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1 including an Honorary Doctoral Degree from his alma
2 mater, the University of Maryland.

3 We are deeply indebted to Congressman Hoyer
4 for helping all of us to understand that democracy in
5 America is meant to be inclusive, not exclusive, open
6 and not closed. In his own words, "Our political
7 processes should not draw a circle to keep people
8 out, but should widen the circle to contain
9 everyone."

10 It is a great honor and personal privilege
11 for me to introduce an outstanding public servant,
12 Congressman Steny Hoyer.

13 CIVIL RIGHTS FOR PERSONS

14 WITH DISABILITIES IN THE UNITED STATES

15 MR. HOYER: Thank you very much, Britt, for
16 that very, very kind introduction. I am very pleased
17 to be with all of you. I am even more pleased to
18 have been right on time. We had somebody downstairs
19 in the lobby as I walked through, just about to get
20 on the phone, saying, "Where's Hoyer?" And she was
21 very pleased to see Hoyer walk through the door, so I
22 have made somebody's life a little easier today, so

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1 we've had a success.

2 I am also pleased to be here at the podium
3 with my good friend, Lex Frieden. I've gotten a
4 number of articles recently about the success of the
5 American with Disabilities Act. Lex Frieden ought to
6 be in all of those articles.

7 I want to assure of that fact, for over the
8 years he has been in the leadership of this effort,
9 which culminated in the House's adoption of a
10 legislation which is landmarked, which I'm going to
11 discuss, but Lex's leadership, Lex's lobbying, Lex's
12 commitment, really made a tremendous difference.
13 Congratulations to you, Lex, for all the success that
14 you've had.

15 I also want to say how pleased I am to be
16 here with members of the faculty and staff and
17 leadership of the University of Maryland. As you
18 heard, I am a graduate of the University of Maryland.

19 I will tell you a brief little story. When
20 I was seventeen and at Suitland High School, a senior
21 in high school, I wanted to go to Princeton
22 University. I thought I wanted to go to an Ivy

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1 League school. I thought that would give me a good
2 send-off in life and, in fact, I did not go to
3 Princeton. I got a scholarship to Lafayette, which
4 is a sort of an Ivy League school. I know the people
5 in Lafayette are going to get very upset with me for
6 saying "sort of," but any event, the fact of the
7 matter is I needed an awful lot more money to go to
8 Lafayette or to go to Princeton or whatever, and I
9 didn't have that kind of money and my family had no
10 money, so I went to the University of Maryland.

11 For the first year I thought that it was
12 really one of the worst things that had happened to
13 me in my life up to that point. I will tell you that
14 it's funny how things happen. I am a great believer
15 in what the Bible has to say and it says in there
16 that -- some of you may know -- that "All things work
17 together for good for them that love God."

18 Throughout my life, I have seen that occur
19 because one of the most important things that ever
20 happened to me, one of the most significant things
21 that ever happened to me, one of the most life-
22 forming, career-forming and -assisting things that

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1 ever happened to me, was that I went to the
2 University of Maryland.

3 And I have had, over the years, a
4 particularly close relationship, but I want to tell
5 you, as an alumnus of that school, as somebody who
6 has, as a State Senator, as a Member of the State
7 Board for Higher Education, as a Member of Congress
8 working very closely with the University, how proud
9 we are that our newly-inaugurated -- now, he's been
10 acting president for some period of time, but just a
11 few weeks he was officially invested with all the
12 powers pertinent to that office, it says here, in
13 fine print.

14 And Britt Kirwan is going to be one of the
15 great educational leaders in our country and
16 internationally and we're very pleased to have him
17 and I was pleased to be introduced by him.

18 I am pleased to be with all of you and I
19 want to thank Dr. Burke and his colleagues for
20 inviting me to participate.

21 You're fortunate, in my opinion, to be
22 holding this conference here as the United States is

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⁵³
the Americans with Disabilities Act

1 on the verge of enacting ~~we act like we've enacted~~
2 it, but we really haven't. We still have a couple of
3 more steps to go. We need to get conference reports.
4 Both Houses are going to pass that conference report,
5 and then, importantly, of course, for our
6 international visitors, as I'm sure all of you know,
7 the President of the United States has to sign it.

8 He is a very, very important player in the
9 legislative process, notwithstanding his
10 protestations to the contrary that you may read from
11 time to time.

12 The legislation which I'm going to discuss
13 ~~and which you have discussed~~ is, in the words of
14 almost every person who has been involved in civil
15 rights legislation through four decades in this
16 nation, the most important civil rights act that we
17 have passed in America since 1964.

18 Indeed, if we pass the Civil Rights Act of
19 1990, Ralph Neas, who is the executive director of
20 our coalition which fights for civil rights in this
21 nation, ~~he~~ says that it may well be the most
22 important year for civil rights in the history of

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1 this country. Every time he tells me that, I wonder
2 about the Emancipation Proclamation and other similar
3 documents. He may have overstated by just a little
4 bit, but in any event, it is obviously important, and
5 I am pleased to have played some role in that effort.

6 ~~As Britt Kirwan has told you,~~ I came of
7 age, at least politically, ~~and into adulthood~~ in the
8 era of John ^{F.} Kennedy ~~when he ran for President of the~~
9 ~~United States.~~ ~~And he did come to the University of~~
10 ~~Maryland and he talked about energy and enthusiasm~~
11 ~~and idealism.~~ Many of you, ~~know~~ in our own country,
12 ~~but~~ ^{and} throughout the world, heard his call to public
13 service and commitment to make life better for not
14 only our ^{who} ~~own~~ citizens in this country but for
15 citizens around the world, ~~in a joint effort.~~

16 I was very enamored and impressed and
17 motivated by that call. ^Q ~~He did not say at the~~
18 ~~University of Maryland, but he did say at another~~
19 ~~time~~ ^A about children who were handicapped, ~~we~~ ^{we now} use the
20 term "disabled," but "handicapped children" was the
21 phrase at that point in time, [↑]

22 ~~He said, this, that~~ "Although these children

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1 are the victim of fate, they shall not be the victims
2 of our neglect." I think that, ~~frankly~~⁹, ought to
3 apply to every citizen, abled or disabled, black or
4 white, male or female, rich or poor; that persons in
5 our societies wherever we find them ought not to be
6 the victims of our neglect.

7 Last June 15th, when the sponsors of the
8 ~~Americans with Disabilities Act~~ ^{and when the sponsor}
9 of the Americans with Disabilities Act ^{Tony Coelho,} decided to
10 leave the Congress of the United States ~~Tony Coelho,~~

11 ~~One~~ of the most able Members of the Congress of the
12 United States and one of the most able politicians in
13 America, ^{he} turned to me -- I was a close friend and
14 also a close ally in the effort to pass the Americans
15 with Disabilities Act -- and asked me to shepherd
16 that bill through the House of Representatives.

17 I might say that Tony Coelho had a special ^{reason}
18 for being a very strong sponsor. He has epilepsy.
19 There were some who historically would have said he
20 was disabled. Any of you who know Tony Coelho, I
21 think the last word that you would apply to Tony
22 Coelho is "disabled" in any sense of the word.

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1 However, prejudice and ignorance had shut
 2 him out. In fact, he had wanted to be a priest and
 3 had gone to seminary for a year and they had said,
 4 when they found out that he had epilepsy, "You cannot
 5 be a priest." Their focus, of course, was on the
 6 "dis" rather than the "ability." Their focus was on
 7 the prejudice rather than the knowledge of
 8 disability.

9 Over the months that I worked on the
 10 Americans with Disabilities ^{Act} in the Congress, I
 11 learned. I learned that ignorance, prejudice and
 12 misconceptions are discrimination, be it based on
 13 race, sex, national origin, religion or disability.

14 I know there are some of you ^{here today} from some of
 15 the central European nations ^{as well as} and other nations of the
 16 world, ~~as well,~~ and I understand there is a
 17 representative here ^{from Poland, Lech Wal} ~~of Solidarity~~ ^{SP?} ~~Lech Walensa~~ gave
 18 one of the most compelling speeches that I have ^{ever} heard
 19 given to a Joint Session of Congress, ~~and~~ he was
 20 joined shortly thereafter in similar sentiments by
 21 Vaclev Havel, the poet-philosopher-president of
 22 Czechoslovakia.

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1 ^{these men}
2 Both of ~~them~~ had a common theme and one of
3 those themes was that the words of Thomas Jefferson,
4 as incorporated in the Declaration of Independence,
5 were some of the most compelling ^{ideas} for those emerging
6 nations as they seek to make their countries more
7 open, more democratic, more free, both in the
8 political sense and in the economic sense. Thomas
9 Jefferson said, "We hold these truths to be self-
10 evident, that all men are created equal, endowed by
11 their Creator" -- not by the state -- "endowed by
12 their Creator" -- a higher being than the political
13 state -- "with certain unalienable rights and among
14 these are life, liberty and the pursuit of
15 happiness."

15 I and my colleagues, ^{and} as I'm sure many of
16 you have learned that the experience of the disabled
17 in one of the nation's of the earth, which Havel and
18 Walesa both said, focused on individual opportunity
19 and rights, unalienable rights.

20 ^o
21 However, even in ~~that~~ nation so perceived,
22 ^{have} I learned from Lex Frieden and thousands of others
 that ~~that~~ ^o was not the reality of daily life in

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the persons with disabilities is not focused on individuals opportunity and rights.

1 American And, as a matter of fact, as I speak about
 2 those thousands, not one of them was more
 3 influential, more dedicated, more effective in the
 4 advocacy of the interests of the disabled and of all
 5 America, than Justin Dart, who has just come into the
 6 room, ~~My~~ good friend, Justin, I'm glad to have you
 7 here, and I'm honored by your presence, sir.

8 I ^{have} also learned in the course of talking to
 9 people who are challenged daily ^{by a disability} about reasonable
 10 accommodation. Now, all of us make reasonable
 11 accommodations every day. ~~Britt makes it to his~~
 12 ~~staff.~~ I make it to my staff, and our staffs make it
 13 to us. There are vagaries of difference in each of
 14 us. You make it to your children. You make it to
 15 your spouses. You make it to your fellow workers.
 16 We all make reasonable accommodation. ^S

17 ~~And~~ We learned that people with
 18 disabilities can, in fact, do an awful lot, very
 19 much, ~~most~~, in fact, if given the opportunity and
 20 ~~sensitivity with~~ reasonable accommodation. I
 21 recognized, as did my colleagues, the parallels ^{between} with ~~the~~
 22 ~~types of discrimination that Americans are more~~ / ~~sketch~~

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1 ~~get~~ familiar with, ^{and} the discrimination based on physical
2 appearance, ^{and} ~~or on~~ the belief that all people with a
3 disease like epilepsy will have uncontrollable
4 seizures ^{or} ~~and~~ that some people hear the world in a
5 different way.

6 It is no different, I ^{have} learned and my
7 colleagues ^{have} learned, than the assumption that a
8 different skin color means one's talents and
9 abilities are inherently different. My learning
10 experience, ~~as I've told you,~~ was not unique. In
11 fact, I believe that the process ^{that} Members of the House
12 of Representatives went through in learning about the
13 needs of the disabled while considering this bill,
14 greatly contributed to our victory last week and the
15 403-to-20 vote for passage ^{of ADA.} ~~because~~ Each Member of
16 the Congress in one way or another shared the
17 experience of education during consideration of this
18 bill.

19 One of the most important results of the
20 ADA and the intensive lobbying effort that was put on
21 by scores, as I have told you, of dedicated
22 individuals with disabilities, was the education of

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1 Members of Congress, and I would amplify that, the
2 education of advocates and opponents.

3 Now, there were really no opponents of ADA.
4 Nobody would ever say they opposed the Americans with
5 Disabilities Act. It's just some changes they wanted
6 to make. Some were more extensive than others, you
7 understand, but there were no opponents of this
8 legislation.

9 They learned as well and that far more than
10 any hearing, fact sheet or forestatement, that
11 learning process, that heightening of consciousness
12 which has been so much a part of every civil rights
13 movement, whether it was the heightening of
14 consciousness in Birmingham by that stark television
15 portrayal of the dogs of Bull Connor confronting the
16 civil rights marchers in Birmingham, the
17 incarceration of Martin Luther King, or whether it
18 was the heightening of consciousness in the women's
19 movement in America, where it was made crystal-clear
20 that, yes, in fact, we discriminated badly against
21 those who were females in our society.

22 We had to raise our consciousness. One of

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1 the things that has happened during the consideration
2 of this legislation over the past four years has been
3 the raising of consciousness. The Members saw and
4 heard from people with disabilities who explained to
5 them their needs, their rights to equality and the
6 effective ways to achieve that end.

7 Although we had not done so previously, we
8 learned to look to the world around us from a
9 different perspective, and saw that it was
10 inaccessible to far too many of our citizens. And it
11 is that education process that must be continued in
12 the coming months, in my opinion, in order to make
13 the Americans with Disabilities Act a successful law
14 in this nation.

15 As far as the result of that effort, in the
16 coming years disability will not dictate and define
17 an individual's course of life, at least
18 theoretically. And it's the course of life that
19 persons with disabilities that this bill is designed
20 to address. The ADA is a comprehensive bill which
21 encompasses all facets of life.

22 It is not simply an employment bill, but it

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1 does protect against discrimination in employment.
2 It is not simply a transportation bill, although it
3 ensures that our nation's transportation systems,
4 public and private, will be accessible. It is not
5 simply a telecommunications bill, although the ADA
6 will finally fulfill the wish of Alexander Graham
7 Bell and provide that the nation's communication
8 system is of some use -- maximum use, hopefully --
9 both to the hearing- and speech-impaired.

10 And finally, it is not solely a public
11 accommodations bill, although it does provide that
12 new buildings will be built accessibly and that our
13 restaurants, movie theaters, doctors' offices,
14 pharmacies, hotels and stores and other places of
15 public accommodation will no longer be able to post
16 signs saying, "Disabled need not enter," for the
17 Americans with Disabilities Act is a law over time to
18 change the face of America and to truly bring the
19 disabled, who have been left out or shut out of so
20 much of American life, come into, invited into,
21 encouraged to come into the mainstream of American
22 cultural, economic, social, educational and traveling

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1 life.

2 The ADA extends civil rights protections to
3 people with disabilities in employment, public and
4 private transportation, public accommodations, state
5 and local government, and telecommunications. The
6 ADA, as I'm sure all of you know, is based -- as Lex
7 Frieden, the former executive director of the
8 National Council on Disability, well knows, and
9 perhaps has already told you -- on the
10 recommendations of that Council, a bipartisan group
11 of 18 persons appointed some years ago by President
12 Reagan.

13 This was truly a bipartisan effort,
14 strongly supported by the President of the United
15 States, whose leadership was critical to the
16 overwhelming timely passage of this legislation.

17 I might parenthetically say that I refer to
18 it as timely, although it is effectively centuries
19 late, as was the 1964 Civil Rights Act. However, it
20 is always timely to correct errors of discrimination.
21 In that sense it is timely.

22 The Council found, after extensive and

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1 exhaustive investigation, that Americans with
2 disabilities faced discrimination in almost every
3 facet of their lives, including employment, housing,
4 transportation, communications and recreation. As a
5 result, people with disabilities are more likely to
6 be poor, are more likely to be unemployed and are
7 more likely to be receiving public assistance.

8 However, they are less likely to travel,
9 are less likely to attend sports and leisure
10 activities, less likely to go to the grocery store
11 and other public accommodations. In fact, people
12 with disabilities are less likely to participate in
13 virtually all aspects of mainstream activities of
14 American life.

15 The solution, we determined, was through a
16 number of sections that address each area
17 specifically. The employment section prohibits
18 discriminations against qualified individuals. It
19 was very difficult to communicate that concept, very
20 frankly, at the outset, that the Americans with
21 Disabilities Act is not telling, nor should it tell
22 employers to hire people who are not qualified to do

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1 the job, the task, at issue.

2 It simply says, however, that those who are
3 qualified ought not to be shut out for some arbitrary
4 distinction which does not adverse impact on their
5 ability to perform the essential functions of the
6 task that the employer needs doing. Very important
7 concept.

8 It is a concept that we know full well and
9 accept full well, if you're dealing with blacks,
10 national minorities, other minorities, women, other
11 discriminated against groups, that arbitrary,
12 capricious distinction was not relevant and we found
13 it not to be relevant. We are now saying the same
14 thing about those who have disabilities, that unless
15 it is relevant to the performance of the job, you
16 cannot, must not, and it is un-American, immoral and
17 bad business to discriminate against abled people.

18 The employer, therefore, is required to
19 make a reasonable accommodation to permit them to be
20 able to do so if it is not unduly burdensome.

21 It further provides that employment tests
22 or qualification standards cannot screen out people

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1 with disabilities unless those requirements can be
2 shown to be job-related and related to business
3 activity. Once again, emphasizing -- we are saying
4 no to arbitrary and capricious discrimination.

5 As I have already mentioned, the law
6 provides that our nation's public and private
7 transportation systems must be accessible. Let me
8 emphasize that throughout the ADA the highest
9 standards of accessibility are reserved for new
10 vehicles and new structures.

11 We understand that there is a cost
12 relationship here. We understand that we needed to
13 be reasonable. We understand that although this bill
14 is late, it is nevertheless in most respects
15 perspective. We are asking people to accommodate the
16 future. We are asking people to plan for the future.
17 We know that that will very substantially minimize
18 the cost particularly in the transportation area.

19 Thus, under the ADA, all new vehicles
20 purchased, including public buses and commuter light,
21 rapid and interstate rail cars must be readily
22 accessible to and usable by those with disabilities.

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1 In fact, there was a very -- one of the most
2 controversial amendments on the floor of the House
3 dealt with that issue, and they were soundly -- there
4 were two such amendments -- soundly defeated by the
5 full House of Representatives, rejecting the concept
6 of separate but equal, as that had been rejected in
7 1954 with respect to education in Brown v. Board of
8 Education.

9 New buildings also must be built accessible
10 and major renovations to a primary function area, as
11 a building must include making the path of travel
12 accessible. So, again, that we will be sensitive to
13 including the disabled, particularly the mobility
14 impaired, in areas where they have difficulty
15 accessing, but the major function of that particular
16 business or public accommodations is located in that
17 particular area.

18 The sum of all these provisions is that one
19 day soon lives will be dramatically changed and
20 enhanced, that the children who have gone through
21 school under the Education of the Handicapped Act
22 graduate and are ready to move into the world, we

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1 will be able to meet their justified expectations.

2 We will no longer be a society which says,
3 "Your work is not valued." "Your presence at our
4 sports events, in our stores and at our public
5 entertainments is not welcomed." "And this public
6 bus, funded with public funds is not for all our
7 citizens." We have rejected all of those conclusions
8 in law and policy.

9 And perhaps the most vital element of the
10 ADA is its totality. As I have told you at least two
11 or three times already, it addresses all facets of
12 life. Each part of the ADA is intrinsically linked
13 to one another, as the various modes of
14 transportation, communication, access to buildings,
15 employment opportunities are inextricably intertwined
16 in our own lives.

17 Perhaps the most vital element is this
18 totality, which you will make a reality. It also
19 recognizes that people with disabilities do not go to
20 the grocery store as I might. -- I think I got a
21 page, or left out a sentence there. I did. Let me
22 go back, because I left out a sentence, because that

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1 doesn't flow at all.

2 I have a reasonable accommodation that I'm
3 too vain to use sometimes, which is why they do the
4 print a little bigger, but sometimes I mess up. You
5 will make a reasonable accommodation in not throwing
6 me off the stand right away.

7 As I was saying, it is a comprehensive bill
8 which recognizes that two-thirds of the working aged
9 disabled do not work. Think of that. In a society
10 where we are on the verge of having a labor shortage,
11 we have about 8, 9, 10 million -- I guess we don't
12 know the specific number, but it's a very significant
13 large number -- two-thirds of that number does not
14 work, not because they don't want to work, not
15 because they don't have abilities with which they
16 could perform certain tasks that our society needs
17 doing, but because our society has not made the
18 accommodation to include them in, to our economic
19 detriment.

20 A recent Lew Harris poll found that 28
21 percent -- that same poll -- of the non-working
22 disabled cited the lack of accessible transportation

1 as the reason they did not work. Again, one of the
2 reasons why it was so important to have a very broad
3 based treatment of this whole challenge, because
4 without the ability to get to work, having a job is
5 somewhat of a meaningless right.

6 It also would have been ludicrous to have
7 set in place a national policy which did otherwise.
8 It would have made no sense to have guaranteed equal
9 opportunity for a job but to have no protections to
10 get into the building in which that job was located.

11 All right. I've told you that we're just
12 about on the verge of passing a major piece of civil
13 rights legislation which reaches out its hand, opens
14 its door and puts down the welcome mat. Now, what do
15 we do?

16 The answer I suggest to you and the reason
17 that this conference is so important, not only for
18 those of us in the United States but for those of you
19 from other countries of the world, it is now a
20 responsibility of each of us to make this policy a
21 reality for the disabled. Nothing happens simply
22 because Congress says it's going to happen. It

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1 happens because people are willing and enthusiastic
2 about carrying out that policy.

3 To our friends from other countries who may
4 not have accomplished an ADA at this point in time,
5 we invite you, we urge you, to join us in this action
6 that we have taken because as the world shrinks, as
7 we travel from one country to another much more
8 easily, as we become a much more integrated economic
9 unit as a world economy, as opposed to individual
10 economies, it is important not only that the citizen
11 who lives next door to me in District Heights,
12 Maryland can get downtown to Washington, D.C. to work
13 on transportation, it's also important that they can
14 get around, perhaps, in London or in Moscow or in
15 Tokyo or in Soweto.

16 Wherever they may be, it is important that
17 we have universal access for the disabled just as we
18 have universal access for most of us in this room who
19 do not have specific challenges which need some
20 reasonable accommodation.

21 The world is opening up like never before.
22 In some respects, ADA is glasnost and perestroika for

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1 the disabled. We have Mr. Gorbechov still here, on
2 the west coast. He's been with us on the east coast
3 for some period of time and he's going to leave, I
4 guess, later today or maybe tomorrow. The walls
5 which stopped the flow of ideas and people are
6 crumbling and so should the barriers to the disabled
7 the world over.

8 Many in the last years have come to
9 Washington to find out about this landmark, nearly
10 unprecedented legislation that the Congress is
11 considering and we will now pass. The United States
12 will soon be, I am told, the first nation to adopt a
13 comprehensive national policy of non-discrimination
14 against people with disabilities.

15 I say "I'm told," because obviously I have
16 not done the research and maybe in one of the
17 countries represented here you have significant
18 legislation from which we can learn, or public
19 policies from which we can learn. One of the great
20 virtues of the explosion of information exchange in
21 the world is that we can better learn from one
22 another.

1 We are looking forward to welcoming many
2 international scholars at the University of Maryland
3 at the Archives Building where we will be containing
4 much of American's experience from which perhaps you
5 can learn and then we can in turn learn from your
6 scholars who visit here. So that we ought to
7 exchange information on both legislation and on
8 policies.

9 Although we have passed this legislation
10 far later than we should, it is now time for us to
11 implement it as quickly and as effectively as we can.
12 We must ensure that not fully including one in six
13 Americans, 43 million Americans -- you've heard that
14 statistic before perhaps. It is an incredible figure,
15 on that I'm sure that most Members of the Congress
16 totally rejected early on in the consideration.

17 I am amazed at how many people have come up
18 to me over the last three or four months that my
19 visible involvement in the Americans with
20 Disabilities Act has been known generally in my
21 community. It's just amazing how many people come up
22 to me and tell me about their spouse, their brother,

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1 their sister, their mother, their father, their
2 neighbor, their friend, their teacher, their
3 coworker, whatever, who have a disability who have
4 not been accommodated. It is amazing and I am more
5 convinced every day that that 43 million is
6 absolutely accurate.

7 Some of those disabilities, of course, are
8 difficult to visually see and therefore we perhaps
9 think they do not exist. Again, no one looking at
10 Tony Coelho would ever think disability, but
11 remember, just as recently as 1962 he was rejected
12 from being a priest because of his epilepsy. Happily
13 the Catholic Church, the Roman Catholic Church has
14 now changed that policy as they have become educated
15 and more sensitive. They lost a tremendous resource,
16 which was the Congress' great gain and the public's
17 great gain.

18 Americans, as I'm sure so many of the
19 people of the world, have an inherent belief there is
20 a place for everyone in our society. A place for
21 everyone in our society, and that place is a full
22 participant and not a bystander.

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1 So, to my American colleagues who are here,
2 I say to you that you have before you an exciting and
3 vital responsibility. It is easy, relatively
4 speaking, to pass a law. We know that it was,
5 relatively speaking, as a result of the heightening
6 of consciousness of 1964, relatively easy -- there
7 were 120 plus who voted against the Civil Rights Act
8 of 1964 in the House of Representatives -- relatively
9 easy to pass that bill.

10 None of us as Americans would be honest in
11 saying that we have fully implemented the premise and
12 promise of that legislation in 1990. Perhaps we will
13 never attain the full goals of that legislation, but
14 hopefully in our country every year that goes by
15 there is a greater consensus that it ought to be
16 accomplished, not only because it is consistent with
17 our principles, but because it is consistent with
18 good sense.

19 We are now confronted with the challenge of
20 having articulated a policy and passed laws which
21 will require architects and builders to accommodate,
22 to make accessible, to allow things to be readily

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1 usable by. We have told people who have businesses,
2 who have doctors' offices, who have places of public
3 accommodation, who have banks, that you and I take
4 for granted and must use day to day for our own use,
5 for the use of our families, for economic intercourse
6 generally.

7 We have said "You must make those places
8 accessible." We have told public and private
9 agencies, "Over time your transportation facilities
10 will be accessible." We have told communications
11 companies, "You will allow people to communicate with
12 one another notwithstanding a hearing or speech
13 impairment."

14 That's what we've said. It says here in
15 the law. Now the somewhat more difficult, long term
16 and perhaps not as dramatic on a day-to-day success
17 basis, will occur. And that is the implementation of
18 this legislation. Most of you in this room are
19 experts. Obviously all of you in this room are
20 sensitive to the challenge, I would hope that all of
21 us together in the United States and around the
22 world.

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1 I will tell you, another hat that I wear,
2 and Britt mentioned, President Kirwan mentioned, is
3 as a co-chairman of the Commission on Security and
4 Cooperation in Europe, the Helsinki Commission. I
5 was delighted when the Speaker's office, just prior
6 to his speech to the Joint Session of Congress, all
7 the leaders of the Congress, the Speaker and George
8 Mitchell and Bob Dole, the Minority Leader of the
9 Senate, Bob Michael, the Minority Leader of the House
10 of Representatives, Dick Gephardt, were all going
11 through the line and shaking hands with President
12 Havel and he was very gracious to them and then when
13 I came, and I'm relatively low down on the totem
14 pole, so I was sort of at the end of the line.

15 When he came to me, he stopped, and he
16 said, "Oh, Steny Hoyer, I know who you are. You're
17 Chairman of the Helsinki Commission." And I had all
18 my hot-shot colleagues standing around. They were
19 kind of impressed with that. Very frankly, I sort of
20 puffed up and said, "That's great."

21 What has the Helsinki Final Act done? It
22 has no army. It has no intrinsic bureaucracy. It

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1 has none at all, as a matter of fact. It has no way
2 to implement the ideas that were enunciated in the
3 final act. What it has done is to provide forums, to
4 talk with people, education people, urge people to
5 live out the promises contained in the 1975 Helsinki
6 Final Act.

7 We need to do that with respect to
8 disabilities. In domestic forums in our own
9 countries, in international fora as well to say to
10 people, "Be sensitive." Understand that passing an
11 act is not enough. Going by the letter of law is not
12 enough. It is the spirit of inclusion that we want
13 to accomplish and that is the vital task that is
14 going to be left to each of you.

15 I opened by saying that John Kennedy said
16 that those children would not be the victims of the
17 neglect of their government, indeed of their society.
18 The disabled for too long have been the victims of
19 our neglect. Not only in our ability to accommodate,
20 but of our neglect, consciously or subconsciously.
21 It is now time for us, having recognized the great
22 opportunity that accommodating very able people who

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1 can do so much for all of us.

2 As the chairman and chief operating
3 officers of one of our big companies said, "Not only
4 is the Americans with Disabilities Act good policy,
5 it is good business." And it is certainly consistent
6 with the principles that we see spreading throughout
7 the world today that says that the final analysis and
8 the test of government is how they treat each and
9 every one of their individuals, based upon that
10 individual's human dignity, which is how the Helsinki
11 Final Act talked about the unalienable rights given
12 by the Creator.

13 The Helsinki Final Act in a less religious
14 framework talks about it in terms of the human
15 dignity. Lex Frieden deserves my accommodation, not
16 because the state says so, but because of his dignity
17 as a human being and because of what he has the
18 ability to offer our society, given his commitment,
19 his talent and his willingness to exercise those
20 talents on behalf of himself, his family and all of
21 us.

22 I thank you for this opportunity to join

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1 you and I look forward to working with you in the
2 coming weeks and months and years, to make a reality
3 a promise of inclusion for those in our world and
4 those in this country who suffer from a disability
5 but ought not to suffer from our insensitivity.

6 Thank you very much.

7 MR. FRIEDEN: You see now why Congressman
8 Hoyer epitomizes the characteristics of leadership
9 that many of us aspire to. He has kindly offered to
10 take a few questions from the audience if you have
11 any particular issues you'd like to raise with Mr.
12 Hoyer before he has to leave.

13 MR. HOYER: If not, thank you very much.
14 Bye, bye. Thanks, Lex.

15 MR. FRIEDEN: Thank you very much. See how
16 cheap that reasonable accommodation was? It wasn't
17 any problem at all. Thank you very much,
18 Congressman.

19 I grew up in Oklahoma and when I was a
20 young person I guess my hero was Mickey Mantle.
21 Despite the fact that Mr. Hoyer may or may not play
22 baseball, as an adult, I have a new hero. Thanks for

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1 being here.

2 At this time we have scheduled a brief
3 coffee break. Let me underline the word "brief." We
4 have other speakers scheduled for this morning. We
5 don't want to run behind on our agenda, so if we
6 could reconvene here in ten minutes, we will continue
7 with our program. Thank you all.

8 (Whereupon, off the record at 10:38 a.m.
9 for a coffee break, until 11:06 a.m.)

10 MR. FRIEDEN: If I could have your
11 attention, please. At this point in time we will
12 move on with our scheduled agenda and it's my
13 privilege to introduce for you Dr. Edwin Martin, who
14 is now the President and CEO of Human Resources
15 Center in Long Island, New York.

16 However, prior to his present position, Dr.
17 Martin served in the government in a variety of
18 capacities, including that of head of the Bureau of
19 Education of the Handicapped and he was, I'm pleased
20 to say, the very first Assistant Secretary of the
21 Office of Special Education and Rehabilitation
22 Services in the Department of Education and that's

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Lex:

Lani began editing then we
rethought how to use this
so please ignore - 4

P-R-O-C-E-E-D-I-N-G-S

9:07 a.m.

MR. FRIEDEN: Good morning. My name is Lex Frieden. Some of you will identify me from my work in Washington, D.C. as executive director of the National Council on Disability. I was there from 1984 to 1988. During ^{this} an exciting time ~~in which~~ we produced a report called, "Toward Independence," which I'm ~~pleased to say has~~ led to some really landmark legislation which is about to be finally passed and signed into law by the President of the United States, the Americans with Disabilities Act.

Others of you will identify me now in my ^{present} ~~president~~ position as a member of the faculty at Baylor College of Medicine in Houston and as executive director of the TIRR Foundation ^{also} ~~there~~ in Houston. [I'm pleased that I have the opportunity from time to time to use some of the experience that I gained while in Washington in a consultant role and in an advisory capacity and I managed to keep the mileage on Continental Airlines up traveling between Houston and Washington.]

delete

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1 Perhaps ~~As~~ as a result of my recent experience
2 representing the President's Committee on Employment
3 of People with Disabilities ^{for} ~~in~~ the Department of
4 Labor as a delegate panel member on a study of
5 disability employment policy at the Organization for
6 Economic Cooperation and Development ^(OECD) in Paris, I've
7 been asked to serve as the conference chairman ^{of} ~~here~~
8 ~~this meeting for the next two days and, in that capacity it's my~~
9 extreme pleasure to welcome all of you to Washington
10 for what promises to be an eventful, educational,
11 provocative, productive and, I believe, enjoyable
12 conference.

13 I'd particularly like to thank those of you
14 who are coming from a ~~number of~~ ⁹ countries
15 representing ^{the} OECD to contribute to the knowledge base
16 ~~that we have here~~ ⁹ in the United States, and I'd like
17 to thank all of my colleagues from the United States
18 for being here to benefit from the experience that
19 our friends have had in other countries with some of
20 ~~these~~ ^{the} important issues ~~and to share your own~~
21 ~~experiences with them.~~ ^{we face.}

22 As you know, this symposium is being

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1 sponsored by the Department of Labor, the Department
2 of Health and Human Services, the ~~International~~⁹
3 Organization for Economic Cooperation and
4 Development, and the University of Maryland at
5 College Park.

6 The sponsors have conceptualized three very
7 important objectives for this meeting and I'll share
8 those with you now. First, ~~and I suppose, quite~~⁹
9 ~~evident, I believe~~⁹ we have an opportunity to
10 familiarize ~~those of us in America~~^{American professionals} with innovative
11 European approaches to employment and service
12 coordination for people with disabilities.

13 (Second, ~~I think we have the opportunity~~¹⁰ to
14 exchange information on disability policies and
15 programs in the United States among ourselves and
16 with our colleagues from other nations.)

17 (Finally, and perhaps most importantly, we
18 have during the next two days the opportunity to
19 identify issues pertaining to three very important
20 subject areas and to construct recommendations for
21 policies and programs related to those areas.

22 After the conference is over, ~~there will be~~⁹

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1 a report which is generated to reflect^{ing} the outcome of
2 our discussions and the suggestions made here during
3 the course of this symposium.^{will be issued} I suspect this report
4 will be of value to us from both the domestic point
5 of view and from an international perspective. I
6 think we can anticipate that the results of our work
7 here will have effects ranging far beyond those which
8 we may recognize immediately as we participate in
9 this conference.

10 ~~Let me underline the word "participation."~~
11 ~~This will be a participatory working conference. By~~
12 ~~the end of tomorrow I suspect we will have disrobed~~
13 ~~to the extent that we have taken our jackets off and~~
14 ~~rolled up our shirt sleeves and really gone to work.~~

15 Each one of us has an important role to
16 play here. Some of us have been called upon to be
17 moderators, others rappoteurs. Some of us will
18 function principally as subject area experts relating
19 to the topic areas to be discussed.

20 ^{Most importantly}
21 ~~And finally,~~ all of us will be participants
22 and as participants we all have a responsibility and
an obligation, I believe, to participate actively, to

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contribute what we know, to contribute the benefits of the experiences that we've had. Each one of us has been invited to this conference. It's not an open conference. Consequently you don't see hundreds of people here this morning as you would have for this meeting had it been a public meeting.

~~And because we are invited,~~ We've been asked because of our particular expertise, our particular knowledge, our particular backgrounds to participate here in developing what should be a valuable product that we can all share when we've finished.

It seems to me that there are three elements which dictate the success of ^a ~~this~~ meeting. ~~and others like it.~~ ^{They} ~~These~~ are good planning and preparation, good subject matter and important issues, and good people with imagination, ideals and perspectives.

I suppose we're all witness at this point to the fact that good planning and preparation has preceded this meeting, and for that we have to thank Drs. Philip Burke, and Margaret and Maggie McLaughlin, Leni Florian, and Lani

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as well as Ms
 1 Sandy ^{Cawley} ~~Hellis~~ from the University of Maryland at
 2 College Park. We have to thank ^{Assistant Secretary} Martin Gerry from the
 3 Department of Health and Human Services and ^{Special Assistant} John Paty
 4 and ^{title} Mel Brodsky from the Department of Labor.

5 ^{Also, insert titles} ~~And finally, I think,~~ David Thomas and Gia
 6 Boyd-Kjellman from the OECD in Paris, ^{deserve our thanks} They've all
 7 done an outstanding job and while we can judge the
 8 results of their work at the end of the conference, I
 9 think ~~it's apparent~~ ^o the good planning and
 10 organization that's gone into this effort, ^{is apparent.}

11 ~~Now, the issues which we've been called~~
 12 ~~upon to address should have ample meaning to each one~~
 13 ~~of us and their importance cannot be overestimated.~~
 14 ~~They should certainly have base validity to us who~~
 15 ~~have been working in the field of disability for many~~
 16 ~~years.~~

17 ~~Finally,~~ ^e The people who have been called
 18 ~~upon here to be speakers, moderators, reporters,~~
 19 ~~consultants, experts, actually all of us have really~~
 20 ~~contributed a great deal in our past experience or we~~
 21 ~~wouldn't have been called here.~~ ^e We represent, I
 22 believe, a blend of different perspectives, unique

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1 experiences, knowledge, backgrounds ^{which} and we will, in
 2 fact, ^{enable us to} ~~be able to~~ play the important role of producing
 3 a report of value to all of us.

4 The challenge for us now ^g today is to use
 5 this opportunity as efficiently and as effectively as
 6 possible so that we can all gain the utmost from the
 7 opportunity and the experience.

8 With that in mind, let's briefly review the
 9 agenda ~~which lies ahead of us, and I believe each one~~
 10 ~~of you has a copy of that agenda in your materials~~ ^g

11 First, this morning we'll have the
 12 opportunity to hear from several outstanding and
 13 prominent leaders and authorities who are abundantly
 14 well-qualified to challenge us with ideas and to
 15 supply us with information. It's a rare opportunity,
 16 to, ~~on the same day,~~ ^g hear speakers of the caliber of
 17 Tom Alexander from the OECD, ^g and Under Secretary of
 18 the Department of Labor, Rod DeArment, ^g and President
 19 of the University of Maryland, ^{at} College Park, Dr.
 20 Kirwan, ^g and Congressman ^g Hoyer and ^g Ed Martin and ^g Martin ^g
 21 Gerry, ^g and ~~we can go on because we really will be~~ ^g
 22 ~~stimulated by the time we reach our small groups this~~ ^g

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1 afternoon.

2 And tomorrow, I might add, we have the
3 opportunity at lunch to hear the newly appointed
4 Chairman of the U.S. Equal Employment Opportunity
5 Commission, the first person with a disability to be
6 appointed to that role, Evan Kemp.

7 This afternoon we'll begin to perform our
8 participant role as small groups ^{begin} address addressing
9 issues in the area of independent living or personal
10 choice; employment, and ^{of} particular supported work; and
11 coordination ^{of} and financing ^{of} for programs for people
12 with disabilities.

13 I'd like for you to make two changes on the
14 agenda concerning the moderators for this afternoon
15 and tomorrow. Wayne Sailor will not be with us and
16 in his place his very close associate and colleague,
17 Dr. Michael Hardman, from the University of Utah.

18 And Dean Moodie, from the Canadian
19 government will not be here. Instead his colleague
20 and associate Donald McLeod will be co-moderator of
21 that group.

22 This evening we have the honor of attending

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1 a reception and dinner at the U.S. Capitol and that's
2 what I meant when I said I thought the next two days
3 would be enjoyable.

4 Tomorrow morning we will continue in our
5 participant role with the shirt sleeves, focusing
6 more specifically on the task of developing
7 recommendations. And tomorrow afternoon we will
8 refine and complete those recommendations.

9 Finally, tomorrow night we'll conclude our
10 activities by having the unusual opportunity to meet
11 and socialize in the inner sanctum of the U.S. State
12 Department, a splendid site, I would say, for wishing
13 one another goodbye.

14 I'm sure that all of you agree that this is
15 an outstanding and challenging agenda. Let me
16 encourage you, if you have any questions or personal
17 needs during the next two days, not to hesitate to
18 contact me or any of the outstanding host team here
19 from the University of Maryland. We hope that you
20 all enjoy and benefit from this meeting.

21 Now, without further ado, I have the
22 privilege of introducing Mr. Thomas Alexander to you.

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1 Mr. Alexander entered the British diplomatic service
2 in 1958 and since then has served in such faraway
3 places as Kuwait, ~~Tripoli~~ He was the British
4 consulate general in Seattle, Washington for a number
5 of years and he ^{also} served in ^{Sudan} ~~Khartoum~~.

6 He has also, during his career, spent a
7 great deal of time in various capacities at the OECD,
8 the ~~Organization for Economic Cooperation and~~
9 ~~Development, in Paris, an international body of which~~
10 ~~the United States is a member, along with the other~~
11 ~~countries represented here~~ and Mr. Alexander will
12 talk more about the OECD's role, vis-a-vis,
13 disability issues in his presentation.

14 Prior to assuming his present job, he was
15 head of the private office of the Secretary General
16 for the OECD in Paris and now he is director of the
17 social affairs, manpower and education division of
18 OECD and also director of the center for educational
19 research and innovation.

20 Please welcome Mr. Thomas Alexander.

21 GREETINGS BY MR. THOMAS ALEXANDER

22 MR. ALEXANDER: Thank you very much, Mr.

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A-F-T-E-R-N-O-O-N S-E-S-S-I-O-N

1:33 p.m.

MR. FRIEDEN: If we could come to order now. We have had an excellent morning filled with inspiring and provoking presentations. We've had a good lunch, in my judgment, and now we're ready for the real work of the conference and that is getting down to the issues that the sponsors and hosts have selected based, I would say, on good advice from many of you, that we will deal with for the next two days.

INTRODUCTION OF SYMPOSIUM THEMES

MR. FRIEDEN: Let me just review those three issues and really the themes of this conference with you, and I think you'll begin to see through this the relationship between these issues.

First we have the issue of Personal Choice, and as it's outlined in the agenda, "Exploration of the roles of the consumer, family and advocates in the coordination of supports and services.

Personal choice is an issue that we, in the United States, have paid a lot of attention to in recent years. Frankly, we've given it a lot of lip

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1 service and those of you in the audience who are
2 people with disabilities or parents of people with
3 disabilities and even some of those of you who are
4 service providers will realize that, as John Fish
5 pointed out this morning, it's much more difficult to
6 do something than it is to talk about it.

7 So we should applaud ourselves, because we
8 have recognized the importance of personal choice.
9 We have begun to talk personal choice in a lot of our
10 papers and in our speeches and our rhetoric reflects
11 a good deal of concern about personal choice and I
12 might add that my experience working with OECD
13 indicates that the other nations represented here, as
14 well, recognize the need for personal choice.

15 But when it gets right down to it, have any
16 of us really taken the opportunity to ensure that
17 people with disabilities, their family members and
18 their advocates, have the most important role that we
19 can provide for them in the whole service continuum,
20 in the process?

21 The ultimate decision-making role, what is
22 the purpose of the system? In my opinion, the

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1 purpose of the system should be to facilitate
2 decision making by the individual affected with the
3 system, and too often I think we've interpreted
4 personal choice as using mechanistic means to
5 evaluate people's skills, using mechanistic means to
6 test people's interests and then providing them with
7 direction, mechanistic or not.

8 But I submit to you that anyone with a
9 disability, regardless of the type of disability --
10 and I want to emphasize that point, because I think
11 sometimes we have, at least historically, tried to
12 distinguish in the area of personal choice among
13 those people who may be intellectually impaired and
14 those who are not. But it's my belief that anyone
15 with any type of disability has the capacity to make
16 decisions which affect their own lives.

17 And family members and advocates should be
18 a part of that decision making process, but the
19 principal responsibility, the bottom line, if we're
20 going to do what we say we should do, must lie with
21 the individual affected.

22 So consequently we need to look at the

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1 programs as a system of facilitating those kinds of
2 decisions, throughout an individual's life, beginning
3 in early years. You know, I had the good fortune, I
4 suppose, to grow up in a small rural community in
5 northwestern Oklahoma. I wasn't disabled at the time
6 and I can remember as a small child my parents
7 demanding, if you will, that I make decisions about
8 my life.

9 Further than that, giving me the
10 opportunity to choose sometimes when I was surprised
11 by having the opportunity to choose. And gradually,
12 and I think naturally as it occurs in most families,
13 I was given the responsibility to choose, the
14 responsibility to make decisions for myself, and
15 frankly, as a result of a bad decision one night, I
16 broke my neck in an automobile accident.

17 So, you know, we all have the right to
18 choose and with that goes the obligation to live with
19 the consequences of our choices and I don't believe
20 we should deny either the right or the obligation to
21 people simply because they happen to have a
22 disability of any sort whatsoever.

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1 Some of you may say, and frankly I doubt if
2 any of you here, but you've shared with me the
3 experience of consulting with someone who regards
4 themselves as an expert in the area of disability,
5 who will tell you, "That's fine, but then what about
6 those people who are most severely impaired?"

7 Frankly, our definition of disability is
8 changing day by day. I can remember when, after I
9 broke my neck, I was a client of the vocational
10 rehabilitation system and they told me I was too
11 disabled to be eligible for services. Too disabled.
12 They denied me any service because I was too
13 disabled.

14 And then a year later they began to open up
15 and liberalize their viewpoint a little and, in fact,
16 in the meantime I had written my Senator, who I
17 suppose dropped them a note from time to time, and
18 they interviewed me again. And at that point they
19 decided, well, maybe I wasn't too disabled to receive
20 some service, particularly since I had a friend in
21 the United States Senate.

22 But I couldn't do what I chose to do.

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1 There was no way I could continue my education with
2 the objective of becoming an engineer because they
3 knew if I really was a good engineer, I'd be called
4 upon to travel, that I might not be able to sit in a
5 single place all day long, most likely next to my
6 bed, and perform a function as an engineer.

7 So, again, they denied me service whilst at
8 the same time they offered me to become an educator, a
9 teacher, a good profession, I might add, and one in
10 which I followed their initial advice, until I came
11 to the school at which you couldn't get up the steps
12 to get into the teaching institution, so as luck
13 would have it, I drifted over to the social science
14 building, which was new built, having ramps and
15 elevators and now I'm here today as a little bit of
16 this and a little bit of that.

17 But, nonetheless, the people -- and I still
18 know them and greet them occasionally -- from the old
19 vocational rehabilitation system that told me I was
20 too disabled to work, to be educated, to travel.
21 I'll bring them from time to time a gift from Sweden
22 or Denmark or Paris, and wish they have a nice trip

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1 there the next time they're invited to go.

2 You see, we may not carry a chip on our
3 shoulder, but we remember.

4 Personal choice for some of you may mean,
5 and be reinterpreted as independent living. After I
6 broke my neck I lived at home and I did so because
7 the community-based service system didn't have the
8 services to provide me the opportunity to live in the
9 community as I had been before I was disabled.

10 And my mother took care of me. Every
11 morning she helped to dress me and every night she
12 helped to undress me, for the three and a half years
13 that it took me to graduate from college.

14 Then I went away from home and I went to a
15 demonstration program, that was funded, by the way,
16 by the Department of Education in 1972 in Houston,
17 Texas. This was a trial program, a kind of bridge
18 program, as many of us have experimented with in our
19 own countries.

20 My parents took me down there and I went in
21 there late in the afternoon, because it had been a
22 long drive from Oklahoma to Texas, and those of you

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1 who have driven through Texas understand it's not a
2 single-day drive.

3 But we arrived late on the second day and I
4 went into this facility which, by the way, had
5 originally been built as a nursing home, but which
6 couldn't be funded as such and had been converted to
7 a kind of transitional residence for people with, as
8 they said, severe disabilities. I went in there in
9 the hallway and it was about time for me to relax, to
10 lie down in bed.

11 In fact, it had been a long day and it was
12 time to go to bed, I thought, and I said to my
13 parents, who had taken me down there, and my sister,
14 "I guess this parting now and you'll go to the hotel
15 and I'll stay here." And my mother said, "Well,
16 who's going to help you?" And I said, "Well, I don't
17 know," but we knew before we came here that they have
18 these services available. And I insisted that they
19 leave and they did so with some reservation.

20 Then I said to one of the fellows -- I
21 didn't see anyone there in the facility with a white
22 coat, nobody with medical gear on or garb or what not

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1 and I didn't know who to ask to help me into bed --
2 and I said to one of the other residents there, "Can
3 you tell me what I do in order to get some assistance
4 getting to bed?"

5 He pointed down the end of a fairly short
6 hallway and said, "You see the fellow standing at the
7 door?" And I said, "The one with the long hair?"
8 And he said, "Yeah." And I said, "The one with the
9 jeans and the T-shirt?" And he said, "Yeah, that's
10 the one." I said, "The one with the earring in his
11 ear?"

12 You see, in Oklahoma in 1972, we only saw
13 pictures and those came from California. He said,
14 "Yeah, that fellow will help you get in bed." Well,
15 I was little bit apprehensive, but I rolled down to
16 him and I said, "Sir, I understand you'll help me
17 into bed." And he said, "Yes, I'd be happy to."

18 And I rolled off to the room I'd been
19 assigned and he followed me. I parked my wheelchair
20 next to the bed, as I had done for the past three and
21 a half year, when my mother got me into bed. And he
22 stood there and I waited for him to help me into bed

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1 and he stood there. And he looked at me and I gazed
2 at him, albeit briefly.

3 He stood there, and I looked at him again
4 and I said, "Sir, can we get into bed now?" He said,
5 "Well, I suppose." And I waited, and I said, "Well,
6 can you take the sliding board and put it under me
7 and then come around behind and slide me into the
8 bed?" And he did it.

9 Then I'm lying in the bed and I'm waiting
10 for him to unfasten my pants and shirt, and to take
11 my shoes off. He stood there looking at me. I
12 thought at the time, you know, these drugs -- we've
13 heard about them. And I didn't know it was as close
14 to home as Texas. Good grief.

15 And I said to him, "Can you unbutton my
16 shirt and my pants?" And he said, "Well, I'd be
17 happy to." And he did. And he looked at me, and I
18 said, "Well, can you pull the pants down and lift the
19 shirt around?" And he did.

20 Then I began to get, you know, a notion of
21 the program. Well, can you do the socks, can you
22 move the bag? And, you know, before I knew it, I was

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1 undressed and I was lying in bed and I was covered up
2 and ready sleep just like I had been every day when
3 my mother had taken care of me.

4 But there was one critical difference that
5 I thought about all night long and that was, this was
6 the first time in three and a half years, since my
7 neck had been broken in an automobile accident, that
8 I had, in effect, undressed myself.

9 Now, you see, we have to translate the
10 concept of personal choice and independence from the
11 theoretical level where we talk about it in speeches
12 and write about it in papers, down to the personal
13 level where individuals with disabilities can
14 manifest their abilities in the process of making
15 decisions, making choices. I submit to you that
16 anybody with any disability, given the appropriate
17 choices to make can do so.

18 I think we have to be constructive and we
19 have to be imaginative and we have to think in terms
20 of continuum, but we nonetheless have an obligation
21 and a responsibility and, in fact, the only way our
22 programs will eventually succeed in making people

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1 with disabilities independent and in giving them the
2 opportunity to success and achieve as we know they
3 can is to translate these theoretical concepts into
4 reality for people with disabilities.

5 It is, frankly, up to us to figure out how
6 to do that. Very few of us have done it, frankly. I
7 mean, we've tried to do it in Houston for many years
8 and to a limited degree, I'd say we've been
9 successful, but only to a limited degree.

10 We have examples of programs here and there
11 and so on in the United States and in other countries
12 as well, but we've never been able to move the
13 concept of personal choice and independence to the
14 level where the system promotes that effectively in
15 an institutionalized kind of way. By that I mean,
16 provides that opportunity for every individual who's
17 affected by the system.

18 So we have one group which will, this
19 afternoon, I hope, begin to flesh out the issues
20 pertaining to personal choice.

21 The second subject we have to deal with is
22 effective integration and support in the workplace.

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1 Now, as Martin said in his presentation, we used to
2 consider work, employment as an issue for people with
3 disabilities and we used to do so in a fairly single-
4 minded focus.

5 Again, we all have made a quantum leap in
6 recent years to the point where we understand and no
7 longer talk about employment by itself, but we
8 realize that when we're dealing with people with
9 severe disabilities, we're dealing with a system, a
10 social system, a political system, an economic
11 system, a service system. That system can't be dealt
12 with on a piece by piece basis, one piece
13 independently from the other.

14 Again, here's an issue that we have tried
15 to address in a variety of different ways, but
16 personally I don't believe, and I think you all would
17 agree, that we haven't found a solution to
18 integrating the concept of life with the concept of
19 employment.

20 You know, everybody except for those with
21 disabilities considers work to be a part of life.
22 People with disabilities have life and then they have

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1 work, some of them. There's a little box out there
2 and the system reinforces the notion that that little
3 box is independent of life, because, you see, we have
4 a rehabilitation counselor or special ed counselor,
5 or, you know, we hear people talking about the need
6 for us to go to work. Our families are preoccupied
7 with work. Where does work fit into life?

8 Now, frankly, I believe that the Americans
9 with Disabilities Act will go a long way into helping
10 fit the work box into the life box for people with
11 disabilities, because regardless of whether we wanted
12 to try and put employment in the life continuum,
13 people with disabilities were smart enough to know
14 that they could go to work, but what good did it do
15 them? They couldn't go out to the theater. They
16 couldn't get in. They couldn't go out to the
17 restaurant. They couldn't get there.

18 You see, we have to realize that life for
19 everyone is a continuum of opportunities and again a
20 continuum of choices. People with disabilities in
21 order really to assert themselves, with the exception
22 of a thin line, and I think in every country

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1 regardless of how good or how bad the system is, we
2 can say there are people with disabilities who are
3 working.

4 There will always be people with
5 disabilities who will work. They are driven by the
6 need to work and some of us are workaholics and our
7 families would say we really don't understand even
8 though we can talk about it, the concept that work
9 fits into life. Nonetheless, that's only a segment
10 of the population.

11 Most people with disabilities recognize
12 that work will lead them to other opportunities in
13 the community and until we believe and understand
14 that notion, there will be no incentive for the vast
15 majority of people with disabilities to go to work,
16 regardless of the kind of work initiatives, work-
17 oriented programs, work-reinforcing programs that we
18 can develop.

19 So, again, I think we have to place work in
20 the continuum of life. We have to realize that for
21 the most severely disabled people, working may
22 involve getting dressed and undressed. It may

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1 involve getting to and from work. It may involve
2 finding a place to live. It may be involved having
3 the opportunity to go to recreation in an integrated
4 setting, and so on.

5 While we've begun from time to time to look
6 at supported employment in a fairly narrow way, and
7 while some of our most successful demonstration
8 projects have focused on supported employment for a
9 small segment of the population of people with
10 disabilities, the concept is much broader than that
11 and I challenge you all this afternoon and tomorrow
12 to address the concept of supported work in the
13 generic, philosophical mode first to understand among
14 ourselves clearly what that concept offers from the
15 standpoint of driving policy and program focus in the
16 future.

17 Because the concept of supported
18 employment, to those of us with disabilities who
19 understand all of the criteria, all of the conditions
20 that are necessary to make work a reality, will tell
21 you that concept is not focused. It's not necessary
22 to confine or narrow or restrict that concept to a

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1 very narrow restricted population.

2 The concept is far broader than that and
3 for the people who fit into the population where
4 supported employment has been most effectively
5 applied today. We have a long way to go because I
6 hear from time to time in my tours around the country
7 and in other countries, in fact, supported employment
8 is simply becoming a substitute for sheltered work.

9 If that's all that happens with supported
10 employment, we have simply succeeded in moving people
11 from one box to another, not from freeing them from
12 the boxes.

13 So, again, I challenge you to take the
14 concept of the effective integration and support in
15 the workplace and move it from a policy and
16 programmatic standpoint beyond the boxes that we tend
17 to view it in today.

18 Finally, I think the sponsors of this
19 conference were wise in the selection of the third
20 topic, given the first two. And that is organizing
21 and financing community services. How can we
22 possibly achieve our objectives in regard to personal

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1 choice and effective integration in workplace
2 employment if we don't have effective coordination
3 and financing for programs that are necessary to
4 provide an infrastructure of community-based support
5 network for people with disabilities?

6 One of the reasons that we have failed,
7 frankly, to develop a continuum of services for
8 people with disabilities in the community is because
9 we haven't been able to apply the theoretical concept
10 of coordination to the practice of dealing with
11 individuals and their specific personal needs.

12 Now, we see some examples from Australia
13 and Canada and the U.S. and other countries of case
14 management, which may give us a clue as to how to
15 move from the conceptual level of coordination as a
16 national policy area down to the level of service
17 coordination for the individual in their home
18 environment.

19 But I suspect that's not the ultimate
20 solution to the problem because without coordination
21 all the way up and down the spectrum we will
22 eventually lose our initiative and our inertia. So

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1 coordination becomes a practical issue and I must say
2 that my experience in developing policy reports here
3 in Washington indicates how difficult it is. I don't
4 mean to underplay it, because when we did the report
5 for the President and the Congress entitled "Toward
6 Independence," we had to deal with coordination as an
7 afterthought, because nobody, regardless of all the
8 research effort we put into it, could come up with a
9 good way of articulating possible solutions to the
10 coordination problem in this country where we have
11 more than 103 separate agencies involved in every
12 disabled individual's life.

13 It seems almost unmanageable, yet in order
14 to succeed and accomplish the objectives we all
15 share, we have to regard it as a manageable problem.
16 We have to address it as though it had a solution and
17 we need to begin to go beyond the point of theory
18 into the point of practice.

19 And here again we have a great opportunity.
20 Financing will vary, depending on where you're coming
21 from and even here in the United States we've
22 discovered that those programs that are most

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1 effective depend on a variety of sources for funding.

2 Nonetheless, we can predict, based on past
3 experience, how programs can most effectively be
4 spread from one community to another, how the good
5 models and examples that we have can be adopted in
6 other communities.

7 So I think it's important to address the
8 question of financing, regardless of the perspective
9 you may bring to the question.

10 I think that we have a limited amount of
11 time to deal with some very important issues. This
12 afternoon what I would suggest is that you in the
13 working groups try to identify a base, a common base
14 of discussion, try to identify the issues that
15 pertain to the separate topic areas.

16 Try to engage in an exchange of information
17 so that everyone's working from the same definitional
18 basis and the same theoretical basis and the same
19 hypothetical basis. But, at the same time, prepare
20 yourselves to deal tomorrow morning at a much more
21 focused and practical level by developing
22 recommendations, identifying barriers to

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1 implementation of some of the ideas that we'll
2 construct this afternoon.

3 There are, as you know, three groups. We
4 will repeat each one of those groups twice this
5 afternoon, once in the early afternoon, the other
6 after a short break. You may choose two of the three
7 groups to participate in.

8 You can go to personal choice now and then
9 later on go to organization and financing, or you may
10 choose another combination, but please choose two of
11 the three, and in doing so, try not to find the place
12 you'll be most comfortable, but perhaps the place
13 that you think you can be most imaginative.

14 Try to develop a common base of
15 understanding. At the same time sample the subject
16 matter in the two groups that you choose and be
17 prepared tomorrow morning to choose one of those
18 groups, a single one of them, to go back to to
19 generate recommendations.

20 See which one of them you can relate to
21 best, knowing that we all can't be everywhere at
22 once, even though we might like to, and knowing at

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1 the same time that we will have an opportunity
2 throughout the course of the next two days to share
3 the results of our various groups, so don't feel as
4 though you'll never hear about personal choice if you
5 decide not to go there.

6 We'll have the opportunity this afternoon
7 to summarize what happened in the personal choice
8 group and again tomorrow afternoon.

9 One thing that we'd like you to keep in
10 mind is that we do have name cards. For the benefit
11 of everyone, please carry your name cards with you
12 and use them on the table so that people can deal
13 with one another on a first-name basis.

14 We'd like for you to cooperate to the
15 extent that this body can with the moderators who
16 have the ultimate responsibility to bring some effort
17 to a conclusion here and to produce something from
18 our work.

19 At this point I'll announce the break-out
20 rooms for each one of the sections. Before I do, are
21 there any questions about the process here for this
22 afternoon and this morning?

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1 We'll be back here, by the way, at 5:00 to
2 wrap up, to exchange the issues that occurred in the
3 different groups and that will be a short meeting so
4 that you'll have time to freshen up before we go to
5 the Capitol for our reception and dinner.

6 The break-out rooms for personal choice are
7 the Logan Salon on this floor around the corner.
8 Those who choose personal choice -- another thing you
9 might do, those of you who have such broad background
10 of knowledge, take a look inside the group and try to
11 distribute yourselves evenly so that we have a good
12 selection of people with different perspectives in
13 each one of the groups.

14 The group for financing will be in the
15 Thomas Salon on this floor around the corner.
16 Coordination and financing.

17 And the finally the group on supported
18 employment will be in Room 3017, upstairs and down
19 the hall. Room 3017 for supported employment,
20 upstairs and down the hall.

21 Thank you all for your attention and good
22 luck this afternoon.

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Institute for the Study of Exceptional
Children and Youth
Department of Special Education
University of Maryland
College Park, MD 20742

FROM:UMCP ED TECH CENTER

TO:

7137997095

AUG 31, 1990

12:36PM

P.02

OUTLINE
Proceedings

International Symposia on Employment of Persons with Disabilities

Preface - Lex Friedan

Provide context for the meeting and introduce the three themes

Labor Market Forces and the Employment of Persons with Disabilities - Roderick A. DeArment

OECD: - Thomas Alexander ?

Civil Rights for Persons with Disabilities in the United States - Steny Hoyer

Economic Consequences of the Unemployment of Persons with Disabilities - Martin Gerry

OECD Response to Employment of Persons with Disabilities - John Fish

Summary of Personal Choice - Lani Florian

Summary of Effective Integration and Support in the Workplace - Debra Neubert

Summary of Organizing and Financing Community Services - Margaret McLaughlin

Summary and Conclusions of Conference - TBA

Agenda

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Employment

Rees.

① Graduate Principle should be non-discrimination

2. Support should be flexible, based on assessed need + time-limited (secondary) not intrusive.

3. TC - positive support - employs

- better into div-
CS-workers.

4. Training should be on the job - correct of education is abundant

4. Reliance on human resources financial support.

5. Tailor-made & community support,

support
for
employees

the guarantee to the employers that the job will be done, no additional costs incurred + there will be no backlog support

6. A number of models of support for indiv

Trust to

empowered
individual as

well as
CS-workers

i) if-Stage teams, include an advocate;
ii) Advocate/Kuwaiti outside the team.

CS-workers & fast support and progress.

→ P/O-

Support + Guarantee to employer

7. ~~8~~ ~~3~~ possibilities; support for employer.

- * subsidised employ. - life long.
- * partially subsidised - dependent on productivity
- * temp. subsidised in initial employment

Diff between
choice + options

Issues for SMEs

How to make support available for employment and still make the best choice

How to organise support. ~~Employer & trade~~

~~Why~~ should an employer employ a person with disabilities?

Why should a person with disabilities want to work?

How can a person with disabilities be involved in policy & process design?

- ~~Need~~ to empower individuals as well as well coordinated services

Barriers

- ~~Social~~ lack of social awareness

lack of continuity & coordination of support

Employer productivity requirements

Conflicting views about ~~individuals~~ ^{goals} for disabled person. Need for coherent policies across depts, risk up to conflict between work & non working life

- ~~Provision~~ Ownership of assets by agencies and professional - competition

corporations are willing to be
involved - but it is a
matter of economic
survival.

Business is not just
people - some provide
lookin about the diversity
mean / motivate
\$1 m for teacher 2
with a science
the employees. Use
them on motion. Show
can do it.

Employees in risk for
the last guest paid
While induction around
transition in coming change.
Parent occurred in past
of look for a case. We
have now moved a long
way beyond this

Develop more effective
relationships between the
school & business - more
integration. Companies come
to do school to give the
school the opportunity to
the business world, large
are not at the top.

State-type limit
young people and families
also involve race and
other forms of discrimination
Real problem is above -
typical

Parents w. Anally, matter
Education does not
with Bankrupt world
Parents of direct communication
with Bankrupt world

Parents must pay
to move to create students
in world of work
role of parents much
to emphasize
limited aspect
some opportunity to be
change
develop from
person / education / social
providing employment here
than other child
the business world, large
are not at the top.



Barriers - must address
on definition of equality
= each of important
on importance of equality
= must eliminate
information.
- need to eliminate
traditional roles and have
the put in

must
research
dynamist
looking for
must include current
media and other

emphasize program
a really different
change report
World leaders is
kind of economic
mind - can move
off to be the real
of women.



NAME

NOTES

Small Groups for Discussion

1) Barriers

2) How to overcome

3) Implications

Principle in Denmark of Work

Right to work is not as important as the opportunity

Combine right to work with the opportunity

~~Definition~~ Definition of work must be broader

Barrier is loss of benefits if you attempt to work

Social system does not assure access. An example is penalty for a social worker

Major barrier is lack of universal health care system.

40 000 requests - medical services is the largest request.

PERSONAL CHOICE

0

1) Gender - ~~are~~ ^{are} choices
the same for males
and females?

2) ^{the question to} who works a right
~~we all have~~
that we all share?

3) ~~Contra Personnel~~
~~thoughts~~

2) What is necessary
to ~~make~~ prepare a
person to make a
informed choice?

3) What is the balance
of responsibility between
government and ~~the~~ the
private sector given
that most employment
is in the private sector

4) What is the nature
of the support you offer
and how do you
place the ~~weight~~ ^{weight} on
control of ~~many~~ ^{many} choice?
How do you teach
a person to choose?



NAME

NOTES



③ Role of Private Government

- Government must eliminate discrimination
- Government must facilitate & stimulate employment opportunities
- Higher standards to work is less of a hindrance
- Fear & lack of know as part of it
- Lack of T. very
- Lack of Technology
- Our social norms model is based on one today, not tomorrow
- Government can provide technical assistance & disseminate information
- Government can do more on technology.

Do OECD countries have a method supplying for the disabled? The in Denmark that they can choose disabled before the normal economy & ~~before~~ create a private system UK has no method of supplying

Also in France

800 in France in line for not employers.

Of employed disabled people 64% work for state & federal government therefore we need an employer incentive program to get more people into employment.

EM comments that employers are open to employment.

Many among disabled people are left out, much emphasis is now placed on more legislative disabilities

④ ~~the~~ What is the nature of support for how do you reach a person to choose personal needs

economic "educate" choice based on equality rights / freedom of access.

We must start with the premise that one thing for everyone else. Don't move them off from this expectation of that produced from they share

every income produced share
government
Tamil
lack of information
policy
third hand support

Networking

Employer work in partnership w/ educator to insure the development of a marketable program product. Employers help design training curricula.

Kuwait is w/ student over a lengthy period of time (8 grade $\rightarrow$ couple yrs after school)

evening/weekend hrs of Kuwait for communication w/ families

Need for attitude change to see that people can make decisions by students

Approach for non-dis is equally good for dis & reverse. How can we transfer a particular prog from 1 pop to another.

be allowed to fail

6x
transparence
determining competency to choose

increasing opportunities for decision making
reduces risk

non-paid (employment)

pre-school decision making

Employer based competencies

Sam McKee

3. barriers

- 1) £30 gender Carol Helen Giza
- 2) prepare to make choices Bob & Martha Jones
- 3) responsibility for public & private sector support to facilitate Kan! SHU
- 4) what supports are necessary to facilitate choices Danielle Norris Jean
- 5) rights to work (is this a responsibility of society?) Phil Jorgensen

1. Gender

Implications

Redefine / reach clarity
on def of equality

Lack of importance
in society / fam / person

structure of educat
system (patriarchal)

Stereotyping of jobs
by gender

Outreaching
research & training
awareness raising

Women's Bureaus
Media

lack of direct
communication w/
the world

Apprenticeship programs

people w/ dis are
isolated by
service providers to
have opportunity to make
educational in gen'l
doesn't prepare to
make choices

parents (esp. dads)
don't include in
world of work

Schools focus on
college more than
other options

uncertainty as to
role of parents in
trans a post

limited expectations
to use choice

③

govt has responsibility
to eliminate barriers
to policy

dissemination of info
particularly in
assistive tech

systems must be willing to
bridge gaps &
make network

govt has responsibility
to stimulate priv
sector initiatives

teaching ability to
generalize to
modifications at & on
job site

UK (ingdom)

- 1) work observation
- 2) work shadowing on specific job
- 3) work placement - phase in w/ mentors from
educ & industry

Personal
Self
Employ
Economic

Choice must be based on equality

Basis is services available to everyone

Barriers to choice
financing

lack of educ
family (overprotective)
lack of innovative opps

~~MM MM MM MM MM~~

no it to work
it to liberty
definition of work

Intra-agency Collaboration, Co-Funding and Service Delivery

- ① Philosophy / Policy Direction — Aims / Objectives.
of Transition.

Additional resources to equalise opportunities

- ② Clients (i) Conception
Individuals
- a) A recipient of services for all
 - b) a recipient of services for disabled
 - c) a recipient of services for a specific disability

(ii) Identification, Entitlement, Empowerment.

- ③ Services (i) ^{Type} Specific / sectoral or Comprehensive.

(ii) Delivery By sector or via link person.

(iii) Management By each agency or by coordinating group.

(iv) Specialist knowledge.

- ④ Finance (i) Governmental Level - National, Regional, Local.
(ii) From Specific or Block Grants.

- ⑤ Responsibilities Whose? The individual / Parent
The broker?

- ⑥ Barriers to Independent living and work.

- ⑦ Possible Solutions

① Tidy-up Legislation

② Vouchers

③ Programme Funding

- Use of Money.

Financing Change

Nagye

Barriers

- ① Turf Guarding
- ② An Action Plan - lack of an agreed action plan.
- ③ Non-Compatibility of Agency Goals / Separation of professional/service interests
- ④ Fashion
- ⑤ Lack of Shared Goals
- ⑥ Conflict of Agency Goals — welfare of organization
welfare of clients
- ⑦ Poor communication at local and other levels
- ⑧ Financial disincentives to open employment
- ⑨ Allocation and use of resources
- ⑩ Cost of change.

Support/Protection in the generic system ^{protection} not from it.
Agreed aims / Not more agencies / People to wait for individuals.

- ① Individual funding
 - ② Case management / brokerage
 - ③ Inter-disciplinary Training.
- } with action plan { Empowerment
Co-ordination

But - who decides what to choose from → co-funding ←

- ④ An ITP starting from school yrs. (inter-agency)
- ⑤ Bench marks for quality of services
- ⑥ What choices are available - Framework for what to
constant make choices.

I Personal Life ~~Barriers~~ Care Advocacy

Barriers

- ① Gender - people with disabilities also face sex-equity issues - relate issue of gender to issue of stereotyping

- ② Knowledge - communication & coordination
 - misunderstanding of what businesses are looking for
 - need to stress what's rather than disabilities

- ③ Private vs. government roles -

- importance of eliminating disincentives to work
- need to effectively coordinate health care/therapies
- role of government in providing support

- ④ Work as a "right" -
 - psycho-social importance of work
 - opportunity to work is more important than the right to work
 - importance of health insurance/medical support

II Integration in Workplace

Meaningful -

- contribute to enterprise
- integration with sharing
- opportunity for growth/progression

Issues

1. How to make support services available but also permit individual choice?
2. Why should an employer hire a person with disabilities?
3. How to organize work?

⑤ Barriers

- lack of active awareness
- lack of community & coordinating services
- productivity
- conflicting goals - employer/employee
- work life/home life
- conflict of interests with career & professions

• Support should be flexible, individually tailored & fine limited

• support should be tripartite: worker, employer, co-ordinator
 • reliance on human rather than financial support

• model should simultaneously meet needs of employer & aided worker

• life stage teams + advocate (creator)

• guarantee to employer that job will be done w/o additional cost

• 3 models of employment:

- permanent, ongoing support
- short-term, intensive support
- temporary subsidization

III. Comprehensive Services

- agreed policies + philosophies
- conception of services for people
- generic services
- availability specific services
- credit - specific services

Independent, organized
 open employment &
 independent living

Barriers

- half quantity
- lack of agreed action plan
- non-compatibility of agency goals + incompatible goals of existing network & service organizations vs welfare of client
- fashion - flavor of the month
- good conflicts
- poor communication
- financial disincentives to go-employment
- allocation & use of resources - "pockets"
- cost of change (inertia)

Solutions:

- practice with the generic system (vs specialized system)
- goal integration
- [no superagency or new agency]

3 major directions

- individual funding: # follows individuals - increased support & clear incentives
- case manager / bridge function: engagement of the individual
- interdisciplinary training - narrow, excluding professions barriers - need for ~~shared~~ "athletes"

• Who decides what an individual is to choose from?

• Agency boundaries for "quality" / "outcomes" / services?

State Department
7th Floor, 6:00 PM