

Minutes of December 21, 1994 meeting of the National Disability Policy Review (NDPR)

The second meeting of the NDPR was held from 2:00-3:35 p.m. and was attended by 31 participants. Belle Sawhill and Jeremy Ben-Ami conveyed the regrets of Carol Rasco and Alice Rivlin (who were in meetings with the President) and facilitated the meeting.

Accommodations:

Liz Savage noted that the group would meet soon and Stan Herr explained that recommendations of the *Federal Disability Accommodations Working Group* were forwarded and that much of the work of this group will be folded into the *Accommodations Work Group* to be convened by Deval Patrick.

Adult Employment:

Susan Daniels distributed the group's charter and explained that at their first *Adult Employment Work Group* meeting, the group discussed some principles relevant to employment. (The possibility of incorporating some of this language in a revised set of *Guiding Principles* was later mentioned.)

School-to-Work Transitions:

Judy Heumann explained that most of the school-to-work programs are not part of the broader re-employment programs. She raised the concern that as one-stop shopping models in this field are being designed, the NDPR must be sure that they will be qualified to serve individuals with disabilities. Although there is clear agreement that collaboration has strong benefits, the collaboration process must be sensitive to service delivery issues.

Belle Sawhill noted the need to align our proposals with the President's proposed Middle Class Bill of Rights.

It was noted that to work effectively on various labor issues, Labor and Commerce participation is essential.

Guiding Principles:

Bob Williams, the convenor of the Guiding Principles group, distributed a preliminary draft based on the initial meeting of the group held on December 14. He summarized the document and the bulk of the meeting was then devoted to comments and reactions. This feedback included the following points:

- * desirability of addressing access to recreational facilities and other activities that contribute to the enjoyment of life

(Jim Lyons);

- * potential of the life cycle approach to address access issues in a variety of contexts in addition of school and work settings; this approach has additional merit of bringing fresh perspective to look at our federal programs (Lisa Fairhall and Belle Sawhill);

- * ADA principles and purpose language is incorporated in this draft, and ADA reaches recreational and other public accommodations (Bob Williams);

- * Jeffersonian principles embodied in the Declaration of Independence (life, liberty, the pursuit of happiness) also embody notion that people should have equal access to full range of life activities, and bear reference in this document (Stan Herr);

- * The Architectural Barriers Compliance Board is also addresses these issues (Belle Sawhill);

- * importance of scheduling an early meeting of the five convenors and Review co-leaders to coordinate work of the overall Review (Belle Sawhill and others);

- * importance of reference to racial equality and fair distribution of goods and services to "all persons with disabilities regardless of race" (John Kraft);

- * commended draftsmen for this "excellent statement" that might work perfectly as a preamble or executive summary., but expressed need for a more concise and discrete statement if possible (Paul Miller);

- * subsequent concurrence that a briefer, more selective statement of principles is needed to really guide and drive the Review (Belle Sawhill and others);

- * various individuals noted portions of this statement that expressed such core principles, drawing attention to Page three, second full paragraph: (beginning "One of the most critical challenges we face..." and followed by 2 bullet points ending with "full and productive lives.") and to page 4 and its first bullet point on equality of opportunity, full participation, independent living, and economic self-sufficiency;

- * utility of cost-benefit analysis raised (David Levine)

- * need to clarify the role of the Federal Government in disability policy (Judy Heumann);

- * need to define the federal role vis-a-vis state and local government roles (Ron Glaser);

* need for nuanced discussion of the allocation of resources and responsibilities between the federal and state levels of government; concern expressed on interpretation that could be seen as handing everything back to the states (Paul Miller);

* strong concern expressed that diminution of federal role could produce conditions that fostered historic discrimination in this field; need for further conversation before we can know how to draft a principle on federalism and disability policy (Bob Williams);

* need to recognize this as an issue of constitutional proportions (Roberta Achtenberg);

* re-direction of policies aimed at increasing capabilities to live independently is the essence (Belle Sawhill and others);

* caution expressed that when the states at one time had full play and plenary power over our issues, massive discrimination resulted (Bob Williams);

* difficult to make generalizations regarding the federal role in issues that vary from civil rights where federal interest is strongest to different types of services and supports; reference to five bullets on page 2 of the statement that offer concise guidance to this NDPR on federal legislative finds on rights and responsibilities of people with disabilities (Stan Herr);

* query: are we getting to what the group had in mind when we initially agreed that a statement of guiding principles is needed? (Jeremy Ben-Ami);

* noted that Bob has done an incredible job and his draft is providing a vehicle for moving the dialogue forward; observed that this type of discussion is helpful as we move to a briefer, clearer public document (Judy Heumann);

* observed that this goes beyond an inside conversation and becomes a public document, important to stress that everyone is at risk of becoming disabled at one point one's life, that disability is not limited to a static group of people, and that the issues are of universal interest and importance (Jeff Levi);

* greater stress should be devoted to the principles underlying ADA since every area of a persons life is implicated by the ADA principles (Marilyn Thornton);

* suggested ADA implications for income support (Lisa Fairhall);

* noted the breadth of government purposes covered under the ADA (Liz Savage);

* questioned whether the principles stated give us an answer when competing values conflict or to the question of means; although

we all probably agree on the goals of ADA, this will not settle some disagreements regarding the means or other programmatic decisions (Susan Daniels);

* suggested that we may not be able to resolve such issues at the front end of this process, but may first need to look at the finding of our five work groups (Jeremy Ben-Ami);

* query: are we spending the 170 billion on disability matters in the most effective way? For her, the crux of the question is that we don't need to do a lot of research to say we aren't, but we need to know if there are certain values we can apply to move forward (Judy Heumann);

* agreed that we absolutely should be thinking in a very zero-based way and thinking about an entire set of programs and how they inter-act with each other; the offer was made to have a meeting to present data on how monies are spent, with general agreement from the group that this would be a good idea. Purpose of formulating principles is to give us discipline in governmental process (Belle Sawhill);

* stressed importance of federal government serving as a model of access since others look to us in compliance with legislation and guidelines (Paul Miller);

Closing Comments

Jeremy Ben-Ami made the following points:

- * NDPR has broad-based purposes, including a look from the ground up at our disability programs and including furthering the goals of ADA; Team members were asked to please inform their staff that there the goals and scope of the Review are indeed broad;
- * it is critical to attend meetings so that there is continuity of participation by all agencies and progress can occur;
- * Alice Rivlin and Carol Rasco are committed to the Review and reiterating that a meeting with the President precluded their attendance on this date;
- * work groups to flesh out detailed steps and come back in January with a work plan for each group;
- * the convenors should meet in early January as per the suggestion made today;
- * NDPR to hold a full meeting in late January;
- * expanded list of advocates to be consulted and revised workplan contained in the packets; members urges to please

submit any comments on those documents;

- * presentation on data/ baseline spending will be scheduled;

Lisa Fairhall made the following remarks:

- * helpful for agencies to present data with brief program description;
- * memo to be distributed with specifications.

Jeremy Ben-Ami:

- * expressed thanks to Stan Herr whose fellowship is ending for his help in this Review and other disability policy matters

Belle Sawhill and Jeremy Ben-Ami adjourned the meeting at 3:35 p.m.

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Stan working this on - Elio

Minutes from December 21 meeting of the National Disability Policy Review

Accommodations:

Stan Herr explained that 3 of the 4 recommendations of the *Federal Disability Accommodations Working Group* will proceed -- much of the work of this group will be folded into the *Accommodations Work Group* to be convened by Deval Patrick.

Adult Employment:

Charter distributed and Susan Daniels explained that a very rough draft was discussed at the first *Adult Employment Work Group* meeting and revisions were made as a group. (The possibility of incorporating some of the language in this group's charter when revising the *Guiding Principles* document was later mentioned.)

School-to-Work Transitions:

Judy Heumann explained that most of the programs are not part of re-employment programs. She raised the concern that as one-stop shopping models are being designed, we must be sure that they will be qualified to serve individuals with disabilities. There is clear agreement that collaboration has strong benefits, but we must pay attention to service delivery issues.

Belle Sawhill: 4 planks -- input on President's Tax -- M-C Bill of Rights.

**** if we are going to work on labor issues -- labor and commerce must be apart of the discussion ** how do you want to transcribe this part of the discussion????**

Guiding Principles:

Jim Lyons: How are we addressing the access question?

Lisa Fairhall/ Belle Sawhill: There are other things that should be going on in addition to school and work -- access is one of them -- not just school and work. The life cycle approach will enable us to address this;

Bob Williams: Lift from the ADA the specific areas to which it applies, one of which is recreation;

Belle Sawhill: The Architectural Barriers Compliance Board is also addressing these issues;

B.J.???: re deck chair -- executive Camp -- convenors

group should meet (check stan's notes)

John Kraft: Mention of minorities needs to be added -- "all persons with disabilities regardless of race" is an important component of this document;

Paul Miller: This excellent statement might work perfectly as a preamble / executive summary. Concern re: a more precise/ discrete statement if possible; (Belle Sawhill later mentioned that she also envisioned a more concise and selective version -- others agreed);

Page three, second full paragraph: (beginning "One of the most critical challenges we face..." and followed by 2 bullet points might work in the more concise draft)

David Levine: Costs and benefits -- to what extent will we consider these tough questions -- Belle agreed this issue needs to be further discussed;

Judy Heumann: Need to establish the role of the Federal Government in disability policy;

Ronald Glaser?: Federal role vis-a-vis state and local roles;

Paul Miller: Allocation of resources/ federal/state -- more specific; concern re: interpretation of handing everything back to the states;

Bob Williams: Would you link the federal role back to historic discrimination? I think we need to have that conversation before any of us can know how to draft that principle;

Belle Sawhill: Re-direction aimed at increasing capabilities to live independently -- general agreement that this is the essence;

Gary Blumenthal: Relationship for sight? (check stan's notes)

Roberta Achtenberg: Need to lead that this is an issue of constitutional proportions;

Bob Williams: The states at one time had full play over our issues and what resulted was massive discrimination;

Stan Herr: Difficult to make generalizations regarding the Federal role; interests vary (stan - you also discussed the 5 bullets on page 2 - general statement)

Jeremy Ben-Ami: Are we getting to what the group had in mind when we initially agreed that a statement of guiding principles is needed?

Judy Heumann: Bob has done an incredible job and is allowing the dialogue to move forward -- we need to go through this type of discussion; too long, not clear enough -- public document - why doing it?

Jeff Levi: Needs to also be something of a public document - almost an inside conversation; important to stress that everyone is at risk of becoming disabled at one point in their lives -- not a static group of people;

Marilyn W. Thornton: Every area of a persons life is addressed in the ADA principles;

Lisa Fairhall: ADA/ income support;

Liz Savage: All purposes of government stated in ADA;

Susan Daniels: Will the principles give us an answer to the question of means? We all probably agree on the goals of ADA, but may have some disagreement regarding the means (programmatic and others); Example -- SSI as based on ???, not lack of ???
**stan's notes!

Jeremy Ben-Ami: I don't know if we can do that at the front end -- we may need to look at the findings of the work groups first;

Judy Heumann: Are we spending the 170 billion in the most effective way? Crux of the question; We don't need to do a lot of research to say we aren't, but we need to know if there are certain values we can then move forward on;

Belle Sawhill: Absolutely -- you should be thinking in a very zero-based way and think about an entire set of programs and how they inter-act with each other; Would it be helpful to have a meeting of data presentations -- \$\$\$ spent? (General agreement that this would be a good idea);

Principles give us discipline

Paul Miller: Role of Federal government -- not lose sight of the fact that with respect to legislation, we ask the Federal government to pay attention to certain guidelines -- we need to set this example;

Closing -- Jeremy Ben-Ami:

- * Purpose: broad-based look from ground zero - to further goals of ADA; please share with your staffs that the goals and scope of the review are broad;
- * It is critical to attend meeting so that progress can occur;
- * Alice Rivlin and Carol Rasco are committed to the review (meeting with the President so unable to attend);
- * Work groups to flesh out detailed steps and come back in January with a work plan for each group;
- * Judy's suggestion that the convernors meet -- beginning of January;
- * Full meeting in late January;
- * Expanded list of advocates and workplan in packet -- please submit any comments;
- * Information presentation with data/ baseline spending;

Lisa Fairhall:

- * Helpful for agencies to present data with brief program description;
- * Memo to be distributed with specifications.

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Jim Lyons (OG) --

P. H.

Activity

Heard

Berkley

John Paul

Spaul Drive

(3rd committee)

Paul Miller

(Blumenthal/Miller)

recreation
Access Bd --

HHS unrepresented;

JH: Judy & Susan → pulling together Eastland + S-T-L

BS: 4 planks -- (insertion Preamble) T & M-C Billy R

JH S-T-W Camp -- reemployment group;

* DOL -- Need attention of D.O.L.
1 stop shopping

BJ -- rearrange deck chair

Exec. Camp - Conenna's group

JH: on Comm

Jefferson -- "having fun"

- Minorities
- racial
- Equal access --

Miller: excellent statement -- preamble
~~para~~ 1st draft
looking discrete + concise //

David Lerner - CEA -- costs and benefits
Economics
"greatest extent possible"
Inconsistent? to be discussed
Further

Judy H -- Rules Fed govt in DP

Paul M -- Allocation / response /
Fed State -- more specific

Belle Samuels -- more concise +
selective -- intellectually
discriminating
policy criteria

Garry Blumenthal -- relationship for right

JH: • Bob's incredible job;
Too long
Not clear enough
re guide
public document -- why doing it?

Levy - NIDS say -- Levy;
too much inside document
49 mil -- not a value /
evaluation for every person
at some point in life --

Thornton -- ADA principles.

Eachall -- ADA -- more support /

Savage -- all programs of govt in support of ADA

Familar
BS - 175 bil better way // to spend it

Principles giving us discipline --
Goals v. means.

Sum - Flexibility / trade-off / compromise
(examples) -- conflict in principles

Meaningful discussion -- re use of \$175 bil.

e.g. SSI as based on 2 MPLs, not
~~not~~ on lack of benefit.

Jeremy Strauss: Think in a 0-based way about
this

BS -- life cycle people not paying
offers program over
offers

CERAP

REBO --

optimizing res -- transaction costs
easier on civil servants --
offers reg view.

P

Fairhall -- work on collab

Accomoda

3/4 recommenda will be processed

Adult

Charter distributed

Susan explained
draft was
distributed -
discussed
revised

* Today suggested sm. mtg of chairs: a few
others to keep on track

Transition -

ReEmployment - most of our programs
now are not partic reempl. program
of concern ~~as~~ -- as these 1 stop
shopping models are being
designed -- how can we be
sure they will be qualified to
serve -- collab has benefit but
~~other agencies~~ must pay attn to serving
indiv & disab

If were going to work on labor issues --
labor : commerce should be a part

Jim Lyons: access question

Gisa Fairhall: other things that should be
Beck - going on in addition to school
work - access

Bob - 1.1 ft from ADA in specific unless

to which it applies one
of which is recreation

Bele - Architect Barriers Compliance Board
also addressing these issues

? mention of minorities
adhering to principles - important
to ~~also~~ mention importance of
access regardless of race

Paul Miller: excellent document
concern re: whatever comes out
of review & 1st draft preamble,
but was thinking about something
more discrete/precise

David: costs, benefits & to what extent
to we ^{consider} ~~make~~ these tough
decisions

Bele: important question we need
to discuss it more

Judy: need to establish role in local govt in
transport policy

(Guy next to Judy)
: local role vis a vis State : local
roles.

Bob: I think we need to have that
conversation B-4 any. v. v. 5 can
know how to draft that principle

Zeile → similar reaction - nice preamble

2nd full TD :

Paul → p. 30 E 2 bullet points

Zeile → re-direction aimed at increasing capabilities to live independently

- general agreement that this is the essence →

Paul → warn re: interpretation of handing back to ^{states}

Bob → would you like he fell roll back to historic discriminating

Pohorva → need to lead that this is a ^{big} issue of constitutional proportions

Bob → he states ^{at} ~~that~~ 1 time he had all plays over ~~our~~ issues & what resulted was massive discrimination -- ~~we also not want to be~~

Stan → can't make generalization re: federal role -- interests vary ~~critical role~~

p. 2 - 5 bullets → primary central statement

Jeremy → are we getting to what you have in mind →

Judy - allowing dialogue to move
forward -- need to go
through this type of discussion

Jeb
Cui needs to also be something of
a public clown +
almost an inside conversa-
-- important to stress that
everyone at risk of
seeming disengaged at
some point in their lives
-- not a static group of
people

First
to Liz
(Maralyn
Thornson) from what I've learned - ADA
- every area of a persons
life addressed in ADA

Susan - will the principles give its answer to
question of means

we all probably agree on goals of
ADA but may have some disagree-
re: means (progranatic: other,)
to achieve these goals

JBA: I don't know if we can do that at
the front end -- we may
need to look at findings
of work groups first

John - we are spending the 170 billion
dollars in the most effective way
-- core of question
- continued to do a lot of research
to say we aren't so but we
need to know where
certain values we can
then move forward on?

Belle - how so when - you should
be thinking in a very zero-based
way: think about entire set of
programs: how they interact
each other

→ would it be helpful to have
amtz. of data presentations
-- ~~spend~~

Paul Miller: role of Fed Govt -- not lose sight
of fact that I expect to
be gov't - we ask Fed Govt
to pay attention to certain
guidelines -- we need to
set this example

Purpose:

JBA - Broad based look from ground
zero to higher goals of APP
- share in global goals of review -
various scope

- Carol: Alice would attend if it weren't for my President
- now for subgroups he flesh out detailed steps -- come back in Jan to work plan for each group
- Judy's suggestion - begin Jan - corners late Jan - full mfg
- + baseline view - information presentation
re: data / baseline spending

USA: helpful for agencies to present 94/5 data - brief description of programs
memo out to specify →

"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. Families, young people, and 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 be 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. Theirs 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 throughout 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. 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 affect 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 United States

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 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.
- 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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(end)

THE WHITE HOUSE

WASHINGTON

December 7, 1994

MEMORANDUM TO NATIONAL DISABILITY POLICY REVIEW TEAM

FROM: Carol H. Rasco, Assistant to the President
for Domestic Policy *CH Rasco*

SUBJECT: Meeting Announcement

The second full meeting of the National Disability Policy Review Team will be held on WEDNESDAY, DECEMBER 21, 1994, 2:00-3:30 p.m. in Room 248 of the Old Executive Office Building.

At this time, we will continue to discuss the over-all review process, and each work group will be asked to give a brief presentation of progress to date.

If you plan to attend, please contact Beverly Petchel at (202)456-5571 and provide her with clearance information (date of birth).

Thank you.

Distribution:

****(STAFF LISTED IN PARENTHESIS WILL NOT RECEIVE AN ADDITIONAL FAX, PLEASE MAKE SURE THAT ALL AGENCY REPRESENTATIVES RECEIVE A COPY. THANKS!)**

Roberta Achtenberg
Bernard E. Anderson
Gary Blumenthal
Carolyn Colvin & Susan Daniels (Ken McGill, Diane Garro)
Speed Davis
Dennis Duffy
David T. Ellwood & Bob Williams (Wendell Primus, Robyn Stone)
Patsy Fleming (Jeff Levi)
W. Scott Gould (Ron Glaser)
Michael A. Grant
Judith Heumann (Amy Bennett, Connie Garner, Howard Moses)
James R. Lyons (Rick Grand)
Frank Kruesi (Nancy Ebersole, Ira Laster Jr.)
Fred Pang (Claiborne Haughton)
Larry Parks (Carolyn Gunney)
Deval Patrick (Liz Savage)

TOTAL NUMBER OF PAGES INCLUDING COVER: 1

CC: Alice Rivlin, Jeremy Ben-Ami, Lisa Fairhall, Richard Green,
Stan Herr

THE WHITE HOUSE

WASHINGTON

December 19, 1994

MEMORANDUM TO NATIONAL DISABILITY POLICY REVIEW TEAM

FROM: Carol H. Rasco, Assistant to the President
for Domestic Policy

SUBJECT: M e e t i n g R e m i n d e r

The second full meeting of the National Disability Policy Review Team will be held on WEDNESDAY, DECEMBER 21, 1994, 2:00-3:30 p.m. in Room 248 of the Old Executive Office Building.

If you have not yet called, but plan to attend, please contact Cookie Walden at (202)456-5566 and provide her with clearance information (date of birth).

Thank you.

Distribution:

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12/16/94

NATIONAL DISABILITY POLICY REVIEW

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December 12, 1994

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(revised 12/7/94)

"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. Families, young people, and 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 be 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. Theirs 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 throughout 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. 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 affect 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 United States

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 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.
- 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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(end)

MEMORANDUM FROM JEREMY BEN-AMI AND STANLEY S. HERR

TO: DESIGNEES TO THE NATIONAL DISABILITY POLICY REVIEW

DATE: December 21, 1994 -- Draft # 2

PRELIMINARY WORK PLAN
Discussion Draft Only
National Disability Policy Review
December 1994 - February 1995

Background

In response to initial memoranda suggesting a National Disability Policy Review, the Domestic Policy Council received comments and input on the Review's proposed agenda and work plan. We have met with all the Departmental designees, first in small groups and most recently as a full team. We have consulted key advocates in the disability community, Congressional staffers, the heads of three presidential advisory committees in the disability field, and other experts. In addition, we have made a presentation on the Review to the full membership of the President's Committee on Mental Retardation, reached out to the Administration's appointees with disabilities, and begun to obtain background policy papers.

Oral and written responses have emphasized that such a review is important, overdue, and should involve significant input from individuals with disabilities and their advocates. The comments also stressed the need to be realistic in setting goals and to focus on some shorter-term achievable objectives while simultaneously engaging in a long-term policy process.

On November 30th, the Review Team met to develop a proposed work plan for the first three months of the Review. Based on the agreements reached at this meeting, we have revised our original draft of the work plan. The following pages outline a rewritten version highlighting the meeting's conclusions and laying out the issue groups formed and concrete assignments to date.

Work Plan

This draft Work Plan proposes two parallel tracks for work during the next three months. On the "Policy Track," work groups will meet and address the issues outlined below. At the same time, the "Consultation Track" will engage in outreach and coordination with the advocacy community, Congressional staff, and the Presidential advisory committees.

I. POLICY TRACK

A thorough review of all aspects of disability policy is an ambitious undertaking. Review Team members and those commenting from outside the Review have agreed that it is sensible to conduct the work in phases, initially focusing on a few discrete issues to make the work more manageable. To this end, the Review Team, at its November 30 meeting, formed five work groups: 1) Guiding Principles, 2) Accommodations, 3) Children's Issues, 4) Employment of Working-Age Adults and 5) School-to-Work Transitions.

1. *Guiding Principles* -- There was significant agreement that the Review would benefit from the early development of a set of principles articulating the values guiding the Review. This statement of principles will not predetermine the policies to be developed through the Review, but instead guide Review Team members and staff in their work. It might eventually become the preamble to the Review's final report, subject to continual modification along the way.

This work group has convened in December to begin drafting an initial statement. The principles it develops should draw not only on Administration policy and statements and Presidential speeches, but on policies incorporated in recent legislation in this area. When the full Review Team meets on December 21, a draft of this statement will be discussed and reviewed.

Convenor: Bob Williams, Commissioner, Administration on Developmental Disabilities, Department of Health and Human Services.

2. *Accommodations* -- This work group will draw on the review process already in place through the *Federal Disability Accommodations Working Group*. Formed in August 1994 by the Domestic Policy Council, this group has begun to examine how the federal government can be a model of making reasonable accommodations that will benefit its customers, job applicants, employees, and the general public.

The work of this group should lead to short-term achievable

administrative recommendations that help demonstrate the Administration's commitment in this area.

Convenor: Deval Patrick, Assistant Attorney General, Civil Rights Division, Department of Justice

3. *Childhood* -- This work group will examine educational, income benefit, and service programs available for children, from birth to age 18. Their work is particularly timely given the formation of the Childhood Disability Commission that will look at the SSI children's program. The group will focus on developing an administration policy that will anticipate and respond to the findings of the Commission and other actors. In addition, the Individuals with Disabilities Education Act (IDEA) is up for reauthorization this year and will certainly raise important policy issues.

Convenor: David Ellwood, Assistant Secretary, Planning and Evaluation, Department of Health and Human Services.

4. *School-to-Work Transition* -- This work group will explore issues related to the transition to adulthood from education programs that serve people until they are 18 to 21 years of age. "Transitions" planning involves helping people to find employment, further schooling, independent or assisted living arrangements, and other activities that maximize their independence and potential.

Convenor: Judy Heumann, Assistant Secretary, Office of Special Education and Rehabilitative Services, Department of Education.

5. *Employment of Working Age Adults* -- All participants in this process have consistently agreed that employment must be a centerpiece of the Review. This work group will focus on the problems associated with the chronic unemployment and underemployment of persons with disabilities and review policy options for helping people enter -- and remain -- in the workforce.

Convenor: Susan Daniels, Associate Commissioner for the Office of Disability, Social Security Administration.

These groups will meet and eventually develop action steps in concert with the values and commitments identified in the *Guiding Principles* document. Additional work groups will be formed as appropriate throughout the process based on the findings of these initial working groups.

II. CONSULTATION TRACK

We would like to proceed on several fronts externally as the policy groups begin their work.

A. Presidential Committees

Each Presidential committee has designated a representative to participate on the Review Team, and we anticipate these committees will be integrally involved in the Review. We look forward to working with the Committees on shared policy concerns. In particular, we expect to coordinate with them in gathering public input on these policy questions, holding public hearings and conducting ongoing outreach efforts.

B. Advocacy Organizations

Each of the five groups referred to in the Policy Track discussion should meet with a wide range of organizations representing the interests of people with disabilities to give them the opportunity to provide information and input into their work. Each work group convener will host a meeting with the advocacy community in order to update interested groups on the substance of the Review as it relates to that particular issue.

C. Legislative Bodies

We will also meet with legislative staff from both chambers and both parties to keep them fully apprised of the work of the Review.

III. AN ON-GOING PROCESS

This document is a working draft that we anticipate will undergo periodic change throughout the Review. It is an on-going process which will be modified in response to the findings of various work groups and input received from interested parties.

TIMETABLE

A possible timetable would be as follows:

November 30	Issue groups formed.
December 21	<u>Guiding Principles:</u> Draft discussed with full Review Team.
January	Initial work products available for review.

Guiding Principles: Draft statement and plan for public comment.

Other work groups: Draft scope of work and timetable for each group.

Mid January

Second meeting of the Review Team to review progress of issue groups and discuss draft of Guiding Principles. Overall scope of work and timetable for the entire Review to be discussed.

Meeting with advocacy groups and the five work group convenors.

Early February

Initial background papers completed. Key policy questions identified.

Review Team meets to determine what policy options each work group should pursue and how.

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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 dependence 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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THE WHITE HOUSE

WASHINGTON

**Second Meeting of the National Disability Policy Review
December 21, 1994
Room 248, Old Executive Office Building**

Agenda

Welcome and Introduction	Carol H. Rasco The White House
	Alice Rivlin Office of Management and Budget
Accommodations Group	Deval Patrick Department of Justice
Guiding Principles Group	Bob Williams Department of Health and Human Services
Adult Employment Group	Susan Daniels Social Security Administration
School-to-Work Group	Judy Heumann Department of Education
Outreach, Next Steps and Closing	Carol H. Rasco

Sample packet

MEMORANDUM FROM JEREMY BEN-AMI AND STANLEY S. HERR

TO: DESIGNEES TO THE NATIONAL DISABILITY POLICY REVIEW

DATE: December 21, 1994 -- Draft # 2

PRELIMINARY WORK PLAN
Discussion Draft Only
National Disability Policy Review
December 1994 - February 1995

Background

In response to initial memoranda suggesting a National Disability Policy Review, the Domestic Policy Council received comments and input on the Review's proposed agenda and work plan. We have met with all the Departmental designees, first in small groups and most recently as a full team. We have consulted key advocates in the disability community, Congressional staffers, the heads of three presidential advisory committees in the disability field, and other experts. In addition, we have made a presentation on the Review to the full membership of the President's Committee on Mental Retardation, reached out to the Administration's appointees with disabilities, and begun to obtain background policy papers.

Oral and written responses have emphasized that such a review is important, overdue, and should involve significant input from individuals with disabilities and their advocates. The comments also stressed the need to be realistic in setting goals and to focus on some shorter-term achievable objectives while simultaneously engaging in a long-term policy process.

On November 30th, the Review Team met to develop a proposed work plan for the first three months of the Review. Based on the agreements reached at this meeting, we have revised our original draft of the work plan. The following pages outline a rewritten version highlighting the meeting's conclusions and laying out the issue groups formed and concrete assignments to date.

Work Plan

This draft Work Plan proposes two parallel tracks for work during the next three months. On the "Policy Track," work groups will meet and address the issues outlined below. At the same time, the "Consultation Track" will engage in outreach and coordination with the advocacy community, Congressional staff, and the Presidential advisory committees.

I. POLICY TRACK

A thorough review of all aspects of disability policy is an ambitious undertaking. Review Team members and those commenting from outside the Review have agreed that it is sensible to conduct the work in phases, initially focusing on a few discrete issues to make the work more manageable. To this end, the Review Team, at its November 30 meeting, formed five work groups: 1) Guiding Principles, 2) Accommodations, 3) Children's Issues, 4) Employment of Working-Age Adults and 5) School-to-Work Transitions.

1. *Guiding Principles* -- There was significant agreement that the Review would benefit from the early development of a set of principles articulating the values guiding the Review. This statement of principles will not predetermine the policies to be developed through the Review, but instead guide Review Team members and staff in their work. It might eventually become the preamble to the Review's final report, subject to continual modification along the way.

This work group has convened in December to begin drafting an initial statement. The principles it develops should draw not only on Administration policy and statements and Presidential speeches, but on policies incorporated in recent legislation in this area. When the full Review Team meets on December 21, a draft of this statement will be discussed and reviewed.

Convenor: Bob Williams, Commissioner, Administration on Developmental Disabilities, Department of Health and Human Services.

2. *Accommodations* -- This work group will draw on the review process already in place through the *Federal Disability Accommodations Working Group*. Formed in August 1994 by the Domestic Policy Council, this group has begun to examine how the federal government can be a model of making reasonable accommodations that will benefit its customers, job applicants, employees, and the general public.

The work of this group should lead to short-term achievable

administrative recommendations that help demonstrate the Administration's commitment in this area.

Convenor: Deval Patrick, Assistant Attorney General, Civil Rights Division, Department of Justice

3. *Childhood* -- This work group will examine educational, income benefit, and service programs available for children, from birth to age 18. Their work is particularly timely given the formation of the Childhood Disability Commission that will look at the SSI children's program. The group will focus on developing an administration policy that will anticipate and respond to the findings of the Commission and other actors. In addition, the Individuals with Disabilities Education Act (IDEA) is up for reauthorization this year and will certainly raise important policy issues.

Convenor: David Ellwood, Assistant Secretary, Planning and Evaluation, Department of Health and Human Services.

4. *School-to-Work Transition* -- This work group will explore issues related to the transition to adulthood from education programs that serve people until they are 18 to 21 years of age. "Transitions" planning involves helping people to find employment, further schooling, independent or assisted living arrangements, and other activities that maximize their independence and potential.

Convenor: Judy Heumann, Assistant Secretary, Office of Special Education and Rehabilitative Services, Department of Education.

5. *Employment of Working Age Adults* -- All participants in this process have consistently agreed that employment must be a centerpiece of the Review. This work group will focus on the problems associated with the chronic unemployment and underemployment of persons with disabilities and review policy options for helping people enter -- and remain -- in the workforce.

Convenor: Susan Daniels, Associate Commissioner for the Office of Disability, Social Security Administration.

These groups will meet and eventually develop action steps in concert with the values and commitments identified in the *Guiding Principles* document. Additional work groups will be formed as appropriate throughout the process based on the findings of these initial working groups.

II. CONSULTATION TRACK

We would like to proceed on several fronts externally as the policy groups begin their work.

A. Presidential Committees

Each Presidential committee has designated a representative to participate on the Review Team, and we anticipate these committees will be integrally involved in the Review. We look forward to working with the Committees on shared policy concerns. In particular, we expect to coordinate with them in gathering public input on these policy questions, holding public hearings and conducting ongoing outreach efforts.

B. Advocacy Organizations

Each of the five groups referred to in the Policy Track discussion should meet with a wide range of organizations representing the interests of people with disabilities to give them the opportunity to provide information and input into their work. Each work group convenor will host a meeting with the advocacy community in order to update interested groups on the substance of the Review as it relates to that particular issue.

C. Legislative Bodies

We will also meet with legislative staff from both chambers and both parties to keep them fully apprised of the work of the Review.

III. AN ON-GOING PROCESS

This document is a working draft that we anticipate will undergo periodic change throughout the Review. It is an on-going process which will be modified in response to the findings of various work groups and input received from interested parties.

TIMETABLE

A possible timetable would be as follows:

November 30	Issue groups formed.
December 21	<u>Guiding Principles</u> : Draft discussed with full Review Team.
January	Initial work products available for review.

Guiding Principles: Draft statement and plan for public comment.

Other work groups: Draft scope of work and timetable for each group.

Mid January

Second meeting of the Review Team to review progress of issue groups and discuss draft of Guiding Principles. Overall scope of work and timetable for the entire Review to be discussed.

Meeting with advocacy groups and the five work group convenors.

Early February

Initial background papers completed. Key policy questions identified.

Review Team meets to determine what policy options each work group should pursue and how.

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NATIONAL DISABILITY POLICY REVIEW

WORK GROUP ASSIGNMENTS

December 12, 1994

Accommodations

Convenor: Deval Patrick/ Justice	514-2151
Speed Davis/ NCD	272-2004
Patsy Fleming (Jeffrey Levi)/ ONAP	632-1090
W. Scott Gould (Ron Glaser)/ Treasury	622-2400 (622-1160)
Michael Grant/ OPM	606-2086
Fred Pang (Claiborne Haughton)/ Defense	703-697-2086 (695-0105)
Bob Williams/ HHS	690-6590
Larry Parks (Carolyn Gunney)/ Commerce	482-6055 (482-2779)

Children's Issues

Convenor: David Ellwood/ HHS	690-7858
Staff convenor: Robyn Stone/ HHS	690-6443
Carolyn Colvin (Diane Garro)/ SSA	410-965-4512 (965-3425)
Judy Heumann (Connie Garner)/ Education	205-5465
Laurel Illston/ OMB	395-7809
(Ruth Katz, Wendell Primus)/ HHS	690-5746, 690-7409
Larry Parks (Carolyn Gunney)/ Commerce	482-6055 (482-2779)
Wendy Taylor/ OMB	395-7316
Bob Williams/ HHS	690-6590

Employment of Working-Age Adults

Convenor: Susan Daniels/ SSA	410-965-3424
Staff convenor: Ken McGill/ SSA	410-965-3988
Bernard Anderson/ Labor	219-6191
Dennis Duffy/ VA	273-5615
Patsy Fleming (Jeff Levi)/ ONAP	632-1090
Michael Grant/ OPM	606-2086
Judy Heumann (Howard Moses)/ Education	205-5465
Paul Steven Miller (Andy Imparato)/EEOC	663-4036 (663-4037)
Bob Williams (Robyn Stone)/ HHS	690-6590 (690-6443)

Guiding Principles

Convenor: Bob Williams/ HHS	690-6590
Robert Achtenberg/ HUD	708-4252
Gary Blumenthal/ PCMR	619-0634
Susan Daniels (Ken McGill)/ SSA	410-965-3424 (965-3988)
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Fred Pang (Claiborne Haughton)/ Defense	703-697-2086 (695-0105)
Larry Parks (Carolyn Gunney)/ Commerce	482-6055 (482-2779)
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School-to-Work Transition

Convenor: Judy Heumann/ Education	205-5465
Staff convenor: Amy Bennett/ Education	205-8555
Bernard Anderson/ Labor	219-6191
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12/16/94

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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.
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- 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.
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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.

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- 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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"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. Families, young people, and 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 be 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. Theirs 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 throughout 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. 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.

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