989). Self-determination. In R. Perske, (Ed.), *National confererence on self-determination*. Minneapolis, MN: Institute on Community Integration.

Williams, P., & Shoultz, B. (1984). *We can speak for ourselves: Self-advocacy for mentally handicapped people*. Bloomington, IN: Indiana University Press.

Wolfensberger, W. (1972). *The principle of normalization in human services.* Toronto, Canada: National Institute on Mental Retardation.

Worth, P. (1989). The importance of speaking for yourself. *TASH Newsletter*, *15*(2), 1-3.

NATIONAL ACADEMY ON PARTNERS IN POLICYMAKING

THURSDAY-SATURDAY, MAY 14-16, 1992
DOUBLETREE HOTEL AT LINCOLN CENTRE
5410 LBJ FREEWAY
DALLAS, TEXAS

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MINNESOTA PIP 1992 AGENDAS
N.D. - Received prior to 1992 Academy

PARTNERS IN POLICYMAKING
SESSION I: THE HISTORY OF THE PARENT MOVEMENT AND THE INDEPENDENT LIVING MOVEMENT

January 17 and 18, 1992
St. Paul Hotel
350 Market Street
St. Paul, Minnesota

FRIDAY, JANUARY 17, 1992

Time of Activity	Activity	Location
11:45 a.m.-12:15 p.m.	Registration.	Mayo Room
12:15 p.m.-12:45 p.m.	Introductions/Panel.	Mayo Room
12:45 p.m.- 2:30 p.m.	Ed Skarnulis, Ph.D., Associate Professor, Augsburg College. "History of Disabilities Movement."	
2:30 p.m.- 2:45 p.m.	Break.	
2:45 p.m.- 4:15 p.m.	Ed Roberts, President, World Institute on Disability. "History of the Independent Living Movement."	Mayo Room
4:15 p.m.- 5:00 p.m.	David Hancox, Senior Planner, MN Governor's Planning Council on Developmental Disabilities. "What Is Partners in Policymaking?"	
5:00 p.m.- 6:00 p.m.	Refreshments/Social Time.	
6:00 p.m.- 7:00 p.m.	Dinner.	Private Dinning
7:00 p.m.- 7:45 p.m.	"Informal Discussions with Case Managers."	Mayo Room
7:45 p.m.- 9:00 p.m.	Colleen Wieck, Ph.D., Executive Director, Minnesota Governor's Planning Council on Developmental Disabilities. "Lessons Learned on Empowerment."	

Partners in Policymaking
Session I: Year VI

SATURDAY, JANUARY 18, 1992

Time of Activity	Activity	Location
8:00 a.m.- 8:45 a.m.	Breakfast.	Mayo Room
9:00 a.m.-10:30 a.m.	Gunnar Dybwad, Ph.D., Professor Emeritus, Brandeis University. "The History of the Parent Movement."	Mayo Room
10:30 a.m.-10:45 a.m.	Break.	
10:45 a.m.-12:00 noon	Gunnar Dybwad, Ph.D. (cont.).	
12:00 noon- 1:00 p.m.	Lunch.	
1:00 p.m.- 2:30 p.m.	Dolores Norley, J.D. "A Personal Perspective."	
2:30 p.m.- 3:00 p.m.	Wrap-Up and Adjournment.	

PARTNERS IN POLICYMAKING
SESSION II: COMMUNITY ORGANIZING SKILLS

February 28 and 29, 1992
Sunwood Inn--Bandana Square
1010 Bandana Boulevard, West
St. Paul, Minnesota

FRIDAY, FEBRUARY 28,1992

Time of Activity	Activity	Location
12:00 noon-12:30 p.m.	Registration.	Depot
12:30 p.m.-12:45 p.m.	Introductions.	Roundhouse
12:45 p.m.- 1:30 p.m.	Richard Male and Dan Lopp; Community Resource Center; Denver, Colorado. "Martin Luther King Tape and Small Group Discussion."	
1:30 p.m.- 2:30 p.m.	"Basic Philosophy of Community Empowerment: • Why People Organize. • History. • Different Approaches to Problem Solving: -- Social Work, -- Advocacy, -- Organizing/Empowerment."	
2:30 p.m.- 2:45 p.m.	Break.	Depot
2:45 p.m - 3:15 p.m.	"Power: • What is it? • How to use it? • Types of power."	Roundhouse
3:15 p.m.- 4:30 p.m.	"Neighborhood/Community Power Analysis: Analyzing the Power in Your Commuity."	Roundhouse
4:30 p.m.- 5:15 p.m.	"Community Organizing Process."	Roundhouse
5:15 p.m.- 6:00 p.m.	Free Time.	
6:00 p.m.- 7:00 p.m.	Dinner.	Burlington
7:00 p.m.- 9:00 p.m.	Dohn Hoyle, Executive Director, Washtenaw Association for Community Advocacy.	Roundhouse

Partners in Policymaking
Session II; Year VI

SATURDAY, FEBRUARY 29, 1992

Time of Activity	Activity	Location
8:00 a.m.- 9:00 a.m.	Breakfast.	Roundhouse
9:00 a.m.-12:00 noon	"Detailed Look at Organizing: • Step I. Building Relationships, • Step II: Leadership/Core Teams, • Step III: Large Groups/ Public Meetings, • Step IV: Negotiation."	
12:00 noon- 1:00 p.m.	Lunch.	Burlington
1:00 p.m.- 2:00 p.m.	"Case Study: Organizing Exercises in Small Groups."	Roundhouse
2:00 p.m.- 2:45 p.m.	"Next Steps in Your Local Area."	Roundhouse
2:45 p.m.- 3:00 p.m.	Wrap-Up and Evaluation.	Roundhouse

PARTNERS IN POLICYMAKING
SESSION III: STATE LEGISLATIVE ISSUES

March 27 and 28, 1992
Kelly Inn
161 St. Anthony Boulevard
St. Paul, Minnesota

FRIDAY, MARCH 27, 1992

Time of Activity	Activity	Location
11:30 a.m.-12:00 noon	Registration.	State Capitol Rotunda
12:00 noon- 1:00 p.m.	Tour of the State Capitol.	State Capitol
1:00 p.m.- 1:30 p.m.	Lt. Governor Joanell Dyrstad. "Greetings from Public Official."	State Capitol Room
1:30 p.m.- 2:00 p.m.	Break.	Capitol Cafeteria
2:00 p.m.- 3:30 p.m.	Scott Magnuson, Director, Senate Information Office. "How Bills Become Law."	State Office Building
3:30 p.m.- 4:30 p.m.	Allan Bergman, United Cerebral Palsy Association (UCPA). "Some Important Tips about Interacting with Legislators"	State Office Building
4:30 p.m.- 5:00 p.m.	"Mock Legislative Assignments."	
5:00 p.m.- 6:00 p.m.	Free Time.	Kelly Inn
6:00 p.m.- 7:00 p.m.	Dinner.	Gilbert
7:00 p.m.- 9:00 p.m.	"Team Work Sessions; Prepare Testimony."	Gilbert Buffington

SATURDAY, MARCH 28, 1992

Time of Activity	Activity	Location
8:00 a.m.- 9:00 a.m.	Breakfast.	Gilbert
9:00 a.m.-10:00 a.m.	Allan Bergman, UCPA. "State of the Union."	State Capitol House Chambers
10:00 a.m.-10:30 a.m.	"Review testimony."	State Office Building, Rooms 5 and 10
10:00 a.m.-12:00 noon	"Concurrent Hearings (Pro)."	State Office Building, Rooms 5 and 10
12:00 noon- 1:00 p.m.	Lunch.	
1:00 p.m.- 2:30 p.m.	"Concurrent Hearings (Con)."	State Office Building, Rooms 5 and 10
2:30 p.m.- 3:00 p.m.	Wrap-Up and Adjournment.	State Office Building, Room 10

PARTNERS IN POLICYMAKING

SESSION IV: EDUCATION, INTEGRATION, AND QUALITY

April 24 and 25, 1992
Sunwood Inn--Bandana Square
1010 Bandana Boulevard, West
St. Paul, Minnesota

FRIDAY, APRIL 24, 1992

Time of Activity	Activity	Location
11:45 a.m.-12:15 p.m.	Registration.	Depot
12:15 p.m.-12:30 p.m.	Introductions.	Roundhouse
12:30 p.m.- 2:30 p.m.	Lou Brown, Ph.D., University of Wisconsin--Madison. "Achieving Integrated Education."	Roundhouse
2:30 p.m.- 2:45 p.m.	Break.	Depot
2:45 p.m.- 5:00 p.m.	Lou Brown, Ph.D. (cont.).	Roundhouse
5:00 p.m.- 6:00 p.m.	Free Time.	Bandana Square
6:00 p.m.- 7:00 p.m.	Dinner.	Burlington
7:00 p.m - 9:00 p.m.	"The state of Education in Minnesota: · Early Education; · K-12; · Transition; · Adult Education; and · Postsecondary Education." (State Department of Education personnel). Small Group Meetings.	Roundhouse

Partners in Policymaking
Session VI; Year VI

SATURDAY, APRIL 25, 1992

Time of Activity	Activity	Location
8:00 a.m.- 9:00 a.m.	Breakfast and Announcements.	Burlington
9:00 a.m.-10:30 a.m.	Charlotte Des Jardins, Director; Coordinating Council for Handicapped Children (Chicago). "The How To's of Advocacy in Team Meetings."	Roundhouse
10:30 a.m.-10:45 a.m.	Break.	Depot
10:45 a.m.-12:00 noon	Charlotte Des Jardins (cont.).	Roundhouse
12:00 noon- 1:00 p.m.	Lunch.	Burlington
1:00 p.m.- 2:30 p.m.	Roberta Kehne Juarez, University of Minnesota--Duluth. "Postsecondary Education." Linda Kjerland, Dakota, Inc. "Early Childhood Education."	Roundhouse
2:30 p.m.- 3:00 p.m.	Wrap-Up and Evaluation.	Roundhouse

PARTNERS IN POLICYMAKING

SESSION VI: SEVERE PHYSICAL DISABILITIES AND TECHNOLOGY

May 29 and 30, 1992
Sunwood Inn--Bandana Square
1010 Bandana Boulevard, West
St. Paul, Minnesota

FRIDAY, MAY 29, 1992

Time of Activity	Activity	Location
11:45 a.m.-12:15 p.m.	Registration.	Depot
12:15 p.m.-12:30 p.m.	Announcements.	Roundhouse
12:30 p.m.- 3:00 p.m.	Joan Bergman, Ph.D., Sparks Center, University of Alabama, Birmingham "Severe Physical Disabilities."	
3:00 p.m.- 3:15 p.m.	Break.	Depot
3:15 p.m.- 5:00 p.m.	Joan Bergman (continued).	
5:00 p.m.- 6:00 p.m.	Free Time.	Bandana Square
6:00 p.m.- 7:00 p.m.	Dinner.	Burlington
7:00 p.m.- 9:00 p.m.	Rachel Wobschall, Executive Director, Governor's Advisory Council on Technology for People with Disabilities. "Minnesota's STAR Program."	Roundhouse

Partners in Policymaking
Session V; Year VI

SATURDAY, MAY 30, 1992

Time of Activity	Activity	Location
8:00 a.m.- 8:45 a.m.	Breakfast.	Burlington
8:45 a.m.- 9:00 a.m.	Announcements.	
9:00 a.m.-10:15 a.m.	Robert Stack, Consultant, New Jersey. Richard Dodds, United Cerebral Palsy of New Jersey. "Assessing Your Technology Needs and Demonstration of Technological Devices."	Roundhouse
10:15 a.m.-10:30 a.m.	Break.	Depot
10:30 a.m.-12:00 noon	Robert Stack (cont.).	
12:00 noon- 1:00 p.m.	Lunch.	Burlington
1:00 p.m.- 2:30 p.m.	Betty Pendler, M.S., Parent. "Letting Go."	Roundhouse
2:30 p.m.- 3:00 p.m.	Wrap-Up and Adjournment.	

PARTNERS IN POLICYMAKING

SESSION VI: COUNTY PLANNING, COUNTY BUDGETING, CASE MANAGEMENT, AND MEETING LOCAL OFFICIALS

June 19 and 20, 1992
Sunwood Inn--Bandana Square
1010 Bandana Boulevard, West
St. Paul, Minnesota

FRIDAY, JUNE 19, 1992

Time of Activity	Activity	Location
12:00 noon-12:30 p.m.	Introductions.	Roundhouse
12:30 p.m.- 2:30 p.m.	Lyle Wray, Ph.D., Executive Director, Citizen's League. "County Planning and Budgeting in Minnesota."	Roundhouse
2:30 p.m.- 2:45 p.m.	Break.	Depot
2:45 p.m.- 4:00 p.m.	Dan McCarthy, Department of Human Services. "What is Case Management and Rule 185?"	Roundhouse
4:00 p.m.- 5:30 p.m.	Fran Smith, Independent Consultant. "Creating a Vision for the Year 2000."	Roundhouse
5:30 p.m.- 6:30 p.m.	Refreshments.	Bandana Square
6:30 p.m.- 7:30 p.m.	Dinner.	Burlington
7:30 p.m.- 9:00 p.m.	Fran Smith (cont.). "The How-To's of Working with Public Officials."	Roundhouse

SATURDAY, JUNE 20, 1992

Time of Activity	Activity	Location
8:00 a.m.- 9:00 a.m.	Breakfast and Announcements.	Burlington
9:00 a.m.-10:30 noon	Fran Smith (cont.) "Small Group Exercises: Preparing to Meet County Officials."	Roundhouse
10:30 a.m.-10:45 a.m.	Break	Depot
10:45 a.m.-12:00 noon	Fran Smith (cont.) "Small Group Exercises: Preparing to Meet County Officials."	Roundhouse
12:00 noon- 1:00 p.m.	Lunch.	Burlington
1:00 p.m.- 2:30 p.m.	"Role Play with County Officials."	Roundhouse
2:30 p.m.- 3:00 p.m.	Wrap-Up and Evaluations.	

PARTNERS IN POLICYMAKING

SESSION VII: SUPPORTED EMPLOYMENT, SUPPORTED LIVING, AND FAMILY SUPPORTS

July 24 and 25, 1992
Sunwood Inn--Bandana Square
1010 Bandana Boulevard, West
St. Paul, Minnesota

FRIDAY, JULY 24, 1992

Time of Activity	Activity	Location
12:00 noon-12:30 p.m.	Registration.	Depot
12:30 p.m.-12:45 p.m.	Announcements.	Roundhouse
12:45 p.m.- 2:30 p.m.	Ian Pumpian, Ph.D., San Diego State University. "Supported Employment Begins in Schools."	Roundhouse
2:30 p.m.- 2:45 p.m.	Break.	Depot
2:45 p.m.- 5:00 p.m.	Ian Pumpian, Ph.D. (cont.). "Issues of Adult Employment."	Roundhouse
5:00 p.m.-6:00 p.m.	Free Time.	Bandana Square
6:00 p.m.-7:00 p.m.	Dinner.	Burlington
7:00 p.m.-9:00 p.m.	Hank Bersani, Ph.D., Legislative Coordinator, ARC Oregon. "Family Supports."	Roundhouse

SATURDAY, JULY 25, 1992

Time of Activity	Activity	Location
8:00 a.m.-9:00 a.m.	Breakfast and Announcements.	Burlington
9:00 a.m.-10:30 a.m.	Hank Bersani, Ph.D. (cont.). "Supported Living, Owning Your Own Home, and the Federal Agenda."	Roundhouse
10:30 a.m.-10:45 a.m.	Break.	Depot
10:45 a.m.-12:00 noon	Hank Bersani, Ph.D. (cont.). "Preparing for Congressional Role Play."	Roundhouse
12:00 noon- 1:00 p.m.	Lunch.	Burlington
1:00 p.m.- 2:30 p.m.	"Role Play with Congressional Staff."	Roundhouse
2:30 p.m.- 3:00 p.m.	Wrap-Up and Adjournment.	

PARTNERS IN POLICYMAKING

SESSION VIII: GRADUATION AND CONDUCTING MEETINGS

September 18 and 19, 1992
Sunwood Inn--Bandana Square
1010 Bandana Boulevard, West
St. Paul, Minnesota

FRIDAY, SEPTEMBER 18, 1992

Time of Activity	Activity	Location
12:00 p.m.-12:30 p.m.	Registration.	Depot
12:30 p.m.-12:45 p.m.	Announcements.	Roundhouse
12:45 p.m.- 2:30 p.m.	Donald Sikkink, Ph.D. "Mastering Robert's Rules of Order."	
2:30 p.m.- 2:45 p.m.	Break.	
2:45 p.m.- 5:00 p.m.	Donald Sikkink (cont.). "Effective Meetings."	
5:00 p.m.- 6:00 p.m.	Break.	
6:00 p.m.- 7:00 p.m	Dinner.	Depot
7:00 p.m.- 9:00 p.m.	Ms. Mary Jo Nichols, Metro Center for Independent Living. "The Americans with Disabilities Act (ADA) and Its Implementation."	Roundhouse

SATURDAY, SEPTEMBER 19, 1992

Time of Activity	Activity	Location
8:00 a.m.- 9:00 a.m.	Breakfast.	Depot
9:00 a.m.-10:30 a.m.	Mr. William Bronston, M.D., World Interdependence Fund. "Effective Youth Leadership."	Roundhouse
10:30 a.m.-10:45 a.m.	Break.	Depot
10:45 a.m.-12:00 noon	Dr. Bronston (cont.). "Global Issues Facing Individuals with Disabilities."	Roundhouse
12:00 noon- 1:00 p.m.	Lunch.	Burlington
1:00 p.m.- 2:30 p.m.	Ed Roberts, President, World Institute on Disability. "Graduation."	Roundhouse
2:30 p.m.- 3:00 p.m.	Wrap-Up and Evaluation.	

TEXAS PIP 1990 AGENDAS
N.D. - Received prior to 1992 Academy

PARTNERS IN POLICYMAKING

Session I: History

August 24 - 25, 1990

Stouffer Hotel
9721 Arboretum Blvd.
Austin, TX

Friday, August 24, 1990

12:00 p.m. - 12:30 p.m.	Registration
12:30 p.m. - 1:00 p.m.	Welcome & Introductions Roger Webb, Executive Director, Texas Planning Council for Developmental Disabilities
1:00 p.m. - 2:45 p.m.	History of Disabilities Colleen Wieck, Ph.D, Executive Director, Minnesota Governor's Planning Council on Developmental Disabilities
2:45 p.m. - 3:00 p.m.	Break
3:00 p.m. - 4:30 p.m.	History of the Independent Living Movement Ed Roberts, President World Institute on Disability
4:30 p.m. - 5:30 p.m.	Break/Social Time
5:30 p.m. - 7:00 p.m.	Dinner
7:00 p.m. - 8:00 p.m.	What is Partners in Policymaking? Colleen Wieck, Ph.D.
8:00 p.m. - 9:00 p.m.	Informal Discussions

Saturday, August 25, 1990

8:30 a.m. - 9:15 p.m.	Breakfast
9:15 a.m. - 10:45 p.m.	History of the Parent Movement Martha Ziegler, Executive Director of Federation for Children and Special Needs
10:45 a.m. - 11:00 a.m.	Break

11:00 a.m. - 12:30 p.m.	History and Personal Perspective of People First Movement **Connie Martinez**, Capitol People First (California) and **Charlene Jones**, Facilitator
12:30 p.m. - 1:30 p.m.	Lunch
1:30 p.m. - 2:30 p.m.	Explanation of Ground Rules and Contracts **Jopie Smith**, and **Terri Kenworthey**, Texas Planning Council for Developmental Disabilities
2:30 p.m. - 3:00 p.m.	Wrap-Up and Evaluation

PARTNERS IN POLICYMAKING

Session II: Education: - Integration and Quality

September 21-22, 1990

Stouffer Hotel
9721 Arboretum Blvd.
Austin, TX

Friday, September 21, 1990

12:00 p.m. - 12:30 p.m.	Registration
12:30 p.m. - 2:00 p.m.	Achieving Integrated Education - Pecos Room Ian Pumpian, Ph.D San Diego State University
2:00 p.m. - 2:15 p.m.	Break
2:15 p.m. - 3:45 p.m.	Pumpian (cont'd)
3:45 p.m. - 4:00 p.m.	Break
4:00 p.m. - 5:00 p.m.	Preparation for Education Roundtable - Pecos Room David Hancox, Director World Institute on Disability - Minnesota
5:00 p.m. - 5:30 p.m.	Break/Social Time
5:30 p.m. - 6:45 p.m.	Dinner - San Marcos Room
7:00 p.m. - 9:00 p.m.	Texas Education Agency Roundtable: - Pecos Room General Directions/Goals - Jill Gray Early Childhood Education - Al Stewart Secondary/Transition - Gene Lenz Compliance/Monitoring - Shirley Weaver Quality/Program Effectiveness - Kim Hoagwood Funding - Terry Lyons

Saturday, September 22, 1990

8:30 a.m. - 9:00 a.m.	Breakfast
9:00 a.m. - 10:30 a.m.	The How-to's of Advocacy in Team Meetings - Pecos Room David Hancox
10:30 a.m. - 10:45 a.m.	Break
10:45 a.m. - 11:45 p.m.	Hancox (Cont'd)
11:45 p.m. - 1:00 p.m.	Lunch - San Saba Room
1:00 p.m. - 2:30 p.m.	Texas Transition Task Force - Pecos Room Leigh Leslie and Jeff Tate
2:30 p.m. - 3:00 p.m.	Wrap-up and Evaluation

PARTNERS IN POLICYMAKING

Session III: Supported Living, Family Supports and Supported Employment

October 26-27, 1990

Stouffer Hotel
9721 Arboretum Blvd.
Austin, TX

Friday, October 26, 1990

12:00 p.m. - 12:30 p.m.	Registration
12:30 p.m. - 5:00 p.m.	Supported Living & Personal Futures Planning - Sabine Room **Jerry Kiracofe**, Executive Director Human Service Institute
5:00 p.m. - 5:30 p.m.	Break/Social Time
5:30 p.m. - 7:00 p.m.	Dinner - San Antonio Room
7:00 p.m. - 9:00 p.m.	Kiracofe (Cont'd.) - Sabine Room

Saturday, October 27, 1990

8:15 a.m. - 9:00 a.m.	Breakfast - Sabine Room
9:00 a.m. - 12:00 p.m.	Supported Employment - Sabine Room **Thomas H. Powell, Ed.D.**, Dean College of Education Eastern Montana College
12:00 p.m. - 1:00 p.m.	Lunch - San Antonio Room
1:00 p.m. - 2:30 p.m.	Family Supports - Sabine Room **Dr. Powell**
2:30 p.m. - 3:00 p.m.	Wrap-up and Evaluation

PARTNERS IN POLICYMAKING

Session IV: Federal Policy & Legislation

November 30 - December 1, 1990

Stouffer Hotel
9721 Arboretum Blvd.
Austin, Texas

Friday, November 30, 1990

12:00 p.m. - 12:30 p.m.	Registration
12:30 p.m. - 2:00 p.m.	The Legislative Process - San Antonio Room Allan Bergman, UCPA/National
2:00 p.m. - 2:15 p.m.	Break
2:15 p.m. - 3:45 p.m.	Medicaid Reform and other Federal Issues Allan Bergman
3:45 p.m. - 4:00 p.m.	Break
4:00 p.m. - 5:00 p.m.	Creating a Vision for the Year 2000 Allan Bergman
5:00 p.m. - 5:30 p.m.	Break
5:30 p.m. - 7:00 p.m.	Dinner - San Marcos Room
7:00 p.m. - 9:00 p.m.	Memory Lane Exercise Fran Smith, UCPA/National

Saturday, December 1, 1990

8:15 a.m. - 9:00 a.m.	Breakfast - San Antonio Room
9:00 a.m. - 11:45 a.m.	Preparing to meet Legislators Fran Smith
11:45 a.m. - 1:00 p.m.	Lunch - Trattoria Restaurant
1:00 p.m. - 2:30 p.m.	Simulated Visits and Feedback
2:30 p.m. - 3:00 p.m.	Wrap-Up and Evaluation

PARTNERS IN POLICYMAKING

Session V: State Legislative Process

January 25-26, 1991

Marriott Hotel at the Capitol
701 E. Eleventh Street
Austin, Texas

Friday, January 25, 1991

12:00 p.m. - 12:30 p.m.	Gather in lobby of Marriott Board buses to Capitol
12:30 p.m. - 3:00 p.m.	Start tour from Capitol rotunda (2 groups) Opening address by Governor's office
3:00 p.m. - 3:30 p.m.	Board buses to Marriott
3:30 p.m. - 4:00 p.m.	Register and pick up packet
4:00 p.m. - 5:15 p.m.	Legislative Process - Salons A,B,C
5:30 p.m. - 7:00 p.m.	Dinner - Salons F,G
7:00 p.m. - 9:00 p.m.	Preparation for hearings - Salons A,B,C

Saturday, January 26, 1991

8:15 a.m. - 9:00 a.m.	Breakfast - Salons A,B,C
9:00 a.m. - 9:30 a.m.	Board buses to Capitol
9:30 a.m. - 9:45 a.m.	Meet in Senate Chamber
9:45 a.m. - 11:30 a.m.	Mock hearing
11:30 a.m. - 12:00 p.m.	Debriefing
12:00 p.m. - 12:30 p.m.	Board buses
12:30 p.m. - 2:00 p.m.	Lunch - Salons A,B,C
2:00 p.m. - 3:00 p.m.	Wrap-up and Evaluation - Salons F,G,H

PARTNERS IN POLICYMAKING

Session VI: Physical Disabilities, Non-Aversive Behavior Approaches, and Technology

February 22-23, 1991

Stouffer Hotel
9721 Arboretum Blvd.
Austin, Texas

Friday, February 22, 1991

12:00 p.m. - 12:30 p.m.	Registration
12:30 p.m. - 5:00 p.m.	Positioning for People with Severe Physical Disabilities - Sabine Room Joan Bergman, Ph.D. Sparks Center, University of Alabama
5:00 p.m. - 5:30 p.m.	Break/Social Time
5:30 p.m. - 7:00 p.m.	Dinner - San Marcos Room
7:00 p.m. - 9:00 p.m.	Non-Aversive Behavior Approaches - Sabine Room Wade Hitzing Society for Community Support Columbus, Ohio

Saturday, February 23, 1991

8:15 a.m. - 9:00 a.m.	Breakfast
9:00 a.m. - 11:45 a.m.	Assessing Technology Needs and Demonstration of Devices - Sabine Room **Robert Stack** and **Richard Dodds** Department of Mental Retardation and DD, New Jersey United Cerebral Palsy, New Jersey
11:45 a.m. - 1:00 p.m.	Lunch - San Marcos Room
1:00 p.m. - 2:30 p.m.	Stack & Dodds (Cont'd) - Sabine Room
2:30 p.m. - 3:00 p.m.	Wrap-up and Evaluation

PARTNERS IN POLICYMAKING

Session VII: The State Service System & Advocacy Organizations

March 22-23, 1991

Marriott Hotel at the Capitol
701 E. Eleventh Street
Austin, Texas

Friday, March 22, 1991 - Salon D

12:00 p.m. - 12:30 p.m.	Registration
12:30 p.m. - 4:30 p.m.	Negotiating the Bureaucratic Maze Mike Bright - ARC/TX Dave Sloane - Advocacy, Inc.
4:30 p.m. - 5:00 p.m.	Protection & Advocacy System Dave Sloane - Advocacy, Inc.
5:00 p.m. - 5:30 p.m.	Break/Social Time
5:30 p.m. - 7:00 p.m.	Dinner
7:00 p.m. - 9:00 p.m.	The DD Council Roger Webb, Executive Director Theda Hoyt, Chair of Advocacy and Public Information Committee

Saturday, March 23, 1991 - Salons A,B,C

8:15 a.m. - 9:00 a.m.	Breakfast		
9:00 a.m. - 9:15 a.m.	The Disability Policy Consortium Roger Webb		
9:15 a.m. - 10:30 a.m.	Advocacy Organizations: Bob Kafka ADAPT	Lucy Garretson ARC/TX	Kay Lambert SAFE & TASH
10:30 a.m. - 10:45 a.m.	Break		
10:45 a.m. - 11:45 a.m.	Belinda Carlton CTD	Patty Anderson UCP/TX	Shirley Uzzell THIA
11:45 a.m. - 1:15 p.m.	Lunch		
1:15 p.m. - 2:30 p.m.	Projects, Wrap-Up and Evaluation		

PARTNERS IN POLICYMAKING

Session VIII: Parliamentary Procedure & Graduation

April 19-20, 1991

Marriott Hotel at the Capitol
701 E. Eleventh Street
Austin, Texas

Friday, April 19, 1991

12:00 p.m. - 12:30 p.m.	Registration
12:30 p.m. - 4:30 p.m.	Understanding Parliamentary Procedure - Salons F,G,H Donald Sikkink, Ph. D.
4:30 p.m. - 5:00 p.m.	Odds and Ends
5:00 p.m. - 5:30 p.m.	Break
5:30 p.m. - 7:00 p.m.	Dinner - Salon E
7:00 p.m. - 9:00 p.m.	Critical Issues for the 90's - Salons F,G,H David Hancox

Saturday, April 20, 1991

8:15 a.m. - 9:00 a.m.	Breakfast - Salon E
9:00 a.m. - 10:00 a.m.	Everything You Ever Wanted to Ask David Hancox
10:00 a.m. - 10:15 a.m.	Break
10:15 a.m. - 12:00 p.m.	Where Do We Go From Here? Ed Roberts
12:00 p.m. - 12:30 p.m.	Evaluation
12:30 p.m. - 2:30 p.m.	Reception/Graduation - Ballroom Terrace
2:30 p.m. - 3:00 p.m.	Wrap-Up

Assignment: Parent Movements; Independent Living.

I. Call or visit: (choose one)

- an Independent Living Center
- a Parent Information Center
- an Advocacy Center

II. Write a brief summary of your visit, which addresses the following:

1. What are the most urgent or common issues at the center this year?
2. What methods are used to address these issues?
3. What does the center view as its major accomplishment?
4. What are the strengths of the center?
5. What are the weaknesses?

III. Write an action plan to address one of the issues identified.

CONNECTICUT PIP HOMEWORK
N.D. - Received prior to 1992 Academy

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* ILLINOIS PIP READING/MATERIALS *
* N.D. - Received prior to 1992 Academy *
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PARTNERS IN POLICYMAKING - ILLINOIS 1990/1991
READINGS & MATERIALS LISTINGS

SESSION #1:

Braddock, D. (1991). Issues in the Closures of State Schools in Texas: A Briefing Paper. Chicago. IL: The University of Illinois at Chicago.

Minnesota Governor's Planning Council on Developmental Disabilities. (1987). A New Way of Thinking. Minnesota: State Planning Agency.

Minnesota Governor's Planning Council on Developmental Disabilities. (1990). Two Year Transitional Plan: October 1, 1989 - September 30, 1991. Minnesota:Author.

Mount, B. & Zwernik, K. (1988). It's Never Too Early, It's Never Too Late: A Booklet About Personal Futures Planning. St. Paul, MN: Minnesota Planning Council on Developmental Disabilities.

Parent Advocacy Coalition for Educational Rights. (1989). An Interview with Ed Roberts. Minneapolis, MN: Author.

Parent Advocacy Coalition for Educational Rights. Thoughts for Those Helping Parents to Become Effective Advocates for their Children with Handicaps. Minneapolis, MN: Author.

World Institute on Disability. (1990). World Institute on Disability: Seven Year Report. Oakland, CA: Author.

Zirpoli, T., Hancox, D., Wieck, C. & Skarnulis, E. (1989). Partners in Policymaking: Empowering People. St. Paul, MN: The Association for Persons with Severe Handicaps.

SESSION #2:

Deal, A. & Dunst, C. (1990). Needs-Based Family-Centered Intervention Practices. Morganton, North Carolina: Family, Infant and Preschool Programs: Western Carolina Center.

Dunst, C. (1990). Family Support Principles: Checklists for Program Builders and Practitioners. Morganton, North Carolina: Family, Infant and Preschool Program: Western Carolina Center.

Dunst, C. & Deal, A. (1990). Individualized Family Support Plans: Model, Methods and Strategies. Morganton, North Carolina: Family, Infant and Preschool Program: Western Carolina Center.

Illinois Planning Council on Developmental Disabilities. (1991). Family Support: A New Way of Thinking. Chicago, IL: Author.

Legal Advocacy for Person with Developmental Disabilities. *Toward an Improved Quality of Life: Quality Program for Adults with Developmental Disabilities: A Guide for Parents, Family Members and Advocates.* Part I & IV. Minneapolis, MN: Author.

Racino, J., O'Connor, S., Shoultz, B., Taylor, S. & Walker, P. (1991 May). *Housing and Support Services: Some Practical Strategies.* Syracuse, NY: Center on Human Policy: Syracuse University. Taken from TASH Newsletter.

Shoultz, B. & Racino, J. (1991 July). *Planning with Individuals.* Syracuse, NY: Center on Human Policy: Syracuse University. Taken from TASH Newsletter.

Varnet, T. *Guardianship and Alternatives to Guardianship.* Chicago, IL: Author.

Varnet, T. *Guardianship and Consent Issues.* Chicago, IL: Author.

SESSION #3:

Forest, M. & Lusthaus, E. (1990 Winter). *Everyone Belongs with the MAPS Action Planning System.* Teaching Exceptional Children.

Forest, M. (1988 Winter). *Full Inclusion is Possible.* MN: Minnesota Impact.

Hablutzel, M.L. (1989). *Section 504 of the Rehabilitation Act of 1973.* Chicago, IL: Author.

Illinois Department of Mental Health and Developmental Disabilities. *Directory of Preadmissions Screening: Annual Resident Review Agents.* IL: Author.

Illinois Early Childhood Intervention Clearinghouse. (1991 June). *Early Intervention.* Springfield, IL: Author.

Illinois Early Childhood Intervention Clearinghouse. (1991 September). *Early Intervention.* Springfield, IL: Author.

Illinois Early Childhood Intervention Clearinghouse. *Information Services for Families of Children with Special Needs.* Springfield, IL: Author.

Legal Advocacy for Persons with Developmental Disabilities. *Adults with Developmental Disabilities: A Guide for Parents, Family Members and Advocates.* Section VII. Minneapolis, MN: Author.

Minnesota Governor's Planning Council on Developmental Disabilities. (1987 July). *Guidelines for Quality Individual Plans.* St. Paul, MN: Author.

Minnesota Governor's Planning Council on Developmental Disabilities. Test Your IQ: Integration Quotient. St. Paul, MN: Author.

Minnesota Governor's Planning Council on Developmental Disabilities. Test Your School's IQ: Integration Quotient. St. Paul, MN: Author.

Minnesota Integrated Education Technical Assistance Project. Integrated School Communities for Students with Developmental Disabilities. Minneapolis, MN: Author.

Parent Advocacy Coalition for Educational Rights. As I See It. Alexandria, VA: Author.

Parent Advocacy Coalition for Educational Rights. Ideas to Help Professionals Include Families in the Planning, Monitoring and Development of Supported Employment. Minneapolis, MN: Author.

Parent Advocacy Coalition for Educational Rights. Opportunity Knocks. Minneapolis, MN: Author.

Pacesetter. (1991 January). Educational Programs: How do Parents Decide? Author.

Pacesetter. (1991 January). Tips on Getting Extended School Year Service. Author.

Varnet, T. Future Financial Planning. Chicago, IL: Author.

Varnet, T. Judicial Update on the E.H.A. Chicago, IL: Author.

Varnet, T. Distinctions Between Section 504 of the Rehabilitation Act and the Education for the Handicapped Act. Chicago, IL : Author.

Walter, S. (1991 March). Public Awareness for Early Intervention Should Be a Family Affair. Springfield, IL: Illinois Early Childhood Intervention Clearinghouse. Taken from Early Intervention.

SESSION #4:

Anderson, O. & Karvounis, V. (1990). Sexuality - Bibliography. Chicago, IL: UAP/DD, University of Illinois at Chicago.

ARC/I. (1988 April). Proposed ARC/I Policy on the Sexuality of Developmentally Disabled Persons. IL: Author.

Bergman, J. & Bramlett, C. (1986). Basic Principles of Seating Achieved Through the Use of Temporary Makeshift Equipment. Author.

Cochran, B. (1974 May). Conception, Coercion and Control: Symposiums on Reproductive Rights of the Mentally Retarded. Taken from Hospital and Community Psychiatry.

Connelly, S. Developing the Sexuality of People With a Handicap. Brothers of Charity Service. Taken from Concepts and Controversies in Services for People with Mental Handicaps.

Cook, R. (1974). Sex Education Program Service Model for the Multihandicapped Adult. Chicago, IL: National Easter Seal Society for Crippled Children & Adults. Taken from Rehabilitation Literature.

Donnellan, A., Mirenda, P., Mesaros, R. & Fassbender, L. (1984). Analyzing the Communicative Functions of Aberrant Behavior. Association for Persons with Severe Handicaps.

Goldman, F. (1978 June-July). Environmental Barriers to Sociosexual Integration: The Insiders' Perspectives. Chicago, IL: National Easter Seal Society for Crippled Children and Adults. Taken from Rehabilitation Literature.

Menolascino, F. (1972 November). Sexual Problems of the Mentally Retarded. New York, NY: Sex Information and Education Council of the U.S. Taken from Sexual Behavior.

Murphy, W. (1987 December). Program Policy Guideline on Sexual Expression for Persons with Developmental Disabilities. IL: Illinois Department of Mental Health and Developmental Disabilities.

Nigro, G. (1976 November-December). Some Observations on Personal Relationships and Sexual Relationships Among Lifelong Disabled Americans. Chicago, IL: National Easter Seal Society for Crippled Children and Adults. Taken from Rehabilitation Literature.

Scales, P. (1980). God, Family and Country: How the Sex Education Opposition Claims Them All. NY: Ed-U Press, Inc.

Schiller, B. (1992 January). Multi Element Treatment Approach Behavioral Programming. Chicago, IL: UAP/DD, University of Illinois at Chicago.

University Affiliated Program. Assistive Technology Unit: Clinic Information & Services. Chicago, IL: University of Illinois at Chicago.

SESSION #5:

Advocates United. (1992 February). State Budget Input Manual. IL: Author.

Community Education and Advocacy for Disabilities. Illinois Budget Cuts Jeopardize Services: We Need Your Help Now. Brookfield, IL: Community Support Services.

Lovett, H., Whaley, R. & Cutler, B. The Autism National Committee: Social Justice For All. Arlington, MA: The Autism National Committee.

Marguerite, L. System Advocacy and Lobbying Defined. Brookfield, IL: Author.

State of Illinois. (1991). Handbook of Illinois Government. Springfield, IL: Author.

Vandercook, T., York, J. and Forest, M. (1989). The McGill Action Planning System (MAPS): A Strategy for Building the Vision. Minneapolis, MN: The Association for Persons with Severe Handicaps.

ILLINOIS PIP HOMEWORK QUESTIONNAIRE
N.D. - Received prior to 1992 Academy

ILLINOIS PARTNERS IN POLICYMAKING 1991-1992

NAME: ________________________ DATE: __________

We would like to make the Partners experience as fulfilling and rich as we possibly can for each of you. Please answer the following questions, that will help us determine specific homework assignments for each of you. We will use this information to attempt to make your homework activities useful and meaningful for your particular needs.

1. What would you like to accomplish as a participant in the Partners Program?

2. Describe the type of homework activities you would be interested in doing? (Please feel free to use the homework/interest rating sheet as a reference for possible activities you might want to do, but do not limit yourself to those ideas.)

3. What disability issues and/or topics are most interesting to you? (Once again, please feel free to use the homework/interest rating sheet as a reference)

4. Would you prefer to work on your own or in a group?

ILLINOIS PARTNERS IN POLICYMAKING 1991-1992

PURPOSE OF HOMEWORK ACTIVITIES

-To make Partners a full experience

-To give you opportunities to put your learning to work

-To strengthen the benefits of Partners to the community

You will each be expected to work on disability issues between sessions of Partners. Some activities will be things we ask everyone to do. Some will be based on your own individual plan of action. At the next session in September, we will ask you to develop an individual plan of action to work on a disability issue that is important to you.

* * * * * *

HOMEWORK ASSIGNMENT #1
Please complete before session #2

1. Bring pictures of you, your family and important people in your life to the next session.
2. Write a description of yourself (and your child if appropriate). Be sure to include your strengths, your interests, and your abilities. (This can be written in your journal.)
3. Describe one change you want to make in your life. (This can be written in your journal.)
4. In addition, write in your journal at least once a week.

l. Collect and review homework assignments with participants.

m. Review budget, handle expense accounts, and reimburse participants expenses.

n. Provide daily management of the project.

CONTENT OF TRAINING SESSIONS. A sample schedule for a training session in included in Appendix 3. The proposed topics for the conferences are:

1. <u>History and philosophy of the parent movement and the independent living movement</u>. This session will start with an overview of the Partners in Policymaking model, its goals and objectives. Dr. Colleen Wieck, David Braddock (UAP/UIC), and Project Staff will be responsible for this session. Then, participants will hear a review the basic philosophical principles and the values of the parent and IL movements, as well as an overview of the historic development of these movements. Potential speakers for this conference include Ed Roberts (World Institute on Disabilities, Elizabeth Boggs, Ph.D. (ARC-US), and Dr. Gershon Berkson (UIC).

<u>Homework</u>: Participants will be asked to prepare a list of individuals actively involved in the policymaking arena in their own localities. This includes identifying elected officials, agency directors, and leaders of local advocacy and political organizations operating in their communities. They will be asked to make special efforts to identify parent or consumer organizations in the area of developmental disabilities. The purpose of this exercise is to increase participants' awareness of the principal players in their local setting.

Participants will also be asked to prepare a list of any sort of personal goals or goals related to developmental disability policy and advocacy. These are goals that they would like to accomplish during their year in the partners project. They will receive a copy of a training manual developed to assist persons with disabilities in setting personal goals (Balcazar & Fawcett, 1989a).

2. <u>Best practices in education</u>. This session will increase participants' awareness of the best current practices and educational models for the habilitation of persons with developmental disabilities. Potential speakers for this session include Adelle Renzaglia, Ph.D. (University of Illinois at Urbana-Champaign), Sharon Freagon, Ph.D. (Northern Illinois University) Ian Pumpian, Ph.D. (University of Wisconsin), and Lou Brown, Ph.D. (University of Wisconsin).

<u>Homework</u>: A) Review and sharing of information gathered about local settings. B) If participants have any school age children, they will be asked to prepare a report about the integration policies and practices in their local school districts. If participants are adults or have adult children with disabilities, they will be asked to identify educational opportunities and programs for adults with developmental disabilities available at local colleges. Participants will be asked to report positive and negative aspects of the educational services and opportunities available to them or their children. They will be asked to present their findings at the next training session.

3. <u>Best practices in employment and living</u>. This session will expose participants to some of the most effective and innovative approaches to employment and independent living for persons with developmental disabilities. Potential speakers include Paul Bates, Ph.D. (Southern Illinois University), Dick Bell, (Executive Director of Services, Inc.) and Hank Bersani, Ph.D. (University of Syracuse). We also would like to schedule a presentation by Rudd Turnbull, Ph.D. (University of Kansas) and/or Theresa Varnet, MSW, J.D. (Spain, Spain, & Varnet) about issues of guardianship for persons who are severely disabled.

<u>Homework</u>: A) Present information concerning educational programs and experience; B) Participants will be asked to identify services and opportunities regarding employment and residential arrangements in their own communities. If any waiting list for services exist, they should specify the type of service, the number of people on the waiting list (if available), and the average waiting period for people on the list. Participants will be asked to interview a person with a disability regarding his/her employment experience. This might include a discussion of topics like satisfaction with their work, salary level, co-workers, supervisors, available support, and needs. They will be asked to present this information at the beginning of the next training session.

C) Participants will be asked to review their own list of personal goals by the next session in light of the information that has been presented to them thus far. Staff members will meet individually with participants to discuss their personal goals.

4. <u>Non-aversive approaches to severe behavior problems, assistive technology developments, and treatment of individuals with severe disabilities</u>. This session will provide an overview of some of the most recent technological advances and practices in the areas of non-aversive approaches to severe behavior problems, assistive technology developments, and treatment of individuals with severe

disabilities. Potential speakers for this session include Joan Bergman, Ph.D. (University of Alabama), Glenn Hedman, Ph.D. (UAP/UIC), Beth Mount, Ph.D. (Consultant), and William Schiller, Ph.D. (UAP/UIC).

Homework: A) Participants will share their homework assignments; B) Participants will be asked to arrange meeting(s) with one or more local public officials, directors of a service providing agency, or leaders of advocacy organizations with the purpose of recruiting that person as a mentor. Participants will receive copies of a training manual developed to teach people with disabilities how to recruit helpers and mentors to attain personal goals (Balcazar & Fawcett, 1989b). Participants will be asked to share their personal goals with their mentors and request their assistance in developing an action plan for attaining those goals. Participants will report the outcome of their meeting at the next session.

5. Effective consumer involvement in advocacy organizations: setting agendas for policymaking. This session will address several areas of community organizing and advocacy in the area of developmental disabilities. Participants will review instructional materials developed to teach people with disabilities how to identify and report issues (Seekins, Balcazar, & Fawcett, 1986a), how to develop a plan for advocacy actions (Seekins, Balcazar, & Fawcett, 1986b), and how to chair action-oriented meetings (Seekins, Balcazar, & Fawcett, 1986c). One session will provide an overview of the People First Movement. Mrs. Nancy Ward (People First of Nebraska) and Bonnie Schoultz, Ph.D. (RTC on Community Integration, Syracuse University) will be invited for this presentation. Another session will address national advocacy organizations for parents and people with developmental disabilities. Allan Bergman(UCP-US). Diane Crutcher (Down Syndrome Congress), Sheila Hebein (National Association of Down Syndrome) will be invited for this presentation.

Homework: A) Participants will share their homework assignments; B) Participants will be asked to identify a consumer advocacy organization in their city and joint it. In those places where no consumer advocacy organization exist, participants will be asked to organize a focus group discussion that might serve as a starting point for the creation of a consumer advocacy organization. Participants will be asked to share their experiences at the beginning of the next training session.

6. Policymaking at the local level. This session will introduce participants to the service delivery system in the state. Topics include access to services, coordination, and the role of advocates. We will invite directors of State

Agencies like DMHDD, DORS, the Special Education department of the Illinois Department of Education, and Illinois Protection and Advocacy. Participants will also hear presentations from several directors of non-for-profit service agencies, such as Elizabeth Lacey (Community Support Services, Inc.), Lynn O'Shea (Seguin Services, Inc.), Art Dykstra, Trinity Services Inc., and/or Joanell Voigt (Community Alternatives Unlimited), as well as presentations by leaders of advocacy organizations in Illinois such as Tea Nelis, President of People First of Naperville. Participants will receive instructional materials and will practice writing letters to public officials (Seekins & Fawcett, 1982a), writing letters to editors of newspapers (Seekins & Fawcett, 1982b), and providing public testimony (Seekins & Fawcett, 1982c).

Homework: A) Participants will share their homework assignments; B) Participants will receive a list of current legislative issues at the state level and will be asked to write a letter to the editor of a local newspaper and to an elected public official regarding a legislative issue of concern. Those participants that choose to provide personal testimony at a public hearing will be asked to prepare it.

7. Policymaking at the State level. This session will be conducted in Springfield. The purpose is to expose participants to the policy making process in the state capitol. Efforts will be made to arrange presentations from the Governor's office staff, representatives from the State Legislature, and Code agencies. Potential speakers also include Cathy Ficker Terrill from the IPCDD, and legislators Judy Baar Topinka, Lee Daniels, and Andy McGann.

Homework: A) Participants will share their homework assignments; B) Participants will be asked to continue recording their advocacy activities for three months after the last training session. They will be contacted monthly by project staff to collect data.

Starting date: 4th month.
Completion date: 10th month.

Measures: We will submit to the Council a complete list of the presentations, presenters, attendants, conference objectives, and topics covered during the presentations. A list of the materials used and copies of participants' homework assignments will also be included.

Potential barriers and contingency plans: We will schedule speakers with ample time in advance and will ask for advance cancellations whenever possible. If a cancellation occurs within one or two weeks prior to the scheduled session, we might be able to find a replacement. In case any of the speakers has a last minute cancellation, we could either ask the other invited speakers to elaborate further in their presentations to cover the additional time or use the time to review participants' projects and advocacy activities in the communities where they live.

Project staff and volunteers will provide pre and post-conference briefings to self-advocates and will be available to assist them with additional support during training sessions as needed. Project staff will also be available for support and technical consultation regarding homework assignments to participants during and between training sessions. We will help answer questions and provide referrals whenever required.

OBJECTIVE 3. Acquaint and connect participants to state organizations and services in the area of developmental disabilities. Specific tasks:

a. Contact and invite directors of state agencies like DMHDD, DORS, the Special Education section of the Illinois Department of Education, the IPCDD, the Illinois Department of Public Aid, and Illinois Protection and Advocacy to attend and address at least one training session. We will also invite several directors of non-profit service agencies to describe their programs and services.

b. Contact and invite leaders of consumer advocacy organizations to address participants and share their experiences and activities.

c. Ask participants to conduct an informal survey of the services available for people with developmental disabilities and their families at their own localities.

d. Ask participants to contact local consumer advocacy organizations to become familiar with the issues and the tactics of consumer involvement.

Starting date: 4th month.
Completion date: 10th month.

Measures: List of agency directors attending sessions, list of advocacy leaders, summary of informal surveys of services conducted by participants, and list of advocacy organizations contacted by participants and issues identified.

Potential barriers and contingency plans: We will notify agency directors in advance in order to increase the chances they might be able to attend the training conference. We will also contact advocacy leaders in the state with sufficient time and will offer to compensate for their travel expenses to make a presentation at a conference.

OBJECTIVE 4. Provide opportunities for participants to apply their advocacy skills in the policymaking and legislative process. Specific tasks:

a. Assist participants in the process of recruiting a mentor from their own community. This person--who should preferably be an elected official, the director of a service provider agency, or the president of a consumer advocacy organization--will provide guidance to participants regarding the politics of advocacy, service provision, and decision making in their own city and at the state level. Participants will receive copies of a training manual designed to assist people in the process of recruiting mentors and potential helpers (Balcazar & Fawcett, 1989b). A half-day training session on this topic will be included in the program.

b. Assist participants in the process of becoming actively involved in a local or state wide advocacy organization. This experience is intended to increase participant's local support and advocacy network. Training materials designed to instruct advocacy group members how to identify and report issues (Seekins, et al., 1986a,b), and chair action-oriented meetings (Seekins, et al., 1986c) will be distributed to participants. Self-advocates will receive copies of materials that were developed by People First organizations and adapted by UAP/UIC staff.

c. Assist participants to prepare for advocacy activities such as writing letters to the editor or writing to public officials, public speaking, and providing public testimony. Manuals prepared to assist consumers with these activities (Seekins & Fawcett, 1982a,b,c) will be distributed to all participants.

d. Assist participants in the process of organizing a focus group discussion of some relevant issue that affects them at the personal level. This is a meeting participants can organize with other people experiencing a similar situation. During the meeting, attendants discuss the dimensions of the problem, how are they affected by the situation, and what can they do to address it. This could lead to the starting of an advocacy organization in some cases. Training materials designed to instruct consumers how to conduct a focus group discussion (Fawcett, Suarez, Johnson, Whang-Ramos, Seekins, & Bradford, 1982) will be distributed to participants.

Starting date: 4th month.
Completion date: 12th month.

Measures: List of participants' mentors, list of advocacy organizations that participants join, copies of letters to editors and public officials, and list of presentations and public testimony delivered by participants.

Potential barriers and contingency plans: We have included several training manuals developed by project staff as resources that will be used by participants to prepare for their advocacy actions. These materials provide examples, role play exercises, and practice opportunities for participants to develop their skills. We will schedule training sessions with participants that will focus of the development of their own advocacy skills. This way we intend to strike a balance between the knowledge and information they receive from leaders in the field, and their hands-on-experience as advocates.

OBJECTIVE 5. Increase participants' awareness of relevant issues pertaining to persons with developmental disabilities. Specific tasks:

a. Contact and recruit national leading figures that will present the state-of-the-art developments in the areas of employment, education, living arrangements, non-aversive behavior management, assistive technology, guardianship choices, and treatment of severe developmental disabilities.

b. Ask participants to identify and evaluate current practices available to them regarding employment, education, living arrangements, non-aversive behavior management, assistive technology, guardianship, and management of severe developmental disabilities.

Starting date: 4th month.
Completion date: 10th month.

Measures: List of presenters and copies of participants' evaluation of their own services.

Potential barriers and contingency plans: Efforts will be made to recruit top national leaders in the various topics we have selected for presentations. For each session concerning national issues we will try to schedule at least two national leaders as presenters. They will be available for interaction with participants during the training session. We will provide participants direct guidance and instructions about how to conduct the evaluation of the services available in their own cities.

OBJECTIVE 6. Evaluate participants' skills and their satisfaction with training materials and procedures. Specific tasks:

a. Prepare evaluation forms.

b. Distribute and tabulate trainees' satisfaction evaluation forms after each training session.

Homework/Reading Assignments

LOUISIANA HOMEWORK/READING
N.D. - Received prior to 1992 Academy

January: Read Louisiana's Community and Family Support System Plan

February: Find out who your state legislators are

March: Write, call or visit your legislator regarding the supports and services you or your family requires

April: Bring your child's IEP/yourIHP to the next meeting

May: Call, visit, or write your BESE board members regarding your local educational concern

June: Come to the July meeting prepared to tell us what you are going to focus on accomplishing when you graduate from Partners

HOMEWORK FOR PARTNERS IN POLICY-MAKING FOR PARENTS

Our focus for the next training session will be on education from infant programs to college and adult education.

Please answer the following questions in preparation for that session:

1. Age of your child: ______

2. What educational services does your child receive?

NEW YORK PIP HOMEWORK
N.D. - Received prior to 1992 Academy

3. Does your child have an IEP? (Individualized Education Plan? ___YES ___No

4. If YES, what is your opinion about its quality and appropriateness?

5. What is your greatest concern about the current education system?

6. What is or was the major problem in your experiences with the education systems?

NEW YORK PIP HOMEWORK
N.D. - Received prior to 1992 Academy

PARTNERS IN POLICY MAKING TRAINING PROJECT

HOMEWORK ASSIGNMENT

THE 1-2-3 ASSIGNMENT

1. Meet with a least one parent or advocacy group to share the information you have gained in this training session and encourage them to become involved in more effective leadership roles in policy making processes.

2. Write two letters , one to your Senator and one to your Assemblyman or Assemblywoman, to introduce yourself, tell your story and concerns, and to ask for their support.

3. Discuss what you have learned at this training session with three other parents or self advocates.

TEXAS PIP HOMEWORK/READING
N.D. - Received prior to 1992 Academy

PARTNERS IN POLICYMAKING
READING/HOMEWORK ASSIGNMENTS

SEPTEMBER 1991

1. A New Way of Thinking, Minnesota DD Council.
2. Circles of Friends, Perske.
3. "People's Voice" (Speaking For Ourselves of Colorado).
4. "Getting On Board" (Speaking for Ourselves of Colorado Newsletter).
5. New Vision Magazine.
6. "Directions," June, 91.
7. "Best Practice Guidelines for Meeting the Needs of All Students in Local Schools" (Vermont).
8. "Caught in the Continuum: A Critical Analysis of the Principle of the Least Restrictive Environment," Syracuse University.
9. How To Get Services by Being Assertive, Coordinating Council for Handicapped Children.
10. National Parent Network on Disabilities (Brochure).

OCTOBER 1991

1. Test Your School's IQ Integration Quotient (ARC).
2. Parental Check List for Quality Education (Rhode Island DD Council).
3. Action for Inclusion, O'Brien & Forrest.
4. "After Your Graduate, What Will You Do?" (TTTF).
5. Texas Transition Task Force Newsletter.
6. "Supported Employment," Article by Tom Powell.
7. American 2000 Education Reform.
8. "Special Edition," Quarterly Newsletter of Advocacy, Inc. Special Education Staff.
9. "Dreaming, Speaking and Creating What I Know About Community," Judith A. Snow.
10. "Toward Economic Self-Sufficiency & Personal Independence For Students with Disabilities," Texas Education Code.

    "A Plan for Reorganization of the Texas Education Agency."

    Individuals with Disabilities Education Act, Pub. Law 101-476.

    State Board of Education, Subchapter G-Special Education.

    Clarification of Graduation Rule, TEA.

    Memo of Understanding on Transition Planning for Students Enrolled in Special Education, TEA.

    Disability Policy Consortium letter on funding weights in special education.
11. "Futures Planning-Supporting A New Vision."
12. Schools Are For Everyone (Brochure).
13. ARC\Guidelines For Quality Individual Plans (Brochure).
14. It's Never Too Early; It's Never Too Late, Minnesota DD Council.

ASSIGNMENTS:
- Visit A State School, nursing home and/or sheltered workshop prior to next session.
- Call America 2000 hotline & voice your concerns on education reform.

NOVEMBER 1991

1. Texas Interagency Council on Early Childhood Intervention Board Nominations.
2. Texas Planning Council for DD Position Statements.
3. "Issues in the Closure of State Schools in Texas: A Briefing Paper," David Braddock, Ph.D.
4. "Texas Department of Human Services In-Home & Family Support Program."
5. Read My Lips, It's My Choice, Minnesota DD Council.
6. "Changing Paradigms," Jerry Kiracofe.
7. "Regenerating Community," John L. McKnight.
8. "Discovering Community," John O'Brien.
9. "Families Meeting Challenge Promoting Change," Oregon DD Council.
10. Family Support Bulletin, United Cerebral Palsy Association.
11. Staying At Home (Family Support Program through TDHS Brochure).
12. "In-Home & Family Support for Persons with Mental Disabilities", TX MHMR.
13. Community Living Assistance & Support Services (Brochure).
14. List of CLASS Providers.
15. "Home & Community Based Services Program Overview," TX MHMR.
16. CTAT Field Report Summer 1990.
17. "Understanding SSI Work Incentives For People with Disabilities," Patti Roth.
18. "Impairment-Related Work Expenses."
19. "Plans for Achieving Self-Support."
20. "Work Expenses of The Blind."

ASSIGNMENTS: Write Governor Richards and Facility Review Task Force to express support of state school closure.

JANUARY 1992

1. "Americans with Disabilities Agenda For Change," (TASH Brochure).
2. "The Americans with Disabilities Act," US Dept of Justice.
3. Word From Washington, "HCFA Awards CSLA to 8 States," and "Part H Reauthorization Signed Into Law."
4. Family Support Bulletin, "Fast Facts on IEPs," and "Myths & Realities."
5. Americans with Disabilities Act Statutory Deadlines.
6. "Lobbying By Letter."
7. "Quality Assurance: Beyond Minimal Compliance," Hank Bersani.
8. ARC Facts: Citizen Monitoring.
9. "Lobbying: By Personal Visit."
10. "Ten Commandments of Lobbying."
11. "Political Power," Hank Bersani, Jr.
12. Action Alert: Town meetings on Health Insurance Crisis.
13. Alert from Texas Planning Council for DD on Facility Review Task Force hearings.
14. "How a Bill Becomes a Law."
15. "Legislative Advocacy," Fran Smith.
16. Roster of Texas Congressional delegation.
17. "Community Supported Living Arrangements (Medicaid/Title XIX)," TPCDD.
18. "Assertiveness Is..."
19. The Americans with Disabilities Act Communication Accommodations Project, Resource for Voluntary Compliance.
20. All Kids Can Learn: Strategies for Integrated Education, Conference Announcement, PEAK.
21. Making A Difference: Active Participation In The Texas Legislative Process, Betty Button & Allen Dietz.

ASSIGNMENTS:
- Attend Town Meetings on Health Insurance Crisis.
- Attend/Testify at Facility Review Hearings.
- Visit Congressperson or staff and send us a copy of thank you letter.

FEBRUARY 1992

1. Accessibility Guide to the Texas State Capitol, TPCDD.
2. Roster of the Seventy-Second Legislature of State of Texas.
3. 1992 Texas Primary Booklet.
4. Order form for The U.S. Congress Handbook for 1992.
5. Alert on Facility Review Task Force Nears Decision on Closure/Consolidation of Texas State Schools, TPCDD.
6. "Briefing Document on Appropriations Issues," TPCDD.
7. Health and Human Services Legislative Appropriations.
8. Testimony to the Joint Committee on Appropriations, TPCDD.
9. "Technological Adaptations to Increase Independence," Robert Stack.
10. Family Support Bulletin, "My Dream IEP Meeting."
11. FY 1991 - HCS Program Providers, TX MHMR.
12. "Office of Special Education Programs Clarifies Right to Assistive Technology," UCPA.
13. Letter from United States Department of Education on Public Meetings/OSEP Review.
14. Work Site Scenario, Richard Dodds.

ASSIGNMENTS: Write to Mock Hearing participants.
Attend/testify at OSEP Review Meetings.

MARCH 1992

1. Summer Institute in Integrated Education & Community, McGill University Announcement.
2. Herb Lovett's Relevant Resource List.
3. "Why Do We Bother With Positioning Anyway?," Joan Bergman, Ph.D.
4. University of Alabama Sparks Center Resources.
5. Therapeutic Positioning & Mobility Selected Bibliography, University of Alabama Sparks Center.
6. Seating and Positioning - A Two Part Series, UCP.
7. "Facilitated Communication," Rosemary Crossley.
8. Disability Policy Consortium Recommendations to Facility Review Task Force.
9. Impact, Feature Issue on Inclusive Education Fall 1991, Institute on Community Integration.
10. Resource Directory, Heath Resource Center.
11. ADA - Your Responsibility as an Employer, EEOC.
12. ADA - Your Employment Rights as an Individual with a Disability, EEOC.
13. ADA - Questions and Answers, EEOC.

ASSIGNMENTS: Call Governor's Hotline and voice support for Facility Review Task Force Recommendations and get 5 others to do the same.

April 1992

1. Guiding Principles of the Disability Policy Consortium (DPC).
2. DPC Advocacy Platform.
3. Roster of DPC.
4. "The Civic Index, A New Approach for Improving Community Life," National Civic League.
5. "The Art of Coalition Building," Cherie R. Brown.

6. Overview of the Texas DD Council.
7. DD Grant Projects List.
8. Texas Health & Human Services Briefing Document.
9. Texas Restructuring Health & Human Services Programs.
10. Legislative Bulletin, 72nd Session.
11. "Self-Advocacy: The Struggle for Equality & Acceptance," B. Carabello et.al.
12. Statement of Governor Ann Richards, 3/26/92.

ASSIGNMENTS:

- Visit legislators about budget crisis and discuss importance of funding community supports and services and your views on state school closure.

- Send us a copy of your thank you notes/letters to legislators.

PARTNERS IN POLICYMAKING OF ALABAMA
TIME/MATCH RECORD

The purpose of this form is to collect information about the amount of time that you spend working on Partners in Policymaking of Alabama. This information will enable the Alabama Governor's Planning Council on Developmental Disabilities to use time that you have devoted to this project as match for the federal grant that is being used to support this project. Please estimate the time to the best of your ability and sign this form in the place provided. Thank you.

Name:____

Date:____

If you are employed, please indicate your hourly rate.
$_________(It is only necessary to provide this information once.)

____
SIGNATURE

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*****************************************
*                                       *
*     ALABAMA PIP TIME/MATCH RECORD     *
*                                       *
* N.D. - Received prior to 1992 Academy *
*                                       *
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PARTNERS IN POLICYMAKING OF ALABAMA

NAME: ____________________________________

DATE: ______________________ REPORTING ON MONTH OF ________________

DATE	TIME ON	TYPE OF ACTIVITY	TOOL FOR ACTIVITIES (i.e. PHONE, LETTER)

BRIEFLY STATE MONTHLY ACTIVITIES RELATED TO P.I.P.A

SINCE LAST COMPLETING ONE OF THESE FORMS, I HAVE SPENT APPROXIMATELY _______ HOURS ON HOMEWORK ASSIGNMENTS, READING, PHONE CALLS, PERSONAL CONTACTS, OR OTHER MATTERS DIRECTLY RELATED TO THIS PROGRAM.

____ ________________

TEXAS PIP TIME/MATCH RECORD
N.D. - Received prior to 1992 Academy

PARTNERS IN POLICYMAKING

TIME/MATCH RECORD

The purpose of this form is to collect information about the amount of time that you spend working on Partners in Policymaking outside of the regularly scheduled sessions. This information will enable the Texas Planning Council for Developmental Disabilities to use time that you have devoted to this project as match for the federal grant that is being used to support this project. Please estimate the time to the best of your ability and sign this form in the place provided. Thank you.

Name:(Please Print) ______________________________

Date: ______________________

I have spent approximately __________ hours on homework assignments, reading, phone calls, personal contacts, or other matters in preparation for this session.

____

Signature

Please give a brief summary of any advocacy activities since last session.

____

____

____

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____

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____

____

____

NATIONAL ACADEMY ON PARTNERS IN POLICYMAKING
THURSDAY-SATURDAY, MAY 14-16, 1992
DOUBLETREE HOTEL AT LINCOLN CENTRE
5410 LBJ FREEWAY
DALLAS, TEXAS

LOGISTICS

CONTENTS

PARTNERS IN POLICYMAKING OF ALABAMA BUDGET

1990-91

ALABAMA PIP BUDGET
N.D. - Received prior to 1992 Academy

Exhibit I (Cont)

Project		29,750	
Benefits		6,286	
Workshop coordinator (Part Time)		960	
Benefits		73	
Project Administrator		6,489	*
Benefits		1,341	*
Project Director @ 20%		5,984	
Benefits		1,330	
Supporting Staff		4,149	
Benefits		1,194	
Partners in Policymaking participants			
Time contributions of participants		23,470	*
	81,026		
Travel and Meetings			
A. Staff Travel		3,500	
B. Volunteer Travel		46,900	
C. Consultant/Conference Speakers		16,567	
D. Meeting Space		1,500	
	68,467		
Printing and Copying		3,000	
Office Supplies		1,000	
Postage and Mailing		600	
Telephone		2,512	
Rental, Lease and Utilities			
A. Equipment Lease		2,100	
B. Rental Space		2,213	*
C. Utilities		1,831	*
Total All Expenses		162,749	
Federal DD Funds		122,062	
Match Funds		40,687	
In-Kind Match	35,344		
Cash Match	5,343		

* Indicates those expenses to be used as match for the project.

January 14, 1992

PARTNERS IN POLICYMAKING
PRELIMINARY COST PROJECTIONS

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****************************************
*                                      *
*        CALIFORNIA PIP BUDGET         *
* N.D. - Received prior to 1992 Academy *
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Participants (including facilitators and attendants)

Area Board IV	19
Area Board V	19
Area Board XIII	17
Total	55

Travel

Meals	$56/person/55 people/5 sessions=	$ 15,400
	$10/person/17 people/1 session=	170
	Total	$ 15,570
Rooms	$66/room/40 rooms/4 sessions=	$ 10,560
	$66/room/42 rooms/1 session=	2,772
	Total	$ 13,332
Flights	$64/flight/17 people/5 sessions=	$ 5,440
Related Travel Expenses	Area Board IV:	
	120 miles/$.24/mile/11 people/4 sessions=	$ 1,267
	150 miles/$.24/mile/11 people/1 session=	396
	$1 toll/11 people/4 sessions=	44
	Total	$ 1,707
	Area Board V:	
	707 miles/$.24/mile/4 sessions=	$ 679
	210 miles/$.24/mile/11 people/1 session=	554
	Transit= $46/session/4 sessions=	184
	Total	$ 1,417
	Area Board XIII	
	330 miles/$.24/mile/5 sessions=	$ 396
	Transit= $210/5 sessions=	1,050
	Parking= $94/5 sessions=	470
	Total	$ 1,916

GRAND TOTAL TRAVEL **$39,382**

Respite/Child Care

$30/session/10 requests/5 sessions=	$ 1,500
$25/session/1 request/5 sessions=	125
$15/session/1 request/5 sessions=	75
$51/session/1 request/5 sessions=	255
$506/session/1 request/5 sessions=	2,530
GRAND TOTAL RESPITE/CHILD CARE	**$ 4,485**

Facilitator/Attendant Fees

Area Board IV	
2 facilitators/$150/session/5 sessions=	$ 1,500
1 facilitator/$200/session/5 sessions=	1,000
Total	$ 2,500
Area Board V	
1 facilitator/$150/session/5 sessions=	$ 750
1 facilitator/$200/session/5 sessions=	1,000
2 attendants/$150/session/5 sessions=	1,500
Total	$ 3,250
Area Board XIII	
2 attendants/$150/session/5 sessions=	$ 1,500
GRAND TOTAL FACILITATOR/ATTENDANT	**$ 7,250**

GRAND TOTAL PARTICIPANTS' COSTS	**$ 51,117**
Faculty Expenses	**$ 9,480**

Support Costs

Personnel	$ 5,280
Operations	2,630
Overhead	5,110
GRAND TOTAL SUPPORT COSTS	**$13,020**

GRAND TOTAL PRELIMINARY COST PROJECTION	**$73,617**

ESTIMATED BUDGET

1991-92 ILLINOIS PARTNERS PROGRAM

31 PARTNERS
7 SESSIONS

ILLINOIS PIP BUDGET
N.D. - Received prior to 1992 Academy

Publicity and Recruitment	$ 3,300
Staff Salaries and Fringes	$53,500
Space, computers, telephones postage, miscellaneous equipment and supplies	$ 6,000
Staff Travel Expenses	$ 4,000
Partner's Respite, Travel and Support	$12,000
Partner's Meals, Lodging, Equipment Rental	$20,000
Partner's Materials	$ 6,300
Speakers (Honorarium, Travel and Support)	$20,000
University of Illinois	$ 6,800
TOTAL	$131,900

The actual grant amount was $75,000. The remaining funds were primarily in kind donations from the UAP, as well as the Illinois Planning Council on Developmental Disabilities, Minnesota Governor's Planning Council on Developmental Disabilities, Illinois Chapter of AAMR, ARC of Illinois and the Coordinating Council for Handicapped Children.

ATTACHMENT TWO TO AMENDMENT ONE

IOWA PROTECTION AND ADVOCACY SERVICES, INC.
CONTRACT #90-321-413-0500-2464-01

Participation in Policy-Making

	PLANNING AGENCY	CONTRACTOR'S SHARE	CONTRACT TOTAL
Personnel			
Project Coordinator	$21,399.00	$.00	$21,399.00
Project Advisor	$3,056.00	$.00	$3,056.00
Project Support	$3,900.00	$.00	$3,900.00
Secretary	$3,710.00	$.00	$3,710.00
Fringe	$3,272.00	$.00	$3,272.00
Subtotal	$35,337.00	$.00	$35,337.00
Travel			
Staff	$1,598.00	$.00	$1,598.00
Steering Committee	$45.00	$1,000.00	$1,045.00
Planning Committee	$950.00	$1,000.00	$1,950.00
'90 Graduates	$2,500.00	$3,834.00	$6,334.00
Subtotal	$5,093.00	$5,834.00	$10,927.00
Other			
Session Expenses			
A. Participant Attendance	$12,858.00	$25,000.00	$37,858.00
B. Participant Materials	$3,729.00	$.00	$3,729.00
C. Facility Expenses	$7,580.00	$.00	$7,580.00
D. Speaker Expenses	$8,614.00	$.00	$8,614.00
E. Local Presentors	$.00	$2,000.00	$2,000.00
F. Participant Accounts	$2,500.00	$.00	$2,500.00
G. Faculty	$2,500.00	$.00	$2,500.00
Office Supplies	$2,260.00	$.00	$2,260.00
Rent	$.00	$.00	$.00
Postage	$1,710.00	$.00	$1,710.00
Phone	$2,195.00	$.00	$2,195.00
Audit	$360.00	$.00	$360.00
Subtotal	$44,306.00	$27,000.00	$71,306.00
TOTAL	**$84,736.00**	**$32,834.00**	**$117,750.00**

IOWA PIP 1991 BUDGET

N.D. - Received prior to 1992 Academy

PROJECT BUDGET (REVISED)

ATTACHMENT TWO
CONTRACT # 90-321-413-0500-2464-01

IOWA PROTECTION AND ADVOCACY SERVICES, INC.
PARTICIPATION IN POLICY-MAKING

	PLANNING AGENCY	CONTRACTOR'S SHARE	CONTRACT TOTAL
PERSONNEL			
Project Advisor	$3,120.00	$.00	$3,120.00
Project Coordinator	$8,835.00	$.00	$8,835.00
Secretary	$1,100.00	$832.00	$1,932.00
Fringe	$420.00	$292.00	$712.00
Subtotal	$13,475.00	$1,124.00	$14,599.00
TRAVEL			
Staff	$800.00	$.00	$800.00
Steering Committee	$400.00	$1,000.00	$1,400.00
Subtotal	$1,200.00	$1,000.00	$2,200.00
OTHER			
Session Expenses:			
A. Participant Attendance	$6,125.00	$12,000.00	$18,125.00
B. Participant Materials	$3,140.00	$.00	$3,140.00
C. Facility Expenses (Rent/Meals)	$3,225.00	$.00	$3,225.00
D. Speaker Expenses	$5,000.00	$.00	$5,000.00
E. Local Presentors	$.00	$2,000.00	$2,000.00
Office Supplies	$810.00	$.00	$810.00
Rent	$.00	$480.00	$480.00
Postage	$575.00	$.00	$575.00
Phone	$1,450.00	$.00	$1,450.00
Subtotal	$20,325.00	$14,480.00	$34,805.00
Total	$35,000.00	$16,604.00	$51,604.00

IOWA PIP 1990 BUDGET

N.D. - Received prior to 1992 Academy

LOUISIANA PIP BUDGET
N.D. - Received prior to 1992 Academy

Partners in Policymaking

7/90

Partners in Policymaking is a leadership training for people with developmental disabilities and young parents. The program will provide intensive training to 30 to 35 people across the state. Partners in Policymaking will provide information, training and skill building to individuals so that they can obtain state-of-the art services for themselves and others. The training sessions will occur one weekend a month for eight months. Contractor will coordinate this project.

TASKS

Provide staff support to steering committee

Recruit, interview, and select participants for training

Schedule training sessions and make hotel accommodations

Choose and schedule speakers for training sessions

Coordinate logistics of training sessions

BUDGET

Personnel		
40% time for Project Coordinator	$14,950	
Consultant/Contractural		
Honorariums for speakers	11,000	
Travel		
Speakers	10,000	
Participants	34,500	
Project Coordinator	800	
Consumable Supplies		
Purchase of training materials	2,000	
Miscellaneous		
Meeting rooms	2,400	
Equipment rental	500	
Child care	1,000	
Respite	4,000	
Personal Care Attendants	1,200	
TOTAL		$82,350

TEXAS VELOPMENTAL DISABILITIES PROGR DATE: 8/29/91
III. GRANT FINANCIAL INFORMATION
91141 A. BUDGET DETAIL B/P: 9/1/91-5/31/92

1. PERSONAL SERVICES: SITION	SALARY & WAGES NAME	ANNUAL SALARY	T.O.P. MO	 %	FEDERAL	MATCH	TOTAL
PROJECT DIRECTOR:	Allen Dietz	31200	9.0	25	5850 ✓	0	5850 ✓
ASSISTANT DIRECTOR:	Betty Button	31200	9.0	15	3510 ✓	0	3510 ✓
Additional Services:							
State Issues Workshop					2500	0	2500 ✓
Federal Issues Workshop					1225	0	1225 ✓
	SUB-TOTAL SALARY & WAGES				13085 ✓	0	13085 ✓
FRINGE BENEFITS:	FICA 7.65				716	0	716
	SUB-TOTAL FRINGE BENEFIT				716 ✓	0 ✓	716 ✓
	PERSONAL SERVICES TOTALS				13801 ✓	0 ✓	13801 ✓
2. TRAVEL (IN STATE):	NONE				0	0	0
	TRAVEL TOTALS				0 ✓	0 ✓	0 ✓
3. PURCHASED SERVICES: A. PROF. SERVICES	ACCOUNTANT				4000	0	4000 ✓
	TRAINER/TRAINEES				105000	0	105000 ✓
	PURCHASED SERVICES TOTALS				109000 ✓	0 ✓	109000 ✓
4. PROPERTY & MATERIALS: A. SUPPLIES/MATERIALS:	CONSUMABLES				250	0	250
	PROPERTY & MATERIALS TOTALS				250 ✓	0 ✓	250 ✓
5. RENTAL & LEASING:	NONE				0	0	0
	RENTAL & LEASING TOTALS				0 ✓	0 ✓	0
6. UTILITIES:	POSTAGE				200	0	200
	TELEPHONE-LONG DISTANCE				900	0	900
	UTILITIES TOTALS				1100 ✓	0 ✓	1100
7. NEG. IND. COST RATE:	NONE					0	0
	BUDGET PERIOD TOTALS				$124151 ✓	$0 ✓	$124151
					100%	0%	

TEXAS PIP BUDGET

N.D. - Received prior to 1992 Academy

TEXAS DEVELOPMENTAL DISABILITIES PROGRAM

Grant Workplan

PART III: FINANCIAL INFORMATION

Budget Detail Summary		FEDERAL	MATCH	TOTALS
1.	PERSONAL SERVICES TOTALS	13,801.00		13,801.00
2.	TRAVEL TOTALS	0.00		0.00
3.	PURCHASED SERVICES TOTALS	109,000.00 wvw ~~4,000.00~~		109,000.00 ~~4,000.00~~
4.	PROPERTY/MATERIALS TOTALS	250.00		250.00
5.	RENTAL/LEASING TOTALS	0.00		0.00
6.	UTILITIES TOTALS	1,100.00		1,100.00
7.	NEGOTIATED INDIRECT COST RATE	XXXXXXXXX		
	BUDGET PERIOD TOTALS	$ 124,151.00 wvw ~~19,151.00~~		124,151.00 ~~19,151.00~~

NOTE: BUDGET CATEGORY TOTALS SHOULD BE ROUNDED/ADJUSTED TO THE NEAREST "THOUSAND" FOR BUDGETING PURPOSES.

TEXAS DEVELOPMENTAL DISABILITIES PROGRAM

Grant Workplan

PART III: FINANCIAL INFORMATION

A. Budget Detail

1. Personal Services:

Salary and Wages

Position/Name	Total Annual Compens.	Time on Project Mos. %	Federal	Match	Totals
Project Director Allen Dietz, CSW-ACP	$31,200.00	9/25%	$5850		$5850
Assistant Director Betty Button, M.A.	$31,200.00	9/15%	$3510		$3510
Additional Services:					
State legislative issues workshop (planning, presentation, tour, and role-play)					2500
Assistance in planning and conducting federal issues workshop					1225

Projected lapse/turnover surplus =	
Subtotal Salary and Wages:	$13,085.00

Fringe benefits*:

FICA	@ 7.65 %	716.00
Workman's compensation	@ ____ %	
Health insurance	@ ____	
Dental insurance	@ ____	
Retirement	@ ____	
Other:		
____	@ ____	
____	@ ____	
____	@ ____	

Subtotal Fringe benefits:	716.00
Personal Services Totals	$13,801.00

T(; DEVELOPMENTAL DISABILITIES PR .AM

Grant Workplan

PART III: FINANCIAL INFORMATION

Budget Detail, continued

	Federal	Match	Totals
2. Travel (in state):	NOT APPLICABLE		
Travel (out of state):	NOT APPLICABLE		
Travel Totals			0.00
3. Purchased Services:			
Accountant fees to conduct project audit			$4,000.00
Trainer/Trainee Agreements - Reimbursement of meeting expenses per signed agreements with trainers and trainee participants in the Partners in Policymaking program (e.g., travel, meals, room, attendant and respite services, supplies, long distance telephone charges).			105,000.00 WDJ
Purchased Services Totals			109,000.00 WDJ ~~$4,000.00~~
4. Property/Materials: Supplies/Materials; Office Supplies:			$250.00
Capital Outlay:	NOT APPLICABLE		0.00
Property and Materials Totals			$250.00

T DEVELOPMENTAL DISABILITIES P AM

Grant Workplan

PART III: FINANCIAL INFORMATION

1. Budget Detail, continued

	Federal	Match	Totals
5. Rental and Leasing:	NOT APPLICABLE		
Rental and Leasing Totals			0.00
6. Utilities:			
Postage (for mailing tickits, confirmations, and checks, and to communicate with participants and speakers.)			200.00
Telephone (Long Distance)			900.00
Utilities Totals			$1,100.00

7. Negotiated Indirect Cost Rate*:

Amount: NOT APPLICABLE

*Attach current approved NICR from federal cognizant agency.

TEX DEVELOPMENTAL DISABILITIES PRO M

Grant Workplan

PART III: FINANCIAL INFORMATION

C. Financial Mangement System Questionnaire

1. APPLICANT RESOURCES:

A. List the source of all the matching funds for this project, including your own agency.

B. Indicate the origin of the contribution, i.e., direct donation, state appropriations, revenue sharing, volunteers, services, materials, etc.

C. Indicate whether each source of funding is federal or non-federal.

NOTE: EACH MATCH SOURCE MUST COMPLETE A LETTER OF COOPERATION/ENDORSEMENT WHICH YOU WILL SUBMIT AS AN ATTACHMENT TO THE WORKPLAN.

A. AGENCY/SOURCE OF FUNDS	B. ORIGIN OF CONTRIBUTION	C. FEDERAL	NON-FEDERAL
NO MATCHING FUNDS			

2. FISCAL SYSTEMS

A. What is your agency's present operating budget? N/A

B. Is a general ledger maintained that clearly summarizes the grant related transactions? YES

C. Are your books maintained on the cash or accrual basis? CASH

D. Who will keep these books? Title? Allen Dietz, Project Director

E. What method is used to document personnel costs (salary and fringe benefits) charged to the project? Time sheets

F. How often do you prepare financial statements? Monthly or quarterly, depending on the needs of the DD Council.

NATIONAL ACADEMY ON PARTNERS IN POLICYMAKING
THURSDAY-SATURDAY, MAY 14-16, 1992
DOUBLETREE HOTEL AT LINCOLN CENTRE
5410 LBJ FREEWAY
DALLAS, TEXAS

EVALUATION

CONTENTS

PARTNERS IN POLICYMAKING OF ALABAMA
WORKSHOP/TRAINING EVALUATION

ALABAMA PIP EVALUATION FORM
N.D. - Received prior to 1992 Academy

SPEAKER____

Workshop Topic__________________________ Date______________________________

Please circle your response to each statement.

		Strongly Agree	**Agree**		**Disagree**	**Strongly Disagree**	**Not Applicable**
1.	The program met my expectations.	5	4	3	2	1	0
2.	I received new information.	5	4	3	2	1	0
3.	The information was helpful and relevant to my needs.	5	4	3	2	1	0
4.	The speaker(s) presented the information clearly.	5	4	3	2	1	0
5.	The speaker(s) encouraged audience participation.	5	4	3	2	1	0
6.	The exercises, if any, helpful me apply the information presented.	5	4	3	2	1	0
7.	The handouts/materials, if any, were helpful.	5	4	3	2	1	0
8.	The audiovisual aids, if any, helped clarify the information presented.	5	4	3	2	1	0
9.	My general reaction to the program was positive.	5	4	3	2	1	0

SPEAKER/PRESENTOR

PARTNERS IN POLICYMAKING OF ALABAMA

Mileage, Travel, and Miscellaneous Expenses Reimbursement Claim Form

Name______________________________

Address______________________________

Social Security Number__________________

Mileage Claim

Date	To / From	# of Miles

total miles at $.22/mile $__________

Travel Claim

Air Fare______________________________
Hotel/motel______________________________
Local Transportation______________________________
Other______________________________
(receipts attached where applicable)

Total Due $__________

Meal Claims
(at established rates)
Breakfast______________________________
Lunch______________________________
Dinner______________________________

Total Due $__________

__________ ______________________________
(date) (signature)

Please respond briefly to each of the following:

1. What were the major strengths of the workshop?

2. The workshop would have been better if:

3. What did you expect to receive from attending this workshop?

4. Did the workshop meet your expectations?

5. What specific skills, techniques, or knowledge did you obtain at this workshop that are relevant and applicable to your work setting?

6. In summarizing my reactions to this program, I would say:

Thank you for completing this evaluation.

PARTNERS IN POLICYMAKING OF ALABAMA

REINBURSEMENT FOR SUPPORT TO PARTICIPANTS

NAME____

ADDRESS____

SOCIAL SECURITY NUMBER________________________________

RESPITE CARE: # OF HOURS_____AT A RATE OF $______

BABYSITTING: # OF HOURS_____AT A RATE OF $______

PERSONAL CARE ATTENDANT:

OF HOURS_____AT A RATE OF $______

I VERIFY THAT I PERFORMED THE ABOVE SERVICE ON THE DATES AND THE RATES LISTED ABOVE.

____
SIGNATURE OF PROVIDER

____
SIGNATURE OF PARTICIPANT

PARTNERS IN POLICYMAKING
SESSION EVALUATION FORM

SESSION I: VALUES AND HISTORY OF THE DISABILITY MOVEMENT EDUCATION: INTEGRATION AND QUALITY

Please circle the number below from 1 to 5 which best reflects your feelings about each question. Please feel free to share additional comments below.

Question	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1. Speakers were prepared, organized, and effective.	5	4	3	2	1
2. Materials presented were relevant to my needs and will help improve my advocacy abilities.	5	4	3	2	1
3. Questions were answered satisfactorily.	5	4	3	2	1
4. Speakers were sensitive to participant's individual situations.	5	4	3	2	1
5. Written materials and handouts were useful.	5	4	3	2	1
6. Meeting rooms, meals, and hotel rooms satisfactorily met my needs.	5	4	3	2	1

7. How will you specifically attempt to use the information and experience gained from this session?______

CALIFORNIA PIP EVALUATION FORM

N.D. - Received prior to 1992 Academy

8. Comments______

ILLINOIS PARTNERS IN POLICYMAKING - 1991-1992
SESSION EVALUATION FORM

Please take a few moments to evaluate your experiences during this Partners in Policymaking session. Your opinions are valuable and will help us improve for future sessions.

1. Overall how satisfied were you with this Partners in Policymaking Session?

____

Not at all satisfied	dissatisfied	somewhat dissatisfied	neither	somewhat satisfied	satisfied	very satisfied

2. Did the program meet your expectations?

1_____ 2_____ 3_____ 4_____ 5_____ 6_____ 7_____
Not at all Completely

3. Was the information presented helpful and relevant to your needs?

1_____ 2_____ 3_____ 4_____ 5_____ 6_____ 7_____
Not at all Completely

Indicate your satisfaction with the following aspects of the program:

Meeting Facilities

4. 1_____ 2_____ 3_____ 4_____ 5_____ 6_____ 7_____
Not at all Satisfied Completely Satisfied

Hotel Accommodations

5. 1_____ 2_____ 3_____ 4_____ 5_____ 6_____ 7_____
Not at all Satisfied Completely Satisfied

Meals

6. 1_____ 2_____ 3_____ 4_____ 5_____ 6_____ 7_____
Not at all Satisfied Completely Satisfied

Program Schedule

7. 1_____ 2_____ 3_____ 4_____ 5_____ 6_____ 7_____
Not at all Satisfied Completely Satisfied

ILLINOIS PIP EVALUATION FORM

N.D. - Received prior to 1992 Academy

**Continued on Back Side

Handouts/Materials (if any)

8. 1_____ 2_____ 3_____ 4_____ 5_____ 6_____ 7_____
Not at all Satisfied — Completely Satisfied

Access to Speakers

9. 1_____ 2_____ 3_____ 4_____ 5_____ 6_____ 7_____
Not at all Satisfied — Completely Satisfied

Access to Staff

10. 1_____ 2_____ 3_____ 4_____ 5_____ 6_____ 7_____
Not at all Satisfied — Completely Satisfied

Access to other Participants

11. 1_____ 2_____ 3_____ 4_____ 5_____ 6_____ 7_____
Not at all Satisfied — Completely Satisfied

12. What did you like least about this session?

13. What did you like best about this session?

14. What specific skills, techniques, or knowledge did you obtain at this training session that are relevant and applicable to your situation?

15. In summarizing your reactions to this session, you would say:

SPEAKER EVALUATION FORM DATE: __________

Speaker's Name: ______________________________

Please rate this speaker in the following areas:

1. Overall how satisfied were you with this speaker?

Not at all satisfied	dissatisfied	somewhat dissatisfied	neither	somewhat satisfied	satisfied	very satisfied

2. How appropriate/clear were the presentation and materials (if any) used by the speaker?

1_____ 2_____ 3_____ 4_____ 5_____ 6_____ 7_____

Not at all appropriate — Extremely Appropriate

3. Is there something you learned from this presentation that you can put into use in your life? If so what?

4. What did you like least about this presentation?

SPEAKER EVALUATION FORM DATE: __________

Speaker's Name: ______________________________

Please rate this speaker in the following areas:

1. Overall how satisfied were you with this speaker?

Not at all satisfied | dissatisfied | somewhat dissatisfied | neither | somewhat satisfied | satisfied | very satisfied

2. How appropriate/clear were the presentation and materials (if any) used by the speaker?

1_____ 2_____ 3_____ 4_____ 5_____ 6_____ 7_____

Not at all appropriate — Extremely Appropriate

3. Is there something you learned from this presentation that you can put into use in your life? If so what?

. What did you like least about this presentation?

Please fill in the following information. No name is needed on this sheet as your answers are anonymous. Thank you for taking the time to answer these questions.

1) Education Level

Some High School/No degree ______

GED ______

High School Diploma ______

Some College/No degree ______

Associate's Degree ______

Bachelor's Degree ______

Some Grad School/No degree ______

Master's Degree ______

M.D./Ph.D. ______

2)Ethnic Background/Race

African-American ______

American-Indian ______

Asian ______

Hispanic ______

White ______

Other ______

PARTNERS IN POLICYMAKING EVALUATION

```
****************************************
*                                      *
*       TEXAS PIP EVALUATION FORM      *
* N.D. - Received prior to 1992 Academy *
*                                      *
****************************************
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Session Title: ______________________

Date: ______________________

Are you a _____Consumer _____Parent?

Please circle your response to each statement.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1. The speakers(s) presented information clearly.	5	4	3	2	1
2. This was relevant to my needs and will improve my advocacy abilities.	5	4	3	2	1
3. Questions were answered satisfactorily.	5	4	3	2	1
4. The advance readings/handouts were helpful.	5	4	3	2	1
5. I felt the speakers were sensitive to participant's individual situations.	5	4	3	2	1
6. My general reaction to the program was positive.	5	4	3	2	1

The thing I liked most about this session was: ______________________

____

____

____

The session would have been better if: ______________________

____

____

____

____

____

In what ways will the knowledge and skills gained this weekend be useful to you? ______________________________

____

____

____

Comments: ______________________________

____

____

____

____

AVERAGE SCORES FROM EVALUATIONS PER SESSION OF 1990-91

	Average Score/Statement								
SESSION	1	2	3	4	5	6	7	8	9
1. **October 19-20:** History of the Disability, Advocacy and Parent Movements, history of the independent living movement.	4.3	4.5	4.3	4.2	4.2	4.3	4.2	4.1	4.7
2. **November 9-10:** Severe Physical Disabilities, Assessing Your Technology Needs and Demonstration of Technologial Devices.	4.8	4.9	4.6	4.9	4.7	4.6	4.7	4.9	4.9
3. **January 11-12:** Education - Quality and Integration	4.3	4.2	4.3	4.5	4.4	4.5	4.6	4.3	4.4
4. **February 8-9:** Family Supports & Entitlement: Insurance Issues, Respite Care, SSI and SSDI.	4.5	4.6	4.2	4.7	4.0	4.5	4.4	4.3	4.6
5. **March 1-2:** Waivers, Vocational Education, Transportation Issues, Grants and Grant Writing, Personal Care Attendant Issues, Supported Employment.	4.2	4.4	4.3	4.2	4.4	4.0	4.2	4.0	4.3
6. **April 12-13:** State Policymaking, Legislative Training Hands on Process	4.5	4.5	4.6	4.5	4.5	4.6	4.6	4.[illegible]	4.6
7. **May 10-11:** Legislation in Action	4.9	4.6	4.8	N/A	N/A	N/A	N/A	N/A	4.9
8. **June 7-8:** GRADUATION	NO EVALUATION ADMINISTERED								

NOTE: Statement = responses to a question in the evaluation form. The participants were asked to, "Please circle the number below from 1 to 5 that best reflects your feelings." Strongly disagree was 1; strongly agree was 5. the statements were:

1. The program met my expectations.
2. I received new information.
3. The information was helpful and relevant to my needs.
4. The speaker presented the information clearly.
5. The speaker encouraged audience participation.
6. The exercises, if any helped me apply the information presented.
7. The handouts/material, if any, were helpful.
8. The audiovisual aids, if any, helped clarify the information presented.
9. My general reaction to the program was positive.

ALABAMA PIP EVAL. SCORES 90-91

N.D. - Received prior to 1992 Academy

IOWA PIP EVAL. SCORES 1991
N.D. - Received prior to 1992 Academy

Attachment #4

N=14

Overall Evaluation

IOWA PARTNERS IN POLICYMAKING 1991

SUMMARY

Strongly Agree — Stron Disag

1. **I achieved the goals I set for myself as a participant in Partners in Policymaking.**
54.5 = 3.89

5	4	3	2	1
1	10	3		

Comments: We've so much yet to do; I need to work on these; most were met; Due to my injury I could not attend all sessions.

2. **Partners in Policymaking is a very effective way to gain knowledge and skills for influencing public policy.**
64 = 4.57

5	4	3	2	1
10	2	2		

Comments: Amen; may it continue for years; presentors were knowledgeable; it's about time someone was fighting for us & helping.

3. **The time commitment required to participate in Partners in Policymaking was realistic.**
60 = 4.29

5	4	3	2	1
7	4	3		

Comments:
Even more meetings; Friday & Saturday were good.

4. **Direction and support from project staff was available when needed.**
62 = 4.43

5	4	3	2	1
8	5		1	

Comments: Really super, bent over backwards; everyone was so helpful; good; David's leaving was a problem.

5. **I will be more effective in areas of advocacy and policymaking as a result of my involvement in this project.**
62 = 4.43

5	4	3	2	1
8	4	2		

Comments:
I will try

6. **In the future, I will strongly urge others participate in Partners in Policymaking.**
65 = 4.64

5	4	3	2	1
10	3	1		

Comments: I already know two who are interested; I already have two names; Yes, a hard challenge, but it's worth (it).

7. Please list 3-4 highlights you experienced during or as a result of your participation in Partners in Policymaking.
Gunnar x 3; Fran Smith x 4; Almo Hawkins x 2; Lowell Junkins, David Hancox, Terry VanderCook; roundtable with Co. Supervisors x 4; organization panel x 2; mock board meeting networking x 2; resources, contacts, all the presentors x 2; meeting other presentors & hosts; I learned a lot about affecting change; I've been empowered with much knowledge & good contacts; understanding the system; gaining confidence that I can make a difference.

Please rate the helpfulness of the following elements of Partners in Policymaking:

		Very Helpful				No Helpf
8. Reading and resource materials.	60 = 4.29	5 x9	4 x3	3x2	2	1
9. Formal presentations.	49 = 3.5	5 x3	4 x6	3x5	2	1
10. Group discussions.	61.5 = 4.39	5 x9	4 x2	3x2	2x1	1
11. Informal networking.	62 = 4.43	5 x10	4 x2	3	2x2	1
12. Personal project(s) related to Partners in Policymaking.	60 = 4.29	5 x8	4 x3	3x2	2x1	1
13. $100 Resource Account.	61 = 4.36	5 x8	4 x3	3x2	2	1x1
14. The Individual Action Plan.	59 = 4.21	5 x8	4 x3	3x1	2x2	1
15 Composition of the participant group (i.e., parents and consumers, younger and older, experienced and less experienced).	56 = 4.0	5 x7	4 x5	3x2	2	1

16. Additional comments or suggestions:

Org. panel should be earlier; keep the program going; appreciate the flexibility of Session V; Presentors were all knowledgeable; the program was good but I did not personally have enough time to give to it; It's good to know someone is helping us fight for what we should get; the variety of partners made it interesting; shorter formal presentations.

PARTNERS IN POLICYMAKING

AVERAGE SCORES FROM EVALUATIONS PER SESSION
YEAR ONE

TRAINING SESSIONS	DATES	AVERAGE SCORE/STATEMENT					
		1	2	3	4	5	6
1. History of Disabilities, Independent Living Movement, Parent Movement, People First Movement	August 24-25	4.5	4.5	4.5	4.5	4.4	4.7
2. Education-Integration and Quality	September 21-22	4.5	4.6	4.3	4.1	4.3	4.6
3. Supported Living, Personal Futures Planning, Supported Employment, Family Supports	October 26-27	4.6	4.5	4.3	4.3	4.7	4.7
4. Federal Policy and Legislative Issues, Advocacy	Nov. 30-Dec. 1	4.5	4.7	4.5	4.6	4.7	4.8
5. State Policy and Legislative Issues, Advocacy	January 25-26	4.7	4.5	4.7	4.4	4.7	4.7
6. Physical Disabilities, Assistive Technology, Positive Approaches to Challenging Behavior	February 22-23	4.6	4.5	4.4	4.3	4.4	4.5
7. Bureaucratic Maze, Advocacy Organizations	March 22-23	4.5	4.6	4.5	4.5	4.7	4.5
8. Robert's Rules of Order, Graduation	April 19-20	4.7	4.6	4.6	4.3	4.4	4.7

NOTE: Statement = responses to a question in the evaluation form. The participants were asked to, "Please circle your response to each statement." "Strongly disagree" was 1; "strongly agree" was 5. The statements were:

1. The speakers(s) presented information clearly.
2. This was relevant to my needs and will improve my advocacy abilities.
3. Questions were answered satisfactorily.
4. The handouts/materials, if any, were helpful.
5. I felt the speakers were sensitive to participant's individual situations.
6. My general reaction to the program was positive.

TEXAS PIP EVAL. SCORES '90-'91
N.D. - Received prior to 1992 Academy

PARTNERS IN POLICYMAKING

AVERAGE SCORES FROM EVALUATIONS PER SESSION
YEAR TWO

TRAINING SESSIONS	DATES	AVERAGE SCORE/STATEMENT 1	2	3	4	5	6
1. History of Disabilities, Independent Living Movement, Parent Movement, People First Movement	September 12-13	4.5	4.5	4.5	4.2	4.7	4.8
2. Education-Inclusion and Quality	October 11-12	4.9	4.8	4.5	4.5	4.6	4.9
3. Supported Living, Supported Employment, Family Supports	November 15-16	4.8	4.6	4.6	4.4	4.6	4.7
4. Federal Policy and Legislative Issues, Advocacy	January 10-11	4.6	4.7	5.0	4.8	4.7	4.7
5. State Policy and Legislative Issues, Advocacy	February 7-8	4.5	4.6	4.7	4.6	4.7	4.6
6. Physical Disabilities, Assistive Technology, Positive Approaches to Behavior	March 6-7	4.6	4.5	4.5	4.2	4.7	4.6
7. Bureaucratic Maze, Advocacy Organizations	April 3-4	4.6	4.7	4.5	4.1	4.6	4.7
8. Parliamentary Procedure, Community Organizing, and Graduation	May 1-2						

NOTE: Statement = responses to a question in the evaluation form. The participants were asked to, "Please circle your response to each statement." "Strongly disagree" was 1; "strongly agree" was 5. The statements were:

1. The speakers(s) presented information clearly.
2. This was relevant to my needs and will improve my advocacy abilities.
3. Questions were answered satisfactorily.
4. The handouts/materials, if any, were helpful.
5. I felt the speakers were sensitive to participant's individual situations.
6. My general reaction to the program was positive.

TEXAS PIP EVAL. SCORES '91-'92
N.D. - Received prior to 1992 Academy

Iowa Partners is Policymaking

1990 Program Evaluation Material

Prepared by
Iowa Protection & Advocacy, Inc.

Project of
Iowa Governor's Planning Council on Developmental Disabilities

IOWA PIP PROGRAM EVALUATION 1990

N.D. - Received prior to 1992 Academy

Objective #8

Action Step 8.2

By June 15, 1990, compile the results for an evaluation tool used by the participants at the end of each training session which addresses a) the effectiveness of the speakers, b) the relevance usefulnesses and sufficiency of the material presented.

Enclosed please find the descriptions of the evaluations for Sessions #1, #2, and #3 of Partners 1990, taken from the Third and Fourth Quarter Reports. Also find enclosed the summary of the overall evaluations completed by the 1990 Partners at the May 4 and 5 weekend.

Action Step 8.3

By June 15, 1990, compile the results for an evaluation tool used by each participant to record policymaking activities as a result of the project which addresses:

A. The number of letters written to policymakers since the beginning of the Project.

During the course of the 1990 Partners in Policymaking Project, the Partners personally wrote 77 letters to local, state, and federal policymakers. Additionally, the Partners networked with friends, relatives, and other parents or persons with disabilities to send 435 postcards or letters to state and federal policymakers.

B. The number of times the Partners testified before policymakers since the beginning of the project.

The 1990 Partners testified nine times before policymakers between January and June of 1990. All nine of these testimony contacts were delivered to local or county policymakers.

C. The total number of contacts that participants had with policymakers at each level of government since the beginning of the Project.

The type of contacts with policymakers was divided into two categories; face to face meetings with policymakers, and telephone calls to policymakers and/or their staff.

Partners met face to face with federal policymakers on 9 occasions, 12 times with state policymakers, and 16 times with local or county policymakers. This is a total of 37 face to face meetings.

The Partners made 68 telephone contacts to policymakers during the course of the Project, 13 of these calls were made to federal policymakers or their staff offices, 24 calls to state policymakers, and 31 calls were made to local or county policymakers.

D. Anecdotal information concerning the way services are delivered to the participants and/or their families as a result of the Project.

From January, 1990 through June, 1990, Partners worked with policymakers, educators, service providers, committees, and existing networks to achieve the following:

- Increased respite and nursing care services following contacts to state DHS policymakers and federal legislators;
- Increased opportunities for school integration or inclusion using resources acquired through Partners in local committee or individual action;
- Entry into financial entitlement services (Family Support Subsidy, Title XIX, and SSI) after making informed contacts to local DHS offices;
- Better quality IEPs, IPPs, and IHPs;
- Federal tax relief for in-home care payments received by the family, for services delivered by family members after contact to US Congressional delegations;
- Enhanced employment opportunities for parents and consumers; and
- A general feeling on the part of the Partners of increased credibility when meeting with professionals and policymakers.

E. The names of the organizations participants joined since the beginning of the Project.

Partners joined the following organizations between the months of January and June, 1990: The Association for Persons with Severe Handicaps (Iowa TASH), The Association for Retarded Citizens - Iowa, the Autism Society of Iowa, University of Iowa Child Health Specialty Clinics Parent Consultant Network, Department of Education Parent/Educator Connection, Area Education Agency Renewed Service Delivery System Area and Building Committees, County MH/MR/DD County Board (Wright County), Schools Are For Everyone (National SAFE Coalition for School Integration),

F. The offices Held by the participants since the beginning of the Project.

Since January of 1990, Partners have been nominated, and/or elected to the following committees and Boards: Secretary of Iowa Protection & Advocacy Board of Directors, member of the Governor's Planning Council on Developmental Disabilities, members of AEA RSDS Advisory Groups, members of Wright County MH/MR/DD Advisory Board, member of ARC-Iowa Education Committee, member of Schools Are For Everyone Organization Committee.

G. Ways in which the Project expanded on previous networking efforts.

Partners in Policymaking provided a number of parents and persons with disabilities increased opportunities to network with other families and consumers, as well as with providers, professionals, and policymakers. The Project provided an increased opportunity for linkage between parents and consumers of services from many geographic areas in the state. For each of the Partners, the opportunities to network with other friends and acquaintances in other network systems, were enhanced by the knowledge and skill acquired in the Partners training. The 1990 Partners became involved in existing networks in the education, employment, health, and transportation arenas.

From the outset, the Partners recognized the potential for growth in existing networks through their meeting. The diverse interests, skills, and needs of the 1990 Partners provided an additional information and support network, as well as opening existing networks to the involvement of new people. As a result, we saw Partners using previous contacts and Partners Network contacts to generate a number of letters and phone calls to state and federal policymakers. These contacts were largely related to the family support subsidy legislative issues during the 1990 Iowa General Assembly Session.

Training and resource opportunities were also shared by the Partners, and a number of Partners were made aware of opportunities about which they would not have heard previous to Partners in Policymaking. Partners attended 43 training sessions, where they learned or strengthened skills, and acquired additional resources to empower them. Partners also assisted four persons with disabilities to register to vote for the 1990 election.

H. The number of public presentations: lectures, workshops, radio, television, etc. (made by the participants on disability issues since the beginning of the Project).

Between January and July, 1990, the Partners gave 22 presentations on disability issues. These were primarily lectures or informal workshop sessions. Additionally, issues brought to the attention of the Iowa press were included in three news articles and one editorial. The news articles appeared in local papers, and the editorial appeared in the Des Moines Register.

Reference Action Step 8.2

Results of evaluations by participants of the training sessions. An identical evaluation form was used for both session #1 and session #2. The Partners are asked seven ratings questions, and then are given the opportunity to respond to five open ended questions. The seven ratings questions are as follows:

1. The presenters were knowledgeable and well prepared.
2. The presenters allowed ample time for discussion, and were effective in facilitating it.
3. Overall, the content was relevant and stimulating.
4. I felt the freedom to express my own views on the topics covered.
5. The printed materials were useful.
6. I will be more effective in areas of advocacy and policymaking as a result of session #1 (or session #2).
7. The organizers were considerate of everyone's physical needs and all the accommodations were adequate.

The rating used for these seven questions was a five-point scale, from strongly agree through neutral, to strongly disagree.

In Session I:

Rating #1 - Ten out of thirteen respondents strongly agreed that the presenters were knowledgeable and well prepared. Three of the thirteen agreed that the presenters were knowledgeable and well prepared.

Rating #2 - "The presenters allowed ample time for discussion and were effective in facilitating it." Five of the thirteen respondents strongly agreed with the statement, six of thirteen agreed, one of thirteen was neutral, and one of thirteen disagreed.

Rating #3 - "Overall, the content was relevant and stimulating." In this question, seven of thirteen strongly agreed, and six of thirteen agreed.

Rating #4 - "I felt the freedom to express my own views in the topics covered." Eleven of thirteen strongly agreed with this statement, while two of thirteen agreed.

Rating #5 - "The printed materials were useful." Six of thirteen strongly agreed, five of thirteen agreed, and two of thirteen were neutral.

Rating #6 - "I will be more effective in areas of advocacy and policymaking as a result of session #1." Six of thirteen strongly agreed, six of thirteen agreed, and one of thirteen was neutral.

Finally, for ratings #7 - "The organizers were considerate of everyone's physical needs and all the accommodations were adequate." Eight of thirteen strongly agreed, four of thirteen agreed, and one of 13 was neutral on this issue.

Additionally, we opened the following areas up for comment:

1. Please list three to four topics for experiences you especially appreciated or learned from during session #1.

   The topics that people listed consistently were "Caring for the Caregiver" presentation by Sister Marie Michelletto; "The Individual Action and Team Work" presentation by Julie Beckett, and Gunnar Dybwad's involvement in speech. People also noted the challenge that David Hancox had presented to the group. Additionally, people mentioned their appreciation for the opportunities to network and share ideas with the other Partners.

2. What parts of session #1 were disappointing, discouraging, or not helpful for you?

   There were comments relative to the length of the presentations (that they might have been shorter or allowed more breaks). There were some comments relative to going off task. Additionally, a number of people were disappointed that Jerry Murray did not show.

3. What information would you have liked to include in session #1 that was not.

   Consistently, the Partners requested following information to have been included: a list of state and national phone numbers for information clearinghouses, newsletters, legal resources, and services, etc.; listing of disability related commissions and task forces, both state and federal; a bibliography to acronyms.

4. How do you plan to make use of the ideas, information, and/or skills gained during session #1?

A number of the partners mentioned that they were planning to take the information that they had gained back to their communities to start groups there or work with existing groups. A number felt that the information they had gained would be helpful in letter writing campaigns regarding certain pieces of legislation, and some Partners mentioned that it would be especially helpful working through and analyzing their Individual Action Plan goals.

Additional comments in session #1 from the Participants were as follows:

- "We really felt extremely comfortable, and I think we were all able to let down our defenses and have more creative ideas."
- "This has given me renewed energy and has been wonderful."
- "I would suggest that some time be scheduled for brainstorming, and that someone be appointed to keep us on task and watch the time (when the speakers get off on tangents)."
- "A large amount of beneficial information was obtained via a personal interactions and discussions."
- "I think people are geared up and ready to dig in!"
- "Allow more free discussion for the Participants, either during a panel group, or at the end of the presentation."
- "The group should continue to meet every three months to review what has been accomplished."
- "The conference overall was super!"
- "I hope we will travel to the Capital and observe a hearing or see someone testify in a setting which will adequately prepare us to do it in reality (mock hearing sessions)."

For session #2, nine of the Partners returned evaluation forms:

Rating #1 - One of nine strongly agreed, six of nine agreed, one was neutral, and one disagreed.

Rating #2 - Two of nine strongly agreed, two of nine agreed, four of nine were neutral, and one disagreed.

Rating #3 - one strongly agreed, four agreed, three were neutral, and one disagreed.

Rating #4 - Five strongly agreed, two agreed, one disagreed, and one strongly disagreed. Item #5: three strongly agreed, four agreed, one was neutral, and one disagreed. Item #6: three strongly agreed, three agreed, two neutral, and one disagreed. Item #7: three strongly agreed, four agreed, and two were neutral.

Especially helpful topics or experiences included: the issue analysis presentations; Dr. Steven Moore's presentation; discovering that change is a slow process; getting more familiar with the problems in disability policy, more familiar with the Partners staff, and more familiar with the Partners themselves; the discussion on Americans With Disabilities Act was helpful; in addition to information gained on other disabilities, learning more leadership skills and more effective networking skills; the skills learned in group communication; problem solving and managing conflict.

Disappointing, discouraging, or not helpful portions of session #2 included: moved very quickly, too much printed information for one session; part of the training may not have been needed by any of the Partners (like junior high school Four H, relative to FCL); parts of the presentations were somewhat insulting or delivered in a sexist fashion; the length of the sessions were noted to long; and a number of the skills and concepts taught were a review for some of the participants.

What information could have been included in session #2 that was not? A suggestion was made that a mix of session #1 and session #2, in terms of the training strategies and styles would have been effective. A number of Partners mentioned they would like to see more in depth coverage of the laws in effect and that are coming into effect in a discussion thereof.

How do you plan to make use of the ideas, information, and skills gained during session two? Most Partners mentioned that they would use the information to help achieve their goals; that the skills learned would be helpful informing parents of disabled persons groups or People First groups; to be more objective in working with others; become a better group member; help organize and use time more effectively and efficiently; become better informed and more politically active.

Additional comments and suggestions from the nine respondents included:

- "Thanks for your hard work and the gifts that you have given me. The resulting blessings are already coming to me and the others."
- "The food was not the greatest, but you can't help that."
- "Maybe next time you could intermix FCL and the information and motivation speakers."
- "I found like I'm being woke up to a world that I thought was gaining ground, and found out it is still the same old 'stuff'."
- "The impact of lobbying is going to pay off as long as it is done by the disabled talking for themselves."
- "At the next session, I would like to have a speaker that directly addresses those with disabilities."
- "Keep up the good work."
- "I think this group has used the information given to them and used it to network among themselves and find their niche. I am proud of the people for the bonding and the love that's shared: I truly care about this group and feel so close to many of them."

Staff analysis of these responses to the evaluations from session #1 and session #2, indicate the impact and the direction of the training has been very positive.

Sixteen participants, including persons with developmental disabilities and parents, evaluated the third Partners in Policymaking weekend workshop experience on May 5, 1990. The following summary information is based on the evaluation tool distributed at the completion of the workshop. Scored items below have been rank ordered on a 1 to 5 scale, 1 being strongly disagree; 5 being strongly agree.

1. The presenters were knowledgeable and well prepared.

   Number of respondents: 16
   Mean: 3.88

2. The presenters allowed ample time for discussion and were effective in facilitating it.

   Number of respondents: 16
   Mean: 3.75

3. Overall the content was relevant and stimulating.

   Number of respondents: 16
   Mean: 3.94

4. I felt the freedom to express my own view on the topics covered.

   Number of respondents: 16
   Mean: 3.88

5. The printed materials were useful.

   Number of respondents: 16
   Mean: 3.31

6. I will be more effective in areas of advocacy and policymaking as a result of Session #4.

   Number of respondents: 16
   Mean: 4.69

7. The organizers were considerate of everyone's physical needs and all the accommodations were adequate.

   Number of respondents: 16
   Mean: 4.06

A number of participants felt that the presentations by Vic Elias, John Foley, and parts of the panelist committee were especially good. The Participants especially appreciated the opportunity to share time with the panelists after the discussion was completed, and gain a better understanding of the county system.

Parts of Session #4 that were discouraging or disappointing to the Participants, included the length of the panel discussion, and the windiness of some of the speakers. A number of the Partners said that a smaller panel or a series of panel discussions would have been more helpful.

Summary of Overall Evaluations

Partners in Policymaking
Iowa Protection and Advocacy
June 8, 1990

Sixteen participants, including persons with developmental disabilities and parents, evaluated the entire Partners in Policymaking experience on May 5, 1990. The following summary information is based on an evaluation tool distributed at the end of the final weekend of Partners. Scored items below have been rank ordered.

General

Responses to these statements were based on a five point scale, with 5 representing "Strongly Agree" and 1 "Strongly Disagree."

1. In the future, I will strongly urge others to participate in Partners in Policymaking.
   N=16 Mean 4.78

2. I will be more effective in areas of advocacy and policymaking as a result of my involvement in this project.
   N=15 Mean 4.70

3. Partners in Policymaking is a very effective way to gain knowledge and skills for influencing public policy.
   N=16 Mean 4.59

4. Direction and support from project staff was available when needed.
   N=16 Mean 4.41

5. The time commitment required to participate in Partners in Policymaking was realistic.
   N=16 Mean 4.09

6. I achieved the goals I set for myself as a participant in Partners in Policymaking.
   N=16 Mean 3.97

Elements of PIP

Participants rated the helpfulness of specific elements of Partners. A five point scale was used, with 5 representing "Very Helpful" and 1 "Not Helpful."

1. Informal networking	N=16	Mean 4.72
2. Composition of the participant group (i.e., parents and consumers, younger and older, experienced and less experienced)	N=16	Mean 4.69
3. Group discussions	N=16	Mean 4.59
4. Reading and resource materials	N=16	Mean 4.50
4. $100 Resource Account	N=16	Mean 4.50
5. Personal project(s) related to Partners in Policymaking	N=16	Mean 4.37
6. Formal presentations	N=16	Mean 3.90
6. The Individual Action Plan	N=16	Mean 3.90
7. Use of Telenet conferencing	N=13	Mean 3.73

Highlights

Participants were asked to list 3-4 highlights they experienced during or as a result of their participation in Partners in Policymaking. Their responses reflect the variety of ways in which Partners served to empower participants in advocacy and policymaking activities.

> Having my eyes opened to school and community integration. Realizing my power with political candidates to get what I need for my daughter.
>
> (1) Getting on the Wright County MH, MR, DD Committee. (2) Getting more comfortable with adults challenged with disabilities. (3) Accessibility to people whose names I heard but now I have met. (4) Empowerment—commitment to hang in there.
>
> For the first time being told of the benefits of integration and the full integration option, learning about appropriate supports and services for children with autism, becoming more informed and aware of the political structure as it exists in Iowa.

Without a doubt, the strength, friendship, knowledge and overall support I acquired through meeting the other PIP trainees is the highlight of highlights.

Networking, Steven Moore, Sister Marie.

(1) Helped me to realize other people's problems and interests. (2) The fact that the system does not work properly. (3) The camaraderie and friendships. (4) Although the Coalition Day was not really part of this project, I came in because of our project.

Made contacts I'm sure will be extremely valuable to me in the future.

I feel that I have made some good friends, learned that I'm not alone, starting to learn about laws—both good and bad things, become more politically aware and hopefully a better advocate.

Seeing that this field has even come close to perfect. Rules are set in the dark ages and still followed by policy makers.

Meeting more people and making new friends. Learned a lot about how to help get through all the red tape.

Comments and Recommendations

David you have me long as you want me in this project. I love doing this kind of work. David I would like to get more involved.

Keep same format.

To have mentally disabled people have assistance as needed during sessions. They didn't gain as much as they could have.

A year ago, I would <u>not</u> dream of writing congressmen, telephoning, getting a board position with MH, MR, DD Advisory Board.

Should focus on the basics of being more vocal in the policy issues.

I would maybe do a different mix of motivational and info, but all of it was great. Maybe delete some parts of FCL.

Continued involvement even in issues not directly affecting you makes you a better citizen!

This has been a vehicle for renewing my active involvement in policymaking. I'm extremely happy that I had the opportunity to meet these wonderful parents.

Too much downtime. Could have practical speaking more in front of each other to gain comfort level for later advocacy. Wish we'd visited the capitol together to practice or to sit in on sessions.

Shorten the length of a days learning sessions.

I would like to be part in 1991 as a service to David.

More time for Q&A with speakers. Work on debate skills and role playing more next year.

More role playing, debating, homework.

I intend to recommend this to every person I meet, know, come in contact with. I am using my PE Connection and they have contacted me for and used information that Partners has provided.

I'd love to see more legislators present.

PARTNERS IN LEADERSHIP PROGRAM EVALUATION

FINAL REPORT

Prepared by

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Social Research Consultant

June H. Twinam
Organizational Development Consultant

July 1991

COLORADO PIP PROGRAM TWO YEAR EVAL.

N.D. - Received prior to 1992 Academy

TABLE OF CONTENTS

1.0 INTRODUCTION

Partners in Leadership is a state-wide program that began in 1989. Its purpose is to help parents of young children with special needs and young adults with special needs develop a variety of skills that can be subsumed under the heading of "leadership".

The program is sponsored by the Colorado Inter-agency Coordinating Council (ICC), which is the implementing agency for Public Law 99-457, and the Colorado Developmental Disabilities Planning Council. The ICC is staffed by the Colorado Department of Education.

At the end of the program's first year, the Association for Community Living in Colorado (ACL) received the contract from the ICC and the Developmental Disabilities Planning Council to operate the Partners in Leadership program. The ACL works with a coalition of individuals, all of whom have been involved in implementing the program since its inception.

A Family Support Technical Assistance Group (TAG), a sub-group of the ICC, provides general oversight for the program. The TAG comprises representatives of a variety of agencies and organizations as well as some individuals. The contractor reports to the TAG at each meeting, issues are discussed and suggestions made.

There are six Partners in Leadership training sessions in a program year. These sessions take place in the Denver area; begin either on a Friday afternoon or Friday evening; and conclude late Saturday afternoon. Participants' costs are fully paid by the program. Two program years have been completed and Partners Three is scheduled to begin in the Fall of 1991.

The external evaluation was planned for and conducted during the second year of the program to develop data to both support future funding and to continue refining the program.

2 0. STUDY DESIGN

The Partners program is only in its second year and still in a formative stage; therefore, the evaluation team chose a qualitative research design that would enable an in-depth exploration of the quality of participants' experiences both during and after their participation in Partners. The study, a utilization focused, formative evaluation is intended to assist both the funding agents and the coalition to better understand how the various elements of the program are working and to decide what actions might be taken to enhance the program's continuing development.

The study began in the Fall of 1990. The team conducted a literature search concurrently with initial phases of data collection. To increase the validity of study results, multiple methodologies were employed to collect program data. These included

* semi-structured, open-ended interviews of three key informants: the Partners Program Manager from the Colorado Department of Education, the Executive Director of the Colorado Developmental Disabilities Planning Council and the Executive Director of the Association for Community Living;

* observation of portions of each of the six training sessions that constituted Year Two of the Partners program;

* semi-structured, open-ended interviews of 19 participants from Year One of the Partners program;

* semi-structured, open-ended interviews of 16 participants in Year Two of the Partners program;

* a focus group interview of the six group facilitators from Year Two;

* ongoing examination of the evaluative portions of Year Two participants' journals, in which respondents reflected back on the sessions and described what stood out for them and why they found those particular activities or ideas meaningful;

* examination of the evaluation forms that Year Two participants completed at the close of some sessions.

Participant interviews were usually conducted in a respondent's home and in small groups of two or three. Some interviews were conducted individually. The interviews attempted to gather in-depth data on

* what respondents are currently involved in with respect to family, employment and /or community activities;

* how respondents became involved in Partners in Leadership, their initial expectations of the program and how the actual experience differed or did not differ from those expectations;

* respondents' definitions of leadership;

- types of leadership experiences respondents have had and their perceptions of how participation in Partners in Leadership affected those experiences;

- respondents' overall assessment of the Partners in Leadership program as well as suggested changes (if any).

Participant interview guides are in the Appendix.

The sample of participants from the program's first year was essentially a stratified random sample with the stratification related to geographic location. The sample from Year Two was also stratified geographically but was only partially random. For example, the team believed that it was important to interview some of the participants who did not complete the program; therefore, these individuals were selected purposefully. Three other individuals were selected deliberately because of behaviors that appeared to differ significantly from other participants.

The following charts describe the samples.

FIGURE 1. RESPONDENTS BY LOCATION AND GENDER

	Year I		Year II	
	Female	Male	Female	Male
Metro Denver	5	1	7	2
Boulder area	2	1	3	
No. Colo.	5	1	1	1
So. Colo.		2	1	1
Western Slope	1	1		

FIGURE 2. RESPONDENTS BY ETHNICITY AND ADVOCACY ORIENTATION

	YEAR ONE	YEAR TWO
PARENT	15	14
SELF-ADVOCATE	4	2
ANGLO	17	10
MINORITY	2	6

Budgetary constraints prevented travel to the Western Slope; consequently, only those Western Slope respondents who could be located and were able to be in Denver at some point during the data collection process were interviewed.

In accordance with the agreement, the evaluation team presented interim reports on preliminary findings and recommendations throughout the study to the Family Support Technical Assistance Group (TAG), the Inter-agency Coordinating Council (ICC) and the Executive Director of the Association for Community Living. Informal verbal feedback was provided upon request to facilitators and other administrative personnel during sessions.

3.0 LITERATURE SEARCH

Despite the program's title, (Partners in Leadership) no singular notion or definition of leadership either provided focus to the original program or acted as a guideline for program content. The approach instead has been to build upon participants' self definitions and to explore the possibilities of various definitions of leadership behaviors. Because this approach had been intuitive on the part of the program developers, it was decided that the evaluation effort would include a literature search regarding the concept of leadership. The search data could then be compared to other information from participants as a part of the study.

"Leadership has been a topic of intense speculation and controversy for thousands of years. The fact that we are still conducting research on leadership tells us that we are dealing with a very complex problem. If there were simple answers, we would have known them long ago." (Fiedler, F. E. and Chemers, M. M., 1984.)

"Leadership is one of those nagging ideals that frequently defy definition. People play leadership roles, regardless of their official positions or titles... What makes the elusive 'leadership' role all the more critical is the changing, unpredictable environment in which we live. Tomorrow's leaders and those who aspire to leadership, must, therefore, become comfortable with the volatile uncertain times..." (Bisesi, M. 1983, Sloan Management Review.)

These statements summarize much of what the evaluation team discovered in a search of the literature on leaders and leadership. Warren Bennis (1985) states that there are more than 350 definitions of leadership but no clear and unequivocal understanding as to what distinguishes leaders from nonleaders or what distinguishes effective leaders from ineffective leaders. "Leadership" Bennis states "is like the Abominable Snowman, whose footprints are everywhere but who is nowhere to be seen"

Major categories of Leadership research are:

1. Trait Studies: personal characteristics of the individual leader;
2. Behavior Studies: what the leader actually does;
3. Process Studies: the interaction of the leader, followers (if present) and the environment.

Trait Studies essentially assume that personal characteristics of the leader determine the ability to influence others and/or to make things happen. Examples of traits are self confidence, ambition, decisiveness, dominance and charisma. Most early research (1900-1968) regarding leadership had a trait focus. The major conclusion from these studies is that while there are some personal characteristics that appear to be associated with leadership effectiveness, there are no universal traits (Stogdill, 1981).

Theories that focus on leader behaviors include several well known efforts; the Ohio State Leadership Studies, Blake and Mouton's Managerial Grid approach and the University of Michigan Studies. This approach focuses on the development of leadership behaviors and the impact of these behaviors on group performance and satisfaction. Examples of leadership behavior include setting clear performance expectations, being supportive of people and trusting others. The major conclusion of these studies is that there are two primary dimensions of leadership behavior: concern for task and concern for people.

Leadership interaction or process approaches propose that leadership is a system and that it is the interaction among parts of the system, such as traits, behaviors (of both the leader and followers) and the environment (situation) that determines effectiveness. Major theorists of this school include Fiedler (contingency theory), House and Evans (path-goal theory) Vroom-Yetton (model of Leadership) and Tannenbaum and Schmidt (continuum of leadership styles).

A vision of the future, risk-taking and commitment are leadership characteristics that are most commonly cited throughout the literature, regardless of the particular theoretical approach. For many authors vision and leadership are synonymous; one does not occur without the other. Si Kahn (1982) discusses " a sense of vision and direction". Bennis refers to commitment, complexity and credibility and states that effective leadership takes risks. According to Bennis, leading is a "deeply personal business" and he argues that leaders must have positive self-regard. Burns identifies "purpose" as the crucial variable influencing leadership. Hall et al (1987) state that an effective leader is "generative"-- making things happen, moving a group to a decision and building commitment to that decision. Argyris (1976) cites "a need to develop leaders in all fields of endeavor who know how to discover the difficult questions, how to create viable problem-solving networks to invent solutions to these questions and how to generate and channel human energy and commitment to produce the solutions." He writes, "...to bring about truly basic changes in institutions...that do not wash out under the pressures of everyday life, human beings will have to develop new values, new skills and new concepts of individual and organizational effectiveness..."

Much of the literature implies that leadership does not exist without "followership". For example, J. M. Burns, whose book, Leadership (1972), is considered a classic in the field, writes,

"Leadership is exercised when persons with certain motives and purposes mobilize, in competition or conflict with others, institutional, political, psychological and other resources so as to arouse, engage, and satisfy the motives of followers."

Such a definition does not appear to recognize the possibilities of demonstrating leadership without "followership". Burns further describes the leadership process as "leaders inducing followers to act for certain goals that represent the values and motivations, the wants and needs, the aspirations and expectations...of both leaders and followers."

In addition to the above, two themes that relate closely to the goals, objectives and activities of Partners in Leadership emerged from the literature search. One of these is "situational leadership". The second is "process politics".

Carew et al define situational leadership as a concept based on the notion that there is no "one best" leadership style. In a 1986 article published in the "Training and Development Journal," the authors explore the implications of this concept for group leaders facilitating group growth and development. The applications of this work for Partners in Leadership facilitators are readily apparent and the evaluation team provided copies of this particular article to the coalition during the second year of the program.

Carew et al contend that leadership styles differ on 3 dimensions:

- the amount of direction a leader provides
- the amount of support and encouragement a leader provides
- the amount of follower involvement present in decision-making.

In conjunction with these dimensions they cite four leadership styles: directing, coaching, supporting and delegating. They argue that a group leader must be able to change styles as the individuals in the group develop greater commitment and competence. Assessing the developmental level of the group members provides a leader with the information needed for determining which of the leadership styles is more likely to be effective at the time.

Fiedler and Chemers, in their discussion of situational leadership, recognize that one individual may be an extremely effective leader in one situation and fail in another. They characterize leadership styles as being primarily "relationship motivated" or "task motivated" and examine situations in terms of the degree of control ("low", "moderate", "high") that the leader possesses. Arguing that it is easier to change the situation than one's style, these authors present techniques for altering the "immediate leadership environment."

The work on process politics deals less with concepts of leadership than it does with the <u>context</u> in which leadership can be exercised more effectively. In addition, process politics focuses on communities as the target for change rather than the individual and/or an organization. Guthrie and Miller (1981) define process politics as a body of techniques that emphasizes:

- influencing institutional as well as individual causes of problems;
- encouraging self-determination;
- increasing cooperation within and among groups;
- developing individual skills;
- spreading ownership of decisions by involving those affected in the decision-making processes;
- valuing individual differences.

The authors identify process politics as a set of assumptions and techniques intended to help groups manage their own processes of growth and to help group members become capable, effective problem-solvers. The following underlying assumptions support the concept.

- Problems are solvable.

- Both creative energy and pragmatism are essential components in problem solving.

- It is essential to pay attention to both long-term perspectives and short-term objectives.

- Any one of a number of different approaches to change can be useful, depending on the situation and its dynamics.

- People count. (This assumption is strongly linked to theories regarding "transformational" leadership.)

- It's important to learn from what we do.

Guthrie and Miller identify the principal role of the process "politician" as that of a change agent and state that the process politician may serve as an educator, an advocate, a fair witness or an idea generator. They argue that process politicians help people learn to be better leaders so that these leaders can increase a group's abilities to achieve goals with the primary goal being more openness in decision-making processes.

The basic concepts and assumptions identified by Guthrie and Miller appear to be very similar to the concepts and assumptions that underlie Partners in Leadership.

A complete listing of the literature that was examined may be found in the Appendix.

4.0 FINDINGS

This section combines findings from interviews, observations and participant journals.

4.1 DEFINITIONS OF LEADERSHIP

4.1.1 Year One

Like the literature, respondents had many definitions of "leadership". The word "responsibility" was included fairly frequently in respondent definitions as were phrases that described, in one way or another, both risk-taking and initiating behaviors. Two self-advocates called leadership the willingness to speak out ("to say what's what!). The word "help" was used in a variety of contexts, including "not being afraid to ask for help...", "one who helps", or "helping others to lead". Both having and sharing knowledge were mentioned as were the concepts of goals and vision. One individual's definition of a leader was "one who does what is in the best interests of the majority of the people he or she leads or represents"; another's was "coming toe to toe with one's beliefs".

Some respondents clearly specified leadership that does not require "followership". One defined a leader as "a person who finds his or her own way--even if there's no one following...leadership is making one's own path". He went on to say that followers are "welcome" but he did not see them as a necessary element. In response the other participant in this interview session commented that one doesn't have to be "out recruiting people to follow... but is willing to have followers...to lead if requested". In another instance, a respondent explained how she had spent much time during the past year watching flights of wild geese and it occurred to her that a leader was like a "goose that breaks the V". We will see in Section 4.0 that many respondents' operational definitions of leadership (definitions that emerge from respondents'descriptions of their own leadership experiences) do not require "followership". This is particularly true for respondents in the Year Two sample.

Other words or phrases that respondents used in their definitions include: "making or allowing things to happen," "strength," "stability," "someone who's in charge," "accountability," "someone others look to for guidance," "enabling," "energetic," "motivator," "good listener," "tenacious" and "willing to admit mistakes". One respondent also discussed a style of leadership that is "not necessarily visible" but through which one is "able to control (outcomes) from the sidelines".

4.1.2 Year Two

Again, participants corroborated Warren Bennis ("over 350 definitions of leadership") and had multiple responses to the request to name the words or actions that they associate with "leadership". In this group, the concepts of vision and goal-orientation were mentioned by a few as was "gaining trust" or being "trustworthy". A couple of people dealt with leaders and "mistakes" in terms of both being able to admit to one's mistakes and learning from one's mistakes. Another person stated "everyday I should teach a little, learn a little and give others the same opportunity".

One respondent defines a leader as one who "functions as the glue" while another believes leaders must have the ability to "see the gray areas and understand that not everything is black and white".

Risk-taking was mentioned as were "commitment", "expertise and/or experience", "strength," "dynamism", and "tenacity". One respondent believes a leader must be "assertive but compassionate...with a little finesse". Another indicated that effective leaders "don't take all the credit".

Other terms used by Year Two respondents included, "inspirer", "motivator", "performer", "listener", "organizational abilities", and "non-judgmental". As with Year One participants, several self-advocates defined advocacy on behalf of others as leadership.

One Year Two respondent described a variety of styles that leadership might take.

"You have a goal in mind and then work within that vision with whatever capacity is necessary to help accomplish the goal...maybe educate..maybe enabling...maybe prodding or outright aggressiveness...Adapt the style according to how the style is going to accomplish the goal. A leader has a lot of different capacities."

Did participation in Partners affect their concepts of leadership?

"Sure it did. I used to think a leader gave orders."

"Yes, now I refuse to do things."

"Rather than <u>shuffle</u> through the system a little longer, I became more vocal regarding my needs."

"I didn't know leaders could admit to mistakes...a leader needs to know when she's gone awry."

"I didn't get disgusted before."

"I realized that being a leader you almost have to take risks. There's a lot more work than I realized...it's more complex."

"Yes! I think a person with developmental disabilities can be a leader...Leadership qualities can be found in people with developmental disabilities...(he/she) may not be a leader of all the world but a leader in one's own sense."

"Now I see that leaders think long-term..leaders see the whole picture."

4.2 EXPECTATIONS OF PARTNERS IN LEADERSHIP

4.2.1 Year One

Respondents typically cited "contacts" and "information" as the benefits they expected to gain from Partners at the time they applied to participate in the program. Some were looking for emotional support, interaction and sharing; others wanted tools for improving their advocacy skills. Only one Year One parent respondent reported that he had expected to meet adults with disabilities, believing they would "have a focus on things I didn't have". He went on to say, "...that expectation was well fulfilled." Another major theme, especially among self-advocates, was the notion of giving help or support to others.

Parent participants universally cited interacting as peers with adults with special needs as the primary difference between their initial expectations of Partners and the reality of the experience. One, who admitted that she had not looked forward to having self-advocates in the group, found that self-advocate participation became one of the elements from which she realized the "most benefit". Another indicated that interacting with self-advocates "made me grow up"; a third stated that having the self-advocates as equal participants in the group was "integral to the whole thing".

From the standpoint of the self-advocates, the reactions were more mixed. One found her interaction with the parents enlightening because prior to Partners she knew "nothing about little kids". Two who grew up in state institutions, found interaction with parents somewhat painful--the talk of small children being raised in their homes resurrected their grief about their own childhood.

"Why," one wondered aloud, "did I have to grow up in the state home?"

Other differences between initial expectations and the actual experience included "tools" (as opposed to just information), more emotional support than anticipated and learning through experience (activity on the statewide pre-school initiative) that one "really can make a difference at the grassroots".

Some respondents noted also that their experiences in Partners and learning new skills had an emotional impact on their lives--primarily enabling them to move out of depression. Several participants noted that the programmatic activities moved them from "being stuck" and feeling powerless to feeling more in charge and self confident.

4.2.2 Year Two

At least three respondents indicated that their expectations were relatively vague when they applied to Partners.

"I didn't know...some valuable skills...but I wasn't sure what."

"I wasn't sure...(I guess) some additional knowledge about developmental disabilities."

"I wasn't sure...but I wanted to be more effective in dealing with my kids' school."

"...increase my knowledge base."

"...learn how to work the ropes."

Several of the parents were hoping to make contacts and have interaction with parents like themselves--not just parents of youngsters with special needs but, as one parent put it, "go-getters". Some respondents were looking primarily for knowledge and information about resources or advocacy skills.

One, who works professionally with special needs families, was not expecting to gain anything for herself...she was "checking it out for others." Now she reports that she tells "any and every parent I can tell about Partners...self-advocates, too." Her experience in Partners "went beyond" her expectations.

"I was overwhelmed with a feeling of validation. I had always believed in collaborative learning and in integrated learning...and I was concerned when I pushed for integration for my own kids because I had no experience with it until Partners...but with the self-advocates there I saw that it worked!"

Like the Year One sample, the majority of parent respondents reported that interacting as peers with the self-advocates was one of the most significant differences between their expectations and their actual experience.

"I was impressed with the number of self-advocates--it was a positive thing that I hadn't thought about before...seeing successful adults with special needs, adjusted to their disabilities was really positive."

"I didn't expect to see so many special needs adults..at first I thought I really didn't belong...After the first couple of sessions, my education began. Now I see how I've been able to apply what occurred."

"The self-advocates helped me to think about my daughter's adult life..I hadn't considered that before..."

On the other hand, a self-advocate indicated in a journal entry that interaction with parents helped her to understand how her own parents had felt as she was growing up.

All of these interactions had a "growth" effect, or, as in the words of one participant, "it opened me up!"

Respondents generally agreed that the benefits from the program exceeded their expectations.

"The collaborative groups were more work than I had thought--but they were very beneficial."

"I received confirmation of my values"

"There was more emotional support than I had expected..people accepted me for what I am...There were effects on my life...you don't see me taking much action but it's in here--in my head...it opened my mind."

"I walked away with tools...I didn't expect those. It didn't happen at first. At first there was kind of a dip...after that I gained tools I could hold onto..."

"I thought I could share (my knowledge and experiences) with others--but I learned a lot...it gave me tools..helped me to be assertive about some things...it more than met my expectations."

"Now I can talk to social workers and teachers".

In addition, some indicated that as they "grew as persons, their needs increased". In other words, the more one learns, the more one needs to learn.

4.3 LEADERSHIP EXPERIENCES

4.3.1 Year One

Every respondent in this sample was involved, at the time of the interview, in at least one activity relating to advocacy or support for individuals with special needs. These activities ranged from boards to committees to support groups to individual volunteering in schools. Most of the self-advocates were employed and living independently while the majority of the parents were raising more than one child (in a few cases more than one child with special needs) and were also employed at least part-time. In addition to activities in the disability movement, several are involved in other community activities such as a church or a recreational group (softball, soccer, etc.).

Respondents described leadership experiences that occurred in a variety of contexts including :

- boards, committees or family support groups;
- child's school or school district;
- work situations;
- social situations.

Two of the respondents reported that their work requires them to demonstrate leadership on an ongoing basis. One of these described an experience in organizing a family support group in a community but wasn't sure if she should use this experience as an example because the mechanics of implementation were "so basic for me". In her view, a recent experience in the workplace, where she was able to facilitate a productive relationship with a co-manager, seemed to her to be a more accurate reflection of leadership.

One self-advocate described her actions on a committee that was screening for a new agency director. She was uncertain that she had actually demonstrated leadership but described "speaking out" on some issues as the session was drawing to a close.

A parent described a lengthy and complicated process in which a public school district was adverse to providing any additional programs for an eighteen-year-old son who was not yet ready to make the transition into adult life. As a result of these efforts, the district is now establishing a program to enable 19 to 21 year-olds with special needs to make more gradual transitions into the community. She is obviously very pleased with the outcome of her efforts, which included bringing a variety of agencies together and amassing a great deal of support for her position. However, if she had it "to do it over, I wouldn't have worried so much...I had myself and my family crazy...you don't have to get yourself so worked up about it".

Another mother described her involvement in integrating a pre-school for youngsters with special needs into the public school where it is located. This effort included organizing a variety of activities that would create both visibility for her cause and have an impact on institutional and parental resistance. She and the other parents and staff, with whom she worked to accomplish this, are now considering traveling throughout the state with their new model.

A father described writing a letter to a school superintendent praising a new and exceptional teacher. The respondent believes his letter was one factor in this teacher's receiving a tenure-track position with the district. Another father described his impact on a personnel committee of a Community Center Board while a mother described her impact on a sub-committee of the Assistive Technology Group. With assistance from some of the others in the interview session, a self-advocate described her impact on two young children who were resisting learning the technologies they must use if they are to communicate. Parents of both children were Partners participants.

Three respondents recalled experiences where boards called executive sessions to prevent them from expressing their opinions on services being provided. In one of these cases, the board now provides time at each meeting for the public to speak. Therefore, according to one respondent, the trouble that she and others went through (being "kicked out" of meetings and being labeled "trouble-makers") "paid off".

Several respondents reported specific instances of advocating for others: these included actions from strong stands at staffings at another person's request to one instance that occurred spontaneously in a public restaurant when a person in a wheelchair had difficulty in using the facility. The respondent, who did not know the person involved, complained to the manager on the individual's behalf regarding the lack of appropriate supports.

For another participant leadership has meant a generalized development of assertiveness. She cited an incident when she called and challenged a radio show host who had made a comment, with which she disagreed, about persons with disabilities. Despite the fact that the talk show host hung up on her, she views the action as an example of leadership. Her husband refers to this action as "that's Partners coming out".

What influence did Partners in Leadership have on these activities? A few respondents indicated they probably might have engaged in their activities without Partners but Partners helped them to "do it sooner". Some stated that it was their Partners experience that enabled them to have a future "vision" about what it was they wanted to work towards.

"My son had been in special schools all the time before we came here. I always knew that was wrong. This time I came with a plan and an alternative and it worked...I learned through Partners not to be mad at the agencies...they were just doing their job...but I learned that no one knows your kid like you do."

One respondent, with respect to the need for a vision, commented,

"There's so much out there--it's awfully easy to get lost in the forest along the way."

Various respondents reported learning to speak up or to stand up for oneself or one's child.

"I used to be afraid of losing my services... they can give you a hard time but they can't pull services."

Respondents reported learning how to get what is needed without making enemies; and "not to let the system define the possibilities for my kids". Other attributes that respondents believe they either gained or enhanced through Partners were "courage", "confidence", "independence" and "timing".

One respondent, who has always perceived herself as a leader, believes that Partners helped her to become "more assertive than aggressive and more honest with myself". A father, who has also always thought of himself as a leader does not believe he gained or enhanced leadership skills through Partners but says he did come away with new knowledge. Another reported that "things don't get to me now" and another said,

"I learned that doctors are not bad, only human...maybe less so."

4.3.2 Year Two

Many of the respondents in the Year Two sample are involved in boards, committees or support groups that are related to families or individuals with special needs. Like the Year One sample, most of the parent respondents are employed at least part-time outside the home and are raising more than one child. A few of the respondents are employed in organizations that serve families or individuals with special needs. Some respondents are also active in other voluntary activities.

Year Two respondents were asked to describe two different leadership experiences--one that occurred before Partners and one that occurred after they began participating in Partners. The majority of the respondents indicated that they had thought of themselves as leaders prior to Partners although one individual prefers the term "impacter" to "leader". One respondent, whose first language is not English, was very clear about the fact that she has never considered herself a leader although people have told her she has the potential for leadership.

Many of the "pre-Partners" experiences that respondents described were related to their work while some were in family situations. Two individuals indicated that they demonstrate ongoing leadership in their work and family. Most of the "pre-Partners" experiences described did not have a "followership" component.

Many of the "post Partners" experiences related to interaction with care or service providers.

"I told the pediatrician that we had been doing it his way for a long time and now I wanted to try it my way...I had to take a stand...I don't know if he got mad or not but he agreed and it's working...I know my child better than the doctors do...I'm getting tired of having doctors run my life!"

What would she do differently if she could do it again? "I'd have done it sooner!"

Other incidents with providers, in which respondents described taking a stand, concerned another pediatrician, a case manager, Individual Habilitation Plan (IHP) processes and therapists. Some of these exchanges have been verbal, some written or both. In a few of these situations, the interaction was continuing at the time of the interview. Some outcomes have been more positive than others but even where the outcome was less than desired the respondents seemed relatively pleased with their own behavior. One described how she "carefully watched how she explained herself" in writing a letter requesting a new case manager. Another, however, would do it differently even though she got what she wanted.

"I wouldn't be so bullish...I'd give them more time to mull it over. I don't like t be known as bull-headed...I should have given them two times to decide instead of one and then gotten bullish."

A self-advocate described a very public (reported in the media) confrontation with the Governor regarding a policy debate on the rights of children who are disabled to attend the school of their choice. Another example of a public demonstration of leadership was described by a parent who influenced a school district to change its practice of not respecting the personal modesty of teens with disabilities. The incident revolved around a place for the youngsters to change clothes for water therapy and did not involve her own child. Nonetheless, she persisted and the district not only changed its practice but acknowledged that its previous practice had been inappropriate.

One respondent described an ongoing issue at work where he is engaged in significant risking behavior in arguing for the needs of his agency.

"They want to know why I keep bringing it up when they've already told me 'no'. I told them 'because no is the wrong answer.' "

Several respondents described presentations they have made to various support groups using materials and ideas from Partners.

The respondent who had earlier indicated that prior to Partners she had not thought of herself as a leader described an experience within her church. Frustrated for some time with what she perceives as insensitivity to minorities, to women and to children with special needs, she recently confronted a clergyman and expressed her concerns.

"He said he appreciated that and that they need to know that. I wish he were higher up and could make changes...I never would have done that before...I was always afraid to make noise...I have to start talking...stand up for my own rights and children's. My children are as good as anyone's!"

These descriptions of leadership experiences are primarily without a "followership" component. Yet in most cases the respondents believe that they either imparted new knowledge to a group or influenced a provider to behave differently at least in a particular situation.

What kinds of changes did respondents see in themselves as a result of their participation in Partners in Leadership?

"I'm more selective now about who I spend time with...I'm tired of hearing people say 'You shouldn't have done that.' I feel less confused."

"I feel less changed than strengthened."

"I felt sorry for myself...now I realize you just work around the language and the disabilities...If I don't do anything, nothing's going to get done."

"I never embraced change easily...now I see change more positively...I'm taking more risks..."

"I'm more able to accept conflict...I'm still practicing but I'm more willing now to go through conflict. Partners got me thinking differently about fighting for the rights of people."

"I used to be really shy...(a member of her support group) told me I'm not the same person I was. Most important I went from thinking of my son as a handicapped child to a mischievous little monster with some physical limitations."

4.4 RECRUITMENT AND SELECTION

4.4.1 Year One

Recruitment for Year One was conducted state-wide. Forty participants were selected on the basis of their written applications. Twenty-five of these were parents of young children, 15 were self-advocates. No pre-screening interviews were conducted prior to acceptance.

Around half of the participants were recruited personally by facilitators, therapists and/or individuals in support and educational groups such as PEP and PEAK. Others in the Year One sample simply responded to one or more Partners in Leadership brochures received in the mail.

4.4.2 Year Two

As a result of the relatively low participation of minority individuals in Year One, criteria for selection in Year Two included a "2X" factor with respect to minority applicants. (This means recruiting twice the proportion that exists in the actual population.) This requirement by funding agents is intended to assure a significant level of ethnic diversity in addition to geographic diversity; a mix of parents and self-advocates; and representation of a wide range of disabilities. A relatively equal proportion of men and women is also a goal.

The selection committee made their decisions from reviewing written applications. No pre-screening interviews were conducted. One couple was included among the participants.

A larger proportion of Year Two participants had, in addition to the mailed brochure, personal or telephone contact with someone who discussed the program with them and/or encouraged them to apply. In some cases, respondents had contact with a Year One participant; in others, a care or service provider informed them about the program and encouraged their applications. Several individuals were contacted by more than source.

One parent participant was approached with his wife at a meeting by an ACL board member who gave them the brochure and encouraged them both to complete applications. They did so, assuming that if they were selected they would attend as a couple. However, only he was selected--probably as a result of the program's need to recruit a higher proportion of minority males. The child with special needs is his step-child and while the respondent expresses both concern and affection for her he was also clear about the fact that he is a step-father who has been involved with the youngster for under three years. He believes strongly that, if only one of them could participate, it should have been the child's mother.

"She was disappointed she didn't get in..she should have been there...we discussed that a lot...guess they needed men...It was benefitting in a sense but it could have been great for her. Those speakers--she could have learned from them."

This participant was one of two who did not finish the program. He indicated that he never decided to drop out.

"It just kind of happened. My intent was there...they just made the wrong choices...It should have been my wife."

Another participant who dropped out did so because of an apparent misunderstanding of the program's requirements and a conflict with her work schedule. She works evenings and could not rearrange her schedule to accommodate the Friday evening session. It would appear that, in their enthusiasm to have her in the program, the individuals recruiting her overlooked this conflict.

4.5 WHAT SHOULD CHANGE?

4.5.1 Year One

Respondents were the most concerned about the failure to keep the group connected when the first year ended.

"Keep us involved".

"I wish we could get together again. We planned on a newsletter but it never happened."

"My understanding was that part of the philosophy behind partners is to establish at the grassroots level a potential network of folks throughout the state who can be a source for rallying around issues..."

"Keeping the group together with some taking leadership roles would have been useful."

Respondents also expressed a need for more unstructured time and more time to speak with one another.

"The pace was rough."

Kathryn A. Peterson
2194 St. Anthony
St. Paul, MN 55104

May 8, 1992

Woman's Day
Rebecca Greer
1515 Broadway
New York, NY 10036

Dear Ms. Greer:

I am writing to submit the enclosed article,"Reflections Through My Favorite Window", for your consideration for publication, on the "Reflections Page", in Woman's Day Magazine. The piece stands as an independent article, but it is also a chapter from an unpublished manuscript.

Diabetes has been with me since I was a teenager and I am now in my forty's. Thirteen years ago I lost my sight to the disease. Within the last five years, I have lived on dialysis and have received a kidney transplant. Most of my movement, is in a wheelchair, due to nerve damage in my legs. The manuscript, "I STILL DANCE", reflects on my life of coping with diabetes and its complications. It is a hard look at the realities of living with handicaps and about drawing on whatever resources one has, in order to deal with them. It is also a look at sorting out what is important in life.

This information is being provided with the thought that you might be interested in serializing the entire book, or selected chapters. I believe the material to be of interest to women in particular and that your magazine would be a good vehicle.

I am happy to send completed chapters, but will await your reply and indication of interest. Thank you for your consideration.

Sincerely,

Kathryn A. Peterson
(612)644-0231

"If you're really trying to get this network going...a little more time is really important for people to share their stories...our lunches always got cut into..we always ended up working during our lunches..."

"Should have had seven meetings instead of six and the last one would have been just to have...just to interact with each other...more one on one time...I needed to know more people better."

Several individuals brought up the possibility of including couples in Partners. One father believe he changed through the Partners experience and it is a disadvantage that his wife missed out on it. Two mothers indicated that they seem to carry a larger share of the advocacy burden because their husbands were not with them in Partners.

"I wish my husband had gone...this was really a loss for him. He relies on me a lot. They need a Partners in Leadership for couples."

These respondents were essentially aware of the issues involved, including the importance of room-mates and the need to reach out to as many people as possible. Nonetheless, they believed their own experience would have been more beneficial had they gone through it with their spouse.

Some respondents also alluded to a need to introduce "normalcy" into their lives. One woman described how she had recently reduced her volunteer activities that relate to the disabilities movement and had joined a women's church group. A male respondent agreed with the need to do this. Another mother indicated that she does not wish to limit her associations to people with disabilities or parents of children with disabilities, saying "a lot of people get into that sort of thing".

4.5.2 Year Two

A major change from Year One to Year Two was the reduction of lecture time and the increase of experiential activities. Journal entries and written evaluations indicate that participants responded well to these activities. One participant said succinctly, "I learn by doing". The collaborative work groups, writing letters to one's state senator or representative and role playing testifying before a legislative committee all appear to have been very worthwhile activities. One participant, who has since actually testified before a legislative committee, commented that the atmosphere was exactly the way it was portrayed in the role play. Another, however, reported that the actual atmosphere was more difficult than the role playing had depicted.

One respondent would have preferred to have more "sayso" with respect to the collaborative work groups. She wonders if it would be beneficial to have the group choose their own topic as opposed to having one assigned. She also posed the possibility of the group's selecting their own facilitator. She is nonetheless aware that if she had been able to choose her own role she would not have selected the one she was assigned--one from which she admits she learned a great deal.

Some respondents expressed a need for more unstructured time.

"You get so much you're not absorbing it anyway...(you need) time just to sit."

This respondent saw the provision of more free time as "modeling taking care of yourself and your own needs" which is something she believes Partners should include in its curriculum. In addition to this she would like to see parents of young children understand how to put equal emphasis on the siblings without disabilities.

"The handicapped child shouldn't always be central--everyone has special needs. Young parents should understand the impact on siblings of having a child with disabilities."

It would seem that this concern is another facet of the concern that was expressed by a few Year One participants for introducing "normalcy".

There was one couple in the Partners Two group. While this couple has a higher than average degree of community involvement and experience, it is interesting to note that they both feel strongly they "could not have gone through the program alone". They supported each other in completing homework assignments, discussing tensions, etc. The most interesting aspect of their experience is that they shifted their own position from wanting to segregate their child to choosing to mainstream him. This change, a direct result of their participation in Partners, has had a major impact on their social life, particularly affecting their interactions with other families who have disabled children and have opted for segregated facilities. Both individuals believe that there is little likelihood that they would have made and acted upon this decision if only one of them had participated in Partners.

Facilitator responses to the concept of including couples are mixed. Some would like to try adding more couples while one sees it as a "distraction". There is a concern that adding more couples would make the atmosphere less welcoming to self-advocates who are typically single.

Both participants and facilitators believe there's a need to strengthen the facilitation of self-advocate participation. While facilitators saw a major improvement in this from Year One, they still expressed concern. One facilitator commented that self-advocates' needs are different than those of the parents at the beginning of the program.

"They (the self-advocates) have lower self-esteem."

Facilitators also expressed concern about the closing session.

"The part we're really missing is tying it together."

They recalled one participant, at the closing session, asking, "What do I do now?"

It is apparent from both facilitators' comments and what the evaluation team observed that the facilitators also have needs and these needs have an impact on the program. No formal training in facilitation has been provided for this group and some of them had no previous experience in group facilitation. One facilitator called the experience "trial by fire".

Facilitators expressed needs for techniques to draw out quiet participants, deal with individuals who monopolize the discussion and handle hostile participants. They also believe that some grounding in group process would have enabled them to be more aware of what to anticipate in the collaborative groups and to handle pressure from group members who objected to their assigned roles, case assignments, etc.

Facilitators would find it useful to have more time to de-brief during the sessions. They also believe they could be more effective if they received copies of all mailings that participants receive; are informed in advance of agenda and other changes; and receive brief summaries of participant journal entries and other internal evaluation activities.

5.0 CONCLUSIONS AND RECOMMENDATIONS

Partners participants from both years express a significant amount of enthusiasm for the program. Most believe that they benefitted from their participation and describe subsequent actions and activities that exemplify those benefits. Like the literature that explores the field, participants perceive leadership in multiple ways--both in general and in terms of their own behavior. Many participants define their enhanced leadership by describing increased organizational participation, more assertive behavior or simply having a clearer sense of one's own situation.

As the evaluation team pointed out at the onset of this study, it is very early in this program's development to assess outcomes. *Are Partners participants having an impact on "the system"?* In a few cases the answer is yes. The parent who has convinced a public school district to develop a program to help 19 to 21 year-olds make their transition has had an impact on that particular system as has the parent who has succeeded in making her child's pre-school a more integral part of the public school in which it is located.

Has a parent who convinces a physician that it's time to "do it her way" made it any easier for the next parent who believes s/he knows what is really best for the child? Possibly--but we have no way of knowing or measuring that. Has that action had a positive impact on the child and the family? Definitely. Might this same parent take some action in the future that will have a broader impact--and will that be the result of her participation in Partners? Very possibly.

Newspaper articles, organizational mailings and letters to editors certainly confirm that a number of Partners graduates--particularly from Year One--are active. It is interesting to note that more Year One graduates report experiences that require a degree of "followership", indicating perhaps what one might expect to see from Partners Two graduates given more time. Research on adult learners shows that adults prefer "hands on" learning. Therefore, one can assume that each post-Partners experience will further the individual development that occurred during the program and that each step will lead to another.

There are actions the coalition can take that the evaluation team believes will enhance the program and increase its impact on the participants and their impact on others.

5.1 RECOMMENDATIONS

Follow-up activities are extremely important, from both the emotional and educational points of view. The evaluation team is aware that Partners is not meant to be an ongoing support group nor is it recommended that it should become one, in spite of reactions of some participants to the contrary. (One person stated "I want to stay connected forever".) The program's very intensity requires that it should not simply end. Periodic follow-up is required to meet participants' needs for some ongoing contact and to enhance the possibilities of participants having positive impacts on others; on organizations and agencies; and on their communities. Concrete plans for at least one activity should be made and presented to each group before it disbands. This step may be even more important for the self-advocates in the program than it is for the parent participants.

The need for some kind of continuing contact relates directly to one of the major themes of Partners--building community and support systems. Given the relatively brief (but intense) interactions participants had with each other, some longer term relationship building is important. Also, abrupt transitions of any kind tend to result in reactions of shock, denial and immobilization; this is negative reinforcement for some participants who may have just begun to learn how to reach out to others.

Follow-up reinforcement is a part of the learning process. Many Year One participants noted a "dip" or plateauing of their activities and understanding immediately following the close of the formal program which shifted after a few months. Follow-up contact within a brief period after the formal program's conclusion might have alleviated this.

Group facilitation is a significant element of the Partners program. Its importance has increased in the second year with the introduction of more small group learning activities.

Facilitators are not only key players who enable the entire process but they are also role models; leadership frequently necessitates group facilitation in order to accomplish one's objectives.

Given their minimal experience and lack of formal training Year Two Partners facilitators performed admirably. However, their impact on participants' development could be greatly enhanced with the provision of in-service training both prior to the onset of Partners Three and throughout the year.

We recommend a one-day training session before the first weekend of Partners Three and two to three half-day sessions during the program year. These half-day sessions would enable facilitators to bring specific situations to the trainer and the group for guidance. A portion of each facilitator training session could be concentrated on ideas for better meeting the needs of the self-advocates.

Facilitator training should also address the distinction between facilitation with a therapeutic focus and that with an educational focus. Participants frequently have needs in both areas; consequently, it is important that the facilitators are clear about the distinction and can help groups and individuals, who are struggling with both these needs, to separate them and to develop strategies to address them--both within and outside of the Partners program. Several participants noted that they were struggling feelings of depression, guilt and anger. If not addressed within the context of Partners, these feelings can prevent participants from fully benefitting from the program's educational focus.

Other issues related to facilitation include assisting facilitators in identifying their own needs and issues that may be triggered by the program and providing adequate debriefing and alone time immediately following sessions. Facilitation is a highly demanding skill which requires recovery time.

It is also important for facilitators to be fully included as program staff, receiving copies of mailings, being informed in advance of agenda changes and receiving ongoing information about the results of internal evaluation procedures.

Coordinators and facilitators might find it beneficial to explore some of the literature discussed in Section 3.0. We recommend particularly "Group Development and Situational Leadership: A Model for Managing Groups" from the June 1986 issue of the Training and Development Journal and Process Politics: A Guide for Group Leaders by Guthrie and Miller.

The proportion of time devoted to experiential learning, as opposed to didactic and/or personal or historical presentations, should continue to increase.

Suggestions for additional role playing situations include:

- self-advocates interviewing potential attendants;
- school or agency staffings;
- both parent and self-advocate interactions with physicians, therapists and other care-givers;
- a parent-teacher conference;
- dealing with family differences and tensions relating to therapy, education and employment decisions.

Role playing activities can be relatively brief and must be structured carefully to make them as comfortable as possible, particularly for participants whose written and verbal skills are not strong. Role playing experiences can prove very useful for individuals when they subsequently encounter similar situations. Participant interviews indicate that some of these suggested role playing situations are the situations in which participants will try to use leadership skills.

In addition, if it's considered important to increase the "ripple" effect, which occurs as participants present the concepts they gained in Partners to other groups, it would be important to give the participants ample opportunity to "perform" before either small groups or the total group.

The evaluation team believes it would be useful to clarify the function and focus of the various presenters used in the program. For example, is the speaker primarily inspirational? a role model? imparting specific skills? presenting a different point of view?

When this determination is made, this framework can be included as part of the presenter's introduction, helping to clarify the participants' expectations. This is particularly important in the early sessions of the program. This framework also suggests when, in the sequence of sessions, the presenter might best be used. For example, using a presenter with a different or opposing viewpoint early in the process tends to confuse participants who may not yet be sufficiently clear about their own values and opinions to enter into a dialogue. An example of this issue relates to "labeling". Opposing views on this issue were presented throughout the training. Some of these views were presented very early when some participants reported simply being angry rather than being able to hear another option.

Data on the reactions of participants to various presenters are very consistent and indicate that the timing suggested here is important.

* Some brief periods of unstructured time should be carefully built into the program throughout each weekend session. The intensity of the schedule can be overwhelming for the participants--particularly in the beginning. The respondent's suggestion that Partners needs to help participants learn to take care of themselves was very significant and is part and parcel of the comments from people who were reducing their volunteer activities and who were trying to introduce "normalcy" into their lives. The respondent who said if she could live her leadership experience all over again she wouldn't have worried so much and described how she made herself and her family "crazy" is another example of the issue.

  The program tends to model a sense of continuous "urgency" which participants may be taking back into their lives. While such a sense is often expected of individuals who advocate either for themselves or their children, it has significant negative consequences in terms of sustaining efforts and in terms of both personal and family well-being. Individuals and families need to develop a sense of balance with respect to these activities. The Partners program can introduce this concept both in informal conversation and in the model that is consciously presented.

* Meals can be used to facilitate interaction among a variety of different groupings. For example, at one meal participants from a particular county or a particular part of the state can be seated together. These individuals can create their own agenda for their informal conversation. Simply eating together once or twice might enable them to create their own links once the formal training has ended.

* A number of issues relate to the recruitment and selection process. In actuality, the process in Year Two worked relatively well. Forty-two participants were selected and thirty-nine graduated although one of the graduates both had and caused a great deal of difficulty at certain points in the program.

  During a Family Support TAG meeting in April, a suggestion was made to move the deadline for applications earlier in the summer to provide opportunities for interviewing the applicants, at least by telephone. We believe that this suggestion should be followed and that in the future some type of interview with potential participants should be fully incorporated into the selection process.

We also suggest that the "2X" factor be carefully monitored. Diversity is very important. However, it is possible that a rigid imposition of these selection criteria can be damaging. While we do not recommend that the selection committee should "cream", accepting only those applicants who are highly likely to succeed under any circumstances, neither do we recommend accepting individuals who fulfill certain demographic criteria but whose chances for success in the program are minimal.

5.2 ONGOING INTERNAL EVALUATION

An effective internal evaluation for Partners in Leadership should include both short-term and long-term components. The short-term research should help those implementing the program to assess the immediate effectiveness of each individual training session and then, later, the year's programming as a whole. Long-term evaluation can assess what longitudinal impact the program has had on the behavior of a sample of participants from each year.

5.2.1 SHORT-TERM EVALUATION

The team believes that elements for short-term evaluation are already in place and can be used on an ongoing basis with some modifications. These include: evaluative journal entries; facilitator debriefing sessions both during and after sessions; telephone conversations with individual participants; a group discussion about "how the program is going" during the third or fourth session; and written evaluations by participants at the conclusion of the final session.

A major change recommended for future years with respect to internal evaluation is that the data collected needs to be regularly summarized and shared with all staff. The team realizes that reading each evaluative journal entry, and analyzing and summarizing the content for distribution to all the coordinators and facilitators is both difficult and time-consuming. However, the information collected will only be useful if those directly involved with implementing the sessions are aware of it. This is also true of the telephone contacts with participants that occur after each session.

The homework assignment for evaluative journal entries should be given regularly at the close of each session with emphasis on the fact that these entries are used to help assess the session rather than their participation. Whether or not participants include their names on these assignments is up to the program coordinators.
The team suggests the following format for the journal entries:

willing to speak with you on the telephone three times, for around 30 minutes each time, beginning this month and then at six-month intervals. If s/he is willing to participate, make an appointment for the first telephone interview within that week.

III. Follow the same process in the Fall of 1992 for Year Three participants. In order to avoid having to conduct too many interviews at once. it may be advisable to contact Year Three participants either the month prior to or the month following the final set of Year Two interviews.

A suggested interview guide follows. Partners in Leadership coordinators, facilitators and those who actually conduct the interviews may find the need to modify this guide for the second and third interviews.

PARTNERS IN LEADERSHIP
INTERNAL EVALUATION
RECOMMENDED INTERVIEW GUIDE

INTRODUCTION

EXPLAIN PROGRAM EVALUATION EFFORT. EMPHASIZE THE NEED TO LEARN ABOUT PARTICIPANTS' EXPERIENCES AND THEIR THOUGHTS AND FEELINGS ABOUT THOSE EXPERIENCES. THERE ARE NO RIGHT OR WRONG ANSWERS. THE PRIMARY FOCUS IS TO LEARN WHAT KIND OF IMPACT PARTNERS IN LEADERSHIP HAS HAD ON PARTICIPANTS OVER TIME. EACH PERSON WHO IS INCLUDED IN THIS ASSESSMENT OF THE PROGRAM WAS SELECTED RANDOMLY.

CURRENT SITUATIONS

LET'S BEGIN WITH DISCUSSING WHAT YOU'RE DOING THESE DAYS. I'M INTERESTED IN LEARNING ABOUT YOUR FAMILY, YOUR WORK (IF YOU'RE WORKING OUTSIDE THE HOME) AND ANY COMMUNITY ACTIVITIES THAT YOU MIGHT BE INVOLVED IN.

LEADERSHIP EXPERIENCES

CAN YOU THINK OF ANY TIMES IN THE PAST FEW MONTHS WHERE YOU THINK YOU (DEMONSTRATED/DISPLAYED/EXHIBITED) LEADERSHIP? (ALTERNATIVE: CAN YOU THINK OF ANY TIMES IN THE PAST FEW MONTHS WHEN YOU THINK YOU WERE A LEADER?)

CAN YOU DESCRIBE WHAT HAPPENED?

(PROBE AS APPROPRIATE FOR DETAILS:)

WHERE WERE YOU?
WHO WAS INVOLVED?
WHAT DID YOU DO?
WHAT DID YOU SAY?
WHAT DID OTHERS DO AND SAY?WHAT WAS THE OUTCOME?
HOW DID YOU FEEL ABOUT IT AFTERWARDS?

WHAT IS IT ABOUT THIS PARTICULAR EVENT THAT MAKES IT STAND OUT FOR YOU?

DO YOU THINK YOUR EXPERIENCE IN THE PARTNERS PROGRAM MADE ANY DIFFERENCE IN THE WAY YOU ACTED IN THIS PARTICULAR SITUATION?

(PROBE AS APPROPRIATE:)

CAN YOU TELL ME WHY NOT?/HOW DID IT MAKE A DIFFERENCE?

HOW DO YOU THINK YOU MIGHT HAVE ACTED IN THIS SITUATION IF YOU HAD NOT PARTICIPATED IN PARTNERS?

CLOSURE

IS THERE ANYTHING ELSE YOU'D LIKE TO SAY OR ANYTHING YOU'D LIKE TO ASK ME?

THANK RESPONDENT FOR HIS/HER TIME; REMIND RESPONDENT YOU'LL BE CONTACTING HIM/HER AGAIN IN ABOUT SIX MONTHS; ETC.

INTERVIEWER GUIDELINES

1. WHEN YOU MAKE THE FIRST CONTACT, BEGIN BY INTRODUCING YOURSELF (OR RENEWING THE ACQUAINTANCESHIP) AND DESCRIBING THE STUDY.

2. EMPHASIZE THE IMPORTANCE OF THE RESPONDENT'S PARTICIPATION AND HOW MUCH YOU APPRECIATE HIS/HER WILLINGNESS TO HELP.

3. WHEN CONDUCTING THE ACTUAL INTERVIEW, TAKE A FEW MINUTES TO WARM UP THE RESPONDENT WITH SOME CASUAL CONVERSATION OR SMALL TALK.

4. USE TRANSITIONS TO KEEP THE INTERVIEW FLOWING. FOR EXAMPLE, "NOW I'D LIKE YOU TO THINK ABOUT" OR "NOW WE'RE GOING TO SHIFT GEARS A LITTLE AND TALK ABOUT ANY LEADERSHIP EXPERIENCES YOU MIGHT HAVE HAD RECENTLY."

5. BRIDGE QUESTIONS BY PICKING UP ON IMPORTANT POINTS FROM THE PREVIOUS CONVERSATION. FOR EXAMPLE, WHEN TELLING YOU WHAT S/HE IS CURRENTLY INVOLVED IN, THE RESPONDENT MAY HAVE ALREADY TOUCHED ON A LEADERSHIP EXPERIENCE. "YOU'VE ALREADY TOLD ME A LITTLE ABOUT A RECENT EXPERIENCE WHERE YOU DEMONSTRATED LEADERSHIP. I'M REALLY INTERESTED IN HEARING MORE ABOUT THAT."

6. PROVIDE FEEDBACK TO THE RESPONDENT. "THAT'S REALLY USEFUL INFORMATION."

7. IF YOU DON'T UNDERSTAND SOMETHING, ASK. "I'D LIKE TO BE SURE I'VE GOT THIS RIGHT."

8. AVOID LEADING, SUGGESTING OR DIRECTING. LET THE WORD, CONCEPT OR IDEA COME FROM THE RESPONDENT.

9. STAY NON-JUDGMENTAL. LISTEN ATTENTIVELY, TAKE NOTES AND TAKE CARE NOT TO OFFER YOUR OPINIONS.

10. PROBES ARE USED FOR ELABORATION AND CLARIFICATION. "TELL ME A LITTLE MORE ABOUT THAT." "PLAY THAT THOUGHT OUT A LITTLE MORE." "ANYTHING ELSE ABOUT THAT?" "THERE'S NO RUSH--TAKE YOUR TIME."

11. ANOTHER TECHNIQUE FOR BEING CERTAIN THAT YOU UNDERSTAND THE IMPLICATIONS OF WHAT A RESPONDENT HAS SAID IS TO REFLECT BACK OR MIRROR WHAT YOU THINK YOU HEARD, USING THE RESPONDENT'S WORDS OR PHRASEOLOGY RATHER THAN YOUR OWN. "I THINK WHAT I'M HEARING IS THAT PARTNERS MADE A DIFFERENCE IN THE WAY YOU HANDLED THIS SITUATION BECAUSE..." THIS OFTEN HELPS THE RESPONDENT TO ELABORATE FURTHER AS WELL AS HELPING THE INTERVIEWER.

This type of interview is referred to as a semi-structured, open-ended interview which requires content analysis rather than statistical analysis. Interviewers should spend significant time learning the interview guide and practicing it (possibly on each other) prior to conducting the first actual interview.

During the final session of Partners Three, it would be helpful to inform the group that some of them will be randomly selected to participate in the evaluation effort. It could be useful to request all of them to keep a "log" of their various interactions and activities in which they believe they demonstrated some degree of leadership. Such a log will help them to monitor their own progress and will better enable the participants sampled to recall their activities at the time they are interviewed.

The evaluation team believes that the combination of actions described in this section will enable Partners to carry out a useful, ongoing, internal evaluation.

APPENDIX A
REFERENCES

Argyris, C. Increasing Leadership Effectiveness. New York: Wiley. 1976

Bass, B.M. Leadership and Performance Beyond Expectations. New York: Free Press. 1985

Bass, B. M. Stogdill's Handbook of Leadership: A Survey of Theory and Research. New York: Free Press. 1981

Bennis, W. "Leadership Transforms Vision into Action." Industry Week, May 31, 1982, 1-3.

Bennis, W. & Nanus B. Leaders: The Strategies for Taking Charge. New York: Haper and Row. 1985

Betz, D. Cultivating Leadership: An Approach. Lanham, MD: Univ. Press. 1981

Bisesi, M. "SMR Forum: Strategies for Successful Leadership in Changing Times." Sloan Mgt. Review, 1983, 25(1), 61-64.

Blake, R. & Mouton, J. The New Managerial Grid. Houston: Gulf Publishing Co. 1978.

Burns, J. M. Leadership. New York: Harper & Row. 1972

Carew, D. K., Parisi-Carew, E., & Blanchard, K. H. "Group Development & Situational Leadership: A Model for Managing Groups." Training & Development Journal, 1986, 40(6), 46-50.

Fiedler, Fred E. & Chemers, Martin M. Improving Leadership Effectiveness: the Leader Match Concept. 2nd Ed. New York: Wiley. 1984

Fiedler, Fred E. & Chemers, Martin M. Leadership and Effective Management. Glenview, IL: Scott, Foreman and Company. 1974.

Fiedler, Fred E. "The Congintency Model and the Dynamics of the Leadership Process." Advances in Experimental Social Psychology, L. Berkowitz ed. New York: Academic Press. 1978.

Fleishman, Edwin A. & Hunt, James G., eds. Current Developments in the Study of Leadership. Carbondale: Southern Illinois University Press. 1973.

Greene, Charles N. "The Reciprocal Nature of Influence Between Leader and Subordinate." Journal of Applied Psychology, April 1975, 187-93.

Guthrie, E. & Miller W. S. Process Politics: A Guide for Group Leaders. San Diego, CA: University Associates. 1981

Hall, T. William, Greenberg, Elinor M. & Zachary, Lois J. Leading effectively: Men and Women of The volunteer Boardroom. Denver: Council for Adult and Experiential Learning. 1987.

Hollander, E. P. Leadership Dynamics: A Practical Guide to Effective Relationships. New York: Free Press. 1978

House, Robert J. & Dessler, Gary "The Path Goal Theory of Leadership: Some Post Hoc and A Priori Tests" Contingency Approaches to Leadership. ed. James G. Hunt, Carbondale: Southern Illinois University Press. 1974.

House, Robert J. & Mitchell T.R. "Path-Goal Theory of Leadership." Journal of Contemporary Business. 1974, 4, 81-91.

Jago, A. J. "Leadership Perspectives in Theory and Research", Management Science. March, 1982, 28.

Kahn, Si. Organizing, a Guide for Grassroots Leaders. McGraw Hill, 1982.

Kelley, H. H. & Michela, J. L. "Attribution Theory and Research." Annual Review of Psychology. Palo Alto, CA Annual Reviews, Inc. 1980. 31, 457-501.

Likert, R. New Patterns of Management. N.Y.: McGraw Hill Co. 1961

Likert, R. The Human Organization: Its Management and Value. N.Y.: McGraw Hill Book Co. 1967.

O'Connell, B. Effective Leadership in Voluntary Organizations. NY: Association PRess. 1976.

Schriescheim, C. A. & Von Glinson, M.A. "The Path-Goal Theory of Leadership: A Theoretical and Empirical Analysis." Academy of Management Journal. 1977, 20, 398-405.

Smith, J. E., Carson, K. P. & Alexander, R. A. "Leadership: It Can Make A Difference" Academy of Management Journal. December 1984, 27, 765-776.

Stogdill, R. M. "Personal Factors Associated with Leadership: A Study of the Literature." Journal of Psychology. January 1948, 25, 35-71.

Tannenbaum, Robert & Schmidt, Warren H. "How to Choose a Leadership Pattern." Harvard Business Review. May-June 1973, 162-172.

Thompson, K. W. (Ed.) Essays on Leadersip: Comparative Insights. Lanham, MD: Univ. Press. 1985

Vroom, V.H. & Yetton, P. W. Leadership and Decision Making. Pittsburg: University of PIttsburg Press. 1973.

Vroom, V. H. & Yago, A. G. "On the Validity of the Vroom-Yetton Model." Journal of Applied Psychology. 1978, 63, 151-162.

Yuki, G. A. Leadership in Organizations. Englewood Cliffs, N.J. Prentice Hall, 1981.

Zaleznik, Abraham, "Managers and Leaders: Are They Different?" Harvard Business Review. May-June 1977, 67-78.

APPENDIX B
PARTNERS IN LEADERSHIP PROGRAM EVALUATION
YEAR ONE PARTICIPANT INTERVIEW GUIDE
WINTER 1990-91

INTRODUCTION

Explain program evaluation effort. Emphasize the need to learn about participants' experiences and our interest in their thoughts and perceptions about those experiences. There are no right or wrong answers. Stress confidentiality (given limitations of the group interview). Explain why tape recorder is useful. Ask permission to tape.

CURRENT SITUATIONS

Let's begin with discussing what you're doing now. Tell me about your family, your work (if you're working outside the home), and any volunteer activities that you might be involved in. (PROBE for details about family situation, level of involvement in workplace and/or community activities, etc.)

HISTORY WITH "PARTNERS"

How did you originally become a participant in PARTNERS IN LEADERSHIP? Describe what you remember about that process--how you first learned about the program, who contacted you--whatever you recall.

When you first applied for PARTNERS, what did you expect to gain from it?

Did your expectations change at all during the year? How?

LEADERSHIP EXPERIENCES

How would you describe what it means to be a leader? What kinds of words or actions come to your mind when you think of the word "leadership"?

Can you think of any times in the past six to twelve months where you think you (demonstrated/displayed/exhibited) what you would call leadership? (ALTERNATIVE: Can you think of any times in the past six to twelve months when you think you were a leader?") Can you describe what happened? (PROBE for details: Where were you? Who was involved? What did you do? What did you say? What did others do and say? What was the outcome? How did you feel about it afterwards?)
Now that you've had a chance to think about it, what is it about this particular event that makes it stand out for you?

Is there anything you would do differently if you had the chance to?

Do you think that your experience in the Partners program made any difference in the way you acted in this particular situation?

Why not?/How did it make a difference? How do you think you might have acted in this situation if you had not been in the Partners program?

What will you say to new Partners participants when you have the chance?

Is there anything else you'd like to say or anything you'd like to ask me?

APPENDIX C
PARTNERS IN LEADERSHIP
YEAR TWO INTERVIEW GUIDE
SPRING, 1991

INTRODUCTION

Explain program evaluation effort. Emphasize the need to learn about participants experiences and our interest in their thoughts and perceptions about those experiences. There are no right or wrong answers. Stress confidentiality (given limitations of the group interview). Explain purpose of tape recorder. Ask permission to tape.

CURRENT SITUATIONS

Let's start with hearing about what you're doing now. I'm interested in knowing about your family, your work (if you're working outside the home), and any volunteer activities that you might be involved in.
PROBE for details about family situation, type of work, level of involvement in workplace and/or community activities, etc.

HISTORY WITH PARTNERS

How did you originally become a participant in PARTNERS IN LEADERSHIP? Describe whatever you remember about that process--how you first learned about the program, who contacted you--whatever you recall.

PROBE for details about decision to apply. Were they encouraged by anyone? Was it an independent decision? Etc.

When you first applied for PARTNERS, what did you hope/expect to gain from it?

Was your actual experience in PARTNERS different from your expectations? How?

Would you say that PARTNERS met your expectations? Why/why not?

LEADERSHIP EXPERIENCES

How would you describe what it means to be a leader? What kinds of words or actions come to your mind when you think of the word "leadership"?

Do you think your ideas about leadership have changed at all during the tine you've been participating in PARTNERS? How?

Have you ever thought of yourself as a leader--either before you began to participate in PARTNERS or after?

Were there any times in the past (before PARTNERS) when you think you were a leader? Is there one event/experience that stands out in your memory?

Can you describe what happened? PROBES: Where were you? Who was involved? What did you do? What did you say? What did others do and say? What was the outcome? How did you feel about it afterwards?

What is it about this particular event/experience that makes it stand out for you?

Now that you've had a chance to think about it, is there anything you'd do differently?

How about since you've been in PARTNERS? Have there been any times since you've been in PARTNERS when you think you were a leader?

Can you describe what happened? PROBES: Where were you? Who was involved? What did you do? What did you say? What did others do and say? What was the outcome? How did you feel about it afterwards?

What is it about this particular event/experience that makes it stand out for you?

Now that you've had a chance to think about it, is there anything you'd do differently?

Do you see any changes in yourself as a result of participating in PARTNERS? Can you describe those changes?

Were there (other) changes you hoped to see in you that you don't see?

ATTITUDES TOWARD PROGRAM

If you were in charge of the PARTNERS program, what kind of program would it be? PROBES: Would it differ from the program as it is now? How?

If you have a chance to talk to next year's participants, what will you say to them?

Is there anything else you'd like to add or anything you'd like to ask me?

APPENDIX D
PARTNERS-IN-LEADERSHIP
YEAR TWO INTERVIEW GUIDE B
SPRING, 1991

INTRODUCTION

Explain program evaluation effort. Emphasize the need to learn about all participants' experiences, including those who chose not to stay in the program. Explain our interest in their thoughts and perceptions about their experiences and that there are no right or wrong answers. Stress confidentiality. Explain why tape recorder is useful. Ask permission to tape.

CURRENT SITUATIONS

I'm really interested in the things you're doing these days. Tell me about your family, your work (if you're working outside the home) and any other activities that you might be involved in.

PROBE for details about family situation, type of work, level of involvement in workplace, community activities, etc.

HISTORY WITH PARTNERS

How did you originally become a participant in PARTNERS IN LEADERSHIP? Can you describe what you remember about that--how you first learned about the program, who contacted you--whatever you recall?

What made you decide to apply to PARTNERS? PROBE for information on the decision-making process. Was it an independent process? Did anyone encourage or try to persuade respondent to apply? Etc.

When you first applied for PARTNERS, what did you expect/hope to gain from it?

Did the program meet those expectations? In what ways did/didn't the program meet those expectations? How was your actual experience in PARTNERS different from your expectation

BARRIERS TO CONTINUED PARTICIPATION

Why did you decide to leave the program?

When you decided to leave the program--had you thought about leaving for a long while or did you make the decision fairly suddenly?

Do you recall what finally helped you decide to leave the PARTNERS program? Can you describe what happened?

Did you discuss your decision with anyone? Who?

How did you feel when you left the program?

How do you feel about it now?

Can you think of any changes, either in your own
have convinced you to stay in the program? PROBE
circumstances that might have facilitated responde

If you were in charge of a program like PARTNERS,
be? PROBES: Would it differ from the program as
would you make?

BENEFITS

Do you think you gained anything from your partici
gain? PROBE for details.

Were there things you hoped to gain that you didn'

Is there anything else you'd like to add or anythi

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FUNDING SUPPORTS

Following are some creative ideas for locating resources to fund Partners programs. These ideas were generated by participants at the 1990 National Academy.

- -- ADD Grants
- -- Banks
- -- Civic Groups
- -- Colleges and Universities
- -- Corporations (McDonalds, IBM, Etc.)
- -- Developmental Disabilities Councils
- -- Disability Organizations (Arc, UCP, etc.)
- -- Federal Funds
- -- Foundations (Corporate, State, and National)
- -- Industry Councils
- -- Legal Rights Organizations
- -- State Demonstration Grants
- -- State Departments of Education
- -- State Departments of Human Services
- -- Parent Training Centers
- -- Private Resources and Donors
- -- Protection and Advocacy Agencies
- -- University Affiliated Programs.

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POSTGRADUATES

CONTENTS

-- ALABAMA PIP Postgraduate Survey
-- ALABAMA PIP Graduate Activities (2)
-- NEW YORK PIP Graduation Certificate
-- TEXAS PIP Graduate Activities
-- TEXAS PIP Graduate Comments

****
* ALABAMA PIP POST-GRAD SURVEY *
* N.D. - Received prior to 1992 Academy *
****

PARTNERS IN POLICYMAKING OF ALABAMA

FOLLOW-UP SURVEY--SIX MONTHS

This survey is an effort to measure some outcomes/results of your participation in the Partners in Policymaking program. One way to evaluate the effectiveness of the Partners program is to collect information about how your participation in the program has helped you become a better self-advocate during the first six-month period after graduation. In this effort, please answer the questions below.

1. It has been six months since you graduated from the Partners program. Overall, how would you rate the program today in regards to improving your self-advocacy skills?

_______a. Excellent
_______b. Very good
_______c. Good
_______d. Fair
_______e. Poor

2. Have you been in contact with local, state, or national public officials during the six-month period after graduation? (Check all that apply.)

_______a. Yes, national public officials
_______b. Yes, state public officials
_______c. Yes, local public officials
_______d. No

3. If "yes" to number 2, please indicate the type of contact (letter, phone, or office visit) and estimate the number of contacts made. (Check all that apply.)

	Estimated Number
	________
_____a. Letters	________
_____b. Phone Calls	________
_____c. Office Visits	________

4. What other opportunities have you had to advocate for yourself or other persons with disabilities? (Check all that apply.)

	Estimated Number
	________
_____a. Testified at public hearings	________
_____b. Service on a committee/ commission	________

5. What opportunities have you had to advocate for yourself or a family member with disabilities within a school or work setting? (Check all that apply.)

	Estimated Number
_____a. School setting	_____
_____b. Work setting	_____

6. If you responded to number 5, please indicate the degree to which your participation in the Partners program prepared you to be an effective advocate.

_____a. I was very prepared as a result of Partners.
_____b. I was somewhat prepared as a result of Partners.
_____c. I was not more prepared as a result of Partners.
_____d. I was less prepared as a result of Partners.

7. Have you participated in any public education efforts about persons with disabilities during the six-month period? (Check all that apply.)

	Estimated Number
_____a. Published newspaper articles/letters	_____
_____b. Conference presentations	_____
_____c. Television appearances	_____
_____d. Radio appearances	_____
_____e. Other (please specify): ______________________________ ______________________________	_____

8. Did the information provided by the Partners program enable you to receive more appropriate services for yourself or a family member with a disability?

_____a. Yes
_____b. No

9. If "yes" to number 8, please provide specific examples here: ______________________

10. Please outline any other benefits or outcomes you can attribute to your participation in the Partners program not mentioned above: ______________________

After you have completed this form, please return as soon as possible to:

Betsy Prince
444 South Decatur Street
Montgomery, AL 36104

I.D. Number____________

ALABAMA PIP GRADUATE ACTIVITIES
N.D. - Received prior to 1992 Academy

THE ENERGY, POWER AND OUTREACH OF P.I.P.A. CLASS OF 1990 - 1991

---

1. *Over 64 news articles generated across the state.*
2. *Over 58 television and radio programs.*
3. *Over 19 presentations at conferences.*
4. *9 University level speaking engagements.*
5. *Over 32 appointments to committees, commissions or task forces.*
6. *Over 450 letters generated to policymakers.*
7. *Over 11 testimonies at county, state and federal hearings.*
8. *Over 235 personal visits to legislators.*
9. *Over 5225 phone calls generated to legislators.*
10. *Children in integrated enviroments.*
11. *Individuals with disabilities and other participants have and are:*
    - *Returning to school*
    - *Changing jobs*
    - *Becoming competitively employed*
    - *Interested in running for public office*

ALABAMA PIP GRADUATE ACTIVITIES
N.D. - Received prior to 1992 Academy

ACCOMPLISHMENTS AND EFFORTS OF P.I.P.A. PARTICIPANTS: CLASS OF 1990 - 1991

---

1. *Initiated and implemented 3 accessibility studies yielding dramatic changes inaccessibility to public buildings.*

2. *Developed 1 local coordinating council as related to P.L.99-457 and many participating in the organization and implementation of these regional councils. 6 individuals are holding office within these councils.*

3. *Wrote 2 grants to meet specific needs within local areas.*

4. *Created 5 support and service organizations to offer support and information to families of persons with disabilities.*

5. *Involved in creating integration opportunities within Alabama's day care system.*

6. *Involved in development of respite care.*

7. *Organized and acted as chairperson of a statewide workshop for parents and professionals.*

8. *Several individuals serving on speakers bureau for state organizations.*

9. *Developed a statewide coalition for persons with disabilities within Alabama.*

10. *Created and increased employment opportunities for persons with disabilities*

11. *Unlimited personal contacts sharing information and offering support to others.*

12. *Increased self-esteem of persons with disabilities and parents of children with disabilities.*

13. *Efforts to inform medical professionals regarding the needs of individuals with disabilities and their families.*

14. *A tremendous interest and effort in developing family support services in Alabama.*

15. Developing and disseminating a newsletter to partners participants including activities and accomplishments of individuals and their families in their own local communities, efforts conducted at state and federal levels, and sharing resources and information.

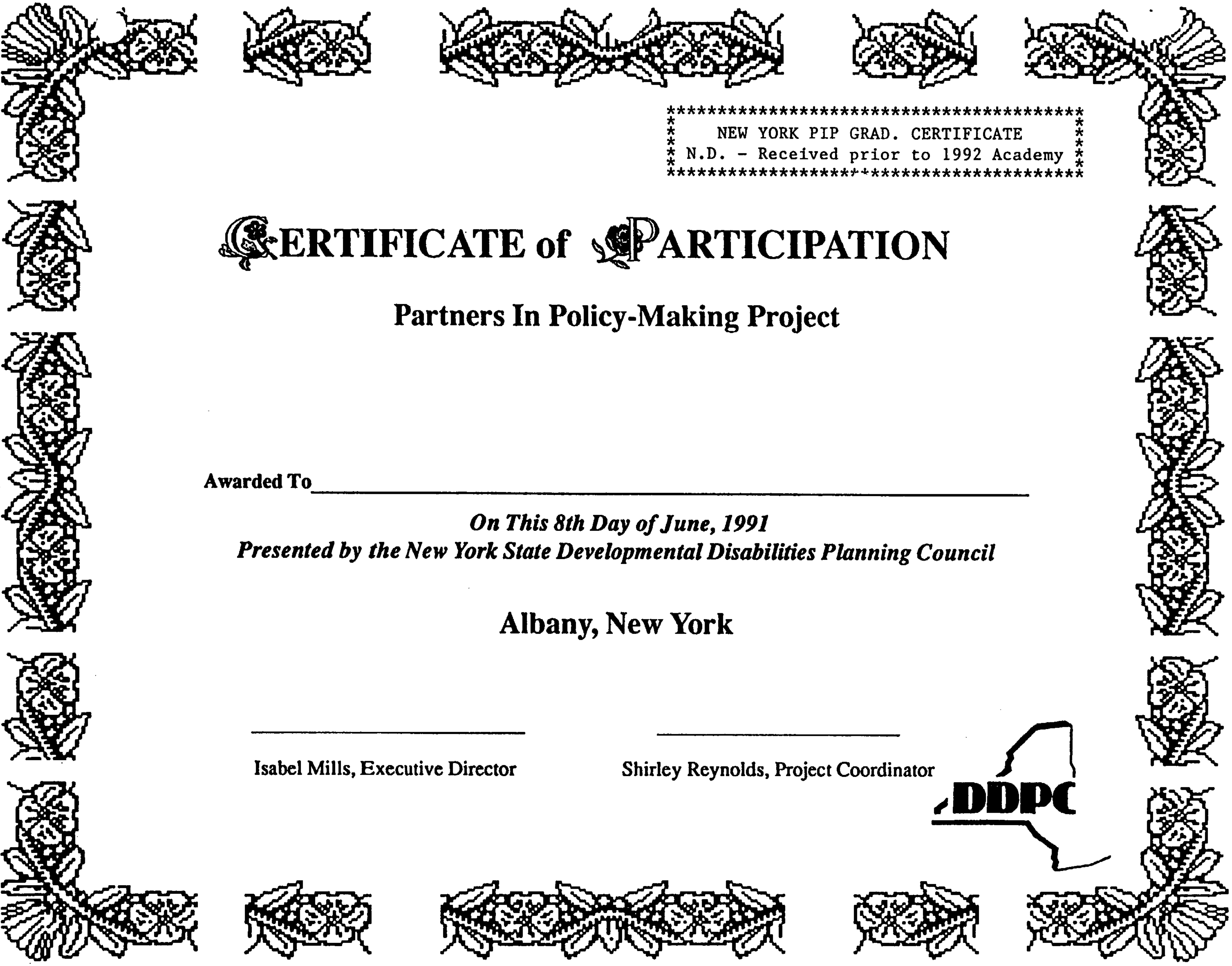
16. Hours and hours of work in establishing legislation mandating services for three and four year olds, a bill creating a catatrophic trust fund and a bill to generate money to sustain this fund.

17. Partners participants:
- *Have a vision for the future*
- *Will seek change.*
- *Are motivated.*
- *Are informed.*
- *Will speak up.*

Michael (7 years old) and Jennifer (5 years old) Gothard

Tammy Gothard, Jackson County - "PIPA has proved to be what it stands for. We are not just parent/friends, we are partners. Strength comes to bond, and energize our capabilities of which we had but didn't know what to do with."

Jennifer, Tammy's four year old daughter, has Spina Bifida with hydrocephalus and paralysis from the waist down. My children are my "lifeline", they keep me going when I feel I can go no longer. I want both my children to have equal opportunities in life, we've just had to fight a little harder for Jennifer to achieve hers, and will have other battles to conquer in the future. I hope to better the quality of life for all people with disabilities, possible making an easier path for someone to follow, being a voice for a child or adult whose parents or guardians don't fight for their rights. Programs, laws, groups, etc. need to be more publicized to reach people, most of parents receive information ear-to-ear."



NEW YORK PIP GRAD. CERTIFICATE
N.D. - Received prior to 1992 Academy

CERTIFICATE of PARTICIPATION

Partners In Policy-Making Project

Awarded To____

On This 8th Day of June, 1991
Presented by the New York State Developmental Disabilities Planning Council

Albany, New York

Isabel Mills, Executive Director

Shirley Reynolds, Project Coordinator

DDPC

Table 3
Advocacy Activities by Year 1 Participants 6 Months Post Graduation

Activity	Number
Level of contact	
With national officials	10
With state officials	21
With local officials	22
No contact with public officials	1
Type of contact with public officials	
Letter	291
Phone calls	154
Office visits	62
Testified at public hearings	18
Served on committee or commission	44
Serve on a Board	17
Other advocacy efforts	
Published newspaper articles/letters	33
Conference presentations	26
Presentations to parent/ groups	58
TV appearances	11
Radio appearances	2
Other (hospitals/churches/ PTA/School Boards)	21

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* TEXAS PIP GRADUATE COMMENTS N.D. - Received prior to 1992 Academy *
****

TEXAS
PLANNING COUNCIL
for
DEVELOPMENTAL
DISABILITIES

Partners in Policymaking Participant Comments

"I have been inspired to dream again and not let others intrude upon my dreams, and to encourage others to dream."

"This has been the most important thing in my life besides my family. It exceeded my expectations by far. I learned more than I ever dreamed of--I have resources to keep learning."

"The speakers validated feelings I had inside, about how persons with disabilities should be treated. And then the taught me how to act on those feelings to secure the rights and responsibilities for persons with disabilities."

"This is an incredibly worthwhile and valuable program... Our hearts are so very full---it is difficult to express how this program has literally changed my life...I am so ready to work hard to change things."

"I am overwhelmed at the opportunities that this program offers. It can only make for a more responsive government that truly represents the needs and desires of its peoples."

"I feel empowered now and want to get the job done."

"I am not afraid to ask for what not only my child needs but what other children need."

"PIP allowed me to dream again---I feel alive again. I was oppressed by my son's disability---I feel free to live again. I'll never be the same."

I wasn't expecting the tremendous network from being in this program."

"I am a changed person...I will, in turn, work hard to change others."

"Partners has taught me so many different and wonderful things. But I think the most important thing I've learned is how one person can make a difference---by both individual effort and as a leader of others."

"It has changed all areas of my life. I can't express that enough."

"Partners to me now is like I have a new family that I can always count on. Thanks for the opportunity to be part of this."

"I want you to know it has changed my life; and probably in ways I don't even know yet! It has fine tuned my advocacy skills and my skills in dealing with people in general. I find myself using the principles I have learned in Partners more and more. I have matured personally."

"The training has given me confidence and educated me regarding best practices. I look forward to learning more and sharing with others. I thank you and consider myself privileged to have been selected."

Quote from Council member, Theda Hoyt, "Partners has changed lives and dropped a pebble in the pond for the future."

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CONTENTS

- -- ALABAMA PIP Miscellaneous Pages from Annual Report
- -- CALIFORNIA PIP Collaborative Group Project
- -- IOWA PIP Individual Action Plan Goals
- -- Nature of Highly Effective Groups

Tina Lightel

Tish Lightel, Dale County - "PIPA has provided me with information that has enabled me to help families receive more appropriate services, especially in the area of education."

Both of Tish's children with disabilities attended Vivian B. Adams School in Ozark prior to being mainstreamed into public schools. "I wanted to become involved in PIPA to learn more; not only for the benefit of my children but others. I have met several frustrated parents of disabled children. If parents and school officials were educated in the appropriate programs, the children could be better served."

J.J. Lightel

ALABAMA PIP
MISCELLANEOUS PAGES FROM ANNUAL REPORT
N.D. - Received prior to 1992 Academy

INTRODUCTION

PARTNERS IN POLICYMAKING OF ALABAMA (P.I.P.A.) is an innovative leadership training program for persons with developmental disabilities, parents of young children with disabilities and other family members. It is sponsored by the Alabama Governor's Planning Council on Developmental Disabilities, the Association for Retarded Citizens of Alabama and the Department of Mental Health and Mental Retardation. Partners in Policymaking is designed to provide state-of-the-art knowledge about issues related to disability and to develop competencies of the participants to become effective advocates in influencing public policy at all levels of government.

The original concept of Partners in Policymaking was developed in 1987, under the direction of Colleen Wieck, Ph.D., Director of the Minnesota Governor's Planning Council on Developmental Disabilities, and Ed Skarnulis, Ph.D., of the Minnesota Department of Human Services.

Partners in Policymaking became a part of The World Institute on Disability (WID) in 1989. WID adopted the program in recognition of it's potential as a national model for leadership training for people with disabilities of all ages. With a grant from the Department of Health and Human Services, Administration on Developmental Disabilities, WID and the Minnesota Governor's Planning Council on Developmental Disabilities conducted a national academy to train representatives of twelve Developmental Disabilities Planning Councils from all over the country to enable replication.

Alabama was chosen as one of the states to begin implementation of the Partners in Policymaking philosophies, strategies and methodologies. The training materials, strategies and methodologies provided by W.I.D. and the Minnesota Developmental Disabilities Planning Council were adapted to meeting the needs of Alabama. In making these changes, P.I.P.A did not depart from the original philosophy.

In this first year of P.I.P.A., thirty-three individuals took part in the training program. The project dramatically increased individual empowerment through participation in local, state and regional policy commissions and task forces. Each participant played an active role in the development of public policy through increased contact and interaction with public officials and policymakers.

The spirit of Partners is in the energy, power and outreach of each participant, who are focused on the rights and abilities of persons with disabilities and their families.

Within this report are selected participant antidotes and photographs, which reflect the undying spirit and heart of the Partners program here in Alabama. The many faces and families reflect the joys, the challenges, the pursuits and victories in every neighborhood across the country.

READ, ENJOY, LEARN AND EXPERIENCE THE PARTNER'S SPIRIT WITHIN THESE PAGES.

Chris Franks, Tuscaloosa County - "All areas dealing with disability issues need improvements and with a law degree, I hope to take an active part in seeing that these policies and improvements are carried out. Areas that need specific concern are those dealing with employment, accessibility and education."

Chris Franks, wife Kim and son Judd

Sharon Albright with husband Chris
and their children Michael and Nicholas

Sharon Albright, Madison County - "I was interested in participating in PIPA because the people in our community are very enthusiastic about being "enabled", however, they lack the togetherness one individual with leadership capabilities could bring. My son Nicholas has Spina Bifida, hydrocephalus and a seizure disorder. He will definitely be as dependent upon technology as Mr. Roberts. So...I feel a new sort of inspiration to keep on moving ahead; and my desire to have him mainstreamed despite his functioning level is stronger than ever. Ed Roberts gave me some ideas on how to do it. Partners is worth every cent to refund it. Two thumbs up!"

PROGRAM DESCRIPTION

Partners in Policymaking of Alabama (P.I.P.A.) provides information, training, and skill building to individuals so that they may obtain state-of-the-art services for themselves and others. The program consists of approximately one-hundred and twenty hours of instruction time delivered during the months of October, November, January, February, March, April, May and a graduation celebration in June. Each session begins shortly after noon on Friday and concludes late Saturday afternoon. During each of the Sessions, experts in specific areas related to disabilities, present and interact with the participants in small groups or one on one.

P.I.P.A. involves and empowers people with developmental disabilities and their families in the policymaking arena. It acquaints and connects people with organizations , opportunities and possibilities in the area of developmental disabilities. It educates the participants about current issues. It familiarizes them about current local, state and federal issues, as well as equips them with the policymaking processes by which policies and laws are established. The overall intent of P.I.P.A. is to foster and achieve productive partnerships between people traditionally unserved and underserved and those in a position to make policy. Through these partnerships, Alabama is creating new opportunities and lifestyles for persons with disabilities and their families as well as creating healthy new attitudes, values and perceptions.

Matthew 7, Teddy 2 and Courtney 1

Susan Ellis, Jefferson County - "Matthew who is seven has Down Syndrome. I want to be the best possible advocate for my son and other children with impairments, so that he and others will be able to maximize their contributions to society and their ability to be fully integrated in work, school and play.

PROPOSED GOALS

1. *To actively provide quality training for parents of young children with disabilities and persons with disabilities to increase their legislative advocacy skills.*

2. *To educate policymakers as to the needs of persons with disabilities and their families, in an attempt to change state policies, so that they may reflect an increased responsibility to individuals who have been traditionally unserved or underserved.*

3. *To become active in the local, state and federal legislative processes through effective letter writing, telephone calling, and personal visits to policymakers.*

4. *To build coalitions between families, agencies and persons with disabilities and create a united, powerful voice on priority issues dealing with all citizens with disabilities.*

5. *To empower families of children with disabilities and persons with developmental disabilities so that they might seek to increase their independence, productivity and integration into the community.*

6. *To develop a partnership between policymakers and persons with developmental disabilities.*

7. *To produce a supply of powerful leaders so that they may participate in planning, service delivery, evaluation and advocacy activities through their service on task forces, commissions, and other in voluntary organizations.*

Mary Jane Evans, Shelby County - "I will not be the same after PIPA. Each academy was enlightening, a little mind boggling at times, but after five months I believe it is all making sense and very helpful and useful."

Mary Jane's five year old son Will has mental retardation and autism, physical impairment and epilepsy. "I was totally ignorant of disabilities until we discovered that Will was not "normal". Having Will has been the most taxing education I've received, he has helped mature me and be much more real. I am already very involved in letter writing, phone calls in advocacy for personal beliefs - I am determined to make a stand and not let laws, etc. pass that will not benefit our society in 50 years."

Mary Jane, Clay, Will and Julia.

Augie Augustine and Randy Stahlecker are off to the State house

Randy Stahlecker, Houston County - "I want to gain independence of living and to help others be more independent in life such as getting laws passed to help the disabled get more independent living."

PROBLEM STATEMENT

1. *People with disabilities have been unserved and underserved here in Alabama.*

2. *People with disabilities and families of children with disabilities lack self-advocacy and empowerment skills.*

3. *Parents of younger children with disabilities are now guaranteed services for their children and the new struggles for quality and integration.*

4. *People with disabilities are expressing an increased desire for full participation in employment and education opportunities.*

5. *The family structure is ever changing and volunteerism is declining.*

6. *There is a need for the increased development of quality education and training programs to meet the needs of persons with disabilities.*

7. *There is a tremendous need for collaboration on public policy issues among disability related groups and individuals with disabilities.*

8. *People with disabilities have allowed others to make decisions for them about how they should live their lives. Now they are demanding the rights to make informed choices and decisions on their own.*

Elouise Woods talking with Senator Chip Bailey.

Elouise Woods, Tuscaloosa County - "I want to help more people learn how to speak up for themselves. I have learned how to talk for myself and meet new people at People First meetings."

IMPACT OF THE PROBLEM - THE NEED FOR LEADERSHIP IN ALABAMA

1. *There are few leadership development programs that prepare persons who are unserved and underserved for positions of leadership in local, state, and national organizations. There is a need for new leadership to assume positions in these organizations.*

2. *Limited grassroots advocacy leadership exists and no systematic training in competencies of influencing public officials.*

3. *There is a need for a shared vision in the self-advocacy movement.*

4. *There is no current mechanism for state and national leaders in the field of disabilities to meet and discuss issues with persons with disabilities who are traditionally unserved or underserved.*

5. *There is no centralized speaker's bureau organized in Alabama which represents the unserved and underserved. There is a continued need to have spokespersons available who can speak on a wide range of issues at local meetings, university classes, conferences, public hearings, state events and national conventions.*

6. *Tremendous service problems exist in regard to employment, housing, transportation, accessibility and education.*

Craig and Tim at an academy workshop.

Craig Stewart, Houston County - "I am single and twenty-four years old. There are so many issues concerning disabled people, awareness of these issues will help! This was the light at the end of the tunnel. I learned more from visiting & talking with legislators than I ever imagined."

Tim Cain, Houston County - "As a member of a local spinal cord injury group, I feel that someone from our area should be representing a growing number of persons with disabilities."

THE SOLUTION: PARTNERS IN POLICYMAKING

Partners in Policymaking of Alabama has proven to be effective in addressing the previously listed areas of concern and instrumental in attempting to eliminate them. The program, as well it's participants, has been a leader in networking throughout Alabama and bringing about systems change through political influence and intervention.

Solutions begin with organization.

1. *P.I.P.A. provides information, training and skill building to thirty-three participants, so that they may receive state-of-the-art services for themselves and others. The training group consists of parents of young children with disabilities and individuals with disabilities.*

2. *P.I.P.A. provides eight, two-day workshop sessions to thirty-three highly motivated, interested individuals.*

3. *P.I.P.A. acquaints and connects people with organizations, opportunities, and possibilities in the area of developmental disabilities.*

4. *P.I.P.A. educates participants about state-of-the-art approaches and current issues at local, state and federal levels.*

5. *P.I.P.A. familiarizes participants with policymaking and the legislative process at local, state and federal levels of government. It gives "hands - on" opportunities with legislators and helps to foster continued relationships and contacts.*

6. *P.I.P.A. provides stimulating workshop weekends devoted to a particular topic related to disabilities or a particular level of government. The presenters are nationally known experts in the field of disabilities, as well as experts from Alabama. Presenters are encouraged to spend the weekend to interact with participants on a more personal basis and respond to individual needs and concerns.*

7. *P.I.P.A. guides participants in the selection of one project of choice as related to their particular area of interest. Participants are also expected to complete small assignments between workshop weekends.*

8. *P.I.P.A. assists participants in achieving a specific set of competencies throughout the duration of the project. A further breakdown of more specific objectives and competencies are defined for each specific academy weekend. (Appendix)*

Steve & Diana Simpson and family, Myles, Caitlin and Margaret.

Stephen K. Simpson, Montgomery County - "Meeting and getting to know disabled, handicapped persons and their relatives has changed my attitudes regarding how to relate to adults with handicaps. I had the opportunity of meeting several different types of legislators and I realized that different advocacy techniques must be tried to reach each one. Legislators are people too!"

Steve's son Myles has a brain condition known as pachygyria that has caused severe developmental delay. "Myles requires more thought, worry, care and help than my older children. I often wonder about the quality of life, since he is non-verbal, unable to walk and does not express emotion in the same way as my other children."

Steve Balton and Cindy Jordan talk with Ed Roberts at graduation.

Cindy Love-Jordan, Montgomery County — "I see the triangle of housing, education and employment as being so intertwined for disabled people to be able to live independently. Having an educational and practical experience in government, I know the importance and influence interest groups can have and this is the way to change the standards of living for so many handicapped people. I had polio with total involvement at the age of three. I have encountered more problems than I ever knew existed in the area of housing and employment. I have been exposed to extreme inaccessibility and knew someday things would have to change."

JUNE ACADEMY

GRADUATION

The excitement of graduation was in the air all during the month of June and finally the day arrived. Everyone was so excited about Ed Roberts, President and co-founder of The World Institute on Disability, being with us. His presence made graduation extra special and set it apart from all of the other academies.

Ed arrived on Thursday night along with his son, Lee and his attendant and friend, John. Many participants had the opportunity to spend some time getting to know him and sharing their children and personal family stories with him. His insight and knowledge inspired them to continue in their challenges and in their quests for quality programs and services. He proved the importance of providing every opportunity for integration in schools and in everyday community living.

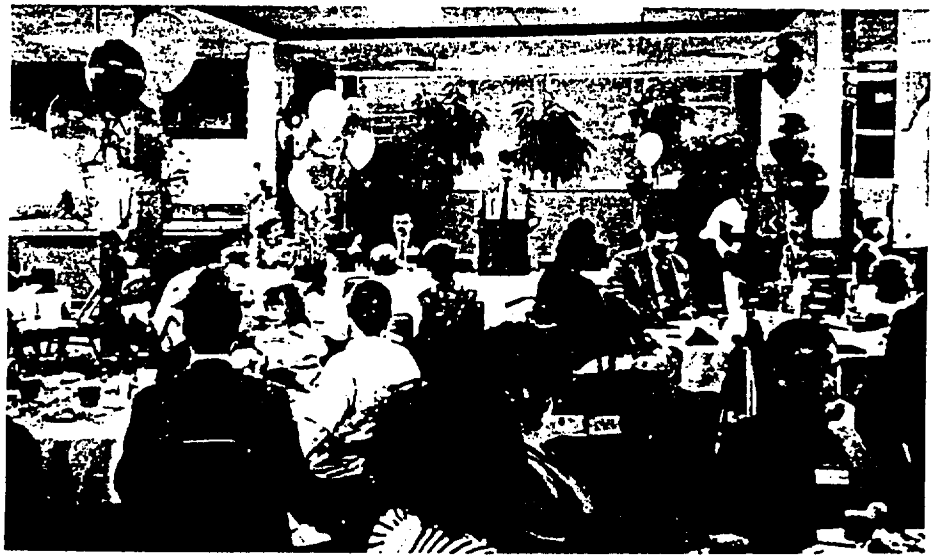
There was a special session featuring Mr. Roberts on Friday afternoon. A captive audience listened and grew in their understanding of persons with disabilities. His ideas, philosophies and beliefs are being put into practice here in Montgomery. Policymakers are echoing these convictions and his impact is still being felt here in Alabama.

Saturday was a very special day of hugs and warm greetings, of meeting families for the first time, and of excitement over the anticipation of the future for persons with disabilities and their families. "The Sky is The Limit With P.I.P.A." was the theme of the celebration. Brightly colored balloons sprang from each table and the room held a *beautiful view of Montgomery. There was a display of the training year in pictures and people were buzzing and reminiscing over each snapshot. It was hard to believe that the first year of P.I.P.A. was coming to an end. What a celebration for all the accomplishments held by each participant!*

Many special guests were present for lunch and anxious to meet participants and hear from Ed Roberts. A beautiful prayer was offered by Jerry Oveson, a participant from Mobile County. (See appendix) It encompassed the very heart of P.I.P.A. and brought each family a little closer together. The day and ceremony were dedicated to Michael Wassman and Chris Franks. Their spirit and courage was present in the room, although they were not with us.

What a beautiful backdrop for a perfect day! Each graduate was given a special diploma and a group picture that had been taken during a previous month. One by one they each proudly came forward to receive their honors. Ed Roberts highlighted the afternoon with words that lifted each person and challenged them to reach heights of which they had only dreamed. With his tremendous message and motivation, there were no doubts about the victories at hand!

Each individual left on Saturday filled with power, knowledge, and self confidence that would carry them through any battle. There was a sense of revival - energy and focus on what must be done for persons with disabilities. Through the experiences and friendships found in Partners in Policymaking of Alabama each graduate left in further pursuit of opportunity and equality for all persons with disabilities and their families throughout Alabama. This was only the beginning!



Royce King, Commissioner of Department of Mental Health/Mental Retardation addresses PIPA graduates.

Charlotte and Garvin Smith with son, David & daughter Julie.

Charlotte Smith, Fayette County - "PIPA has been the greatest source of information that I have ever encountered! When my deaf son was younger, one of my main frustrations was not having information AND not knowing where to go to get information. With PIPA, I have been provided access to all relevant information, limited only be the extent of my interest. I am truly amazed at the opportunities. I have already had to go back into my own community and share what I've learned, to make life easier for other parents."

RECRUITMENT

Individuals traditionally unserved or underserved were targeted for recruitment by direct mailings and contacts with organizations serving persons with disabilities and their families.

Contacts with advocacy, service, employment and educational organizations which represent people with disabilities were established via personal contact, phone calls and mailings. In addition to these contacts, information and applications were distributed to the media: television, radio, and newspapers throughout Alabama. Letters and applications were published in newsletters of various organizations whose readers might spread the word. All hospitals and pediatric specialists were contacted within Alabama. Many social service agencies, citizen advocacy organizations, and local support groups were also targeted.

All of the above contacts were made in an attempt to improve outreach to a broad spectrum of individuals with disabilities (both cognitive and physical), ethnic and racial minorities, low income families/individuals and single parent families, urban and rural communities from every corner of Alabama.

Every effort was made to identify and provide the necessary support services needed by an individual to facilitate that individual's full participation in the sessions.

Eric Matney, son of Fred and Sheryl Matney.

Sheryl Matney, Pike County - Sheryl's son Eric has low vision and cerebral palsy. "I am a strong believer in early intervention for infants with developmental disabilities. I am constantly amazed that more parents with children with disabilities do not know how to take advantage of services that are offered. We were told that Eric would be severely handicapped but with the therapy we are receiving we have been pleasantly surprised and delighted with this progress."

THE VISION

Partners in Policymaking of Alabama (P.I.P.A.) is a diverse blend of individuals, representing many diverse disabilities. An extensive network throughout Alabama has developed that can gather and disseminate information quickly; can reach all disability groups; can impact policy changes at all levels throughout every region of Alabama; and can build upon the strengths of persons with disabilities and their families.

Partners in Policymaking of Alabama dreams of the day when every state will realize the capabilities, strengths and power available through empowering persons with disabilities and their families; when each state will take an active role in training persons with disabilities and family members as leaders and, when networks can extend beyond state boundaries.

Programs like Partners in Policymaking are helping to make this dream a reality and determine the future for persons with disabilities and their families! The opportunities and possibilities created for persons with developmental disabilities and their families through Partners in Policymaking of Alabama are limitless. Every group working on issues dealing with disabilities needs experienced, knowledgeable leaders that can pilot the effort through storms and turbulence and insure a safe landing on success!

There is a general lack of parent and self-advocate participation in advocacy, volunteer organizations and efforts. This league of individuals can have tremendous power and when channeled in the right directions, can change the future for children and adults with developmental disabilities in Alabama and across this nation.

Empowerment and self-determination can help to change age old attitudes of dependence and reliance into voices of independence and self sufficiency. Most people with disabilities grow up in a society that considers them powerless. These negative attitudes are frequently internalized, and people with disabilities are left doubting their ability to ever lead their own lives. The necessity for empowerment and self-determination exists if people with disabilities are to gain control over their own lives and fully participate in society. Leadership development and personal empowerment are at the core of all social movements. By preparing people with disabilities and their families to take the first step into self-advocacy, many will continue on to become group leaders, system-change advocates and eventually leaders of social change.

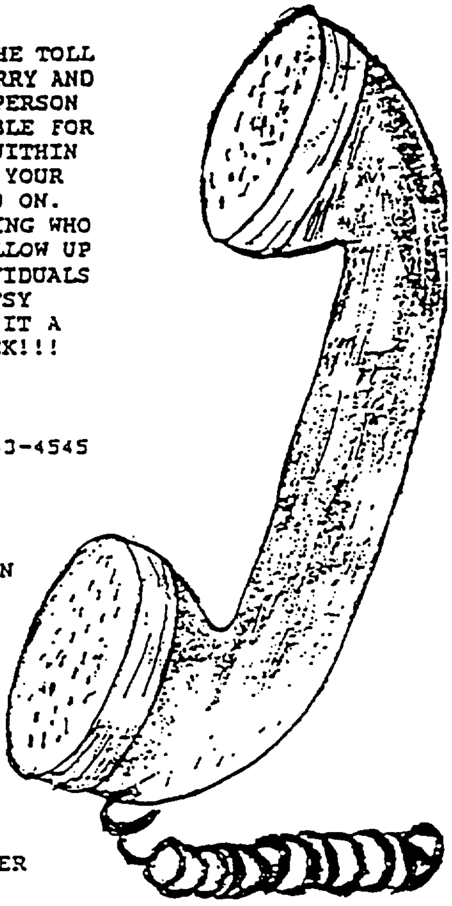
Jennifer Oveson, daughter of Jerry and Diane Oveson.

Gerald G. Oveson, Mobile County - "PIPA has opened my eyes to the coming issues that link the various disability groups. The ARC of Alabama through PIPA has nurtured "seedlings" and will, in the months and years to come, witness a lush forest carpeting the State and bringing about fundamental changes in our environment. PIPA empowered that component of our population that has long been silent at the same time being very close to the real needs of the disabled population."

"My daughter, Jennifer, has Spina Bifida which has resulted in significant developmental delay and physical disabilities. I have been active in forming a local Spina Bifida support group and I have noticed a lack of motivation in teens and young adults that prevent them from seeking job training and employment. Employment would enhance self image and facilitate independent living so it is this area that interests me perhaps more than some of the other major areas of concern."

PARTNERS IN POLICYMAKING OF ALABAMA - 1-800-237-0665

TELEPHONE PYRAMID - TO BEGIN CHAIN REACTION, CALL BETSY AT THE TOLL FREE NUMBER, SHE WILL ACTIVATE IT BY CALLING JERRY AND SHARON. THEY IN TURN WILL BEGIN CALLING THE PERSON DIRECTLY UNDER THEM. EACH PERSON IS RESPONSIBLE FOR CALLING THE PERSON DIRECTLY UNDER THEIR NAME WITHIN A 24 HOUR PERIOD. IF YOU ARE UNABLE TO REACH YOUR CONNECTION, SKIP AND CALL THE NEXT NAME AND SO ON. SHARE ALL INFORMATION WITH YOUR CONTACT INCLUDING WHO YOU WERE UNABLE TO REACH, SO THAT BETSY CAN FOLLOW UP WITH A PHONE CALL AFTER THE DEADLINE. THE INDIVIDUALS AT THE BOTTOM OF THE TWO LISTS ARE TO CALL BETSY REPORTING COMPLETION ON THE CHAIN. LET'S TRY IT A COUPLE OF TIMES AND SEE HOW IT GOES! GOOD LUCK!!!



SHARON ALBRIGHT ⟷ BETSY PRINCE ⟷ JERRY OVESON
852-2315 H-277-2285 H-633-3756 W-343-4545

SHARON ALBRIGHT
852-2315
↓
AUGIE AUGUSTIN
H-883-4210 W-883-8657
↓
TAMMY GOTHARD
H-632-6454 W-638-4418
↓
JUDITH MONTGOMERY
H-350-2808
↓
VIRGINIA GOODLOE
H-381-6716 AFTER 3:30
↓
ANNETTE M. COONER
H-932-7826
↓
CHARLOTTE SMITH
H-689-4091
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MELISSA LAGROUE
H-252-7810
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SUSAN ELLIS
H-823-1033
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H-640-4491 W-934-3270
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CHRIS FRANKS
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H-333-1917 W-752-3521
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(ELOUISE WOODS
ROSEY GOODMAN
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JERRY OVESON
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PARTNERS IN POLICYMAKING 1992

COLLABORATIVE GROUP PROJECT

"None of us is as smart as all of us!"

GOALS:

1) To learn how to clarify, frame, and state the problem or issues in a given situation;
2) To learn what systems offer which services to support people with challenges and how to use these systems;
3) To explore natural community and personal resources which exist;
4) To examine the laws regarding people with disabilities;
5) To learn about "best practices";
6) To learn to work collaboratively in a structured group process to praise people who are working well to confront people without hostility.

COLLABORATIVE GROUP OUTCOME:

Develop a collaborative imaginative report on your issue to present at Partners Session #5.

GROUNDRULES:

1) The way the group functions is as important as the end result of your study.

   A. Each member must actively participate.
   B. Each person in the group will be assigned a different role:

Coordinator	(leads group discussions)
Recorder	(makes notes of group's progress)
Time Keeper	(helps group meet time deadlines)
Summarizer	(reports on what the group did)
Praise Giver	(gives people credit for doing well)
Research Person	(notes when group needs more resources)
Participation Checker	(checks that everyone contributes)

   C. You will evaluate how well your group works together at the end of each session.

2) Each group will develop its own problem-solving process together.

   A. The group will assign each person to do specific tasks as homework between sessions.
   B. When the group meets, each person will share input from individual work.

3) Kinds of activities that members of the group might do:

   A. Talk to people in your community about resource people, ideas, etc;
   B. Interview people who work for various agencies and systems to get information;
   C. Ask one of the Partners leaders for good reading materials or videos that are current;
   D. Sit in, listen, and observe at meetings that relate to this issue;
   E. Inquire about and visit "model" places;
   F. Research the federal and state laws that relate to your issue;
   G. Study "state of the art" or "best practices" -- the newest, best thinking on this issue;
   H. Other ideas:

TASKS FOR COLLABORATIVE GROUPS
SESSION #1

10 minutes 1) Discuss group roles and assign.

10 minutes 2) Read aloud and discuss your Case Study.

25 minutes 3) Discuss the following <u>Focus Questions</u>:

A. **"What are the issues?"**
List all the issues involved here (and be sure that everyone contributes).

B. **"What do we need to know?"**
List any questions you need to get answers for or more information about.

C. **"What resources can we use?"**
List all the possible resources which might be useful including:

- Kinds of agencies
- Resource people in your community
- Resource people in the state
- Books or written article
- Videos
- Other resources:

10 minutes 4) Form work teams to select on of the Focus Questions listed above. Each Team will develop a detailed outline of how to proceed with your Case Study to bring back to the next Session.

5 minutes 5) Discuss, **"How did we work as a group today?"**

- Was everyone involved?
- Did everyone participate?
- Did we listen to each other?
- What can we do better the next time as a group?
- What can we as individuals do better?
- How did you find your role in the group -- easy or hard?

CASE STUDY #1 -- WALTER JONES
PINK GROUP

Walter Jones is a one-year old boy who lives with his mother and ten-year old sister in the San Diego area.

Walter's parents recently separated. Walter was just diagnosed as having cerebral palsy and has significant medical needs. Mrs. Jones is overwhelmed by her family situation. She has no idea where to turn for help and support.

Mrs. Jones would like Walter to have the same opportunities as his sister, but is not sure whether it is possible.

PROBLEM: *Starting with the initial adjustment period and continuing up until Walter's 16th birthday, discuss what will allow Walter to have the same opportunities as his sister.*

Use the Focus Questions:

A. **"What are the issues?"**
List all the issues involved here (and be sure that everyone contributes).

B. **"What do we need to know?"**
List any questions you need to get answers for or more information about.

C. **"What resources can we use?"**
List all the possible resources which might be useful including:

Kinds of agencies
Resource people in your community
Resource people in the state
Books or written article
Videos
Other resources:

CASE STUDY #2 – TINA RODRIGUEZ
GREEN GROUP

Tina Rodriguez is a twenty-year old with Down Syndrome who lives with her parents and two teenage brothers in the San Diego Area. She likes to spend her free time listening to rock music, swimming, and shopping at the mall for clothes. At her large high school she is taking five regular education classes and has recently started an in-school job in the attendance office one period a day.

Last week the supervisor in the attendance office contacted Tina's parents about some incidents of inappropriate sexual behavior (such as kissing boys) in the office. Mr. and Mrs. Rodriguez have requested a meeting with the school to discuss Tina's behavior.

Tina's parents have worked very hard for her to have the same kind of opportunities as her brothers. In the future, they hope that she'll have a job that she likes, be able to get around the city on her own, live in her own apartment (with a roommate she chooses or alone if she prefers), and have friends she chooses to do things with in her free time. They also want her to have supports when she needs them.

PROBLEM: *What can Tina and her parents do to realize these opportunities?*

Use the Focus Questions:

A. **"What are the issues?"**
List all the issues involved here (and be sure that everyone contributes).

B. **"What do we need to know?"**
List any questions you need to get answers for or more information about.

C. **"What resources can we use?"**
List all the possible resources which might be useful including: Kinds of agencies; Resource people in your community; Resource people in the state; Books or written article: Videos; Other resources.

Potential Individual Action Plan Goals
From Partners Session IV
Saturday, March 23, 1991

1. Get appointed to a Council or Board:
   - DD Council
   - County MH/MR/DD Advisory Board
   - School Special Education or Educator Advisory Board
   - etc.;
2. Conduct or arrange for teacher inservice presentations;
3. Become part of a legislative alert telephone network;
4. Conduct public education to have an impact on public attitudes;
5. Develop rapport with my state legislators, county board of supervisors, etc.;
6. Join and become involved with an advocacy group or start one;
7. Speak to my school board;
8. Run for school board;
9. Volunteer to help with an election campaign;
10. Learn about other cultures.

IOWA PIP
N.D. - Received prior to 1992 Academy

THE NATURE OF HIGHLY EFFECTIVE GROUPS

1. THE MEMBERS VALUE EACH OTHER AND SUPPORT THE PURPOSE OF THE GROUP.

2. THE LEADER AND GROUP MEMBERS ARE SKILLED IN THEIR ROLES AND CAN USE THE GROUP PROCESS PRODUCTIVELY TO MAKE COMPLEX DECISIONS.

3. THE GROUP HAS A RELAXED WORKING RELATIONSHIP AMONG ITS MEMBERS.

4. THE GROUP GOALS ARE A SATISFACTORY INTEGRATION OF THE GOALS OF ITS MEMBERS AND THE ORGANIZATION IT SERVES.

5. ALL INTERACTION, PROBLEM-SOLVING AND DECISION-MAKING ACTIVITIES OCCUR IN A SUPPORTING ATMOSPHERE.

6. RESPECT IS SHOWN FOR THE VIEWS OF OTHERS.

7. THERE ARE REAL AND IMPORTANT DIFFERENCES OF OPINIONS, BUT THE FOCUS IS ON FINDING SOUND SOLUTIONS.

8. THE GROUP ATMOSPHERE IS SUFFICIENTLY SUPPORTIVE FOR MEMBERS TO BE ABLE TO READILY ACCEPT CRITICISM THAT IS OFFERED AND MAKE CONSTRUCTIVE USE OF IT.

9. MUTUAL HELP IS CHARACTERISTIC OF EFFECTIVE GROUPS. MEMBERS BELIEVE THAT EACH GROUP MEMBER CAN ACCOMPLISH THE "IMPOSSIBLE".

10. THE GROUP IS DIVERSE IN ATTITUDES, CHARACTERISTICS AND BACKGROUND.

11. THE GROUP DOES NOT DEMAND CONFORMITY, BUT ENCOURAGES CREATIVITY.

12. THE GROUP KNOWS THE VALUE OF "CONSTRUCTIVE" CONFORMITY ON MECHANICAL AND ADMINISTRATIVE ITEMS TO FACILITATE THE BEST USE OF TIME.

13. THERE IS STRONG MOTIVATION ON THE PART OF EACH MEMBER TO COMMUNICATE FRANKLY AND FULLY TO THE GROUP ALL INFORMATION THAT IS RELEVANT TO THE GROUP'S ACTIVITY.

14. MEMBERS FEEL SECURE IN MAKING DECISIONS WHICH SEEM APPROPRIATE TO THEM, BECAUSE THE GOALS AND PHILOSOPHY OF OPERATION ARE CLEARLY UNDERSTOOD AND PROVIDE A SOLID BASE FOR DECISIONS.

15. THE LEADER OF A HIGHLY EFFECTIVE GROUP IS ELECTED CAREFULLY. HIS LEADERSHIP ABILITY IS SO EVIDENT THAT HE WOULD PROBABLY EMERGE AS A LEADER IN ANY UNSTRUCTURED SITUATION.

NATIONAL ACADEMY ON PARTNERS IN POLICYMAKING
THURSDAY-SATURDAY, MAY 14-16, 1992
DOUBLETREE HOTEL AT LINCOLN CENTRE
5410 LBJ FREEWAY
DALLAS, TEXAS

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FOR
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May 14-16, 1992

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Revised 4/8/92

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