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National Disability Policy Review: Work Group Materials: Children's Work Group

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U.S. Department of Health and Human Services

The Office of Disability, Aging and Long-Term Care Policy
Room 424-E, Humphrey Building
200 Independence Ave., SW
Washington, D.C. 20201

FAX (202)401-7733

TO: Elisabeth Cohen FAX NUMBER: 456-7028

NUMBER OF PAGES: 2 DATE: 4-7-95

FROM:

Michele Adler ☐	Nancy Eustis ☐	Brooke Lindsay ☐
Kathleen Bond ☐	Andreas Frank ☐	Cheryl McDuffie ☐
Darlene Bostic ☐	Mary Harahan ☐	Robyn Stone ☐
Floyd Brown ☐	Jennie Harvell ☐	Tammy Terrell ☐
Robert Clark ☐	Ruth Irwin ☐	Brenda Veazey ☐
Pamela Doty ☐	Ruth Katz ☑	
John Drabek ☐	Crystal Kuntz ☐	

REMARKS/COMMENTS

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary

Washington, D.C. 20201

MEMORANDUM

APR 8 1995

TO: White House Disability Policy Review Children's Group

FROM: Robyn Stone

SUBJECT: Upcoming Meetings -- **NOTE SCHEDULE CHANGE AND ADDITIONAL MEETING ON TUESDAY, APRIL 18 AT 3:00!!!**

Our April 3 meeting was excellent; OSERS staff presentation of the reauthorization led to a very interesting and useful discussion of program interactions between special education and SSI. In fact, the discussion was so good that the speakers were unable to complete the presentation. They have agreed to come back to finish on April 17. We initially planned to have education advocates as guests on April 17. They will instead join us on Monday May 1.

In addition, Virginia Reno of the National Academy of Social Insurance (NASI) has agreed to come talk to the group about NASI's recommendations regarding SSI reform for children. We wanted to fit this presentation in soon, because we will all need to understand this proposal as the Senate moves forward on SSI reform. So we have scheduled an additional meeting on Tuesday, April 18 at 3:00 in Room 415F of the Humphrey Building.

To summarize, please plan to join us at the following meetings, all in Room 415F:

Monday, April 17: (11:00) Finish IDEA reauthorization and discuss Connie's Coordinated Services paper.

Tuesday, April 18: (3:00) Presentation on NASI proposal by Virginia Reno

Monday, May 1: (11:00) Meeting with Education Advocates

U.S. Department of Health and Human Services

The Office of Disability, Aging and Long-Term Care Policy
Room 424-E, Humphrey Building
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FAX (202)401-7733

TO: Diane Fortuna *FAX NUMBER:* 450-7028

NUMBER OF PAGES: 1 Heaven *DATE:* 3/31/95

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John Drabek ☐	Crystal Kuntz ☐	

REMARKS/COMMENTS

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary

Washington, D.C. 20201

Elis. FYI

MEMORANDUM

MAR 31 1995

TO: Members, Children's Work Group
White House Disability Policy Review

FROM: Robyn Stone
Ruth Katz

SUBJECT: Upcoming Meetings

Please note the dates of the upcoming meetings of the Children's Work Group and plan to join us.

Monday, April 3, 11:00 - 12:30; Room 415F, Humphrey Building: Presentation by Education Department staff on the IDEA reauthorization.

Monday, April 17, 11:00 - 12:30; Room 415F, Humphrey Building: Discussion with education advocacy group representatives.

We will also leave some time at each meeting for the subgroups to update us on their activities.

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary

Washington, D.C. 20201

MAR - 9 1995

MEMORANDUM

TO: Members, Childhood Disability Work Group, White House Policy Review

FROM: Judy Feder
Robyn Stone
Ruth Katz

SUBJECT: Next Meeting -- Monday, March 20

The Childhood Disability Work Group will hold its next meeting on Monday, March 20, from 11:00 - 12:30 in Room 415F, Humphrey Building. Please plan to join us.

In the interim, the subgroup leaders will be meeting to discuss: (1) how their workplans will be coordinated; and, (2) how to best use the Childhood Disability Work Group to review the work of the subgroups and feed into the White House's larger task -- the disability policy review. We will present the results of this discussion on March 20.

Between now and March 20 we anticipate that individual groups will pursue the short term activities outlined in the work plans that were presented on February 27. The leaders of the subgroups should come to the March 20 meeting prepared to summarize progress to date on short term activities and any changes in or revisions to the original work plans.

Also on the agenda for March 20 -- Education officials have been invited to present an overview of the IDEA reauthorization. The Childhood Disability Group members will have the opportunity to comment on the provisions of the reauthorization that potentially interact with or have an impact upon other federal programs, including Medicaid, SSI, and MCH programs.

If you have any questions before March 20, you may call Robyn or Ruth at 690-6443.

U.S. Department of Health and Human Services

The Office of Disability, Aging and Long-Term Care Policy
Room 424-E, Humphrey Building
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TO: Elizabeth *FAX NUMBER:* 456-7028

NUMBER OF PAGES: 1 + Cover *DATE:* 1-31

FROM:

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Kathleen Bond ☐	**Andreas Frank** ☐	**Cheryl McDuffie** ☐
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Pamela Doty ☐	**Ruth Katz** ☒ tel. 690-5746	
John Drabek ☐	**Crystal Kuntz** ☐	

REMARKS/COMMENTS

per your request to Robyn Stone.
The list of attendees at yesterdays
W.H. Disability - Children's Group.
Call if you have questions

1/30/95

Children's Issues Workgroup

Carolyn W. Colvin	SSA	410-965-4512
[illegible] Yarrie	ED	202-205-8124
Robyn Stom	DHHS/ASPE	202-690-6443
Don Johnson	HCFA	690-7762
Mary Hale	ASPE	690-6613
Ruth Katz	ASPE	690-5746
Laura Oliver	OMB	395-4718
Wendell E Primus	ASPE	690-7409
Barbara Broman	ASPE	690-6461
Robert Valdez	PHS & HCFA	260-1281
Judy Feder	ASPE	690-7858
Diana Fortuna	DPC - WH	456-5570
Richard Green	OMB	395-7398
Jack Smalligan	OMB	395-7759
Laurel Illston	OMB	395-4930
Scott Campbell Brown	ED/OSERS	205-8117
Diane Garro	SSA	410-966-5425
Christie Provost	HCFA	202-690-6001
Sharman Stephens	ASPE	202-690-0772
Julia Paradise	ASPE	202 690 6476
Michele Adler	ASPE	(202) 690-6172
Brooke Lindsay	ASPE	202 690-6624

DRAFT WORK PLAN

EDUCATION SUBGROUP OF THE CHILDREN'S DISABILITY WORKGROUP

WHITE HOUSE DISABILITY POLICY REVIEW

BACKGROUND:

Based on the guiding principles developed by the members of the National Disability Policy Review, the following work plan is presented as a framework for analyzing the educational experience of children with disabilities as it:

1. strengthens the capacities of children with disabilities through providing coordinated services and supports, which maximizes their control over their own lives and futures in the mainstream of American life.

2. supports the efforts of families with children with disabilities to raise their children at home and to include them in every facet of family and community life. (learning to get out in a fire basic skills)

3. assures that children with disabilities come to school healthy and ready to learn, thus supporting growth and development and lifelong wellness.

Although education is primarily a state responsibility, it is also a national priority. The role of the Federal government is especially defined through its history of commitment to preserve and provide for equity and basic individual rights of individuals with disabilities under the Constitution.

Through Federal activities that help to ensure equal access to education, children with disabilities are better prepared to transition as youths to attain quality employment within their community and compete in a global economy.

GOALS:

SHORT TERM

1. Identify strategies to support the Administration's proposal for the reauthorization of the Individuals with Disabilities Education Act.

   ... Convene a group of administration officials to discuss areas of concern within the reauthorization of IDEA. (week of March 13)

to support from larger public policy arena

... Develop a white paper for the Disability Review Group which articulates support for this law within the larger context of public policy. (week of March 28)

2. Respond to proposals or amendments to the IDEA that come from Congress.

paper on how to support legislation big picture
- a lot of house interest in supporting legislation -

... Develop position paper on IDEA

... Disseminate as appropriate to Congress through (Leg. Office) individual meetings or public affairs.

3. Identify other programs being discussed by Congress that developmentally/educationally support children with disabilities, and develop a response to Congress regarding those programs from the disability perspective.

universal design.
- identify other programs that provide support services for all children that will really affect children w disab if scaled.

... Identify programs that provide support services for all children whose potential scale back or elimination would particularly impact children with disabilities or at risk for disability.

... Develop a response for consideration by the White House Disability Review on behalf of the disability perspective.

LONG TERM

gives you what you need for the long term

- transition element - age 14 3 up when kids begin to have multiple plans.

1. Identify and analyze the service needs that support the educational outcomes of children with disabilities and the current state of the Federal delivery system for those services.

2. Develop a plan for assuring that the transition needs of children with disabilities at all ages are addressed in a comprehensive way through coordinated interagency efforts.

3. Recommend a set of strategies to achieve a universal design across Federal programs that support the developmental/educational needs of all children and their families, regardless of disability status.

HEALTH CARE SUBGROUP

DRAFT WORKPLAN

Objectives:

1. Identify short term options to improve delivery of health care services to disabled children.

2. Analyze and react to health provisions of Capitol Hill proposals regarding SSI and IDEA. Analyze and react to proposals regarding Medicaid.

3. Provide analytical assistance to Childhood Disability Commission with respect to Commission recommendations.

4. Develop health care provisions for HHS position on SSI reform

---

I. Short Term Options

A. Identify Short-term Options

1. Contact Medicaid Bureau and PHS staff to identify goals and options to improve delivery of health care services for disabled children. Focus on options unique to program as well as options to improve coordination and integration among health programs. (March 13)

2. Contact Medicaid Bureau and Department of Education for short term options with respect to IDEA reauthorization. Focus on options to improve coordination of services between two programs. (March 13)

a. Contact HHS School Health Workgroup (Feb. 28)

b. Contact outside groups for recommended options

3. Develop paper on short-term options (March 31)

B. Implement Short Term Options

1. Select options to pursue from paper (April 22)

2. Coordinate program staff (Medicaid, PHS, DoEd etc.) to implement options (April 29)

II. Analyze Legislative Proposals

A. Coordinate review/analyses of reform bills affecting health services for disabled children among appropriate program staff (As Needed)

B. Provide technical analysis (As Needed)

C. Assist with development of Department and/or Administration position (As Needed)

III. Childhood Disability Commission

A. Assist Commission staff and SSI subgroup of Children's Issues Workgroup with health services program information and data.

B. Provide technical assistance to Commission (As Needed)

1. Initial contact with Commission staff (Feb. 23)

IV. HHS SSI Reform Position

A. Provide assistance with development of position on SSI reform with respect to health care services (March 22)

1. eligibility
2. benefits and services
3. financing, administration
4. interaction with other health care programs

B. Identify program data needs (March 29)

1. contact Medicaid Bureau, PHS for information
2. coordinate with other SSI workgroups

C. Coordinate with outside experts (As Needed)

D. Develop Draft Proposal (May 31)

E. Coordinate with other SSI workgroups (As Needed)

DRAFT WORK PLAN

SSI SUBGROUP OF THE CHILDREN'S DISABILITY WORK GROUP

WHITE HOUSE DISABILITY POLICY REVIEW

The purpose of this workplan is to articulate a process and schedule for accomplishing the following concurrent activities:

Overarching Activities

1. Articulating a set of principles to guide Administration policy on SSI Childhood disability program reform.

2. Developing an analytical plan to ensure ready access to the data and analysis needed to inform the specific tasks enumerated below.

Specific Tasks

1. Identifying, analyzing, and pursuing shorter term reforms of the SSI program for children, leaving its current structure essentially intact.

2. Reacting to proposals for SSI reform that emerge from Capitol Hill.

3. Working with the Childhood Disability Commission, particularly to support its analytical needs and reacting to the Commission's recommendations.

4. Developing an HHS position on SSI reform. - options / recommendations

---

OVERARCHING TASKS

I. Principles

A. Convene group to develop principles to guide Administration activities in SSI childhood disability reform. (March 6)

B. Obtain consensus and finalize principles. (March 27) ex: do we screen out SSI shows target severely disabled

C. Discuss principles with White House officials; revise as needed. (April 3)

D. Use principles to guide implementation of all activities in this plan. (ongoing)

II. Analytical Plan

A. Revise draft analytical plan. (March 8)

B. Prepare data requests and submit to SSA, others. (March 15)

SPECIFIC TASKS

I. SHORT TERM REFORMS

A. Identify short term options

1. Contact SSA staff (both SSI and Regs staff) to identify all short term options that have been identified. (March 6)

2. Contact Commission staff to identify any additional short term options. (March 6)

3. Contact National Academy of Social Insurance to identify additional short term options. (March 6)

4. Identify other individuals/organizations and contact them to identify additional short term options. (March 10)

B. Compile short term options (March 24)

1. Develop a paper outlining and analyzing each option, including:

   - description of option
   - projected cost
   - projected timeline to accomplish
   - impact on beneficiaries and potential beneficiaries
   - data/analytical needs to better understand and to accomplish proposal
   - political viability
   - whether statutory or regulatory change is needed
   - evaluation of consistency (or lack of it) with principles articulated under Task IV (HHS reform strategy)

2. Identify which short term options should be pursued (April 15)

   - obtain SSA/HHS agreement
   - designate who will lead effort for each selected option

- initially and continually ensure that selected options make sense in context of Congressional, Administrative, and Commission activities

C. Pursue short term options (ongoing)

II. <u>React to Proposals from Capitol Hill</u>

A. Review Ways and Means Committee bill. (when available)

B. Provide materials for mark up, through Public Affairs office. (as needed)

1. Determine whether additional analyses can be provided via principles and analytical plan activities described under overarching activities, above.

C. Provide materials for full House. (as needed)

D. Provide principles, comments to Public Affairs for their daily talking points. (ongoing)

E. If appropriate, provide principles, analyses to Senate. (as requested)

F. Track Senate activities.

III. <u>Childhood Disability Commission</u>

A. Coordinate analytical plan with Commission staff to ensure that all points are covered and duplication is eliminated.

B. Coordinate data requests with Commission.

C. Attend Commission meetings.

1. Brief all involved staff, senior officials on Commission meetings.

IV. <u>HHS Proposal</u>

A. Convene principal staff to work toward consensus on elements of SSI reform proposal. (March 22) At a minimum, the following should be addressed:

- Eligible population

- Benefits (services or cash or both; which services?)

  + interaction with other federal, state, local benefits

- Financing

- Administration

- Quality Assurance/Enhancement

B. Identify data/analytical needs to support developing a position. (March 29)

1. Ensure these needs are addressed in analytical plan activities.

2. Review needs in context of current Department (or other) research activities; ensure coordination.

C. Identify whether experts could assist in detailing components of the proposal (e.g., consult with experts in identifying/assessing functional disability in children to work toward defining eligible population; consult with state officials, DDS officials to discuss options for administrative strategies; etc.) (March 29)

D. As appropriate, convene groups of experts to address specific issues. (April and May)

E. Develop draft reform proposal. (May 31)

F. Review proposal in context of House, Senate proposals/bills and Commission's work to date. (ongoing)

2/27/95 - children's workgroup

discussion of gp: adv group mtgs
what will we use
will the gp drive adm policy
: will it drive policy decisions
" be a p.r. document
RIGO - pay attn to what's happening
- anything coming out should have disability slant

how sup. groups should be working
short vs. long term
+ some concept of anticipated products

Judy report is nice → workgroup must
preserve protections / rationale programs

stay close to the politics of the moment of the welfare reform bill

Richard G - regulatory vs. legislative Δs
. identification of severely disabled popula

Robin Tasks - expert mtg to look at defini'n severe disab.
how to re-define if we do
how would we identify this pop.

encouragement of ambiguous lang around disability
so we have time

Jody - Wendell is how we link work group
→ feed into - welfare reform? strategy mtgs
"full cmte mark-up"

* our role - childhood disab commission

Sedus * group in agreement that we need to look carefully at eligibility (goes well-beyond SSI as an activity)
(: benefits : cash vs. service)

EDUCATION - connie

taking policy approach
- educa needs to be looked at differently

NDPRT
2/22/95

Guiding Principles Discussion

The comments and suggestions below were generated by representatives of the disability advocacy community in response to the draft of the Guiding Principles (1/8/95). The responses outlined represent a synthesis of input from approximately 30 individuals participating in two meetings held within the past week. Our goal today is to review and discuss this input. It is our expectation that this afternoon's discussion will result in consensus of the full Policy Review Team leading to a final document.

I. PRINCIPLES: Consensus on the following:

1. A context is needed, which may be set out in a preamble. This should succinctly describe the following:

the history and evolving nature of the disability movement; identify the numbers of individuals with disabilities and the % of America's families this represents; that disability is a part of life and that at some point or another most families are likely to utilize the protections and services specific to individuals with disabilities as well as the unpredicatable nature of the onset of disability;
the need to reevaluate policy to measure its allignment with best thinking- does this policy encourage independence, inclusion and empowerment?

[This may be accomplished by pulling from the original draft document]

2. Document must lead off with a strong explicit statement on the necessity and appropriateness of the federal government's role.

There will need to be some discussion regarding the concept of the shared responsibility of the local and state governments to enforce and develop appropriate disability policy.

Bullet #6: Great concern over possible misinterpretation of this concept. There is not necessariyly a link between local flexibility and consumer-driven service design and delivery. Self empowerment might be viewed as inconsistent with federal role and that is not the intent here. How to encourage consumer driven services as a quid pro quo. We must make clear that there is a role for states.

3. Need a clear statement on adults living in the community.
the Right to live in the community and to access an array of

services that will facilitate this.

suggested: Individuals with disabilities have the right to
1) live in communities
2) have their legal and civil rights protected
3) exercise choice

4. Q: Listing laws & services?
Bullet #1 Remove naming specific laws- it is seen as too limiting

Bullet # 2 Add examples to needed services and supports such as: housing, transportation, health care personal assistant services

5. Need to infuse policy for persons with disabilities as a forethought rather than an afterthought. Policy must be inclusive by design...every policy should be looked at in regard to the implications it has for persons with disabilities (bullet #8 reworked will address this.) Or is a new bullet needed which states "all generic programs must take issues concerning persons with disabilities and thier families into consideraation so that 2 systems are not perpetuated

II. ISSUES: The following are some concerns that were identified. There may or may not have been consensus in these areas.

-Focus and tone is based on a need based, care taking model
-Addresses public sector only - What about role of private sector
-Haven't addressed the benefits to the community
-Frame in economic context eg."we can ill afford to promote dependence..."

III. WORD CHANGES non-substantive changes (done deal)
Opening paragraph: 4th line: add recreation to economic, social etc. Add the word gender to line 6.

1st bullet: substitute the work fair with full
2nd bullet: delete the word and, insert the word by
8th bullet: delete the word eligible and move this up to closer to the top
5th bullet : delete "65 and over" and add across the life span.

U.S. Department of Health and Human Services

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FAX (202)401-7733

7028

TO: Elisabeth Cohen *FAX NUMBER:* 202-456-~~5571~~

NUMBER OF PAGES: 2 +cover *DATE:* 2/22/95

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Darlene Bostic	☐	Mary Harahan	☐	Robyn Stone	☐
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Pamela Doty	☐	Ruth Katz	☐		
John Drabek	☐	Crystal Kuntz	☐		

REMARKS/COMMENTS

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary

Washington, D.C. 20201

MEMORANDUM

TO: Members, Children's Disability Work Group

FROM: Judy Feder

SUBJECT: Meeting, Monday, February 27
Possible Calls from Childhood Disability Commission Staff

This is a reminder that the Children's Disability Work Group will meet in David Ellwood's conference room on Monday, February 27 from 11:00 a.m. to 12:30 p.m. The agenda will include presentation and discussion of draft work plans by each subgroup (i.e., health, education, and SSI).

In addition, for your information, attached is a memo that went to Mary Jo Bane, Shirley Chater, Phil Lee and Bruce Vladeck notifying them that they (or their staff) may be contacted by staff of the Childhood Disability Commission. As you know, the Commission's work is separate from the work of the White House Disability Review - Children's Work Group, although the substance overlaps in many cases. Thus, recognizing that Commission staff have not been involved in the Work Group's deliberations, please be aware that you may be asked for information that you have already provided to the Work Group.

Looking forward to seeing you on Monday.

DEPARTMENT OF HEALTH & HUMAN SERVICES Office of the Secretary

Washington, D.C. 20201

MEMORANDUM

TO: Mary Jo Bane, ACF
Shirley Chater, SSA
Phil Lee, PHS
Bruce Vladeck, HCFA

FROM: Judy Feder, Principal Deputy, ASPE

SUBJECT: Inquiries from Childhood Disability Commission Staff

The purposes of this memo are to notify you that you or members of your staff may receive inquiries regarding your programs from the staff of the Childhood Disability Commission and to request your cooperation in providing the necessary information.

This Commission, whose members were appointed by the Secretary in January, will be studying the SSI program for children with disabilities. As part of their work, they will be taking an overarching look at all federal programs that serve children with disabilities. The Commission is expected to forward its recommendations for SSI reform to Congress by November, although it is possible that a report may be developed by June or July. The Chair of the Commission is former Representative Jim Slattery and the Staff Director is Elaine Fultz.

I would appreciate it if you would advise key staff members that they may be receiving calls from Elaine's staff. Please note that Commission staff have not participated in the meetings of the Children's Work Group of the White House Disability Policy Review. Therefore, some of the Commission's questions may duplicate work or briefings that have been provided to the Work Group or to OMB as part of the overall White House Disability Policy Review.

Nevertheless, the Commission's work may assist the Administration in its deliberations related to the SSI program for children. Any help you can give Commission staff will be useful. Thank you.

cc: Members, White House Disability Policy Review, Children's Work Group

DRAFT 2/22/95

People with Disabilities and Employment[1]

Current Status

People with disabilities are significantly less employed than people without disabilities and have been over many years.[2]

Two-thirds of working age people with disabilities are not working. Of the 15.6 million people who have a work disability, 10.2 million, or 65.5%, are not in the labor force. Only 19.7% of working-age people without work disabilities do not participate in the labor force (CPS 1993).

In 1986, 66% of people with disabilities who were surveyed were not employed; in 1994 68% of those surveyed were not employed (Lou Harris and Associates 1986, 1994).

African Americans have a higher rate of work disability [3] than whites or Hispanics and are more likely to have a severe work limitation.

About 14.2% of working-age blacks have work disabilities with 73.9% considered severe. The comparable rate for whites is 9.0% (with 55% severe) and for Hispanics 9.4% (with 69.7% severe).

Many people with disabilities who are not working can and want to work.

At any one time, approximately 55,000 people with disabilities receiving SSI benefits (those who have been determined to have severe work disabilities) report earnings from work (SSA 1994).

In 1993, approximately 300,000 SSDI recipients report earnings from work (SSA 1994).

79% of people with disabilities surveyed who were not working wanted to work (Lou Harris 1994).

When people with disabilities do work, it is often part time, at entry level low-paying jobs and without benefits.

60.8% of those with a work disability who were employed were working irregularly or part time compared to 36.7% without a work disability (CPS 1990; NIDRR May 1992).

18.2% of people with a work disability were working full time in 1988, compared to 60.6% of people without work disabilities. (CPS 1988).

People with disabilities who work full time have a 12.3% poverty rate compared to a 2.65 poverty rate of those without disabilities who work full time (CPS 1993).

People with disabilities are significantly poorer than people without disabilities.

About 28.9% of people with work disabilities have incomes below the poverty level compared to 10.1% of the working-age population without work disabilities (CPS 1993).

Since 1984, the number of working age people on Federal disability income support programs has doubled (??) (xx million to yy million), doubling (??) the cash outlay from $xx billion per year to over $yy billion per year in 1994.

People with disabilities who work are less likely to be poor than those who don't work.

15.6% of those who work are poor, while 37.6% of those who do not are poor (CPS 1993).

Despite recent increases, people with disabilities remain less educated than people without disabilities.

41% of students with disabilities exited secondary school by dropping out compared with 20.9% of students without disabilities (NLTS 1993)

Despite recent increases, young people with disabilities participate less in post-secondary training and education and are less likely to secure good jobs than their peers without disabilities.

Up to 3 years after leaving school, 57% of students with disabilities are competitively employed, compared to 69% of youth in the general population. Jobs tend to be low-skill and low-paying (Wagner 1993).

22.5 % of students with disabilities enroll in post secondary education programs compared to 55.7% of students without disabilities (NLTS 1993).

The number of SSI and SSDI beneficiaries under age 30 increased by 43% between 1989 and 1993 (SSA 1994).

People with disabilities experience widespread discrimination both in and outside the workplace due in part to myths, fears and stereotypes that make it more difficult for them to prepare for work and pursue meaningful careers than it is for people without disabilities.

At the time the ADA was enacted, Congress found that people with disabilities had experienced systemic discrimination in such areas as employment, education, job training, housing, transportation, communications, public accommodations and government services.

As of Dec. 31, 1994, the EEOC had received almost 40,000 ADA complaints alleging discrimination against private sector employees. 19,000 of those were received in FY '94 alone.

Since January 1992, The Department of Justice has received over 6000 ADA complaints alleging discrimination by government entities and public accommodations.

1. Major data sources for determining the employment status of people with disabilities are the Current Population Survey (particularly the annual March Income Supplement), Bureau of the Census; the Survey of Income and Program Participation, Bureau of the Census; and the Health Interview Survey, National Center for Health Statistics, Centers for Disease Control. These surveys ask different questions to determine the presence of a disability and thus yield somewhat different results. According to these surveys, the number of working age people with a disability ranges from x million (x percent of the working age population) to y million (y percent of the working age population).

2. Even though different surveys provide different estimates of the number of people with disabilities who are and are not working, all data confirm a notable discrepancy between the level of employment of those with and without disabilities. Other estimates include the following:

> The employment rate of people with disabilities was 52% in 1992 and 80.5% for people without disabilities (McNeil 1993 SIPP)
>
> HIS estimate....

3. Work disability is defined by the Bureau of the Census as a self-reported limitation in the type or amount of work a person is able to perform due to chronic illness or impairment.

Causes of the Problem

Reasons why people with disabilities do not fully participate in the labor force include the following.

People with disabilities experience:

societal beliefs that they are not expected to work

architectural, communication and attitudinal barriers

limited accessible housing and transportation

limited access to work-study programs, vocational training and transition services

limited rehabilitation services

limited support services, such as personal assistance services and assistive technology

worry about potential episodes of poor health that would require job termination

relative security of public benefits compared to work

lack of access to adequate health insurance except via public benefits

lack of knowledge about rights and limited skill in self-advocacy

Employers report the following concerns:

increased costs for accommodations, health insurance

liability for safety of all employees

discomfort in interacting with people with disabilities in the workplace

confusion resulting from conflicting laws and requirements

dearth of available people with disabilities who are qualified to fill their vacancies

UPDATE ON SCHOOL TO WORK TRANSITION GROUP

To date, the School To Work Transition Group has met twice. At the last meeting on February 7, many more agency representatives were in attendance. Additional agency representatives are still being recruited address comprehensive issues relating to successful transition outcomes.

The group discussed components of successful transition for individuals with disabilities. Also, a working definition of transition was explored which will be refined at the next meeting. This definition will be employed to drive the group's focus. Available data on outcomes for youth with disabilities was presented. The best available data source is the National Longitudinal Transition Study which survey 8000 students with disabilities over a five year period. The Social Security Administration also has comprehensive data on youths who are receiving disability benefits. These and other data sources will be considered at the next meeting.

A matrix was proposed to depict the funding of specific transition services across federal agencies. Program funds, number of projects and FTE will be reflected by the matrix. This would enable the group to examine areas of concentration and gaps as well as possible service components where future coordinated efforts would be appropriate. The matrix will be used as a basis for the group work plan in that recommendations will be made to address identified areas of need.

FEDERAL PROGRAMS PROVIDING TRANSITION SERVICES FOR YOUTH WITH DISABILITIES

Types of Services and Financial Investments

	ACF	ADD	Americorp	DOC	DOJ	DOL	NIDRR	OSEP	PCEPD	RSA	SSA	STW
Advocacy												
Assessment												
Assistive Technology												
Environmental Modifications												
Health Care												
Housing												
Independent/Supported Living												
Information Services												
Job Development												
Job Placement & Support												
Mentor Training & Mentoring												
Parent Training												
Personal Assitance Services (PAS)												
Personnel Preparation												
Post Secondary Education Access & Support												
Reader/Interpreter Staff												
Self Determination & Awareness												
Technical Assistance												
Transportation												
Other												

SSA, OMB, DHS, HCFA

The ARC / CDF / ASPE / HCFA / DDD / Bazelon Ctr / UCPA /

1/17 - Children's / Advocacy

- SSI → house / senate - discuss various types of voucher program / flexibility
- profiles of people / documents, surveys
- caregivers / time from full-time employm
- ARC - need to quit - health insur.
- range of needs - SSI payment not a work compensation - wasn't designed to (unless your at the low end of work force)
- Bazelon study - enact fed - Johnnie Bazelon - information very anecdotal - how do people use "back benefit" - how do they spend $? - no mystery / not much variation - no matter how you carry it out - Mats it
- unfunded mandates?
- when more of medical staff → very basic expensi
- administration of disinsuring according to disab - a mess - not practice → mental disab - broken windows / Rising Tide
- JBA - defend progress is → Let's discuss "fall back lines" - reform feel while preserving basic integrity of program
- 20% children & mental / behav problems → cases 600 ADA / learning - small portion but very problematic
  - good sample of mistype which is 12-20% of ~~disab~~ SSI popula & mental
  - Mental Imp ≈ 60% entire pop

how well is disability defined / working?

problems:

double counting in domains - over-rated the severity - asks adjudicator to over-rate - progr is inherently judgemental

- guides for adults also criticized for same reason

anecdotal coverage

JIBA - so strategically, how do you defend the program

representative payee issue - BIG PROBLEM - are they really informed.

Gap between statute : reality

contin disab review (CDR)

DDS - calendaring - expectation of continual review - not done - so kids stay on when should get off.

anonymous 800# - suspect program violation ringing off the hook

Judge F: I hear you want us to put the problems in perspective

I'm wondering, what issues need to be addressed - & lets say we do the testimony - what

Rhonda Schulzinger: integrity of program must be protected - its a rigorous assessment tool

discussions in Canada - euthanasia - we have to be aware of this

Maryl Lee Allen - COE - 662-3573

Rhonda Schweitzer - Baylor Coll. - 467-5730

Marty Ford - Dr Arc - 785-3388

Jennifer Simpson - UCPA - 842-1266

WHITE HOUSE DISABILITY POLICY REVIEW

CHILDREN'S ISSUES WORK GROUP

Proposed Policy Priorities

1. **Health Care**

- **Can we improve access to health care for uninsured children with disabilities and their families without increasing in the aggregate federal costs for disability related programs?** Suggested strategies to consider include: better coordination between Medicaid, Idea and Maternal and Child Health programs; program consolidation; insurance reform; financing experiments with vouchers or cash payments to empower families to purchase private insurance; substitution of health insurance coverage for some portion of cash assistance etc.

- **How can we induce/encourage health care providers to effectively serve children with disabilities and their families** e.g., provider training, incentives to encourage health care providers to either develop proficiency in or specialize in treating people with disabilities, etc.

- **How can we improve the willingness and capacity of managed care providers in the private sector to enroll and effectively serve children with disabilities and their families?** Suggested strategies could include: developing improved capitation methods; technical assistance around best practices regarding prevention, rehabilitation, risk management, enrollment incentives; developing and operationalizing quality assurance protections; and coordinating with personal assistance and other supportive services.

- **How can we insure that public managed care arrangements are responsive to the special needs of people with disabilities?** Suggested strategies could include: systematic evaluation of the experience of people with disabilities in Medicaid managed care; experiments with alternative financing methodologies; risk sharing between states and the federal government, etc.

2. **Education**

- **How can we encourage wider availability of proven early intervention services for children who can benefit from them, without increasing costs?** How can medical, educational, and social services be coordinated to improve long term outcomes for young children with disabilities, or at-risk of developing disabilities?

- **How can special education services and financing be better coordinated with health care, income support and social service systems to best serve children with disabilities?**

- **How can federal education, income support and employment policies and financing be best combined and coordinated to enhance the school to adult life transition for youth with disabilities?**

- **How can the special education emphasis on inclusion be reconciled with other programs which provide categorical services to children and youth with disabilities?**

3. **Income Supports**

- **Should SSI cash assistance for children with disabilities and their families be better targeted to focus on those most in need?** (e.g., target eligibility to a sub-population of SSI children with the most significant disabilities or those with the greatest economic need; limit the number of cash payments which a single family unit can receive; impose a 2/3 reduction if a family unit has more than one qualifying child, etc.

- **Should the provision of cash payments be carefully coordinated with the receipt of other public benefits for children to maximize the cost effectiveness of federal disability expenditures?**

- **Should SSI and Medicaid eligibility continue to be linked or should there be separate eligibility for each program?**

- **What mechanisms could improve program accountability and how could they be implemented?** For instance: vouchers; limiting cash payments to documented disability related expenses, etc.

- **Should AFDC and SSI be better coordinated and how?**

4. **Baseline Information for Policy Development**

- What types of information are essential for policy development in this area?

- How should it be financed, collected and analyzed?

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1/9, 2:30 -

Judy Feder, Robyn Stone, SBA, Lynn, Diana, Elis

short term: SSF - need

long: more gen quest - NCHI pol towards Chit

→ 3 tasks: • basic info - need for what is growth in case load costs in format every comm C

• Talking point side: cause we'd make going we need. to cogr re: further study

• Begin looking at options for feedback - concurrent paper voucher option

in terms of broad progr revision

→ proposal → do women else → seniors?

→ sub group: outside groups to meet regarding legislative realities - geboy - IDEA-SSF

United
skin, CCD, Cerebral Palsy, CDF,

→ should we have mtg ~~too~~ later in wk.

→ 2 wks

big picture plan?

① health, educa: income groups of 3 broad areas.

③ ④ - data needs.