
Future Plight of Retarded Adults Tied to School's Uncertain Fate

By JONATHAN RABINOVITZ

SOUTHBURY, Conn., March 12 — More than three decades ago, following the advice of doctors, Edward D. Walen moved to Connecticut so he could place his son in what was regarded as one of the finest institutions for the mentally retarded in the world, the Southbury Training School.

Today, Mr. Walen's son Jimmy, 43, has the I.Q. of a 3-year-old, and a physical impairment precludes him from making noises other than grunts, yelps and a siren-like squeal. Every morning, he fastidiously sets tables and cleans dishes at the campus cafeteria. At night, he sleeps in a crowded room with eight other men.

On a visit from his father, Jimmy could hardly contain his excitement and immediately pulled him into a corner to share his newest hobby, a cart filled with blocks and baubles. Around him were men and women, largely unsupervised, rocking back and forth in their chairs, their arms wrapped around their chests and shoulders, some staring blankly at a soap opera on television, others looking into space.

"I know it doesn't have all the amenities," Mr. Walen, 73, admitted. Indeed, United States Justice Department examiners last year said that care at Southbury did not meet modern standards and called it a "very dangerous place." But Mr. Walen bridle at the popular alternative, moving the remaining resi-

Enduring Institutions

Care for the Severely Retarded

A special report.

dents, many who suffer from the most severe level of retardation, into group homes and apartments.

The deinstitutionalization movement has been widely hailed as a liberating revolution for the mildly and moderately retarded, but the question gets more complex for the most severely retarded like Jimmy, still in state institutions. Many of the patients are so limited, it is not clear whether they will benefit from a community setting. And while group homes are generally less costly to taxpayers than institutions, there is little if any cost saving for deinstitutionalizing the most profoundly retarded, who need costly intensive supervision regardless of the setting.

"This, in effect, is Jimmy's home," Mr. Walen said of the 1,600-acre campus in western Connecticut. "These advocates are mesmerized by the mystique that all institutions are bad, that the buildings should be razed, the earth bulldozed over and then salt poured on the grounds so it will never rise again."

Increasingly across the country, such parents are finding themselves locked in a difficult battle with other advocates for the retarded and civil

Continued on Page B6, Column 1

Debating What Is Best For Severely Retarded

Continued From Page A1

rights groups.

Those advocates are pushing to close Southbury, the state's last large institution for the retarded, and move its 867 residents into group homes. In the last 25 years, as state facility after facility has been closed, the institutionalized population has decreased by 60 percent nationally.

But the question of phasing out the remaining institutions has provoked debate across the nation. The California chapter of the Association for Retarded Citizens has been torn by the issue, with some of its top officials arguing against closing institutions there. In New Jersey, a state advisory council has recommended phasing out all institutions, but the state Department of Mental Retardation favors keeping some open.

In Connecticut, Southbury has some powerful supporters. The new governor, John G. Rowland, has included money in his budget to maintain it, reversing the previous administration's plans to shut it. And an ad hoc legislative task force has proposed expanding the facility and opening admissions for the first time in nine years.

They have been spurred by a group of politically astute parents like Mr. Walen, who argue that the profoundly retarded Southbury residents need the safety of an isolated institution and the medical services it offers.

Sarah E. Bondy, president of the Southbury parents' group, the Home and School Association, said: "One of the things that really upsets us is when people talk about our guys going out into the world and holding jobs and going to church and making friends. Then you go into cottage 7A and you'll see people 35 and 40 who are curled up on a mat, and someone is taking a feather, and running it across their cheek just to get the kind of reaction you would want from a 3-month-old child.

"And they're telling us they can go out? I mean, it's crazy."

Southbury has some powerful detractors, too. The Justice Department is expected to cite the state for violating a 1986 court agreement to improve the facility. And in October, advocates for the retarded sued the state on behalf of seven residents, saying Southbury provided inadequate services. The suit could lead to Southbury's closure.

"I've never heard of anything in an institution that can't be done better in a community setting," said Margaret Dignotti, the executive director of the Arc of Connecticut, an advocacy group for the retarded. "There is no magic in green tile and a large day room. It's expertise of staff and other factors that improves the quality of life. If you have talented staff at an institution, why can't you just move them to a community setting?"

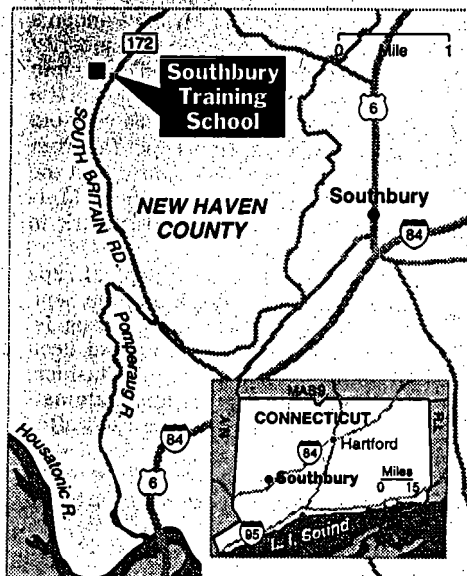
The Model

A Campus Environment

Established in 1940 as a "school for mental defectives," Southbury was intended to be a model of compassionate care.

In contrast to the long wards that characterized many institutions, Southbury looked more like a New England prep school with red-brick, colonial-style architecture and dozens of small residential buildings, called cottages, perched on a hillside. It became the place where celebrities sent their children.

But in the early 1970's, a revolution began in attitudes and courts ruled that institution-



The New York Times

alizing these people violated their civil rights. From 1967 to 1992, the national population of institutionalized retarded people dropped from 195,000 to 77,618 — and some experts predict it could reach zero by 2020.

New York, for instance, plans to close all its institutions in the next decade.

In 1993, Connecticut closed the Mansfield Training School, its oldest institution for the retarded, and Gov. Lowell P. Weicker Jr. declared that Southbury would be next.

But the new governor, Mr. Rowland, who volunteered at Southbury as a teenager, disagreed. "It's a great facility," he said recently. "Many Southbury residents have been there 35 or 40 years. If you see them, you know they won't be able to function with any better quality of life out in the community."

Since 1970, the population of Southbury has dropped by two-thirds, leaving the most disabled. About 78 percent of Southbury's residents are severely retarded, with one-third unable to walk. The average age is 48.

While some can talk and move around independently, others cannot carry out the most basic human functions by themselves. In several cottages, residents require feeding tubes and wear diapers. Staff members reposition them in their wheelchairs every few hours to prevent atrophy.

Southbury supporters contend that an institution, with doctors, nurses and psychologists, is the best setting for such care.

The Problems

'Good, the Bad And the Ugly'

Still, there is little doubt that Southbury is troubled.

Thomas Howley, its director, began a tour saying it would include "the good, the bad and the ugly." After showing the newly renovated Cottage 22, the only unit that won praise from the Justice Department, he went on to Farm 1.

A man sat alone in a dark foyer, his head slumped against a coat closet, frozen in that position for the 10-minute visit. A dozen men were in the day room, a few shouting, as the only staff member in the room folded laundry.

"You don't see much individualization here," Dr. Howley said. "There's not any kind of attention."

Dr. Howley walked upstairs, opened a door and two men were running down the hallway screaming at each other. One fell to the floor, rolled onto his back, pulled down his pants and kicked his legs.

Dr. Howley quickly walked downstairs. "Excuse me," he said to a passing staff member. "I think we need some supervision upstairs."

Upon leaving, Dr. Howley described it as "very damning." Too many people live in that building, but there is nowhere else to put them, he said. When similar people were moved into Cottage 22, where it was less crowded and they received more attention, they showed marked improvement, he said.

Justice Department investigators have described several dozen examples of abuse and neglect. On Jan. 31, 1993, one patient was "found in bed with a broken coat hanger in his hand, bleeding from the nostrils, with blood covering the sheets and on the floor." Three days later, he was found with blood on his shirt and a broken hanger in his hand. A month later, he was found again in bed with hangers and a bloody face.

The Justice Department observed that feeding practices posed "immediate life-threatening problems" from choking, that psychotropic drugs were overused and that most residents were "almost never engaged."

Dr. Howley said that Federal investigators overlooked improvements such as participation in recreational and occupational day programs that increased from 15 percent in 1986 to 90 percent today.

Many problems could be solved with more staff, Dr. Howley said. At Southbury, the staff to resident ratio is 1.9 to 1, compared to 2.5 to 1 at New York institutions.

Although Governor Rowland has not proposed increasing Southbury's budget, many advocates believe that the state inevitably must spend substantially more. If not, they say, the courts are likely to intervene.

The question is whether the investment should be in Southbury or in group homes.

Group Homes

Encouraging Self-Confidence

On a recent morning, a state-operated group home in East Hartford smelled of chocolate chip cookies fresh from the oven. With its sliding glass doors, television and sofa, the living room looked like countless suburban living rooms except for one noticeable difference.

Two severely disabled people lay on a "mat table" — a king-size mattress on a platform with padded sides — as an aide massaged their spindly limbs.

It was a home for the profoundly retarded, none of whom could walk or talk. The six residents had lived at the Mansfield Training School, and Stephen Lyford, the group home's supervisor, had worked with them there for 20 years. "I didn't want them to move," Mr. Lyford said.

The six residents, however, quickly adjusted to having their own rooms and began going on trips into town. Staff took them shopping, to lunch at a nearby McDonald's and to swim at a recreation center.

One woman, who spent years with her head bent down, began to look around. She no longer insisted on eating in only one spot, but was relaxed enough to take her meals in different places.

"She's more alert and more sociable," Mr. Lyford said. "This place has been better for her. It's been better for all of them."

Mr. Lyford said the change is partly a result of better staffing, up to a ratio of three or four staff to six residents per shift.

James Conroy, a researcher who has studied the transition from institutions to group homes in Connecticut, said that the former Mansfield residents he tracked showed improvement after moving into

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tored closely, can become mini-institutions. And, it is not always clear what the retarded prefer.

Asked about her years at Mansfield, one retarded resident of a group home fondly recalled working in the institution's kitchen. "Used to help the baker man at Mansfield," she said. "He would give me milk. He would give me four cups of coffee. Learned to cook, learned to cook potatoes."

Two of her house mates expressed relief at being out of Mansfield, but not this woman. "I like Mansfield more," she said.

The Cost Factor

Do Savings Apply In Extreme Cases?

Studies show that group homes cost about 75 to 92 percent of what institutions cost, largely because of cheaper labor. But experts say that with the severely impaired, the difference shrinks, as the group homes must offer more services.

David Braddock, a former president of the American Association on Mental Retardation, said: "I've been very reluctant to use the argument that community living is less expensive than institutional in making the case for group homes. It probably is somewhat cheaper for most clients. For some, it may be a wash. For a small minority, it may be more."

The State Department of Mental Retardation estimates that almost half the Southbury residents are so disabled that they would need to be placed in group homes classified as "Intermediate Care Facilities," which have a high staff-to-resident ratio. While the average per diem for a Southbury resident was \$344.49 in 1994, it cost just \$11 less to be in a privately run intermediate care group home; and \$61 more in a state-run home.

By contrast, a moderately retarded person could live in a supervised apartment for \$93.63 per diem.

Still, the department estimates that closing Southbury would save \$23 million annually by the year 2000. It contends that servicing these residents in the community would cost \$63.3 million, versus \$86.65 million for a remodeled Southbury.

The Southbury parents' group rejects these figures, saying that the department wrongly assumed that 20 percent of Southbury's remaining population could be placed in much cheaper supervised homes and apartments that are not heavily staffed. To support this criticism, they note that this year's budget has funds to provide such placements for 54 residents at a low per diem of \$100 per person. That amount so far has been insufficient to get anyone out of Southbury.

Case Study

A Patient Trapped Against His Will?

Because of this lack of funding for community placements, advocates say that Richard Messier has been trapped in Southbury against his will.

Mr. Messier, a profoundly retarded 50-year-old, has been listed as the lead plaintiff in the lawsuit that charges the state with failing to provide adequate services at Southbury.

Although Mr. Messier is scheduled to move in the next few months to an apartment with a roommate, the transition is far from certain. Jean Bowen, a leader of the drive to close Southbury, has been toiling for months to overcome the odds.

Ms. Bowen is reviled by members of the Southbury parent group who describe her as an anti-institution zealot. Ms. Bowen said that she is simply listening to what retarded people want.

Unfortunately, it is difficult to gauge what residents like Mr. Messier think about all this, as he does not talk. Recently, he sat stiffly and silently, his expression blank, his dark eyes shifting back and forth. A reporter asked him questions and got responses from Ms. Bowen.

She heads the Western Connecticut Association for Human Rights, the state-contracted advocate for Southbury residents, and said she discovered Mr. Messier years ago when she noticed one of his creations, an elegant paper sculpture, hanging near his bed. "I knew something was going on with this man," she said.

Mr. Messier had lived at Southbury for 25 years without a visitor, she said. He would hide in his room, rarely venturing out.

Since then, Ms. Bowen helped find him a guardian. Her agency made sure he had a job at a sheltered workshop, a bottle redemption business.

"When I first met him, there was a sadness about him that I don't see any more," Ms. Bowen said. "There's something about his cheeks, his eyes, an expressiveness about him that's changed."

"There are lots of labels for him — profoundly retarded, autistic — but anyone who can do 500-piece puzzles is no more disabled than I am," she said.

Legislation

Both Sides

Testify in Hartford

Earlier, this month, the civil war over Southbury went to the capital, as both sides

mobilized dozens of people in testimony that proposed expanding the institution. The legislation would require a \$25 million to turn Southbury into a specialized facility for the aged and medically fragile retarded.

Lined up against it were nonprofit agencies that operate group homes, advocacy organizations, former Mansfield and Southbury residents and parents of retarded children who are on the state's waiting list for group homes. In the last decade, this coalition has made much progress in expanding community services, but now they are on the defensive.

It is a remarkable shift, largely the result of the Southbury parents.

Mrs. Bondy, the parents' president, claims the group represents more than half of the residents' families. The group's power is enhanced through a parent-sponsored foundation that acts as the guardian for about 25 percent of the residents, who are without families. The foundation spends roughly \$100,000 a year on a lawyer to represent them.

Last year, during the gubernatorial race, the parents — who are typically in their 70's — held several meetings with Mr. Rowland and vigorously supported him. They have hired one of Hartford's most prominent lobbying firms.

Asked why she would not consider placing her 39-year-old son Stevie, in a group home, Mrs. Bondy answered, "Safety." While her husband described Stevie as "reasonably coordinated," they worry about his inability to communicate and his fear of dogs. Mrs. Bondy said other parents might disagree.

While those who wish to close Southbury gush about the potential of Southbury residents to grow, Mrs. Bondy mentions their limits. In sharp contrast to the advocates, who talk about the "tremendous contribution" that someone like Mr. Messier could make to society, Mrs. Bondy dwells on how her son would be spurned. While the advocates predict that Mr. Messier would learn to speak, Mrs. Bondy was pessimistic that her son's new speech therapy sessions would lead anywhere.

Some might consider Mrs. Bondy and the other Southbury parents patronizing. They see themselves as realists. The mindset is born from decades of knowing too well the disappointments of being a mother to a son at Southbury.

Mrs. Bondy understands parents who no longer visit their grown children: "It's very hard to come there if you've got somebody who gives you nothing back. You're thinking, this is my child, and it's nothing that you're proud of."

"You know," she said, "it's very hard to make."

group homes. At least 10 studies have shown that parents who had opposed such a move later reported greater satisfaction with the new arrangement.

The Southbury parents say such studies are biased. Philip K. Bondy, a retired Yale Medical School professor whose wife, Sarah, heads Southbury's parents association, noted that it was difficult to find doctors and dentists outside of institutions who were willing to treat the profoundly retarded. Parents also cite state statistics that show group homes have a higher incidence of abuse and neglect than Southbury, although some experts dismiss these findings.

Even advocates for community living acknowledge that group homes, if not monitored closely, can become mini-institutions.

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C O N N E C T I C U T



Photographs by Suzanne DeChillo/The New York Times

TOP Jimmy Walen and his father, Edward, string beads in his cottage.
LEFT Richard Messier's suit says the state is not providing services.
ABOVE Jean N. Bowen is a leader of the drive to close the institution.
BELOW Taking care of two people at the same time, Stacy Santos
wipes the face of Marilyn Sackman, left, as Dorothy Babbs watches.



NCD/Bristow/Speed Davis

Customer input/focus gps.

How to mesh LT w/ NPR/Cong

Mandate to monitor ADA

- report today
- turn of states
- 7/26 5th anniversary

* CR or VP to any of these? - LM
5 yr baseline - revisit
(increasingly neg re ADA)

Pol. Summit - Sept

- summary of policy
- 200 people
- vision smet.

Want to bring NCD/NPR tag - was extension
Given election
GP to grassroots

Outreach - Beltway advocates use, beyond
of not contrav, worth g-r alt

(11 by 2/22)

* Cl take staff to states

* Newsletters - to
many orgs

* Internet

Release widely
before 2/22? *

* Do a public
piece - they'll

PC over CR/AR sign

out of DC

Natl Assoc of P+A Systems

Natl Council on Indep Living

Pres C → Govs

NOT to next level → street

Internet common → structure carefully
Must actually listen / 2

1/26/95

Inclusion rpt -
IDEA rpt.

March rpt - 10 hrs
summary

mand APR?
done process
zero rejects

IDEA - \$, slow to
refer
how much inclusion?

Gooding letter - DEA
Dr Colleague
secure

Phys Dis over-rep'd
Deaf, MI, blind, etc
Need x-disab floor

TB - NPR on dial

TB* Micro-agencies - how
man viable

Prophone 30 days -
NPR team

Done in 90 days

convenors
Advocates
Big mtg

PAIMI - SAMHSA
- 6 block grant
- 576 flex

S-4926

~~RECEIVED~~

MEMORANDUM

To: Carol, Jeremy, and to Whomever This May Concern (I now know it's Diana and Lynn)

From: Stan

Re: Transitions and Open Matters

Date: December 22, 1994 revised January 5, 1995

This memorandum should be read in conjunction with my November 23rd memo on the DPC and Disability Policy which outlines ongoing projects and the work that someone here needs to pickup.

This is a followup to the meeting on January 5th where Jeremy and I orally briefed Diana and Lynn.

1. National Disability Policy Review (NDPR)

See notebook on desk and tray for background materials.
Contact Ruth Katz 690-5746 at HHS re outcome of Childhood Disability subgroup meeting on Jan. 4th.
Contact Bob Williams on status of his redraft of Guiding Principles. File on surface topic on "Guiding Principles".

2. Federal Disability Accommodations Working Group

See notebook on desk, tray, and four large accordion files (bottom left file cabinet).
Contact Deval Patrick re folding in this group into the Accommodations Group of the NDPR.

3. Appointees with Disabilities Group

See multiple files labeled "Disability Appointees Group" for names, addresses, past agendas, etc. (top left file cabinet).

This group meets every 6 weeks or so and is about due for another meeting. Last one was held on November 8th.

4. ADA Alert and Preservation

Bobbie Silverstein has requested a meeting with Carol (or a phone call) to develop better lines of communication with the affected Federal agencies should the ADA come under Congressional siege.

Mixed signals from the Hill on the likelihood of such a rollback on ADA. Alex Vachon, Sen. Dole's disability staffer, reassured a visiting delegation that they had no plans to alter ADA. The Speaker, however, has toyed with the idea of turning

back such nondiscrimination matters to the states in an interview with George Wills. Constituency groups are very anxious. National Council on Disability is now focusing on continued need for the ADA in outreach forums.

5. PCMR Executive Orders

PCMR is seeking any comments on a proposed executive order on their mission. I received this on Dec. 19th. Any comments are due them by Jan. 20th. I may offer some after I leave here as one of their so-called "PCMR Associates." If anyone here wants to weigh in, see file on surface top and/or fax PCMR at 205-9519.

6. Hamp's article

ASHA has accepted it; Carol needs to provide them with a photo of Hamp for the cover. See file on surface top.

7. Sandy Turner

This is a semi-closed matter involving a friend of the First Family seeking links as a newly disabled person to the disability rights movement, etc. I successfully introduced her to the head of the Arkansas P & A program, and for now she seems quite satisfied. You can close the file if she makes no further contact here in 6 months.

8. Ginny Heiple correspondence

There is a file on the surface top that probably can be closed since I wrote her on december 9th and heard nothing further.

9. Speaking engagement with the American Foundation for the Blind

This group would be fine to schedule. Last month I passed on some information on the desirability of speaking to this group. I don't know whether or not Carol accepted or will need talking points at some point.

10. "Mothers of Invention" Reunion-- Mattell Foundation

This project is in limbo. Mattell Foundation representative did not return my phone calls after an initial interest in co-sponsoring a meeting between Carol and the mothers of other children with disabilities featured in US NEWS & World Report. I'm not sure if its still worth pursuing. File on surface top.

11. Over-the-Road Buses

ADA issue to follow. No intervention appropriate from here. See

file on top.

12. Childhood Disability Commission

Potentially very sensitive; waiting for names to be announced from HHS. See file on top. Jeremy can also brief you on the backlog/reengineering issue at SSA in general.

13. FYIs from Carol

See file on top so labeled re matters from Carol.
Good background material

14. Key papers

See tray marked "Priorities" for the key papers you requested, including my comprehensive memo on the Status of the ADA, and various statements by the President on disability policy.

15. Completed Assignments and Communications with Carol

For background or for archives, I have left these next to my computer. A full set of my memos to Carol on disability, homelessness, and related topics are in the hard drive under C: Carol.mem.

16. Farewell and Best Wishes!

This is one of the best places I've ever worked. Diana and Lynn, enjoy your new assignments. If you wish to consult with me, my card is in the desk drawer. (410)706-3191

**Carol and Jeremy, you've been terrific colleagues.
Thanks again for the chance to do great work for this country!
I'll think of you and be in touch.**

Minutes of January 9, 1995 meeting of the National Disability Policy Review Convenors.

The first meeting of the convenors of the National Disability Policy Review (NDPR) was held from 3:15-4:15 in room 211 OEOB and was attended by the following participants:

Carol Rasco, Jeremy Ben-Ami, Bob Williams (HHS), Kate Warren (HHS), Judy Huemann (Educ.), Connie Garner (Educ.), Susan Daniels (SSA), Ken McGill (SSA), Judy Feder (HHS), Lynn Margherio, Lisa Fairhall (OMB), Richard Green (OMB), Diana Fortuna, Liz Savage (DOJ), Elisabeth Cohen.

INTRODUCTION/ REVIEW FOCUS AND DIRECTION:

Carol Rasco, who facilitated the meeting, welcomed convenors, commented on official membership of commissioners on the review team and encouraged work groups to enlist their participation;

Judy Heumann then stressed the challenge of over-arching principles incorporating the various perspectives of the working groups;

NEXT MEETING OF FULL REVIEW TEAM/ AGENCY INFORMATION REQUEST:

* stressed the importance for convenors to meet regularly (at least once before each meeting of full review team (Carol Rasco);

a sample agency information request form was then distributed by Lisa Fairhall; before next full meeting of the team, Lisa and Richard plan to present information thus providing a common starting point; (the group agreed to get comments to Lisa by close of business Wednesday 1/11 - final request form to be sent out with updated work plan and letter from Carol Rasco and Alice Rivlin requesting form completion).

{For the next full meeting of review team we will also presenting the lay of the land/ changing attitudes by bringing in speakers and providing papers either already in existence or drafted by Judy Heumann. The need was also expressed that all review team members be as educated and aware as possible with regard to issues affecting individuals with disabilities}

NEXT STEPS:

Guiding Principles:

* highlighted the importance of giving thought to two issues: 1) how we will get wide spread input from other agencies and the community and how to incorporate this input and 2) whether we intend them to be or not, they will become public and we should be thinking through the consequences of that (Bob Williams).

Adult Employment:

* work group has met and discussed and modified a charter and short-term work plan. Each participant was asked to provide data - no full response at this time. Next meeting scheduled for

Wednesday 1/11; need employment and training side -- working on labor representation at next meeting (Susan Daniels);

School-to-Work:

* highlighted the importance that review principles remain in sync with over-all administration view. Example: cash benefit programs -- helpful for DPC staff to provide information to ensure consistent direction (Judy Heumann);

* balance between cash and in-kind benefits is difficult to discuss when we're not sure what other thinking is taking place (Susan Daniels);

* the group will be meeting next week -- pushing for labor to attend -- will look at data and charter and use Lisa's information request (Judy Heumann);

Accommodations:

* currently looking at accommodations policy developed in Bush administration and adopted by all agencies; will meet by the end of the month to review/ reality check (Liz Savage);

Childhood:

* the short-term agenda will include: IDEA and SSI options; and the long-term agenda will identify broad areas - health, education, income support, data (in terms of what data do we need?), consolidation and streamlining issues; asked each member to take the lead on an issue; meeting with advocacy groups late next week (Judy Feder);

ADVOCACY GROUPS:

Jeremy Ben-Ami expressed an interest in a meeting of convenors and advocacy groups, the timing and list of groups were then discussed; some comments listed below;

* might be wise to have more meat on the bones: data/ clarity/ time line; we are currently meeting with advocacy community to discuss IDEA -- mentioned possibility of sending a letter or an over-view memo (Judy Heumann);

* mentioned the possibility of including advocacy groups in the discussion of the guiding principles amongst the convenors prior to presenting the principles to the full team -- possibly in 3 or 4 weeks? (Carol Rasco and Jeremy Ben-Ami);

* February is more realistic (Bob Williams/ group agreed);

Jeremy Ben-Ami gave an overview of activity on the legislative end including the bi-partisan composition of meetings on the hill. Carol Rasco highlighted the importance of including representatives early.

Group agreed to meet at the end of the week of 1/31 to discuss guiding principles.

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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Byron A. A. A. A. A.

THE WHITE HOUSE

WASHINGTON

December 16, 1994

To all participants in the 11/2/94 meeting:

Thank you for attending the meeting held last month to discuss the **National Disability Policy Review**. We have now launched that Review, and we plan to schedule a second meeting with you in the near future.

Following our November meeting and the first meeting of the Review Team, the Team reached an agreement to initially divide into the following five working groups: Accommodations, Children's Issues, Employment of Working-Age Adults, Guiding Principles, and School-to-Work Transition. While we are beginning the work in these five broad areas, we are interested to know your thoughts and are open to further suggestions.

As we discussed, we want to expand our outreach in an effort to involve a larger number of groups in the Review process. We have enclosed what we hope is a more thorough and inclusive list of key organizations to contact regarding future meetings and briefings. It includes the original ten groups that participated in November's meeting and has been expanded with the assistance of some of the participants in that meeting. Please contact Elisabeth Cohen (202-456-2846) if you have any additions or comments.

At our next meeting, representatives of the five work groups listed above will give presentations to familiarize you with our initial proceedings and discuss progress to date. Thanks again for attending the first meeting, and we look forward to working with you.

Sincerely,

Jeremy Ben-Ami
Chief of Staff
Domestic Policy Council

Stanley S. Herr
Kennedy Public Policy Fellow
Domestic Policy Council

ORIGINAL DPC LIST OF DISABILITY ADVOCACY GROUPS

Nancy Bloch
Executive Director
National Association of the Deaf
814 Thayer Avenue
Silver Spring, Maryland 20910
p-301/587-1788 TDD-301/588-9551
f-301/587-1791

Dan Bross, Executive Director OR
Aimee Berenson, Legislative Counsel
AIDS Action Council
Suite 700
1875 Connecticut Avenue, NW
Washington, D.C. 20009
p-986-1300 x.11 f-986-

Judi Chamberlin
Center for Psych Rehab
Boston University
730 Commonwealth Avenue
Boston, Massachusetts 02215
p-617/353-3549 f-617/353-7700

Justin Dart
Real Health Care for All
907 6th Street, SW
Apt. 516C
Washington, D.C. 20024
p-202/488-7684 TDD-202/484-1370

Al Guida, Executive Director OR
Elizabeth Burrows
National Mental Health Association
1021 Prince Street
Alexandria, Virginia 22314-2971

Joe Manes
Bazelon Center for Mental Health Law
1101 15th Street, NW
Suite 1212
Washington, D.C. 20005
p-467-5730 TDD-898-1670
f-223-0409

Paul Marchand

Director, Government Relations
The Arc
1522 K Street, NW
Suite 516
Washington, D.C. 20005
p-785-3388 f-467-4179

Scott Marshall
Director, Governmental Relations OR
Denise Rozell, Government Relations Representative
American Foundation for the Blind
1615 M Street, NW
Washington, D.C. 20036
p-457-1487 f-457-1492

Oral Miller
Executive Director
American Council of the Blind
1155 15th Street, NW
Suite 720
Washington, D.C. 20005
p-467-5081 f-467-5085

Becky Ogle
Project: AccessAbility
625 Sisters Lane
Suite 200
Alexandria, Virginia 22314-1171
p-703/836-6263 f-703/836-6730

Minutes from 1/9/95 meeting of National Disability Policy Review Convenors.

Present: Carol Rasco, Jeremy Ben-Ami, Bob Williams (HHS), Kate Warren (HHS), Judy Huemann (Educ.), Connie Garner (Educ.), Susan Daniels (SSA), Ken McGill (SSA), Judy Feder (HHS), Lynn Margherio, Lisa Fairhall (OMB), Richard Green (OMB), Diana Fortuna, Liz Savage (DOJ), Elisabeth Cohen.

INTRODUCTION/ REVIEW FOCUS AND DIRECTION:

Rasco: commented on official membership of commissioners on the review team and encouraged work groups to enlist their participation;

Huemann: stressed the challenge of over-arching principles incorporating various perspectives;

NEXT MEETING OF FULL REVIEW TEAM/ AGENCY INFORMATION REQUEST:

Rasco: important for convenors to meet regularly (at least once before each meeting of full review team;

Fairhall: distributed sample agency information request form; before next full meeting of the team, Lisa and Richard to present information -- provision of common starting point; (group agreed to get comments to Lisa by close of business Wednesday 1/11 - final request form to be sent out with updated work plan and letter from Carol Rasco and Alice Rivlin requesting form completion).

{For the next full meeting of review team we will also presenting the lay of the land/ changing attitudes by bringing in speakers and providing papers either already in existence or drafted by Judy Heumann.}

NEXT STEPS:

Guiding Principles:

? **Williams:** Judy give the sum, but important to highlight two ~~issues on principles~~ once this small group has hammered them out. Must give great thought to both 1) how we will get wide spread input from other agencies and the community and how to incorporate and 2) whether we intend them to be or not, they will become public and we should be thinking through the consequences of that.

Adult Employment:

Daniels: work group met and discussed and modified charter and short-term work plan. Each participant was asked to provide data - no full response at this time. Next meeting scheduled for Wednesday 1/11; need employment and training side -- working on labor representation at next meeting;

Primer?

School-to-Work:

Heumann: helpful to keep principles in sync with over-all administration view. Example: cash benefit programs -- helpful for DPC staff to provide info. to ensure consistent direction;

Daniels: balance between cash and in-kind benefits is difficult to discuss when we're not sure what other thinking is taking place;

Heumann: meeting next week -- pushing for labor to attend -- will look at data and charter and use Lisa's information request;

Accommodations:

Savage: looking at accommodations policy developed in Bush administration and adopted by all agencies; will meet by the end of the month for reality check;

Childhood:

Feder: short-term agenda: IDEA and options; SSS
long-term: identified broad areas - health, education, income support, data (in terms of what data do we need?), consolidation and streamlining issues; asked each member to take the lead on an issue; meeting with advocacy groups late next week;

ADVOCACY GROUPS:

Ben-Ami: plan on meeting of convenors and advocacy groups -- let's discuss timing;

Heumann: would like to have more meat on the bones: data/ clarity/ time line; we are meeting with advocacy community to discuss IDEA -- could we send a letter/ over-view memo?

Rasco/ when 5 convenors meet to discuss guiding principles,
Ben-Ami: could we include advocacy groups and discuss principles with them before bringing it to the full review team -- 3 or 4 weeks?

Williams: February is more realistic (group agreed);

Ben-Ami/ overview of legislative end; bi-partisan basis,
Rasco: important to include representatives early.

Group agreed to meet at the end of the week of 1/31 to discuss guiding principles.

late!

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.

Transitions - head start

J. Herman wanted conclusions report

Ed - IDEA

SSA - SSI

Herr -

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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THE WHITE HOUSE

WASHINGTON

October 3, 1994

MEMORANDUM TO SECRETARY LLOYD BENTSEN
SECRETARY JESSE BROWN
SECRETARY RONALD BROWN
SECRETARY HENRY CISNEROS
SECRETARY FEDERICO PENA
SECRETARY WILLIAM PERRY
ATTORNEY GENERAL JANET RENO
SECRETARY DONNA SHALALA
SECRETARY ROBERT REICH
SECRETARY RICHARD RILEY
COMMISSIONER SHIRLEY CHATER
DIRECTOR JAMES KING

FROM: Carol Rasco 
Assistant to the President for
Domestic Policy

Alice Rivlin 
Director
Office of Management and Budget

SUBJECT:- Disability Policy

National programs affecting persons with disabilities have developed rapidly over the last quarter century. New policies, laws, and social expectations have dramatically changed the lives of those with disabilities in areas ranging from entitlements to education, civil rights to transportation. With the Census Bureau estimating that 49 million Americans have some type of disability, the issue is of obvious national importance.

Both of us believe the timing is right to organize a review of the direction of, and next steps for, national disability policy. This important undertaking will need to be inclusive and wide-ranging, seeking the views of people with disabilities, their advocates and service providers, experts in the field, members of Congress and their staff, and federal, state and local officials.

We have asked our staffs to think about how such a review could be structured and what issues could be included. The attached memorandum reflects their initial thinking, and we believe it provides an effective starting point for discussions in and out of the Administration about this review.

October 3, 1994

Page 2

We are asking that each Department designate one or more key policy officials, perhaps at the Assistant Secretary level, to serve as participants in this policy review, which we will co-chair. We are asking our staff leads to meet with your designees as part of their outreach in the next month to develop a proposal for the structure, agenda, and work plan for this review. We would greatly appreciate it if your office would notify the DPC of your designated participants by calling 456-5566 by Wednesday October 12.

We have asked the staff coordinators to complete their initial meetings prior to and to prepare a proposal for a meeting of the Domestic Policy Council in early November. We appreciate in advance your cooperation with this important undertaking.

cc: Leon Panetta
Bob Rubin
Christine Varney



EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF MANAGEMENT AND BUDGET
WASHINGTON, D.C. 20503

SEP 30 1994

MEMORANDUM FOR CAROL RASCO AND ALICE RIVLIN

FROM *JBA* *SH*
 Jeremy Ben-Ami and Stan Herr
 LF *RG*
 Lisa Fairhead and Richard Green
SUBJECT Draft Proposal for National Disability Policy Review

Background

You have agreed to begin planning a review of the issues surrounding Federal and national responsibilities for providing assistance to and protecting the rights of individuals with disabilities.

Below, we propose an agenda and structure for the Review, and some first organizational steps. The questions we have proposed to form the agenda are provisional; our initial conversations with key individuals will seek to validate their inclusion in the agenda, to determine what other issues must be addressed, and to set priorities for the Task Force that will undertake this effort.

I. PROPOSED AGENDA

The Task Force should be guided by the President's credo of supporting public and private initiatives to enhance the independence, inclusion, and productivity of persons with disabilities. The Task Force should answer, to the extent possible, the following questions, in order to articulate and refine the Administration's overall disability policy:

National Disability Policy:

- Can we articulate a national disability policy to animate or guide Federal law and regulations?
- What is the Federal role in a national disability policy? What is the rationale for each specific Federal responsibility (e.g., constitutional right, insurance, indemnity, need)? Do the scope and nature of the responsibilities differ based on age (children vs. adults) or severity of disability?
- What are the policies and realities in other countries (e.g., Sweden, Canada, Germany) that may offer insight and direction to our policies and programs?

Federal Disability Programs:

- How are we meeting current responsibilities? What is the current array of programs? What services/benefits are they providing? What values do they promote? How delivered? To whom? What are the gaps and overlaps? How are the Federal programs/services integrated with State and local government programs? Are there exemplary State and local government programs? How can good practices be disseminated/encouraged?
- What do we know about the effect of each program and policy on recipients? What data are we currently collecting in each area? What do we need to answer the impact questions better?

Identifying and Implementing Change:

- What changes are needed to program purposes and program structure to better meet current Federal responsibilities? Are we currently identifying and reaching those individuals in need of services? Are we providing the most effective array of services and benefits for the costs incurred by each level of government, the individual, and the private sector?
- For those responsibilities identified but not addressed, what should be done, and by whom?
- How can we make sense of eligibility criteria for various programs, to minimize overlap and duplication of services and benefits, and ease administration and assessment of program performance and move each program's focus towards participant outcomes (e.g., enhanced independence, community integration, self-sufficiency, greater productivity)?
- Are there new strategies to promote independence and self-sufficiency for persons with disabilities?

Federal Government as a Model:

- How well does the Federal Government serve as a model, in both employment policies and practices, and customer service? How can this be improved for the benefit of job applicants, employees, customers, and members of the general public with disabilities?

Program/Issue Areas:

Program areas to be reviewed would include (but need not be limited to):

- o services to infants and toddlers

- o education programs
- o cash benefit programs (insurance, income assistance, and retirement)
- o medical and other health programs
- o social services and family supports
- o school-to-work transitional services
- o rehabilitation services and training
- o employment services
- o transportation services
- o housing
- o advocacy services, information and referral
- o personal assistance
- o civil rights enforcement
- o services for older persons
- o technology-related assistance
- o programs of prevention and minimization of disability severity

The work product should take the form of a report outlining the Task Force's answers to these questions, and recommendations for further action, including actions the Administration can take through changes to law, regulation or funding priorities, grants and contracts, and administration of the Federal Government's own internal activities (e.g., employment and customer service practices). The Task Force should be charged to make recommendations that are "budget neutral."

II. TASK FORCE COMPOSITION

We recommend the following structure for the task force:

- The Task Force would be jointly directed by the White House and OMB, but would rely heavily on agency participation.
- The Task Force would be headed by the two of you, as "co-chairs."
- Each of the key agencies with an interest in disability issues (which would include at least ED, HHS, SSA, DoD, VA, OPM, DOL, HUD, and the Treasury) would be invited to participate at the policy level through designees of the agency heads, presumably Assistant Secretaries responsible for key program and policy areas. Where appropriate, more than one Assistant Secretary could be designated for an agency.

We recommend the following structure for the support team:

- Designate "co-team leaders" from OPD/DPC and OMB staff -- these are the people who would be responsible for making the task force happen. The co-team leaders would be responsible for organizing Task Force meetings and for directing the work of the support team.
- Designate as additional support team members OPD/DPC and OMB staff who are currently involved in the disability area. For OMB, PADs would designate the examiners responsible for accounts funding key disability programs to be members of the support team. The Administrator of OIRA should also designate one or more staff to join the team.
- The agencies would be asked to designate staff to participate as members of the support team. We would expect each policy official to designate two or three people from their areas to be members of the team.
- Even though this could result in a fairly large number of staff, we envision the support team dividing into small subgroups, each tasked with researching specific areas along the lines of the proposed agenda.

We recommend that the Task Force utilize the following for advice:

- Draw on the expertise of the three Presidential advisory councils -- the President's Committee on Employment of People with Disabilities, the National Council on Disability, and the President's Committee on Mental Retardation -- in the design of the agenda and how it will be carried out. These councils could also provide the forum (formally or informally) to tap disability community sentiments.
- Invite the Architectural and Transportation Barriers Compliance Board, the Equal Employment Opportunity Commission, and the Federal Communications Commission to participate as appropriate.
- Individuals with disabilities, members of their families, and their advocates should be consulted regularly (formally and informally).

III. TIME FRAME FOR ACTION

We recommend that the Task Force be constituted, the support team named, and the agenda (see above) agreed on in November. The Task Force could be initiated at a meeting of the DPC, co-chaired by the two of you, with other appropriate department or agency heads invited. We recommend that the timeframe for this Review be lengthy enough to ensure a

comprehensive and thoughtful deliberative process, and to analyze and synthesize the findings of the Task Force and support group and develop recommendations. The specific dates for interim and final reports should be determined by the Task Force. The Task Force itself would meet at least once every three months.

IV. NEXT STEPS

This National Disability Policy Review is a significant undertaking, of tremendous importance to the disability community, and no doubt will be subject to a great deal of comment and scrutiny both in and out of the Administration. To get the review off on the right foot, we propose devoting time in October and early November to laying the groundwork internally and externally through a series of meetings outlined below, before the Task Force Team begins its work. This outreach and initial leg-work will improve our design and create good will by informing and involving people on the front end and ensuring avenues for communication and input throughout the process. We will take care to make very clear that the suggestions received from this outreach process will be considered in the development of the agenda, but that we do not expect every recommendation to be included.

Pending your review and approval, we would propose the following steps and schedule:

Early October: We (working as a kind of DPC/OMB staff "advance team") would hold preliminary meetings with administration officials at key agencies to explore the idea of a Review, brainstorm about its structure, work plan, and agenda. With help from Mike Lux in the Office of Public Liaison and from the Office of Legislative Affairs, we would identify and meet with key advocates and Hill staff to give them advance notice and discuss avenues for their input and consultation throughout the Review.

We would also meet with the three existing Federal advisory groups whose mandate is to provide advice to the President in this area: the President's Committee on Employment of People with Disabilities, the National Council on Disability, and the President's Committee on Mental Retardation.

We believe it is vital to the success of the Review to ensure that there is strong ongoing communication concerning the Review with members of Congress and their staff, advocates, and persons with disabilities. The three national commissions mentioned provide a logical starting point for such communication. Based on meetings with those commissions and their staffs, the Task Force will include in its recommendations a plan for outreach and communication regarding the Review.

Early November: The two of you present the idea for a National Disability Policy Review to a special meeting of the Domestic Policy Council, also attended by other appropriate department and agency heads (e.g., Treasury, Defense), perhaps prefaced by an

LEVEL 1 - 1 OF 5 STORIES

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January 23, 1995, Monday, FINAL EDITION

SECTION: TELEGRAPH (NEWS), Pg. 1A

LENGTH: 3610 words

SERIES: SERIES -- THE DISABLING OF AMERICA. Second in a series.

HEADLINE: America's most wanted welfare plan
Addicts squander checks on drugs

BYLINE: Jim Haner and John B. O'Donnell, Sun Staff Writers

BODY:

They found Delmont Williams' body in an alley off Harlem Avenue, lying under the bald branches of a withered willow tree, staring up at the afternoon sky through dead eyes on "check day."

He had enough alcohol and heroin in his veins to intoxicate three men.

And you paid for it.

The homeless Army veteran overdosed with money from a Social Security program that doles out monthly checks to 8 million people who are too old or disabled to work. But 250,000 of them are believed to be hard-core substance abusers who routinely squander the cash on drugs and alcohol.

This week, the new Republican-led majority in Congress will examine the problem in hearings on Capitol Hill. Some are already vowing to give addicts the ax.

But they will soon learn that it's easier said than done because of one little-known fact: Most of the addicts and alcoholics on the rolls -- perhaps as many as three out of four -- are retarded, blind, crippled or suffer from some other disability that would entitle them to the \$ 458 monthly checks.

And Congress has refused for two decades to provide treatment for them in spite of a chronic shortage of even the most basic rehabilitation. Fearing that any appearance of coddling drug abusers would invite voter backlash, the nation's lawmakers have ignored social workers and drug counselors who say that intensive long-term treatment is the only answer.

"The first reaction of right-wing conservatives will be to gut the program completely," says Dr. Sally Satel, a Yale psychiatrist. "And the real liberal types won't want it touched. But either of those courses would simply perpetuate this crisis."

Says Pam Rodriguez, a Chicago drug counselor: "We have never seen a population like this before. For years, Social Security saw its job as to simply write checks. Now, we're getting [people] and they're ruined. We don't even know where to start."

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Checks for the drug abusers are costing taxpayers \$ 1.4 billion a year. Most are alcoholics. The vast majority are men. Four out of 10 are white. Their average age is 42. And few ever kick their habits. Rather, they usually end up dead or in prison within seven years of receiving their first check.

The case of Delmont Williams is typical.

A bearded father of two who drifted from North Carolina to Baltimore, his medical records show that Social Security knew he was a hard-core alcoholic when it mailed him his first check in 1987.

His liver was swollen from years of heavy drinking. His heart was congested. Half his teeth were missing. And his skull -- bashed in years earlier in a drunken brawl -- was webbed with cracks like a piece of glued-together pottery. He suffered from seizures and mental illnesses.

There could be little question that he wasn't capable of holding a job, or that he would squander the money Social Security gave him for his fractured skull and manic depression unless he got off drugs and alcohol. But the agency offered him no help. Just a check.

"Delmont knew he was dying," says Curtis Mann, a drug counselor at the Health Care for the Homeless free clinic on Park Avenue. "All the dealers came circling around him on check day like vultures. A week later, he'd crash from whatever dope he was using and feel terrible.

"Those were the times that he'd go looking for help. The problem was that we could never find it for him before that damn check came in the mail on the first of the month and the whole cycle started all over again."

In a city with some 2,400 addicts on the disability rolls and the highest per capita rate of heroin-related emergency room admissions in the country, there is not even short-term treatment available for nine out of 10 addicts, the nonprofit Abell Foundation found last year.

And the kind of in-patient care that removes hard-core addicts from their drug-infested haunts long enough to learn a new way of life is not available at all in Baltimore.

Time and again, Delmont Williams was confronted by waiting lists of up to a year, then headed back out onto the street to blow his aid money on blinding binges that ended in trash-strewn alleys, jail cells and hospitals all over the city.

On the afternoon of June 1, police came upon his corpse in a West Baltimore alley wrapped in a filthy red polo shirt. Just four hours earlier, he had picked up his last \$ 446 check from a mail drop at the clinic and cashed it at a nearby liquor store.

Delmont Williams died homeless, stoned and alone at 49.

"With his history, there's no way he should have been walking around with that much money in his pocket," says Lauren Siegel, a social worker at the free clinic. "But they gave it to him anyway. Every month, no strings attached, the check would come and Delmont would spend it on drugs and alcohol. Until it

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finally killed him."

The money came from a program known as SSI, for Supplemental Security Income -- a plan set up by Congress two decades ago with little deliberation or debate. The idea was to provide food, shelter and clothing to disabled poor people.

It is one of two such programs for the disabled run by the Social Security Administration. The other is called DI, for Disability Insurance. Since 1956, it has let workers who have paid into Social Security's retirement trust fund draw benefits early if they become injured, ill or addicted.

Both programs are in trouble.

Contradictory law

Envisioned as modest proposals to help a few million aged and disabled Americans, SSI and DI now cost \$ 65 billion a year -- fueling the national debt and sapping the fund that retired Americans rely on to pay their bills.

The two programs are covered by the same set of rules passed by Congress in 1972.

Even then, thousands of recipients were known drug addicts and alcoholics. But the rules placed few controls on how they spent the money -- except that they could not use it to buy drug treatment.

In a glaring contradiction written into the law, Congress deemed that letting handicapped addicts spend their checks on treatment would violate the philosophical underpinnings of the aid program: to provide basic expenses for those who couldn't work.

That decision set blind, retarded and mentally ill addicts adrift in lives of despair because it cut them off from private clinics, where treatment is generally available to anyone who can pay for it. And the prohibition has remained unchanged for more than 20 years. Further, tucked inside the law was one sentence that said addiction alone could qualify as a disabling disorder, making it possible for virtually anyone hooked on dope or booze to get a monthly check even though they have no other disability.

Before then, an addict or alcoholic had to prove that his substance abuse was so severe that it had caused disabling brain or liver damage, conditions that usually took decades to develop.

But under the 1972 rules, an addict has only to prove that his drug abuse is bad enough to keep him from holding a job -- opening the door for thousands of young substance abusers who aren't physically disabled and who probably never would have qualified for aid under the old rules.

They are men like Ernie Hernandez.

The 34-year-old heroin addict and father of two sits in the brown grass outside the San Joaquin County drug clinic in French Camp, Calif., a desolate farm town gone bust on the high desert plateau east of San Francisco.

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He fidgets with his beefy hands as he describes his six years on SSI.

A one-time cannery worker and farm laborer, he has no apparent physical problem that would keep him from working. He is lucid in conversation. And at 6 feet tall and 225 pounds, he's built like a weight lifter.

"I admit it," he says. "I don't look sick."

But he's collecting \$ 458 per month for his addiction, which qualifies him for a \$ 200 supplemental payment from the state, bringing his tax-free monthly take to \$ 658 -- about the same amount that the average retiree gets from Social Security after a lifetime of labor.

"The money definitely changes you," he admits. "I just ain't going to risk losing that money by working at some minimum-wage job. Next thing I know, I get too stoned, I lose the job. Then what am I gonna do to feed my kids?"

"You can tell them congressmen, if they stop SSI, the crime rate around here is going to go through the roof. It's all a lot of us have."

And Ernie Hernandez knows about crime. He says he's been using heroin and cocaine since he was a teen-ager, landing in prison at least nine times.

He'd like to get himself clean and back to work -- if for no other reason than to get his family off his back and to "be able to spend a weekend in the mountains without having to come home early because I ran out of dope."

But he has never been able to rehabilitate himself. Even when he wants it, there is little in the way of intensive treatment available.

On this sweltering day in July, he wants it in the worst way.

Jittery from a dose of black tar heroin he shot into his leg the night before, he considers his options as he fingers a small, gummy "booger" of heroin in his pocket.

'I'm really gonna kick'

Cheap and plentiful, black tar has spawned a plague of addiction in the cities and towns along Interstate 5 that has helped make California -- with at least 34,000 addicts on the aid rolls -- the "Disability Capital" of the nation.

"You back again, Ernesto?" asks Floyd Brown, the chain-smoking assistant director of the clinic.

"Yes, sir," Ernie Hernandez replies, hoisting himself up from the grass. "I want to get on the waiting list. I'm really gonna kick this time."

Both men know his chances of getting off heroin are nil. Since he's been on SSI, he's been in and out of the clinic so many times that they've both lost count.

He is one of 6,000 heroin addicts in the valley who rotate on and off the out-patient treatment program throughout the year. In a region that has become a hotbed of disease, many of them suffer from tuberculosis and AIDs. Three out

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of every four are getting disability checks, according to a recent county survey.

"They'll test positive for heroin and we'll flunk them out of the program," Mr. Brown says. "Then they'll sign back up on the waiting list and the whole thing starts all over again. I can honestly say that in my 21 years in this business, I have never had a disability recipient successfully complete the program."

When Congress first decided to let addicts like Ernie Hernandez get aid for merely being addicted, it ordered Social Security to herd them into treatment as a condition of their getting checks.

Any addict who refused was to be cut off -- except for DI addicts, because Congress deemed that they had "earned" their benefits when they were working and should be free to spend them as they saw fit.

The treatment rule was supposed to keep poor addicts on SSI from simply using the money to feed their habits. But former agency officials and legislative aides say they warned Congress as early as 1969 that there were nowhere near enough in-patient treatment slots for them. And no one expected out-patient treatment to work.

But the nation's lawmakers were less interested in accountability for addicts, the aides say, than they were in insulating themselves against outraged taxpayers should the program go wrong. Then-Sen. Russell Long, the legendary Louisiana Democrat, was the prime mover.

"He told us there was no way in hell he would support giving checks to dope addicts without at least making it look like we were getting tough with them at the same time," says Tom Joe, a Washington social policy analyst who helped write the disability rules. "Everybody knew that they probably wouldn't be able to actually find treatment."

Then, or now.

Today, a minimum of 3.2 million addicts and alcoholics need help, according to federal, state and private estimates. But there are slots available for less than half. And at least 100,000 people are on waiting lists for those slots at any time. For others, there are no lists.

Consider North Carolina, a state with 6,200 addicts on the federal disability rolls and few publicly funded in-patient treatment slots.

In Asheville, a small town in the pine-blanketed foothills of the Great Smoky Mountains, a downtown Social Security office draws scores of disabled people from the surrounding countryside. Many are illiterate, hobbled by years of hard labor in mines and lumber mills, and suffering from addictions to rot gut wine and moonshine.

"We're basically telling them to get treatment when there isn't a treatment facility within 200 miles of here," says Sharon DeLong of The American Federation of Government Employees, who represents local caseworkers.

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"We try to push them into Alcoholics Anonymous or something like that. But how long can they last when all they're getting is a couple hours of group therapy before they head back out to sleep in the woods with a dozen other alcoholics? It's utterly demoralizing."

Her frustration is echoed by caseworkers and drug counselors from Baltimore to Seattle who say Congress and the Social Security Administration have never been serious about rehabilitating addicts -- or in understanding how treatment works.

Counselors surveyed by The Sun say programs like the San Joaquin methadone clinic and Alcoholics Anonymous that bring addicts in off the street for a few weeks of detoxification or a few hours of group counseling every day are the least likely to succeed with hard-core substance abusers.

"It amounts to drive-by therapy," says Dr. Satel, a professor of psychiatry at Yale and the University of Pennsylvania who has worked with addicts for seven years. "It may work fine for the early stage addict who still has a home, a family and a job. But that's not who you see on disability."

"These people are seriously debilitated drug abusers, and they need months of heavy-duty residential care that cuts them off from their addict friends and their old hang-outs, and teaches them a new way of life."

And it is precisely this kind of treatment that Congress has refused for 20 years to provide to the destitute substance abusers on federal disability. Today, there are only 68,000 federally funded in-treatment slots in the entire country.

"It's one of the terrible ironies of the disability program," says Dr. Satel. "Congress tells addicts, 'You have to be in treatment, but we're not going to give it to you -- and you can't use your check to buy it on your own.'"

Under the rules set up by Congress, Social Security must stop checks to addicts who are caught spending them in a residential program.

Adding insult to injury, counselors say, Congress ordered Social Security last summer to carry out a plan to cut off addicts' checks after three years. The agency says the move will trigger \$ 275 million in notification, processing and legal costs -- enough to buy residential treatment for 35,000 addicts.

"Instead, we're spending it to shove these people back out onto the street in 36 months," says an exasperated Jack Gustafson, who represents state rehabilitation directors in Washington. "We'll buy their drugs for them for three years, but we won't give them in-patient treatment. It's insane."

Nor will the crackdown achieve the results that Congress promised to taxpayers when it vowed to purge addicts from the rolls. That's because most of them suffer from other physical or mental disabilities that will still qualify them for aid.

"The fact is that drinking and drugging is usually just part of the problem," says Joe Manes, a Washington mental health activist. "They usually have a complex of ailments that may or may not be related to their substance abuse."

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Willard Redpaint is a walking illustration.

'Pints away from dead'

Most mornings, the 42-year-old Dakota Indian can be seen stumbling down Larimer Street on the graffiti-scrawled industrial fringe of downtown Denver, a bottle of Wild Irish Rose wine in his trembling hand and a glassy film across his bloodshot eyes.

At 10:30 on a bright, clear morning in August, he is already drunk. So drunk that when he blows into a Breathalyzer at a nearby homeless shelter he registers a potentially lethal .42 blood alcohol level -- four times the amount to be considered legally intoxicated.

"God almighty, Willard!" blurts Bob Cote, director of the shelter. "You're about two pints away from dead!"

He breaks into a heated lecture, brow-beating, accusing. He reminds Willard Redpaint that at least 41 men have killed themselves on Larimer Street with disability aid money in the past few years.

"You knew a lot of those guys, didn't you?" Mr. Cote demands. "You want to end up like them?"

"I like my wine," Willard Redpaint replies sleepily. "I like to drink."

Reeking of urine and garbage from four nights sleeping in an alley, he says he can't remember how long he has been getting disability checks for alcoholism. Court records show it has been at least since 1985.

But alcoholism is far from his only problem.

Willard Redpaint is mentally retarded. And his brain is damaged from a car accident that sent him hurtling through the windshield of a pickup truck when he was a kid. He signs his name with an "X" because he cannot read or write.

When he was 4, a gang of thugs strangled his father during a robbery. A few years later, his mother was taken away to a mental institution. By the time he was 15, he was drifting the Western high country alone.

His earliest arrival in Denver is recorded in court files at age 25, when police found him stumbling drunk down the center of a six-lane interstate in the middle of the night. Since then, he has been arrested 16 times in alcohol-related incidents.

In 1988, he beat another homeless man to death with a slab of concrete over a stolen radio. Convicted of manslaughter, he served three years in prison, feeding his habit with homemade potato wine.

"It gives you a hangover in the morning," he says of his drinking. "And I'll end up dying. But that's the only bad part."

Each morning, he goes to a homeless aid station where social workers dole out his monthly check to him in \$ 10 installments.

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"I can buy four bottles of wine with that much," he says. "That's a lot of wine."

Left without treatment, counseling or supervision, Willard Redpaint receives just enough money every day from U.S. taxpayers to drink himself to the edge of death.

And the crackdown launched by Congress last summer with much election-year rhetoric will do nothing to stop him. If Social Security cuts off the checks he gets for his alcoholism, all he will have to do is reapply, citing mental retardation and brain damage.

Nor do drug counselors and social workers expect any of the other measures Congress passed in August to have much effect. Among the mandates were orders for Social Security to force addicts into treatment programs that don't exist and to hire special inspectors to make sure they don't abuse their checks.

But the agency has had inspectors in 18 states for years. And they say they have been consigned to failure by a lack of funding.

Little supervision

In California, Social Security monitored addicts so poorly that it continued to send checks to 119 of them while they were in prison, the state attorney general found last year. And in Illinois, a Chicago firm lost track of 7,000 more because Social Security never provided a list of their names.

And Social Security does not expect to be able to tighten supervision with the money Congress wants to spend on the job. Rather, private firms will be paid roughly \$ 600 per addict to monitor their whereabouts and make sure they are signed up on waiting lists until their checks run out in 36 months.

"Obviously, one long-term goal is to rehabilitate people," says Commissioner Shirley S. Chater, the agency's head. "And the way we do that is to have these monitoring agencies encourage the addict's sense of individual responsibility to find treatment for himself."

But Social Security estimates that the majority of substance abusers on disability -- perhaps as many as 200,000 -- will continue to get checks and go untreated long after the three-year cutoff because of loopholes in the law.

As many as three out of five are exempt because they have other disabilities. And another two out of three are collecting DI checks that can't be cut off until three years after they are actually accepted into a treatment program because Congress decided they "earned" their benefits.

Meanwhile, new addicts continue to pour onto the rolls. Social Security estimates that the number drawing checks today will almost double by the turn of the century.

"It's insane to go on giving them cash," says Dr. Satel, the Yale psychiatrist. "But it also makes no sense to just take that money away and plow it into some other program. Congress has to wake up to the fact that we need hard-nosed treatment to interrupt this cycle of addiction, crime and punishment that is costing taxpayers a fortune in more ways than one."

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Estimates by the National Association of State Alcohol and Drug Abuse Directors are that every dollar spent on drug treatment saves \$ 14 in police, court, emergency room and prison costs.

But so far, Congress and Social Security have been unwilling to spend the money -- even in the case of men like Delmont Williams who desperately want treatment and will surely die without it.

"It's not our job to solve the problems of the addict population," says Deputy Social Security Commissioner Larry Thompson. "Our job is to write checks."

GRAPHIC: COLOR PHOTO, SCOTT ANGER/SPECIAL TO THE SUN, After years ruined by alcohol and cocaine, Jack Gordon Hill Jr. of Baltimore thought he'd found peace with his kitten Serenity in a California drug treatment center. Months later, he was out on the street, Social Security disability cash supporting his habits.; PHOTO 1, Hours after cashing his last check, Delmont Williams overdosed in a Baltimore alley.; PHOTO 2, JOSEPH D. POELLOT/SPECIAL TO THE SUN, Most days, Willard Redpaint can be seen on Larimer Street on downtown Denver's graffiti-scrawled fringe, a bottle of Wild Irish Rose in his hand and a glassy film across his eyes.; PHOTO 3, SCOTT ANGER/SPECIAL TO THE SUN, "If SSI was around 20 years ago when I was trying to get straight, I'd probably be dead right now," says former heroin addict Floyd Brown, assistant director of a drug treatment center in French Camp, Calif.; PHOTO 4, SCOTT ANGER/SPECIAL TO THE SUN, Freddie Tafoya (center) used SSI to get treatment and go to college. Ernie Hernandez (left) and David Abitia are still addicted.; PHOTO 5, JOSEPH D. POELLOT/SPECIAL TO THE SUN, 41 men have killed themselves on Larimer Street with disability aid money, says Bob Cote, director of a Denver homeless shelter.; GRAPH, HHS Inspector General/SUN STAFF GRAPHIC, WHO GETS CHECKS?; MAP, SUN STAFF GRAPHIC, FRENCH CAMP

LOAD-DATE-MDC: January 24, 1995

the city's declining number of appeals

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Men and Women Use Brain Differently, Study Discovers

By GINA KOLATA

Using a powerful new method for glimpsing the brain in action, researchers have found the first definitive evidence that men and women use their brains differently.

The investigators, who were seeking the basis of reading disorders, asked what areas of the brain were used by normal readers in the first step in the process of sounding out words. To their astonishment, they discovered that men use a minute area in the left side of the brain while women use areas in both sides of the brain.

Dr. Sally E. Shaywitz, a behavioral scientist at the Yale University School of Medicine who was a principal author of the study, said, "As far as I know, this is the first time that anyone has been able to demonstrate anything functionally different" between the brains of men and women.

The new findings follow on a rich body of research looking for sexual

differences in the brain. Psychologists have found that women do better on certain tests, like those measuring verbal speed, and that men do better on other tasks, like imagining what an object would look like if it were rotated. Neurologists have found that women seem to recover better from strokes in the left hemisphere of the brain, where language abilities are thought to be situated. Autopsy studies have shown that male brains are more asymmetrical than female brains.

But these previous studies were

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PHOTOCOPY
PRESERVATION

Men and Women Use Brain Differently, Study Discover

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indirect. The psychological studies could not prove that it was nature, not nurture, that elicited the differences. The anatomical studies could not show what the actual effects of the brain differences were.

The new study, in contrast, showed actual differences in the parts of the brain used when men and women were thinking, and coming up with the same answers.

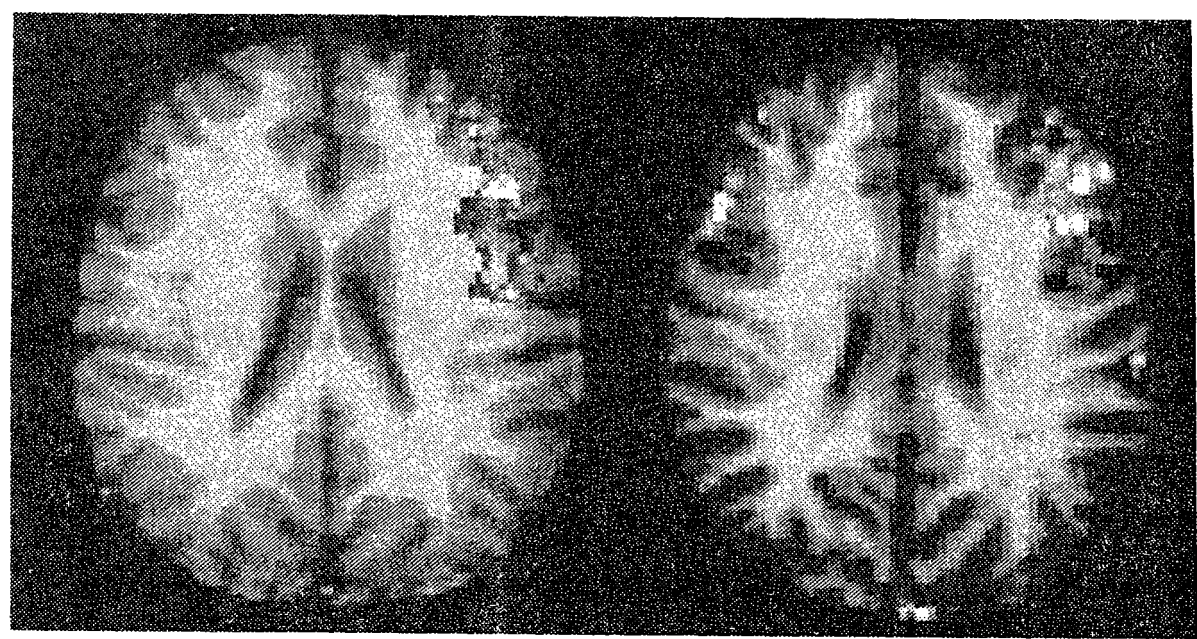
Dr. Shaywitz said the finding meant that "the brain is a lot more complicated than people envisioned." But it does not say that women's brains are better at this task than men's or vice versa. Although the men and women used their brains differently, she added, the fact that they sounded out words equally well means that "the brain has a lot of different ways to get to the same result."

Dr. Elizabeth Hampson, a neuroscientist at the University of Western Ontario, said the finding "provides definitive evidence" that men and women can use their brains differently to perform the same task. Nothing was conclusive until now," she said. It means, she said, "we should be open to that possibility in other areas of the brain as well."

Dr. Shaywitz said she was particularly surprised to see differences between men and women in decoding words. Reading, she said, has nothing to do with basic survival skills or reproduction, for which men and women might have developed different brain functions during the long course of evolution. "This is a difference that involves cognition," she said. "And it is the most complex human functions. Reading is the pinnacle of what humans can do."

Dr. Reid Lyon, director of extramural research on language disorders and learning disabilities at the National Institute of Child Health and Human Development, said the discovery went far beyond a mere curiosity. It is a huge step in a comprehensive research program that is allowing scientists to understand why some children and adults have such difficulty learning to read and its immediate implications for tests for reading disabilities and strategies to overcome them, he said.

It also might explain why it is that though girls and boys are equally likely to have difficulty learning to read, women seem to compensate better than men for their disability, said.



Magnetic resonance images of a man's brain, left, and a woman's brain show differences between the sexes in the decoding of words. Men use a small area on one side of the brain, whereas women use areas

on both sides of the brain. The lighted spots along the upper right side of the image on the left show man's brain in action. The image of the woman brain shows activity on upper right and upper left

A new tool to study the brain may offer help to children with reading disabilities.

Dr. Shaywitz, her husband, Dr. Bennett A. Shaywitz, a neurologist, and their colleagues are publishing their findings today in the journal *Nature*.

The Shaywitzes' main interest has been to understand the neurological underpinnings of reading disorders. In recent years, they and others have discovered that dyslexia, a difficulty in learning to read, is not a visual problem, not a problem that involves reversing letters, but is instead a language problem. People with reading disabilities have great difficulty breaking words into their most basic units, phonemes. A test for an ability to separate words into phonemes might be to ask a person to say philosophy without the "la" or Germany without the "ma."

Dr. Bennett Shaywitz explained that "by convention, we have adopted rules that say that certain sounds in print correspond to certain letters and certain letters form phonemes.

The trick in reading is to get from print into phonemes, then it's automatic."

In studying people with reading disabilities who nonetheless learned to read, Dr. Sally Shaywitz said she and others found that they learned to compensate for their inability to decode words into phonemes. "They used other higher order cognitive abilities: their vocabulary, their reasoning power," she explained. But, she said, reading was never easy or automatic for these people.

Within the last year, researchers discovered a method that can potentially show the brain in action and that is completely harmless to subjects.

The new method, functional magnetic resonance imaging, can show differences between blood carrying oxygen and blood that is depleted of oxygen. An active area of the brain gets fresh supplies of oxygenated blood. The trick to using functional M.R.I.'s is to design thinking experiments carefully so that they will isolate a particular task.

The Shaywitzes and their colleagues asked their subjects, 19 men and 19 women, to recognize whether nonsense words, like "jete" and "lete," rhyme. The only way to know is to sound them out. And the only way to do that is to use phonemes.

The men used a tiny area of the brain, about a centimeter, or less than half an inch, in diameter, near Broca's region, an area in the front of the left side of the brain, at the temple, that is thought to be used in producing speech. Women used this region but also used a comparable area on the right side of the brain.

The next step, which is under way is to see how children and adults with reading disorders use their brains. The Shaywitzes, who say they cannot comment yet on what they are finding, hinted that those with reading disabilities had profoundly different functional M.R.I. patterns.

Soon, Dr. Lyon said, it should be possible to design simple tests that will reliably detect young children who will have reading disabilities before they are faced with the daunting task of learning to read. It may also be possible to design ways to help these children overcome or even avoid the coming struggle.

Shirley Kramer, executive director of the National Center for Learning Disabilities, an advocacy group based in New York, said she could hardly wait. The new work, she said, "has moved this field forward by leaps and bounds," adding, "There is a real momentum going now."

GOP to Tighten Cash For Disabled Children

By Spencer Rich
Washington Post Staff Writer

In 1989 the Supplemental Security Income (SSI) program for disabled children had only 290,000 beneficiaries and paid out \$1.3 billion a year. For fiscal 1995, the number of beneficiaries will be 890,000 and expected outlays \$5 billion, Secretary of Health and Human Services Donna E. Shalala said last week.

Now House Ways and Means Committee Republicans are moving to block the explosive growth of the program that provides cash payments of up to \$458 a month to low-income families with severely disabled children.

Rep. Jim McCrery (R-La.), detailed by human resources subcommittee Chairman E. Clay Shaw Jr. (R-Fla.) to draft possible changes that could curb the program's rapid growth, said he agreed yesterday with a Democratic ally, Rep. Gerald D. Kleczka (Wis.), on the outlines of a plan abolishing the monthly cash payments that have been made by the program for two decades.

Instead, the children would receive only specified services they need to help them live with their disabilities, McCrery said. This presumably would cost less than cash payments that can be used for anything by the child's family.

"Children would continue to receive Medicaid and in addition receive other services from the states," McCrery said, which might fund those services in whole or in part with funds from the federal government. "We're close to hammering out the details."

McCrery said lawmakers plan to redefine the term "severely disabled" to modify the effect of a 1990 Supreme Court decision

that expanded the definition and contributed to the number of children qualifying under the program. "We will continue to provide essentially the same level of services for truly severely disabled children as now," he said.

Ways and Means Republicans believe that the huge increase in the rolls is in part the result of new mental impairment rules and a 1990 Supreme Court decision that made it possible for children with only marginal disabilities to qualify for benefits. In some cases, children reportedly have been

The number of beneficiaries in the program has tripled since 1989.

told by parents to fake or exaggerate conditions such as attention deficit disorder to get extra cash.

The proposed changes are likely to face strong opposition from groups representing the disabled and from many Democrats as the legislative process unfolds.

Although the SSI Children's Disability Program is far smaller than HHS's other disability programs for adults or the general welfare program, Aid to Families with Dependent Children, it is considered a crucial safety net for some of the most vulnerable members of society.

"The changes would be devastating to almost 1 million families," said Rhoda Schulzinger, a senior staff attorney at the non-profit Bazelon Center for Mental Health Law.

She said wiping out cash pay-

ments would be particularly harmful, since families in most cases are very low income or working poor and need flexibility as to how to help the child. Moreover, "The most crucial need for the disabled child is a secure home where the mother (it's usually the mother) need not work full time to help support the family but can devote large amounts of time, and often stay home altogether, to care for the child's tremendously difficult needs."

Schulzinger said that instead of drafting proposals now for inclusion in the GOP's welfare package, Congress should await the report next fall of a study commission headed by former representative Jim Slattery (D-Kan.) that Shalala appointed Jan. 9.

Schulzinger said the rises in the rolls from malingering are "grossly exaggerated" and result mainly from rising poverty and outreach efforts as well as rules changes. The Clinton administration wants to wait for the Slattery report.

Kleczka, in a recent white paper on the issue, cited various reports of program abuse: A family refused to allow counseling of a child with disruptive disorders for fear the child would improve and lose benefits; parents of a child with attention disorder refused to allow medication for fear "it would screw up his SSI."

Kleczka emphasized that the \$458 payment level encourages families to try to get children on SSI, because the amount is far more than is available through AFDC. In his state, he said, a mother with two children can get \$6,204 a year from AFDC, but switching one child to SSI jumps the total to \$11,700.

There is no clear evidence on the extent of abuses. The General Accounting Office found that in recent years, 70 percent of all new benefits went to children so severely disabled that they would have qualified under almost any rules.

Moreover, it found that only 21 percent of all new mental impairment awards in 1993 were for the attention disorders or personality disorders frequently cited as the basis for false claims.

LEVEL 1 - 2 OF 2 STORIES

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January 24, 1995, Tuesday, FINAL EDITION

SECTION: TELEGRAPH (NEWS), Pg. 1A

LENGTH: 3768 words

SERIES: SERIES -- THE DISABLING OF AMERICA. Third in a series.

HEADLINE: America's most wanted welfare plan
Immigrants walk off the boat and onto SSI disability rolls

BYLINE: Jim Haner and John B. O'Donnell, Sun Staff Writers

BODY:

They came in a huddled mass, tired, poor and yearning to breathe free. Then, they saw the ads.

"You are disabled, mental disabled, having serious sickness or being wounded, you may be eligible," proclaimed one offer in a Cambodian newspaper in Santa Ana, Calif.

"Free counseling," said another in Beverly Hills. "Client will only pay after receiving money."

And again in San Jose: "We are professionals on SSI -- with 85% successfulness!"

Through such ads, thousands of immigrants have stepped onto U.S. soil in recent years and found their way to hucksters, con men and entrepreneuring social workers who steered them onto a federal welfare program for the disabled called Supplemental Security Income. Without working so much as a day, the new arrivals begin collecting \$ 458 a month.

In just five years, their numbers on the SSI rolls have doubled to more than 700,000 -- making them the second-fastest growing group in a Social Security program originally intended for poor Americans too old or disabled to support themselves.

In 1994 alone, their monthly payments absorbed almost \$ 4 billion in taxes -- enough to buy a four-year education at Harvard University for every graduating high school senior in the Maryland public school system.

And more are on their way from such places as Mexico, Vietnam and Russia as an immigration boom almost unprecedented in U.S. history continues.

Now, the new Republican majority in Congress is gunning for them. Spurred by the mounting voter outrage that led California to cut off services to illegal aliens in November, the GOP is expected to call later this week for deep cuts in disability aid to noncitizens.

"It's time for them to live up to the commitments they made when they came to this country," said Sen. Rick Santorum of Pittsburgh, a former Republican

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representative who parlayed promises to purge the foreigners into a successful Senate campaign. "We cannot allow ourselves to become the dumping ground for the world's problems."

But records make clear that Congress is largely responsible for the problem. It triggered the surge by inviting thousands of mentally ill refugees into the United States and allowing them onto SSI just as it was passing the most generous mental disability rules in history.

As a result, more than 1 million "mentally disabled" people came onto the rolls. And mental problems became the No. 1 claim of those seeking aid -- citizens and noncitizens alike.

Records show that immigrants came onto the rolls for mental disabilities at a faster rate than any other group except children, demonstrating the combined effects of open-handed immigration policies and relaxed rules on mental disability.

Today, Social Security pays out more than \$ 25 billion to 6.3 million disabled and elderly people. One out of every eight is a legal alien or refugee. Of the disabled, one out of every three is getting checks for a psychological problem.

These two facts are closely related. Behind them is the story of a 24-year immigrant boom that caught Social Security unaware, the rise of America's disability culture and how they were both promoted by Congress. And it might not have been told at all if not for a man named Simardy McNeil Chan.

A 33-year-old San Diego County social worker, he ran a cottage industry from the front seat of his gray BMW 318i sedan helping Southeast Asian refugees scam money from Social Security.

For a fee of \$ 2,700, he led able-bodied aliens into a federal office building in San Diego, took them before Social Security caseworkers and fabricated harrowing tales of wartime suffering that he claimed left his clients too traumatized to hold a job.

He had been able to do this for seven years, he boasted to a group of potential clients last year, because few of the agency's caseworkers could speak foreign languages well enough to question immigrants directly.

"Not to worry," he assured them. "They are Americans. We are Cambodians."

Posing as a translator, Chan did all the talking. He then steered his clients to psychologists who -- citing the mental disability rules passed by Congress -- confirmed that they were mentally ill and couldn't work. Social Security would then begin mailing them monthly payments.

In this manner, Chan once boasted, he had no trouble getting checks for 2,000 of his countrymen, a population that would cost U.S. taxpayers more than \$ 10 million a year.

He had no way of knowing that three of his customers were undercover informants for the California attorney general's office or that his sales pitch was being recorded by hidden microphones.

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Caught red-handed, Chan was convicted last year of lying to caseworkers to get his clients government aid.

In exchange for a lenient sentence, he agreed to help state agents "sting" doctors, druggists and psychologists running "disability mills" for Southeast Asian refugees in Southern California. One Vietnamese doctor and another Cambodian translator have been indicted so far.

"They are big men from the SSI -- rich men," said Sombath Uon, a 44-year-old Cambodian who helped bring down McNeil Chan. "You see them in their big houses with their new cars. And the people are waiting in line outside their door to get the SSI like beggars. They are teaching the people to lie, to steal from the government.

"They are like godfathers."

Powerful figures

From San Diego to Seattle, the middle men have become powerful figures, he said, commanding respect once reserved for village elders.

Some are trained and bonded translators who help refugees with everything from drivers' licenses to mortgage settlements. But others are fly-by-night hustlers who herd the sick, the poor and the gullible through Social Security's English-speaking bureaucracy, then take a cut of the check and disappear.

They advertise in California's Vietnamese newspapers and on Cambodian radio talk shows. They rent office space in places such as Long Beach, where 100,000 refugees have given the city what is said to be the largest Cambodian population outside Cambodia. They do business in Thai, Laotian, Filipino and Japanese.

Alerted by the California attorney general's office to the fraud and unabashed marketing of the troubled aid program, Congress and President Clinton approved a raft of paper changes to the SSI law last summer.

What they did not do is fix long-standing flaws in the program that have allowed untold millions of dollars in fraud and waste to flourish for more than two decades.

They did not give Social Security money to hire or train more bilingual caseworkers. Rather, Mr. Clinton is cutting the work force at a time when only 14 percent of the agency's 30,000 caseworkers speak anything but English and less than 1 percent speak the Asian or Eastern European languages involved in most of the known fraud.

Congress did not address the fact that federal law enforcement agencies have turned a blind eye to the fraud, leaving 300 Social Security field investigators on their own. It is the equivalent of asking one Baltimore Police Department district station to cover the entire state of Maryland.

And Congress did not acknowledge that it is largely responsible for the problem it is now complaining about.

In the grip of the Cold War, the nation's lawmakers began as early as 1965 to loosen immigration rules for refugees fleeing Communist countries, giving

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automatic residency to many and triggering a sharp rise in immigration.

A decade later, they created SSI -- telling taxpayers that the program was for elderly and disabled Americans who could not help themselves.

But low-level legislative aides who wrote the program's rules inserted a sentence that wiped out long-standing residency requirements that once kept immigrants from getting government aid for years. And it meant that refugees were eligible the moment they stepped off the boat.

Then, beginning in 1984, Congress approved new mental disability rules that made it easier for the mentally ill to get on SSI -- just as a tide of mentally stressed refugees was streaming through America's golden door.

The fall of South Vietnam, the civil war in Cambodia, the exodus from Fidel Castro's Cuba, the U.S.-backed contra war in Nicaragua, the collapse of the Soviet Union, the fall of the Berlin Wall, the disintegration of Haiti and other calamities brought more than 15 million legal aliens into the United States.

It was 25 percent of the total U.S. immigration since 1820, packed into little more than two decades. And almost half came from the Asian and former Communist bloc countries of Eastern Europe that now account for most reports of translator fraud.

"We're dealing with an alien community isolated by language and cultural barriers that has been traumatized by unbelievably brutal wars and incredible poverty," said Chris Rodriguez of the California attorney general's office. "And we have a set of mental disability rules that practically any of them can pass, even though they may be working and supporting their families."

The new immigrants arrived to find a Social Security Administration that had failed to train its work force in foreign languages.

"It's a problem we weren't even aware of until the last few years," said Lenore Carlson, who oversees the agency's 1,300 field offices.

Few facts, big problems

Social Security never kept a comprehensive record of which offices were being hardest hit, she said, and never compiled enough data on immigrants to get a true picture of the boom. Likewise, no congressional audit of disabled aliens has ever been done.

Meanwhile, caseworkers were drowning -- caught between time-consuming applications from aliens and demands from supervisors to keep the cases moving in the face of a shrinking work force.

"We get all the runaways, homeless and vagabonds from four states," said Jeff Saul, a Seattle caseworker. "They're babbling at you in four dialects of Chinese, 13 Asian tongues, Spanish, Russian, Ukrainian and Filipino. We're using translators and sign language to prepare their applications.

"And God help you if you make a mistake or your productivity slips. Friend, you don't know what frustration is until you've spent a day in an SSA field office."

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That's not the way Social Security Commissioner Shirley S. Chater tells it.

"I recently returned from a trip out West and was greatly heartened to see our people all pulling together in a spirit of cooperation to get a handle on this problem," she said in a recent interview. "And I believe we are. There's an optimism and positiveness that is inspiring."

Of the 913 Social Security field workers in the Seattle region, only 26 speak Asian or Eastern European languages, leaving them heavily dependent on free-lance translators. And none speak Cambodian.

Given these circumstances, caseworkers say, events that unfolded there last year should come as no surprise.

After nearly four years of gathering leads on a suspected translator fraud ring, the state Office of Special Investigations drew the interest of the U.S. attorney's office in Seattle, which launched the only federal investigation to date into immigrant fraud.

FBI agents tracing the clients of one translator uncovered 50 unqualified applicants who would have drawn almost \$ 17 million in benefits in their lifetimes had they not been caught, said Assistant U.S. Attorney Steve Schroeder.

"If that isn't enough to drive you crazy, consider the fact that we have taken down three of these guys so far," Mr. Schroeder said. "And between the three of them, we're talking about potential losses in excess of \$ 200 million to U.S. taxpayers."

Typical was the case of a 63-year-old Vietnamese translator named Thanh Huyen "Jimmy" Vo.

American dream

Jimmy Vo came to the United States in 1975 after the fall of Saigon, after fording the Mekong River into Thailand with his wife and eight children, after living for months in squalid refugee camps.

Landing in Tacoma, the family began pursuing the American dream as thousands of immigrants before them had done: the hard way. They picked fruit and vegetables in the fields east of the city by day, attended school at night and saved their money.

Within a year, Jimmy Vo bought his first home off Yakima Street -- "Little Vietnam" -- Tacoma's refugee quarter. By 1980, he had his U.S. citizenship and a master's degree in social work from the University of Washington.

Soon, he opened his own business, Refugee Professional Services. Increasing respectability followed. He became a volunteer counselor for abused children and campaigned on behalf of a Little Vietnam community center.

Then, Jimmy Vo's American success story came unraveled.

"We paid him \$ 500 to assist us," a Cambodian named Sophan No told Tacoma police. "Jimmy Vo helped my wife and I to lie to the doctors and to the

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government people in order to qualify for SSI."

"I pretended to the doctors to be very stupid, and this was a lie because I am very smart," said another immigrant, Savoeun David Sam. "I pretended to the doctors that I could not work, and this was a lie because I was able to work very well."

Between them, the two Cambodians qualified for \$ 32,000 in SSI and other government benefits after bluffing their way through mental examinations with Jimmy Vo's help, court records show. In exchange for their cooperation and a promise to pay the money back, they drew a few weeks in jail. Jimmy Vo got five years in federal prison.

To investigators working the case, Vo demonstrated just how easy it is for almost anyone to exploit Social Security's mental disability rules with the right coaching or a sympathetic doctor. And there are signs that his is not an isolated case.

Unequal equation

Today, there are about 1,500 people on SSI living in and around the compact Little Vietnam neighborhood that covers a few square blocks near Tacoma's Lincoln Park. On their behalf, Social Security pumps about \$ 3 million every year into the tiny community of neat clapboard homes and apartment buildings.

Social Security officials say most refugees on SSI -- two out three -- are simply too old to work. But Tacoma turns that equation on its ear. Of the 1,500 recipients in Little Vietnam, records show, only 200 are elderly.

Still, Ms. Chater said she is confident that fraud among refugees is not widespread.

"We don't want the American people to think this whole program is rife with fraud and start petitioning their Congress members to kill it," she said. "The fraud we're talking about represents a tiny fraction of cases."

Mr. Schroeder, the Seattle prosecutor, is not so sure.

"We keep hearing over and over again that we're making a mountain out of molehill," he said. "But the fraction we've been able to prove amounts to millions of federal taxpayers' dollars. And I stress the words 'able to prove.' The fact is, nobody has dug very deeply into this problem."

That's because Social Security's police force -- the 300 agents in the Health and Human Services Inspector General's Office -- are so busy investigating scams in other federal programs that they barely have time for anything else.

And federal prosecutors are too busy handling drug cases in most jurisdictions to be of much help. Even when local investigators manage to crack an SSI fraud case, they usually have trouble finding a U.S. attorney's office willing to take it to court.

"If you look at individual cases of SSI fraud, you're not generally looking at large dollar losses," said Linda Summers, a senior Inspector General's investigator in the Los Angeles regional office. "And that's what we need to

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justify spending \$ 300,000 on a full-blown investigation. We're not exactly overstaffed either."

Her office's 13 agents cover a 75,000-square-mile swath of two states that stretches from Los Angeles to Las Vegas -- an area that contains no less than 400,000 SSI recipients, zip code records show. To perform a cursory review of that many case files would take each of her agents nine years.

"Finding the fraud would be like trying to find a needle in a haystack," Agent Summers said.

And even when agents prove fraud by a translator they cannot automatically kick his clients off the rolls. Under rules set up by Congress in 1984, they must also prove that the recipient is, in fact, not disabled.

"We're investigators, not psychologists," she said. "How are we supposed to determine whether somebody has a disabling mental condition when four psychologists will examine the same guy and give you four different opinions?"

"The bottom line is that once somebody qualifies for benefits, especially for a mental problem, it's very difficult to get them off the rolls."

And that observation is not lost on the rip-off artists.

Investigators in the San Diego and Seattle probes gave strikingly similar accounts of how crooked translators coach their clients to fake mental disorders instead of physical handicaps -- because mental disorders won't show up on an X-ray.

Bluffing through

Further, tests for psychological problems like post-traumatic stress and manic-depression are often highly subjective and can easily be foiled, if they are administered at all.

"The psychological examinations typically last eight to 10 minutes, and the translator answers most of the questions," said Mr. Schroeder, the federal prosecutor.

"We have cases of refugees who reported severe psychological trauma from witnessing their parents being killed and tortured in Cambodia, then we check their immigration files and find out their parents were with them when they came into the U.S. But they had no problem bluffing their way through the psychological exams and getting checks."

In Long Beach, Calif., where 15,000 residents are collecting \$ 6.7 million a month in SSI checks, investigators identified one psychologist who certified 300 SSI applicants as mentally retarded in a single year.

Relaxed rules

Today, about one out of three immigrants qualify wholly or in part on mental disorders, according to Social Security. And investigators agree that it is because of the relaxed rules Congress put into place in 1984 at the behest of disability lawyers and social workers.

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Under the old rules, applicants had to prove they were suffering from a condition so severe it prevented them from holding any job. Now, they need only show that a combination of symptoms prevents them from functioning in a competitive workplace.

In effect, Congress expanded the definition of mental disability at the same time that it limited the number of jobs an applicant could be expected to perform. It also said that "pain alone" could qualify -- even if there is no medical cause -- opening disability aid to people with psychosomatic disorders that are difficult to disprove.

Further, the same generous rules apply to another Social Security program called Disability Insurance that lets workers who have paid into the retirement trust fund draw benefits early if they become injured or ill. It, too, has been hit by a sharp rise in mental disability claims.

"There also is little on the record to suggest that Congress recognized the dimensions of the revisions," the Congressional Research Service reported in a recent study. "The probability of being awarded benefits is greater now than it was in 1985."

And the probability that fraud will be detected once checks have been granted has dropped to something approaching zero.

"The whole game is won or lost at the application stage," said Agent Summers. "Once they get in, it's hard to get them out."

Social Security officials say they are painfully aware of the fact.

New avenue for fraud

Commissioner Chater cited recent efforts to hire more bilingual caseworkers and to set up telephone conferences so they can help other offices process immigrant claims. But the agency also is expanding its use of volunteer translators.

Lenore Carlson, the field operations chief, said such "freebies" save taxpayers money. But her caseworkers say it's a new avenue for fraud.

In one typical experiment, Social Security now allows immigrants in Bridgeton, N.J., to fill out applications at a Hispanic community center run by volunteers -- who turn the paperwork over to the agency's local office each day.

"We are now handling applications from people we have never seen or met," said Frank Comito of the American Federation of Government Employees. "We don't even know for sure that they exist."

CAN YOU QUALIFY FOR MENTAL DISABILITY?

Here is a list of symptoms that Social Security uses to determine whether an applicant is eligible for \$ 458 monthly disability checks for emotional, psychosomatic or personality disorders.

Emotional disorders:

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A. If you have four of the following, you may be depressed:

1. Loss of interest in activities.
2. Trouble sleeping.
3. Agitation.
4. Decrease or increase in appetite resulting in weight change.
5. Decreased energy.
6. Feelings of guilt or low self-esteem.
7. Difficulty concentrating.
8. Suicidal thoughts.
9. Hallucinations, delusions or paranoia.

B. If you have three of the following, you may be manic:

1. Hyperactivity.
2. Racing thoughts.
3. Uncontrollable talkativeness.
4. Inflated self-esteem.
5. Decreased need for sleep.
6. Easy distractibility.
7. Failure to recognize unpleasant consequences of actions.
8. Hallucinations, delusions or paranoia.

C. If you have a combination of the above symptoms, you may be manic-depressive.

Psychosomatic disorders:

If you have one of the following, you may qualify:

1. A history of unexplainable symptoms beginning before age 30 that resulted in unnecessary medication, doctors visits and changes in living habits.
2. Frequent disturbances of sight, hearing, speech, sensation or use of limbs with no known physical cause.
3. Unrealistic actions based on imaginary physical symptoms.

Personality disorders:

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If you have one of the following ingrained behaviors, you may qualify:

1. Seclusiveness, unreasonable suspicion or hostility.
2. Odd thinking, speech or behavior.
3. Mood swings.
4. Chronic dependency, passivity or aggression.
5. Unstable relationships and impulsive damaging behavior.

Any of the above combined with at least two of the following may make you eligible:

1. Restriction of daily activities.
2. Inability to function socially.
3. Inability to concentrate or complete work tasks.
4. Deteriorating work quality.

SOURCE: Social Security Administration

GRAPHIC: COLOR PHOTO, FREDERICK D. JOE/SPECIAL TO THE SUN, Sophan No, a Cambodian refugee, admits paying a middleman to help his family fool doctors and caseworkers in order to qualify for SSI.; PHOTO 1, Posing as a translator, Simardy "McNeil" Chan defrauded Social Security. One Cambodian client likened him to a "godfather."; PHOTO 2, TACOMA NEWS TRIBUNE, An American success story gone wrong, Thanh Huyen "Jimmy" Vo got a five-year sentence for helping refugees bluff their way onto SSI.; PHOTO 3, WES POPE/SPECIAL TO THE SUN, In Tacoma's "Little Vietnam," more than 1,500 people are collecting \$ 3 million a year in SSI disability. Social Security says most are too old to work, but records show that only 200 are elderly. Tacoma is the site of the only federal probe into refugee fraud.; MAP, SHIRDELL MCDONALD/SUN STAFF GRAPHIC, WASHINGTON -- TACOMA

LOAD-DATE-MDC: January 27, 1995

Disability Agency Profile

January 31, 1995

Memorandum To Lisa Fairhall
Thru: Larry Parks
From: Carolyn Gunney
Subject: Commerce Programs for People with Disabilities

The information requested by the National Disability Policy Review Team on federal programs for people with disabilities is attached. The programs cited are not covered by a specific statute and budgetary implications are difficult to ascertain.

Also, per our conversation, I am providing you with copies of memorandums (previously sent) that address what the Department of Commerce is doing to meet the needs of people with disabilities.

- o National Telecommunications and Information Administration is using its vast National Information Infrastructure (NII) and Global Information Infrastructure (GII) resources to provide data bases accessible to those who have visual, physical, or mental disabilities;
- o United States Travel and Tourism Administration is working with the Organizing Committee to ensure that those with disabilities receive the same welcome as those tourist who are physically able, and will also be working with the Paralympic Games to coordinate the visits of key targeted international delegations, i.e., policy makers for the Paralympic Policy Congress and procurement decision makers for the Abilities Expo and Trade Initiative; and
- o Minority Business Administration is working to ensure that minority vendors, especially those with physical disabilities, are given priority for the Paralympic Games contracts.

Contact Person - Anthony Das, Executive Secretary, (202) 482-3934

II. Agency: Department of Commerce
 Bureau: Office of the Secretary
 Account: None
 Title: Accessible Computer Technology Exhibit

The Accessible Computer Technology (ACT) exhibit is held annually in October, Federal Disability Awareness Month. The Department of Commerce (DOC), Office of Information Resources Management (IRM) has hosted the Accessible Computer Technology exhibit for the last seven years which is funded on a volunteer basis by government agencies.

Exhibitors are invited to stage their technology (e.g., computers, enlarged screens, alternative keyboards, sound synthesizers, workstations, software) in the lobby and demonstrate its application. There is no cost to the vendor as the DOC does not charge for space and utilities. Volunteers from the bureaus within the Department of Commerce are used intermittently during the planning for various tasks like stuffing envelopes (four hours), setting up tables with covers (8 hours) and five meetings.

Types of Service and Benefits provided:

- J. This program provides information on the latest computer technology available for people with disabilities.

Number and Demographics of Individuals Served -

- o Approximately 1000 people are served annually.

Budget Authority and Outlays for FY 1994 and FY 1995 (estimated)

- o The average cost of the ACT is about \$23,000 annually.

Funding Provided by Federal/non-Federal Sources -

- o Funding is provided by the voluntary, participating agencies by Memorandum of Understanding (MOU). Funds are transferred to the DOC into an Advance and Reimbursement (A&R) account.

Nature and Periodicity of Data Collected -

- o None

Roles of Federal/non-Federal Entities -

- o Participating Agencies provide resources to fund the table rentals, coverings, drapes, electrical hookup, telecommunications connectivity, graphics, printing, mailings, sign language interpreters, security and advertising. Staff resources are provided on a volunteer basis and used for an average of four hours each during the two-day exhibit to assist with the activity.

Major Programmatic and Administrative Issues -

- o The program provides information on computer technology available for people with disabilities.

Any Additional Information -

- o None

Name of Contact Person -

- o Judy Westbrook, Computer Specialist (202) 482-0214

III. Agency: Department of Commerce
 Bureau: International Trade Administration
 Account: J401310165003124
 Title: Disabled Employee Fund

The International Trade Administration implemented a program which allows each unit, headed by an Assistant Secretary, to respond positively to request for reasonable accommodations. Four units set aside \$1500 and the Office of Administration contributes \$1000. Funds are replenished, as needed, throughout the year and may exceed the set aside amounts contributed by each unit.

Disabled employees make a written request to their supervisor. If the supervisor agrees, the request is forwarded to the Handicap Coordinator. A committee consisting of one representative from each unit reviews and approves all submitted requests. If the request is approved, the appropriate Assistant Secretary is notified of the need to authorize the allocation of funds.

Types of Service and Benefits provided:

- J. The service enables ITA to procure equipment for employees with disabilities without budgetary concerns. The program allows employees, through necessary equipment purchases, to become more productive and efficient in the work place.

In addition to eliminating concerns associated with the cost of providing accommodations, this fund has increased managers' willingness to hire more qualified individuals with disabilities.

Number and Demographics of Individuals Served -

- o Approximately five people per year

Budget Authority and Outlays for FY 1994 and FY 1995 (estimated)

- o Outlays for FY 1994 - \$6962, FY 1995 - \$7,000

Funding Provided by Federal/non-Federal Sources -

- o

Nature and Periodicity of Data Collected -

- o Data is collected annually on the names of employees, and the type and price of equipment procured.

Roles of Federal/non-Federal Entities -

- o None

Major Programmatic and Administrative Issues -

- o Providing equipment access to people with disabilities.

Any Additional Information -

- o None

Name of Contact Person -

- o Andrew Collier, Staffing Specialist, (202) 482-3301

IV. Agency: Department of Commerce
 Bureau: Office of the Secretary
 Account: None
 Title: Student Volunteer Service Program

The Office of Human Resources Management (OHRM) developed and entered into a student volunteer service agreement with Montgomery County (Maryland) Public Schools' (MCPs) School-to-Work Transition Program. The agreement enables students with disabilities to work uncompensated for the Office of the Secretary and bureaus serviced by the Office of Personnel Operations, OHRM. The MCPs provide job coaches at the work sites to observe the students.

Types of Service and Benefits provided:

- J. This program provides voluntary work experience to students with disabilities.

Number and Demographics of Individuals Served -

- o Approximately four students are served annually.

Budget Authority and Outlays for FY 1994 and FY 1995 (estimated)

- o None

Funding Provided by Federal/non-Federal Sources -

- o None

Nature and Periodicity of Data Collected -

- o None

Roles of Federal/non-Federal Entities -

- o None

Major Programmatic and Administrative Issues -

- o Providing students with training

Any Additional Information -

- o None

Name of Contact Person -

- o Russell Forrester, Director, (202) 482-4861

V. Agency: Department of Commerce
 Bureau: Office of the Secretary
 Account: None
 Title: Cooperative Agreement with Gallaudet
 University

The Office of the Secretary entered into a Department-wide Cooperative Education Agreement with Gallaudet University. The agreement allows Commerce operating units to employ Gallaudet University students in cooperative agreements without additional modifications to the agreement.

Types of Service and Benefits provided:

J. The agreement will provide work experience to students at Gallaudet University.

Number and Demographics of Individuals Served -

- o two to three students annually

Budget Authority and Outlays for FY 1994 and FY 1995 (estimated)

- o None

Funding Provided by Federal/non-Federal Sources -

- o None

Nature and Periodicity of Data Collected -

- o None

Roles of Federal/non-Federal Entities -

- o None

Major Programmatic and Administrative Issues -

- o Allowing students to get on-the-job training.

Any Additional Information -

- o None

Name of Contact Person -

- o Andrew Forrester, Director, (202) 482-4861

If I can be of further assistance, please let me know. My telephone number is (202) 482-2779.

attachments

September 23, 1994

Memorandum For Stanley S. Herr

Thru: Larry Parks
From: Carolyn Gunney
Subject: Commerce Activities in Support of Federal
Disabilities Accommodations

The Department of Commerce is fully committed to providing reasonable accommodations for people with disabilities. As part of that commitment, operating units implemented many mechanisms which allowed Commerce to be responsive to the needs of employees and visitors that are disabled.

I. A listing of specific accomplishments, by operating units, follow.

Office of the Secretary

- Three sets of brass rails were installed at entrance steps of the main building.
- The braille elevator emergency procedures signage has been completed in all elevators.
- A survey was completed at the main building to determine the number of rest rooms needing modification to accommodate people with disabilities.

Bureau of Economic Analysis

- The Bureau of Economic Analysis (BEA) relocated to a new facility. The building is fully accessible to people with disabilities.
- For individuals with a hearing impairment, TDD systems are provided in the Public Information Office and at individual work stations.
- For individuals with a sight impairment, public access, information, and emergency signs have the information in braille. Recently released data from BEA is available in voice recorded messages for sight impaired clients and the general public.

Census Bureau

- All employees who have a hearing disability were provided with an opportunity to obtain an automated vibrating system that alerts them to situations requiring immediate evacuation.
- Permanent accessible parking spaces was established for visitors with disabilities.
- A directional sign was posted at the main entrance in Suitland, Maryland to notify people with physical disabilities that assistance is provided upon request.
- A TTY was installed in the Public Information Office to enable people with hearing disabilities to request products and information.
- The Equal Employment Opportunity Office and the Public Information Office purchased decoders to provide close captioned videos for persons who have hearing disabilities.
- Accessible restrooms, including showers, were installed in the exercise facility in Jeffersonville.
- Dual access door operators were installed at seven locations in Jeffersonville.
- TTYs and directional signs were installed in all regional offices and telephone centers.

National Institute of Standards and Technology

- Restrooms were modified throughout the site to accommodate people with disabilities.
- Accessible ramps, handicapped parking areas, and drinking fountains were installed throughout the facility to accommodate people with disabilities.
- A sound amplification system was installed in the auditoriums.
- A TDD phone mail system was installed in the office of Civil Rights. A pay TDD was installed near the auditoriums for visitors.
- Elevators were modified by adding auditory and braille features.

National Oceanic and Atmospheric Administration

- NOAA relocated to four newly constructed buildings in Maryland that are all fully accessible to people with disabilities.
- Regional offices and laboratories renovated bathrooms, provided parking services, built ramps, and installed electric doors to accommodate people with disabilities.

Patent and Trademark

- Parking spaces for the handicapped were installed.
- Restrooms were updated to accommodate people with disabilities.
- Stairwells in Crystal Plaza 3 and 4 were updated.

II. Commerce has written several reports addressing Federal Accommodations for the Disabled. Titles of some of the more recent reports are listed below.

- The Bureau of the Census recently completed a report entitled "Americans with Disabilities: 1991-92" -- the first comprehensive disability survey ever undertaken by the Bureau. This report will be useful in establishing baseline numbers as the Nation works to reduce barriers faced by persons with disabilities.
- The Bureau of the Census prepared a statistical brief entitled "Americans with Disabilities". The brief addressed, in part, the impact of having a disability on employment status.
- The National Institute of Standards and Technology released a report, for public comment, entitled "The Information Infrastructure: Reaching Society's Goals." The first chapter addresses meeting the needs of people with disabilities in developing the National Information Infrastructure. The report was prepared by the Committee on Applications and Technology of the Information Infrastructure Task Force.
- Commerce's Affirmative Action Program Report for People with Disabilities was prepared, and submitted to the Equal Employment Opportunity Commission, in accordance with the Rehabilitation Act of 1973, as amended, 29 U.S.C. Section 791 ET SEQ.

III. Commerce encourages new and innovative ideas on how to continue meeting the needs of people with disabilities. Listed below are a few notable accomplishments that might bear on the charge of the working group.

- In honor of the Federal Disability Awareness Month, the Department of Commerce is hosting the sixth annual interagency Accessible Computer Technology (ACT) exhibit. Ronald H. Brown, the Secretary of Commerce, will be the keynote speaker at the opening ceremony on October 5, 1994, at 9:30 A.M. in the Main Commerce Auditorium on the first floor, 14th Street and Constitution Avenue, N.W. Awards will be presented for outstanding performances by Federal workers, managers and vendor.

Exhibitors are invited to stage their technology in the lobby and demonstrate its application. The ACT, held this year October 5 & 6, 1994, is a collaborative effort of fourteen government agencies which contribute toward employing those with disabilities. This year private sector associations are being invited to join in the ACT. Commerce is very proud of this tradition and the good works that have come from it. As a result of the past ACTs, a wave of new accessible technology has been made available.

The General Services Administration's (GSA) Clearinghouse on Computer Accommodation (COCA) and Council on Accessible Technology (COAT) has coordinated and will present a free seminar on October 5 at 1:00 P.M. - 3:00 P.M. in the Main Auditorium. The seminar entitled "National Information Infrastructure: Electronic Access for All" will focus on Advancing Modality Choice Through Captioning. A panel of consumers with disabilities, researchers and commercial developers will exchange views and demonstrate progress with applications that support user choice of information media.

In keeping with the goals of the National Performance Review (NPR), this initiative promotes getting the information to the entire American community by the most efficient and effective means possible.

The exhibits are open in the Commerce Main Lobby following the opening ceremony until 4:00 P.M. and the next day, October 6, 9:00 A.M. - 2:00 P.M.

- The International Trade Administration implemented a program which allows each unit, headed by an Assistant Secretary, to respond positively to request for reasonable accommodations. Each unit must set aside \$1500. Disabled employees make a written request to their supervisor. If the supervisor agrees, the request is forwarded to the Handicap Coordinator. A committee consisting of one representative from each unit reviews and approves all submitted requests. If the request is approved, the appropriate Assistant Secretary is notified of the need to authorize the allocation of funds.

Recent examples of its use include the purchase of special equipment including a large 20 inch monitor, a closed circuit television, zoom caps that enlarge keyboard keys, and a voice activated computer.

- Commerce revised the Real Property Management Manual to increase compliance with accessibility requirements in facilities leasing program. The revised provision should help reduce physical barriers for persons with disabilities to Commerce programs and activities.
- Under a Cooperative Research and Development Agreement with United Technologies' Otis Elevator, the National Institute of Standards and Technology is working to develop fire safe elevators to be available to evacuate disabled individuals in emergency situations.
- Larry Irving, the Assistant Secretary for The National Telecommunications and Information Administration, attended a meeting on Americans with Disabilities on August 4, 1994. He addressed the importance of building in accessibility for the disabled to the equipment and networks of the National Information Infrastructure at the onset rather than waiting to retrofit products and the infrastructure.
- Additionally, the National Telecommunications and Information Administration will hold an electronic hearing on the issue of universal access to the National Information Infrastructure. Access points will be set up in public libraries which will provide Americans with disabilities an excellent opportunity to have additional input into the process of redefining universal service.
- The Patent and Trademark Office developed an applicant referral system for individuals with disabilities. This system has markedly increased applicant referrals for individuals with disabilities.

July 26, 1994

Memorandum For Christine Varney

From: Rob Stein

Subject: Commerce Activities in Support of Americans with Disabilities Act of 1990

Commerce is actively engaged in activities to support the Americans with Disabilities Act (ADA).

- Commerce's National Institute of Standards and Technology (NIST), the government's preeminent civilian industrial technology laboratory, is conducting research in several areas which will benefit Americans with disabilities.
 - Under a Cooperative Research and Development Agreement with United Technologies' Otis Elevator, NIST is working to develop firesafe elevators to be available to evacuate disabled individuals in emergency situations.
 - NIST is also working with the Veterans Administration on hearing aid testing, and is further working to improve artificial hips and other medical prosthesis.
 - Finally, NIST is working to develop improved robotic actuators to mechanically perform certain functions for disabled individuals.
- Commerce's Bureau of the Census has recently completed a report entitled "Americans with Disabilities: 1991-92" -- the first comprehensive disability survey ever undertaken by the Bureau. This report will be useful in establishing baseline numbers as the Nation works to reduce barriers faced by persons with disabilities.
 - The report found that only about half of persons aged 15 to 64 with a severe disability had private health insurance compared with 80 percent of persons with no disability.
 - The report also found that an estimated 34.2 million Americans 15 years of age or older had difficulty performing one or more of six functional activities (seeing, hearing, speaking, lifting and carrying, walking, and climbing stairs.)

- In addition, Commerce is an active participant in the United States Architectural and Transportation Barriers Compliance Board working to develop accessibility guidelines for ADA implementation. Commerce serves on the Board's Executive Committee and is a member of the Board's Recreation Access and Children's Environments Rulemaking Committees.



U.S. Department of
Transportation

Office of the Secretary
of Transportation

Assistant Secretary

400 Seventh St., S.W.
Washington, D.C. 20590

MEMORANDUM TO: Carol Rasco
Assistant to the President
for Domestic Policy

Alice M. Rivlin
Director
Office of Management and Budget

FROM: Frank E. Kruesi *fr*
Assistant Secretary
for Transportation Policy

SUBJECT: National Disability Policy Review:
Department of Transportation Programs
Serving Individuals with Disabilities

Enclosed is a description of programs and activities administered by, and supported by funds from, the U.S. Department of Transportation (DOT). This information is submitted in response to the request contained in your memorandum to members of the National Disability Policy Review Team (under "Next Steps").

Your staffs may direct any questions about DOT's submission to Donald R. Trilling at (202) 366 4420 or Ira Laster at (202) 366-4859.

DEPARTMENT OF TRANSPORTATION
Baseline Inputs on Disability Programs
for Domestic Policy Council Review

Agency

Federal Transit Administration (FTA)

Program Title

Urbanized Area Formula Program (\$2.2B); Nonurbanized Formula Program (\$133M); Elderly and Persons with Disabilities Program (E&PD) (\$59M)

Program Summary

Formula grants for state and local governments to buy new transit vehicles accessible to persons with disabilities; build accessible rail systems; modernize/make accessible old rail cars and stations; provide demand response (van) service for those with disabilities unable to use the accessible fixed route services; and fund eligible operating costs. Capital grants require a 20 percent local match. E&PD grants go to certain private, non-profit (PNP) agencies, states and localities to buy vehicles and require a 20 percent local match.

Statute

Chapter 53, U.S.C., Federal Transit Laws, 49 U.S.C. 5301 et seq. Implementing statute is Transportation for Individuals with Disabilities; Final Rule, Part IV, Statute 49 CFR PARTS 27, 37, AND 38, Sept. 6, 1991, p. 45584-45778.

Service/Benefit

Accessible transit vehicles and stations are used to provide service by over 600 local government agencies. Formula grants help fund a 53,000 bus fleet, 33 rail systems, and 14,000 paratransit vehicles. There is no direct DOT subsidy to system riders for the 8 billion annual transit trips provided. E&PD funds go to 3,673 PNP and public agencies to transport eligible persons with 12,226 vehicles purchased with FTA funds.

Population Served

ADA Paratransit Service--about 1 million persons are certified as eligible, however only about 200 of the 535 paratransit areas have certified that they are in full compliance (all systems are expected to complete ADA implementation by the January 1997 deadline). Ridership on fixed-route systems by persons with disabilities is unknown, but is estimated to be many times the

number of ADA paratransit riders. E&PD providers serve primarily the elderly and persons with disabilities, and vehicles are equally divided among the two populations.

FY94 Budget

There is no specific ADA appropriation in transit formula funding. Lifts, vehicles, and station upgrades are eligible for formula funding along with other eligible transit projects. FTA estimates the total industry capital costs of ADA public transit compliance at about \$280M per year; the Federal share (80%) of these costs is about \$220M. Since the transit industry used its entire Federal operating expense entitlement before the ADA enactment, FTA funds do not appear to have contributed to defraying ADA-related industry operating costs. FTA estimates the industry's ADA paratransit operating costs at \$400M. E&PD program budget authority (BA) was \$58.7M.

FY94 Budget Outlays

There are no specific formula outlays for ADA; lifts, vehicles, and station renovations are combined with other transit eligible projects. ADA-related 1994 formula capital outlays were roughly \$150M. E&PD program outlays were \$58.7M.

FY95 Budget Authority

There are no specific appropriations for the ADA in transit. Probably, about \$220M in BA will be used to add lifts, purchase paratransit vehicles, and fund station renovations. E&PD BA was \$59.2M.

FY95 Budget Outlays

There are no specific ADA transit outlays; accessibility projects are combined with other eligible transit projects. In 1995, ADA-related capital outlays probably will be about \$180M; paratransit operating costs will run about \$500M; and E&PD program outlays will be about \$59.2M.

Non-Federal Funding

The FTA estimates the total industry ADA transit compliance cost at \$930M, of which roughly \$200M is funded from Federal capital grants to the industry. The remaining \$700M is funded from state and local sources; most of this amount supports the operating costs of ADA paratransit services. A 20% match for the E&PD programs comes from states or service providers.

Service Data

There are no reporting requirements for fixed-route systems on the number of trips provided to persons with disabilities. One-way bus and rail transit trips probably exceed 5 percent of all trips, or one-half billion annual trips. In 1994, over 30 million ADA paratransit trips were provided to eligible persons, according to data reported by agencies in their ADA paratransit plan update submissions. This annual reporting requirement may be eliminated in future, as part of the regulatory reform effort. The E&PD program has helped purchase 12,226 vehicles that providing millions of annual trips.

Federal/Non-Federal Roles

Federal and state governments provide funding grants to operators. Operators are usually county or city public agencies, but may be state agencies. The operators provide the bus, rail, and paratransit services. Federal and state agencies provide limited technical assistance and research efforts.

Policy Issues

A major issue for many cities involves the removal of non-disabled elderly from paratransit systems. Prior to ADA, 50% of paratransit patrons were able-bodied elderly who qualified for service based on age. Under ADA, they are no longer eligible for service and the costs of their carriage cannot be claimed as part of ADA implementation. Also at issue is the practice of client shedding by DHHS funded social service agencies onto public transit agencies' ADA mandated paratransit service. Many localities view ADA paratransit operating as an unfunded Federal mandate costing them roughly \$700M annually.

Contact Person

Robert W. Stout, Director of Regional Operations, Office of Grants Management, FTA (202) 366-1656.

No Funds in FY95

There is no FTA program with an appropriation authorization without funding in 1995.

Agency

Office of the Secretary

Program

AIR CARRIER ACCESS ACT Final Rule: Nondiscrimination on the Basis of Handicap in Air Travel and Federally Assisted Programs

Program Summary

In March 1990, DOT issued a final rule implementing the Air Carrier Access Act (ACAA) of 1986 to prohibit U.S. carrier discrimination against travelers with disabilities, consistent with the safe carriage of all passengers. It includes general provisions on accessible passenger services, information, carrier facilities, special personnel training and complaint resolution officers, and enforcement. Required access features on new or refurbished aircraft (as of April 1992 and dependent on seating capacity) include: movable armrests on 50% of aisle seats (planes w/30 or more seats); aisle wheelchairs (60 or more seat aircraft); cabin stowage space for one or more folding wheelchairs (100 or more seats) and fully accessible lavatories on twin aisle planes. ACAA rule definition of disability: A "qualified handicapped individual" is one who presents a valid ticket for flight, and meets nondiscriminatory contract of carriage requirements that apply to everyone.

Statutory Authority

Section 3.1 and subsection 404(c) of the Federal Aviation Act of 1956, 49 U.S.C. 1374(c).

Implementing Statute

14 CFR Part 382; 49 CFR Part 27

Service Benefits

Aircraft Access Status: As of year end 1994, DOT estimates about 800 aircraft with 30 or more seats (roughly 20% of the fleet) were equipped with movable armrests on 50% of aisle seats. All such aircraft should have such armrests by 2000. Few aircraft below 30 seats have armrests. Cabin wheelchairs are now provided on most planes with over 55 seats. About 200 new aircraft with over 99 seats have cabin stowage space for a folding wheelchair. Many existing larger aircraft also provide storage for such wheelchairs in coat closets. Accessible lavatories are required on new twin-aisle aircraft; about 15% are estimated to be so equipped to date.

Customer Services: All carriers, on request, supply passengers assistance in boarding and deplaning aircraft (over 29 seats) and transfers to connecting flights; priority cabin stowage of folding wheelchairs and other aids; help with meal preparation; stowage of battery-powered wheelchairs in baggage compartments and packaging spillable batteries. Some carriers offer incubators, stretchers, respirators and medical oxygen, at extra fees in some cases. Carriers should have Complaints Resolution Officers at all airports served to resolve issues on the spot, or supply information on DOT's complaints process.

Training: As of March 1992, carriers should have trained all existing personnel having public contact (including contractors) to full proficiency about DOT's regulations, proper handling of accessibility aids and appropriate response to the needs of travelers with disabilities. Carriers must continue to provide training to newly hired employees and contractors.

Consumer Guidance on ACAA Regulations: Since 1992, about 40,000 booklets, "New Horizons for the Air Traveler with a Disability," developed by DOT to help people understand their rights to accessible air travel, have been mailed to advocacy groups, the air travel industry, and the public. DOT also distributes a fact sheet summarizing the ACAA regulations.

Population Served

DOT cannot estimate the number of travelers served

Budget

None

Non-Federal Funding Sources

DOT issued a Final Regulatory Impact Analysis along with its final ACAA rule that estimated the national annual compliance cost of the rule to the aviation industry at roughly \$20 million (in 1990\$). In FY 1995, DOT plans to amend the rule to require carriers to provide accessible boarding equipment for commuter aircraft (with 19-29 seats), at an estimated cost of \$1 million to \$8 million annually.

Issues

DOT monitors air carrier compliance through complaints from the public and conducts follow-up investigations with carriers. Major complaint categories include improper handling of wheelchairs/batteries; denied boarding assistance, refusal of some carriers to supply medical oxygen on aircraft (not required by

DOT's rule) and inadequate training of personnel to comply with various provisions of the ACAA rule.

DOT has encountered delays in issuing a commuter aircraft boarding equipment rule to enable travelers in wheelchairs to board these aircraft. DOT is awaiting results of a Canadian government safety study of certain commuter aircraft lifts on the market that could impact our regulations.

Major Congressional Support:

Senator Robert Dole

Persons Responsible for Program Information:

Nancy Ebersole, Sr. Policy Analyst
Office of the Secretary, Phone (202) 366-4864

Robert Ashby, Deputy Asst. General Counsel for Regulations
Office of the Secretary, Phone: (202) 366-9306

Agency

Federal Highway Administration (FHWA)
Office of Motor Carrier Standards

Program Title

Handicapped Driver Waiver Program (HDWP)

Program Description

The FHWA administers the HDWP program for limb-impaired drivers through the Office of Motor Carrier's (OMC) Regional Directors. This program provides an opportunity for physically challenged drivers unable to meet the physical requirements of the Federal Motor Carrier Safety Regulations, to become medically qualified to operate commercial motor vehicles in interstate commerce. Upon satisfactory completion of a skill performance evaluation by an FHWA specialist, a driver is issued a "waiver of physical defects," signed by the OMC Regional Director. This serves as validation that the driver was evaluated and meets all requirements for waiver issuance.

Statutory Authority

FHWA is authorized by statute to establish minimum qualification requirements for drivers of CMVs. This authority was

DOT Baseline Inputs for DPC Policy Review

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transferred from the ICC to DOT in 1966 with enactment of the Department of Transportation Act (49 U.S.C. App. §1655(e)(6)(C), repealed Pub. L. 97-449, 96 Stat. 2413, 2443, §7(b)(1983) (an act to recodify without substantive change).

The Congress provided DOT with alternate regulatory authority by enacting the Motor Carrier Safety Act of 1984 (49 U.S.C. App. §2501-2520 (Supp. III 1985)). This Act directed DOT to set minimum safety standards to ensure, inter alia, "the physical condition of operators of CMVs is adequate to enable them to operate such vehicles safely..." 49 U.S.C. §31136(a)(3).

Implementing Statute

Physical qualification regulations for drivers in interstate commerce are found at 49 CFR 391.41. Instructions to health care professionals for performing physical exams of drivers are at 49 CFR 391.43. Procedures for waiver of certain physical defects are found at 49 CFR 391.49.

Type of Service or Benefit Provided

DOT qualifying standards cover 13 areas directly related to the driving function. A person's qualification to drive is determined by a medical examiner knowledgeable about his/her functions and whether a specific condition would interfere with his/her ability to operate a CMV safely. Section 391.41(b)(1) cites a person as physically qualified to drive a motor vehicle if there is (1) no loss of a foot, leg, hand, or arm, or if he/she is granted a waiver pursuant to §391.49; (2) has no impairment of: (i) a hand or finger which interferes with prehension or power grasping; or (ii) an arm, foot, or leg interfering with performing normal tasks associated with operating a vehicle; or has a waiver granted under §391.49.

The HDWP benefits drivers unable to meet physical requirements under Section 391.41(b)(1), but are otherwise qualified, to medically qualify to operate CMVs in interstate commerce.

Number and Demographics of Individuals Served

There are about 1,000 physically disabled drivers in the HDWP, with disabilities including total/partial amputations of arms or legs; disarticulation of ankles or knees; some have multiple problems (birth defect affecting a hand, foot and ankle).

Budget Authority and Outlays for FY94 and FY95

Not applicable

DOT Baseline Inputs for DPC Policy Review

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Funding Provided by Non-Federal Sources

Not applicable

Nature and Periodicity of Data Collection

The 10 OMC Regional Offices maintain records on HDWP activities for their region. The type of data maintained includes: number of waiver holders; approximate number of miles driven by waived drivers, and the number of reportable accidents.

Federal and Non-Federal Roles in Administering the Program

OMC's Regional Directors administer HDWP. While some States express interest in involvement in program administration, only two states participate in HDWP Skill Performance Evaluation.

Program Manager

Mr. James E. Scapellato, Director, Office of Motor Carrier Research and Standards, 202-366-1790

Agency

Federal Highway Administration (FHWA)
Office of Motor Carrier Standards

Program Title

Medical Waiver Study Programs (Vision and Diabetes)

Program Description

FHWA initiated these programs to accommodate persons unable to meet the driver physical qualification requirements of the Federal Motor Carrier Safety Regulations (FMCSRs); to be consistent with the spirit of the ADA and provide DOT with on-road performance data that would shed light on the validity of the existing vision requirements.

The Vision Waiver Study Program began in July 1992. Waivers were granted to individuals with less than standard vision in one eye, who were able to produce medical evidence of their visual condition, medical opinions as to sufficient vision to operate a CMV, proof of CMV driving experience (with the visual deficiency) for at least three years immediately preceding the application, and verifiable motor vehicle records showing a "clean driving record." In addition, waived drivers had to agree to an annual eye examination and certain

reporting requirements. The deadline for submitting applications was December 31, 1992.

The Diabetes Waiver Study Program has been underway since July 29, 1993. The waiver is valid for a period of 3 years unless revoked for failure by the driver to comply with the conditions of the waiver, or until resolution of a concurrent rulemaking action, whichever occurs first. To obtain a waiver, an applicant must have at least 3 years of recent experience driving a CMV while using insulin to control his or her diabetes, a safe driving record, and must be recently examined by a board-certified/eligible endocrinologist and an ophthalmologist. The deadline for submitting applications for waivers was April 30, 1994.

Statutory Authority

The statutory authority for this program is the same as that cited for the HWDP program described above.

Type of Service or Benefit Provided

The qualification standards cover 13 areas directly relating to driving functions. Most of the standards require a judgment by the medical professional knowledgeable about the driver's functions as to whether a particular condition would interfere with his/her ability to operate a CMV safely. In the case of vision, hearing, insulin treated diabetes and epilepsy, the current standards are absolute providing no discretion to the examining physicians. A person's qualification to drive is determined by a medical examiner knowledgeable about his/her functions and whether a particular condition would interfere with the ability to operate a CMV safely.

Section 391.41(b)(3) states that a person is physically qualified to drive a motor vehicle if that person has no established medical history or clinical diagnosis of diabetes mellitus currently requiring insulin for control. Section 391.41(b)(10) states a person is physically qualified to drive a motor vehicle if he/she has distant visual acuity of at least 20/40 (snellen) in each eye without corrective lenses, or visual acuity separately corrected to 20/40 (snellen) or better with corrective lenses, distant binocular acuity of at least 20/40 (snellen) in both eyes with/without corrective lenses, field of vision of at least 70 degrees in the horizontal meridian in each eye, and ability to recognize colors of traffic signals/devices of standard red, green, and amber.

The medical waiver study programs provide an opportunity for physically challenged drivers, who do not meet the physical requirements under Sections 391.41(b)(3) and 391.41(b)(10),

but who are otherwise qualified, to become medically qualified to operate CMVs in interstate commerce.

Number and Demographics of Individuals Served

Vision - The Vision Waiver Program received 3,700 applications. Waivers were issued to 2685 drivers. About 2400 drivers are currently holding vision waivers. Visual disorders and impairments include amblyopia (lazy eye), strabismus, cataracts, chorioretinitis, optic nerve damage and monocular vision, with amblyopia being the most common impairment in the waived drivers. The majority of the vision waiver drivers are between ages 31 and 65.

Diabetes - About 450 applications were received. As of January 31, 1995, 177 diabetes waivers have been issued. The balance are in various stages of processing. All waiver holders require insulin to control their diabetes. A majority of the diabetes waiver drivers are ages 31 to 60.

Budget Authority and Outlays for FY94 and FY95 (Research Support)

FY94 - \$650,474.

FY95 - \$500,000. (Anticipated but not obligated)

Funding Provided by Non-Federal Sources

None

Nature and Periodicity of Data Collected on Services/Benefits Provided and Populations Served

Once a driver is granted a waiver, he or she was, and is, required to submit monthly driving reports and submit the results of an annual eye exam to the FHWA. Also, the waived drivers must notify the FHWA of accidents and/or citations in their commercial vehicles. The FHWA periodically verifies the waived drivers' reported accidents and citations through each driver's state motor vehicle record.

Roles of Federal and Non-Federal Entities in Administering the Program

The medical waiver program is administered by the Office of Motor Carrier Research and Standards and supported by a contractor.

Other Program Information Important for Policy Decisions

Vision - On August 2, the U.S. Court of Appeals for the D.C. Circuit ruled against the FHWA, with regard to the required

safety finding necessary for the issuance of waivers. Specifically, the Court ruled that the FHWA failed to meet the two-pronged waiver test established by the Motor Carrier Safety Act of 1984. Consequently, the Court concluded that the FHWA's adoption of the waiver program was contrary to law, and vacated and remanded the rule to the agency. The Advocates for Highway and Auto Safety brought the action against the FHWA.

As a result of the adverse court decision discussed above, the FHWA published in the Federal Register on October 6, 1994, a "Notice and Request for Comments," proposing continuation of the program until March 1996.

On November 17, 1994, a "Notice of Final Determination and Change in Research Plan," was published in the Federal Register allowing the program to continue and existing 2,398 drivers to drive until March 31, 1996. As part of the research, the FHWA plans to conduct a public hearing in Washington, DC, during the summer of 1995 to gain a broader perspective of the public's view point concerning studies, data and experiences to enhance the agency's knowledge on performance-based vision requirements.

Diabetes - The FHWA plans to pursue research to arrive at appropriate physical qualification requirements for this group of affected drivers for use in the evaluation of commercial drivers in interstate commerce. The Office of Motor Carrier Research and Standards has met with contracts and procurement officials and plans to have announcements for diabetes research by March 1995.

Program Manager

Mr. James E. Scapellato, Director, Office of Motor Carrier
Research and Standards, 202-365-1790

Agency

National Highway Traffic Safety Administration

Program Title

Work Group on Automotive Safety for Persons with Disabilities

Program Summary

This Group, established in April 1994 and composed of 17 members from all NHTSA Offices, works with the Society of

Automotive Engineers, Adaptive Devices Standards Committee; Association of Driver Educators for the Disabled, and National Mobility Equipment Dealers Association to collect and evaluate data on adaptive automotive equipment usage; crash test results for modified autos, and the annual number of accidents involving such vehicles. Long range program goals are to improve drivers' knowledge about the use of adaptive equipment, and to assess possible equipment safety issues.

Statute

Not applicable

Service/Benefit

Program achievements include: (1) issuance of a NHTSA Consumer Advisory against using a spanner bar over an air bag; (2) adding an adaptive equipment category to the National Accident Sampling System forms; (3) data requests to national groups regarding the adaptive automotive equipment user population, crash test results and the annual number of crashes involving modified vehicles; (4) on-site assessment of a disabled driver evaluation and vehicle modification program, (5) participation in the Virginia "Working Group on Vehicle Modification for People with Disabilities: Standards and Safety Review" sponsored by the Virginia Center for Innovative Technology, and (6) proposal of a potential DOT rule for platform lifts on buses.

Population Served

In 1992, the Center for Disease Control estimated the number of adaptive device users in the U.S. at 211,000.

Budget Authority/Outlays

Not applicable.

Policy Issues

To be determined as part of the long range goal of assessing potential safety issues involving adaptive devices.

Contact Person

Ms. Gayle Dalrymple, NHTSA, Office of Rulemaking,
(202) 366-5559

DOT Baseline Inputs for DPC Policy Review

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Agency

National Highway Traffic Safety Administration (NHTSA)

Program Title

Rulemakings Concerning Motor Vehicle Safety Standard Issues Impacting on Drivers and/or Passengers With Disabilities.

Program Summary

NHTSA's Office of Rulemaking is responsible for the agency's regulatory activities involving the Federal motor vehicle safety standards (FMVSS) for which DOT has statutory responsibility. Current regulatory activity involves issues concerning passengers and drivers with disabilities under the following FMVSS: Standard 209 (Occupant Crash Protection), Standard 213 (Child Seating Systems), and Standard 222 (School Bus Passenger Seating).

Authorizing Statute

The National Traffic and Motor Vehicle Safety Act of 1966.

Service/Benefit

Safety information, research, and where appropriate, modifications in regulatory content.

Population Served: UnknownBudget Authority/Outlays

Covered by itemized presentation of related activities as follows:

Standard 213: Current NHTSA activity and outlays related to child safety seat concerns involving special needs children are described in the next program category administered by the Office of Traffic Safety.

Standard 222: NHTSA provided the University of Virginia with \$100K for FY94 to support development of an ANSI/RESNA (Rehabilitation Engineering Society of North America) standard for dynamic load requirements for wheelchairs.

Contact Person

Gayle Dalrymple, NHTSA, Office of Rulemaking, (202) 366-5559

Agency

National Highway Traffic Safety Administration (NHTSA)

Program Title

National Traffic Safety Programs

Program Summary

This program involves outreach and funding assistance to state and local safety personnel to provide technical expertise in the area of traffic safety program activities and components.

Statute

Highway Safety Act of 1966 (23 U.S.C.), Section 403, Highway Safety Research and Development.

Service/Benefit

Federal program funds enable the provision of nationwide traffic safety research and development activities to be conducted by public or private agencies, institutions and individuals.

Population Served: UnknownFY94 Budget Authority

The Office of Traffic Safety Programs has a cooperative agreement with the Easter Seal Foundation that provides them with funds to develop, implement, and promote a curriculum for hospital based education and learner programs that include a focus on special needs children. The Kids Are Riding Safe program (KARS and Special KARS) was developed by physical and occupational therapists, doctors and parents. The curriculum promotes use of child safety seats and responds to parental concerns.

FY94 and FY95 Budget Outlays

In FY 92-94, NHTSA allocated \$50,000 for Easter Seals to develop, implement, and pilot test the curriculum. This is the final year of funding for this project.

FY 95 funding to Easter Seals of \$10,000 provides the resources for promoting the program.

Contact Person

Ms. Cheryl Neverman, NHTSA, Office of Traffic Safety Programs
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Agency

Office of the Secretary

Program Title

People with Disabilities Program

Short Description

DOT's People with Disabilities Program monitors compliance of the agency to Section 504 of the Rehabilitation Act of 1973, as amended, and the Americans with Disabilities Act, where applicable. In particular, the Program ensures that no DOT applicants or employees are not excluded from participating in, denied the benefits of, or subjected to discrimination under any DOT conducted program or activity or any program or activity receiving financial assistance from the Department. Program funding is included in DOT's budget for staffing.

Authorizing Statute

Section 504 of the Rehabilitation Act of 1973 (29 USC 794), as amended 1978 and the Americans with Disabilities Act of 1990/

Citations for Implementing Regulations

49 CFR Part 28 "Enforcement of Nondiscrimination on the Basis of Handicap in Department of Transportation Conducted Programs"

Type of Service or Benefit Provided

The People with Disabilities Program Manager:

Provides counseling, services and information to applicants or employees with disabilities, evaluates problems and works with applicants/employees and supervisors/managers to resolve them.

Maintains a resource file for services, contacts, and organizations to assist persons with disabilities;

Provides brochures and information to assist management in the recruitment, advancement, and accommodation, and assistance of applicants and employees with disabilities.

Provides training for employees and managers to develop agency wide disability awareness.

Assures that all employees with disabilities receive full consideration for vacancies and training opportunities and recommends training program modifications if needed to accommodate employees with disabilities.

Assists in the planning and development of the next fiscal

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year's compliance activities, including beginning on site reviews, for Title VI grant recipients.

Number and Demographics of Individuals with Disabilities Served

3,285 DOT employees have voluntarily identified themselves as having disabilities.

Budget Authority for FY94

\$228,500 or \$100.00 per disabled employee benefitted

Budget Outlays for FY94

\$228,500 or \$100 per employee benefitted

Budget Authority for FY 95

Same as FY94

Budget Outlays Estimated for FY95

Same as FY94 estimates

Funding Provided by Non-Federal Sources

None

Nature and Periodicity of Data Collected on Services/Benefits Provided and Populations Served

Numbers provided by DOT's Consolidated Personnel Management Information System, which is continually updated. Services and benefits are tracked by People with Disabilities Program Manager.

Role of Federal and Non-Federal: Entities in Administering the Program

Administration of the program comes from the Work Force Diversity Special Program Division.

Name, Position and Telephone Number of Contact Person Responsible for Program

Kenneth Tiktin, Program Manager
Work Force Diversity Special Program Division
Office of the Secretary
Phone: (202) 366-5840