

June 3, 1993

MEMORANDUM FOR CAROL RASCO

FROM: LYNN MARGHERIO
SUBJECT: ARC OF MARYLAND SPEECH

The ARC of Maryland will be primarily concerned with how persons with mental retardation will be treated under reform.

Here are some highlights of how health reform addresses the needs of this community.

- Persons with mental retardation will be covered under the comprehensive benefits package

Health reform ensures that all Americans, regardless of how sick they are, how young or old, employed or unemployed, will be covered under the guaranteed benefits package. Health plans are required to take all who apply - - they can't exclude someone because they might be considered a bad risk. And, they have to guarantee the same price to all who apply - - they can't charge more for someone due to illness.

- ★ • Health reform expands home and community-based care

Under reform, persons who have difficulty in performing three or more activities of daily living, such as eating, bathing, dressing and toileting; or for people with mental retardation will be eligible for expanded home and community-based care.

Each state defines the array of long-term care services offered under the new program. Services may include (but are not limited to):

- Homemaker and chore assistance
- Adult day care
- Assistive devices
- Habilitation and rehabilitation
- Home health services beyond those that are provided under the comprehensive benefit package

- * • **A tax credit available to persons with disabilities who work to help pay for personal assistance services**

To encourage participation in the workforce, health reform establishes a tax credit for 50% of the costs for personal assistance services for persons with disabilities who work.

- * • **Health reform promotes the availability and improves the reliability and quality of the private insurance policies covering long-term care through tax incentives and regulation**

Under current law, people have to pay for long-term care insurance with after-tax dollars. Under reform, expenditures for long-term care insurance will be deducted from taxable income, and employers will be able to deduct payments they make for these policies.

States will be responsible for monitoring and enforcing long-term care insurance standards set by the federal government, which include such things as: 1) clearly defining what services are covered by the policy; 2) prohibiting limiting coverage because of preexisting conditions; 3) providing uniform definitions across policies so that individuals don't have to take expensive guesses about what's covered; 4) establishing appeals processes for beneficiaries; 5) training and certifying agents who sell policies.

I also wanted to share with you some of the major areas of concern that came up during the meeting I had with Peggy Schneider, Cindy Mahan and a group of direct service providers and advocates for people with developmental disabilities from Arkansas.

- * 1) They felt restricted by the intense regulation of residential and community-based centers
 - Different eligibility determination processes for SSI and SSDI, cumbersome regulations for survey and inspections, cumbersome paperwork

Response: The Department of Health and Human Services is exploring how to streamline the determination processes so that it's more comprehensible to consumers.

2) • **Managed care system/gatekeepers:**

The status of severely disabled people is very unlikely to change. Even so, they're required to undergo a medical checkup and exam to requalify for services.

Response: As you know, we're currently looking at two options for long-term care. The less expensive package is one that's means-tested. If this option is chosen, for home and community-based services, eligibility determination will be entirely up to the states.

If the other option to provide home and community-based services for the severely disabled (not means-tested), then there will be federally mandated standards for eligibility determination. They will be different for those with permanent disabilities and those, like some elderly people, whose situations ebb and flow.

3) • **The emergence of for-profit agencies to provide care**

They're concerned that managed care will open up the field to anyone who can provide services more cheaply, and therefore quality will suffer.

Response: Under reform, we are not prohibiting for-profit providers from entering the market. We are protecting consumers from poor-quality care in the following ways - - consumer boards so that those who receive the care have a say in how it's delivered; consumer satisfaction surveys that measure the performance of care providers.

4) • **Case management**

In some states today, case management for the MR/DD population is done by an entity separate from the provider. They expressed concern that if case management were removed from the provider, it slows the process down. "Sometimes it takes a month to review."

Response: This is a controversial issue that we've been exploring. States will have the flexibility to determine where case management services should be provided - - at the state level or by the providers themselves. Providers will be prohibited from conducting eligibility determination, though.

empowerment
Power cannot be taken away
Commitment
no one can make you feel inferior w/out your consent
Always do right - this will gratify some people & astonish the rest. - NT woman
Sharon Rosewell

UCPA
 Wednesday, April 28, 1993
 Radisson Plaza Hotel
 Alexandria, Virginia
 1 p.m.

It is wonderful to be here before you...as I have told some other selected audiences in recent weeks...what other way is there to start a speech before a group like yours than I am happy to be here...you are special, you represent the services that I have worked for throughout the last twenty years of my life ~~and~~ and above all you represent the services that have worked FOR me.

Insert (explain Hamp if not already done...child diagnosed as cerebral palsied at approximately 10 months of age, I knew it sooner)

You and your peers in the field, be they ^{clients,} volunteers (the capacity in which I worked exclusively from my son's until he was 7 and a half), center administrators, center workers, ^{family members, associates} and so forth daily create the success stories in family's lives like my own - you help to enable our determination, our capacity to ^{best} take on responsibility and teach responsibility-and above all you care.

A recent headline in the Ark. Democrat / Gazette which profiled me as one of the Arkansans making the move to DC stated something to the effect that "son's life leads local woman to White House." And indeed it has.

I bring to the Domestic Policy Council what is seen by some as a simple statement of purpose: All children shall be empowered to develop to their fullest potential. You and I know that the only way children can do so is if each of us as human beings are given that ongoing opportunity-and it is in that context I both speak today and carry out the daily tasks entrusted to me by President Clinton.

In order to carry you through specific program priorities let's use the President's five priorities given to us at the cabinet/staff retreat very early in this administration. At the same time it is impossible for me not to relate as much as possible to where I come from in a very personal manner.

Economic package: this means work, investment in people as well as deficit reduction. The 1992 Rehabilitation Act's presumption of employability is a ^{valued} tenet ~~here~~ for us in the DPC...personally, my son ~~soon~~ graduated from high school and coming from a community based instruction program in the public schools I am vitally concerned about employability, the job he will obtain and the ongoing lifelong training he will receive, the role of

And I believe you'll hear
through
an echo of your
priority goals for '95

assistive technology. VP Gore and I have had numerous conversations on this issue...there is a genuine commitment. ^{on our part} As we move ahead on National Service, school to work transition and these other job training issues we want to be aware always of the words ~~behind us here~~ (inclusion, not exclusion; independence, not dependence; and empowerment, not paternalism)

Spoken by candidate Clinton

② Health Care Reform: the many pieces being put together, not ready to reveal the details but let's look:

- ~~Your statement~~ non-discrimination
- comprehensiveness
- appropriateness (one of the few groups to talk about availability)
- equity
- efficiency

Long term care will be addressed and the need for community based care and the array of services needed to make that real...we can't accomplish it all at once but we hope to present a comprehensive blueprint. * Health care is tough...far tougher than living facilities in residential neighborhoods.

NIMBY

concern

Expand home / community based care

③ Welfare Reform: ^{one, again} - work, education, training, empowerment

- Work in exchange for welfare
- Work instead of welfare

④ Campaign finance/lobbying reform } Trying to be sensitive to prev non-profit - delicate balance in order to further impact you
⑤ National Service: look not only as how you can participate as student participants but also as services within your programs...look to state mechanism.

where is

~~Finally~~ EDUCATION: (inherent in all but one of the priorities and thus not a separate category)

- reauthorizations
- Goals 2000

mention of disabilities...if we truly mean inclusion, mainstreaming perhaps we have to work on implementation and not set aside words...think about it

What Ed

-GOALS: ~~these goals~~ if we mean all children quite naturally my child, my adult now, and quite frankly we as a community of believers should demand that, and stop quibbling over words that don't necessary produce the actions...hard work does. In these goals we find avenues to push for reform, inclusion, early prevention,

intervention programs...we will do it!

ADA, an overlay to all. You help us monitor, you help us determine where we need to give nudges or bulldozing pushes.

When I look at the last 20 yrs of my life it is an embodiment of I know the meaning of the education goals from early childhood through adult life-long learning.

Hamp Masco was born over 19 years ago and I was told to take him home, love him and make a decision about an institution...we've worked hard with family, medical professionals, therapists, parent educators, teachers, school administrators, you name it... he's been in public schools all his life, he did indeed finally talk at age five, he moved into a small group setting last August, he's taking a college "woman" as he put it to me to his high school prom, in less than two weeks and his senior class peers and school administrators approached him to give a speech at graduation...their rationale "We have learned so much from Hamp" - he's unlike anyone we've ever known. And as Hamp says he's going to conclude in that graduation speech: It's been a lot of fun, but now it's time to move on!

His mother is confident he'll move on in a very positive way w/ a ~~good~~ good ~~ground~~ ~~in decision~~ making, independent thinking, & love of life... & ~~love of~~ ~~people~~ people.

f this Admin-
I've talked about what the President ~~has done and what he~~ wants to do. We've begun to shift course. But this is just the beginning. We must have the courage to change--to recognize mistakes, to abandon what doesn't work, to challenge ourselves to do better. ~~In short, we adults have some growing up to do.~~

I know that many of you in this room are ~~tired after the~~ *often feel why tired* ~~last twelve years.~~ Without you, many of the programs that serve children and families would have been gutted. They weren't, and you've earned ~~a~~ *all the battles you wage daily for rights, funding, services.*

But we're asking you to go another round. The President can't pass or fund his initiatives alone. He can't break the gridlock alone. He still needs your help, and so do America's children *and adults with disabilities*

~~For the first time in a long time,~~ your efforts will be supported--~~not rebuffed--~~ by the executive branch of this government. ~~The details remain to be worked out.~~ But for sure, there will be an ongoing, high-level focus on children and families, ~~cutting across agency, departmental, and programmatic lines, coordinated by the White House, responsible not to any single constituency but to the national interest and directly to the President of the United States.~~

Concern for our *people with disabilities* children must start at the top--but it can't end there. We must empower parents, neighborhoods, communities and voluntary organizations across this great nation to do what our ~~children~~ *children* need. The President can take the lead--but only you can complete the task.

I believe At last, a new day is dawning for America's *people - all people* children and their families. We will work together with you. We won't always succeed, and we won't always be able to do everything that you--and we--would want.

But I can promise you this: we will never relent in our effort to give every ~~child~~ *child* a chance to develop--fully. Because at the end of Bill Clinton's second term, at the dawn of the third millenium, I want to be able to say to Hamp Rasco and Mary Margaret Rasco and to all ~~the children~~ of America, with a clear conscience and a full heart: We did our best. And I want all of you at this ~~summit~~ *summit* to join me in being able to look at one another and say: We did our best.

Thank you very much.

Diagram 23:

DISABILITY PERSPECTIVE ON HEALTH CARE REFORM

Non-Discrimination People with disabilities of all ages and their families must have access to health care which:

- prohibits pre-existing condition exclusions;
- prohibits rating practices that discriminate against higher users of health care;
- ensures that all persons, regardless of income or health status, have access to all needed health-related services; and
- ensures continuity and portability of coverage.

Comprehensiveness In addition to acute care hospital and physician services, comprehensive health-related services include:

- preventive services, including services to prevent the worsening of a disability;
- health promotion/education services;
- diagnostic services;
- long and short term home and community-based services;
- prescription drugs, biologicals and medical foods;
- mental health and counseling services;
- rehabilitation services, including audiology, occupational therapy, physical therapy, respiratory therapy, speech-language pathology services, cognitive, vision and behavioral therapies, and therapeutic recreation;
- personal assistance services and independent living services; and
- durable medical equipment and other assistive devices, equipment, and related services.

Appropriateness Services must be provided to persons with disabilities on the basis of individual need, preference and choice which:

- ensures consumer choice in relation to services and provider;
- ensures a range of service settings through an integrated delivery system;
- ensures appropriate amount, scope and duration of services; and
- ensures the availability of trained personnel.

Equity People with disabilities and their families must be ensured equitable participation in the nation's health care system and not burdened with disproportionate costs. An equitable system:

- limits out-of-pocket expenses and cost sharing requirements for participants;
- provides access to services based on health care need, not income level or employment status; and
- ensures adequate reimbursement for service.

Efficiency The health care system should provide maximum appropriate effective quality services with minimum administrative waste. An efficient system:

- reduces administrative complexity and minimizes administrative costs;
- allocates resources in a more balanced way between preventive services, acute care, rehabilitation and chronic care management;
- maintains effective cost controls so that all people can get the health care services which they need.

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ADA Technical Assistance Programs

with its The Americans with Disabilities Act (ADA) opens new opportunities for persons with disabilities. It also places ^{new} responsibilities on employers, transit and communications systems, state and local governments, and public accommodations. To assist covered parties understand and comply with the ADA, NIDRR has funded ten Regional Disability and Business Accommodation Centers. These centers will provide technical assistance, training, and resource referral on all aspects of the ADA. Their work will be complemented by two other NIDRR ADA-related programs: three materials development projects and two national peer-training projects.

The Arc

of Maryland, Inc.

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June 9, 1993

Ms. Carol Rasco
Assistant to the President for Domestic Policy
The White House
1600 Pennsylvania Avenue
Washington, D.C. 20006

Dear Carol:

Your presentation before the assembly at The Arc State Convention was absolutely terrific. The way you drew the Administration's five priorities into relationship to those of The Arc of Maryland, all interwoven with the story of Hamp's triumph at graduation, was breathtaking.

I'm going to submit your speech to The Arc - National Headquarters as an article for publication in their newsletter, as well as reprint it in Maryland's. (I'll send you copies when they appear.)

You made a lot of new friends this past weekend. This old friend was mighty impressed, too.

It was wonderful to see you and especially to see you doing so well, you really do look in top form. The boys and I are eager to visit you and Mary Margaret in late August; I'll be back in the office as of Monday, August 16.

Thank you so much. Please let me know whatever I can do to help you out if I can.

Warm regards,



Jane Browning
Director of Community Services

The Arc

of Maryland, Inc.

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*Call 2/4 3/11 if I
haven't heard from
her -*

January 25, 1993

Ms. Carol Rasco
Assistant to the President for Domestic Policy
The White House
1600 Pennsylvania Avenue
Washington, D.C. 20006

Dear Carol:

Wow! Congratulations!

The Brownings watched in awe all last week as the Clinton administration lifted off into myth and legend...taking Carol with them!! I am totally confident of your skills and stamina, your ability to take all matters well in hand.

Forgive my intrusion on your precious time, but will you be available for any speaking engagements in the near future? The Arc of Maryland (we have 4050 members!) state convention will be in Ocean City on June 5-6, and we would be vastly honored to welcome you as a keynoter on health policy issues, perhaps focusing on the impact of ADA.

Thank you for considering the possibility. Let me know if you think you could.

Again, we are thrilled to see the opening of this new chapter in your life. We wish you nothing but the best, and our prayers are with you and your family every day.

Sincerely,

*Jane (and John, Jack
and Paul!)*
Jane Browning
Director of Community Services

P.S. I've enclosed a copy of a speaking request I sent to Hillary Clinton, via Patti Solis, just for your information.

"Advocating for people with mental retardation and their families; empowering self-advocates"
(formerly the Association for Retarded Citizens/Maryland, Inc.)

**The
Arc**

of Maryland, Inc.

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Carol Fyfe

January 25, 1993

First Lady Hillary Rodham Clinton, Esq.
The White House
1600 Pennsylvania Avenue
Washington, D.C. 20006

Dear Ms. Clinton:

It was thrilling beyond words to personally witness the Inauguration. Even though John and I are technically Marylanders now, we were Arkansas proud last week. The advent of the new administration provides genuine inspiration for turning renewed hands and hearts to the challenges before us.

My current focus is on the prevention of Fetal Alcohol Syndrome, now the leading known cause of mental retardation. Containing health care costs is uppermost on the nation's agenda; the estimated life time care costs for each individual with FAS is \$1.4 million. The true bottom line on FAS is that it is 100% preventable.

To design an agenda for grass-roots prevention, The Arc of Maryland is sponsoring The Arc National Summit on Fetal Alcohol Syndrome Prevention in Baltimore, April 23-25, 1993. We are expecting 250 people to attend the public reception and keynote address opening the conference on Friday evening.

As a lifelong advocate for children and key leader in national health reform, your presence at this conference would power the prevention agenda as nothing else could. The Arc of Maryland formally invites you to address the National FAS Summit assembly, either Friday evening, April 23 or at your convenience during any other time during the weekend, or on Monday: The Arc of Maryland hosts a statewide Public Policy Institute on Fetal Alcohol Syndrome on Monday, April 26.

I know the demands on your time are enormous, and that you must choose your speaking engagements carefully. However, the topic is clearly within your interests and Baltimore is close; I am hopeful you will give careful consideration to this request.

Thank you for your courage and commitment. I am at your service.

Sincerely,

Jane Browning
Director of Community Services

"Advocating for people with mental retardation and their families; empowering self-advocates"
(formerly the Association for Retarded Citizens/Maryland, Inc.)

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of Maryland, Inc.

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3-4 hours

Roz
Call & tell her time / title
June; ~~will be there~~
~~by 8:45~~ Send her resume,
tell her you have no
B & W glasses at this
time.
April 16, 1993

Ms. Carol Rasco
Assistant to the President for Domestic Policy
The White House
1600 Pennsylvania Avenue
Washington, D.C. 20006

Dear Carol:

I've been "watching" your activities through the news and I must say I don't envy the schedule you've been keeping. I am grateful to you, though, for taking on these tremendous responsibilities on behalf of all of us, especially in seeking equitable and efficient health care reforms.

My heart truly goes out to Hillary in the loss of her father; as you know, John and I both lost our Dads in the last two years and we know how painful and difficult it is, particularly at a distance. Of course, it also greatly increases your share of the work to be done. Please know we are thinking of you!

Perhaps by June you can take a bit of a breather. Surely, Hamp is very excited about his graduation and especially about having you visit in Little Rock. You had mentioned that the family would be travelling East as a graduation present: in case you'd like to spend an extra day at the shore, we have condos available. Get word to me if you'd like me to reserve one.

I'm enclosing materials on the state convention June 4-6. Please confirm that the time of your presentation is agreeable to you (the agenda remains flexible on this point), and suggest a different title if you'd like. We would like to have a black and white glossy photo for publicity purposes if you have one to spare, and you might want to submit a biographical sketch for introductory purposes.

Please let me know if you have questions, problems, or just want to talk. See you soon!

Sincerely,

Jane Browning
Director Community Services

Please - you & I need to talk about logistics, Roz.

Tell her thanks, our schedule is booked.

P.S. Also tell her M-M not coming until August. kids to May Marquet would have a friend there

Sorry this is so rough but I thought you'd like a sense of the convention's content

JB

Friday, June 4

2:00-6:00 Registration **Terrace Lobby**

2:00 Exhibits Opened
Coffee & sodas available

3:00-5:00 THE ARC OF MARYLAND SHOWCASE
Presenters: *Donna Fluke, President*
Cristine Boswell Marchand,
Executive Director
Volunteer & Staff Leadership

This year has been exciting as the Arc of Maryland introduced several new projects and strong legislative agenda to further the Association's priority goals. The Showcase will feature Governmental Affairs, Systems Advocacy, The Arc National FAS Prevention Summit, FAST-ASTICS outreach to students, "Celebrating Lives" Person Centered Training Grant and more! Come and learn what your state Arc does for you and then join us for a lively "Open Mike Session" to speak out about your views.

Conference Rooms 1, 2 & 3

5:15-5:45 "First Timers" Convention Orientation & Tour
Presenters: *The Arc of Harford County*
This session is for people who are attending the Arc/MD conference for the first time. We will review the conference schedule and do a walk through of the hotel.

Conference Room 1

6:30-11:00 "Sand Blast" Dinner & DJ
Join us for dinner from 6:30 to 8:00. There will be a cash bar and dancing until 11:00.

Pool & Deck Area

From : MERCINDUS, INC. 410 838-2103

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From : MERCINDUS, INC. 410 838-2103 PHONE No. :

MAY 21 1993 5:27PM P05

successes as they make waves to achieve fully integrated and inclusive education for their sons and daughters
Conference Room 2

- D. **"Celebrating Success", Gerald Adams**
 Gerald Adams will facilitate a group for individuals to share stories of success and achievement in attaining "Citizenship": A Respected Life.

Conference Room 3

- E. **"Grantwriting and Foundations", Joan Eads**
 Diversifying funding through the private sector. Identifying and establishing relationships with foundations and corporations. Information also on proposal letters to the private sector.

Rooms 318/320

- F. **"The Use of a Canine Companion as a Facilitator", Michael Cosel and Alan Randlov**
 Dogs have long been known for their friendship, intelligence, and ability to help people do all kinds of tasks. Canine Companions has tapped into dogs as a way of making the world a little more accessible for people with disabilities. Alan Randlov and his canine companion will show you how this program offers more choices and control for people with disabilities.

Conference Room 6

12:00-1:30 MEMBERSHIP AWARDS LUNCHEON

Crystal Ballroom

1:45-3:00 WORKSHOPS

- A. **"FAS Prevention" Debbie Ramsey & Maria Feit**
 This workshop will provide an introduction to Fetal Alcohol Syndrome (FAS) and it's implications for children and their families. Information will be shared from the recent national summit on FAS, hosted by The Arc of Maryland and The Arc National, which will include prevention strategies.

Conference Room 1

B. "Enhancing the Staff-Family-Consumer Relationship in Adult Services" Chaya Kaplan & Nancy Rhoad

When an individual enters the adult service system, many changes must be faced by the person with disabilities, his/her family, and the service provider staff. This workshop focuses on staff-family-consumer relationships on entering a program and over the years. Issues that three parties must negotiate and procedures and strategies to enhance working relationships will be discussed. This presentation is based on experiences of Howard County ARC during the past three years.

Rooms 318/320

C. "Integrated Education", Jim Haas

An overview of a two year pilot program for inclusion at Southhampton Middle School will be presented. Issues concerning inclusion will be discussed and slides will be shown. A question and answer period will be provided.

Rooms 302/304

D. "Effective Lobbying: Making Waves in Annapolis", Delegate Mary Louise Preis & Senator Beatrice Tignor

A discussion of how to approach legislators with your ideas, how to follow through to get results you want, what to say, how to say it, and when to get involved.

Conference Room 2

E. "Fundraising: Making a SPLASH with Special Events", Panel Presentation, Mara Walter & Joe Berkowitz, Moderators

panel members share their secrets on what works across Maryland. Get "in the swim" with current trends in fashion shows, auctions and sports tournaments for funds and FUN.

Conference Room 6

TO MARRA WALTERS

F. "Whose Team Is It, Anyway?"

Susan Burke Harrison

Frustrated with your IHP? Sick and tired of listening to people talk about you and not with you in your meeting? This discussion is designed with you in mind. Susan Burke Harrison of the community Support and Access Unit will facilitate this session. Self-advocates are encouraged to share stories and will develop strategies to reclaim their meetings.

Conference Room 3

3:00-3:15 Break

3:15-4:00 THE ARC OF MARYLAND
BOARD OF DIRECTOR'S MEETING

Banquet Hall 2A

4:00-5:15 ANNUAL MEMBERSHIP MEETING
& ELECTIONS

Banquet Hall 2A

3:15-4:15 WORKSHOPS

A. "Progressive Management", *Lou Van Holland*
Archway is a rehab program for people with psychiatric disabilities. The 65 staff people average 5.4 years of service partially due to Archway's personnel philosophy and techniques which will be discussed.

Rooms 312/304

B. "Trusts and Wills", *Randy Van Dolson*
The presenter is an attorney with McQuire, Woods, Battle, and Boothe. He has many years experience in setting up trusts and wills for individuals with disabilities and their families.

Rooms 318/320

C. "Transition to Employment: Andrew's Story",
Mike & Romie Colet
How Andrew's parents made waves to change the system. Covers inclusion, mainstreaming, community involvement, attitudes, technology, Medicaid Waiver, Circles of support, etc.

Conference Room 1

From : MARIJINDUS, INC. 410 838-2103

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3

D. "Natural Supports in Supported Employment"

Shella Wilson

The session will explore strategies for facilitating connections and relationships for individuals with severe disabilities. The basic information will be from the presenter's book chapter but will also include references to situations occurring at the present job with Easter Seal Society of Del-Mar, Inc.

Conference Room 2

E. "Your Rights Under the Rehab Act",

Paul Marchand

The congress passes a new law for employment and training. Come and learn what your rights are.

F. "Family Support Around the State-Pieces of the Pie",
Kathy Cooper, June Bond, Heather Lee & Kris Froehlich

This presentation is designed to offer 3 dimensions of Family Support. We'll discuss ideas for finding resources within a family, between families, and outside the family.

4:15-6:00 ROUNDTABLE DISCUSSION ON BUILDING COMMUNITY WITH GEORGE DUCHARME

Mr. DuCharme has had years of experience and success in building community for individuals with disabilities. Come spend some time in an informal discussion with Mr. DuCharme and your co-workers from around the state.

Conference Room 6

6:30 Children's dinner & Pool Party

Conference Room 1

6:30 Cash Bar

Terrace Lobby

7:00 AWARDS BANQUET

Crystal Ballroom

Sunday, June 6

**8:30-9:30 THE ARC OF MARYLAND
PEOPLE ON THE GO MEETING**

Rooms 302/304

**8:30-9:30 Ecumenical Service with Dave Denham
Conference Rooms 1&2**

9:00-9:30 Continental Breakfast Terrace Lobby

**8:30-10:15 PLENARY SESSION
"Community Building", George DuCharme
Conference Rooms 4, 5 & 6**

10:30-11:45 WORKSHOPS

**A. "Quality Assurance in the Community",
Celia Feinstein & Donna Fluke
What is it? What is needed? Quality of life
Issues and licensing and monitoring.
Captain's Quarters**

**B. "Effective Boards", Gerald Adams
A panel discussion of various aspects of
building and maintaining effective Boards.
Conference Room 4**

**C. "Community Building (Continued)",
George DuCharme
Community Building: Including people with
disabilities fully in community life-By listen-
ing, by creatively connecting people to one
another, by walking with people on the long
journey towards their dreams and goals.
Conference Room 5**

**D. "Ways to Empowerment Without Losing
Hope & Energy", Dr. James Wilburn
This presentation will review the basic
concepts of establishing a more self-directed
working environment in the human service
delivery system. The expectations, demands,
stress, and time of each worker in this area is
constantly taxed and challenged. One avenue
to address these concerns while taking the**

From : MERRILLIS, INC. 419 878-2103

PHONE NO. :

MAY 21 1993 5:25PM P03

Sunday, June 6 (Continued)

quality of service to the next level is the formation of self-managing work teams that have more responsibility and accountability for unit operations. **Conference Room 6**

- E. "Listening in a New Way, Celebrating Lives,"**
** Dave Denham and Yoonne Dunham*
 This workshop will focus upon building networks of support for personal goals without a provider being involved. The leaders will present learnings from the Community Response Network, a project of Service Coordination Systems, a division of the Arc of Frederick County. This project has supported individuals to find homes through the help of other persons and groups without the intervention of a provider. This workshop will offer strategies that work, as well as those that have not worked.

Conference Room 2

- F. "And into the Light" - Panel Discussion with Consumers About Living in Institutions,**
Susan Burke Harrison
 This discussion will focus on stories of self-advocates from Maryland who have lived in our state institutions. Hear each person's story of making a life in the community and celebrate the success! This is a "don't miss" session for those engaged in the pursuit for human and civil rights.

Conference Room 3

- 10:30-11:45 "Self Advocacy Leadership Development",**
Kathy Raggio
BY INVITATION ONLY
Conference Room 1
- 11:45-1:00 "LUNCH"**
 -Celebrating Lives Video
 - Special Surprise Finale **Banquet Hall 1**

Sunday, June 6 (Continued)

quality of service to the next level is the formation of self-managing work teams that have more responsibility and accountability for unit operations. **Conference Room 6**

E. "Listening in a New Way, Celebrating Lives,"
Dave Danham and Yvonne Danham
This workshop will focus upon building networks of support for personal goals without a provider being involved. The leaders will present learnings from the Community Response Network, a project of Service Coordination Systems, a division of the Arc of Frederick County. This project has supported individuals to find homes through the help of other persons and groups without the intervention of a provider. This workshop will offer strategies that work, as well as those that have not worked.

Conference Room 2

F. "And into the Light" - Panel Discussion with Consumers About Living in Institutions,
Susan Burke Harrison
This discussion will focus on stories of self-advocates from Maryland who have lived in our state institutions. Hear each person's story of making a life in the community and celebrate the success! This is a "don't miss" session for those engaged in the pursuit for human and civil rights.

Conference Room 3

10:30-11:45 "Self Advocacy Leadership Development,"
Kathy Raggio
BY INVITATION ONLY

Conference Room 1

11:45-1:00 "LUNCH"
-Celebrating Lives Video
-Special Surprise Finale **Banquet Hall 1**

Saturday Highlights

(9 a.m. to 4:15 p.m.)

PLENARY SESSIONS:

~~Carol Rasco~~ – Assistant to the President for Domestic Policy
"Charting a New Course"

The Honorable Eileen Rehrmann – County Executive, Harford County

WORKSHOPS:

Paul Marchand – What's Happening in Congress and the New Administration

Patti Saylor – Practical Realities: ADA and Child Care

Debbie Ramsey and Jane Browning – FAS National Summit

The Honorable Mary Louise Preis – Effective Lobbying: A Delegate's View

Mike and Ronne Cosel – Making the Waiver Work for Families

Sheila Wilson – Natural Supports in Supported Employment

Randy Van Olson – Wills and Trusts

Chaya Kaplan – Staff, Parent, Consumer Relationships

James Haas – Neighborhood Inclusion: Systems Change

MEMBERSHIP AWARDS LUNCHEON

The Arc of Maryland Board of Directors Annual Meeting
(3:15 to 5:15 p.m.)

Annual Membership Meeting and Election of Officers

1993 Annual Awards Banquet and Dance
(7:30 to 9:00 p.m.)

The Arc of Maryland Priority Goals for 1993

1. To create and sustain a person-driven service delivery system that incorporates the preference, addresses the needs, and protects the rights of persons with mental retardation;
2. To empower persons with mental retardation and members of their families;
3. To advocate for the full inclusion of all persons with mental retardation in the life of the community;
4. To create a strong beginning and a firm foundation for children with mental retardation by supporting them and their families;
5. To promote the efforts to prevent and reduce the incidence of mental retardation in the general population; and
6. To ensure that The Arc of Maryland is financially stable and capable of fulfilling its mission.

Friday Highlights

Registration – From 2:00 p.m.

The Arc of Maryland Showcase. Learn what the Arc does for you;
meet Arc staff and volunteer leaders.
(3:00 to 5:00 p.m.)

PRESENTERS:

Donna Fluke, President
Cristine Boswell Marchand, Executive Director
Staff and Volunteer Leadership

TOPICS:

Person Centered Planning Grant
Prevention – Activities and Summit
ADA and Child Care
"Celebrating Lives"
Mentor Project
FASTACTICS
Legislative Advocacy

"First Timers" Convention Orientation and Tour
(5:15 to 5:45 p.m.)

"Sand Blast" Beach Party – Food, DJ and Dancing
(6:30 p.m.)

The Arc of Maryland Convention REGISTRATION

Please complete a form for each person attending.
Please type or print clearly.

Name _____

Address _____

Phone _____

REGISTRATION

_____ Postmarked by May 21, 1993	\$30.00	_____
_____ Postmarked after May 21, 1993	35.00	_____

Friday, June 5

"Sand Blast" Beach Party Buffet	\$27.00	_____
Food - DJ - Dancing		
Kids (Ages 4 to 12)	13.00	_____
(3 and under free)		

Saturday, June 6

Continental Breakfast and Lunch	\$20.00	_____
Awards Dinner and Dance	30.00	_____
For Kids: Arc/Harford County Pool Party Hamburgers and Hot Dogs (Ages 4 and up) (3 and under free)	10.00	_____

Sunday, June 7

Continental Breakfast and Box Lunch	\$12.50	_____
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TOTAL ENCLOSED _____

HOTEL RESERVATIONS

FOR HOTEL RESERVATIONS: Contact: **The Sheraton Ocean City**
10100 Ocean Highway
Ocean City, Maryland

1-800-638-2100

Be sure to ask for The Arc of Maryland "Convention Rate."

MAKE ALL CHECKS PAYABLE TO: The Arc/Harford County

MAIL YOUR CHECK AND REGISTRATION TO: **The Arc/Harford County**
P.O. Box 610
Aberdeen, Maryland 21001

Attention: Pat McMann

REGISTRATION AFTER MAY 28TH WILL NOT INCLUDE MEALS.

SPECIAL NEEDS

Check here for:

_____ Special Dietary Needs (Please specify) _____

_____ Interpreter

_____ Child Care

Please contact Rosemary at (410) 879-6785

Carol - Sara's memo is essentially accurate - there are gaps in coverage for the chronically disabled. There are however, attempts to narrow existing gaps, and improve coverage for the disabled. This memo lays out the policy.

There are still issues around ADA/IDEA provisions, and responsibility for funding. (HHS and Education have been at odds

about this) I'd like to further explore the issues spatially of that - particularly if we reschedule the Thursday mtg. Please advise.

Christie



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary

Washington, D.C. 20201

May 26, 1993

Memorandum to Carol Rasco

From: Atul Gawande
Re: Coverage for rehabilitative services

Christine relayed a request to clarify the current status of the reform proposal regarding coverage of rehabilitative services.

Rehabilitation therapies (including physical, speech and occupational therapy) used to regain function after illness or injury are covered under the benefit packages we have been looking at.

This is consistent with coverage under current comprehensive private health plans. As long as function is improving or limitations on functional ability can be further minimized, rehabilitation is covered. Currently there are no fixed day limits on coverage of therapy (e.g., a maximum of 60 days) in the benefit package as costed, although private plans often do have such limits. There is, however, a 100 day limit on stays in extended care facilities (skilled nursing facilities or rehabilitation hospitals).

Coverage for therapy where no recovery is likely -- e.g., for maintenance therapy for a permanently disabled person -- is not covered by the benefit package. This coverage falls into the realm of chronic and long term care.

We have offered two major options for consideration on long term care. One option is limited to low income persons and includes the following components of coverage for disabilities (net Federal cost: \$11.8 B in 2000):

- A new program of home and community-based/personal assistance services for low-income people with severe chronic disabilities.
- A new closed-end program for institutional and community-based services for people with mental retardation and other developmental disabilities (MR/DD).

The other option provides a new program of home and community based coverage for the severely disabled, including MR/DD, without regard to income (net Federal cost: \$22.8 B in 2000).

In addition, Medicaid will continue to cover chronic care

services in nearly all States for low-income, and in some States for high cost, persons with disabilities.

However, there are gaps. For example, middle class families with a member who is disabled but not in need of assistance in at least three ADLs, i.e., activities of daily living, (e.g., eating, dressing, bathing) would not be covered in the reform, although social services programs are still available. The above chronic/long-term care programs, though limited, were already being scrutinized carefully due to concerns about the expense of the reform package. The use of further Medicare savings for deficit reduction in the reconciliation bill puts these programs at further risk.

Taken together, the reforms assure full acute care coverage for all Americans, may offer home and community-based services for those with the most severe disabilities, including the MR/DD population, and maintains spend-down protection through Medicaid for those with chronic but less severe needs. Universal and seamless coverage for chronic and long term care rehabilitation and maintenance beyond acute illness is currently not included in the reform package.

To give you a clear example, a woman with multiple sclerosis is covered for care when first diagnosed in an acute flare. Therapy to help her regain function is covered and she returns to normal life. As she gets older, however, her condition worsens. Acute flares continue to be covered to help return her to a baseline state, but maintenance therapy is not covered unless she is on Medicaid due to the family's low income or her having very high medical expenses. Over the years, her condition deteriorates to the point that she needs ongoing assistance in 3 ADLs. If she is institutionalized, she would be fully covered today. In addition, if the long term care package is accepted, she would qualify for home-care, personal assistance and maintenance therapy.

If you have any further questions, please feel free to call (690-7858).