

SARAH - NIMH MH proposals

PHOTOCOPY
PRESERVATION

NATIONAL INSTITUTE OF MENTAL HEALTH

Clinical Trials

Summary of Proposal: In early fall, the National Institute of Mental Health (NIMH) plans to award contracts to conduct clinical trials in two areas of pressing need: new antipsychotic medications that have fewer side effects for the treatment of severe mental illnesses like schizophrenia, and intervention strategies for the treatment of patients who have depression that is resistant to available treatments. These trials will make objective comparisons among similar treatments to determine which are best for which patients.

Background: NIMH has reinvigorated its focus on clinical trials of medications for mental disorders, and the new awards will further the goal of achieving new, more effective treatments for those affected by mental illness. Recently, the institute awarded contracts to investigate medications for areas where adequate knowledge and effective treatments are critically needed: bipolar (manic-depressive) illness and for mental disorders in children and adolescents.

New Antipsychotic Medications. A series of new medications are becoming available for treating severe mental disorders, such as schizophrenia. Compared to their predecessor developed in earlier decades, these antipsychotic compounds have a relative lack of severe side effects. One of the earlier of these new medications, clozapine (Clozaril), was introduced in the U.S. nearly eight years ago. Since then, several others have been approved for use in this country, including risperidone (Risperdal), olanzapine (Zyprexa) and Quetiapine (Seroquel). In addition to their effectiveness against schizophrenia's "positive" symptoms, such as hallucinations and delusions, these new medications may also reduce the disabling "negative symptoms" of the disorder, including social withdrawal resulting from loss of motivation and interest in activities. A further benefit of these antipsychotics is that they are less likely to produce tardive dyskinesia, a potentially irreversible neurological syndrome, which is perhaps the most feared adverse consequence of long-term use of standard therapies for schizophrenia.

Treatment Resistant Depression. Major depression is one of the most common mental disorders. There are many treatment options available for treatment of depression, including medications and psychotherapy. However, many persons with depression do not respond optimally to treatments, even when appropriate treatment is provided. When initial treatment includes antidepressant medications, approximately 20-30% of depressed patients do *not* respond satisfactorily. In addition, it has been estimated that as many as 60-70% of depressed patients achieve only a partial resolution of their symptoms. Treatment resistant depression is a major public health problem because it is very difficult for a depressed person to be optimally productive, and because there is an increased risk of suicide. The management of treatment resistant depression clearly represents a substantial portion of the cost of depression accounting for a disproportionate amount of clinician time, patient disability, and associated complications.

Proposal:

(1) NIMH plans to award contracts to conduct trials of the newer antipsychotic drugs in patients with schizophrenia, psychotic depression, and dementia. The trials will be based on a public health model of intervention research, with a focus on effectiveness and outcome, rather than efficacy alone. They will also examine cost-effectiveness and the impact of external factors on

treatment delivery, compliance, and eventual outcome. A major objective is generalizability: the trials will be as inclusive as possible; a premium will be placed on demographic (age, sex, and race) and geographic (urban and rural) diversity; and multiple treatment and residential settings will be included. Research participants with comorbid disorders (e.g., drug abuse) will not be excluded, and will be actively recruited. Only FDA-approved, marketed antipsychotics will be studied. One of the anticipated results of this initiative is the development of a network of sites and investigators able to respond to future needs for outcome focused treatment research. At this time NIMH is considering the following aims and hypotheses for each trial: In schizophrenia, the overriding issue will be how these drugs affect long-term outcome: not only positive and negative symptoms, but overall level of function in multiple domains including cognition, mood, suicidality, interpersonal interactions, vocational achievement, and quality of life. In psychotic depression, the objectives are to determine the relative risks and benefits of chronic, prophylactic treatment with newer medications. In patients with dementia, the questions will address acute efficacy and safety: defining which symptoms and behaviors are appropriately treated with the new antipsychotics, unique safety issues, and effects on long-term outcome.

(2) NIMH intends to conduct trials of intervention strategies for the treatment of adults, including older adults, who have less than optimal responses to initial treatment of their depression. A public health model of effectiveness research is the central feature of the approach taken in this initiative. In order to address the full spectrum of public health questions related to treatment resistant depression, conventional randomized clinical trial designs will be complimented by naturalistic studies of treatment resistance in a wide range of clinical practice settings. In addition to controlled comparison of specific interventions, this initiative will include study of treatment algorithms involving sequences of interventions.



**PRESIDENTIAL
TASK FORCE ON
EMPLOYMENT
OF ADULTS
WITH
DISABILITIES**

200 Constitution Avenue, NW
Room S2312
Washington, DC 20210
Phone: 202-219-6081
TTY: 202-219-0012
Fax: 202-219-6523
www.dol.gov

MEMORANDUM FOR: Audrey Haynes, Special Assistant to the Vice President and Chief of Staff to Mrs. Gore
Marsha Scott, Deputy Assistant to the President and Deputy Director for Presidential Personnel
Chris Jennings, Deputy Assistant to the President for Health Policy
Sarah Bianchi, Assistant Director for Health Policy
Gina Tesaura

FROM: Rebecca Ogle, Executive Director *RO*
Presidential Task Force on Employment of
Adults with Disabilities

SUBJECT: Presidential Task Force Initiative for
the White House Mental Health Summit

The following are respectfully submitted for your consideration:

**TITLE OF INITIATIVE: ACCESS AMERICA FOR PEOPLE WITH
DISABILITIES**

SUMMARY OF PROPOSAL

**NEW ONE-STOP ACCESS TO GOVERNMENT SERVICES FOR PEOPLE WITH
DISABILITIES**

One-stop Internet access to government services for people with disabilities.

BACKGROUND: In February, Vice President Gore announced his new "Access America for Seniors," an Internet site providing a wide range of services to older Americans -- an example of his vision of one-stop Internet access to government services. The new web site, www.seniors.gov, provides information and services offered by virtually every major Federal government agency, civilian and military. All are accessible with a few clicks from the Access America for Seniors home page. "This is an excellent example of our efforts to reinvent government to provide services that the American people need and care about," Vice President Gore said. "Through this new web site, seniors can change their address with the Post Office, compare nursing homes, request Social Security statements, get IRS tax forms and find a variety of other government information."

PROPOSAL: The Presidential Task Force on Employment of Adults with Disabilities recommends doing the same thing for people with disabilities, "Access America for People with

Put Ability to Work!

Disabilities," and link to an abundance of helpful federal agency sites, information, programs and services: WIA, IDEA, SSA, DOL programs, SAMSHA, the new EEOC information for small businesses and so on.

→ NIMH

For the White House Conference, emphasis would be placed on topic areas relevant to mental health (consumer organizations, peer support, etc.) The Task Force will use \$100,000 toward development of the website and build on what has already been accomplished.

→ great - let's work on
freshing out ~~out~~
what this website
will be what kind
of resources will be
available - including
some things specific
to mental health.
~~what~~ Also please confirm
that all the agencies
involved are ok w/ this
by week.

→ also what happened
to employment stuff



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MAY - 6 1999

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Gina Tesaura

FROM: Rebecca Ogle, Executive Director *Rebecca Ogle*
Presidential Task Force on Employment of
Adults with Disabilities

SUBJECT: Submission of New Initiatives/Announcements at
the White House Mental Health Summit

The following are respectfully submitted for your consideration:

1. The President announces the elimination of the stricter standards for excepted appointments in the federal workplace currently applied to adults with psychiatric disabilities and extends to these individuals opportunities currently available to individuals with mental retardation and severe physical disabilities.

2. The President unveils the model plan developed by the Office of Personnel Management to increase the representation of adults with disabilities in the federal workforce and directs agencies and departments to implement the plan.

3. Mrs. Gore announces that she will conduct a Town Hall meeting sometime in the Fall of 1999 in conjunction with the Presidential Task Force on Employment of Adults with Disabilities. The Town Hall meeting will focus on employment and mental health issues be announced as part of Ms. Gore's follow-up to the Summit.

4. The President directs OPM to make the FEHBP move to parity by year 2001.

FEHBP move to parity sets an example for the rest of the nation to follow. In addition, OPM would be responsible for collecting information concerning the costs associated with the implementation of full parity.

*we need
one
paper
for
this*

Put Ability to Work!

5. In the interim before parity, the President directs HHS to provide clarification concerning Medicare coverage for mental health services such as reimbursement and coverage issues as well as treatment options.

Clarification of Medicare coverage for mental health services would reduce confusion among providers and beneficiaries and possibly increase the use of the benefit.

6. The President directs HHS to issue clarification of Medicaid coverage for community mental health services to ensure access to effective wrap-around services and intensive community-based services for beneficiaries (children and adults.)

Currently, Medicaid has no mental health benefit. Instead, states must make mental health services fit into categories that were defined years ago in regulatory language that no longer reflect current best practices particularly for those persons for whom the current system has proven most inadequate.



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FROM: Rebecca Ogle, Executive Director *RIO*
Presidential Task Force on Employment of
Adults with Disabilities

SUBJECT: Administration's FY 2000 Budget to be Highlighted at the
the White House Mental Health Summit

The following are respectfully submitted for your consideration:

• **Funding the Work Incentives Improvement Act in the President's Budget.** The FY 2000 budget includes the full Work Incentives Improvement Act. This proposal, which costs \$1.2 billion over 5 years, would improve access to health care by providing new options for workers with disabilities to buy into Medicaid and Medicare; modernizing employment-related services for workers with disabilities; and creating a work incentives grant program to provide benefits planning and assistance and better integrate services to people with disabilities working or returning to work.

• **Work Incentives Assistance Program** In its FY 2000 budget, the Administration has proposed an expanded \$50 million Work Incentives Grants program that includes \$23 million for the outreach grants currently in S. 331, but adds \$27 million for a second component to provide system building grants. The expanded program includes:

- outreach and counseling grants that are the same as the grants in S. 331 except that the grants would be administered by DOL, funding would be new appropriations in the DOL budget, and services would be extended to persons with disabilities who are not SSDI and SSI recipients; and
- systems building grants for the purpose of better integrating the provision of all

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employment-related services for persons with disabilities through the One-Stop Career Center system.

- **\$1,000 Tax Credit.** Under this proposal, workers with significant disabilities would receive an annual \$1,000 tax credit to help cover the formal and informal costs that are associated with and even prerequisites for employment, such as special transportation and technology needs. This tax credit, which will help 200,000 to 300,000 Americans costs \$700 million over 5 years.

- **Improving Access to Assistive Technology.** This new \$35 million initiative would accelerate the development and adoption of information and communications technologies, which can improve the quality of life for people with disabilities and enhance their ability to participate in the workplace.

- **Encouraging Small Businesses to Offer Health Insurance.** This new initiative encourages small businesses to offer health insurance to their employees through: a new tax credit for small businesses who decide to offer coverage by joining coalitions; encouraging private foundations to support coalitions by allowing their contributions towards these organizations to be tax exempt; offering technical assistance to small business coalitions from the Office of Personnel Management.

- **Improving Access to Health Insurance through Medicaid and CHIP.** The budget increases access to health insurance by restoring Medicaid and CHIP eligibility for legal immigrants affected by welfare reform; extending Medicaid eligibility to foster children up to age 21; improving transitional Medicaid for people moving from welfare to work; and providing states with \$1.2 billion over 5 years for children's health outreach activities. The budget provides \$144 million over five years for increased CHIP funding for Puerto Rico and the territories.

- **\$1000 Tax Credit.** This new tax credit compensates for a wide range of formal or informal long-term care for people of all ages with three or more limitations in activities of daily living (ADLs) or a comparable cognitive impairment. This proposal would benefit about 2 million Americans and costs \$5.5 billion over five years.

- **National Campaign to Educate Medicare Beneficiaries about Long-term Care Options.** This \$10 million campaign would provide Medicare beneficiaries with information about State administered home and community based care options including: what long-term care Medicare does and does not cover; Medicaid and Older Americans Act programs; and what to look for in a quality private long-term care policy.

- **Offering Quality Private Long-term Care Insurance to Federal Employees.** Proposal allows OPM to offer non-subsidized, private long-term care insurance to all federal employees, retirees, and their families at group rates. Roughly 300,000 Federal employees are expected to participate in this program.

- **New Community Based Long-term Care Options.** This proposal would provide States with

a new option to eliminate the institutional bias in Medicaid and provide Medicaid coverage to individuals of all ages with income up to 300 percent of SSI who have been determined to require an institutional level of care but continue to live in residential rather than institutional settings.

Project Employ

Project Employ is a program initiated in 1996 by the President's Committee on Employment of People with Disabilities to expand and enhance employment opportunities for persons with cognitive disabilities. The program promotes the hiring of people with disabilities in jobs which pay higher than minimum wage, include benefits, and promotional opportunities. In the President's FY 2000 budget the President's Committee on Employment of People with Disabilities has budgeted \$200,000 to develop a similar program for persons with psychiatric disability.

Joe
everyone has
their own
like this
is it
can
need
you
love



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FROM: Rebecca Ogle, Executive Director *RO*
Presidential Task Force on Employment of
Adults with Disabilities

SUBJECT: Break-out Sessions at the
the White House Mental Health Summit

The following are respectfully submitted for your consideration:

1. **Work Incentives Improvement Act** - facilitated by Commissioner Apfel, Nancy-Ann Min DeParle, Senator Kennedy, Senator Jeffords?
2. **Mental Health Parity/Patient's Bill of Rights** - facilitated by Secretary Shalala, Bernard Arons, Senator Paul Wellstone, Representatives Marge Roukema, (D-NJ), Peter DeFazio (D-OR) and Bob Wise (D-WV)
3. **Best Practices** - facilitated by Administrator Alvarez, Representatives Charles E. Schumer (D-NY), Janice D. Schakowsky (D-IL), Steny H. Hoyer, (D-MD) {Note: HHS, DOL could provide summaries of best practices from NY, IL, MD to initiate a discussion}

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FACSIMILE TRANSMITTAL FORM

Date: 5/6/99

Total Pages: 6

To: Gina Tesaura

From: Bill McKinnon

Fax #: 456 6298

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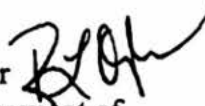


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DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Institutes of Health
National Institute of Mental Health
6001 Executive Blvd.
Bethesda, Maryland 20892

Older Adults—Depression and Suicide

Summary of Proposal: The National Institute of Mental Health (NIMH) proposes to partner with the Social Security Administration, Veterans Administration, and possibly with one or more voluntary organizations for the mailing of a depression cue card, that could be included along with beneficiary checks or other mailed materials, to provide information to older persons on how to talk to their doctors about symptoms of depression.

Background: Nearly 5 million of the 32 million Americans age 65 and older suffer from some form of depression.

Older Americans are disproportionately likely to commit suicide. Comprising only 13 percent of the U.S. population, individuals ages 65 and older account for 20 percent of all suicide deaths, with white males being particularly vulnerable. The highest rate is for white men ages 85 and older: 65.3 deaths per 100,000 in 1996 (the most recent year for which statistics are available), about 6 times the national U.S. rate of 10.8 per 100,000.

According to one study, many older adults who commit suicide have visited their primary care physician very close to the time of the suicide: 20 percent on the same day, 40 percent within one week, and 70 percent within one month of the suicide. These findings point to the urgency of enhancing both the detection and adequate treatment of depression as a means of reducing the risk of suicide among the elderly.

Proposal:

Both doctors and patients may have difficulty recognizing the signs of depression. In an effort to improve the recognition of the illness and promote discussion about depression during medical visits, the NIMH has developed a cue card for older adults providing information on recognizing symptoms of depression and talking to their doctor about how they are feeling.

NIMH proposes to partner with the Social Security Administration, the Veterans Administration, and other agencies that regularly send out beneficiary checks. The cue card would be inserted into beneficiary check mailings and mailed to recipients. Estimated beneficiaries are the 44,185,000 persons who receive Social Security benefits; 62% of these are retired workers; 72% are aged 65 or older and another 8.8% are aged 62-64. The veteran's population is estimated at 25.6 million, and the estimate would be as high as 70 million if veterans' dependents and survivors of deceased veterans are counted. A significant percentage of these individuals are in the older age brackets.

NIMH
National Institute
of Mental Health

Page 2 – NIMH Proposal, Older Adults—Depression and Suicide

NIMH would also like to explore the possibility of partnering with voluntary organizations that distribute materials to older Americans. Most notably, the American Association of Retired Persons, with its 30 million members, would represent an excellent channel for distributing the cue card.

Costs would involve the printing of the cue card and any associated handling costs related to inserting the card into mailings.

No new legislation would be needed in connection with this initiative.

People impacted would be Americans age 65 and over, along with some in their late fifties and early sixties. Caregivers of the elderly would also be helped; many of them are currently unaware of the symptoms of depression in older people and the fact that the disorder is treatable.

The information imparted would be beneficial to older Americans with symptoms of depression, their caregivers, and their doctors, who in many instances have the best opportunity to observe signs of depression. Ultimately, this information initiative will help prevent suicides in the older population.

For further information contact:

Clarissa Wittenberg
Associate Director for Communications
National Institute of Mental Health
6001 Executive Boulevard, Rm. 8184, MSC 9663
Bethesda, Md 20892-9663
Tel: 301/443-3600
Fax: 301/443-0008
Email: wittenbc@nih.gov

March 29, 1999

Older Adults

**Before you say,
"I'm fine"...**

Ask yourself if you feel:

- ☐ nervous, or "empty"
- ☐ guilty or worthless
- ☐ very tired and slowed down
- ☐ you don't enjoy things
the way you used to
- ☐ restless or irritable
- ☐ like no one loves you
- ☐ like life is not worth living

Or if you are:

- ☐ sleeping more or less than usual
- ☐ eating more or less than usual
- ☐ having persistent headaches,
stomach aches, or chronic pain

**These may be symptoms of Depression,
a treatable medical illness.**

**But your doctor can only treat you
if you say how you are really feeling.**

**Depression is not
a normal part of aging.**

Talk to your doctor.

NIMH

National Institute
of Mental Health
www.nimh.nih.gov

Toll Free: 1-800-421-4211
Fax Back System: 301-443-5158

March 29, 1999

Doctors

**Before you diagnose,
ask your patients...**

- ☐ How are things going at home?
- ☐ How are you sleeping?
- ☐ Are you enjoying life?

**Answers to these questions
may reveal signs of Depression.**

**Depression
frequently co-occurs
with other illnesses
and needs separate treatment.**

**Depression is not
a normal part of aging.**

**Recognize and treat
depression.**

NIMH

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of Mental Health

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New England Child Care Conference

Briefing prepared by Sarah Bianchi

Event Time: Friday, May 7, 1999

8:30pm-9:15pm

EVENT

You are participating by satellite in the New Hampshire Association for Education of Young Children Child Care Leaders Forum being hosted in Portsmouth New Hampshire. This conference is designed to bring together many of the This conference is being attended by approximately 1500 people from around New England (although the majority of participants are from New Hampshire). Participants include child care providers, policy leaders businesses

LOGISTICS

- You join the Satellite and make brief introductory remarks
- You, Governor Shaheen, and Senator Jeffords answer questions from the audience (see questions attached)
- You, Governor Shaheen and Senator Jeffords wrap up the discussion and close the satellite

YOUR ROLE AND CONTRIBUTION

ATTACHMENTS

Remarks provided by speechwriting

Background on the Administration's Child Care Initiative

Background on this conference and key participants

Participants and Questions

PHOTOCOPY
PRESERVATION

The Administration's Child Care Initiative

The Administration's child care initiative responds to the struggles our nation's working parents face in finding ^{quality of} ~~child care they can afford, trust and rely on~~. The balanced budget includes a package of proposals to help working families pay for child care, build a good supply of after-school programs, improve the safety and quality of care, and promote early learning.

- **Providing Child Care Subsidies to More than One Million Additional Children.** The Administration budget would expand the Child Care and Development Block Grant to help working families struggling to afford child care. In FY 1997, states provided child care assistance to only 1.25 of the roughly 10 million low-income children eligible for assistance. The Administration's budget request would increase funding for child care subsidies by \$7.5 billion over five years, enabling the program to serve an additional 1.15 million children by FY 2004.
- **Promoting Early Learning.** The budget increases the block grant to provide challenge grants to communities (distributed by states) to promote early learning and improve the quality and safety of child care for children ages zero to five. Research shows that children's experiences in the earliest years are critical to their development and ability to reach school ready to learn. The budget includes \$3 billion over five years to help get children ready to learn.
- **Improving Child Care Quality.** Last year, Congress fully funded the Administration's request to increase investment in improving child care by providing states with additional resources for quality enhancement efforts such as performing inspections of child care facilities, providing resource and referral services for parents, assisting providers with training and scholarships, and creating networks for family day care providers. The President's budget includes \$173 million for this effort to improve quality.
- **Greater Tax Relief for Child Care to Three Million Working Families.** The President's budget includes \$5 billion over five years to expand the Child and Dependent Care Tax Credit for nearly three million working families paying for child care. We are proposing to expand to families earning under \$60,000, to provide an additional average tax cut of \$354 for these families, and to eliminate income tax liability for nearly all families with incomes below 200 percent of poverty that claim the maximum allowable child care expenses.
- **Providing Tax Relief to Parents Who Stay at Home.** To support parents in whatever choice they make for the care of their children, the Administration has proposed to enable parents who stay at home with children under one to take advantage of the Child and Dependent Care Tax Credit by claiming assumed child care expenses of \$500.

- **Creating New Child Care Tax Incentives for Businesses.** We are proposing to create a new tax credit to businesses that provide child care services for their employees, by building or expanding child care facilities, operating existing facilities, training child care workers, or providing child care resource and referral services. The credit covers 25 percent of qualified costs, but may not exceed \$150,000 per year. The President's budget includes approximately \$500 million over five years for these tax credits.
- **Expanding After-School Opportunities.** The budget includes \$600 million in FY 2000 to help roughly 1.1 million children each year participate in after-school and summer school programs. In awarding these new funds, the Education Department will give priority to school districts that are ending social promotion by requiring that students meet academic standards in order to move to the next grade.
- **Expanding Head Start and Early Head Start.** You announced that the budget includes a significant new investment in Head Start by an additional \$607 million in FY 2000 to reach an additional 42,000 children with Head Start and Early Head Start services, enabling the program to serve 877,000 low-income children. The Administration is committed to reaching his goal of enrolling one million children in Head Start by 2002, and doubling the number of infants and toddlers in Early Head Start.

The Administration Has Made Progress on Child Care Over The Past Year Including: Winning our full budget request -- \$200 million -- to serve a quarter of a million children with after-school programs; securing a \$182 million increase to help states make critical improvements to the quality of child care; winning an increase of \$313 million for Head Start; implementing effective background checks on child care providers;

KEY FACTS ABOUT THIS CONFERENCE

Lifetime Television “Caring for Kids” Campaign

Lifetime Television is also a major participant in this conference and may air this entire program at some point. The First Lady recently helped launch the second phase of Lifetime Television’s “Caring for Kids” campaign to provide parents with the information they need, and give them the opportunity to have their voices heard. Lifetime has formed partnerships with key child care experts and advocates and developed a documentary film of parents talking about their child care struggles and needs which aired on Lifetime on April 20. Lifetime is continuing its work with a diverse group of partners, from child care providers to law enforcement officials, to amplify the voices and struggles of parents and others around the issue of child care. Their goal is to work to make child care a central issue in the 2000 elections and is gearing up to produce voter guides, etc.

Governor Shaheen’s Role in Child Care.

Governor Shaheen recently appointed a Business Commission on Child Care to look at ways that the private sector can help assure more affordable child care for families throughout the state of New Hampshire. They have compiled a report that the Governor is planning to release in the next couple of weeks. While clearly one of the Governor’s greatest successes has been instituting kindergarten in the state of New Hampshire, she has been reluctant to propose state funding for child care given the crisis in New Hampshire that there is not enough funding to support the state’s K-12 education system.

The National Association for the Education of Young Children

NAEYC is the nation’s largest organization of early childhood professionals and others dedicated to improving the quality of early childhood programs. It is the largest accrediting organization in the country. The child care providers that will be at this conference are mostly accredited by NAEYC or are working to get accreditation.



GALLAGHER, CALLAHAN & GARTRELL

PROFESSIONAL ASSOCIATION

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(603) 228-1181
(800) 528-1181
Facsimile (603)-226-3477

To: Lydia
Dan Taylor
Fax: (202) 456-1606
(202) 456-6231

From: Stefany A. Shaheen

Date: May 4, 1999

Re: New Hampshire Association for the Education of Young Children
Child Care Policy Leaders Forum
Background and Timeline

Comments: I look forward to speaking with you soon.

TOTAL NUMBER OF PAGES INCLUDING THIS COVER SHEET: 4

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Maxwell
Rowland

The New Hampshire Association for the Education of Young Children Child Care Policy Leaders Forum

BACKGROUND:

The Organization

NHAEYC, the New Hampshire affiliate of the National Association for the Education of Young Children (NAEYC), is hosting the annual New England-wide conference in Portsmouth, NH from May 6-8, 1999. The conference is expected to have approximately 1,200 conferees in attendance.

→ NAEYC

The NAEYC is the nation's largest organization of early childhood professionals and others dedicated to improving the quality of early childhood education programs. Founded in 1926, NAEYC's membership grew to more than 103,000 in 1998 and includes a national network of more than 400 local, state and regional early childhood organizations affiliated with NAEYC.

The Forum

On May 7, 1999, the NHAEYC will hold a policy leaders forum on child care as part of the New England-wide conference. Governor Shaheen will be hosting this bi-partisan event and is planning to invite child care policy leaders on the state and national level to discuss the value of early childhood education and quality child care. The News Director for WMUR-TV, Karen Brown, has agreed to moderate the discussion. Lifetime Television, a cable network, will also be sponsoring the event. We anticipate statewide and national media coverage of this unique and relevant discussion.

The policy leaders forum will be held in the Whittemore Center at the University of New Hampshire and will be open to the public. University students, business leaders, state legislators, child care providers and advocates, and other policy-makers will be encouraged to attend. We anticipate over 2,500 attendees and will be videotaping the event for distribution to more than 400 NAEYC affiliates throughout the country, representing all 50 states.

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**The New Hampshire Association for the Education of Young Children
Child Care Policy Leaders Forum
Timeline**

6:30-7:15pm

Pre-Reception with Child Care Policy Leaders and Sponsors

Photographs to be taken of Sponsors with Child Care Policy Leaders

7:30pm-8:40pm

Child Care Policy Leaders Forum

7:30pm

Karen Brown, News Director for WMUR-TV

Welcome and Introduce Mark R. Ginsberg

7:32pm

Mark R. Ginsberg, Executive Director of the National Association for the Education of Young Children
Introduce Governor Jeanne Shaheen

7:34pm

Governor Jeanne Shaheen

Brief Remarks and Introduce

Senator James Jeffords (R, VT), Chair of the Senate Labor and Human Resources Committee

Joan Lombardi, former Deputy Assistant Secretary of Children and Families and

former Director of the Child Care Bureau for the Department of Health and Human Services

Meredith Wagner, Senior Vice President of Public Affairs for Lifetime Television

7:44pm

Senator James Jeffords (R, VT) →

Brief Remarks

7:50pm

Joan Lombardi

Brief Remarks

7:53pm

Meredith Wagner

Introduce Lifetime Television's *Caring for Kids* Campaign and Documentary

7:55pm

Lifetime Television Vignette

8:00pm

Governor Shaheen

Present Proclamation to Lifetime Television

*5 m. campaign
get parents
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child care*

*public
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*Senate new finding
child care subsidies
low income
egregious budget report
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this is your
more resources
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**The New Hampshire Association for the Education of Young Children
Child Care Policy Leaders Forum**

Timeline cont.

8:05pm

Child Care Policy Leaders

Answer Audience Questions

8:35pm

Karen Brown

Signals Final Question

8:40pm

Governor Shaheen

Closing Remarks

8:45pm-9:30pm

Reception for Attendees

believe brain development
working → time voices
are hearing conference
now time address

Congress Dafford/Didd.

→ progress made → bipartisan
WCS. 781

Sarah Bianchi - 456-5557

From Alan Weil 265-3165

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The Family Insurance Plan (FIP): A Health Insurance Plan for Families

Proposal Outline

The Family Insurance Plan (FIP) is an expansion of the new Children's Health Insurance Program (CHIP) to reach the parents of children insured under Medicaid or under the new CHIP program. Federal funds would be made available to states at the CHIP matching rate. In addition, states spending less than their current CHIP allocation could reallocate a portion of their unspent funds to family coverage.

Administration. States would administer the program, as they do CHIP, and they would be permitted the same options as CHIP. That is, they could expand Medicaid eligibility or they could establish a separate insurance program. States would submit a plan for approval by HHS. Program oversight would be by HCFA.

Benefits. States would be required to offer a benefit package comparable to a commercial plan. As with CHIP, there would be a series of benchmark equivalents a state could use (e.g., the largest commercial IIMO, the state employees' plan).

Cost sharing. Premium payments by enrollees would be prohibited for adults in families with income below 100% of the federal poverty level. States could establish premium requirements for higher income families. Similar restrictions would apply to copayments.

Financing. New federal matching funds would be made available to support this program. States could reallocate their unspent CHIP funds so long as the state has an operating CHIP program and the eligibility levels for adults do not exceed those for children.

Supporting Data

NOTE: These data are drawn from multiple sources, and there is significant controversy over the quality of various data sources related to health insurance. Further analysis is necessary, but they illustrate the general parameters of the problem.

Of the approximately 51 million adults in families with income below 200% FPL, 35% or 18 million are uninsured (35% have employer-sponsored insurance (ESI), 21% have Medicaid, and 10% have other source coverage). For the 48.5 million adults between 200 and 400% FPL, 15% are uninsured, and for the 56 million above 400% FPL, 5% are uninsured.

Within the group of uninsured families below 200% FPL, in those between 100 and 200% FPL, only 6% do not have a family member who works full-time or part-time. For those below 100% of FPL, 29% do not have a working member. Thus, the large majority of low income uninsured families are working families. (These figures are for individuals, not families, but the ratios should be approximately correct.)

Of the 11.3 million uninsured children, 9.1 million are in households with income below 200% FPL. Of the 5.9 million parents in those households, 5.1 million, or 86%, are uninsured. Thus, the parents of low-income uninsured children are overwhelmingly uninsured themselves.

I do not have data on the insurance status of the parents of children enrolled in Medicaid. Very few of these parents have private health insurance, and they are currently eligible for Medicaid only if they are 1) receiving TANF or transitional benefits after leaving TANF; 2) pregnant; or, 3) disabled. It is safe to assume that the large majority of these parents are uninsured.

Policy Considerations

Advantages

This program builds on the strengths of the CHIP model. That is, state administration generates political support by governors and allows for tailoring of program design to state-specific factors. Federal oversight assures accountability, but is limited, allowing flexibility and experimentation. The enhanced match of CHIP provides a strong motivation for state participation.

This program encourages enrollment in CHIP (and the new program) because it holds families together. It treats low-income families like employed families in that the family unit applies for coverage, rather than having separate eligibility for each child and generally no eligibility for adults.

This program retains continuity of coverage for women after they have children, so they don't go uninsured (and without family planning benefits) and only return to insured status if they become pregnant again.

This program encourages families to stay together by providing insurance benefits to low-income working fathers. Relatively few of these fathers can obtain insurance through employment.

By building on CHIP, this program increases the likelihood that funds allocated to CHIP but not spent continue to go towards solving our nation's health insurance problem, rather than having them reallocated to another purpose.

Disadvantages

State flexibility means there will be no federal minimum standards for coverage. Early analysis of CHIP indicates that states with historically strong safety net programs tend to take the greatest advantage of the new funds to expand coverage. Thus, variations in public coverage, already quite large, are likely to grow with a program that leaves major design decisions up to the states.

Many adults remain uninsured. Parents with incomes above the CHIP eligibility limits, but low enough that they cannot afford health insurance, are not eligible. In addition, childless adults are ineligible. Of course, any incremental program leaves some uninsured. It is an open question whether from an equity standpoint parents of low-income children are more deserving of public support than other uninsured adults. However, if one goal is to bring more children into CHIP by making it easier for families to gain coverage, this is the correct group to target.

Three Specific Issues

Comparison to a tax credit

This proposal, like CHIP, relies upon states to establish and administer a program. This stands in contrast to tax credit proposals that offer funds directly to families and allows them to make choices about their coverage. A strong case can be made that, especially for the income group targeted by this proposal, a tax credit will be of limited value. While a full discussion of this issue is quite lengthy, generally speaking a tax credit approach is of greater appeal as one moves up the income ladder. This is because cash-flow issues for low-income families are greater than for higher income families, and the limited availability of employer sponsored insurance for low-income families means a tax credit leaves those families in the relatively costly individual insurance market.

Substitution or crowd-out

All programs that offer public subsidies for a good or service that some people purchase on their own face a loss of efficiency through substitution. That is, some portion of the new public moneys simply substitute for current private funds and have no effect on the underlying problem. Again, this topic is complex. However, two features of this proposal help with the substitution issue. First, relatively few people are likely to drop their employer sponsored insurance for the new FIP plan because the FIP program is likely to be less desirable. Second, the income group targeted here has relatively few resources going towards health insurance, so there are few dollars that can be substituted.

Can States buy in to private coverage?

An important program design feature currently at issue in CHIP is the degree to which States can use their CHIP funds to help families purchase coverage through their employer. Under the right circumstances, this option can be cost effective, promote enrollment in the program, and help ensure that the program is equitable across groups of similarly situated people. Yet, this option also increases the possibility of substitution, because it makes participation in CHIP (or FIP) more desirable. This issue can be set aside at the outset, but should not be forgotten.

Cost estimates

One advantage of FIP is that, like CHIP, it is fully scalable. That is, it can be limited by appropriation and increased or decreased over time. Of course, the lower the level of funding, the fewer people will gain new health insurance.

Estimates of the uncapped cost of the program depend on extremely unreliable assumptions—particularly about the take up rate (how many eligibles will actually enroll) and the substitution rate (how many who currently have insurance elsewhere will drop that coverage and enroll in FIP). Over time, larger substitution effects might occur with shifts in the overall employer sponsored insurance market, but these are impossible to predict with any confidence.

One author has estimated the cost of a program like this at \$12.2 billion per year, providing coverage to 5.1 million currently uninsured adults. This estimate assumes all states participate in the expansion, which seems quite unlikely. If only parents of CHIP children are permitted to participate, the cost is \$4 billion per year, with 1.7 million

newly insured adults. This option has serious equity problems—why should higher income parents (those of CHIP kids) be offered insurance when lower income parents (of Medicaid kids) are excluded? These estimates are total costs, so federal costs, if one uses the CHIP match rate, are about 70% of these figures. I have not used the author's estimates of the extent of substitution because I do not know their basis.

Again, it is important to note that cost projections are heavily based upon assumptions that are difficult to make. If enrollment projects are high, the funds are not spent. If they are low, states will hit their budget caps. If substitution estimates are too low, funds are spent even more efficiently than projected. If too high, the program insures fewer than hoped. These are serious issues, but no amount of analysis will make them disappear.

I forgot to note that parents of Medicaid kids can already be made eligible for Medicaid under new federal laws & state activity in this area is quite limited. A few reasons for this. The primary one, I imagine, is that states are very reluctant to expand Medicaid eligibility, while they are more willing to operate capped, state-run programs.

**NATIONAL HUMAN GENOME
RESEARCH INSTITUTE, NIH**



FAX TRANSMITTAL SHEET

TO: Sara Bianchi

FAX: 202-456-5557

FROM: Kathy Hudson, Ph.D.

DATE: May 21, 1999

of pages including cover sheet: several

Return FAX number: (301) 402-0837

If there are problems, call (301) 402-0955.

Comments:

Please see the attached. I hope this is helpful. If you have any questions, please feel free to call me.

Kathy

Using New DNA Chip Technology to Understand The Role of Multiple Genes in Health and Disease

Most scientists are like the blind men in the fable who are trying to describe an elephant after feeling just one part of it. Biologists have been trying to describe the human cell by looking at the smallest bits of it. In most experiments today investigators have looked at one gene at a time. Yet human's are thought to have 80,000 genes, and they work in concert or committees (we call these pathways) to get things accomplished. Ultimately, to really understand the behavior of the human organism, what we'd really like to be able to do is look at the behavior of all 80,000 genes in a single experiment. That might finally give scientists a true picture of what's going on inside the body. Although this vision is not yet a reality, it is almost within grasp.

As the Human Genome Project hurtles towards completion, we appear on the threshold of having an inventory of all of the genes expressed within the human organism. Against this background, several developing technologies are being used to gain insight into the human cell and to transform the study of human genetics. Much of it is borrowed from the computer chip industry and the devices are often called "DNA chips."

Work emanating in part from the NHGRI's intramural research program has developed robotic tools to tap the surface of a microscope slide and leave behind a microscopic drop of fluid. Each drop contains millions of strands of DNA-copies of a single gene, creating an array of 15,000 tiny drops on each of the slides. Each spot is a detector or specific assay reagent. The strands of DNA in it are like tiny pieces of velcro that stick only to the products of one particular gene. When researchers pour the contents of a cell over that slide, the spots that pick up evidence of active genes can be made to glow. The thousands of glowing dots provide a landscape of active genes that could suggest how tumor cells work or how a cell responds to disease.

Investigators within the National Human Genome Research Institute of the NIH (and other centers as well) have now used this approach to examine a number of disease states including cancer and infectious diseases. For example, scientists in NHGRI laboratories have examined in blood cells the effect of the Ebola virus as it replicates and ultimately kills the human host cell, determining which genes are turned on or off. Watching the landscape of genes one can observe the fate of cells destined to die, watching the genes turn on and off as the effect of the virus infection progresses.

This approach also has been focused upon the study of cancer, particularly breast and prostate cancer, melanoma (a deadly form of skin cancer), and a particularly aggressive childhood cancer of the muscle (called alveolar rhabdomyosarcoma). Insights gained from these studies have yielded a remarkable picture of the landscape of cancer. The landscape (or variation in gene expression) observed in human cancers is in fact orderly and rich in information – strongly suggesting that in some cases we may find a recognizable molecular signature, even for a disease as complicated as cancer.

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glossary of genetic terms

microarray technology

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defined: A new way of studying how large numbers of genes interact with each other and how a cell's regulatory networks control vast batteries of genes simultaneously. The method uses a robot to precisely apply tiny droplets containing functional DNA to glass slides. Researchers then attach fluorescent labels to DNA from the cell they are studying. The labeled probes are allowed to bind to complementary DNA strands on the slides. The slides are put into a scanning microscope that can measure the brightness of each fluorescent dot; brightness reveals how much of a specific DNA fragment is present, an indicator of how active it is.

explained: [Listen to a detailed explanation.](#)

Dr. Michael Bittner, of the National Human Genome Research Institute's Laboratory of Cancer Genetics, defines microarray technology.

illustrated: [View illustration](#)

related terms: [cell](#), [deoxyribonucleic acid \(DNA\)](#), [gene](#)

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DIVISION OF INTRAMURAL RESEARCH
media release DNA micro chip**NHGRI Researchers Use DNA Chip To Sequence Breast Cancer Gene Region In Chimps, Gorillas, and Orangutans**

Bethesda, MD—Scientists at the National Human Genome Research Institute (NHGRI) report that they have used new DNA micro chip technology to analyze the structure of a significant gene region in several species of animals, including three of humanity's closest relatives: the chimpanzee, the gorilla, and the orangutan.

The NHGRI study, which appears in the February, 1998, issue of *Nature Genetics*, marks the first time the chips have been used to sequence DNA from nonhuman primates. The tiny DNA chips—each the size of a postage stamp—represents a new way of analyzing genetic material that is expected to have a formidable impact on the future of both clinical and research genetics.

The study demonstrates, the scientists say, that chip technology can deduce with close to 100% accuracy the sequence of nucleotides in a particular ape gene if the analogous human sequence is known already. "Which is to say that you don't have to start analyzing those genomes from scratch, which would be much more time-consuming and expensive," said Francis S. Collins, the paper's corresponding author, who heads NHGRI and directs the Human Genome Project.

"This technology is a rapid and accurate way of obtaining information about these genomes," said NHGRI's Joseph G. Hacia, the paper's first author. "You have to make a big investment to get human sequences, but then you can use that investment to get the sequences of our closest relatives at a relatively cheap price."

The researchers believe their approach has a number of potential benefits. It will be valuable, they say, for determining not only gene structure, but also gene function, regulation, and evolution. And it could eventually make possible a fairly quick and relatively inexpensive Chimpanzee Genome Project—the mapping and sequencing of chimp DNA. Chimp and human DNA are believed to differ in only about 1.5% of their sequences. Identification and study of the small genetic variations between the two species could help explain why chimps and people are so different—why, for example, the human brain is so much larger, and possesses more complicated mental capacities.

"Eventually, the scientific community will determine what the small differences between human and ape genomes are, and then figure out how that makes us distinct on the biochemical level," said Dr. Hacia. "It will be really exciting to apply this DNA sequence-based approach toward understanding the evolution of higher cognitive functions."

The chip approach could also save time and perhaps money, Dr. Hacia said, if employed as a backup confirmation of gene sequences determined by the standard method, called dideoxy sequencing.

The chips in the study compared the structure of a 3.4 kilo base strand of

BRCA1, a human gene that causes hereditary breast and ovarian cancer, with corresponding DNA regions from other animals, mostly nonhuman primates. The researchers used the BRCA1 chip because they have recently been employing it to look for disease-causing mutations in that gene, so it was readily available.

Their mutation research had demonstrated that the BRCA1 chip is good at finding subtle sequence changes in a large gene. "You can think of a chimp as a collection of sequence changes relative to humans, so if it worked for finding disease-causing mutations it ought to work pretty well at finding sequence differences between humans and other primates, as long as there are not too many of them," Dr. Collins said.

The chip was less accurate when the researchers analyzed DNA from other primates, including rhesus monkey, galago, and red howler monkey, and least accurate of all when they studied dog DNA. But even the distantly related genomes contained some identical blocks of nucleotides, apparently conserved in several species throughout their evolution.

"The chips work best when you're looking at very close relatives like chimps, gorillas, and orangutans. But in DNA regions that are strongly conserved, which is true of the coding regions of many genes, you might also be able to use the chip to look further away to other mammals,"

Dr. Collins suggested. "The regions of a gene that are most strongly conserved are often the parts that are most important functionally. With some more development, this might be a way of assessing what's the most functionally important part of a gene--not only its coding region, but also its regulatory regions, which is an area that we are really not that far along with."

The NHGRI oversees the NIH's role in the Human Genome Project, an international research effort to develop tools for gene discovery.

-30-

To arrange an interview with Drs. Collins or Hacia, contact Jeff Witherly, 301-402-8564 or Galen Perry, 301-402- 3035.

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DIVISION OF INTRAMURAL RESEARCH
background
information DNA micro chip

The DNA Microchip: A Large-scale Hunt for Genetic Alterations

As individuals, we face an inherent risk of developing certain common diseases such as cancer, heart disease, and diabetes. Interestingly enough, however, our collective knowledge of such occurrences is strikingly limited. In fact, few of us understand how high our risk is and which of these diseases may lie in our future.

Today, scientists at the National Human Genome Research Institute (NHGRI) are attempting to broaden our knowledge base through old-fashioned research enhanced by advanced technology - a DNA microchip smaller than a postage stamp. Already they have used the chip to identify alterations in BRCA1, a gene believed to trigger upwards of half the number of hereditary breast and ovarian cancers, and perhaps other cancers as well. In addition, scientists are utilizing the chip technology to investigate other genes suspected of triggering cancer, such as BRCA2, a second breast cancer gene.

While NHGRI researchers utilize the chip technology solely for research, it may one day be applicable in genetic testing. Presently, the researchers are conducting population studies in an effort to establish the degree of risk associated with each particular genetic alteration. They are also working with physicians to develop individualized, alteration-specific, treatment plans. The researchers expect the chip will, in time, enable them to understand more fully the processes behind genetic alterations leading to breast cancer in individuals without a family history of the disease.

The Chip and How It Works

The By design, the microchip enables the collection of genetic information more rapidly and cost effectively than previously possible. The system, developed by Affymetrix, a California-based biotechnology firm, is comprised of a black plastic casing slightly larger than a microcassette which houses the glass plate or "chip". To develop the chip, Affymetrix adapted automated photolithographic methodologies developed in the semiconductor industry to make DNA probes that bind to, and reveal mutations in, complementary DNA sequences.

The chips Affymetrix develop for NHGRI contain probes with artificially constructed genetic sequences identical to a normal gene segment such as BRCA1 and BRCA2. Developing the template for a particular chip costs a few thousand dollars. The template is reusable, however, so the economy of scale will come with high-volume testing.

The Final Results

The researchers obtained the DNA to be tested against the probes from small amounts of blood from patients with known mutations in the BRCA1 gene, and also from unaffected individuals with normal BRCA1 genes. Multiple copies of the DNA are produced by PCR, its double helix is copied into single stranded RNA sample, affixed with molecules of fluorescent dye, and fragmented into small pieces. The patients' copied RNA sample is tagged with

red dye, and the normal copied RNA sample is tagged with green dye. A red-tagged sample and a green-tagged sample are then inserted into the chip containing the probes.

After several hours, the chip is washed to remove sample that doesn't bind to the probes and is then run through a laser scanner that analyzes fluorescence patterns. Most of the patient's sequences hybridize normally with the probes, but where a mutation is present binding does not take place, and these spots show up as a decrease in fluorescence intensity during the scan.

When both the red and green samples hybridize with the probes identically, the test sample is normal. "If they're identical one would expect that for every probe, half will be bound with green reference DNA and the other half with the red test samples. If the signals start to decrease, for example, meaning the red test sample does not bind as well as the green reference sample, we can see if that's statistically relevant," says NHGRI's Dr. Joseph G. Hacia. In a recent study, the scientists confirmed that a mutation was present by determining the sequence of the sample DNA with a time-proven technique called dideoxy sequencing.

In that study, published in *Nature Genetics* (December 1996), the NHGRI research team identified 14 out of 15 genetic alterations in patients with known mutations. A study of 20 unaffected individuals with no family history of breast cancer revealed no mutations. The analysis covered approximately 3,500 of the nearly 3.5 billion nucleotides contained in the total human genome.

Change In False Negative Rate

Hacia, the paper's first author, notes the early findings are encouraging in that they indicate the rate of false positives will be low with the chip technology. Hacia indicates the rate of false negatives will most likely fall, at most, in the 5- to 10-percent range. The research group is now trying to define the accuracy rate more precisely.

Why the Chip?

The major advantage of the chip technology is that once scaled-up it will be more cost effective than today's methods for locating gene alterations; the present cost for analyzing BRCA1 and BRCA2 via dideoxy sequencing is nearly \$2,500. The chip technology is expected to cost one-tenth of that, perhaps even less. Smaller labs with limited equipment budgets may find the chip system easier to acquire than other sequencing technologies, many of which are more laborious and may involve radioactivity.

Hacia notes that by year's end, NHGRI will acquire a new laser scanner that is expected to reduce scanning time by 75 percent, bringing the total run-time from the present 80 minutes for a single sample to nearly 20. At present, one scientist working a 16-hour day can scan for mutations in about ten patient samples of DNA that include only about 60% of the BRCA1 gene. With the new scanner, Hacia says, 10 samples will take considerably less time - and the analysis will cover the entire gene, not just a segment.

The chip system is particularly suited for analysis of genes like BRCA1 - a large gene with many randomly distributed possible alterations capable of producing disease. Well over 100 such alterations have been identified in BRCA1, which greatly complicates the task of developing tests for identifying people at risk.

NHGRI researchers are working to place two or three different breast cancer genes on a single chip, making it possible to search an individual's DNA for mutations in different genes that might increase his or her chance of developing

the disease. It is expected that DNA microchips will eventually make it possible to define an individual's risk of developing many kinds of cancer, and also other common disorders such as heart disease and diabetes.

As noted in the Nature Genetics paper, "The use of DNA chips for mutation detection should be extensible to virtually any gene by synthesis of the appropriate chip." Complex analyses such as these, however, are not on the horizon at the moment.

"Hopefully, this process will provide clues about eventual therapies that could be more effective for people who have certain mutations, and also point to areas of research that people should concentrate on," Hacia notes.

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media release

New "Tissue Chip" to Illuminate the Cancer Development Process

Bethesda, MD—Some cancer patients respond well to a particular cancer therapy or combination of therapies. Others do not, but may respond to a different treatment. If doctors knew how to tell those patients apart, they could individualize treatment by designing an optimum therapy for each cancer patient.

Scientists at the National Human Genome Research Institute (NHGRJ) at the National Institutes of Health (NIH), in collaboration with the University of Tampere in Finland and the University of Basel in Switzerland, are developing a new research tool, which they call the "tissue chip," that they expect will eventually help clinicians design such individual treatment plans.

The chip technology, they believe, will illuminate the process of cancer development. Such detailed new information can then be used to identify critical molecules for development of cancer therapies. They also hope the tissue chip will help them learn how to distinguish among subgroups of cancer patients and eventually predict which ones will respond to specific therapies.

"Traditionally, pathology laboratories have analyzed patient tissues one specimen at a time," says Dr. Jeffrey Trent, scientific director of NHGRI's Division of Intramural Research. "However, this new technology now makes it possible to test thousands of specimens simultaneously. The power of this technology will accelerate numerous areas of research, including testing of newly isolated genes to determine if they may be of clinical utility as molecular cancer markers."

Like the DNA chip, which scans the genome for alterations or abnormal gene expression, the tissue chip is a microarray that permits massive parallel processing of biological samples. But unlike the DNA chip, the tissue chip makes it possible for researchers to simultaneously compare a variety of molecular markers--DNA, RNA, and protein--in cancer tissues from hundreds or thousands of patients. The scientists report that as many as 1,000 tissue biopsies from individual tumors can be studied in a single tumor tissue microarray.

In their initial study of breast cancer tissue microarrays, published in the July issue of Nature Medicine, the researchers analyzed six gene amplifications and expression of the p53 and estrogen receptor genes believed to play a role in breast cancer.

The biopsies from up to 1,000 tumors are embedded and arrayed in paraffin to create a tissue microarray. This tissue array is sliced like a loaf of raisin bread into remarkably thin sections with each of the 1,000 tumors then being represented as minuscule dots on ordinary glass microscope slides. Because each array can be sliced into 200 consecutive sections of 5 micrometers each, it is possible to quickly analyze hundreds of molecular markers in the same set of specimens.

"Our analysis of eight cancer markers was completed in about one week," says Dr. Olli-P Kallioniemi, of NHGRI's Cancer Genetics Branch, the paper's corresponding author. "With traditional methods, going through the specimens one at a time would have taken from 6- to 12-months to analyze them all."

Kallioniemi emphasizes that the tissue chip is a tool for research, not diagnosis. It will be used to identify better diagnostic markers for distinguishing cancer from normal tissue, better markers to predict how aggressive a tumor will be, and biological properties of

particular tumors that might have therapeutic value.

The tissue chip is expected to be particularly useful in analyzing the thousands of tumor tissue samples stored in pathology labs all over the world. "It's just not imaginable to stain and analyze thousands of archived tumor tissue samples for hundreds of molecular markers - one at a time. Now with the tissue chip pathologists can take their existing archives, turn them into tumor arrays, and analyze an entire archive with just a few experiments," said Dr. Juha Kononen, also of the NHGRI and the first author on the paper.

Tissue chips could also help molecular biologists identify novel molecular pathways that play a role in cancer development. This is important in order to be able to design treatment methods specifically targeted against these critical pathways.

Pathologists can also array archived tissue samples from clinical trials of existing cancer drugs, and look for markers--a gene expression pattern or set of genetic changes in the tissue--associated with whether or not a specific participant in the trial responded to the therapy. Eventually clinicians might be able to use those results to design individual treatments, comparing tumor tissue from a current patient with the historical samples in order to predict how quickly the tumor will progress and which therapeutic approach is likely to work best.

NHGRI oversees the NIH's role in the Human Genome Project, an international research effort to develop tools for gene discovery.

For interviews or more information contact:

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CATALOGING HUMAN VARIATION:
THE KEY TO PREDICTING DISEASE SUSCEPTIBILITY AND DRUG
RESPONSIVENESS

Francis S. Collins, M.D., Ph.D.
Director, National Human Genome Research Institute
National Institutes of Health

Virtually every disease has a genetic component, and we are all susceptible to something. In fact, it is estimated that each of us carries between 5 and 50 DNA misspellings that place us at significant risk of future illness. For many of those illnesses, preventive medicine strategies involving life style, diet, and medical surveillance can reduce the risk of serious disease. But it is impractical to offer everyone a long list of such interventions, some of which are unpleasant and/or expensive, on a "one size fits all" basis. Genetic analysis provides a means of identifying individual risks of disease and would allow the design of an individualized plan of preventive medicine. Tailoring health care to each individual's unique set of genetic risk factors offers a powerful tool to prevent disease in a cost-effective manner. A newly announced goal of the Human Genome Project, cataloging human DNA variation, is poised to catapult this strategy forward, and represents a revolution in our thinking about genetic medicine and public health.

The Human Genome Project has already developed genetic maps, physical maps, gene maps, and the DNA sequence that investigators can use to track down the precise cause of a highly heritable disorder in a matter of weeks. Most human diseases, however, have genetic contributions that are less dramatic -- diabetes, heart disease, the common cancers, and the major mental illnesses all have heritable components, but they are due to the simultaneous effect of multiple genes and are therefore more difficult to identify precisely. Genome project tools, especially the development of a catalog of human genetic variation, now are bringing clarity to the scientifically murky health problems of more common complex diseases.

It is likely that most of the genetic contributions to common illnesses arise from common variants in the genome. An example is a variant in the gene for apolipoprotein E (apoE). There are three common spellings of this gene: E2, E3, and E4. People with the E4 spelling have a significantly increased risk of developing Alzheimer's disease. For most other common diseases, however, it is not now possible to guess which of the roughly 80,000 genes might be involved, and a systematic means of surveying the entire genome for such disease susceptibility variants is needed. Developing a detailed catalog of such variants, which has now been initiated as an explicit goal of the Human Genome Project, should allow the success of this strategy, even in circumstances where the genetic pathway could not have been guessed.

Variation in the human genome is encountered about every 300 - 500 base pairs in the genome. Most of this variation consists of single letter substitutions (for example, an A instead of a G), which are referred to as single nucleotide polymorphisms (SNPs, pronounced "snips"). The identification of SNPs will eventually allow clinicians to better adapt therapies to the individual. Not only will the genetic contributions to many

common illnesses likely arise from the presence of SNPs in vulnerable parts of the genome, large differences in the effectiveness of medicines may also exist from one individual to the next as a result of common genetic variants. Some toxic reactions to drugs may also be a consequence of genetically encoded host factors.

For example, researchers have discovered that the spelling of the ApoE gene predicts responsiveness of Alzheimer's patients to the drug tacrine. This finding will help data analysis of clinical trials of Alzheimer's therapies and will promote targeting of new therapies specifically to genetic subsets of Alzheimer's disease. This basic principle has spawned the burgeoning new field of pharmacogenomics, which aims to use information about genetic variation to predict responses to drug therapies and tailor drug design.

Last Fall the NHGRI and 15 other institutes and centers of the NIH banded together and awarded \$38 million over the next 3 years to develop a catalog of SNPs. In April, a consortium of 10 pharmaceutical companies and the Wellcome Trust unveiled a plan to award \$45 million over the next two years to academic genome centers to catalog up to 300,000 SNPs. The Consortium will deposit their data in freely accessible databases for use by both academic and industry scientists worldwide.

The entrance of these 10 major private companies into this unique consortium is testimony to the value of this powerful new research tool. It also illustrates how basic science initiatives in the public and private sectors can be designed in a synergistic fashion to accelerate discovery, maximize resources, and bring benefit to the whole research community.

A catalog of SNPs will allow researchers worldwide to embark upon powerful studies to identify the precise genetic contributors to disease susceptibility and drug responsiveness. We can anticipate a time (perhaps in 10 years) where healthy young adults can undergo genetic testing to determine their individual susceptibility to future illness, and then, with the help of their health care providers, design a program of individualized preventive medicine to focus on staying well. For those who still fall ill, the illness will be much more precisely understood by genetic analysis, and the drug or gene therapies chosen will be precisely tailored to that individual's molecular circumstances.

We must make sure that the genomic revolution in medicine is accompanied by the appropriate safeguards against the misuse of genetic information, or the public will be fearful of using this powerful new technology. Hence there is pressing urgency in passing federal legislation to prevent genetic discrimination in health insurance and employment. Vice President Gore has been a leader in the effort to provide this much-needed blanket of protection. With the proper safeguards in place and the continued support of genome research, the great promise of the genomic revolution in medicine can be realized.

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SHATTUCK LECTURE—
MEDICAL AND SOCIETAL CONSEQUENCES
OF THE HUMAN GENOME PROJECT

Sant -

*See page 20
for "vision of
future"*

Slide 1

Francis S. Collins, M.D., Ph.D.

The history of biology was forever altered a decade ago by the bold decision to ^{The Human Genome Project,} begin a directed research program to characterize in ultimate detail the complete set of genetic instructions of the human being. The idea captured the public imagination, perhaps not so much like America's targeted health wars on cancer or AIDS, but rather like the great expeditions—those of Lewis and Clark, Sir Edmund Hillary, and even Neil Armstrong. Scientists wanted to map the human genetic terrain, knowing it would lead them to previously unimaginable insights, and from there to the common good. That good would include a new understanding of genetic contributions to human disease and the development of rational strategies for minimizing or preventing disease phenotypes altogether.

The endeavor was both awesome and chancy. The instruction book—the human genome—was vastly larger than any genetic endowment tackled so far, and in 1990, the tools were not yet powerful enough to perform the task. Critical social questions, such as whether the new technologies for reading our genetic constitution would challenge our identities, our fundamental right to privacy, or our freedom from discrimination, loomed without answers.

Yet, a public science initiative focused so sharply on the molecular essence of humankind was too intriguing and too promising to forego. Since the 1970s, nearly all biomedical research avenues increasingly led to the gene, for genes contain the basic information about how a human body carries out its duties from conception until death.

In between, of course, our bodies struggle to survive in a challenging environment.

To a significant extent,
~~Largely, but not entirely,~~ at the behest of our genes, we fare better or worse.

Not surprisingly, disease researchers wanted to bag their leading gene suspects as soon as possible at the least expense. This was no small order—the 80,000 or so human genes are scattered throughout the genome like stars in the galaxy, with genomic light-years of non-coding DNA in between. The “billions and billions” of uncharted DNA units (approximately 3 billion base pairs in the human) frustrated searches regularly in the late 1980’s, often at great health and financial cost. If gene hunters were to mine miracles from the human genome, they needed more powerful tools and more ambitious strategies.

Slide 2

GOALS FOR SEQUENCING THE HUMAN GENOME-

A STUDY IN ACCELERATION

In 1988, the U.S. Congress appropriated funds to the Department of Energy (DOE) and the National Institutes of Health (NIH) to begin planning the Human Genome Project. Planners set a 15-year time frame, estimated a \$3 billion price tag, and laid out formal goals to get the job done (1). On October 1, 1990, the Human Genome Project officially began (2). According to early plans, the human race would witness its own blueprint in fine detail in the year 2005.

In the fall of 1998, though, improvements in technology, success in achieving early mapping goals (see below), emerging research opportunities, and accelerating demand for human DNA sequence prompted project leaders in the United States and abroad to promise the blueprint—the complete DNA sequence of the human genome—two years ahead of schedule, in 2003 (3). The technology to accomplish such a task is at hand. Indeed, only six months later, in March 1999, 15 percent of the sequence was in a finished or near-finished state. The largest Genome Project centers received new grant awards to ramp up to full-scale sequencing of the human genome, and the timetable was moved up yet again. Pilot sequencing projects had been so successful that planners of the Human Genome Project now felt confident that at least 90 percent of the human sequence could be completed in “working draft” form by the spring of 2000, considerably earlier than expected.

NIH and DOE genome programs in the United States expect to contribute 60–70 percent of that sequence. Scientists funded by the Wellcome Trust at the Sanger Centre in Cambridge, England, along with other international partners, will produce the remainder.

In the course of completing the entire human genome sequence by 2003 (or perhaps earlier), the “working draft” sequence, though initially of lower accuracy and contiguity, will nevertheless be very useful, especially for finding genes, exons, and other genomic features. But because the working draft will contain gaps, it will not be as useful as finished sequence for studying DNA features that span large regions or require high sequence accuracy over long stretches.

The final product must have four characteristics—the “4 A’s” of the Human Genome Project: 1) The sequence must be **accurate**, that is, the DNA spellings must have an accuracy of 99.99 percent or better. If this is the “Book of Life”, we should not settle for a rough draft over the long term, but should remain committed to a final, highly accurate version. 2) Large-scale sequencing relies on the accurate assembly of smaller lengths of sequenced DNA into longer, genomic-scale pieces, so human sequence will be **assembled** into long pieces that reflect the original genomic DNA. 3) Because human DNA sequence must also be **affordable**, technology development will aim to reduce cost as much as possible. 4) Finally, high-quality, finished human DNA sequence should be **accessible** within 24 hours through public databases.

With regard to this last point, it is imperative that genome sequence, the fundamental building blocks of biomedical research, rapidly be made freely available to scientists around the world. The human DNA sequence arms scientists seeking to understand disease with new information and techniques to unravel the mysteries of human biology. This knowledge will dramatically accelerate new strategies for diagnosis, prevention, and treatment of disease, not just for single gene disorders, but for the host of more common complex diseases (e.g. diabetes, heart disease, schizophrenia, and cancer) where genetic differences may contribute to disease risk and response to particular therapies.

An international group of scientists involved in large-scale genomic DNA sequencing passed a unanimous resolution in 1996 that all human genomic DNA sequence produced by the Human Genome Project should be freely available and in the public domain, in order to encourage research and development and to maximize its benefit to society (Second International Strategy Meeting on Human Genome

Sequencing, 1996). These scientists felt that public availability of these data would create the most efficient sequencing strategy by encouraging coordination and collaboration among scientists, while eliminating duplication of efforts.

As a result, planners of the Human Genome Project adopted a policy of releasing data every 24 hours into a free, publicly accessible database. In the United States, GenBank (<http://www.ncbi.nlm.nih.gov>), run by the National Center for Biotechnology Information, serves as the public repository of sequence information. The value of this database as a resource for medical scientists around the world is incalculable. Genbank receives over 200,000 queries a day for gene sequence information. It took 16 years to get the first billion bases in the database, and only 15 months to get the second billion bases. Over 39,000 species are represented and over 60,000 sequence comparison searches are conducted each day.

Because researchers around the world participating in the public sequencing effort have agreed to submit their data to free public databases within one day of verification, any scientist, whether at a university, corporation, or government lab, can log on by computer and have full and rapid access to the sequence data. The sooner the public effort to sequence the human genome is complete and deposited in a free and publicly accessible database, the sooner it will benefit all scientists working to understand and treat disease at a molecular level. In addition, scientists understand human genes by comparing human DNA with DNA from mice, flies, roundworms, and yeast. These comparisons make the human sequence much easier to understand.

As Human Genome Project plans for the period between 1998 and 2003 were being developed, two corporate ventures announced initiatives to sequence a major

fraction of the human genome, using strategies that differ fundamentally from the publicly funded approach. The stated intention of one of those ventures to release its data publicly creates the possibility of synergy with the federal effort. If the corporate data and the public data can be merged, the depth of sequence coverage will be even greater. And, because the public sequence will be obtained from mapped DNA, it will provide critically-needed anchoring to sequence data generated by private-sector efforts.

THE HUMAN GENOME PROJECT IS ABOUT MORE THAN JUST THE SEQUENCE

Many people assume that most of the effort of the Human Genome Project since 1990 has been devoted to large-scale sequencing. But this activity is actually a relatively recent arrival on the scene, as many other kinds of genome information were needed before full-scale sequencing could be undertaken. Prior to the 1998-2003 plan, Human Genome Project scientific goals addressed mostly genome mapping, technology development, and work to characterize the genomes of certain laboratory organisms. One type of map, known as a genetic map, is particularly helpful for following the inheritance of a disorder through several generations of a family. Genetic maps consist of a series of sequence-based markers that can be used to pinpoint the likely neighborhood of an altered gene responsible for a disease phenotype or other trait. Such maps have been invaluable in identifying and isolating highly penetrant gene mutations with Mendelian inheritance patterns. The goal was to establish markers close enough to give a gene hunter a high likelihood of placing a gene in a reasonably searchable interval. A year ahead of schedule, an international consortium with major players in France and the United States published a genetic map containing almost 6,000 markers, spaced less than

1 million bases apart (4). Such detail was four- to six-times greater than the 1990 goals called for.

A second type of map, known as a physical map, provides cloned and ordered sets of contiguous DNA that represent regions of a chromosome, or even a whole chromosome. Once genetic markers define the region containing the sought-after gene, cloned pieces from the physical map provide a resource from which investigators can then isolate the gene. A copied replica of 98 percent of the human genome, consisting of thousands of linked pieces of DNA, is complete and meets the genome project's goal for physical mapping (5). This map contains over 41,000 DNA markers, known as "sequence-tagged sites," or STSs, that properly align the pieces. At that marker density, any gene in the human genome should lie within fewer than 100,000 bases of an STS.

The Human Genome Project also recognized from its inception its responsibility not only to develop gene-finding and analysis technologies, but to address the broader societal implications of these newfound abilities to decipher genetic information. So, the project commits 5 percent of its annual research budget to study the "ethical, legal, and social implications (ELSI)" of genome research. Historically, the ELSI program has focused on four high-priority areas: 1) the use and interpretation of genetic information; 2) clinical integration of genetic technologies; 3) issues surrounding genetics research; and, 4) public and professional education and training about these issues.

The plan covering the years 1993-1998 expanded the mapping goals and explicitly included new objectives for identifying and mapping not just systems of anonymous markers, but the genes themselves (6). Scientists at the National Library of Medicine, genome research centers, and in private industry later began a program to

position expressed DNA from gene regions, or "expressed sequence tags," or ESTs, on the physical map. After two editions, this gene map represents the most extensive effort so far to locate and identify the 80,000 genes in the human genome. Over 38,000 gene tags now give disease-gene hunters a ready list of candidate genes residing in the chromosomal neighborhood they know is involved in a disease (5).

Before 1996, goals for DNA sequencing largely targeted toward genomes of model organisms. From those efforts, scientists have sequenced the genomes of *Saccharomyces cerevisiae*, a species of yeast valuable to biologists and commonly used by bakers and brewers (7) and *Escherichia coli*, a mainstay of basic biology and the biotechnology industry (8). The first complete genome sequence of a multi-cellular organism, the round worm *Caenorhabditis elegans*, was completed in late 1998.

The yeast genome, which was the first eukaryote to be completely deciphered, contains 12,057,500 base pairs in its nuclear DNA. Containing some 6,000 genes arranged on 16 chromosomes, yeast has already provided biologists with a valuable resource for determining the function of individual human genes involved in medical problems such as cancer. Now, the complete source book for that organism will allow scientists to piece together for the first time a comprehensive look at how all the genes in a eukaryotic cell function as an integrated system.

The 100 million base-pair *C. elegans* genome is distributed among six chromosomes and contains over 19,000 genes. Although barely visible with the naked eye, the tiny roundworm has become an invaluable tool for studying biological processes such as development, neurobiology, and aging. The worm project began in 1990, as a collaboration between researchers at Washington University, in St. Louis, Missouri, and

at the Sanger Centre in Cambridge, England. Computer comparisons between the worm sequence and those of other organisms have shown that about 74 percent of named human genes have a definite homolog in *C. elegans*.

The 1998-2003 plan can be thought of as the development of a new and more diverse set of "power tools", all of which are to be given away (Fig. 1). These tools include the development of the catalog of variations in human DNA sequence; new technologies and strategies for studying gene function on a whole-genome scale; and new areas of ELSI research (the "safety goggles"), such as identifying and addressing issues that link genetics to personal identity and racial or ethnic background, and their implications for philosophical and religious traditions.

IMPLICATIONS OF GENE DISCOVERY

FOR UNDERSTANDING HUMAN GENETIC ILLNESS

Maps and other genome technologies provide the tools for a gene-isolation technique known as positional cloning (9). This technique allows a researcher to confirm the genetic basis of a disease and identify the responsible gene, even when little is known about the gene's function. So far, over 100 disease-linked genes have been isolated using the positional cloning technique. Whereas gene discovery by this route once took years to decades, an investigator using these powerful tools can now sometimes map and isolate a gene in a matter of weeks. Increasingly, gene hunters are combining positional cloning techniques with information in EST databases to narrow their gene searches to rational candidates. This method, called "positional candidate cloning" (10), has been used to isolate many altered genes associated with human disease.

Gene isolation provides the best hope for understanding human disease at its most fundamental level (Fig. 2). Knowledge about genetic control of cellular functions will underpin future strategies to prevent or treat disease phenotypes. The recent isolation of genes for Parkinson's disease (PD) (11, 12, 13, 14), for example, has dramatically pushed molecular research forward on that baffling disease. In one study of a large pedigree with early onset PD, gene hunters mapped a suspect gene to a region of chromosome 4 (11). The region contained approximately 100 genes, amongst which was one known to encode the protein alpha-synuclein. Earlier research had shown alpha-synuclein builds up in brain cells of people with Alzheimer's disease (15), and people with PD have similar deposits in the substantia nigra. In just a few months, the researchers showed conclusively that a missense mutation in the alpha-synuclein gene caused Parkinson's disease in the study families. Further research has shown that a mutation in a gene encoding a protein critical to the breakdown of alpha-synuclein and other proteins also results in the PD phenotype in a different family (14). While most cases of PD appear to have limited heritability, studying rare families of this sort provides crucial clues to the pathways involved—alpha synuclein is found in the Lewy bodies of virtually all cases of PD. Understanding the genetic control of the proteolytic processes of brain proteins may provide new targets for interventions in a number of related neurodegenerative disorders characterized by the accumulation of protein deposits, including Alzheimer's disease, Huntington's disease, and spinocerebellar ataxia.

Even before a gene's role in disease is fully understood, diagnostic applications can be useful in minimizing or reducing the development of health consequences (Fig. 2). DNA tests that look for the presence of disease-linked mutations, for example, are

proving to be the most immediate commercial application of gene discovery and the one now encountered most frequently by clinicians. These tests may assist in the correct diagnosis of a genetic disease, foreshadow the development of disease later in life, or identify healthy heterozygote carriers of recessive diseases. Genetic tests can be performed at any stage of the human life cycle, with increasingly less-invasive sampling procedures. Whereas genetic testing was once sought almost exclusively by couples with a family history of early onset disease for the purpose of family planning, information about genetic status is increasingly sought by individuals who wish to learn their own predisposition to later-onset illness.

In a growing number of instances, strategies can be implemented to reduce or prevent illness when a genetic etiology or predisposition is known. Successes in reducing disease through treatment have been achieved for the hereditary disorders hemochromatosis, phenylketonuria, and familial hypercholesterolemia, among others. Risk-reduction through early detection and lifestyle changes may be available for disorders associated with predisposing mutations, such as some cancers. As therapies build on knowledge gained about the molecular basis of disease, increasing numbers of illnesses, now refractory to treatment, may in the future yield to molecular medicine.

The recent discovery of an altered gene (HFE) that leads to hereditary hemochromatosis (HH) (16), a common disorder of iron metabolism, provides an interesting example of the potential for using mutation information to prevent an adult-onset disease phenotype. A recessive condition, HH affects about 1 in 300 individuals of northern European descent and is easily treatable if diagnosed early. Its major symptoms—liver cirrhosis, heart failure, diabetes, arthritis, and other organ damage—do

not occur until mid-life and are easily misdiagnosed. Untreated, the disease causes early death, but treatment by phlebotomy to remove excess iron allows people with HH to live a normal life span. A single substitution of the amino acid cysteine by tyrosine at codon 282 accounts for the majority of cases (17).

At first glance, HH seems like an ideal target for public health approaches to hereditary disease prevention: the disorder is common; the number of disease-linked mutations in the gene are few; and effective treatment can minimize or eliminate the effects of the disease. But closer examination reveals a number of complexities that have so far mitigated against rapid introduction of this genetic test as a tool for disease prevention (16). Because the penetrance of the altered HFE gene is reduced, especially in females, clinical signs can range from none detectable to severe organ damage from iron overload. At the moment, simple detection of the mutation does not predict the most likely clinical course. Before population testing for HFE mutations is considered, further research is needed to explain the variations in phenotype among mutation carriers and to correlate genotype more closely with health outcomes.

IMPLICATIONS FOR THE STUDY OF COMMON DISORDERS

The rather straightforward Mendelian rules that govern inheritance of disease traits have been worked out for many rare disorders resulting from highly penetrant changes in a single gene. But teasing out the genetic components of the so-called "complex" disorders—diabetes, heart disease, most common cancers, autoimmune disorders, and psychiatric disorders, which result from the interplay of environment, lifestyle, and small effects of many genes—remains a formidable task. Most successes in identifying genes associated with common diseases have focused on highly heritable

subsets, including BRCA1 (18) and BRCA2 (19) for breast cancer, HNF-4 α for maturity onset diabetes of the young (MODY) 1 (20), GCK for MODY 2 (21), HNF-1 α for MODY 3 (22), hMSH2 (23, 24) and hMLH1 (25) for hereditary non-polyposis colon cancer, and α -synuclein for Parkinson's disease (11). Linkage analysis and positional cloning techniques are well-suited to discovering genes with such strong influence. But strategies for finding the multiple, low-penetrance variants, which in the aggregate account for a larger percentage of illnesses, are not currently as easily applied. Identification of weakly penetrant alleles contributing to common disorders requires new and more powerful approaches.

To assist in those efforts, the Human Genome Project is initiating new studies on genetic variation in the human population to provide a dense map of common DNA variants. DNA sequence variations include insertions and deletions of nucleotides, differences in the copy number of repeated sequences, and single-nucleotide polymorphisms, or SNPs (pronounced "snips"), which occur most frequently throughout the human genome. About 1 in every 300-500 bases in human DNA may be a SNP.

SNPs can be used as markers in whole-genome linkage analysis of families with affected members, as well as in association studies of individuals in a population. Association studies may directly test a potential functionally important variant, or may take advantage of the phenomenon of linkage disequilibrium—in which a marker and a gene are inherited together—to map gene variants associated with disease. Because the human species consists of relatively few generations, recombination events have not disrupted linkage disequilibrium over distances of 3,000-100,000 bases in most populations. Consequently, association studies view large human populations as

evolutionary families and do not rely on nuclear family studies for gene mapping (26, 27).

Some SNPs may contribute directly to a trait or disease phenotype by altering function. Though most SNPs are located outside of protein-coding sequences, those within coding sequences, called cSNPs, are of particular interest because they are more likely to affect gene function. A large, well-characterized collection of SNPs will become increasingly important to the discovery of DNA sequence variations that affect biological function. Work is already underway through NIH support to develop a catalog of 60,000 or more SNPs. A recently announced pharmaceutical consortium will support the production of 300,000 more, with the work being done in the publicly funded genome centers and all of the data being deposited in the public domain. This is a wonderful example of a public-private partnership to develop a powerful set of research tools that all can use.

NEW TECHNOLOGIES FOR GENETIC ANALYSIS AND RISK ASSESSMENT

The transition from genetics to "genomics" marks the evolution from understanding single genes and their individual functions to understanding the actions of multiple genes and their control of biological systems. Whereas Human Genome Project tools initially advanced research on single genes, they are now forming the basis for genomic-scale analysis of the human organism.

The so-called "DNA chip" currently provides one promising approach to genome-scale studies of genetic variation (28), detection of heterogeneous gene mutations (29), and gene expression (30). A next-generation adaptation of filter blot hybridization techniques, DNA chips, also called microarrays, generally consist of a thin slice of glass

or silicon about the size of a postage stamp upon which threads of synthetic nucleic acids are arrayed. Sample probes are added to the chip, and matches are read by an electronic scanner. As with semiconductors, the capacity of DNA arrays has doubled about every two years. So, chips that held a few hundred arrays not so long ago now hold hundreds of thousands.

Microarray technology has been applied to detection of DNA variations as well as expression of mRNA in individual cells and tissues. Microarrays are used clinically for monitoring HIV sequence variation, detection of p53 gene mutations in breast tissue, and expression of cytochrome P450 genes. In the laboratory, microarray technology has also been applied to genomic comparisons across species (31), genetic recombination (32), and large-scale analysis of gene copy number and expression, as well as protein expression in cancerous tissues (33).

Application of microarrays and other new technologies to detection of DNA variation holds promise, along with family histories and data from large population studies, for establishing an individual's risk of developing common, adult-onset disorders. A baseline genome scan could provide helpful information about an individual's disease risk profile and point to which prevention strategies—when available—should be put into place.

GENETIC KNOWLEDGE AND PERSONALIZED MEDICINE

Identifying human genetic variations will eventually allow clinicians to subclassify diseases and adapt therapies to the individual. Large differences in the effectiveness of medicines may exist from one individual to the next. Toxic reactions can also occur and are likely in many instances to be a consequence of genetically encoded

host factors. That basic principle has spawned the burgeoning new field of pharmacogenomics, which aims to use information about genetic variation to predict responses to drug therapies.

For example, researchers discovered that Alzheimer's patients with the gene subtype ApoE4, which affects cholinergic function in the brain, are less likely to benefit from the cholinomimetic drug tacrine (34). Such a finding will help data analysis of clinical trials of Alzheimer's therapies and will promote targeting of new therapies specifically to ApoE4 carriers.

In another example, cholesteryl ester transfer protein, or CETP, plays an important role in the metabolism of HDL, a lipoprotein associated with lowered susceptibility to atherosclerosis. A certain genetic variant of the CETP gene correlates with higher plasma CETP levels and lower concentrations of plasma HDL. One study showed that men who carried this genetic variant responded to the drug pravastatin with a slowed progression of coronary atherosclerosis (35). This finding may allow physicians to predict which patients with coronary artery disease will benefit from treatment with pravastatin.

In a third example, formation of venous blood clots in the brain and legs are rare but serious side effects of taking birth control pills. One study has shown a dramatically increased risk of cerebral vein thrombosis among women taking oral contraceptives who also carry the blood-clotting variant Factor V-Leiden (36). The risk of other venous thrombotic events is also increased in this group. Foreknowledge of the presence of that variant, and consideration of alternate forms of birth control, might be useful in minimizing risk of thrombosis in those individuals.

Not only will genetic tests predict responsiveness to drugs on the market today, genetic approaches to disease prevention and treatment will include an expanding array of gene products developed into tomorrow's drug therapies. Since the Food and Drug Administration's approval of recombinant human insulin in 1982, over 50 additional gene-based drugs have come on line. These include drugs for the treatment of cancer, heart attack, stroke, and diabetes, as well as many vaccines (37).

Not all therapeutic advances from gene discovery will be genes or gene products. In other instances, molecular insights into the disorder, derived from gene discovery, will suggest a new treatment. Phenylbutyrate, for example, which is approved for the regulation of blood ammonia, is being tested in clinical trials for the treatment of cystic fibrosis (CF) (38). The main clinical phenotype in people with CF results from a mutation in the cystic fibrosis transmembrane conductance regulator (CFTR) gene, which prevents normal amounts of CFTR protein from crossing the cell membrane, diminishing the ability of chloride and water to enter and exit the cell. Phenylbutyrate apparently stimulates expression of the CFTR protein, allowing more of it to reach its correct location.

THE ETHICAL, LEGAL AND SOCIAL IMPLICATIONS OF GENETIC KNOWLEDGE

One of the most active ELSI areas has been policy development related to the privacy and fair use of genetic information, particularly in health insurance, employment, and medical research. Debates in this area focus largely on the potential of genetic information to predict an increased likelihood that a currently healthy individual will later develop a disease phenotype.

Although many states have attempted to address "genetic discrimination" in health insurance and the workplace, federal legislation would provide the most comprehensive protections. In research, fears about privacy of genetic information and the loss of a job or insurance coverage may make people hesitant to use medical advances or to volunteer for studies of disease-linked gene mutations for fear the results could be used against them.

Based largely on recommendations from workshops held by the Human Genome Project and the National Action Plan on Breast Cancer (NAPBC), the Administration endorsed the need for Congressional action to protect against genetic discrimination in health insurance and employment. In 1996, Congress enacted The Health Insurance Portability and Accountability Act (HIPAA), which took a significant step toward protecting access to health insurance in the group market but left several serious gaps in the individual market that still must be closed.

In the area of workplace discrimination, the Equal Employment Opportunity Commission (EEOC) has interpreted the Americans with Disabilities Act (ADA) to cover on-the-job discrimination based on "genetic information relating to illness, disease or other disorders." But there have been no genetic discrimination complaints filed with the EEOC, and the guidance has yet to be tested in court. So, the amount of protection actually provided by the ADA remains uncertain.

In the area of privacy, as part of the NAPBC-Human Genome Project partnership, medical researchers, policy makers, and representatives of law, government, the insurance industry, and public health have recently assessed current policies and practices to protect confidentiality in genetics research and have identified areas where new or

modified policies or practices might enhance privacy protections and promote the conduct of research. The group is developing a set of principles for researchers, research institutions, state and federal agencies, and policy makers to consider in formulating privacy protections for research information.

Other significant steps have been taken to ensure the responsible integration of genetic tests into clinical practice. For the most part, genetic testing in the United States has developed successfully, providing options for avoiding, preventing, and treating inherited disorders. But the rapid pace of test development combined with the rush to market may create an environment in which the tests are available to health care consumers before they have been adequately validated. Upon the recommendation of the Task Force on Genetic Testing (39), created by the Human Genome Project's NIH-DOE ELSI Working Group, the Secretary of the U.S. Department of Health and Human Services has created an advisory panel to ensure safe delivery of genetic tests into clinical practice.

Completion of the first human genome sequence and expansion of human genetics research to include studies of genetic variation among human subpopulations have raised new ELSI questions. The 1993-2003 plan includes goals for examination of those issues as well as the integration of genetic technologies and information into health care and public health activities; the integration of knowledge about genomics and gene-environment interactions into non-clinical settings; how new genetic knowledge may interact with a variety of philosophical, theological, and ethical perspectives; and how racial, ethnic, and socioeconomic factors affect the use, understanding, and interpretation

of genetic information, the utilization of genetic services, and the development of policy (3).

A HYPOTHETICAL GRAND ROUNDS FROM 2010

General visions of a future of gene-based medicine are useful, but many health care providers are probably still puzzled by how this will affect the daily practice of medicine in a primary care setting. To illustrate a hypothetical clinical encounter in 2010 is described here.

John, a 23-year old college graduate, is referred to his physician because a serum cholesterol level of 255 was detected on his employment physical. He is in good health, but has smoked one pack of cigarettes per day for six years. Aided by a patient-driven computerized family history tool available in his physician's office, a strong paternal family history of myocardial infarction is noted, with his father having died at age 48.

To obtain more precise information about his coronary artery disease risk, and to survey for other risks of future illness, John agrees to consider a battery of genetic tests that are available in 2010. After working through an interactive computer program that explains the benefits and risks of such tests, John agrees (and signs informed consent) to 15 genetic tests that provide risk information for illnesses where a preventive medicine strategy is available to reduce risk. He declines against an additional 10 tests for which no clinically validated intervention is yet available.

A cheek swab DNA specimen is sent off for testing, and the results are returned in one week (Table 1). The main focus of his subsequent counseling session with the physician and genetic nurse specialist is on those conditions where his risk differs

substantially (more than two-fold) from the general population. Like most patients, John is interested both in his relative risk and his absolute risk.

John is pleased to learn that genetic testing doesn't always give bad news—his risk for prostate cancer and Alzheimer's disease is reduced, based upon his carrying low risk variants of the several genes known in 2010 to contribute to these illnesses.

But he is sobered by the evidence of increased risk for coronary artery disease, colon cancer, and lung cancer. Confronted with the reality of his own personal genetic data, he arrives at that crucial "teachable moment" where a lifelong change in health behavior, focussed on reducing these specific risks, is possible. And there is much to offer—by 2010, the field of pharmacogenomics has blossomed, and a prophylactic drug regimen can be precisely prescribed, based on knowledge of his personal genetic program, to reduce his cholesterol and coronary artery disease risk to below normal. His colon cancer risk can be addressed by beginning a program of annual colonoscopy at age 45, which in his situation is a very cost-effective way to avoid colon cancer. And his substantial individual lung cancer risk provides the key motivation for him to join a support group of other individuals at genetically high risk for serious complications of smoking, and he successfully kicks the habit.

This vision of genetically-based individualized preventive medicine is exciting, and could make a profound contribution to human health. For it to be realized, however, protections against misuse of genetic information will need to be firmly in place. And another critical challenge must be met—every physician, nurse, and health care provider will need to become familiar with this emerging field of genetic medicine. The need for medical genetic specialists who can sort out the most complex cases will be considerable,

but there will not be enough of them to go around, and most genetic medicine will be delivered by primary care providers. Numerous surveys document that we are not currently prepared for this—most practitioners in primary care have had not a single hour of instruction in genetics as part of their formal training.

To meet this urgent educational need, the National Human Genome Research Institute, the American Medical Association, and the American Nurses Association have recently banded together to form the National Coalition for Health Professional Education in Genetics (NCHPEG). NCHPEG is a national effort to promote health professional education and access to information about advances in human genetics. An interdisciplinary group, NCHPEG is now comprised of leaders from approximately 100 diverse health professional organizations, consumer and voluntary groups, government agencies, private industry, managed care organizations, and genetics professional societies. By facilitating frequent and open communication between stakeholder groups, NCHPEG seeks to capitalize on the collective expertise and experience of members and to reduce duplication of effort. For more information, see www.NCHPEG.org.

CONCLUSION

Since the Human Genome Project's beginning, the increasing detail and quality of genome maps have reduced the time it takes to find a gene from years, to months, to weeks. We have learned the location of approximately half of the 80,000 or so genes packaged on human chromosomes. Genome researchers are at the forefront of cross-disciplinary technology development for identification and analysis of not just single genes, but of whole genomes.

Most recently, we have begun to get the first glimpses of the human genome at its most detailed level: about 15 percent of the 3 billion bits of DNA code that spell out instructions for every function a human body carries out is now available in public databases. In just twelve months, a highly useful working draft of 90 percent of the genome will be available, and by 2003 the full DNA sequence of the human will give us unprecedented opportunities to observe and understand the literal Book of Life.

As hoped, genome maps, sequence and analytical tools are providing a robust technological infrastructure for biomedical research well into the next century. The project's commitment to make these powerful tools freely available means any scientist with an Internet connection can already apply genomic approaches to individual research problems. High-technology research tools developed by the Human Genome Project will offer unprecedented opportunities to study human biology and disease in entirely new ways.

As genome technologies move from the laboratory into the health care setting, new methods will make it possible to read the instructions contained in an individual's DNA. Such knowledge may foretell of future disease and alert patients and their health care providers to begin better prevention strategies. In the wrong hands, however, that same information could be used to discriminate against or stigmatize an individual. In response to this concern, the Human Genome Project has catalyzed the development of policy options for lawmakers to consider their efforts to prohibit genetic discrimination and to protect the privacy of genetic information. The stage is set to solve these vexing problems with effective federal legislation, but that window of opportunity will not stay open indefinitely.

Writing 97 years ago, Sir William Osler described the goals of medicine this way: "To wrest from nature the secrets which have perplexed philosophers in all ages, to track to their sources the causes of disease, to correlate the vast stores of knowledge, that they may be quickly available for the prevention and cure of disease-- these are our ambitions." (40). The Human Genome Project, with its audacious goals to provide the tools to uncover the hereditary factors in virtually every disease, has become a major modern component of Osler's vision. The genetic revolution in medicine is underway.

ACKNOWLEDGMENT

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REFERENCES

1. Committee on Mapping and Sequencing the Human Genome. Mapping and sequencing the human genome, National Academy Press, 1988.
2. U.S. Department of Health and Human Services, U.S. Department of Energy. Understanding our genetic inheritance: The U.S. human genome project: The first five years: FY 1991-1995. NIH publication No. 90-1590, 1990.
3. Collins FS, Patrinos A, Jordan E., et al. New goals for the U.S. human genome project: 1998-2003. Science 1998; 282: 682-689.
4. Murray JC, Buetow KH, Weber JL, et al. A comprehensive human linkage map with centimorgan density. Science 1994; 265: 2049-2054.
5. Deloukas P, Schuler GD, Gyapay G, et al. A physical map of 30,000 human genes. Science 1998; 282: 744-746.
6. Collins FS and Galas D. A new five-year plan for the U.S. human genome project. Science 1993; 262: 43-46.
7. The yeast genome directory. Nature 1992; 387(6632 Suppl):5.
8. Blattner FR, Plunkett G III, Bloch CA, et al. The complete genome sequence of Escherichia coli K-12. Science 1997; 277: 1453-1462.
9. Collins FS. Positional cloning: Let's not call it reverse anymore. Nature Genetics 1992; 1: 3-6.
10. Collins FS. Positional cloning moves from perditional to traditional. Nature Genetics 1995; 9: 347-350.
11. Polymeropoulos MH, Lavedan C, Leroy E, et al. Mutation in the alpha-synuclein gene identified in families with Parkinson's disease. Science 1997; 276: 2045-2047.
12. Glasser T, Muller-Myhsok B, Wszolowski-Zk, et al. A susceptibility locus for Parkinson's disease maps to chromosome 2p13. Nature Genetics 1998; 18: 262-265.
13. Jones AC, Yamamura Y, Almasy L, et al. Autosomal recessive juvenile parkinsonism maps to 6q25.2-q27 in four ethnic groups: detailed genetic mapping of the linked region. Am J Hum Genet 1998; 63: 60-71.
14. Leroy E., Boyer R., Auburger G, et al. The ubiquitin pathway in Parkinson's disease. Nature 1998; 395: 451-452.

15. Ueda K, Fukushima H, Masliah E, et al. Molecular cloning of cDNA encoding an unrecognized component of amyloid in Alzheimer disease. *Proc Natl Acad Sci USA* 1993; 90(23):11282-6.
16. Burke W., Thomson E., Khoury MJ, et al. Hereditary hemochromatosis. Gene discovery and its implications for population-based screening. *JAMA* 1998; 280: 172-178.
17. Feder JN, Gnirke A, Thomas W, et al. A novel MHC class I-like gene is mutated in patients with hereditary haemochromatosis. *Nature Genetics* 1996; 13: 399-408.
18. Miki Y, Swensen J, Shattuck-Eidens D, et al. A strong candidate for the breast and ovarian cancer susceptibility gene BRCA1. *Science* 1994; 266: 66-71.
19. Wooster R, Bignell G, Lancaster J, et al. Identification of the breast cancer susceptibility gene BRCA2. *Nature* 1995; 378: 789-792.
20. Yamagata K, Futura H, Oda O, et al. Mutations in the hepatocyte nuclear factor 4 alpha gene in maturity-onset diabetes of the young (MODY 1). *Nature* 1996; 384: 458-460.
21. Froguel P, Zouali H, Vionnet N, et al. Familial hyperglycemia due to mutations in glucokinase: definition of a subtype of diabetes mellitus. *New Engl J Med* 1993; 328: 697-702.
22. Yamagata K, Oda N, Kaisaki PJ, et al. Mutations in the hepatocyte nuclear factor 1 alpha gene in maturity-onset diabetes of the young (MODY3). *Nature* 1996; 385: 455-458.
23. Fishel R, Lescoe MK, Rao MR, et al. The human mutator gene homolog MSH2 and its association with hereditary nonpolyposis colorectal cancer. *Cell* 1993; 75:1027-38.
24. Leach FS, Nicolaides NC, Papadopoulos N, et al. Mutations of a mutS homolog in hereditary nonpolyposis colorectal cancer. *Cell* 1993; 75: 1215-25.
25. Papadopoulos N, Nicolaides NC, Wang F, et al. Mutation of a mutL homolog in hereditary colon cancer. *Science* 1994; 267: 1625-9.
26. Schafer AJ and Hawkins JR. DNA variation and the future of human genetics. *Nature Biotechnology* 1998; 16: 33-39.
27. Collins FS, Guyer MS, and Chakravarti A. Variations on a theme: cataloging human DNA sequence variation. *Science* 1997; 278: 1580-1.

28. Wang DG, Fan J-B, Siao C-J, et al. Large-scale identification, mapping and genotyping of single-nucleotide polymorphisms in the human genome. *Science* 1998; 280: 1077-1082.
29. Hacia JG, Brody LC, Chee MS, et al. Detection of heterozygous mutations in BRCA1 using high density oligonucleotide arrays and two-color fluorescence analysis. *Nature Genetics* 1996; 14: 441-447.
30. DeRisi J, Penland L, Brown PO, et al. Use of cDNA microarray to analyse gene expression patterns. *Nature Genetics* 1996; 14: 457-460.
31. Hacia JG, Makalowski W, Edgemon E, et al. Evolutionary sequence comparisons using high-density oligonucleotide arrays. *Nature Genetics* 1998; 18:155-8.
32. Winzeler EA, Richards DR, Conway AP, et al. Direct allelic variation scanning of the yeast genome. *Science* 1998; 281: 1194-1197.
33. Kononen J, Bubendorf L, Kallioniemi A, et al. Tissue microarrays for high-throughput molecular profiling of tumor specimens. *Nature Medicine* 1998; 4: 844-7.
34. Poirier J, Delisle M-C, Quirion R, et al. Apolipoprotein E4 allele as a predictor of cholinergic deficits and treatment outcome in Alzheimer disease. *Proc Natl Acad Sci USA* 1995; 92: 12260-12264.
35. Kuivenhoven JA, Jukema JW, Zwinderman AH, et al. The role of a common variant of the cholesteryl ester transfer protein gene in the progression of coronary atherosclerosis. *N Engl J Med* 1998; 338: 88-93.
36. Martinelli I, Sacchi E, Landi G, et al. High risk of cerebral-vein thrombosis in carriers of a prothrombin-gene mutation and in users of oral contraceptives. *N Engl J Med* 1998; 338: 1793-1797.
37. *New Medicines in Development: Biotechnology* 1998. Pharmaceutical Research and Manufacturers of America. p.35, 1998.
38. Rubenstein RC, and Zeitlin PL. A pilot clinical trial of oral sodium 4-phenylbutyrate (Buphenyl) in deltaF508-homozygous cystic fibrosis patients: partial restoration of nasal epithelial CFTR function. *Am J Respir Crit Care Med* 1998; 157: 484-90.
39. *Promoting Safe and Effective Genetic Testing in the United States. Final Report of the Task Force on Genetic Testing.* Holtzman NA and Watson MS eds., 1997.
40. Osler W. Chauvinism in Medicine. *Montreal Medical Journal* 1902; 31: 684ff.

Figure Legends

Figure 1. The Human Genome Project can be thought of as an enterprise devoted to the production of "power tools" that are given away free, and greatly facilitate the work of researchers around the world in uncovering the causes of disease. The physical maps and genetic maps (lower left) of the human genome have already been completed, and the remaining eight items depict the current goals of the Human Genome Project from 1998-2003 (3). While much of current attention focuses on the completion of the human DNA sequence, vigorous efforts are underway in seven other areas to provide critically important information and methodologies to interpret the sequence, and to ensure its safe and beneficial utilization to improve human health.

Figure 2. The genetic revolution in medicine can be depicted as occurring in a series of steps. Uncovering the genetic contribution to an illness is accomplished by positional cloning, using the tools of the Human Genome Project. Once the contributing genes and their disease-predisposing variants are identified, diagnostic tests can be set up to predict future risk—but those are most effective when a preventive medicine strategy is available to reduce risk in those found to be predisposed. Another rapidly developing application of diagnostics is pharmacogenomics, the prediction of drug responsiveness. Ultimately, the real pay off of genetic research will be the development of new gene therapies and drug therapies, but those will in general require years more of intensive research.

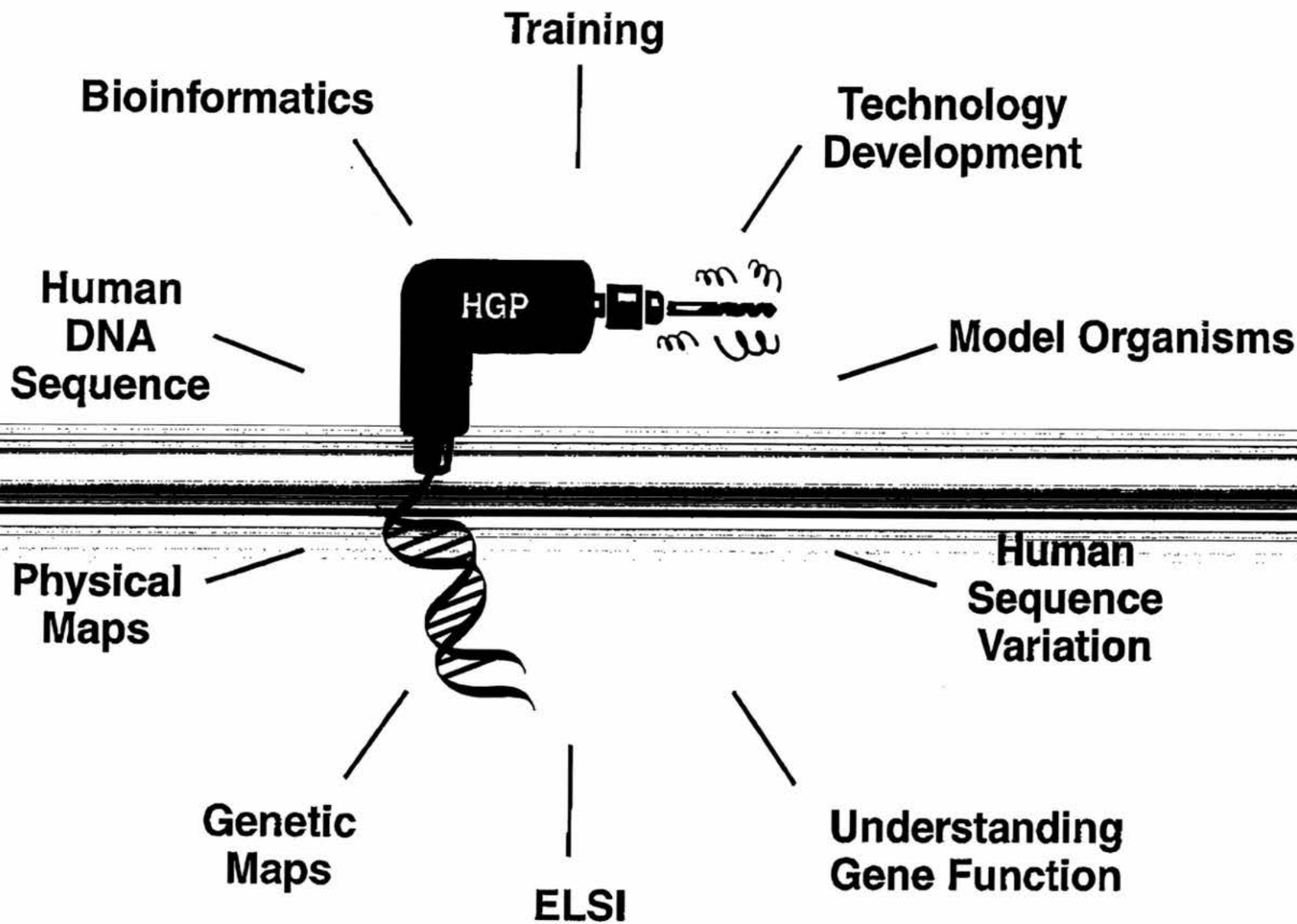


Fig. 1

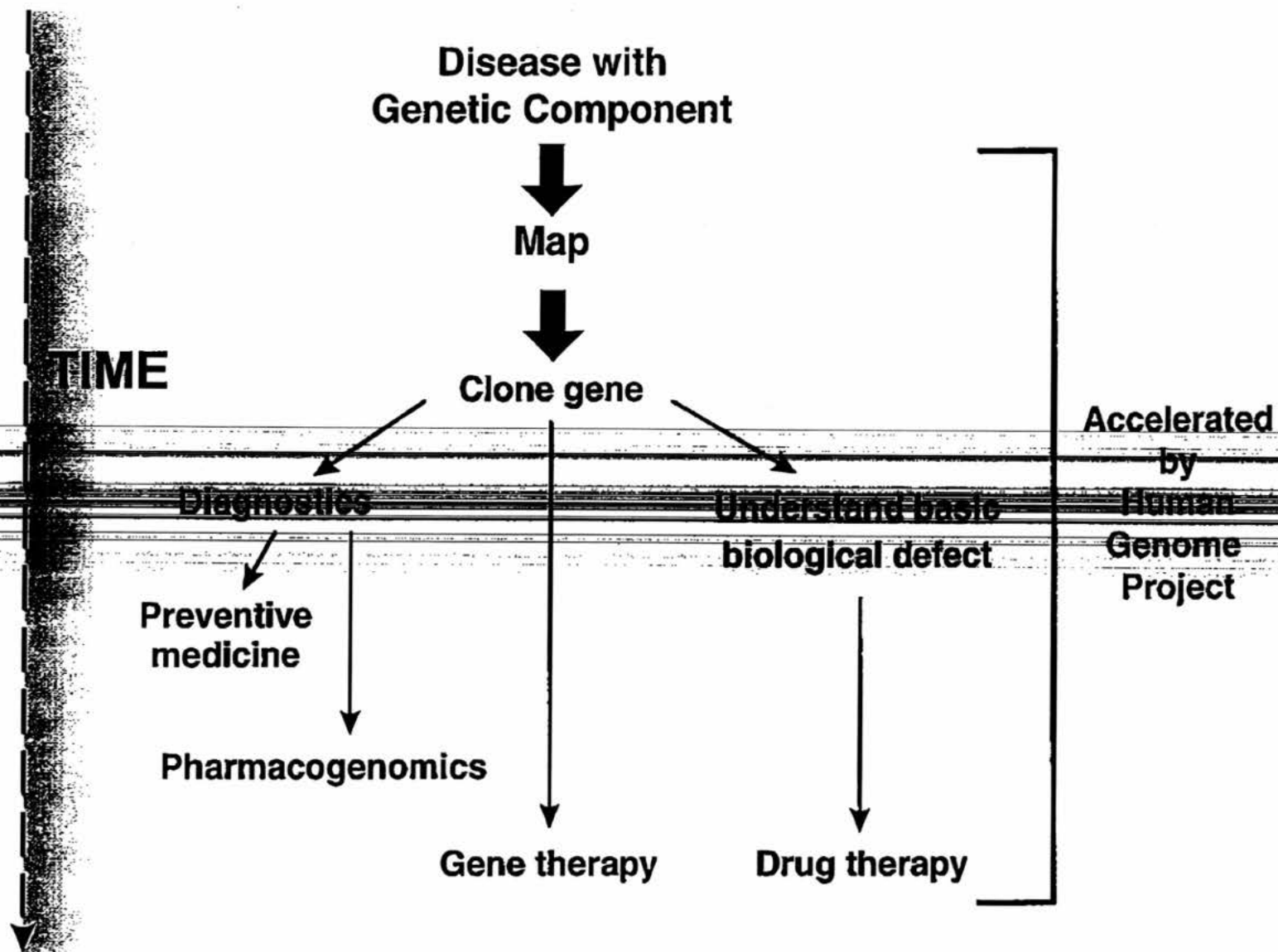


Fig. 2

<u>Condition</u>	<u>Genes Involved</u>	<u>Fold Elevation of Risk</u>	<u>Lifetime Risk</u>
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Reduced Risk:

Prostate Cancer	HPC1, HPC2, HPC3	0.4	7%
Alzheimer's Disease	APOE, FAD3, XAD	0.3	10%

Elevated Risk:

Coronary artery disease	APOB, CETP	2.5	70%
Colon Cancer	FCC4, APC	4	23%
Lung Cancer	NAT2	6*	40%

* Risk only applies to smokers

Medical School Objectives Project (MSOP)

In January 1996, the AAMC embarked on the Medical School Objectives Project (MSOP). The primary purposes of the MSOP were to delineate the attributes - that is, the knowledge, skills, attitudes, and values - that medical students should possess at the time of graduation from medical school, to develop within the medical education community a consensus on those attributes, and based on that consensus to set forth learning objectives for the medical student education program.

The first report of the MSOP, published in the January 1999 issue of *Academic Medicine*, contains a summary statement of the attributes that physicians should possess to practice medicine at the beginning of the 21st Century, followed by the learning objectives that reflect the contribution that the medical student education program should make to the attainment of those attributes. The attributes and the corresponding objectives are summarized here.

Physicians must be altruistic - Compassionate, empathetic, honest, able to deal with the dying, to make decisions in the context of differing beliefs and values

Physicians must be knowledgeable: Must understand the scientific basis of medicine and be able to apply that understanding to the practice of medicine. They must be prepared and willing to learn throughout their lives.

Physicians must be skillful: They must be highly skilled in providing appropriate care to individual patients, including the collection of information, its interpretation and management. They must be able to communicate with patients and colleagues both orally and in writing.

Physicians must be dutiful: They must feel obligated to collaborate with other health care professionals and to use systematic approaches for promoting, maintaining, and improving the health of individuals and populations.

Report II of the MSOP focuses on two contemporary issues in medicine - medical informatics and population health. This report was published in the February 1999 issue of *Academic Medicine*.

The Association reaffirms its longstanding commitment to the principle that the faculty of each medical school, working in concert with the school's administration, is responsible for determining the objectives for the school's educational program and for the design and conduct of the school's curriculum. The Association intends for the program objectives set forth in this report to be used only to guide and inform the deliberations of individual medical school faculties as they consider whether or not changes should be made in the design, content, and conduct of their curriculum in response to the contemporary educational imperatives they now face. The ultimate purpose of the MSOP is to facilitate that process and, in so doing, to assist schools in

maintaining the quality of medical student education.

To that end, a group of schools, whose deans contacted AAMC about their involvement in the project, has formed a consortium. The consortium schools have begun to wrestle with the implementation of the MSOP Reports I and II. Listed below are the goals and work plan for the consortium during 1999.

MSOP Schools Consortium

Mission

The mission of the Consortium is to facilitate the implementation of the Medical School Objectives Project (MSOP) by working together to accomplish the following goals.

Goals

- Serve as sites for the implementation of objectives defined by the MSOP
- Provide insights to MSOP staff and other medical schools into what works and what does not work, and what is needed for implementation of objectives-driven curriculum renewal.
- Share and learn from experiences of other schools
- Serve as models for curriculum reform
- Serve as sites for the inclusion of contemporary issues in the medical school curriculum (e.g., ethics, evidence-based medicine, medical informatics, population health, etc.).
- Serve as sites for implementation of effective and innovative models of teaching and learning
- Develop and implement assessments of learning outcomes and methods
- Serve as focus for multi-institutional studies of curriculum renewal (using a systematic analysis)

Next Steps

- 1) ● Curriculum Management Information Tool (CurrMIT)
 - All 141 medical schools on-line by June 1, 1999
 - 40 schools have completed a test phase and enhancements have been done to the database
- 2) ● Develop a Web presence for MSOP
 - provide information about individual schools/contacts
 - information about objectives/measurement approaches

- 3) • Continue writing MSOP Reports on Contemporary Issues
MSOP Report III - Communications will be completed in June 1999
- 4) • Present MSOP focus at each 1999 GEA regional meeting
- 5) • Develop an “outcomes tool kit”
Task Force of Consortium school representatives will work with Jim on the “Assessment Center” project
Task Force volunteers include:
 - Paul Mazmanian
 - Vic Del Bene and Amy Blue
 - Louise Arnold
 - Larry Rooks
 - Joe O'Donnell
- 6) • Work with Philip Szenas on “Peer Assessment Project”
Task Force of Consortium school representatives will work with Phil on the Peer Assessment project
Task Force volunteers include:
 - Tom Norris
 - Sharon Krackov
 - Henry Pohl
 - Steve Smith
 - Karen Mann
 - Kerin Frisa
- 7) • Develop and produce a catalogue of “Principles of Educational Program Design”
Task Force of Consortium school representatives needed

QUESTIONS to continue to consider:

- What are the educational principles/characteristics of the undergraduate education program?
- What are the processes/strategies for determining the content of the curriculum?
- Are we assessing behaviors that reflect attributes or can we assess attributes?
- What is the spectrum of goals of medical education?
- How do you support and encourage innovation?
- How do you deal with criticisms of faculty who try innovations?

- How do you encourage innovation in the context of the present evaluation system?
- 8) • Publish MSOP Report of Consortium activities in *Academic Medicine* supplement
Task Force of Consortium school representatives needed

The March 29-30 meeting of the Consortium focused on:

- a comprehensive approach to the ALTRUISM attribute

Develop a format for reports on each attribute to include:

Examples of school objectives for each attribute

Educational methods

Assessment methods

**Remarks by the First Lady at the Redbook Magazine
"Mother & Shakers of 1998" Awards Ceremony
June 2, 1998
The White House
Washington, DC**

We've come together today to salute eight extraordinary women who have made a very real difference in the lives of families in their own communities and across the nation. At our table during lunch, I learned a lot more about what some of these women have accomplished and I am just delighted that the country will learn more about what they have achieved because if we could take all of their achievements and put them together we would have a much better system of child care nationwide. Somebody who believes that and has worked with me to that end is my friend, Tipper Gore who is also with us and I'd like to acknowledge Tipper and ask her to please stand.

Tipper and I have spent a lot of time in the last years talking about our own children and also talking about children throughout our country and indeed the world. So for us to be able to acknowledge the accomplishments of all of you gives us a great deal of satisfaction. Whether it was establishing child care centers or setting up hotlines for parents or partnering with businesses or lobbying elected officials, you have been working in your own ~~communities~~ to promote child care and to move it to the forefront of the national agenda by giving working parents more choices and more opportunities to succeed at home and at work. It is important to pause once in a while to take measure of how far we've come and to honor those who've helped us get there so I want to commend Redbook for creating these mothers and shakers awards and for running the article on child care in its June issue, Kate, because I think that we still have some work to do in both raising public awareness and dispelling stereotypes about the difficult choices families face in finding the child care they need.

You've performed an important public service because you've helped to shine the spotlight on women who've worked diligently and often in the shadows to improve the lives of children and working families and help raise public awareness by providing parents with critical information about to find safe affordable child care.

Today as we anticipate the extraordinary possibilities of the next century it's a little hard to imagine what life was like for women living in America just a century ago: Certainly our life span was much shorter -- many of us would not be around at the age that we are. We would have lost those of us who have had children, many of the babies we birthed we would have seen some succumb to infectious diseases for which there were no cures or antibiotics or vaccinations and Redbook was first published nearly a century ago in 1903 and it has helped to chart the lives and the changes in the lives of American women back then.

Certainly our nation has undergone profound changes as more and more women have not only lived longer and survived childbirth, two major accomplishments of this century, but have themselves joined the workforce outside the home transforming their lives and the life of this nation forever. We saw a great move into the workforce as a result of World War II, and we saw the government, when it needed women to be part of the war effort, step in to provide child care so that those women could go to work.

We've made a lot of progress but of course we have a lot left to do. This country has a great economy right now, we are blessed with prosperity and much of that is because women are working. Women who are using their skills, their education, their talents in our workforce and creating not only better opportunities for themselves and their families but for the rest of us as well. We know that women make up almost half of the workforce and as a result we

dispelling stereotypes

1757-

know that many children have to spend some or all of their day away from their parents in child care. We also know that we many single women who are raising their children themselves and are their sole support and ~~have no choice~~ but to work.

Now over the years I, like many of you, have spent many many hours talking to working mothers. First when I myself was a working mom and sitting around kitchen tables or in the bleachers at sporting events or at playgrounds or in my office I found that the uppermost issue on most working mothers minds was child care and the dilemma that we have all lived with that is raised by the conflict between family and work and the need for all of us to do a better job in balancing those competing demands. What we tried to do was to take that dialogue that conversation that every one of has on our own and take it out of the kitchens and out from around the water coolers and out from the supermarket aisles where I often had it, and put it into the national arena.

That's why the President and I hosted the first ever White House Conference on Child Care last year as well as the Conference on Early Childhood Development. We knew from the work the scientists were doing how critical the first three years are to a child's intellectual and emotional growth and we also knew how difficult it is for many parents to feel that they were doing right both by their jobs which put food on the table and by their children who are the most important people in their lives, Now thanks to you we have made child care a national priority and we have presented legislation to the Congress.

As you know the President has proposed a historic investment in child care, over 20 million dollars over the next five years that will make child care more affordable to America's working parents. It will also expand opportunities to promote early learning and child development. It will also ensure greater safety and quality enhance efforts for background checks help parents and schools establish after school programs in their communities. But one of the things that I have found is that often times when a President announces something as he did in the State of the Union and then follows it up with legislation, many Americans think the work is over . I was recently with Congresswoman Tausher in her district in California and we had a panel discussion in a wonderful facility a school that had an added-on building where they were running a very good after school program and the Congresswoman and I were sitting with experts from the community and people who had supported this program and the questions and the comments were all assuming that the Presidents plan was going to get through the Congress we heard from the Superintendent who said "You know, we'll sure be able to use that money because we're still not reaching all of our students". We heard from a teacher who said "You know, I'm so excited that the federal government is finally going to help us because we don't have the facilities we need in our poor areas of this county for after-school care". And you know the Congresswoman and I were somewhat surprised because of course we know how difficult it is to get legislation like this through in the current Congress and so we have to re-instill a sense of urgency in America's working families, and teachers and advocates and business leaders who have applauded this commitment as being not only good for children and families but good for America. So you are helping us to get that word out by coming together to honor people who have been on the front lines doing the work that needs to be done.

But I have to ask you all of you who are hear at this lunch to do what you can to make sure that this critical issue stays on America's agenda. That we don't have a sigh of relief throughout the country because people somehow think that since the President proposed this legislation it's going to necessarily be passed and implemented. The President is committed to continuing to fight for his proposal to make child care better, safer, more affordable. There are good child care bills on both sides of the aisle. Child care should not be a partisan issue we are not talking about taking care of democratic or republican or independent children we are talking about taking care of American children and we have to continue to push for significant legislation this year on behalf of our children.

We have a related issue that is connected to this one and that is the tobacco legislation that

is currently in the Congress. We have an opportunity to reach agreement on historic legislation to save our children from the dangers of smoking. There are obviously difficult issues left unresolved but this is also a challenge to what kind of nation were going to be and how much care concern and protection we are going to extend our youngest citizens. Congress should act quickly to pass tobacco legislation and I hope that every citizen will make their voices heard on this important issue as well. Because we have an opportunity when it comes to the President's education reform agenda, when it comes to his child care legislation when it comes to his proposal to try and do what we can to end teenage smoking. We have an opportunity to really continue to move forward on the American agenda for America's children but I am under no illusions that this will be an easy effort, there are many forces arrayed against these pieces of the President's agenda for reasons that I think have very little to do with the well being and future prospects of our children. So I hope that we will take the energy that is in this room and take the example that we will hear more about that is set by each of our honorees and redouble our own efforts on behalf of doing what we can to bring about significant child care legislation in this session of Congress.



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Teen Pregnancy Prevention Event

Briefing prepared by Sarah Bianchi

Event Time: Thursday, April 29, 1999

1:45pm - 2:30pm

EVENT

You are participating in a round table with community leaders who have worked on innovative approaches to reduce teen pregnancy. You are also highlighting a new HHS study that shows that from 1991 to 1997 teen birth rates declined by 16 percent and a new regulation that provides financial rewards for states that reduce their out-of-wedlock birth rates. **This event is open to pool press.**

LOGISTICS

- You enter the Roosevelt Room, accompanied by Brandi Chapple, Enrique Arreola, Sharon Rodine, and Reverend Willie Davis.
- You make brief welcoming remarks, and begin the discussion, asking a question of each participant.
- You make closing remarks and depart.

YOUR ROLE AND CONTRIBUTION

This event is designed to highlight the important declines in teen birth rates and to emphasize that more needs to be done to assure that our young people understand they should delay parenthood until they are truly ready to nurture and support a child of their own. At this event, you are highlighting: (1) a new HHS study that shows that teen births declined 16 percent between 1991 and 1997 in all fifty states and across racial and ethnic groups; and (2) new incentives for states to reduce out-of-wedlock birth rates by allowing up to five states to qualify for up to \$25 million each if they successfully reduce the percentage of children born out-of-wedlock without increasing abortions.

This week, the National Campaign for Teen Pregnancy - in honor of National Teen Pregnancy Prevention Month - is also unveiling new information to support values and encourage actions across all parts of the nation to promote a pregnancy-free adolescence. Their efforts this year are focusing on the important positive role that teens have in influencing other teens to prevent teen pregnancy.

ATTACHMENTS

- Background on announcements and accomplishments
- Event participants
- Remarks prepared by speechwriting

ANNOUNCEMENTS

New Study Showing That Teen Birth Rates Are Down

You are highlighting a new Department of Health and Human Services report showing that teen birth rates declined nationwide by 16 percent from 1991 to 1997, and by four percent since 1996. This decrease has occurred in every state in the country and across racial and ethnic groups. The report also showed that out-of-wedlock births continue to decline across the nation. The Department of Health and Human Services study found that:

- **Birth rates have fallen among teens.** The birth rate for teenagers has fallen 16 percent -- from 62.1 births per 1,000 women aged 15-19 years in 1991 to 52.3 in 1997.
- **Teen birth rates are down in all fifty states.** The report shows that teen birth rates are down in all fifty states. In 10 states and the District of Columbia, the rate is down by more than 20 percent.
- **Teen birth rates are down across ethnic and racial groups.** Teen birth rates declined for white, black, American Indian, Asian or Pacific Islander and Hispanic women.
- **Out-of-wedlock birth rates are also declining at record numbers.** The report also found that out-of wedlock births continue to decline-- from six percent from the peak in 1994 and two percent since 1996. The birth rate for unmarried teens fell nine percent from its peak in 1994.

New Incentives to Reduce Out-of-Wedlock Birth Rates. To give states incentives to reduce the out-of-wedlock birth rates even further, you are highlighting a recent final rule that rewards states who have the greatest success in reducing out-of-wedlock births. Beginning in FY 1999, up to five states can qualify for up to \$25 million each if they successfully reduce the percentage of children born out of wedlock (without increasing abortions). These bonus funds, which were part of the 1996 welfare reform law, are designed to encourage and reward state efforts to develop effective solutions for addressing this critical social issue. Children who are born into homes without two parents are more likely to drop out of school, get involved in crime and drugs, and end up in poverty.

The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (welfare reform law) established this \$100 million a year bonus and outlined most of the terms of the competition. In order to avoid unintended consequences, the statutory language makes clear that the bonuses will go only to states that simultaneously reduce both out of wedlock births and abortions. The regulation closely tracks the statute in this area.

In addition to establishing the Illegitimacy Reduction Bonus, the law also took a number of other steps to address these issues. The 1996 welfare law requires unmarried minor parents to stay in school and live at home or in a supervised setting; encourages "second chance homes" to provide teen parents with the skills and support they need; and provides \$50 million a year in new funding for state abstinence education activities.

Birth Rate Trends

	1991	1996	1997	% change 1991 - 1997	% change 1996-1997
Teen birth rate (births per 1,000 women 15 - 19)	62.1	54.4	52.3	- 16%	- 4%
Number of teen births	519,577	491,577	483,220	- 7%	- 2%
Birth rate to unmarried women (births per 1,000 unmarried women 15 - 44)	45.2 ^{1/}	44.8	44.0	- 3 %	- 2%
Birth rate to unmarried teens (births per 1,000 unmarried women 15 - 19)	44.8 ^{2/}	42.9	42.2	- 6%	- 2%

1/ Birth rate for unmarried women 15- 44 peaked at 46.9 in 1994 and fell 6% from 1994 to 1997.

2/ Birth rate for unmarried teens 15 - 19 peaked at 46.4 in 1994 and fell 9% from 1994 to 1997.

Administration Accomplishments on Preventing Teen Pregnancy

Since 1993, the Administration has supported innovative and promising teen pregnancy prevention strategies. The National Campaign to Prevent Teen Pregnancy, a private nonprofit organization, was formed in response to the President's call for a national effort to involve in the 1995 State of the Union address. In addition, significant components of the President's comprehensive effort to reduce teen pregnancy became law when the President signed the welfare reform law in 1996. The law requires unmarried minor parents to stay in school and live at home or in a supervised setting; encourages "second chance homes" to provide teen parents with the skills and support they need; and provides \$50 million a year in new funding for state abstinence education activities. Finally in 1997, the President announced a National Strategy to Prevent Teen Pregnancy, which already has succeeded in ensuring that HHS-supported programs reach one-third of all communities in the United States.

The National Campaign to Prevent Teen Pregnancy The National Campaign to Prevent Teen Pregnancy works to support values and encourage actions across all parts of the nation to promote a pregnancy-free adolescence, such as encouraging and promoting local action, working with national media to send a more responsible message about preventing teen pregnancy, and issuing valuable reports and user-friendly tips for parents, teens, and faith community leaders to get involved. This year, the Campaign is focusing on the important positive role that teens have in influencing other teens to prevent teen pregnancy. The Campaign was created in response to President Clinton's 1995 State of the Union challenge to "parents and leaders all across this country to join together in a national campaign against teen pregnancy." In honor of Teen Pregnancy Prevention Awareness Month, this week the Campaign is releasing a number of new information and pamphlets on strategies to prevent teen pregnancy. This year's focus is on teens influencing peers.

EVENT PARTICIPANTS

Brandi Chapple is a senior at Laurel high school in Maryland, who has been a leader on preventing teen pregnancy, including serving as a host for the Black Entertainment Television's "Teen Summit" program and judging a series of essays about the opportunities that delaying parenthood can give teens.

Brandi, tell us about your involvement in preventing teen pregnancy and why you think abstinence is so important for young people?

Follow-up: What is the role of the media in helping teens make responsible choices and delay parenthood?

Enrique Arreola [En-ric-kaa] directs the male involvement pregnancy prevention program at the Mexican American Community Services Agency (MACSA) in Santa Clara County, CA.

Enrique, why is it so important to engage young males in teen pregnancy prevention efforts and what is your organization doing to promote this?

Sharon Rodine is a coordinator for the Oklahoma Institute for Child Advocacy, which involves local schools, neighborhoods, businesses, churches and others in the community to encourage teens to make responsible choices and delay parenthood.

Sharon, share with us how Oklahoma City is working together on an issue where not everyone necessarily sees eye to eye?

Reverend Willie Davis is the Executive Director of the Monroe County Council on Teen Pregnancy in Rochester, New York, which involves churches and local community leaders in teen pregnancy prevention efforts.

Willie, what can faith-based communities and leaders such as yourself do to help address this important problem?

PHOTOCOPY
PRESERVATION

Brandeis University

Policy Center on Aging

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callahan@blnh.cc.brandeis.eduJames J. Callahan, Jr., Ph.D.
Director

MEMORANDUM

5/21/99

To:

Matthew Granade
From: Jim CallahanHere is some NORC material & Gene
Cohan #Gene Cohan MD
G.W. University
Center on Aging
301-946-7066

NORCs PROGRAM IDEA*J. CALLAHAN + S. Lensberg*

Heller School, Brandeis University

Program Idea

The underlying concept of the proposed Health and Supportive Services Program in Naturally Occurring Retirement Communities (HSSP-NORCs) is to demonstrate that dense populations of older people (NORCs) provide singular opportunities to:

- deliver health and supportive services more cost efficiently
- increase service availability
- organize cooperative health promotion, crisis prevention, and community improvement initiatives
- develop new human, financial, and neighborhood resources for the benefit of older residents.

The program's key elements are reliance on consumer involvement and choice in determining the services to be offered; capitalizing on economies of scale; and recognizing the influence of healthy communities on older people's quality of life and ability to age in place, as is usually their preference.

Background

As the aged population both grows and itself becomes older, systems as well as individuals confront many challenges.

Older people use more inpatient hospital days, make more visits to physicians, and utilize home health care and other long term care services to a greater extent than any other population group. The older people are, the more services they are likely to use. These realities promise to place heavy demands on the acute and long term care health and supportive services systems, as well as on family and community informal supports.

Strategies for dealing with these health factors include an amalgam of cost controls, increased user premiums, highly targeted assessment mechanisms, and managed health care. The consequences of these strategies are not yet clear. Moreover, positive health outcomes are often compromised by inadequate

supportive services, housing that needs adaptations or repairs, isolation, and deteriorating neighborhoods. Yet proposed solutions often overlook these considerations. Demonstration of alternative strategies to supplement, complement, or challenge current efforts is clearly needed.

To older consumers, efforts to control costs and service utilization often appear to reduce choice or add complications to obtaining needed care. At the same time, it is difficult for consumers to find information about services and housing and to coordinate their own services. Those who need or desire assistance often are ineligible for publicly subsidized services, yet unable to afford market rate services.

The HSSP-NORCs program proposes to test another strategy to deal with the health care demands arising from the growing elderly population. Building on the fact that at least eight million older people live in buildings or neighborhoods with a high density of older residents -- areas often referred to as naturally occurring retirement communities, or NORCs -- the strategy makes use of high density to:

- Take advantage of economies of scale in organizing and delivering supportive and health services more cost-effectively.
- Take advantage of older residents' common interests and existing social organizations to increase their understanding of the changing health and supportive service systems and their effectiveness as consumers.
- Take advantage of the opportunity to reduce health risks through neighborhood activities that promote health and improve safety and security for all residents, especially elders.
- Expand the local resources available through such mechanisms as forming purchasing cooperatives, utilizing community development block grant programs, buying services in quantity from local agencies, and developing more affordable housing options, such as respite care or assisted living.
- Provide an organized, two-way link to managed care organizations for supportive services, more effective appropriate health care services utilization, and health promotion.
- Enhance community cohesion and improve individuals' quality of life by building on the idea of older people as a resource in their own behalf.

Additionally, the proposed program offers opportunities to

- Meet consumer preferences to "age in place" cost-effectively without sacrificing safety and quality
- Promote intergenerational linkages
- Support and increase the supply of informal caregivers
- Promote innovative business involvement in the community
- Rehabilitate and preserve neighborhoods
- Empower elders through participation in community development activities

Since the early 1980s, several initiatives that have capitalized on economies of scale, including programs that "cluster" health and supportive services and link senior housing or NORCs with services, have had promising results. Some of these programs have demonstrated cost savings, enhanced consumer access to services, delayed institutionalization, and improved quality of life. The ultimate impact of most of these experiments, however, has been limited by location, auspices, and scope. Some, for example, have taken place in planned senior housing or in single agencies delivering few services in few sites; many have targeted services to a very limited group of consumers. The proposed HSSP-NORCs offers an opportunity to test more systematically a holistic approach that incorporates clustering as well as community-building and consumer empowerment strategies. Moreover, the fact that over eight million older people live in NORCs -- compared to about two million in planned senior housing -- suggests that successful programs may affect a significant number of people, be widely replicable, and influence overall health and supportive service delivery strategies.

The Program

The HSSP-NORCs is aimed primarily at agencies and organizations that have neighborhood roots and do not ordinarily deliver health and supportive services. Examples are community development corporations, neighborhood councils, settlement houses, housing cooperatives, and not for profit housing sponsors. Participating agencies or organizations would receive start-up funding to develop a program in one or more local NORCs over a three-year period. Applicants would designate one or more target areas, of no more than three square miles each, in which at least 35% of heads of household are 65 or older. The minimum number of older people to be served in all target areas would be 1000.

Proposals would be evaluated according to:

- The number of older people to be served.
- The number of target areas and the geographic scope.
- The characteristics of the target population, with emphasis on consumers over age 80, ethnic and cultural diversity, and neighborhoods that include both multi- and single-family housing.
- Demonstrated intent and ability to sustain the program beyond the grant period and to expand it beyond the initial site(s).
- Financial and other support from the applicant, relevant service agencies, and governmental and community organizations.
- Overall feasibility of the project.
- Commitment to and ability to conduct market research.
- Experience in integrating funds from diverse sources.
- The nature, extent, and credibility of active, meaningful consumer participation in project design, implementation, and monitoring.
- Demonstrated consumer, housing owner, or housing manager interest in the program in the targeted areas.
- Demonstrated formal linkage(s) to one or more HMOs or other managed care entities.

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Although policy and practice schisms persist between housing, health care, and long-term care, public and private efforts have occurred in settings with disproportionate numbers of older residents. These efforts include the U.S. Department of Housing and Urban Development (HUD) Congregate Housing Services Program, state congregate programs, the HUD service coordination program, and the New York State NORCs program, and the Supportive Services Program in Senior Housing (SSPSH) and its successor, No Place Like Home (NPLH). The latter two are described later in this section.

Four approaches to delivering services in settings with critical masses of older people have evolved:

- A fragmented or "patchwork" approach describes the common situation in which consumers, families, neighbors, housing managers, and local agencies piece together services as best they can.
- Service clustering (or cluster care), usually involving supportive services³, appears to improve efficiency and flexibility and keep costs low in delivering services to older people living in senior housing or NORCs (Balinsky and LaPolla 1997; Feldman et al. 1996).
- On-site service coordination, usually carried out by property management company or social service agency staff, serves all residents rather than providing case management for the few who are most frail. The coordinator helps residents to learn about and access existing services, organize new services, and arrange building events.
- On-site nursing services are usually provided by a nursing professional assigned regularly to a site, employed by the site, a health clinic, a visiting nurse service, or other entity. These nurses may serve as gatekeepers, direct service providers, or both, often depending on the financing arrangements.

Two or more of these approaches often co-exist, depending on the service, the provider, the financing source, and the resident.

Although no significant research synthesis concerning housing and services linkages has been undertaken, relevant research includes:

- Issue overviews and documentation of resident demographics and service needs (for example, Holshouser 1988, NCSHA/NASUA 1987, and Lawton et al. 1985)
- Case studies illustrating different solutions to problems in linking housing, health, and home care (Milbank Memorial Fund 1997; Pynoos et al. 1994)

³Typically, home care workers are assigned for a predetermined number of hours (often with two-, or even four-, hour minimums) to individual consumers, without considering geography or setting. Services clustered in senior housing or NORCs decrease the minimums and increase flexibility. For example, one worker may help four people get up and dressed, for 30 minutes each; then do laundry for three people at once; then shop for two people at the same time.

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- Program evaluations and cost analyses (for example, HUD 1996a, 1996b; Scanlon 1994; Heumann 1991; Sherwood et al. 1985)
- Studies identifying key elements in the service coordinator's role, analyzing service usage, or evaluating the operations of selected programs (Lanspery 1997; Schulman 1996; Holland et al. 1995; Lanspery 1995a, 1995b; Scanlon 1994; Sheehan 1993)
- Policy analyses attempting to bridge housing, health, and long-term care (for example, Pynoos 1997, 1990; Newman 1985; Struyk et al. 1989)

Without systematically assessing changes and outcomes, many of these studies hint at possible associations between housing and services programs and certain positive effects for individuals, neighborhoods/communities, and systems. The following list, summarizing the outcomes most frequently mentioned, will inform the proposed project's evaluation strategies and tools:

- *Reducing* the use of police, fire, ambulance, emergency room, and hospital services; the use of in-room pull cords; apartment turnover; the number and nature of complaints and disputes; the number of threatened or actual evictions; the rate of or avoidable trauma of residents' relocations
- *Improving* resident and community well-being (for example, amount of resident activity, social interaction, morale, satisfaction, perception of locus of control, attachment to community, informal supports, self-reported health and functional status, formal links to community agencies, family involvement, and the community health and interaction).

The SSPSH/NPLH, funded by the Robert Wood Johnson Foundation, relied on market analysis, consumer organization, and cross-cutting participation (by housing owners and managers, service providers, and residents) in service design, delivery, and financing. Developers supported capital expenses, service coordination, and service start-up subsidies. Residents, despite low incomes, paid for most of the new SSPSH services (Scanlon 1994). Some who were eligible for free or less expensive services paid for SSPSH services due to higher quality, convenience, or other desirable features. In the model, (1) consumers identify problems experienced and services desired, (2) the focus is on resource development and service coordination, not care management, (3) service providers, housing developers and managers, neighborhood organizations, and consumers share costs, and (4) strategies capitalize on the interdependence of community and individual health. Over 700 developments have participated in the SSPSH and its successors.

Border

A growing number of programs across the country intentionally link NORCs and services (Callahan and Lansperry 1997). In some, an apartment building owner, manager, or cooperative association contracts with an agency or hires staff to assist residents to obtain services. Some agencies offer training and technical assistance on health, safety, and services to managers of planned senior housing or NORC buildings; help NORC residents form associations; cluster or target their own services according to economies of scale (e.g., reorganizing senior van or home-delivered meal routes); or organize new private-pay services.

The most extensive NORCs programs are in large New York City apartment or cooperative buildings. Working closely with agencies, these programs facilitate access to a range of publicly subsidized, private-pay, formal, and informal services. The best known, the Penn South Program for Seniors (PSPS), offers social, health, and individual services at Manhattan's Penn South cooperative housing. The United Jewish Appeal-Federation established PSPS (now a nonprofit corporation) in 1986. PSPS now helps over one thousand people per year to obtain health and supportive services, or to participate in group activities. PSPS attributes its success, in part, to group endeavors organized according to residents' interests (and often planned or run by residents). These activities enrich residents' lives, decrease isolation, and build trust in program staff. As a result, residents are more likely to seek and accept help when needed. Other NYC NORCs programs have incorporated many PSPS features:

- Residents influence program offerings and operations through surveys, focus groups, forums, and committees
- The cooperative corporations and the residents pay a substantial share of the supportive services costs
- A social service agency directs, and a committee (representing management, the board of directors, residents, and service providers) governs the on-site program
- Residents provide a measurable share of the group services through a volunteer corps

The NYC programs' success led the NY State Legislature to appropriate \$1 million in 1994 to fund ten NORCs projects statewide under the Naturally Occurring Retirement Community Supportive Service Program. The projects delivered over 100,000 units of service to over 10,000 persons in the first year, reaching two-thirds of the sites' older residents (NYSOFA 1995, p. 19). Residents created programs; served on boards and committees; made recommendations



about programming, services, and policy issues; taught classes; and acted as friendly visitors and shopping escorts for other residents. Fund raising strategies to sustain the programs included the following (NYSOFA 1995, p. 9):

- Soliciting bequests and grants for endowment funds and operations
- Exploring increases in client fees for services, activities, education
- Expanding reimbursable services and identifying free services
- Promoting contributions from housing management, residents, and clients
- Developing group purchasing programs

The proposed project will also draw on the experience of other programs incorporating a neighborhood approach, such as the parish nurse and block nurse programs, in which a nurse conducts outreach and serves as a central access point for older residents of an area or congregation; and the Bay Area Independent Elders Program, in which a social worker "walks a beat" to accomplish similar goals, and also works with local businesses, reminding them of the importance of their older customers and suggesting ways to keep them satisfied and independent. Two Massachusetts program resources incorporating elements of the proposed model are as follows:

- The Circle of Friends program, facilitated by the Health and Social Services Collaborative on Boston's South Shore, organizes informal groups of families, friends, and neighbors to provide assistance with activities of daily living for people with disabilities. Formal services fill gaps, but the program has been successful in providing reliable assistance for help with all but the most personal care.
- The Chelsea/Dudley Partnership for Families and Neighborhoods is a collaborative project attempting to create a consumer-driven model of human service delivery. Serving two racially and economically diverse areas of Boston, it aims to increase the communities' capacity to build upon resources and assets and control the conditions under which human service delivery and economic and community development take place.

An appropriate conclusion for this section is the following quotation from a needs analysis in the proposed project area:

Elders not only need advocates willing to voice needs for them ... elders themselves need to be empowered to do the same. [They are often reluctant] to speak out ... feeling that their voice will go unheard, their needs unmet, and their wisdom unheeded. In these days of managed care, when options are diminished, [they] sense that after decades of making choices they are no longer allowed, even trusted, to continue to do so. (Central Mass Agency on Aging 1998, p. 17)

3. Specific Objectives

The goal of the proposed Worcester, Massachusetts project is to demonstrate that communities can restructure and reorganize health, supportive, and social services for residents with chronic illness in NORCs. Based on the SSPSH/NPLH

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experience, Brandeis has developed a NORCs program model (Callahan and Lanspery 1997) in which supportive services and activities are open to frail and non-frail elders (and often to younger people), to attract the broadest possible base of residents, which keeps prices lower and avoids the stigma associated with service use. Consumers identify problems experienced and services desired. The focus is on resource development and service coordination, not care management. Service providers, housing developers and managers, neighborhood organizations, and consumers share costs. Strategies capitalize on the interdependence of community and individual health. The model also encompasses community and economic development. Consumer involvement, with flexibility, is the key. Consumers are encouraged in word and deed to see themselves as customers purchasing desired products and citizens taking part in a community effort, rather than as needy seniors receiving handouts from an omniscient service system. The consumer orientation promotes autonomy, overcomes resistance, and builds in sensitivity to multicultural issues. Using consumer choice in the SSPSH, in the context of population density,

made the woodwork effect an advantage ... The more customers, the lower the cost per customer. And, the lower the cost per customer, the more customers. The cycle works to consumers' advantage. (Retsinas and Retsinas, 1992)

The proposed project's objectives are to effect changes in individuals, neighborhoods, and systems, in the areas of health, housing, and happiness. Specifically, it is intended to:

- Develop new consumer-driven health and supportive services that supplement, not supplant, existing services
- Improve the coordination and clustering of existing health and supportive services
- Influence managed care organizations serving Worcester to take community and density issues into account
- Increase collaboration among community agencies, organizations, consumers, and caregivers
- Educate and seek financial support from those who own or manage properties housing older residents
- Assist elders who own their own single- or multi-family homes to repair and maintain their homes
- Improve individual and neighborhood quality of life, including relationships between older and younger residents
- Increase flexibility in state and local policy with respect to services delivered to target area residents

Over the short term, a successful project will benefit NORCs residents and their neighborhoods. Over the long term, it will improve the organization, delivery, and financing of health care services for people with chronic illnesses

Brandeis

throughout the city (which has a disproportionately high percentage (20%) of older residents) and the state, by (1) encouraging policymakers and housing and health care professionals to consider the housing implications of health care policies and practices, and the health care implications of housing policies and practices, (2) promoting the inclusion of innovative housing-health care-supportive services linkages in Medicare, Medicaid, state regulations, and initiatives to coordinate community-based long-term and acute care services for the very frail (e.g., PACE, the Social/HMO, and Massachusetts Medicaid's Senior Care Organizations (SCOs)), and (3) offering information, options, and models to address long-term care needs cost-effectively without compromising quality. If truly successful, the project will be replicable in other NORCs.

4. Methodology and Workplan

Governance structure. The Central Massachusetts Agency on Aging (CMAA) will oversee the proposed project. CMAA, an area agency on aging (AAA)⁴, is the largest AAA in Massachusetts, serving 61 cities and towns and 130,000 elders. For project staff, CMAA will first hire and supervise a full time project manager. The project manager and senior CMAA staff will hire two neighborhood coordinators, one for each of the targeted NORCs, in partnership with two neighborhood-based organizations that will house and jointly supervise the coordinators. These two neighborhood organizations, along with CMAA, the project manager, the coordinators, and two health and supportive service organizations, will comprise a project operations team that will meet monthly. A larger steering committee, to meet quarterly or biannually, will also be formed from among the community representatives who have participated in planning meetings⁵ and other relevant community and neighborhood organizations or service providers, many of which are mentioned throughout the narrative. (Appendix A describes the planning process undertaken for this proposal.) Brandeis consultants Susan Lanspery, Ph.D. and James J. Callahan, Jr., Ph.D. will provide technical assistance throughout the project.

⁴With federal Older Americans Act (OAA) funding, AAAs advocate on behalf of vulnerable older people, provide information and referral services linking older people and community programs, oversee OAA funding for nutrition and supportive service programs, assess community needs, and coordinate community services.

⁵Several planning meetings and two focus groups of neighborhood residents occurred during the development of this proposal. Appendix A lists planning group participants and briefly describes the planning process and focus groups.

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CMAA staff, especially the project manager, will work closely with the neighborhood-based coordinators, conducting training, providing resources and contacts, and monitoring progress. The project manager will also negotiate, or assist the neighborhood coordinators in negotiations, with health and supportive service providers to reorganize service delivery in the NORCs, develop new services, and improve coordination and collaboration.

Target neighborhoods. Worcester is a city of neighborhoods, many largely self-contained. Residents often identify closely with their neighborhood, and many services and organizations are decentralized. Most older Worcester residents have lived in the city for all or a substantial portion of their lives. These factors lend themselves to the proposed project's neighborhood focus. The project will target NORC residents with chronic illnesses in two Worcester neighborhood NORCs. Greater Elm Park and Oak Hill together have about 20,000 people, with an elder population of about 8,000 (40%). The project will focus on two compact census block groups in these neighborhoods: #7315 in Elm Park (about 40% age 60+) and #7324 in Oak Hill (about 35% age 60+). The 60+ population in these areas is somewhat older than the Worcester average, as well as disproportionately large. In the 1990 census, #7315's 60+ population was 931 (26% ages 80+, 37% 70-79); #7324's 60+ population was 1,248 (22% ages 80+, 36% 70-79).

Because of the high percentage of older residents, the prevalence of chronic illness is proportionately higher in these areas than in the general population. Local service providers estimate that approximately 35% of the elders in the targeted areas have chronic conditions and require some assistance; they also report a relatively high proportion of younger adults with disabilities in these neighborhoods. In all, they estimate that at least one thousand people with disabilities and chronic illnesses and 250 caregivers reside in these two areas. Over the three-year period, the proposed project's intent is to reach about half of this group (625 people) directly (e.g., through use of new consumer-driven supportive services or health services arrangements, or substantial contact with project staff) and another 1,200 people (including those with disabilities and chronic illnesses and others) indirectly (e.g., through participation in neighborhood councils, meetings, and social or educational events).

The targeted neighborhoods contain large and small multifamily buildings (including five subsidized planned senior housing developments and one subsidized NORC development) and single-family homes. In Elm Park, over half of owner-occupied properties are owned by people over 60, suggesting that housing-related issues may be especially important. In

Barden

Oak Hill, a higher than average proportion of older people reside in nursing homes, suggesting that more community-based alternatives may be in order.

Residents' incomes range from low to moderate. Ethnic, racial, and cultural backgrounds vary. The largest minority elder populations in Elm Park are Hispanic and Greek; in Oak Hill, Polish and Lithuanian residents comprise a sizable elder subgroup. Many elders in these two neighborhoods are first-generation immigrants.

The Worcester project. Worcester already has a rich array of health and supportive services for people with chronic illnesses and disabilities, but services are not always easy to obtain and overlaps exist. They are generally limited to those who meet income and functional need requirements, often have waiting lists even for those deemed eligible, and may not be available in the amounts or at the times needed or desired. An overview of the city's and targeted neighborhood's resources is also located in Appendix A.

The project will coordinate services and organize new, self-supporting services according to consumer interest. Although market survey and other research results will dictate program specifics, planning meeting participants and two focus groups of older residents (see Appendix A) reported concerns about health care access, transportation, service delivery and financing fragmentation, preventive health care, caregiver support, housing deterioration⁶, resident isolation and inactivity, lack of employment opportunities, community disintegration, and educational, language, and cultural barriers. The focus groups in particular underscored the potentially devastating impacts of environmental problems on older residents' health and ability to age in place. Together, the groups suggested the following interventions:

- interorganizational collaboration to streamline access to services
- developing mobile health vans for x-rays, mammography, routine checkups, and lab, blood pressure, and glucose testing
- keeping costs low through cluster care
- offering translators

⁶Older people living in homes that are in poor repair, unsafe, subject to extreme heat or cold, inaccessible to people with mobility impairments, poorly ventilated, and lacking in smoke detectors are subject to falls and other injuries; hypothermia or heat stroke; isolation; lack of exercise; allergic reactions to excessive mold, dust, and pollutants; and injuries or death from fires. Further, many target-area older multi-family building owners avoid renting out units because they cannot make needed repairs and fear renting to strangers. Thus they forego income, reducing further their resources for repairs, and reduce available rental housing. When these owners die, their heirs often sell the building to speculators, contributing to community instability.

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- providing respite services and screening and treatment for depression and other ailments to enhance caregivers' health and ability to continue
- organizing support for people who live alone and need hospice services
- housekeeping
- home repair
- forming purchasing cooperatives or other cooperative endeavors (such as telephone assurance programs, neighborhood improvement programs, or caregiving or other service exchange programs modeled after successful child care cooperatives)
- buying services (such as home maintenance or housekeeping) or products in quantity or wholesale from local vendors
- developing affordable independent or supportive housing
- prescription and grocery delivery services
- escort services
- health promotion and disease/injury prevention activities
- social and recreational activities
- support groups for people with specific illnesses or conditions and for caregivers
- advocacy in areas such as landlord/tenant issues
- "gatekeeper" programs, wherein mail carriers, meter readers, and others who regularly travel the neighborhoods are trained in outreach and referral (what to look for and what to do if problems arise)
- intergenerational arrangements (e.g., teenagers programming VCRs, setting up computers, or cleaning up the neighborhood; seniors using middle schools to learn to use computers)
- conducting home maintenance training for owners
- developing nonprofit, low-cost property management or management assistance firms
- promoting new initiatives to train current welfare beneficiaries to maintain and repair homes
- creating financial reserves for no- or low-interest home maintenance loans

Recent Worcester research will also guide the proposed project. For example, the 1990 Living Here Tomorrow study ranked lack of affordable housing as "the dominant human care issue facing area residents" and named low-income older Worcester residents as one of the hardest-hit groups. According to the CMAA 1997 needs survey, the top four

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respondent needs were legal and financial issues, housing and household issues, social support and counseling, and transportation. Worcester EOE senior center survey respondents said that they were most interested in a senior center sponsoring (1) information about programs and services, (2) events such as dances, concerts, or organizational meetings, and (3) health clinics for medical care, information, and screenings.

NORCs programs can help community groups working with NORCs residents, and their HMO partners, to discover new, more customer-oriented, and more cost-effective ways of delivering services. At the same time, developing NORCs programs and encouraging linkages with HMOs and other providers will offer new choices to older consumers in their struggle to maintain health and quality of life in familiar neighborhoods. Although specific links between consumers, the project, and health care providers will also depend on consumer input and negotiations, HMOs have expressed interest in the NORCs program's potential to:

- Increase participation in the health promotion programs HMOs currently offer to members and non-members
- Expand the community benefits⁷ HMOs offer (programs, services, grants, and other assistance; for example, Fallon offers a "Senior Health Resource Line")
- Recruit new members from existing groups while promoting positive image, saving marketing dollars, and attracting those who may not otherwise choose managed care
- Provide lower cost, higher quality service to enrollees due to efficiencies gained through economies of scale and consumer orientation and to the potential infusion of additional support (e.g., from property managers, residents, foundations, local businesses and community groups) for NORCs programs and services
- Retain members due to their participation in the project
- Reduce inappropriate use of emergency and other medical services and relieve strain on HMO staff resulting from Medicare clients calling about non-medical, but important, problems
- Learn more about older consumers from the program's market research

Furthermore, the SSPSH-NPLH experience suggests that the model's emphasis on empowerment and community-building leads to people helping each other more: without substituting for professional help, volunteers can extend professionals' ability to prevent or mitigate crises, especially if they feel that the NORCs project offers backup. In addition, the model's respectful treatment of consumers (informing them about constraints and consequences and obtaining input from

⁷ HMOs are required to report annually to the Massachusetts Attorney General on their community contributions.

05/21/99 02:16 FAX 6173328084

MASS HEALTH COUN

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MASSACHUSETTS HEALTH COUNCIL, INC.

4 Garrison Street

Chestnut Hill, MA 02187/617-865-3711

To: James Callahan**From: Susan****Date: 5/21/99**

I received your call. Thank you for taking the time to call the speakers. Feel free to arrange the speakers in any order you like. We were asked by two of the speakers if they could bring a second person to appear on the panel with them. This is very unusual for us but we agreed to their request; consequently, Dr. Paul Barreira and Joan Mikula will be on the panel for the Dept. of Mental Health and Deborah Bridge and Kim Sholt will be participating from M-Power. It's alot of speakers but they were told they must share the 15 minute allotted time period for speakers.

Thank you for all your help and call me if you have any questions or need additional information. Ruth Smith, Ph.D. is the Chairman of the Program Committee. Also, feel free to call her at the Shriver Center 781-642-0229.

Paul Barreira, M.D. or Joan Mikula 617-727-5500 x 476
 Dan Rome, M.D. 781-466-9460
 Deborah Bridge or Kim Sholt 464-1400
 David Mattesodo 781-855-3520
 Angelo McClain 617-790-4000
 Lisa Lambert 617-227-2925

Could you also remind them to send me a short paragraph about themselves for the purposes of introduction? It was mentioned in their confirmation letters but I have only received Paul's. They can fax them to me at 617-332-8084.

FAX TO 293 - 8811
BONNY ROZEN
FROM PAUL WEINSTEIN

May 24, 1999

DRAFT

MEMORANDUM FOR THE VICE PRESIDENT

THROUGH: RON KLAIN
ELAINE KAMARCK

FROM: SARAH BIANCHI
MARK MAZUR
ROBERT ROZEN
PAUL WEINSTEIN

Sarah
FBI
[Signature]

SUBJECT: **Health Care Coverage Subsidy Initiative**

Background

The Census Bureau recently estimated that 43.7 million Americans are uninsured – an increase of 1.7 million from 1996 and nearly 5 million more than in 1992. After initial efforts to expand coverage to all Americans, this has continue to propose incremental reforms to provide more Americans access to affordable health care coverage.

Proposal

To provide a tax credit for the premium subsidies provided by a health insurer. Under this proposal, a health insurer would receive a tax credit to offset a portion of the costs associated with providing each new individual with health care coverage. The credit would only be available to insurers who agree to provide a comprehensive package of health care coverage. Credits would be allocated to State governments who are responsible for choosing the providers eligible for credit. Each State would negotiate a coverage package with the insurer based on guidelines from the Federal government. The agreements could be reached as part of a competitive process.

Only individuals who are currently not covered, who meet certain income criteria, who choose to purchase insurance through the individual marketplace, and who are not eligible for existing government health assistance including Medicaid, Medicare, and CHIP, would be eligible for coverage under this program. State governments would be responsible for certifying that each new individual in the plan was uninsured prior to joining the plan. The insurer can continue to take the credit as long as the individual stays in the program. Individuals whose companies later decide to provide health care coverage would no longer be eligible.



Audrey Choi
05/06/99 11:19:54 AM

Record Type: Record

To: Thomas A. Kalil/OPD/EOP@EOP, Sarah A. Bianchi/OVP@OVP, Christopher C. Jennings/OPD/EOP@EOP, David W. Beier/OVP@OVP

cc:

Subject: Health Care in the Information Age

FYI, thought you might find this interesting.

----- Forwarded by Audrey Choi/OVP on 05/06/99 11:18 AM -----



owner-benton-compolicy@CDINET.COM
05/05/99 02:59:00 PM

Record Type: Record

To: Audrey Choi@ovp@eop

cc:

Subject: Health Care in the Information Age

May 5, 1998

Contact: Rachel Anderson
(202) 638-5770
rachel@benton.org

BENTON RELEASES REPORT ON HEALTH CARE IN THE INFORMATION AGE

Benton Foundation's Communications Policy and Practice program releases the latest report in its "What's Going On" series, *Networking for Better Care: Health Care In the Information Age*. The report describes efforts currently under way to use information tools to improve the health care system and identifies issues that must be addressed in order to advance the information revolution in health. The goal, in part, is to serve as a bridge between the health care sector, where many of these issues are familiar, and the broader public.

A growing number of policymakers, health care providers, and consumers believe information resources offer great hope for addressing concerns about cost, quality, and access to health care. *Networking for Better Care* begins by describing how judiciously collected and effectively communicated information can help professionals provide better care, turn patients into more enlightened consumers of health services, and ultimately enable individuals and communities to address some of the root causes of illness before professional intervention is required.

**PHOTOCOPY
PRESERVATION**

Networking for Better Care: Health Care In the Information Age is made possible with generous support from the Robert Wood Johnson Foundation.

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PACE UNIVERSITY
NEW YORK CITY • WESTCHESTER

May 25, 1999

N.Y. Campus
NYC 10038

861 BEDFORD ROAD
PLEASANTVILLE, NY 10570-2799
(914) 773-3200

PLEASANTVILLE CAMPUS

Chris Jennings
Health Policy Coordinator
White House
Washington, D.C.

Dear Sir;

I have been involved in mental health issues, policies, practice for at least 30 years. I read of your conference in the N.Y. Times and believe I have much to contribute to the conference.

I would ask you to include my knowledge and experience.

Sincerely Susan P. DelBene PhD, MEd
- Assoc. Professor

PHOTOCOPY
PRESERVATION

515 B upa r.w. ---
Stratford, CT
06614

PACE UNIVERSITY
Lienhard School of Nursing

CURRICULUM VITAE OF: Susan B. Del Bene, Ph.D., R.N., C.S.
TITLE: Associate Professor, BS Nursing and Master's Program, New York

(203) 375 8656

EDUCATIONAL BACKGROUND

<u>Dates</u>	<u>Institution</u>	<u>Degree</u>	<u>Functional Major</u>	<u>Clinical Major</u>
1965	University of Bridgeport Bridgeport, CT	A.D.	Nursing	
1970	University of Bridgeport Bridgeport, CT	B.S.	Nursing	
1976	Fairfield University Graduate School of Education Fairfield, CT	15 crs.	Education	
1980	Hunter College of the City of New York-Hunter/Belle- vue School of Nursing New York, NY	M.S.N.	Nursing	Psych/Mental Health Nursing
1985	Graduate Center City University of New York New York, NY	Ph.D.	Social Science	

CERTIFICATION/SPECIALIZATIONS

Clinical Psychiatric Specialist - American Nurses' Association, 1987
Psychiatric/Mental Health Nursing of Adults/Administration minor (M.S.)
Medical Sociology - Gerontology

PROFESSIONAL EXPERIENCE

<u>Dates</u>	<u>FT/PT</u>	<u>Institution</u>	<u>Position and/or Function</u>	<u>Clinical Area</u>
1987-	FT	Pace University	Associate Professor	Women's Health
Present		Lienhard School of Nursing New York, NY	Specialty Master's and RN Upper Division Family Nurse Practitioner	Nursing Research
1985-87	FT	Pace University Lienhard School of Nursing Pleasantville, NY	Assistant Professor Generic & Specialty Master's Programs Family Nurse Practitioner	Psych/Mental Health; Conceptual Frame- works of Nursing
1981-85	FT	Pace University Lienhard School of Nursing Pleasantville, NY	Instructor Generic & Specialty Master's Programs	Nursing Research; Group Dynamics; Community & Mental Health Nursing; Community Health; Community Health Nursing
1980-81	FT	* Sacred Heart University Fairfield, CT	Instructor-Undergra- duate, upper-division nursing program	Theoretical Intro- duction to Nursing Research in Nursing

Susan B. Del Bene (continued)

PROFESSIONAL EXPERIENCE

<u>Dates</u>	<u>FT/PT</u>	<u>Institution</u>	<u>Position and/or Function</u>	<u>Clinical Area</u>
1978	FT	University of Bridgeport Bridgeport, CT	Adjunct Instructor	Med/Surg Nsg (lecture & clinical); Bio-psycho patterns of life process
1976-77	FT	St. Vincent's Medical Center Bridgeport, CT	Instructor-Practical Nurse Program	Community health, Adults and children

PRESENT PROFESSIONAL MEMBERSHIPS

<u>Dates</u>	<u>Organization</u>
Ongoing	American Nurses' Association
Ongoing	Connecticut Nurses' Association: District III
Ongoing	American Association of University Professors
Ongoing	American Nurses' Historical Society
Ongoing	Association of Orthopsychiatry
Ongoing	Sigma Theta Tau

ACTIVITIES WITHIN THE COMMUNITY

<u>Dates</u>	<u>Organization</u>	<u>Involvement</u>	<u>Description of Activity</u>
1988	Beth Israel Medical Center New York, NY	Member, Search Committee	Search Committee for Dean Phillips-Beth Israel School of Nursing
1985-90	Westchester Coalition for the Homeless		
1986-94	Stratford Visiting Nurses Association	Consultation	Psychiatric/Mental Health Consultations

LIENHARD SCHOOL OF NURSING COMMITTEES

<u>Dates</u>	<u>Committee</u>	<u>Involvement</u>
1990-Present	Faculty Development Committee	Member
1986-89	Lienhard School of Nursing Curriculum Committee	Member
1986-88	Ad hoc Committee: Refinement of Philosophy and Conceptual Framework	Member
1986	NUR 503 Community and Rehabilitation Nursing	Course Coordinator
1985-86	NUR 503 Psychiatric/Mental Health/Community Nursing	Course Coordinator
1985-86	Curriculum Committee	Chairperson
1985	Psychiatric/Mental Health for Generic Baccalaureate Program	Consultant for Psych/Mental Health component
1985	Conceptual Framework Refinement	Member
1984-85	Student Orientation: Lienhard School of Nursing	Coordinator
1983	Faculty Development	Member
1982-85	Curriculum Task Force	Member
1982-84	Student Orientation	Coordinator
1982-83	Student Affairs Committee	Chairperson
1982-83	Ad hoc Committee: Development of Conceptual Framework and Philosophy of Lienhard School of Nursing	Member
1982-83	All Generic Master's Clinical Agencies	Clinical Coordinator
1982-83	All Nursing Programs	Student Ombudsman
1982	Lienhard School of Nursing: Reaccreditation for NLN	Member

Susan B. Del Bene (continued)

CONTINUING EDUCATION ATTENDED

<u>Dates</u>	<u>Sponsoring Organization</u>	<u>Title of Conference</u>
1993	Thomas Jefferson University Philadelphia, PA	Reaccreditation Process for Colleges and Universities
1992	Sabbatical	
1989	National League for Nursing Seattle, WA	Annual Meeting
1987	American Orthopsychiatric Association Washington, D.C.	The Family System
1987	University of Genoa Genoa, Italy	Family Therapy in Cancer Patients
1986	Professional Training Workshops in Mental Health and Education New York, NY	Depression: Optimizing Treatment Strategies
1986	Harvard Medical School Boston, MA	Forum on Homeless Persons
1985	Professional Training Workshops in Mental Health Education	Group Therapy: Irvin Yalom
1985	American Nurses' Historical Society Philadelphia, PA	Annual Conference
1985	Harvard Medical School Boston, MA	Teenage Suicide
1985	Graduate Center of the City University of New York New York, NY	The Ethos of Bereavement
1985	New Rochelle Hospital New Rochelle, NY	Perspectives on Aging
1985	Graduate Center of the City University of New York New York, NY	Occupation and Work Forum

HONORS

<u>Dates</u>	<u>Honor</u>
1986-87	Pace University Summer Scholarly Research Grant
1985-86	Partial Scholarship for Doctoral Studies
1985-86	Pace University Summer Scholarly Research Grant
1979-90	Sigma Theta Tau
1978-80	National Institute of Mental Health Grant for Graduate Study
1969	Health and Education Grant for Undergraduate Study

PHOTOCOPY
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CURRENT RESEARCH

<u>Dates</u>	<u>Title of Project</u>
1989-93	Pro-Choice in the Occurrence of Post-Traumatic Stress Disorders in Women, funded by Pace University Summer Research Award for \$925
1987	Family Theory and Family Therapy for Families of Cancer Clients, funded by Pace University Summer Research Award for \$2,500 at the University of Genoa, Italy
1985-90	The Use of an Educational Support Group for the Mental Wellness of the Families of Alzheimer's Disease Patients - Funded by Pace University Summer Research Award, Summer 1986 for \$1,200

COMPLETED RESEARCH

<u>Dates</u>	<u>Title of Project</u>
1985-93	Professionalization of Nursing: A Historical Analysis and an Examination of the Segmentation of Nurse Practitioners
1986-90	Geropsychiatry: The Impact on Wellness in the Elderly
1980	Locus of Control, Life Crisis Events and the Occurrence of Emotional Isolation in Mid-Life Women

SCHOLARLY PRESENTATIONS

<u>Dates</u>	<u>Sponsoring Organization</u>	<u>Title of Paper/Workshop/Panel</u>
1993	Stratford Visiting Nurse Association Stratford, CT	Family Theory and Therapy
1988	Mt. Sinai Hospital New York, NY	RN Completion Program
1988	Regents Hospital New York, NY	Family Theory and Family Therapy
1987	University of Genoa Genoa, Italy	Five week seminar: Family Theory and Family Therapy for Families of Cancer Patients
1986	Pace University Health Education Series Pleasantville, NY	Women and Loss
1985	3rd Annual Health Education Series of the Lienhard School of Nursing, Pace University Pleasantville, NY	Women and Loss
1985	State University at Binghamton Scholarly Research Day - Sigma Theta Tau Binghamton, NY	Professionalization of Nursing: A Historical Analysis and an Examination of the Segmentation of Nurse Practitioners
1985	New Rochelle Hospital Medical Center New Rochelle, NY	Geropsychiatric Implications for Nursing
1985	First Annual Westchester County/Citibank Women's Health Conference Westchester Community College Valhalla, NY	Emotional Isolation and Mid-Life Women: The Impact of Loss

The City of New York

The Department of Mental Health, Mental Retardation, and Alcoholism Services
93 Worth Street, New York, NY 10013 - (212) 219-5380/3; Fax (212) 219-5405



Neal L. Cohen, M.D.
Commissioner

Ernest E. Batson
*Associate Commissioner
for Alcoholism and
Substance Abuse Services*

November 20, 1998

Susan Del Bene Ph.D, R.N.
Pace University
1 Pace Plaza
New York, N.Y. 10038 - 1598

Dear Dr. Del Bene:

I am responding on behalf of Mayor Rudolph W. Giuliani to your letter regarding the nursing students' debate on the pros and cons of the use of the drug Methadone.

The department commends you for helping to increase the awareness in one of the city's critical public health challenges. You may submit the findings from the debate to my attention at New York City Department of Mental Health, Mental Retardation and Alcoholism Services, 93 Worth Street, Room 1205, New York, New York 10013. We will review the findings and provide you with feedback.

Thank you for sharing this information with us.

Sincerely,

A handwritten signature in cursive script, reading "Ernest E. Batson", is written over the typed name.

Ernest E. Batson
Associate Commissioner

EEB\lc

cc: Rosa M. Gil, D.S.W.
Neal L. Cohen, M.D.

Scral

May 17, 1999



David Beier
Chief Domestic Policy Advisor
to the Vice President
Office of the Vice President
Old Executive Office Building
Room 286
Washington, D.C. 20501

Dear David:

This letter is in follow-up to the message I left you last week concerning the June 2, 1999, meeting of the American Hospital Association's (AHA) advisory committee on integrated delivery systems. This meeting, which will take place at AHA's Washington, D.C. office, brings together many of our largest AHA members for an intimate, interactive dialogue on issues of concern to integrated delivery systems. We would appreciate your willingness to speak to this group to discuss Administration priority issues, including Medicare reform. The meeting will begin at 10:00 am and will conclude at 3:00 p.m. We are very flexible in terms of timing of the agenda items and we would be more than willing to accommodate your scheduling needs on that date.

I will call you within the next several days to determine your availability. Thank you for your consideration.

Sincerely,

Mary Beth Savary Taylor

Mary Beth Savary Taylor
Director
Executive Branch Relations



Washington, DC Center for Government and Public Affairs
Chicago, Illinois Center for Health Care Leadership

Liberty Place, Suite 700
325 Seventh Street, N.W.
Washington, DC 20004-2802
(202) 638-1100

MAY 17 '99 02:39PM AHA WASH DC OFFICE

Susan K. Neely
Vice President for Communications



ASSOCIATION OF
AMERICAN
MEDICAL COLLEGES

2450 N Street, N.W., Washington, D.C. 20037-1127
Telephone: (202)828-0459 Fax: (202)828-1123
E-Mail: skneely@aamc.org
Web Site: <http://www.aamc.org>



PHOTOCOPY
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2450 N STREET, NW WASHINGTON, DC 20037
PHONE 202-828-0400 FAX 202-828-1125
HTTP://WWW.AAMC.ORG

April 15, 1999

Diane Magrane, M.D.
Associate Dean for Medical Education
The University of Vermont
College of Medicine, E109 Given Building
Burlington, VT 05405

Dear Dr. Magrane,

Enclosed is an agenda for the meeting of the working group on family-centered care on May 17. As you will note, the purpose of the meeting is to advise the AAMC on how it can foster the inclusion of the precepts of family-centered care in the medical education curriculum. Of relevance to the working group's discussion may be background materials on several related AAMC initiatives. These include the following items:

- Summary of the AAMC's Medical School Objectives Project

The AAMC embarked on the Medical School Objectives Project (MSOP) three years ago. The primary purpose of the project is to delineate the attributes that medical students should possess at the time of graduation from medical school, to develop within the medical education community a consensus on those attributes, and based on that consensus to set forth learning objectives for the medical student education program. The third MSOP report on communications skills will be released shortly.

- "What Americans Say About the Nation's Medical Schools and Teaching Hospitals"

The association has conducted extensive opinion research on public attitudes toward issues affecting medical schools and teaching hospitals. Enclosed is a report on the latest research findings. In particular, the section entitled, "Definition of a Good Doctor," on pages 9-13 may be of particular interest to the working group.

- Summary of ACCESS Survey

Recently, the association conducted a short, electronic survey on family-centered care and the undergraduate and graduate curricula. The enclosed report summarizes the responses from member institutions.

In addition, we have included a list of the confirmed participants for the working group meeting. We are pleased to have representatives from different aspects of the medical education process. We look forward to a lively, productive discussion on May 17.

By now you should have already received a travel expense report for your journey to Washington, DC. If you have any logistical questions related to your travel and hotel accommodations please contact my assistant, Nathalie Tavel at 202/828-0542 or ntavel@aamc.org. There will be a dinner for early arrivals at 6:30 p.m., on Sunday, May 16 at BeDuCi Mediterranean Restaurant. The restaurant is located at 2100 P Street, NW, just 3 blocks from the Monarch Hotel. We hope your travel schedule will allow you to join us for this social gathering as well.

Sincerely,



Susan K. Neely
Vice President for Communications

C: Darrell Kirch, M.D.
Jordan Cohen, M.D.
Beverley Johnson

Attached: Agenda
MSOP Summary
Public Opinion Research Report (II)
Summary of ACCESS survey
List of attendees



JEANNE SHAHEEN
GOVERNOR

STATE OF NEW HAMPSHIRE

OFFICE OF THE GOVERNOR

603-228-1180
Stephanie Shaheen

Baldick

March 19, 1999

MAR 19 1999

Rout

Vice President Al Gore
c/o Ms. Lisa Berg, Scheduler
VIA FACSIMILE

Dear Vice President Gore:

I would like to cordially invite you to participate in a policy leaders forum on child care as part of the National Association for the Education of Young Children's (NAEYC) New England conference. The forum will be held in the Whittemore Center at the University of New Hampshire on Friday, May 7, 1999 from 6:30pm-9:00pm.

NAEYC is the nation's largest organization of early childhood professionals and others dedicated to improving the quality of early childhood education programs. Founded in 1926, NAEYC's membership has grown to more than 103,000, and includes a national network of more than 400 local, state, and regional early childhood organizations. Over 6000 of these member organizations are from New England.

I will be hosting this child care policy leaders forum and would be delighted if you could participate. Your dedication to our nation's children and your commitment to addressing the need for out-of-school care will greatly contribute to this discussion. I will also be inviting Senator Jeffords from Vermont to discuss the *Health, Education, Labor and Pensions* Committee's work on child care policy. The News Director for WMUR-TV, Karen Brown, has agreed to moderate the discussion. Lifetime Television, a cable network, will also be covering and sponsoring the event. We anticipate statewide and national media coverage of this unique and relevant discussion.

The policy leaders forum will be open to the public. University students and professors, business leaders, state legislators, child care providers and advocates, and other state policy-makers will be encouraged to attend. We anticipate over 2,500 attendees and will be videotaping the event for distribution to more than 400 NAEYC affiliates throughout the country, in all 50 states.

A representative from my office will contact your scheduler in the next few weeks to discuss the possibility of your attendance. I look forward to seeing you in New Hampshire in the near future.

Very truly yours,

Jeanne Shaheen

Jeanne Shaheen

policy leaders forum

Official role of Gov Sen. Jeffords

May 7

*Open hall roundtable questions from audience
Lifetime is developing list of ?'s for aud. to ask*

SPONSORSHIP PROPOSAL

The New Hampshire Association for the Education of Young Children Child Care Policy Leaders Forum

BACKGROUND:

The Organization

NHAEYC, the New Hampshire affiliate of the National Association for the Education of Young Children (NAEYC), is hosting the annual New England-wide conference in Portsmouth, NH from May 6-8, 1999. The conference is expected to have approximately 1,200 conferees in attendance.

The NAEYC is the nation's largest organization of early childhood professionals and others dedicated to improving the quality of early childhood education programs. Founded in 1926, NAEYC's membership grew to more than 103,000 in 1998 and includes a national network of more than 400 local, state and regional early childhood organizations affiliated with NAEYC.

The Forum

On May 7, 1999, the NHAEYC will hold a policy leaders forum on child care as part of the New England-wide conference. Governor Shaheen will be hosting this bi-partisan event and is planning to invite child care policy leaders on the state and national level to discuss the value of early childhood education and quality child care. The News Director for WMUR-TV, Karen Brown, has agreed to moderate the discussion. Lifetime Television, a cable network, will also be sponsoring the event. We anticipate statewide and national media coverage of this unique and relevant discussion.

The policy leaders forum will be held in the Whittemore Center at the University of New Hampshire and will be open to the public. University students, business leaders, state legislators, child care providers and advocates, and other policy-makers will be encouraged to attend. We anticipate over 2,500 attendees and will be videotaping the event for distribution to more than 400 NAEYC affiliates throughout the country, representing all 50 states.

BENEFITS OF SPONSORSHIP:

By sponsoring the child care policy leaders forum, your company will be:

- Associating with state and national policy leaders who are making a difference in the lives of working parents throughout the country.
- Establishing a strong corporate image among community leaders, working parents, child care providers and advocates, and other policy-makers.
- Positioning yourself as a corporate citizen committed to the needs of all New Hampshire families, including your own employees.
- Leading the way for other businesses to participate in a dialogue about the importance of quality child care.

SPONSORSHIP OPPORTUNITIES:

Corporate Gold Sponsor \$10,000

- Corporate Logo strategically displayed directly behind policy leaders on the stage before 2,500 guests and statewide and national media coverage
- Corporate Logo and mention in all event publicity
- Corporate Logo to appear on videotape of the event for distribution to more than 400 NAEYC affiliates throughout the country, representing all 50 states.
- Admittance to a pre-event reception with policy leaders
- Photograph with policy leaders during the pre-event reception
- Corporate Logo on the invitation
- Corporate Logo on the program cover
- Corporate Logo to appear in the Final NAEYC Conference Program
- Corporate name mentioned at the beginning of the event
- Corporate Information Distribution at the Whittemore Center
- Admittance to a post-event reception with policy leaders and conferees
- 20 tickets for floor seating at the event

Corporate Silver Sponsor \$5,000

- Admittance to a pre-event reception with policy leaders
- Photograph with policy leaders during the pre-event reception
- Corporate Logo to appear in the program
- Corporate Banner and signage strategically displayed around the Whittemore Center
- Corporate name mentioned at the beginning of the event
- Corporate Information Distribution at the Whittemore Center
- Admittance to a post-event reception with policy leaders and conferees
- 15 tickets for floor seating at the event

Corporate Bronze Sponsor \$2,500

- Corporate Logo to appear in the program
- Corporate Information Distribution at the Whittemore Center
- Corporate name mentioned at the beginning of the event
- Admittance to a post-event reception with policy leaders and conferees
- 10 tickets for floor seating at the event

OTHER SPONSORSHIP OPPORTUNITIES:**Reception Sponsor \$10,000**

- Corporate Logo to appear on cocktail tables
- Corporate Banner and signage strategically displayed in reception area
- Admittance to a pre-event reception with policy leaders
- Photograph with policy leaders during the pre-event reception
- Corporate Information Distribution at the Whittemore Center
- Corporate name mentioned at the beginning of the event
- Admittance to a post-event reception with policy leaders and conferees
- 20 tickets for floor seating at the event

Printed Materials Sponsor \$5,000

- Corporate Logo on the invitations
- Corporate Logo on the back program cover
- Corporate Information Distribution at the Whittemore Center
- Corporate Banner and signage strategically displayed around the Whittemore Center
- Corporate name mentioned at the beginning of the event
- Admittance to a post-event reception with policy leaders and conferees
- 15 tickets for floor seating at the event

TO: INTERESTED PARTIES
FR: BETSY MULLINS
RE: HONORARY CHAIR REQUEST
DA: APR 27 99

Lisa Brown has signed off on the attached invitation for VP/MEG to serve as the honorary chairs of "A Family Celebration: One Giant Leap for Charity," which will honor Gladys Knight's 50th year in show business.

Benefits from the Sept. event go to the Associates for Breast & Prostate Cancer Studies at the John Wayne Institute and the Child Welfare League of America, in association with We Care About Kids.

Lisa Brown suggested the VP/MEG's titles be "National Honorary Chairs." The event details are below:

Honorees:

Gladys Knight, for her 50th year in entertainment
The entire cast of ABC's "The Practice."

Honorary Chairs:

Joanna and Sidney Poitier
Tracy and Kenny "Babyface" Edmonds
Ann and Vernon Jordan
Will Smith and Jada Pickett

(NB: These are the people invited to serve as chairs, however, not all have accepted. The event's producers will not invite anyone else to serve as honorary chairs without OVP/MEG approval.)

Celebrities performing at the Sept. event:

Dan Akroyd
Mariah Carey
Stevie Wonder
Natalie Cole
Dionne Warwick
Fran Drescher
Gladys Knight
Patti LaBelle

Charity Board:

Kyle Eastwood & Laura Gomez (Kyle is the son of Clint, Laura is his wife)
Allan Rich (producer) & Fran Drescher (actress and Allan Rich's wife)
Elaine Rich ("the agent")
Michael Goldstein (CEO of Toys R Us)
Bill Scott of Panavision

A FAMILY CELEBRATION **"One Giant Leap for Charity"**

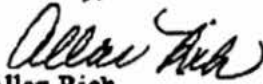
April 9, 1999

Mr. David Jones
Office of Public Liason

Dear Mr. Jones,

Thank you for speaking with me today. Enclosed is the letter of request in addition the letter of commitment from Gladys Knight that shows this event is taking place. Also, please note that Vice President and Mrs. Gore do not need to be in attendance, unless they are able, in order for us to make them the Honorary Chairs. I know Gladys Knight was thrilled with the suggestion of this possibility.

Sincerely,


Allan Rich
Event Producer

A FAMILY CELEBRATION "One Giant Leap for Charity"

March 18, 1999

Vice President and Mrs. Gore
c/o Mr. David Jones

Dear Vice President and Mrs. Gore,

I am writing to you about a very important event taking place on Sunday, September 26, 1999 at The Regent Beverly Wilshire Hotel in Beverly Hills, California. The event is entitled: A FAMILY CELEBRATION: "One Giant Leap for Charity." The celebrity-studded evening will celebrate Gladys Knight on her 50th year in Show Business and will benefit The Associates for Breast & Prostate Cancer Studies at The John Wayne Cancer Institute and the Child Welfare League of America in association with We Care About Kids.

It is my hope that you will both accept the honor of being our Honorary Chairs for the evening. We are simply asking that you lend your name for the event.

We are excited that A FAMILY CELEBRATION: "One Giant Leap for Charity" has generated a great amount of interest and support. Throughout the evening, many celebrities will offer their personal views and stories on family, interspersed with great musical moments. In addition, we will present personal video segments from Ron Howard, Brian Grazer, David E. Kelley, Roger Moore, Drew Carey and Larry King. With the collective support of all involved, this evening will be filled with entertainment, love and compassion.

With The John Wayne Cancer Institute's tireless dedication to research and the Child Welfare League of America in association with We Care about Kids' mission to educate young people and promote tolerance by investigating and depicting all aspects of human prejudice through the medium of film and discussion, clearly so many will benefit from this evening's proceeds.

Vice President and Mrs. Gore, we sincerely thank you for your consideration and look forward to hearing from your offices soon. Your lending your names will help to ensure a successful and memorable event.

Please do not hesitate to contact me should you have any questions at all. I can be reached at (310) 657-6763.

With warm regards,


Allan Rich
Co-Producer

TO: LISA BROWN
FR: BETSY MULLINS
RE: VETTING FOR HONORARY CHAIR REQUEST
DA: APR 26 99

*ok if ok with
Sarah Bianchi
- we should make the
VP/MBG co-honorary
chairs + others
on honorary
committee
of
pass. b.c.*

Attached please find a copy of an invitation to the VP and MEG to serve as honorary chairs of a charity event in LA that will be held in Sept.

Due to circumstances beyond my control, time has passed since this invite was sent over here, and **they're now under a gun**. I told the assistant to show producer Alan Rich, that I would give him some guidance on Tuesday or at the very least an update as to when we might have an answer.

Also, the invitation has not been drafted yet since they're waiting on an answer from us. He understands that a blue line of that invite will have to go through a vetting process as well.

Per the recommendation of Mary Lou McHugh, I've attached a copy of the invite for your review. Below please find other details about the event:

Honorees:

Gladys Knight, for her 50th year in entertainment (heavily vetted in preparation for last year's performance at the WH, according to the organizer of this event, who worked on that event as well).

The whole cast of ABC's "The Practice" (I've attached the bios from ABC's web site)

Honorary Chairs (some have not confirmed, but have been invited. The event organizer understands that if any other names are added at any point before the Sept. event, he has to get our approval first.):

Joanna and Sidney Poitier

Tracy and Kenny "Babyface" Edmonds

Ann and Vernon Jordan

Will Smith and Jada Pinkett

Celebrities performing at the Sept. event:

Dan Akroyd

Mariah Carey

Stevie Wonder

Natalie Cole

Dionne Warwick

Fran Drescher

Gladys Knight

Patti LaBelle

Charity Board:

Kyle Eastwood & Laura Gomez (Kyle is the son of Clint, Laura is his wife)

Alan Rich (actor) & Fran Drescher (actress and Alan Rich's wife)

Elaine Rich ("the agent")

Michael Goldstein, CEO of Toys R Us

Bill Scott of Panavision



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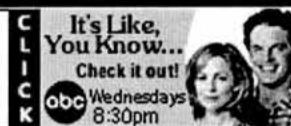
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the practice **Cast Bios**

DYLAN MCDERMOTT
 Bobby Donnell

Whether a gunslinger, army grunt, murdering villain, obsessed writer or romantic leading man, Dylan McDermott brings a recognizable presence and quiet intensity to his body of work.



McDermott currently stars in the critically acclaimed television series, **THE PRACTICE**, created by David E. Kelley, which airs on ABC. He spent his summer of '98 hiatus filming the Warner Bros. romantic comedy, **THREE TO TANGO**, with Matthew Perry and Neve Campbell. In the film, McDermott stars as a rich and successful two-timing businessman.

McDermott's other film credits include Paramount Pictures' **HOME FOR THE HOLIDAYS**, directed by Jodie Foster and co-starring Holly Hunter and Robert Downey, Jr. Also, in 1995, he starred in Rysher Entertainment's **DESTINY TURNS ON THE RADIO**, opposite Nancy Travis and Quentin Tarantino.

McDermott starred alongside renowned director Richard Attenborough and Elizabeth Perkins in John Hughes' 1994 remake of **MIRACLE ON 34TH STREET**. In early 1994, McDermott portrayed the villainous John Stark in Imagine/Universal's **THE COWBOY WAY**, opposite Woody Harrelson and Kiefer Sutherland.



In 1993, McDermott received numerous accolades for his role as Clint Eastwood's secret service partner in director Wolfgang Petersen's **IN THE LINE OF FIRE**. Having leapt the crucial 100-million-dollar hurdle in domestic box office receipts, the film propelled McDermott to the vanguard of Hollywood's leading men.

Born in Connecticut and raised in New York City, Dylan McDermott first developed an interest in acting in high school, due in part to the encouragement of his stepmother, playwright Eve Ensler. In fact, one of his first appearances on the stage was in the production of Ensler's original play, **SCOOONCAT**.

Earning his drama degree at Fordham University, McDermott joined the prestigious Neighborhood Playhouse in New York, where he seized the chance to study under acting legend Sanford Meisner. His first professional role came as Wykowski Selridge in Neil Simon's Broadway production of **BILOXI BLUES**.

He premiered on the big screen in **HAMBURGER HILL**, followed

Other Bios

MICHAEL BADALUCCO
 Jimmy Berluti

LARA FLYNN BOYLE
 Helen Gamble

LISAGAY HAMILTON
 Rebecca Washington

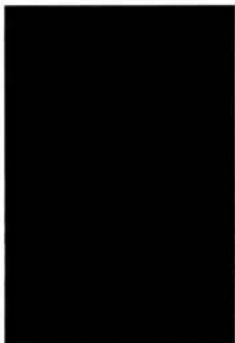
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 Eugene Young

CAMRYN MANHEIM
 Ellenor Fruit

DYLAN MCDERMOTT
 Bobby Donnell

KELLI WILLIAMS
 Lindsay Dole





by STEEL MAGNOLIAS, with Julia Roberts. His television credits include the critically acclaimed Showtime film, THE FEAR INSIDE, with Christine Lahti.

McDermott currently maintains residences in both New York and Los Angeles. ○

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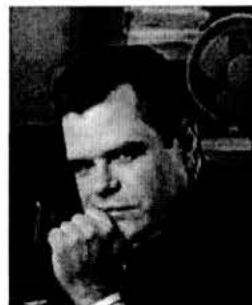
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Cast Bios

MICHAEL BADALUCCO
 Jimmy Berluti

Michael Badalucco got his start in the entertainment industry at a very young age, going to work with his father who was a carpenter on movie

sets. During the filming of FAIL-SAFE, starring Henry Fonda, a photo of a young boy was needed. Eight-year-old Badalucco posed for the picture, and thus began his acting career.



While earning a B.A. in theater arts from SUNY New Paltz, Badalucco performed in more than 20 plays with the New Paltz Repertory Company. His New York stage credits include WAITING FOR THE DOUGH, THE TOOTH OF CRIME, OF MICE AND MEN, STEEL ON STEEL and THE LOVE OF DON PERLIMPLIN FOR BELISA IN HIS GARDEN.

His first speaking part in a feature film was in RAGING BULL, which led to additional roles in such movies as BROADWAY DANNY ROSE, MILLER'S CROSSING, SLEEPLESS IN SEATTLE, JUNGLE FEVER, THE PROFESSIONAL, MAC, THE SEARCH FOR ONE-EYE JIMMY and ONE FINE DAY. This past summer Badalucco filmed YOU'VE GOT MAIL, with Tom Hanks and Meg Ryan.

On television, Badalucco has been seen in guest-starring roles on the series, LAW & ORDER, SOUTH BEACH and CENTRAL PARK WEST.

He and his wife, Brenda, make their home in New York City. Michael Badalucco is known as a raconteur, often entertaining his friends and colleagues with his myriad stories.

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Other Bios

MICHAEL BADALUCCO
 Jimmy Berluti

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 Helen Gamble

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LARA FLYNN BOYLE
Helen Gamble

Lara Flynn Boyle stars as Helen Gamble in the series, THE PRACTICE. Her most recent feature film appearance was in 1997's AFTERGLOW, directed by Alan Rudolph, starring Nick Nolte and Julie Christie.



Other Bios

MICHAEL BADALUCCO
Jimmy Berluti

LARA FLYNN BOYLE
Helen Gamble

LISAGAY HAMILTON
Rebecca Washington

STEVE HARRIS
Eugene Young

CAMRYN MANHEIM
Ellenor Frutt

DYLAN MCDERMOTT
Bobby Donnell

KELLI WILLIAMS
Lindsay Dole



Lara's past film credits include EQUINOX, also directed by Alan Rudolph; RED ROCK WEST, directed by John Dahl; Alan Parker's THE ROAD TO WELLVILLE, Clint Eastwood's THE ROOKIE, Penelope Spheeris' WAYNE'S WORLD and Mark Rocco's WHERE THE DAY TAKES YOU.

Lara got her first big break when she starred in David Lynch's TWIN PEAKS for ABC. She also starred in the highly publicized movie for television, THE PREPPY MURDER.

A native of Chicago, Lara began her career upon graduation from The Chicago Academy for the Arts. Free time for Lara includes recreational activities with her four dogs -- Bella, Rory, Lucy and Cleo. She currently resides in Los Angeles.



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Cast Bios

LISAGAY HAMILTON
 Rebecca Washington

**A graduate of the
 Juilliard School's
 drama division,
 LisaGay Hamilton's
 extensive theater credits**
 include MEASURE FOR MEASURE
 at the New York Shakespeare
 Theater Festival, opposite Kevin
 Kline and Andre Braugher. She also starred in the original
 Broadway company of August Wilson's THE PIANO LESSON.



Last year Hamilton earned the Ovation
 nomination for best actress for her work in
 Athol Fugard's play, VALLEY SONG, at
 the Mark Taper Forum in Los Angeles.
 That performance, in the role of Veronica,
 also won her an Obie Award, the Clarence
 Derwent Award and a Drama Desk
 nomination.

In addition to her
 starring role on

THE PRACTICE, Hamilton has been seen
 on LAW & ORDER and HOMICIDE. Film
 credits include Quentin Tarantino's
 JACKIE BROWN, and the independent
 releases, PALOOKAVILLE and DRUNKS.
 Hamilton will next be seen on the big
 screen in the Jonathan Demme film,
 BELOVED, opposite Oprah Winfrey and
 Danny Glover. She spent the summer of
 '98 shooting Clint Eastwood's TRUE
 CRIME for Warner Brothers. ◊



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Other Bios

**MICHAEL
 BADALUCCO**
 Jimmy Berluti

LARA FLYNN BOYLE
 Helen Gamble

LISAGAY HAMILTON
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Cast Bios

STEVE HARRIS
 Eugene Young

Steve Harris stars as Detective Buddy Ruskin of Internal Affairs in the filmed version of THE MOD SQUAD, due out next year. He was featured in the Sean Connery/Nicolas Cage action movie, THE ROCK, and in the feature film, SUGAR HILL.



An experienced stage actor, Harris appeared off-Broadway in HELIOTROPE BOUQUET and in regional productions of MACBETH, RICHARD III, JULIUS CAESAR and THE GREAT WHITE HOPE.

On television, Harris has guest starred in LAW & ORDER, NEW YORK UNDERCOVER, MURDER ONE and HOMOCIDE. He also appeared in the miniseries, HEAVEN AND HELL, and the cable television movie, AGAINST THE WALL.

Harris currently splits his time between Los Angeles and New York. ©

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Cast Bios

CAMRYN MANHEIM
Ellenor Frutt**Camryn Manheim has appeared in a long list of hit films, as well as television and stage productions.** Her recent

motion picture credits include ROMY AND MICHELLE'S HIGH SCHOOL REUNION, ERASER, JEFFREY, THE ROAD TO WELLVILLE, BONFIRES OF THE VANITIES, DAVID SEARCHING, WIDE AWAKE with Rosie O'Donnell, and MERCURY RISING with Bruce Willis and Alec Baldwin. She appears in the soon-to-be-released films, YOU ARE HERE, THE TIC CODE with Gregory Hines, FOOL'S GOLD, and HAPPINESS, which was written and directed by Todd Solondz.



On television, Manheim guest starred on CHICAGO HOPE, four episodes of LAW & ORDER, TOUCHED BY AN ANGEL and NEW YORK UNDERCOVER; the television movie, DEADLY WHISPERS; and the ABC Afterschool Special, NOTES FOR MY DAUGHTER. A popular actor on daytime dramas, Manheim has appeared on such programs as LOVING, ONE LIFE TO LIVE and ALL MY CHILDREN.

A versatile and talented stage actress, Manheim starred in WAKE UP, I'M FAT, her own one-woman show at the Joseph Papp Public Theater in New York. She won a 1995 Obie Award for her performance in Craig Lucas' MISSING PERSONS at the Atlantic Theatre Company. She is proud to have worked at such renowned theaters as the New York Shakespeare Festival, Lincoln Center, Yale Repertory, New York Theatre Workshop, Classic Stage Company and Home for Contemporary Theater.

The role of Ellenor Frutt was adjusted to reflect some of Manheim's personality, including the 12 earrings she wears in her right ear. In New York City, where she lives, Manheim can often be seen riding her Honda CB650 motorcycle in traffic, no matter what the weather. Manheim is also a sign language interpreter and holds an MFA from NYU, where she currently teaches.

[Click here to visit Camryn's personal web site!](#)■ ■ [See THE PRACTICE Video Clips](#)

Other Bios

MICHAEL BADALUCCO
Jimmy Berluti**LARA FLYNN BOYLE**
Helen Gamble**LISAGAY HAMILTON**
Rebecca Washington**STEVE HARRIS**
Eugene Young**CAMRYN MANHEIM**
Ellenor Frutt**DYLAN MCDERMOTT**
Bobby Donnell**KELLI WILLIAMS**
Lindsay Dole



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Cast Bios

KELLI WILLIAMS
Lindsay Dole

Kelli Williams made her feature film debut in director Floyd Mutrux's

THERE GOES MY BABY, opposite Dermot Mulroney and Noah Wyle. She later appeared in the independent film, **E=MC2**, with Jeremy Piven.



Williams was a series regular on the television drama, **NEW YORK NEWS**, with Mary Tyler Moore, where she played an eager and ambitious journalist. She has starred in movies for television, including **THE JIM AND JENNIFER STOLPA STORY**, Ron Silver's **LIFEPOD**, as well as **FOR THEIR OWN GOOD**, opposite Elizabeth Perkins and Laura San Giacomo. She was most recently seen in the critically acclaimed telefilm, **MARY AND TIM**, with Candice Bergen. In addition, she has guest starred on numerous series, including **LAW & ORDER**, **PARTY OF FIVE**, **SISTERS** and **CIVIL WARS**."

A Los Angeles native, Williams currently resides in the Los Angeles area with her husband, who is a writer. ☺

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Jimmy Berluti

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Helen Gamble

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Declining Medicaid Rolls

Introduction

This memo presents preliminary findings concerning welfare reform and dynamics in both welfare caseload and Medicaid enrollment. The findings are based on analyses of program data and the Current Population Survey (CPS) from 1995 through 1997, and on research on the subject and reports from the field.

Attachment 1 is a table that displays the data used for the analysis presented here. Attachment 2 outlines research that is underway or planned, and describes the efforts the Department and other parties are making to improve Medicaid outreach and increase participation among eligible children and families.

Background

Until passage of the Personal Responsibility and Work Opportunities Reconciliation Act of 1996 (PRWORA), eligibility for Medicaid was automatic for those receiving cash assistance under the Aid to Families with Dependent Children (AFDC) program. PRWORA replaced AFDC with a new program of block grants to the states -- Temporary Aid to Needy Families (TANF) -- and severed the historical linkage between welfare and Medicaid eligibility for families. Also, together with sweeping changes in immigration law, PRWORA restricted the eligibility of new immigrants for Medicaid and welfare.

In a specific effort to preserve Medicaid coverage for those affected by welfare reform, PRWORA required states, under a new *section 1931*, to continue to provide Medicaid to families who meet the AFDC eligibility criteria that were in effect on July 16, 1996¹ -- regardless of whether they are eligible for cash under their states' new TANF programs. Thus, states must, at a minimum, maintain their old AFDC eligibility criteria for purposes of determining Medicaid eligibility, even though they apply different eligibility criteria for TANF. However, under section 1931, states also have flexibility to expand Medicaid coverage beyond previous levels.

Acknowledging the new administrative burden on states that resulted from delinking Medicaid from cash receipt, PRWORA provided \$500 million in enhanced matching funds to help states cover the increased costs associated with outreach and Medicaid eligibility determinations in the new environment. The law also gave states two new Medicaid options -- presumptive eligibility for children and 12-month continuous eligibility -- to improve coverage among poor families. Since PRWORA passed, HCFA, the Department, and others have undertaken substantial efforts to improve Medicaid outreach and increase the participation of eligible children and families at risk of losing Medicaid -- or never enrolling -- as a consequence of welfare changes. Further, the Children's Health Insurance Program (CHIP) provides a new mechanism for finding Medicaid-eligible children.

Current Findings

State variation in the timing and character of welfare reform, and variation in Medicaid policies and economic conditions, pose a formidable challenge to research aimed at defining or modeling the impact of welfare reform on Medicaid enrollment dynamics. Also, the state and national data necessary for such analysis are only gradually becoming available. For all these reasons, research is still at an early stage. Nonetheless, the following important preliminary findings can be drawn from data on poverty, welfare, and Medicaid (see Attachment 1).

- Raw Poverty Numbers are Down* -- Between 1995 and 1997, the total population in poverty fell by 800,000 (2.3%). A drop of 600,000 in the number of poor children made up a significant share of the decline. These declines continued a downward trend in poverty numbers that began with this Administration. Since 1993, the number of poor adults has fallen by almost 4 million (9%) and the number of poor children has fallen by 1.6 million (10.3%).
- But Poverty Rates Have Changed Little* -- Although the number of poor fell between 1995 and 1997, the poverty rate among adults fell only from 13.8% to 13.3% in this period, and the poverty rate among children fell by just under one point, from 20.8% to 19.9%. Nonetheless, these declines in the poverty rate continue a trend that began under this Administration: in 1993, the poverty rate among adults was 15.1% and the poverty rate among children was 22.7%.
- Welfare Rolls Are Falling Much Faster than Poverty* -- From 1995 to 1997, when the population in poverty fell by 800,000, the average monthly welfare caseload dropped by 3 million -- a 23% decrease. The data show that the drop in welfare caseload appears to be accelerating rapidly: from 1995 to 1996, caseload fell by about 1 million; from 1996 to 1997 caseload fell by an additional 2 million; and the newest available data, from 1997 to June 1998, show that the welfare caseload fell by another 2 million.
- Medicaid Enrollment Is Dropping Much Less than Welfare Caseload* -- In contrast to the 3 million (23%) drop in welfare caseload from 1995 to 1997, the number of people enrolled in Medicaid fell by 1.1 million (2.7%) over this period. Although the number of adults and children receiving welfare-related Medicaid fell by about 25%, the number who receive non-welfare-related Medicaid rose by 23%. Because the increase in non-welfare-related Medicaid was not large enough to completely offset the decrease in welfare-related Medicaid, there were 600,000 fewer adults and 700,000 fewer children on Medicaid in 1997 than in 1995.
- The Uninsured Rate and the Private Coverage Rate Among the Poor Have Both Increased* -- Despite the overall drop in the number of poor people since 1995, the number of poor adults and children who have private coverage rose by 200,000 and 100,000 respectively. At the same time, the number of poor adults and children who are

uninsured increased by about 250,000 each.

Discussion

It appears from the data that many low-income families -- especially children -- who can qualify for Medicaid through eligibility groups that are not tied to welfare are now being covered under such other categories. However, the net loss of 1.1 million people enrolled in Medicaid still warrants attention to ensure that those whose economic status has not improved, but who have been affected by welfare reform, make the transition from welfare-related to non-welfare-related Medicaid coverage.

[It is unlikely that the 1.1 million-person decrease in the Medicaid rolls translated strictly into coverage losses among the poor.] While the number of poor adults and children who were uninsured did indeed rise over this period (by 250,000 each), so did the number with private coverage (by 200,000 and 100,000, respectively). In addition, some of those no longer covered by welfare-related Medicaid could have been among the 800,000 people lifted out of poverty altogether; in that case, we can only speculate about whether they obtained private coverage or became uninsured as a result.

In short, the data suggest that despite the changes in welfare, the availability of Medicaid through non-welfare-related routes preserved coverage to a substantial extent. The Medicaid caseload drop in the poorest group bears watching, and closer study of the transitions experienced by this population since welfare reform is critical to better identification of gaps and better targeting of outreach. The 2.7% drop in total Medicaid enrollment also warrants notice, as net increases in Medicaid caseload might have been expected over this period if the phase-in of poverty-level children continued to add children to the rolls, and if section 1931 maintained enrollment of families, as intended.

The apparent acceleration of welfare caseload declines -- the rolls dropped by 1 million between January 1997 and June 1998 alone -- argues for careful monitoring with regard to Medicaid enrollment dynamics. Because the availability of Medicaid data lags behind welfare data, it remains to be seen whether non-welfare-related Medicaid eligibility continued to preserve coverage for the increasing numbers of people not on welfare, as well as it appeared to between 1995 and 1997.

Other Study Findings

The data findings of Medicaid coverage declines and rising uninsurance among the poor are consistent with the results of various studies that have specifically examined Medicaid enrollment and participation in relation to changes in welfare and immigration policy, as follows.

Medicaid caseload analysis

- * In an analysis for the Urban Institute's *Assessing the New Federalism* (ANF) project, Ellwood and Ku analyzed Medicaid caseload changes between 1995 and 1996. They found a net decline of nearly 2 percent in Medicaid enrollment of children and non-disabled adults – the first downturn in nearly a decade of eligibility expansions and rising Medicaid participation rates.²
- * Analyzing state Medicaid enrollment data from five states, Ellwood found enrollment drops from January 1995 to January 1998 of 12 to 18 percent in New York, California, and Florida, and 29 percent in Wisconsin. Only Minnesota showed an increase, of 1 percent. However, this study did not track the insurance status of those who left Medicaid to determine what proportion found private coverage and what proportion became uninsured.
- * An analysis of administrative data from Los Angeles County generated important findings regarding immigrants. Applications for Medicaid and welfare benefits by non-citizen-headed families declined sharply following enactment of PRWORA, while approvals of citizen cases did not change. Approvals of non-citizen-headed cases fell by 52% between January of 1996 and 1998, explaining the entire 23% drop in total approvals over the period. Non-citizen applications for Medicaid-only benefits also declined. Finally, the number of citizen children of non-citizen parents applying for Medicaid and welfare declined sharply -- approved applications dropped by 48% between January of 1996 and 1998, compared to a 6% increase for citizen children of citizen parents during the period.

Studies of welfare "leavers"

- * Preliminary 1997 results from the National Evaluation of Welfare-to-Work Strategies (formerly the JOBS evaluation) indicate that as members of both experimental and control groups left AFDC in increasing numbers, health coverage among both groups declined. Evaluation sites that experienced greater impacts on employment and welfare receipt typically also had greater reductions in health coverage among the treatment group, despite increasing rates of employer sponsored insurance (ESI), because more families lost Medicaid than gained ESI. These findings will be addressed in greater detail in a forthcoming report.
- * In a widely cited 1989-92 analysis of families leaving welfare, uninsurance among mothers exiting welfare was found to rise over the three years they were followed, from 23 to 45 percent. The study findings highlight the particular exposure of mothers, who are not protected by poverty-related Medicaid eligibility, and also the importance of Medicaid during the early period following exit, when low-wage work without ESI is typical.³
- * A May 1997 GAO study of three states showed that, despite continued eligibility for Medicaid, participation plummeted in households where welfare benefits were

terminated. Before termination, Medicaid participation ranged from 84 to 100 percent across the three states; after termination, the rates ranged from 26 to 61 percent.⁴

- * The finding of decreased Medicaid enrollment is also typical of states' own studies of their welfare "leavers." ESI increases have not offset these reductions in Medicaid enrollment.⁵

Effects of Re-engineering Welfare

Welfare reform profoundly changed both the administration of welfare and welfare "culture" in the states. The major restructuring of the welfare system and related operational challenges, and transformation in public attitudes toward welfare, may cause reduced participation in Medicaid as well as welfare during this period of fundamental transitions.

- * As welfare offices are transformed into "job centers" and former caseworkers are re-trained as "job counselors," the new emphasis on job placement and reducing dependency may be eclipsing any focus on determining eligibility for medical (and food) assistance, despite their importance as work supports.
- * Former welfare caseworkers, who in their new role, become front line Medicaid eligibility workers, may actually have little or no training or experience making Medicaid eligibility determinations. They may not understand that, unlike before, Medicaid eligibility for applicants does not flow strictly from receipt of cash benefits, and that applicants who do not qualify for TANF must be evaluated separately for Medicaid eligibility under section 1931.
- * The profound changes in public attitudes toward welfare and in welfare itself (e.g., time limits) may result in fewer people entering welfare/job offices. Non-participation in welfare may cause non-participation in Medicaid as well if those who decline to apply for TANF do not make contact with the Medicaid program otherwise.
- * Reports from the field provide mounting evidence that misinformation, confusion, and discouraging messages also contribute to suppressed Medicaid enrollment among eligible children and families, including immigrants.
- * The New York Times recently reported that welfare offices in New York City, which are actively discouraging application for welfare, are also systematically failing to provide and process applications for Medicaid (and Food Stamps) promptly, despite clear federal policy guidance that they do so. City statistics show that while 53 percent of the people who asked to apply for welfare, food stamps and Medicaid were successful in the past, about 25 percent receive benefits at the city's new "job centers."

Conclusion

The net results of the latest data and research in this area counsel both concern and optimism. Medicaid enrollment is down overall during a period when increases might have been expected. Moreover, the fact that the net drop results from the decline in enrollment in the poorest Medicaid coverage group implies a need for more outreach to those who have dropped from the welfare caseload but remain eligible for Medicaid.

At the same time, the data indicate that the drop in Medicaid enrollment is nowhere near the level that many worried would result from welfare reform. A significant number of those no longer qualifying for welfare-related Medicaid appear to be finding their way into Medicaid through other eligibility pathways. Some of those who do not show up on the Medicaid rolls are families whom the economy has boosted out of poverty and/or into jobs with insurance. Some, like many young adults, do not realize the importance of having health insurance for themselves and their children. But clearly, some leaving the welfare-related Medicaid rolls, and some who do not show up in Medicaid as a result of the immigrant policy changes, are becoming uninsured.

The data findings should be considered preliminary and tentative and some caveats should be noted. The data sets analyzed measure different periods of time and they measure in substantially different ways. Furthermore, the data instruments are not sensitive to volatility in income, employment, and coverage within a year that undoubtedly complicate the results. Finally, the data cover only two years; as data from subsequent years become available, the longer series will provide a more reliable picture of trends in poverty and program participation.

Especially given reservations about the data currently available for analysis, other research and reports from the field are important sources of information and insight, and should help guide future study and monitoring efforts. It is clear from a mounting body of such work that confusion about eligibility, both in the public and among eligibility workers in state and local offices, is a consequence of the delinkage of Medicaid from welfare. The separate processing of Medicaid applications for those who are denied welfare benefits may not occur promptly or automatically. Formal and informal welfare diversion programs probably produce diversion from Medicaid as well, because while the programs are decoupled, many continue to believe that eligibility for them remains linked. If eligible families fail to become enrolled in Medicaid for any of these reasons, then the work support offered by transitional Medicaid will also remain unrealized. Finally, the welfare and immigration changes that have transformed the program have also changed the larger "culture," sending new messages that discourage participation, not only in welfare but also in other public benefits. Those who decline to apply for welfare may either decline to apply separately for Medicaid, or simply fail to.

The importance of health insurance for low-income families and children, and its importance as a work support, both suggest that dynamics in coverage among this population should be a critical focus of monitoring for the Department. In particular, we need to monitor states' implementation of welfare reform as it affects Medicaid, and their implementation of section 1931, so that we can more narrowly identify the obstacles to Medicaid participation and better design outreach efforts.

ATTACHMENT 1

Changes in Poverty and Program Caseload Between 1995 and 1997				
	1995	1997	Difference	Percent Change
CPS Poverty Data				
Total Population in Poverty	36.4 m	35.6 m	-800,000	-2.3%
Adults	21.8 m	21.5 m	-300,000	-1.4%
Children	14.7 m	14.1 m	-600,000	-3.8%
ACF Welfare Data				
Total AFDC/TANF Caseload	13.4 m	10.4 m	-3 m	-22.6%
HCFA Medicaid Data				
Total Medicaid Enrollment	41.4 m	40.3 m	-1.1 m	-2.7%
Non-Disabled Adults	9 m	8.4 m	-600,000	-6.3%
Welfare Related	5.4 m	4.0 m	-1.4 m	-26.0%
Non-Welfare Related	3.6 m	4.5 m	+800,000	+23.0%
Non-Disabled Children	20.4 m	19.6 m	-700,000	-3.5%
Welfare Related	11.2 m	8.4 m	-2.8 m	-25.0%
Non-Welfare Related	9.2 m	11.3 m	+2.1 m	+22.6%
CPS Insurance Data				
Poor Uninsured Adults	11 m	11.2 m	+250,000	+2.2%
Poor Uninsured Children	3.1 m	3.4 m	+250,000	+7.4%
Poor Adults w/ Private Coverage	8.1 m	8.3 m	+200,000	+1.8%
Poor Children w/ Private Coverage	2.7 m	2.8 m	+100,000	+4.1%

Note: Non-Disabled Adults + Non-Disabled Children do not add to Total Medicaid enrollment because Total Medicaid Enrollment includes SSI groups and the elderly.

ATTACHMENT 2

Further Research

Numerous research efforts currently underway or in development focus specifically on the impact of welfare reform on Medicaid participation.

- * HCFA has awarded a major contract to analyze national trends in Medicaid utilization, expenditures, duration and continuity of enrollment, shifts across eligibility categories, and the profile of enrolled children and families, and to attempt to disentangle the effects of welfare reform from other effects.⁶
- * Phase Two of the 1998 DHHS-funded study of formal welfare diversion programs, which is now underway, entails case studies in five states focused on the implementation of diversion policies. A specific emphasis of these case studies is the manner in which Medicaid eligibility and enrollment are handled in processing applicants who are diverted from TANF.⁷
- * ASPE has awarded grants totaling \$2.9 million to 13 states and counties to study the outcomes of families who leave or are diverted from welfare.⁸ All the grantees will link Medicaid and TANF files, as well as collect health insurance information via survey. Nearly all other states are conducting their own welfare “leavers” studies as well.
- * The GAO plans a study of four to five states to explore the extent to which Medicaid enrollment trends are due to state-specific welfare variables.⁹
- * The Kaiser Family Foundation (KFF) recently funded eight focus groups in California to learn more about how well low-income families with uninsured children understood their Medicaid eligibility. KFF plans to fund a national survey of low-income people to profile eligible-but-not-enrolled individuals, document the reasons for non-participation, describe state policies and practices that pose barriers to enrollment, and identify promising outreach and enrollment strategies.
- * Building on their earlier effort under *Assessing the New Federalism*, Ellwood and colleagues will conduct in-depth case studies in five states, focusing on state administrative procedures and practices for assuring that people leaving the welfare rolls are enrolled in Medicaid-only coverage. Analysis of longitudinal data on enrollees will supplement the work, and will have a sub-focus on use of transitional Medicaid for adults going to work.¹⁰

In addition to studies focused narrowly on welfare reform and its impacts, community studies with broader research interest may provide valuable data and information concerning health insurance coverage of low-income populations, and a needed contextual framework for considering findings in this area:

Community Tracking Study, funded by the Robert Wood Johnson Foundation (RWJ), will collect extensive information on changes in health insurance coverage over several years.

"Cherlin project," a multi-disciplinary longitudinal study of low-income families in selected metropolitan areas, is focused primarily on the implications of welfare reform for child well-being. An HHS-funded supplement will explore how welfare reform affects the well-being of persons with disabilities.

Los Angeles Study of Families and Children (LASFC), conducted by RAND with over \$7 million from NICHD, is a four-year longitudinal survey of children, their families, and their neighborhoods in LA. The study will bring together extensive survey information and administrative data that may illuminate the effects of welfare reform at the neighborhood level. ASPE is considering funding a supplement to obtain richer data on health insurance coverage.

Outreach

Both the public and private sectors are taking steps aimed at improving health insurance coverage for low-income families affected by welfare reform. These outreach initiatives entail identifying eligible children and families, as well as ensuring that they are enrolled.

Department Efforts: DHHS and its agencies are engaged in numerous activities to promote outreach. They include:

- * efforts to educate state officials about Medicaid and CHIP outreach obligations and opportunities;
- * bringing state officials together to share experiences and provide state perspectives;
- * developing a "Working Families Initiative," which will include proposals to increase Medicaid coverage for low-income working families; and
- * coordinating the Interagency Task Force on Children's Health Insurance Outreach.

Private Sector Efforts: Private sector groups have also directed substantial resources to examining potential problems for Medicaid resulting from welfare reform and to expanded outreach efforts.

- * RWJ is creating a grant program to promote the development of state-wide coalitions of state welfare, Medicaid, and CHIP officials, to address outreach and enrollment, eligibility simplification, and coordination across health insurance programs.
- * The Center on Budget and Policy Priorities has published several issue papers identifying problematic state welfare policies and promoting approaches that may help states extend Medicaid coverage to low-income working families.
- * Families USA is seeking to support work by state groups that will focus on the impact of welfare reform on the insurance status of low-income families.

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Endnotes

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1. Section 1931 also gives States limited authority to use more restrictive eligibility criteria than those in place for AFDC as of July 16, 1996, and broad flexibility to use more liberal eligibility criteria.
2. Marilyn Ellwood and Leighton Ku, *Welfare and Immigration Reforms: Unintended Side Effects for Medicaid*, Health Affairs (May/June 1998).
3. Moffitt and Slade, *Health Care Coverage for Children Who are On and Off Welfare*, The Future of Children, Spring 1997.
4. General Accounting Office, *Welfare Reform: States Early Experiences with Benefit Termination* (1997).
5. For a discussion of the state studies (covering various periods between 1996 and 1998), see generally Mark Greenberg, Issue Paper: *Participation in Welfare and Medicaid Enrollment*, Kaiser Commission on Medicaid and the Uninsured (September 1998).
6. Embry Howell, Marilyn Ellwood et al., *The Impact of Welfare Reform on Medicaid Populations*, Mathematica Policy Research (Expected completion October 2000).
7. Kathleen Maloy et al., *Diversion as a Work-Oriented Welfare Reform Strategy: The Experiences of Five Local Communities*, The Center for Health Policy Research, George Washington University (Expected completion December 1998).
8. For brief descriptions of the grants awarded, see <<http://aspe.os.dhhs.gov/hsp/isphome.htm>>
9. General Accounting Office, *The Impact of Welfare Reform on Medicaid Enrollment*, by request for Reps. Coyne and Levin (Expected completion Spring/Summer 1999).
10. Marilyn Ellwood, et al., *Moving from Welfare/Medicaid to Medicaid Only Coverage for Families*, Mathematica Policy Research (Expected completion January 1999).

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response on background?