



Office of the Secretary
Washington, D.C.

DATE: Wed Mar 8 18:46:00 1995

FNX TO: Diana Fortuna

FROM: Bob Williams, ADD FAX:202-401-9507 PH:202-690-6590

SUBJECT: Draft Principles

FAXED FROM THE US NETWORK!

If you need this fax to be retransmitted, please call the originator above.

----- MESSAGE -----

I will be in Georgia the rest of the week. If you have thoughts on how this can be further refined and shortened please fax them by Tuesday. My personal fax number is 202 401 9507.

As President Clinton has stated, "Having a disability does not diminish one's right to participate in all aspects of mainstreaming society." In fact, in today's society, having a disability is seen as a much more natural part of the human experience than any other time in history. In the United States alone, it is estimated that:

One in five Americans (43 million) experiences a disability;

One in ten Americans (25 million) is temporarily disabled at any one time;

Nearly one in three Americans over age 65 (11.2 Million) has a disability; and,

Moreover, African Americans, Hispanic Americans, Native Americans and low income Americans are more likely to have a disability.

Given that Americans with disabilities are, and have a right to be, full participating members of their families, communities and Nation. President Clinton has directed the Domestic Policy Council to "craft policies of inclusion, independence and empowerment that will inspire positive changes in this country and in nations around the world". The purpose of this comprehensive Policy Review, therefore, is to carry out the President's charge by:

- o Analyzing how a broad cross section of Federal policies and programs currently affect Americans with disabilities and their families; and,

- o Recommending ways to craft a more coherent set of policies which will result in the greater inclusion, independence and empowerment of all people with disabilities in our nation.

We view the President's challenge as vital in its own right and central to our overall mission. For today, Americans with disabilities and their families are in the vanguard of those calling for a New Covenant with their government. People with disabilities no longer want government to take care of them as it has tried to do in the past. Instead, they expect government at all levels to be more responsive to their individual hopes and aspirations; fears and frustrations. They expect government to work with them, supporting their efforts to lead independent, productive and responsible lives.

Everyday in our country persons with even the most significant disabilities are exceeding the expectations which our society has traditionally set for them. In doing so, people with disabilities and their allies from across the political spectrum are redefining what it means to be a fully participating member of the American community.

In recent decades, a fundamental role of all governments has been to assure that people with disabilities of all ages, genders, ethnic backgrounds and income levels have the equal opportunity to maximize their independence, exercise self-determination and to be productive throughout their lives. However, despite the tremendous progress being made in assuring equal opportunities for and promoting the independence of people with disabilities, critical gaps and contradictions exist in a wide array of federal policies and programs that affect the daily lives of millions of these individuals.

Such counterproductive policies and programs fuel discrimination and prejudice and deny individuals with disabilities the opportunity to be productive in our nation and cost the United States billions of dollars in unnecessary expenses resulting from dependency and nonproductivity. Remedying these gaps and contradictions will require the Executive and Congress to work closely with the States, people with disabilities, their families and allies, and the American public to:

- o Strengthen and learn from policies and programs which provide people with disabilities and their families access to supports and accommodations which increase their abilities to lead responsible lives of their own choosing and direction; and,

- o Redirect laws and programs and remove other barriers which hinder or infringe upon the rights and abilities of such individuals to lead full and productive lives.

We believe conducting a comprehensive review of all pertinent

federal policies and programs is a vital first step in better understanding how they affect people with disabilities and their families as well as the health and vibrancy of the Nation. Moreover, we believe it is in the National interest that federal policies, programs, benefits and activities affecting individuals with disabilities be designed and implemented to:

dropped

- o Create equal opportunity and end discrimination against Americans with disabilities in employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, access to public services and other areas through the full enforcement of all civil rights laws and the Constitution.
- o Assure that all public policy, programs and activities foster greater equal opportunity, independence, the full participation and economic self-sufficiency of every member of the public, including persons with disabilities.
- o Develop effective strategies to address links between inequities based upon race, gender, minority status, disability, discrimination and poverty in our country.
- o affirm and support the efforts of families with children with disabilities to raise their sons and daughters at home and to include them in every facet of family and community life. ✓
- o Maximize the ability and opportunity of all individuals, regardless of the level of their disability or age, to live in the community as full, participating members of their families. ✓
- o Assure that assistance or services provided to people with disabilities are carried out in a manner consistent with their strengths, resources, priorities, concerns, and abilities.
- o Afford States and local governments flexibility in delivering community services, provided that, people with disabilities and their families have a lead role in designing, overseeing and evaluating those services which affects them most.
- o Stimulate, demonstrate and disseminate new ideas, knowledge and practices that promote the inclusion of all people with disabilities in their homes, in public schools, in the workplace and in all aspects of community life. ✓
- o Foster strong public-private partnerships to identify and develop innovative approaches for enabling individuals with disabilities to have greater control over their lives and contribute more fully to their home, family, school, work and community life. ✓
- o Make it pay for such individuals to work by creating incentives rather than disincentives to work and to pursue careers.

Our Nation's greatness rests with its people's potential to make the most of their lives and thereby shape the future of the rest of the country as well. Americans with disabilities represent an enormous almost untapped reservoir of such potential and power. Tapping into this reservoir requires empowering people with disabilities by creating a strong and consistent policy framework for fostering their independence and self-determination. As a

Government and as a People, it requires us to heed the
President's urgent call to action:

"We must not rest until America has a national disability
policy based on three simple creeds: inclusion, not
exclusion: independence. not dependence: and empowerment.
not paternalism." Bill Clinton, 1992



Office of the Secretary
Washington, D.C.

DATE: Wed Mar 1 15:58:00 1995

TO: Diana Fortuna

FROM: Bob Williams, ADD FAX:202-401-9507 PH:202-690-6590

SUBJECT: Your internet address

FAXED FROM THE US NETWORK!

If you need this fax to be retransmitted, please call the originator above.

----- MESSAGE -----
THE FOLLOWING MESSAGE HAS BEEN SENT OUT ON COMMISSIONER WILLIAMS' BEHALF BY
RON FILEWICH, AN ASSISTANT TO THE COMMISSIONER:

From: Ron Filewich
Assistant to the Commissioner
Administration on Developmental Disabilities
Washington, D.C.

internet address: rfilewich@acf.dhhs.gov

phone: (202) 690-5975

*Fortuna - D@PAI
EOP.GOV*

Dear Ms. Fortuna:

Bob has asked me to contact you for YOUR INTERNET ADDRESS.
He would like to establish a method of rapid communication among network
members to more effectively meet the challenges that are coming up.

Please send this information to my internet address: RFILEWICH@ACF.DHHS.GOV

I will then include your internet address in Bob's electronic mail service.

Thank you, Ron Filewich



Office of the Secretary
Washington, D.C.

DATE: Wed Mar 1 16:59:14 1995

FAX TO: Diana Fortuna

FROM: Bob Williams, ADD FAX:202-401-9507 PH:202-690-6590

SUBJECT: GUIDING PRINCIPLES

FAXED FROM THE US NETWORK!

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----- MESSAGE -----

THE FOLLOWING IS THE LATEST DRAFT OF THE GUIDING PRINCIPLES. CHANGES AND ADDITIONS MADE BELOW BASED ON THE MEETINGS WITH REPRESENTATIVES FROM THE DISABILITY COMMUNITY AND THE FEBRUARY TWENTY SECOND MEETING OF THE FEDERAL DISABILITY POLICY REVIEW PANEL ARE IN CAPS. I WOULD APPRECIATE FEEDBACK BOTH ON CONTENT AND POSSIBLE NEXT STEPS BY THIS FRIDAY. THANK YOU.

"WE MUST NOT REST UNTIL AMERICA HAS A NATIONAL DISABILITY POLICY BASED ON THREE SIMPLE CREEDS: INCLUSION, NOT EXCLUSION; INDEPENDENCE, NOT DEPENDENCE; AND EMPOWERMENT, NOT PATERNALISM." BILL CLINTON, 1992

INCLUSION, INDEPENDENCE AND EMPOWERMENT. TODAY, MORE THAN AT ANY OTHER TIME IN OUR NATION'S HISTORY, AMERICANS WITH DISABILITIES AND THEIR FAMILIES ARE SEIZING CONTROL OVER THEIR OWN EVERYDAY LIVES AND FUTURES. THEY ARE NO LONGER LOOKING TO THE FEDERAL, STATE OR LOCAL GOVERNMENT TO SIMPLY TAKE CARE OF THEM AS GOVERNMENT HAS TRIED TO DO AND FALLEN FAR SHORT OF DOING IN THE PAST. INSTEAD, THEY EXPECT GOVERNMENT AT ALL LEVELS TO CARE DEEPLY ABOUT THEIR INDIVIDUAL HOPES AND ASPIRATIONS; AND THEIR FEARS AND WORST NIGHTMARES. MOST IMPORTANTLY, THESE INDIVIDUALS AND THEIR FAMILIES EXPECT GOVERNMENT TO WORK WITH THEM AND

SUPPORT THEIR EFFORTS TO BE INDEPENDENT AND PRODUCTIVE TO THE GREATEST EXTENT POSSIBLE.

EVERYDAY IN OUR COUNTRY PERSONS WITH EVEN THE MOST SIGNIFICANT DISABILITIES ARE EXCEEDING THE EXPECTATIONS WHICH OUR SOCIETY HAS TRADITIONALLY SET FOR THEM. OFTEN, THIS IS DONE IN WAYS UNIMAGINABLE JUST A FEW YEARS AGO. IN DOING SO, PEOPLE WITH DISABILITIES AND THEIR ALLIES FROM ACROSS OUR POLITICAL SPECTRUM ARE HELPING TO REDEFINE WHAT IT MEANS TO BE A FULLY PARTICIPATING MEMBER OF THE AMERICAN COMMUNITY. HOWEVER, DESPITE THE TREMENDOUS PROGRESS BEING MADE IN ASSURING EQUAL OPPORTUNITIES FOR AND PROMOTING THE INDEPENDENCE OF AMERICANS WITH DISABILITIES, CRITICAL GAPS AND CONTRADICTIONS EXIST IN A WIDE ARRAY OF FEDERAL POLICIES AND PROGRAMS THAT AFFECT THE DAILY LIVES OF MILLIONS OF THESE INDIVIDUALS.

SUCH COUNTERPRODUCTIVE POLICIES AND PROGRAMS FUEL DISCRIMINATION AND PREJUDICE AND DENY PEOPLE WITH DISABILITIES THE OPPORTUNITY TO COMPETE ON AN EQUAL BASIS IN OUR NATION AND COST THE UNITED STATES BILLIONS OF DOLLARS IN UNNECESSARY EXPENSES RESULTING FROM DEPENDENCY AND NONPRODUCTIVITY. MOREOVER, REMEDYING THESE GAPS AND CONTRADICTIONS WILL REQUIRE THE EXECUTIVE AND CONGRESS TO WORK TOGETHER WITH THE STATES, PEOPLE WITH DISABILITIES, THEIR FAMILIES AND ALLIES, AND THE AMERICAN PUBLIC TO:

- 0 STRENGTHEN AND LEARN FROM PUBLIC POLICIES AND PROGRAMS WHICH PROVIDE PEOPLE WITH DISABILITIES AND THEIR FAMILIES ACCESS TO SUPPORTS AND REASONABLE ACCOMMODATIONS WHICH INCREASE THEIR CAPABILITIES TO LIVE LIVES OF THEIR OWN CHOOSING AND DIRECTION; AND,
- 0 REDIRECT LAWS AND PROGRAMS WHICH INFRINGE UPON THE RIGHTS AND ABILITIES OF SUCH INDIVIDUALS TO LEAD FULL AND PRODUCTIVE LIVES.

IT IS VITAL THAT WE UNDERTAKE THIS COMPREHENSIVE REVIEW OF FEDERAL POLICIES AND PROGRAMS AND HOW THEY AFFECT PEOPLE WITH DISABILITIES BECAUSE DISABILITY REACHES AND TOUCHES US ALL. IT IS A NATURAL AND MUCH MORE COMMONPLACE PART OF THE HUMAN EXPERIENCE THAN ONCE THOUGHT TO BE THE CASE. IN FACT, IT IS ESTIMATED THAT:

ONE IN FIVE AMERICANS (43 MILLION) EXPERIENCES A DISABILITY;

ONE IN TEN AMERICANS (25 MILLION) IS TEMPORARILY DISABLED AT ANY ONE TIME; AND,

NEARLY ONE IN THREE AMERICANS OVER AGE 65 (11.2 MILLION) HAS A DISABILITY.

NOT SURPRISINGLY, IT IS OFTEN SAID THAT DISABILITY IS AN EQUAL OPPORTUNITY CONDITION. THIS IS CERTAINLY THE CASE IN THAT ANY INDIVIDUAL COULD BECOME DISABLED AT ANY POINT IN THEIR LIFE. BUT, WE ALSO KNOW THAT AFRICAN AMERICANS, HISPANIC AMERICANS, NATIVE AMERICANS AND OTHER MINORITY AND LOW INCOME AMERICANS FACE A DOUBLE JEOPARDY IN THIS REGARD: BY BEING MORE LIKELY TO HAVE A DISABILITY; AND, TO FACE TWICE THE DISCRIMINATION AS A RESULT. EFFECTIVE STRATEGIES, THEREFORE, MUST BE DEVELOPED TO ADDRESS LINKS BETWEEN INEQUITIES BASED UPON RACE, MINORITY STATUS, DISABILITY, DISCRIMINATION AND POVERTY IN OUR COUNTRY.

The fundamental role of ALL governments in respect to individuals with disabilities HAS BEEN AND MUST CONTINUE TO BE to assure the right of such persons to enjoy full inclusion and integration in the educational, economic, HOUSING, political, social, RECREATIONAL and cultural mainstream of American society. IN

ORDER TO DO THIS EFFECTIVELY, GOVERNMENT must assure that people with disabilities of all ages, GENDERS, ethnic backgrounds and income levels have the equal opportunity to exercise their full rights and responsibilities to live as independently as possible; enjoy self-determination; make choices; and, to be productive throughout their lives.

It is, therefore, in the Nation's interest that FEDERAL policies, programs, benefits and activities affecting such individuals be designed and implemented to:

O END DISCRIMINATION AGAINST AMERICANS WITH DISABILITIES IN EMPLOYMENT, HOUSING, PUBLIC ACCOMMODATIONS, EDUCATION, TRANSPORTATION, COMMUNICATION, RECREATION, INSTITUTIONALIZATION, HEALTH SERVICES, VOTING, ACCESS TO PUBLIC SERVICES AND OTHER AREAS THROUGH THE FULL ENFORCEMENT OF ALL CIVIL RIGHTS LAWS AND THE CONSTITUTION.

O ASSURE THAT ALL PUBLIC POLICY, PROGRAMS AND ACTIVITIES ADDRESS THE FULL NEEDS, INTERESTS AND ABILITIES OF EVERY MEMBER OF THE PUBLIC, INCLUDING THOSE WITH DISABILITIES, AND FOSTER GREATER EQUAL OPPORTUNITY, FULL PARTICIPATION, INDEPENDENT LIVING, AND ECONOMIC SELF-SUFFICIENCY FOR SUCH INDIVIDUALS IN THE NATION'S MAINSTREAM.

O ENABLE INDIVIDUALS, REGARDLESS OF THE LEVEL OF THEIR DISABILITIES OR AGE, TO BE FULL, PARTICIPATING MEMBERS OF THEIR FAMILIES AND COMMUNITIES.

O MAXIMIZE THE CONTROL SUCH PERSONS HAVE OVER OWN THEIR LIVES BY ENSURING THAT ASSISTANCE PROVIDED THEM IS CARRIED OUT IN AN INDIVIDUALIZED MANNER, CONSISTENT WITH THEIR STRENGTHS, RESOURCES, PRIORITIES, CONCERNS, CHOICES, ABILITIES AND CAPABILITIES.

o Support the efforts of families with children with disabilities to raise their sons and daughters at home and to include them in every facet of family and community life.

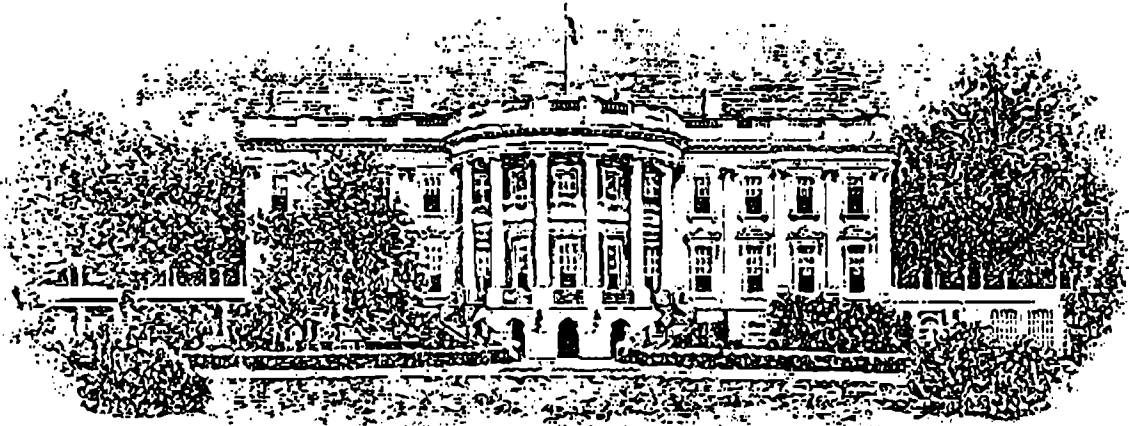
O EXPAND THE ABILITY OF THE FEDERAL, STATE AND LOCAL GOVERNMENTS TO PROVIDE PEOPLE WITH DISABILITIES AND THEIR FAMILIES WITH A LEAD ROLE IN DESIGNING AND IMPROVING ACCESS TO THOSE SERVICES, TECHNOLOGY AND SUPPORTS WHICH ENABLE THEM TO HAVE GREATER CHOICE AND CONTROL IN LIFE AND CONTRIBUTE MORE FULLY TO THEIR HOME, FAMILY, SCHOOL, WORK AND COMMUNITY.

o Make it pays for such citizens to work by creating incentives rather than disincentives to work and to pursue careers.

02/17/95 14:29 8

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The White House



DOMESTIC POLICY

FACSIMILE TRANSMISSION COVER SHEET

TO: Stan Herr

FAX NUMBER: (410) 706-5856

TELEPHONE NUMBER: _____

FROM: Diana Fortuna

TELEPHONE NUMBER: (202) 456-5570 (202) 456-7028

PAGES (INCLUDING COVER): 2

COMMENTS: Note: For your review 6-5584

Diana -- This has got
to be able to "sing" better --
I'm available to translate.
The ~~end~~ home bullet at the
2nd point. It's really
there but it's still awfully
clunky sounding. Good luck. Stan

National Disability Policy Review Guiding Principles

DRAFT

DRAFT

The fundamental role of Governments ^{has a} in respect to individuals with disabilities should be to assure the right of such persons with disabilities to enjoy full inclusion and integration in the educational, economic, political, social, and cultural mainstream of American society. In practical terms, therefore, governments must assure that people with disabilities of all ages, ethnic backgrounds, and income levels ^{have} the equal opportunity to exercise their full rights and responsibilities to live as independently as possible: to enjoy self-determination; to make choices; and to be productive throughout their lives. ^{the public and private sectors must} It is, therefore, in the nation's interest that public policies, programs, benefits, and activities affecting such individuals be designed and implemented to: ^{afford them}

(This requires

carried out

- o End discrimination against Americans with disabilities and strengthen our nation's communities and economy by providing strong, effective, and fair enforcement of the Americans with Disabilities Act, Title V of the Rehabilitation Act, the Fair Housing Act Amendments, and the Individuals with Disabilities Education Act.

There are two points - just break down see to reflect individuals

Strengthen the capacities of each persons ^{with disabilities to} and assure that needed services and supports are provided in a coordinated fashion which maximizes their control over their own lives and futures in the mainstream of American life.

separate coordinate needed services supports to enhance self-determination, productivity, and the availability of choices

Assure that any assistance provided to such a person is ^{individualize services and assistance to} carried out in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, choices, abilities, and capabilities of that individual.

- o Support the efforts of families with children with disabilities to raise their sons and daughters at home and to include them in every facet of family and community life.
- o Assist individuals with disabilities of all ages, including ^{senior citizens} those 65 and older, to play valued roles as participating members of their families and communities.

issue item

- o Expand the ability and flexibility of states and local governments to work directly with people with disabilities and their families to fashion more effective and responsive solutions to the challenges we face as a nation.

to further these rights and responsibilities

- o Improve access to the assistance, technology, and supports that enable these individuals to have greater control over their lives and contribute more fully to their home, family, school, work, and community life.

This point correlated to the coordination point above

Assure that all current and future programs and activities are designed and implemented to meet the needs of those eligible members of the public who have disabilities.

Sooner a bill was passed and creative

- o Make it pay for such citizens to work by creating incentives rather than disincentives and increase their opportunities for entering and staying in the workforce.

very high up

March 23, 1995

Note to Carol
Jeremy

This is the draft letter to lots of disability advocacy groups reassuring them about our position on the ADA and other key disability legislation, and mentioning the disability policy review. Let me know if you have any comments.

Diana

March 23, 1995

MEMORANDUM FOR DIANA FORTUNA

FROM: Debbie Fine

SUBJECT: Letter from the President

Attached is the letter revised with suggestions from Elaine Kamarck, OVP, and Lisa Fairhall, OMB. Please look it over and let me know what you think. Thanks.

cc: Deborah Pearlstein
Steve Hilton

REVISED DRAFT

As of 3/22/95

Dear Colleague:

I believe it is important to review the mass of existing federal regulations to make government more effective, and under the Vice President's leadership my administration will continue to move forward and to streamline and improve Federal rules wherever possible. However, I want to make it clear that I regard the ADA as a landmark piece of civil rights legislation, and this administration remains committed to full its implementation and enforcement.

In order to continue our efforts to empower individuals with disabilities to live as independently as possible and remain productive throughout their lives, this Administration has launched a full-scale review of all policies and programs serving individuals with disabilities. This National Disability Policy Review is a joint effort of the Domestic Policy Council and the Office of Management and Budget, and is guided by the set of principles enclosed. I am optimistic that this initiative will ensure the development and continued improvement of systems serving people with disabilities and their families.

We intend to strive towards achieving a national disability policy based on three simple creeds: inclusion, not exclusion; independence not dependence; and empowerment, not paternalism. As we move forward in our efforts to build a brighter future for all Americans, I welcome your continued involvement.

Sincerely,

POTUS

Neq 51
Extend/Connect Help - teachers w/SE/building capacity
Metzler - Q
Deliver to agency/prog hds - how?
2/16/95

DRAFT

National Disability Policy Review
Guiding Principles
DRAFT

gender; Wright
recreation: Arch

The fundamental role of governments in respect to individuals with disabilities should be to assure the right of such persons to enjoy full inclusion and integration in the educational, economic, political, social, and cultural mainstream of American society. In practical terms, therefore, governments must assure that people with disabilities of all ages, ethnic backgrounds, and income levels have the equal opportunity to exercise their full rights and responsibilities to live as independently as possible; to enjoy self-determination; to make choices; and, to be productive throughout their lives. It is, therefore, in the nation's interest that public policies, programs, benefits, and activities affecting such individuals be designed and implemented to:

Marchand: Govts do + must. Among fund roles
Peter: would? No (that's what all)

- End discrimination against Americans with disabilities and strengthen our nation's communities and economy by providing strong, effective, and fair enforcement of the Americans with Disabilities Act, Title V of the Rehabilitation Act, the Fair Housing Act Amendments, and the Individuals with Disabilities Education Act. + end of all kinds, incl. assumes no more disc. - where cannot disc. pre ext'g cond. by
- Strengthen the capacities of such persons and assure that needed services and supports are provided in a coordinated fashion which maximizes their control over their own lives and futures in the mainstream of American life. Peter: Warm + fuzzy; LHM, job, educ
- Assure that any assistance provided to such a person is carried out in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, choices, abilities, and capabilities of that individual. not nec in this doc.
- Support the efforts of families with children with disabilities to raise their sons and daughters at home and to include them in every facet of family and community life. Tony: set job, hwp in these prog -
- Assist individuals with disabilities, of all ages, including those 65 and older, to play valued roles as participating members of their families and communities. Peter/Kate: across life span
- Expand the ability and flexibility of states and local governments to work directly with people with disabilities and their families to fashion more effective and responsive solutions to the challenges we face as a nation. as well as fed - Sylvia PW right, scares her - rewrite to reflect what Bob said - QPG
- Improve access to the assistance, technology, and supports that enable these individuals to have greater control over their lives and contribute more fully to their home, family, school, work, and community life.

Assure that all current and future programs and activities are designed and implemented to meet the needs of those eligible members of the public who have disabilities. Marchand: Govts by responsibility where are

Make it pay for such citizens to work by creating incentives rather than disincentives to work and to pursue careers. How to get non-D prog to be sensitive; Reich, Petia

What is good price?

How to deal w/ current F policy vs where pp.
Marchand: Govts do + must. Among fund roles
Peter: would? No (that's what all)
Bob: reflect strategies of GP to address
Marchand: Govts by responsibility where are
Peter/Kate: across life span
Tony: set job, hwp in these prog -
Pete/Kate: across life span
PW right, scares her - rewrite to reflect what Bob said - QPG
Marchand: Govts by responsibility where are
How to get non-D prog to be sensitive; Reich, Petia
What is good price?

Should I be aggressive
say the PCVS
believers in S+L
flexibility π overall
but must be
applied to each
area thoughtfully

Main: Too public sector
Comm: State/local, No
Empowerment - use word

Blond woman; Too much
a nihilist
also elderly
top fund / context
*DOJ - mission stmt/NPR
2/21

National Disability Policy Review
Guiding Principles
DRAFT

DRAFT

Fixed role: is process
involvement?

The fundamental role of governments in respect to individuals with disabilities should be to assure the right of such persons to enjoy full inclusion and integration in the educational, economic, political, social, and cultural mainstream of American society. In practical terms, therefore, governments must assure that people with disabilities of all ages, ethnic backgrounds, and income levels have the equal opportunity to exercise their full rights and responsibilities to live as independently as possible; to enjoy self-determination; to make choices; and, to be productive throughout their lives. It is, therefore, in the nation's interest that public policies, programs, benefits, and activities affecting such individuals be designed and implemented to:

the afford dependence

bulletize - bullets too
caretaking

9 sometimes range of rights How does it work - Crest - enforcement of rights at least

1 End discrimination against Americans with disabilities and strengthen our nation's communities and economy by providing strong, effective, and fair enforcement of the Americans with Disabilities Act, Title V of the Rehabilitation Act, the Fair Housing Act Amendments, and the Individuals with Disabilities Education Act.

2 self-determined unique needs: Strengthen the capacities of such persons and assure that needed services and supports are provided in a coordinated fashion which maximizes their control over their own lives and futures in the mainstream of American life.

don't lose
unique large

3 Assure that any assistance provided to such a person is carried out in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, choices, abilities, and capabilities of that individual.

4 Support the efforts of families with children with disabilities to raise their sons and daughters at home and to include them in every facet of family and community life.

5 Assist individuals with disabilities of all ages, including those 65 and older, to play valued roles as participating members of their families and communities.

6 Expand the ability and flexibility of states and local governments to work directly with people with disabilities and their families to fashion more effective and responsive solutions to the challenges we face as a nation.

7 Improve access to the assistance, technology, and supports that enable these individuals to have greater control over their lives and contribute more fully to their home, family, school, work, and community life.

8 Assure that all current and future programs and activities are designed and implemented to meet the needs of those eligible members of the public who have disabilities.

caretaking
benefit to comm.

9 Make it pay for such citizens to work by creating incentives rather than disincentives to work and to pursue careers.

also survival
the etc.

National Disability Policy Review
Guiding Principles

DRAFT

AR: Outside/inside doc??
DRAFT

The fundamental role of governments in respect to individuals with disabilities should be to assure the right of such persons to enjoy full inclusion and integration in the educational, economic, political, social, and cultural mainstream of American society. In practical terms, therefore, governments must assure that people with disabilities of all ages, ethnic backgrounds, and income levels have the equal opportunity to exercise their full rights and responsibilities to live as independently as possible; to enjoy self-determination; to make choices; and, to be productive throughout their lives. It is, therefore, in the nation's interest that public policies, programs, benefits, and activities affecting such individuals be designed and implemented to:

- o End discrimination against Americans with disabilities and strengthen our nation's communities and economy by providing strong, effective, and fair enforcement of the Americans with Disabilities Act, Title V of the Rehabilitation Act, the Fair Housing Act Amendments, and the Individuals with Disabilities Education Act. 504
- o Strengthen the capacities of such persons and assure that needed services and supports are provided in a coordinated fashion which maximizes their control over their own lives and futures in the mainstream of American life.
- o Assure that any assistance provided to such a person is carried out in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, choices, abilities, and capabilities of that individual.
- o Support the efforts of families with children with disabilities to raise their sons and daughters at home and to include them in every facet of family and community life.
- o Assist individuals with disabilities of all ages, including those 65 and older, to play valued roles as participating members of their families and communities. Partner with business?
- o Expand the ability and flexibility of states and local governments to work directly with people with disabilities and their families to fashion more effective and responsive solutions to the challenges we face as a nation. (GA: when we partner w/ states, etc. make?)
- o Improve access to the assistance, technology, and supports that enable these individuals to have greater control over their lives and contribute more fully to their home, family, school, work, and community life.
- o Assure that all current and future programs and activities are designed and implemented to meet the needs of those eligible members of the public who have disabilities. []
Winter: ~~strengthen that not just PWD~~
- o Make it pay for such citizens to work by creating incentives rather than disincentives to work and to pursue careers.

*Fed check list
- description of the program - separate

Fed mea culpa - No

FACSIMILE TRANSMISSION

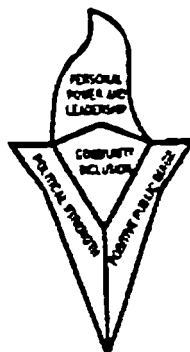
of the

Administration on Developmental Disabilities

Hubert H. Humphrey Bldg - Rm 329D
200 Independence Avenue S.W.
Washington D.C. 20201

Tel: (202) 690-6590 Fax: (202) 690-6904

ADDRESSEE: (Name, Organization, City, State & Phone Number)	FROM: (Name & Phone #)
Lynn Margheria Dianna Fortuna Elizabeth Cohen	Bob Williams/ Kate Warren 690-6120
ADDRESSEE FAX NO:	DATE:
202 456-7028	TOTAL PAGES: Cover sheet and <u>2</u> page(s)
REMARKS:	



Should we attach re Susan D's problems?
add indep?
what can Rdo?

The following represents the collective thoughts and creative energies of Judy Heumann, Howard Moses, Susan Daniels, Liz Savage, Paul Miller, Andy Imp..., Speed Davis, Kate Warren and myself. It is meant to be a point of departure rather than a final product. Thank you! Bob Williams

Prob smet? Data
not policy
 The fundamental role of governments in respect to individuals with disabilities should be to assure the right (of such persons (citizens?)) to enjoy full inclusion and integration in the educational, economic, political, social and cultural mainstream of American society. In practical terms, therefore, governments must assure that people with disabilities have an equal opportunity to live as independently as possible; enjoy self-determination; make choices; and, to be be productive throughout their lives. It is, therefore, in the Nation's interest that public policies, programs, benefits and activities affecting such individuals be designed and implemented to:

not
 o Provide strong, effective and fair enforcement of the Americans with Disabilities Act, Title V of the Rehabilitation Act, the Fair Housing Act Amendments, and the Individuals with Disabilities Education Act to help end discrimination against Americans with disabilities and strengthen our Nation's communities and economy.

not
 o Strengthen the capacities of such persons and assure that needed services and supports are provided in a coordinated fashion which maximizes their control over their own lives and futures in the mainstream of American life.

flex alloc level
more reason
separate bullet
str + imp + sml
flex
 o Assure that any assistance provided to such a person is carried out in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, choices, abilities and capabilities of that individual.

o Support the efforts of families with children with disabilities to raise their sons and daughters at home and to include them in every facet of family and community life.

o Improve access to the assistance, technology and supports which enable these individuals to have greater control over their lives and contribute more fully to their home, family, school, work and community life.

Bob W
will draft some options
 o Assure that qualified individuals with disabilities have the opportunity to achieve equally effective results in all programs and activities by insuring such support is universally designed to meet the needs of the public and disability related needs as well.

o Make it pays for such citizens to work by creating incentives rather than disincentives to work and to pursue careers.

oldsters - family members

January 24, 1995

MEMORANDUM TO: Members of the National Disability Policy Review
Team, Guiding Principles Workgroup

FROM: Bob Williams, Commissioner
Administration on Developmental Disabilities
Convener, Guiding Principles Workgroup

SUBJECT: Process and timeline for review of Guiding Principles

I am writing to update you on the status of a discussion draft of the Guiding Principles.

A subcommittee of the full workgroup has continued to work on refining the document per input from the December meeting. This draft will be shared with the conveners of each workgroup in a meeting scheduled for the first week in February.

Following the conveners' review, a draft will be faxed to each of you and shared with the advocacy community for additional discussion and comment. The guiding principles workgroup may be convened prior to the full NDPRT meeting February 22 should comments received require further discussion.

Members of the full policy review team will discuss and adopt a final version of the Guiding Principles document at the meeting scheduled for February 22nd.

Should you have any questions, please contact Kate Warren at (202) 690-6120.

*Also, please check this
as to process timeline before it goes out
Thank,
Kate*

DF

THE WHITE HOUSE
WASHINGTON

Meeting of the Work Group Convenors
National Disability Policy Review
February 8, 1995
Room 211, Old Executive Office Building

* Sep NPR mtg
- KA to convene
mtg

Agenda

Welcome and Introduction

Carol H. Rasco

Work Group Updates:

- o Adult Employment
- o School-to-Work - spillover
- o Accommodations
- o Childhood

Each Convenor will
be asked to make
brief remarks

Guiding Principles

Bob Williams to lead
discussion of substance,
process and time-line

Inventory of Agency Program
Information

Lisa Fairhall, Richard
Green & Lynn Margherio

Advocacy Groups

Diana Fortuna & Lynn
Margherio

Next Steps

! - 9ps sensitive to any
Just say no - JCS

Immediate concerns - SD
* Consal - ETA
* VR
Enf of SOY Howard

NPR
* Add Gaynor/DVE
* Add DOL - who?

Status of Agency Responses to Data Request

Agriculture: under development
Commerce: material has been submitted (mostly internal employee accommodations, outreach, and recruiting activities)
Defense: no submission to date
Education: under development
EEOC: no submission to date
HHS: under development
HUD: under development
Interior: no submission to date
Justice: material has been submitted (covering primarily enforcement activities)
Labor: material has been submitted (currently does not include information on Black Lung or FECA)
OPM: material has been submitted (currently does not include information on disability/disability retirement programs)
SSA: material has been submitted
Transportation: under development
Treasury: material has been submitted (currently does not include tax policy information)
VA: no submission to date

The following represents the collective thoughts and creative energies of Judy Heumann, Howard Moses, Susan Daniels, Liz Savage, Paul Miller, Andy Imp..., Speed Davis, Kate Warren and myself. It is meant to be a point of departure rather than a final product. Thank you! Bob Williams

The fundamental role of governments in respect to individuals with disabilities should be to assure the right of such persons (citizens?) to enjoy full inclusion and integration in the educational, economic, political, social and cultural mainstream of American society. In practical terms, therefore, governments must assure that people with disabilities have an equal opportunity to live as independently as possible; enjoy self-determination; make choices; and, to be productive throughout their lives. It is, therefore, in the Nation's interest that public policies, programs, benefits and activities affecting such individuals be designed and implemented to:

1 o Provide strong, effective and fair enforcement of the Americans with Disabilities Act, Title V of the Rehabilitation Act, the Fair Housing Act Amendments, and the Individuals with Disabilities Education Act to help end discrimination against Americans with disabilities and strengthen our Nation's communities and economy.

2 o Strengthen the **capacities** of such persons and assure that needed services and supports are provided in a coordinated fashion which maximizes their control over their own lives and futures in the mainstream of American life.

3 o Assure that any assistance provided to such a person is carried out in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, choices, abilities and capabilities of that individual.

4 o Support the efforts of families with children with disabilities to raise their sons and daughters at home and to include them in every facet of family and community life.

5 o Improve access to the assistance, technology and supports which enable these individuals to have greater control over their lives and contribute more fully to their home, family, school, work and community life.

6 o Assure that qualified individuals with disabilities have the opportunity to achieve equally effective results in all programs and activities by insuring such support is universally designed to meet the needs of the public and disability related needs as well.

7 o Make it pays for such citizens to work by creating incentives rather than disincentives to work and to pursue careers.

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DRAFT ONLY -- NOT FOR DISTRIBUTION

"We must not rest until America has a national disability policy based on three simple creeds: inclusion, not exclusion; independence, not dependence; and empowerment, not paternalism." Bill Clinton, 1992

Today, more than at any other time in our Nation's history, increasing numbers of Americans with disabilities are realizing their birthright: Leading lives that are central to the vibrancy of their families, communities and country. Adults with disabilities have consistently rejected society's low estimation of their worth -- a far greater barrier than any common limitation of body or mind. Along with Congress, the White House, State Houses, and the judiciary, they have worked to achieve the same rights and equal opportunities available to all Americans. These individuals, their families, and allies from across our political spectrum have redefined both what it means to have a disability in America and a full, first class United States citizen as well.

To reflect the rich heterogeneity and diversity of the 49 million Americans with disabilities, the guiding principles in designing our public policy affecting Americans with disabilities must necessarily be broad and universal. Such principles can both refine our ideals and test future specific policy proposals against those ideals and the real-world constraints we face. This draft is intended to begin a national conversation to achieve consensus on how oft-stated goals of inclusion, empowerment, and independence will be realized.

Americans with disabilities and their families are focusing on the same crucial life goals which have become synonymous with the responsibilities and the very meaning of good citizenship:

- o Getting a good education;
- o Gaining a decent job for a decent living and pursuing a career;
- o Finding ways to contribute to our family, community and nation; and,
- o Raising our children to the best of abilities and drawing upon the needed support of our family, friends and community to do so.

Individuals with disabilities and their families are thus shaping a better life and future both for themselves and for our country as a whole. There is an American success story in progress. It is one which all Americans can identify with, aspire to and work together to help realize more fully.

Due in large part to their efforts, passage of key legislation, beginning at the State level in the early 1970's, and later at the federal level, in the areas of educational access, barrier free design and employment opportunities opened doors which had been slammed shut for decades:

- o In 1975, an estimated two million children with disabilities received a totally inadequate education or were barred from attending the public schools, altogether. Today, 5 million students with disabilities receive a free and appropriate education, many alongside their nondisabled classmates.
- o In 1967, around 200,000 Americans with developmental disabilities lived in large state institutions under some of the most degrading and deplorable conditions ever known in our nation. Today, over 375,000 of these individuals and others like them are supported in family or community settings. Approximately 75,000 residents, however, still live in State institutions.
- o Throughout the 60's, 70's and even the 80's, it was common for people with disabilities to be routinely denied access to their community's schools, swimming pools, banks, restaurants and even to the voting booth. Today, these acts are now not only illegal but unconscionable in the hearts and minds of Americans of every race, region and political persuasion.

Laws such as the Americans with Disabilities Act, the Individuals with Disabilities Education Act, the Rehabilitation Act Amendments of 1992 and the Technology-Related Assistance Act have challenged age old myths and stereotypes, creating hope and opportunity in the everyday lives of Americans with disabilities and many others through out our country.

A strong legislative foundation exists to strengthen the abilities of people with disabilities to exercise their rights and responsibilities as citizens to:

- o live as independently as possible;
- o enjoy self-determination;
- o make choices;
- o pursue meaningful careers; and,
- o participate fully in the economic, political, social, cultural and educational mainstream of society.

Building upon this foundation will not be easy, however. For, despite progress in assuring equal opportunities and promoting independence for Americans with disabilities, significant gaps and contradictions exist in a wide array of federal policies and programs that affect the daily lives of these citizens.

In its historic report, *Towards Independence*, the National Council on Disability underscored a disturbing truth:

With surprising consistency, the branches of American Government, disabled individuals and their families,... have agreed that the overall goal of the nation in regard to persons with disabilities is to insure the rights of such individuals to equality of opportunity and to independence.

Confusion and inconsistency have resulted, not from lack of consensus about the goal, but from the historical and continuing failure to structure and administer some Federal laws and programs in such a way as to reflect and further the national goal... Federal programs and laws that should serve as paths toward this goal have often deviated or even retreated from it.

One of the most critical challenges we face, therefore, as a Nation and a people is to steer a clearer, steadier course towards independence and inclusion. This means that the Executive and the Congress must work together with the States, people with disabilities, their families and allies, and the American public as well to:

- o strengthen and learn from public policies and programs which provide people with disabilities and their families access to supports and reasonable accommodations which increase their capabilities to live lives of their own choosing and direction; and,
- o redirect laws and programs which infringe upon the rights and abilities of such citizens to lead full and productive lives.

Americans with disabilities and their families are no longer looking to their Federal, State or local government to simply take care of them as government has tried to do and fallen far short of doing in the past. Instead, these citizens expect something far more profound of government at all levels: They expect their government to care deeply about their individual hopes and aspirations; their fears and worst nightmares; and, to support their efforts to be independent to the greatest extent possible.

This approach will require a fundamental break with many paternalistic and destructive policies, programs and practices of the past and present. The Executive and Congress should work hand in hand with Americans with disabilities and their families to review and overhaul Federal laws and programs that impact their lives. This effort should be guided by the following fundamental principles and truths, regarding the needs, rights and abilities of Americans with disabilities:

- o Historically, people with disabilities have been subjected to pernicious and pervasive discrimination and prejudice in every aspect of their lives.
- o Continuing unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and costs the U.S. billions of dollars in unnecessary expenses resulting in dependance and nonproductivity.
- o The Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals.
- o Strong, effective and fair enforcement of the Americans with Disabilities Act, Title V of the Rehabilitation Act, the Fair Housing Act Amendments, and the Individuals with Disabilities Education Act can help to eradicate discrimination against Americans with disabilities and strengthen our Nation's communities and economy.
- o For some individuals with disabilities, lifelong access to needed supports, like personal assistance and assistive technology, is critical. In fact, for millions of Americans with disabilities, it is the only thing, that can begin to tear down, the walls of myths, prejudices and stereotypes, which would otherwise inhibit or prevent them from leading full and productive lives.
- o All children, regardless of the level of their disabilities, belong with and do best with families. There is a clear national interest in supporting the efforts of families with children with disabilities to raise their sons and daughters at home and to include them in every facet of family and community life.
- o Young infants and toddlers with disabilities have a right to receive early intervention and childhood development services along with their nondisabled playmates.
- o All children with disabilities have the right to receive and benefit from a free and appropriate public education in an integrated, well supported classroom suited to their needs.
- o Inclusive education works best for children with and without disabilities when all students and their teachers receive the support they need to learn from each other and excel both at school and in life.
- o The role of public education is the same for students with and without disabilities alike: to challenge them to do

their best, to develop to their fullest potential and to assume their rightful roles and responsibilities as productive and contributing members of their families, communities and Nation.

- o Given the unnecessarily high rates of unemployment and under-employment of working age Americans with disabilities, effective school to work strategies must be developed to offer young people with disabilities the opportunities, skills and support they need to gain work experience, a positive work history, increased self confidence and success.
- o Welfare Reform, the School-to-Work initiative and AmeriCorp National Service efforts create crucial opportunities to assist young Americans, with and without disabilities, to gain first-time job, internship and volunteer community service experiences, together.
- o It should pay for Americans with disabilities to seek out and gain meaningful employment in our economy. Accordingly, social security and Federal tax policies should create real incentives rather than disincentives for working-age individuals with disabilities to work and to pursue careers.
- o The fear of losing Federal health benefits, and access to such vital supports as personal assistance, is often cited by disabled Americans as a major reason why they either have never worked or do not want to "risk" returning to work. It is imperative that such massive disincentives to employment be eliminated from every vestige of Federal law, policies and programs.
- o If given the chance and the needed support, many more working-age Americans with disabilities can make work pay off in their lives. However, substantial numbers of these individuals will require on going income support as well as access to community-based supports, personal assistance and assistive technology services.
- o Welfare Reform presents critical opportunities for the Federal government and the States to develop effective strategies for addressing the links between race, minority status, disability and pervasive poverty in our country.
- o States are developing community services that are cost effective and responsive to the needs of people with disabilities and families. Often, however, these States must seek waivers from current Federal Medicaid rules to do what is right. Such underlying policies and practices should be examined and remedied.

(continued)

#localities

- o States need flexibility to work with people with disabilities and their families to fashion responsive solutions to the challenges we face as a Nation.

(f:\...cbw\npr.sh)

(end)

Secondary list
to read program



DEPARTMENT OF HEALTH & HUMAN SERVICES

Social Security Administration

Refer to:

Baltimore MD 21235

2/6/95

Note to Lynn Margherio and Diana Fortuna:

Susan Daniels wanted you to have a copy of the attached document for your background. These are simply some thoughts and ideas that she's had -- nothing formal has been distributed.

Please call me if you have any questions. Hope to see you at our Employment Work Group on Wed. 2/8.

Sincerely,

A handwritten signature in cursive script, appearing to read "April Waugh", is written over the typed name and title.

April Waugh
Program Analyst
Office of the Associate Commissioner
(410) 965-8046

cc Jeremy (orig to Diana)
for Diana
This is much more
than I thought it
would be.

A small, handwritten mark or initials, possibly "TD", is located at the bottom right of the page.

A Dozen Principles

What follows is based on the work of members of another Panel studying the same issue as we are. I have taken great license with them. These principles operate at somewhat different levels, there will be some overlap -- as indeed there should be, if they are a coherent set.

A. General Programmatic Principles

Principle 1: Social and Economic Goal

The goal of disability policy is to promote the social and economic functioning [in the community] and the personal autonomy of persons with disabilities in addition to their economic security.

Rationale: Disability policy should be conceived as broader than civil rights, rehabilitation or income support policy. This does not imply that these policy arenas are unimportant, indeed, they are crucial; but stating the general goal of disability policy in a broader form has implications for the structure of all these programs.

Illustration: Rehab programs obviously aim to carry forward this idea in their general focus on improving economic functioning and, more recently, the desire to entertain methods of administration that emphasize choice by recipients. For example, from the perspective of this principle rehab efforts and civil rights enforcement need not be justified solely, or even primarily, in terms of future savings.

Principle 2: Building on Capacities

Disability policy should focus to the extent possible on individual capacities rather than individual incapacities.

Rationale: Most of us can agree that general labelling of recipients of programs as "????disabled" is bad and that disability policy should be altered whenever possible to focus everyone's attention on possibilities for individual achievement rather than on excuses for nonperformance.

Illustration: DOL programs....What can we say about "special" education in this context?

Principle 3: Disabilities are Created

Disability policy should seek to locate impediments to desired levels of functioning in the interaction between individuals and their physical, social, and economic environment. Programs should be targeted strategically on that interaction.

Rationale: Policies with respect to persons with disabilities should clearly focus on the interaction of individuals, their physical or mental limitations and their physical, social and economic environments, rather than simply being riveted on identifiable, individual limitations.

Nevertheless, it remains unclear in the abstract whether policy should attempt to operate on the person (increased motivation or training), the limitation (medical or prosthetic intervention) or the environment (employer attitudes, physical barriers, etc). It is, of course, highly likely that programs should address all three areas if we are to have an effective overall national policy. However, given the heterogeneity of the population of persons with disabilities, their personal histories and their local environments, it may often be sensible to emphasize one type of intervention rather than another individual cases. The notion that is that policies should be developed that recognize the breadth of the opportunities for intervention and have the flexibility to intervene selectively where one or another strategy seems more effective.

Illustration: The combination of ADA and rehab promotes this principle. A broad range of interventions are available, and a number of them operate on the environment rather than the individual. Pursuit of principles three might suggest further refinements, e.g., providing consultative services to employers to assist them in accommodating workers, special ed interventions aimed at teacher behavior, etc.

Principle 11: Full Empowerment is the Best Way to Achieve Individualization.

Simplicity of administration is consistent with individualized treatment only in systems that confer unreviewable discretion on either caseworkers or clients. The latter is

preferred.

Rationale: This principle is meant to put starkly the choice between official and individual consumer discretion in a system which, by assumption, must be relatively simple to administer because of constrained resources. It also highlights the notion that if one does not want to choose either of these loci of discretion (because of concerns about program integrity) then one had better rethink administrative resource constraints. In any event, the idea is to put us on record as favoring individualization through client autonomy where feasible.

Illustration: The different modes of administration in those programs that propose vouchers nicely illustrate the choice, but the problems with setting voucher amounts and the worries about how they might be used could mean that this is an area where the "presumption" for client choice should be overridden. When vouchers are broad, they become "cash."

Principle 4: Generic Approaches are Preferable to Specialized Ones

Disability policies that meet specific needs that may arise for anyone in the whole of the population should be accessible to all citizens.

Rationale: This principle responds to several instincts. The first is that universal programs are generally stronger politically than targeted programs (Social Security), have less risk of imposing stigma on individuals (special ed), and also have a lesser tendency to create boundaries between categories of individuals that must be defended administratively (like those in SSI) and that may appear unfair. Yet more generally, this principle responds to my desire to see the notion of "disability" or "the disabled" disappear as much as possible from all aspects of public policy and public discourse.

Illustration: School-to-Work. It would be better yet to have a strong transition to work social services network that could be accessed by anyone in need of those services so that the "for disabled only" boundary would not have to be defended.

Principle 5: Making Work Pay

All means tested programs should be structured to avoid work disincentives that are unnecessary to achieve resource targeting.

Rationale: This principle is in some sense a truism, but it also seeks to recognize that there is a necessary work disincentive built into any means tested program and that there is a tradeoff between limiting work disincentives and providing security for only those who can not provide for themselves.

Illustration: Long term care proposals rated high on this principle.

Principle 6: Decoupling Services from Income Supports

Goods/services/supports to persons with disabilities should be linked to the receipt of cash benefits only when the linkage of cash and in-kind benefits promotes an important policy goal that cannot be achieved effectively by alternative means.

Rationale: As we know, the linkage of goods/services/supports to cash benefits tends to create notch effects as well as all or nothing decisions that deny services to persons who need them whether or not they can work. On the other hand, programs might sensibly create linkages, for example that cash benefits are payable to those believed to be temporarily disabled only on the condition that they accept rehabilitation, training and other supports that are designed to promote their capacity for self-support.

Illustration: The Clinton long-term care provisions in the health reform plan were not coupled to SSI or means tested.

Principle 7: Services/Goods/Supports Should be Tailored to Individuals

Particular in-kind and service benefits targeted on persons with disabilities should, in general, not be structured as discrete entitlement. Such support should be provided as part of an entitlement to an overall support plan, where coordinated effort is thought to be essential; or, alternatively, should be accessed by clients through an entitlement to vouchers or tax subsidies -- systems that maximize the service user's autonomy.

Rationale: The idea that while certain universal, non-cash programs could be structured as entitlement (e.g., health care, PAS, food stamps, etc.), the decoupling of in-kind benefits and services for persons with disabilities from income programs could create serious administrative problems. If each particular type of benefit were its own

free-standing entitlement, determining eligibility (and defending those decisions) might well be an administrative nightmare. The principle suggests that there are two plausible models for such goods/services/supports, but with radically different administrative implications.

* The first is the provision of goods/services/supports as part of an overall plan, such as occurs, for example, in programs for developmentally disabled children. There is an entitlement here, but it is an entitlement to an overall, coordinated service plan, not to particular benefits.

* Alternatively goods/services/supports might be accessed through voucher or tax subsidy systems. The great advantage of such systems, of course, is their capacity to maximize user autonomy in selection of service and providers. Once again the voucher or the tax subsidy is an entitlement, but one that is much more easily administered than entitlement to discrete goods/services/supports.

Illustration: The long term care proposals allowed both client choice or professional planning in administration, and yet clearly viewed PAS as a "package" entitlement rather than an entitlement to each discrete service or activity. A tax credit approach is still being considered for working adults.

Principle 8: Localize/Privatize

The delivery of goods/services/supports should be localized and/or privatized to the extent possible.

Rationale: Administering services confronts, not only the highly various needs of the population served, but also great variations in local resources and public capacities.

Many argue that the federal government will never, and should never, staff itself to deliver such benefits or services and that, wherever feasible, these sorts of service provision or good provision activities should be policed by competitive markets in the private sector.

Illustration: Special education services are very localized now, though not privatized. Medicare is both.

Principle 9: Setting Realistic Goals and Funding Them

Goods/services/supports policies, administrative procedures and appropriations for administration of programs must be carefully coordinated to avoid mismatches between program aspirations and program performance.

Rationale: This is an incomplete design principle. Alternatives include adopting substantive policies that can be administered effectively with available administrative resources, or "re-engineering" processes to make them more efficient.

Illustration: How can increased individualization of decision-making and aggressive service provision be squared with downsizing the govt work force? One possibility is privatizing and "vouchering" the process, but it should be recognized that these devices may actually change the output of the program.

Principle 10: Salad Bar Approach

All or nothing decisions tend to create unwelcome, demoralizing and expensive levels of conflict concerning programmatic decision-making. This implies that administrative systems should either be highly individualized and fluid (an unlikely prospect given administrative resource constraints) or should provide clear, structured alternatives that can be accessed by claimants themselves.

Rationale: It seems to be everyone's view that there is entirely too much conflict, too many levels of appellate review, legal intervention and so on in disability programs (perhaps all entitlement programs). My sense is that most requests for services by persons with disabilities ought to be answered by the provision of a great variety of goods/services/supports. If that is our view, and if we also do not desire increased resources for administration, then one needs a system that provides consumers with staged eligibility to a menu of alternative means of assistance that they can negotiate for themselves (or with the help of their existing social support network). Decision-making is like a tree in which official eligibility sends people off down different roads (that they travel mostly on their own), but seldom tell them that they have hit a dead end street. The programmatic possibilities here are obviously nearly limitless.

Illustration: Too obvious to require comment?

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Simplicity of administration is consistent with individualized treatment only in systems that confer unreviewable discretion on either caseworkers or clients. The latter is preferred.

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Principle 12: The Fairest and Best Decisions Are Reached Through Consumer Involvement.

The legitimacy of service/ benefits decision-making should be sought primarily through an emphasis on consumer participation, understanding and control.

Rationale: The current system, at least as it relates to some of our programs (special ed., income support) seems to seek legitimacy through multiple levels of review and the application of legal intervention. This has produced an enormously cumbersome process and that seems to suffers from recurrent, low levels of perceived legitimacy. To be sure, the basic decision to provide services/goods/supports or not is likely to be conflictual or contested in any system, and it obviously must be "official" decision by someone who can be held accountable. Nevertheless, it would seem possible to do better through earlier and stronger involvement of claimants in these decisions and a shift to a system in which decisions are not all or nothing. Moreover, in the absence of armies of highly trained "disability experts", the understanding of options, and participation in, if not control of, choices by consumer, seems to be essential.

Illustration: Some current approaches (IL) and future proposals do seem to imply much earlier and stronger interchange between the consumers and the deciders that the current system. The service possibilities might also be structured as a menu from which consumer could choose; it can be made clear exactly what happens when a temporary or short term service ends; etc. This, of course, does not preclude ultimate resort to hearings and other legal forms where people remain aggrieved.

Enough on principles. These are surely incomplete and some are controversial.

Thank you Jerry !

SUSAN
Phone 410-965-3424

—
guiding
principles
draft

distributed! discussed at
12/21 mtg.

Draft--Guiding
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- o strengthen and learn from public policies and programs which provide people with disabilities and their families access to supports and reasonable accommodations which increase their capabilities to live lives of their own choosing and direction; and,
- o redirect laws and programs which infringe upon the rights and abilities of such citizens to lead full and productive lives.

Americans with disabilities and their families are no longer looking to their Federal, State or local government to simply take care of them as government has tried to do and fallen far short of doing in the past. Instead, these citizens expect something far more profound of government at all levels: They expect their government to care deeply about their individual hopes and aspirations; their fears and worst nightmares; and, to support their efforts to be independent to the greatest extent possible.

This approach will require a fundamental break with many paternalistic and destructive policies, programs and practices of the past and present. The Executive and Congress should work hand in hand with Americans with disabilities and their families to review and overhaul Federal laws and programs that impact their lives. This effort should be guided by the following fundamental principles and truths, regarding the needs, rights and abilities of Americans with disabilities:

- o Historically, people with disabilities have been subjected to pernicious and pervasive discrimination and prejudice in every aspect of their lives.
- o Continuing unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and costs the U.S. billions of dollars in unnecessary expenses resulting in dependance and nonproductivity.
- o The Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals.
- o Strong, effective and fair enforcement of the Americans with Disabilities Act, Title V of the Rehabilitation Act, the Fair Housing Act Amendments, and the Individuals with Disabilities Education Act can help to eradicate discrimination against Americans with disabilities and strengthen our Nation's communities and economy.
- o For some individuals with disabilities, lifelong access to needed supports, like personal assistance and assistive technology, is critical. In fact, for millions of Americans with disabilities, it is the only thing, that can begin to tear down, the walls of myths, prejudices and stereotypes, which would otherwise inhibit or prevent them from leading full and productive lives.
- o All children, regardless of the level of their disabilities, belong with and do best with families. There is a clear national interest in supporting the efforts of families with children with disabilities to raise their sons and daughters at home and to include them in every facet of family and community life.
- o Young infants and toddlers with disabilities have a right to receive early intervention and childhood development services along with their nondisabled playmates.
- o All children with disabilities have the right to receive and benefit from a free and appropriate public education in an integrated, well supported classroom suited to their needs.
- o Inclusive education works best for children with and without disabilities when all students and their teachers receive the support they need to learn from each other and excel both at school and in life.
- o The role of public education is the same for students with and without disabilities alike: to challenge them to do

their best, to develop to their fullest potential and to assume their rightful roles and responsibilities as productive and contributing members of their families, communities and Nation.

- o Given the unnecessarily high rates of unemployment and under-employment of working age Americans with disabilities, effective school to work strategies must be developed to offer young people with disabilities the opportunities, skills and support they need to gain work experience, a positive work history, increased self confidence and success.
- o Welfare Reform, the School-to-Work initiative and AmeriCorp National Service efforts create crucial opportunities to assist young Americans, with and without disabilities, to gain first-time job, internship and volunteer community service experiences, together.
- o It should pay for Americans with disabilities to seek out and gain meaningful employment in our economy. Accordingly, Social Security and Federal tax policies should create real incentives rather than disincentives for working-age individuals with disabilities to work and to pursue careers.
- o The fear of losing Federal health benefits, and access to such vital supports as personal assistance, is often cited by disabled Americans as a major reason why they either have never worked or do not want to "risk" returning to work. It is imperative that such massive disincentives to employment be eliminated from every vestige of Federal law, policies and programs.
- o If given the chance and the needed support, many more working-age Americans with disabilities can make work pay off in their lives. However, substantial numbers of these individuals will require on going income support as well as access to community-based supports, personal assistance and assistive technology services.
- o Welfare Reform presents critical opportunities for the Federal government and the States to develop effective strategies for addressing the links between race, minority status, disability and pervasive poverty in our country.
- o States are developing community services that are cost effective and responsive to the needs of people with disabilities and families. Often, however, these States must seek waivers from current Federal Medicaid rules to do what is right. Such underlying policies and practices should be examined and remedied.

(continued)

- o States need flexibility to work with people with disabilities and their families to fashion responsive solutions to the challenges we face as a Nation.

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