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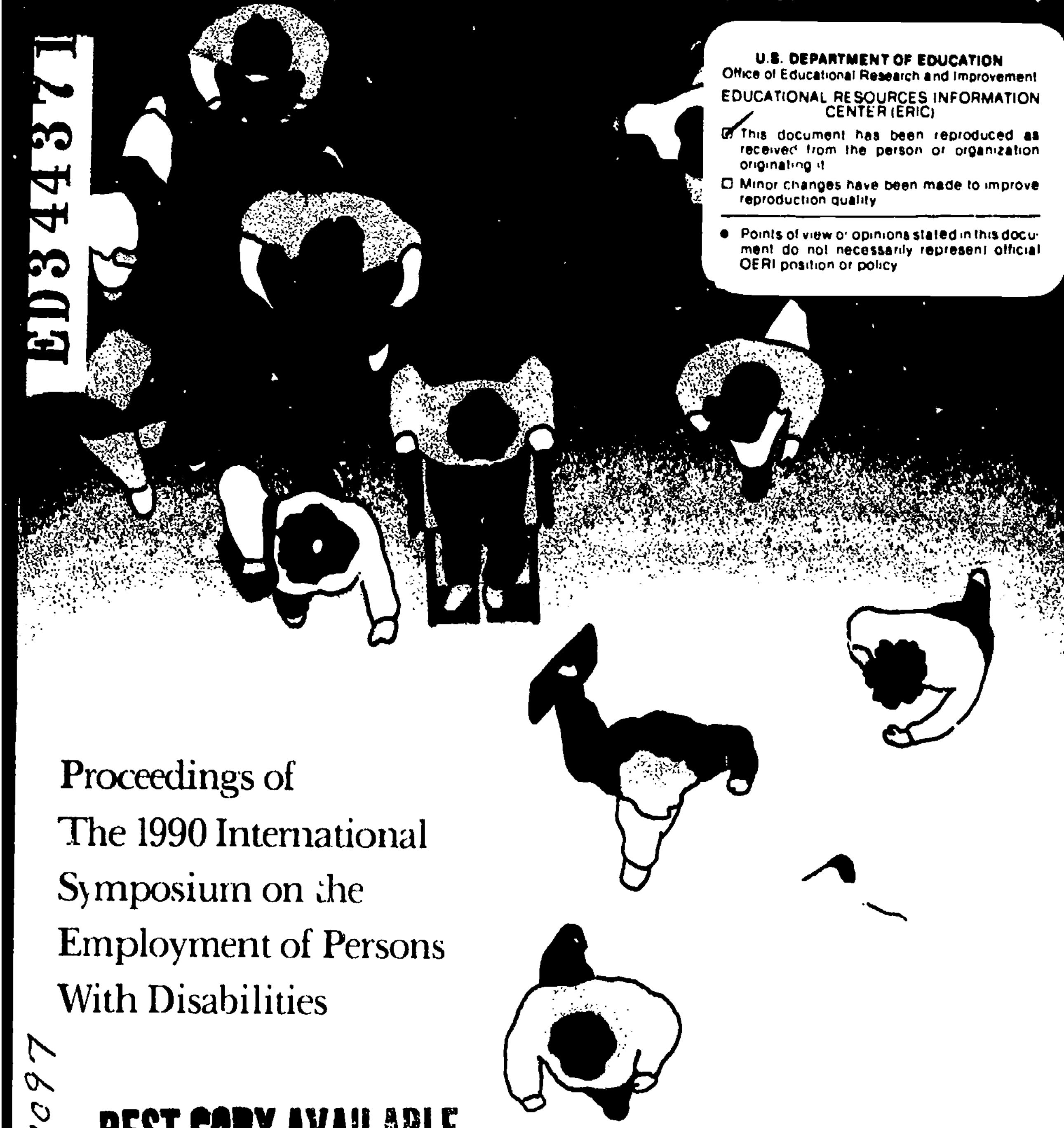
ABSTRACT

This document presents the proceedings of a symposium which discussed critical issues in employment of persons with disabilities in Europe, Australia, and North America. After introductions, the major presentations included the following: "Labor Market Forces" (Roderick A. DeArment, U.S. Department of Labor); "Civil Rights in the United States" (Steny Hoyer, U.S. House of Representatives); "Economic Consequences" (Martin Gerry, U.S. Department of Health and Human Services); and "Towards an Adult Working Life" (John Fish, Consultant to the Organisation for Economic Cooperation and Development). Small group discussions are summarized. These focused on personal choice, effective integration, and organizing and financing community services, respectively. The conference resulted in seven recommendations and conclusions including: (1) because of the lack of accurate information, audits are needed to establish databases on resources devoted to disability; (2) a balance between government and private sector funding of programs for persons with disabilities is needed; (3) because employment offers regular social interaction in an integrated setting, it is particularly important for young people with disabilities; and (4) a benefit system should be established which encourages and supports individuals as they move in and out of the workforce. Appendices include a fact sheet on the Americans with Disabilities Act, a list of OECD publications, and a list of participants. (DB)

EMPLOYMENT



Proceedings of
The 1990 International
Symposium on the
Employment of Persons
With Disabilities

INSTITUTE FOR THE STUDY OF EXCEPTIONAL CHILDREN AND YOUTH
UNIVERSITY OF MARYLAND AT COLLEGE PARK

TRANSITIONS TO EMPLOYMENT

PROCEEDINGS OF THE 1990 INTERNATIONAL SYMPOSIUM ON THE EMPLOYMENT OF PERSONS WITH DISABILITIES

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UNIVERSITY OF MARYLAND AT COLLEGE PARK

PREFACE

This document presents the proceedings from an international symposium that was held on June 3, 4, and 5, 1990 in Washington, D.C. Co-sponsored by the United States Department of Labor, the Organization for Economic Cooperation and Development (OECD), and the University of Maryland, the symposium was planned to create a forum to discuss critical issues in employment of persons with disabilities in Europe, Australia and North America.

The initial idea for the symposium evolved from the discussions of Department Chair Dr. Philip J. Burke, Drs. Margaret J. McLaughlin and Lani Florian of the Department of Special Education at the University of Maryland, and Mr. Martin Gerry, Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. At the time, Mr. Gerry was Visiting Scholar in disability policy studies at the University of Maryland and consultant to the Organization of Economic Cooperation and Development. Mr. Gerry's awareness of the efforts OECD countries were expending on preparing young adults with disabilities to transition into the workplace led to the development of a symposium designed to disseminate information gathered by the OECD concerning successful strategies within member countries to assist young adults with disabilities make the transition from school to sustained gainful employment.

In 1987, the United States Department of Labor offered a grant to the OECD to support research on employment of persons with disabilities. The Department extended this grant to the OECD to support the symposium. The University of Maryland and the Department of Health and Human Services also contributed support. Mr. Lex Frieden, a prominent disability rights activist and United States Department of Labor representative to the OECD, was the natural choice to chair the symposium.

The symposium was planned as a small working meeting. Participants were invited based on their experience with developing transition and employment initiatives. Individuals from various countries were assigned to one of three working groups to discuss issues and suggest policy options in each of three areas related to employment:

Personal Choice; Effective Integration and Support in the Workplace; and Organizing and Financing Community Services. Presentations by high ranking policymakers created an exciting context for the symposium. At the time of the symposium the United States was on the verge of passing the Americans with Disabilities Act, a comprehensive civil rights bill for individuals with disabilities which includes important anti-discrimination provisions regarding employment. This document presents those presentations and the summaries of the two days of discussion and dialogue concerning critical issues related to employment of persons with disabilities. The document provides the context for understanding better the problems and exigencies of developing full employment policies as well as the varied approaches nations are using to support such policies.

ACKNOWLEDGEMENTS

This document is the work of many hands. A number of individuals deserve special thanks for their involvement in planning the symposium and editing the lengthy transcripts that resulted in this document. Ms. Sandra Warren and Ms. Sandra Cawley were invaluable in planning every detail - both business and social - of a comfortable and congenial meeting. Mr. Mel Brodsky of the Department of Labor gave much time to planning the conference and preparing materials for participants.

We have endeavored to make the best presentation of volumes of material. The work would not have been possible without the excellent assistance of Ms. Janet Gallant, technical editor, and Dr. Charles MacArthur who assisted in producing the final document. Thanks are also due to all the presenters and participants who reviewed various sections of the document. Finally, Nancy Domchik and Eileen Gaffney are appreciated for their skillful word processing.

We hope this document conveys the essence of what was a very stimulating and informative conference.

Editors

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PART ONE

INTRODUCTIONS

INTRODUCTION TO THE INTERNATIONAL SYMPOSIUM ON EMPLOYMENT OF PERSONS WITH DISABILITIES

LEX FRIEDEN, EXECUTIVE DIRECTOR,
TIRR FOUNDATION, HOUSTON, TEXAS

It is my pleasure to welcome all of you to Washington for what promises to be a productive and provocative conference. The participants in this symposium represent a unique blend of perspectives, experiences, knowledge, and backgrounds. We have experts from Norway, Sweden, Denmark, Australia, Canada, Italy, and the United Kingdom joining a wide range of American participants.

As you know, this symposium is sponsored by the United States Department of Labor, the Department of Health and Human Services, the Organization for Economic Cooperation and Development (OECD), and the University of Maryland. These sponsors have set three very important objectives for this meeting.

The first is to familiarize American professionals with innovative European approaches to employment and service coordination for people with disabilities. Over the past 10 years, OECD, with the support of the United States Departments of Labor and Education, has been studying the transition of young people with disabilities as they move from school to the workforce. The OECD results (see bibliography) are relevant to experience in the United States, and our symposium will help disseminate this valuable information.

The sponsors' second objective is to exchange information on disability policies, programs, and the labor market situation in the United States. With the recent passage of the landmark Americans with Disabilities Act (see Appendix for a fact sheet on the Act), the United States has taken a major step toward ensuring the civil rights of citizens with disabilities. On another front, the American business community's involvement in job training and education has yielded encouraging results which we will share here.

The third, and perhaps most important, objective of this conference is to discuss specific issues and make recommendations for policy and program changes. On a focused and practical level, we will identify barriers to implementing effective programs, and look for ways to overcome those barriers.

The success of a meeting such as this depends on critical elements: good planning and preparation, good subject matter focusing on important issues, and good people. This symposium has all of these. The challenge for us now is to use this opportunity as efficiently and effectively as possible so we can all gain from the experience. With that in mind, I would like to review our agenda for the next two days.

First we will hear from Thomas Alexander of the OECD who will introduce the results of that organization's studies on transition from school to the workforce. Roderick DeArment of the U.S. Department of Labor will discuss labor market trends and how they affect the employment of persons with disabilities.

Next, United States Representative Steny Hoyer, sponsor of the Americans with Disabilities Act, will explain the significance of that legislation. Martin Gerry of the Department of Health and Human Services will talk about the economic consequences of the unemployment of people with disabilities, followed by John Fish who will discuss the OECD transition studies in detail.

After this exchange of information about U.S. and international experiences, we will begin group discussions. Each group will meet twice today for repeating sessions and once tomorrow for in-depth follow up. You should attend two different groups this afternoon, and choose one to return to tomorrow. During the final joint meeting, we will summarize the findings of all the sessions.

For these group discussions, the sponsors of this conference have selected three important issues based on advice from many of you. I would like to review the issues with you and examine their relationships to each other.

The first issue is personal choice, a subject we in the United States have paid a great deal of attention to in recent years. The decision-making role is the most important one for persons with disabilities. Yet, too often we have interpreted personal choice to mean using mechanistic tools to evaluate people's skills and interests, and then providing them with directions.

We have to translate the concept of personal choice and independence from the theoretical level to the personal level so individuals with disabilities can manifest their abilities in the process of making decisions. I submit that anyone with a disability, given appropriate choices to make, can do so. Our programs should facilitate decision-making throughout an individual's life.

Yet, while we have examples here and there of programs that work, we've never been able to effectively promote personal choice in a systematic, institutionalized way. It is up to us to figure out how to do that, and in our discussion group, we can begin talking about practical ways to make personal choice a reality for people with disabilities.

The second group will focus on effective integration and support in the workplace. Until recently, we talked about work as an isolated subject. But for people with severe disabilities, work involves interrelated social, political, economic, and service systems. It involves practical issues: getting dressed and ready each day, commuting, finding a place to live, finding opportunities for socializing and recreation. Those of us with disabilities understand all the conditions necessary before employment is possible.

Most people with disabilities do not see work as an integral part of their lives, and they don't recognize that work will lead to other opportunities in the community. As long as persons with disabilities have no incentive to go to work, supported employment and other reinforcement programs will be ineffective.

We have to expand our concept of successful integration. The Americans with Disabilities Act will go a long way toward moving people with disabilities into the workforce because its approach is system wide. Beyond that, we have to broadly define supported employment to include whatever is needed to make work a meaningful part of life for individuals with disabilities.

The third topic for group discussion is a wise and necessary one: organizing and financing community services. How can we achieve our objectives of personal choice and successful integration into the workforce when we don't have effective coordination and financing for programs?

For the most part, we haven't been able to apply the theoretical concept of coordination to our dealings with individuals. We have examples of successful case management in Australia, Canada, the U.S., and other countries. These give us a clue to moving from coordination as a national policy to the actual coordination of services to people in their home environment. But I suspect that case management is not the ultimate solution; without coordination at all levels, we will lose our initiative and momentum.

Coordination is a practical issue. But because of the number of agencies involved in every disabled person's life, coordination can seem almost unmanageable. Financing can also seem an overwhelming issue. The amount of money available depends on time, place, and economic conditions, and many of the most effective programs look to a variety of sources for funding.

Yet difficult as coordination and financing may seem, we have to regard them as manageable problems and address them as though they have solutions. That is the best way to accomplish our objectives.

In our groups, we will have only a limited time to discuss very complex subjects. I suggest that each group first arrive at a common understanding of the main issues, then move to a practical level by developing recommendations, and identifying and addressing barriers to implementing change.

The work we will do here is important. As our speakers this morning will tell you, the majority of people with disabilities are capable of meaningful and valuable work. However, few achieve what they are capable of and many remain dependent all their lives. This is a loss not only for individuals but for society. Economically, socially, and culturally, we are all hurt when large numbers of our citizens are left out of the workforce.

SYMPOSIUM GREETINGS

PRESENTED BY THOMAS J. ALEXANDER
DIRECTOR FOR SOCIAL AFFAIRS, MANPOWER, AND EDUCATION,
ORGANIZATION FOR ECONOMIC COOPERATION AND DEVELOPMENT

Let me express my thanks that the Organization for Economic Cooperation and Development has been able to collaborate in this conference. As international organizations go, the OECD is unique. It is a forum where the 24 industrialized democracies of the world meet together. We also have Yugoslavia, a member with special status. It's not a homogeneous group. We have the United States. We have Portugal. We have Japan. We have a range of economic performance, and do have a common uniting theme: pluralistic democracy based on the philosophy of the market. Demographic trends in OECD countries are changing the composition of the labor force. The number of young people entering the labor force is diminishing and these traditionally have been the most adaptable, highly skilled workers in the market.

Skill shortages are emerging, have emerged in some countries, and paradoxically they often coexist with high levels of unemployment. The changing character of jobs and skills and the labor markets themselves pushed by technological change have increased interdependence and globalization.

These are all challenges that labor market policy makers are going to have to face because unless labor markets adjust to these new challenges, the growth we expect, the growth we hope for, is going to be forestalled. Governments, therefore, agree that policy should now shift from passive support to active measures in labor market policies.

The object is to improve labor supply in quality and in quantity. Training will be an essential element in this and so will improved employment services. It will be essential to ensure that training and other measures are adapted for those people who for one reason or another have been excluded from the labor market. All people should be given the opportunity to participate in the mainstream of economic and social life. This encapsulates the notion of the active society providing the means for those who want to participate in society to do so.

Opportunities for new job openings for people with disabilities are being created. Perhaps the greatest challenge will be to cope with the changing skill requirements of the labor markets in the 1990s and to demand life-long learning and retraining. The evidence is clear that a very high percentage of young people with severe disabilities are capable of employment and independent living, provided that they have appropriate education and training in their middle 20s, and that appropriate support continues to be available to them when needed.

But in practice, only a small percentage of people with severe disabilities achieve these objectives in adulthood. Many leave education for a dependent type of life. Transition is often a process characterized by a fragmented pattern of national, regional, and local responsibility for individuals and families and more often determined by special interests, budgets, and tradition than by the needs of the individual.

Several OECD studies have identified a number of factors needed for successful transition. The transition phase must be identified and find a response in policies and services. There should be clear aims for the phase of transition and its process. Opportunities should not be limited by stereotyped attitudes at the end of education. All agencies concerned should recognize each other's contribution and work toward a core of national efforts to agreed ends. Agencies and professionals must involve parents and families in the discussion of aims and programs.

Innovative practices can be helped or they can be hindered by the course or framework within which they are developed. All too often policy can have unintended side effects. For example, a benefit system that is available only when an individual is employed and cannot be used to support low wage work, creates obstacles to supported employment.

Creative policies must be developed to facilitate innovation. Despite the fact that integration is accepted as a reality in most OECD countries, much remains to be done. The time has now come to look afresh at policies and practices.

This symposium is taking place at a time when c [illegible] se of OECD work on transition for those with disabilities is draw [illegible] conclusion. Your deliberations will not only be an effective mean [illegible] isseminating the work in the United States, but I'm sure that new issues will emerge from your discussions which will provide us with much material for further study.

PART TWO

PRESENTATIONS

LABOR MARKET FORCES AND THE EMPLOYMENT OF PERSONS WITH DISABILITIES

PRESENTED BY
RODERICK A. DeARMENT, DEPUTY SECRETARY,
U.S. DEPARTMENT OF LABOR

It's a special privilege to open the International Policy Symposium on the Employment of Persons with Disabilities.

I would like to take this opportunity to describe current U.S. labor market trends and how the employment of persons with disabilities is being affected. The United States is now in the midst of significant demographic and technological changes that have far-reaching implications for everyone, particularly for persons with disabilities.

Labor market statistics indicate the total number of persons with disabilities is more than 43 million, or about 1 in 6 Americans. Only about 1 in 3 persons with disabilities is in the labor force, compared with 65% of the general population. Over 15% of individuals with disabilities are unemployed, compared with approximately 5% of the U.S. population. The most disturbing figure and, indeed, the reason we're here today, is that the majority of special education students in the U.S. leave school for some form of dependency.

These are discouraging statistics. There are several critical factors converging that make employment prospects for people with disabilities much brighter in the days to come. The growth of the labor force is slowing as a result of declining birth rates, which will force employers to look beyond their traditional sources for entry-level workers, for example, to people with disabilities.

Indeed, we expect that over the 1990s the labor force will only grow about 1% a year. During a really rapid period in the 1970s, the labor force was growing at about 2.7% So, with the 1% growth in the labor force and the economy growing at a higher rate, there is going to be a constraint on the number of available workers, and employers will have to turn to non-traditional methods of recruitment if they expect to remain competitive in the labor market.

At the same time, the restructuring of the American economy will continue to demand overall higher and broader levels of basic skills in the workplace. For individuals with disabilities this changing environment means that as the number of jobs requiring manual skills decreases, physical limitations will become less and less relevant.

Although the Department of Labor shares the responsibility for serving persons with disabilities, all agencies in this Administration are committed to increasing access to the labor market. Furthermore, the rights of persons with disabilities will be reinforced when the President signs the Americans with Disabilities Act.

The Labor Department's primary vehicle for training individuals at risk is the Job Training Partnership Act. We are currently seeking to strengthen this Act through amendments that will target the disadvantaged youth and adults most at risk of long-term unemployment. We expect that this will lead to more services for individuals with disabilities.

State employment agencies, which are funded through Department of Labor grants, provide services for applicants with disabilities who need help in obtaining employment. Local employment service offices generally have at least one staff member assigned to ensure that applicants are given counseling, occupational testing, job search assistance, employability appraisal, and placement services. Often local offices work closely with other community-based organizations to provide training, rehabilitation, and supportive services.

The Department's employment and training administration also provides funding for seven national advocacy organizations for individuals with disabilities to provide a wide range of information exchange, training, and job placement opportunities. One of those organizations is the Association of Retarded Citizens of the United States. This group is extremely active with supported employment efforts. As a result, this organization reports placing more than 37,000 people in competitive jobs over the last two decades. Employers today know it is in their interest to help expand the ranks of trained, employable persons with disabilities. Companies can communicate their needs to rehabilitation professionals. But we believe business must become even more directly involved in the training process by becoming a partner in existing programs.

The Department of Labor is anxious to publicize private sector successes in assisting persons with disabilities find competitive jobs. Some of these successes are highlighted in a recent study prepared for the Department, entitled "Opportunity 2000." This study includes numerous strategies for recruiting, developing, and retraining disabled workers as well as minorities, the economically disadvantaged, older workers, and veterans

In cooperation with federal and state governments, IBM has been working to provide computer programming training courses for persons with physical disabilities. Since 1982 more than 2,500 persons have graduated from 38 training centers around the country, and IBM proudly states that 80% of the graduates are being placed in jobs starting at $20,000 a year or more.

Another success story is Marriott Corporation's program to train workers with mental retardation to perform jobs in the company's cafeterias. At the conclusion of 13 weeks of training, the company may hire them for openings in a nearby Marriott facility or send them job-ready to a referring agency for placement with another company. Similar training programs and training geared toward other persons with disabilities are offered regularly in Marriott operations around the country and these efforts have earned the corporation many awards from rehabilitation agencies.

Once workers with disabilities are integrated into the workplace, attitudes will change. The Department of Labor is anxious to work with all of you to make a reality that benefits all of us. I'm sure this two-day meeting will provide a better focus for helping people with disabilities find employment in today's economy, particularly those young people trying to make the transition from school to work.

Before I leave I want to share with you a thought that was expressed by Anne Sullivan during an address to a conference on the education of Helen Keller. Close to 100 years ago this famous teacher gave the conference a charge. "I ask you to free your minds from preconceived notions and theories regarding this case and give it the thought and study it deserves, with a view to satisfying yourselves whether the same or similar results can be obtained when children are so fortunate as to have eyes and ears with which to see and hear." Anne Sullivan's charge holds even today and I urge you to step back and take a fresh look at these problems.

CIVIL RIGHTS FOR PERSONS WITH DISABILITIES IN THE UNITED STATES

PRESENTED BY
THE HONORABLE STENY HOYER
MEMBER OF THE U.S. HOUSE OF REPRESENTATIVES

I am pleased to be with all of you. You're fortunate, in my opinion, to be holding this conference here as the United States is on the verge of enacting the Americans with Disabilities Act (ADA, see Appendix for a fact sheet on the ADA).

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

Indeed, if we also pass the Civil Rights Act of 1990, Ralph Neas, who is the executive director of our coalition which fights for civil rights in this nation, says that it may well be the most important year for civil rights in the history of this country. Every time he tells me that, I wonder about the Emancipation Proclamation and other similar documents. He may have overstated by just a little bit, but in any event, it is obviously important, and I am pleased to have played some role in that effort.

I came of age, at least politically, in the era of John F. Kennedy. Many of you, in our own country and throughout the world, heard his call to public service and commitment to make life better for not only the citizens in this country but for citizens around the world.

I was very enamored and impressed and motivated by that call. About children who were handicapped, we now use the term "disabled," but "handicapped children" was the phrase at that point in time when Kennedy said, "Although these children are the victims of fate, they shall not be the victims of our neglect." I think that ought to apply to every citizen, able or disabled, black or white, male or female, rich or poor: that persons in our societies wherever we find them ought not to be the victims of our neglect.

Last June 15th, *the* sponsor of the Americans with Disabilities Act, Tony Coelho, one of the most able members of the Congress of the United States and one of the most able politicians in America, decided to leave the Congress of the United States; he turned to me - I was a close friend and also a close ally in the effort to pass the Americans with Disabilities Act - and asked me to shepherd that bill through the House of Representatives.

I might say that Tony Coelho had a special reason for being a very strong sponsor. He has epilepsy. There were some who historically would have said he was disabled. I think the last word that you would apply to Tony Coelho is "disabled" in any sense of the word.

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

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

I know there are some of you here today from some of the Central European nations as well as other nations of the world, and I understand there is a representative here from Poland. Lech Walesa gave one of the most compelling speeches that I have ever heard given to a Joint Session of Congress; he was joined shortly thereafter in similar sentiments by Vaclev Havel, the poet-philosopher-president of Czechoslovakia.

Both of these men had a common theme and that theme was that the words of Thomas Jefferson, as incorporated in the Declaration of Independence, were some of the most compelling ideas for those emerging nations as they seek to make their countries more open, more democratic, more free, both in the political sense and in the economic sense. Thomas Jefferson said, "We hold these truths to be self-evident, that all men are created equal, endowed by their Creator" - not by the state - "endowed by their Creator" - a higher being than the political state - "with certain unalienable rights and among these are life, liberty and the pursuit of happiness."

However, even in a nation so perceived, I have learned from Lex Frieden and thousands of others that the reality of daily life in America for persons with disabilities is not focused on individual opportunity and rights.

I have also learned in the course of talking to people who are challenged daily by a disability about reasonable accommodation. Now, all of us make reasonable accommodations every day. I make them to my staff and our staffs make them to us. There are vagaries of difference in each of us. You make accomodations to your children. You make them to your spouses. You make them to your fellow workers. We all make reasonable accommodations.

We learned that people with disabilities can, in fact, do an awful lot, very much, in fact, if given the opportunity and reasonable accommodation. I recognized, as did my colleagues, the parallels between types of discrimination that Americans are more familiar with, and discrimination based on physical appearance, or on the belief that all people with a disease like epilepsy will have uncontrollable seizures or that some people hear the world in a different way.

It is no different, I have learned and my colleagues have learned, than the assumption that a different skin color means one's talents and abilities are inherently different. My learning experience was not unique. In fact, I believe that the process that Members of the House of Representatives went through in learning about the needs of persons with disabilities while considering this bill greatly contributed to our victory and the 403-to-20 vote for passage of ADA. Each Member of the Congress in one way or another shared the experience of education during consideration of this bill.

One of the most important results of the ADA and the intensive lobbying effort of scores of dedicated individuals with disabilities was the education of Members of Congress, and the education of advocates and opponents.

There were really no opponents of ADA. Nobody would ever say they opposed the Americans with Disabilities Act, but there were some changes some wanted to make. Some changes were more extensive than others, but there were no opponents of this legislation.

The opponents learned well, and far more than from any hearing, fact sheet, or floor statement; the learning process included a heightening of consciousness which has been so much a part of every civil rights movement, whether it was the heightening of consciousness in Birmingham by that stark television portrayal of the dogs of Bull Connor confronting the civil rights marchers in Birmingham, the incarceration of Martin Luther King, or whether it was the heightening of consciousness in the women's movement in America, where it was made crystal-clear that we discriminated badly against females in our society.

We all had to raise our consciousness with respect to persons with disabilities, and one of the things that has happened during the consideration of this legislation over the past four years has been that raising of consciousness. The Members saw and heard from people with disabilities who explained to them their needs, their rights to equality, and the effective ways to achieve that end. We learned to look to the world around us from a different perspective, and we saw that it was inaccessible to far too many of our citizens. It is that education process that must be continued in the coming months, in my opinion, in order to make the Americans with Disabilities Act a successful law in this nation.

In the coming years, disability will not dictate and define an individual's course of life, at least theoretically. It is the course of life for persons with disabilities that this bill is designed to address.

The ADA is a comprehensive bill which encompasses all facets of life. It is not simply an employment bill that protects against discrimination in employment. It is not simply a transportation bill, although it ensures that our nation's transportation systems, public and private, will be accessible. It is not simply a telecommunications bill, although the ADA will finally fulfill the wish of Alexander Graham Bell and provide that the nation's communication system is of use - maximum use, hopefully - to the hearing- and speech-impaired.

Finally, it is not solely a public accommodations bill, although it does provide that new buildings will be built accessibly and that our restaurants, movie theaters, doctors' offices, pharmacies, hotels, stores, and other places of public accommodation will no longer be able to post signs saying, "Disabled need not enter." The Americans with Disabilities Act is a law that over time will change the face of America by truly bringing, inviting, encouraging the disabled, who have been left out or shut out of so much of American life, into the mainstream of American cultural, economic, social, and educational life.

The ADA is based on the recommendations of the National Council on Disability, a bipartisan group of 18 persons appointed some years ago by President Reagan. The ADA was truly a bipartisan effort, strongly supported by the President of the United States, whose leadership was critical to the overwhelming, timely passage of this legislation. I might parenthetically say that while I refer to it as timely, it is effectively centuries late, as was the 1964 Civil Rights Act. However, it is always timely to correct errors of discrimination, and in that sense it is timely.

The National Council on Disability found, after extensive and exhaustive investigation, that Americans with disabilities faced discrimination in almost every facet of their lives, including employment, housing, transportation, communications, and recreation. As a result, people with disabilities are more likely to be poor, are more likely to be unemployed, and are more likely to be receiving public assistance. They are also less likely to travel, are less likely to attend sports and leisure activities, less likely to go to the grocery store and other public accommodations. In fact, people with disabilities are less likely to participate in virtually all aspects of mainstream activities of American life.

The solution, we determined, was through a number of sections that address each area specifically. The employment section prohibits discrimination against qualified individuals. It was very difficult to communicate that concept, very frankly, at the outset, that the Americans with Disabilities Act is not telling, nor should it tell employers to hire people who are not qualified to do the job. It simply says, however, that those who are qualified ought not to be shut out for some arbitrary distinction which does not adversely impact on their ability to perform the essential functions of the task that the employer needs doing... a very important concept.

It is a concept that we know and accept full well when we deal with national minorities, women, and other discriminated against groups. We are now saying the same thing about those who have disabilities, that unless it is relevant to the performance of the job, you cannot, must not - it is un-American, immoral and bad business to - discriminate against able people. The employer, therefore, is required to make a reasonable accommodation to permit them to be able to be employed.

The ADA further provides that employment tests or qualification standards cannot screen out people with disabilities unless those requirements can be shown to be job-related and related to business activity. Once again, we are saying "no" to arbitrary and capricious discrimination.

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

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

Thus, under the ADA, all new vehicles purchased, including public buses and commuter light, rapid, and interstate rail cars must be readily accessible to and usable by those with disabilities. In fact, there were two very controversial amendments on the floor of the House dealing with that issue, and they were soundly defeated by the full House of Representatives, rejecting the concept of separate but equal transportation systems, a concept that had been rejected in 1954 with respect to segregated education in *Brown v. Board of Education.*

New buildings also must be built to be accessible as must major renovations to a primary function area, such as making the path of travel accessible.

The sum of all these provisions is that one day soon lives will be dramatically changed and enhanced. For the children who have gone through school under the Education of the Handicapped Act and are ready to move into the world, we will be able to meet their justified expectations.

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

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

ADA is a comprehensive bill which recognizes that two-thirds of the working-age persons with disabilities do not work. Think of that. In a society where we are on the verge of having a labor shortage, two-thirds of that number do not work, not because they don't want to work, not because they don't have abilities with which they could perform certain tasks that our society needs doing, but because our society has not made the accommodation to include them, even to our economic detriment.

For example, a recent Lou Harris poll found that 28% of the non-working persons with disabilities cited the lack of accessible transportation as the reason they did not work. Therefore, one of the reasons why it was so important to have a very broad-based treatment of the whole challenge was the internal nature of the problem. Without the ability to get to work, having a job is somewhat of a meaningless right. It would have made no sense to have guaranteed equal opportunity for a job but to have no protection to get into the building in which that job was located.

Now that we're on the verge of passing a major piece of civil rights legislation which reaches out its hand, opens its door, and puts down the welcome mat, now, what do we do?

The answer I suggest to you is that it's a responsibility of each of us to make this policy a reality for people with disabilities. Nothing happens simply because Congress says it's going to happen. It happens because people are willing and enthusiastic about carrying out that policy.

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

It is important that we have universal access for the those with disabilities just as we have universal access for most of us in this room who do not have specific challenges for which we need some reasonable accommodation.

The world is opening up like never before. In some respects, ADA is *Glasnost* and *Perestroika* for people with disabilities. Many in the last years have come to Washington to find out about this landmark, unprecedented legislation. The United States will soon be, I am told, the first nation to adopt a comprehensive national policy of non-discrimination against people with disabilities. Yet, maybe in one of the countries represented here today you have significant legislation or public policies from which we can learn. One of the great virtues of the explosion of information exchange in the world is that we can better learn from one another.

Although we have passed this legislation far later than we should, it is now time for all of us to implement it as quickly and as effectively as we can. We must ensure that we fully include one in six Americans, 43 million Americans in daily life. That number is an incredible figure, one that I'm sure most members of the Congress totally rejected early on in the consideration of the legislation.

I am amazed at how many people have come up to me over the last three or four months as my involvement in the Americans with Disabilities Act has become known in my community. They tell me about their spouse, their brother, their sister, their mother, their father, their neighbor, their friend, their teacher, their coworker, whomever, who has a disability and has not been accommodated. It is amazing and I am more convinced every day that 43 million is absolutely accurate.

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

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

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

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

We are now confronted with the challenge of having articulated a policy and passed laws which will require architects and builders to accommodate, to make accessible, to allow things to be readily usable by persons with disabilities. We have told this to people who have businesses, who have doctors' offices, who have places of public accommodation, who have banks that you and I take for granted and must use day to day for our own use, for the use of our families, for economic intercourse generally.

We have said, "You must make those places accessible." We have told public and private agencies, "Over time your transportation facilities will be accessible." We have told communications companies, "You will allow people to communicate with one another notwithstanding a hearing or speech impairment." That's what we've said in the law. Now the somewhat more difficult, long-term and perhaps not as dramatic will occur, and that is the implementation of this legislation. Most of you in this room are experts. Obviously all of you in this room are sensitive to the challenge; I would hope that all of us together in the United States and around the world will become sensitive to the challenge.

Another hat that I wear is as a co-chairman of the Commission on Security and Cooperation in Europe, the Helsinki Commission. What has the Helsinki Final Act done? It has no army. It has no intrinsic bureaucracy. It has none at all, as a matter of fact. It has no way to implement the ideas that were enunciated in the final act. What it has done is to provide forums to talk with people, educate people, urge people to live out the promises contained in the 1975 Helsinki Final Act.

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

I opened by saying that John F. Kennedy said that children with handicaps would not be the victims of the neglect of their government, indeed of their society. Individuals with disabilities for too long have been the victims of our neglect, consciously or subconsciously. It is now time for us to recognize the great opportunity of accommodating very able people who can do so much for all of us.

As the chairman and chief operating officer of one of our big companies said, "Not only is the Americans with Disabilities Act good policy, it is good business." And it is certainly consistent with the principle that we see spreading throughout the world today that says that the final analysis and the final test of government is how it treats each and every individual, based upon that individual's human dignity.

The Helsinki Final Act speaks in terms of human dignity. Lex Frieden deserves my accommodation, not because the state says so, but because of his dignity as a human being and because of what he has the ability to offer our society, given his commitment, his talent, and his willingness to exercise those talents on behalf of himself, his family, and all of us.

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

ECONOMIC CONSEQUENCES OF THE UNEMPLOYMENT OF PERSONS WITH DISABILITIES

PRESENTED BY MARTIN GERRY, ASSISTANT SECRETARY
FOR PLANNING AND EVALUATION, U.S. DEPARTMENT OF HEALTH
AND HUMAN SERVICES

I thought what I would try to do is talk a little bit about why we needed this conference in the first place. Many of you who have been to OECD conferences have sometimes asked yourselves that question. They're usually held in very nice places, so there are always good reasons to be there, but the question of why we're actually having the conference seemed to be one that I might want to tackle briefly from the American policy standpoint.

We believe, and the President strongly believes, in the concept of transition from school to work. He believes in the concept of the integration of people with disabilities in the social and economic mainstream. And we have some very good models in the United States that address those issues.

What we do not have is a system. We don't have the translation of good ideas, both from outside the United States and inside the United States, into actual system changes that would affect virtually all people with disabilities.

We need such a system, and specifically we've identified several of the elements that are most important. They all somehow come down to "case management." I try to avoid this term in the United States because "case management" is a term that sounds a lot like pushing paper. Let's call it "case advocacy or coordination." That is, the way to create within the social infrastructure of our government - and realistically it has to be in local government - the capacity to really be of assistance and to coordinate all of the services and resources that are necessary to effectively support and create equity in the system for people whose abilities and disabilities require supports that are not consistently provided to others.

We have tried different approaches, just as you in the various countries that are represented here have tried different approaches and we now need to come down to some final solutions. I think Congressman Hoyer's speech illustrates quite dramatically in an extraordinarily timely way the need to do it soon.

The Americans with Disabilities Act (ADA) will simply increase the demands on the system to change, but it does not contain the design of that change. It contains pressures on employment. It contains pressures on education. It contains pressures on transportation systems and public accommodations. The mechanism of how we're going to pull the services together in a federal system like the United States and make them really available to families and individuals is something we have not yet accomplished. It's a design that we, particularly in the Executive Branch of government, are going to be expected to create.

I think one of the things that is important in trying to take a look at where we are in the United States is to briefly take a look at the evolution of federal disability policy. We have, I think, reversed the relationship between economic policy and social policy that existed up until President Bush's inauguration. It's clear to me that during the last decade economic policy played a preeminent role and that the dialogue within the American social policy arena was: "How much money do we have?" "What can we afford to spend?" and then finally, "What should we spend it on?" The use of the money was the last of the series of questions and the money drove social policy.

Now, it seems clear to me we need to re-order the relationship of economic policy to social policy. This is not to say that we have all the money that we need for everything we want to do, but the relationship ought to be that the social policy drives the amount of money.

So if we reverse the order and ask a slightly different set of questions, I think they would be: "What are our social goals?" and then secondly, "In what way should government act to assist individuals to meet these goals? What's the role of government in doing something about that?" and then finally, "What economic resources will government require to carry out its role successfully?" We have to realize that there are economic resources devoted constantly by non-governmental sources to this problem as well, but we're talking only about governmental resources.

Briefly, "What are the social goals and principles?" Having worked in several of the countries represented here that I think have something that we do not have, which is a social policy, I believe it might be good to talk about what that social policy could be.

I would have to observe that at least up until 1988, neither political party had put forth anything that could be called a coherent vision of a social policy. There were views and positions and concepts but no social policy.

Social policy is not disability policy. It's a policy about people, about the expectations of how we hope our society will work for the people in it. The test of a good social policy, it seems to me, is whether it works for all of the people in a society, because if it doesn't, then it's not a social policy, it's a policy for some subset.

Disability policy was beginning to fall into the trap of becoming the exception policy. We have a social policy for "regular" people, and then we have a disability policy. Of course, the minute you fall into that trap, no matter how wise the policy, you're headed for significant disappointments both in terms of the content of the policy and the resources that are dedicated to it.

On the other hand, countries that I worked with have demonstrated that it is quite possible to frame a social policy that incorporates, perhaps even better than most disability policies would, the basic principles around which we want to organize this society.

I've tried to draw from the President's statements, both during the campaign and since he's been elected, a few of those social policy principles, which I hope will form a background for our conference.

The first is that the philosophy of normalization requires us to establish a unitary social vision. Individual goals include the maximizing of the opportunities and choices realistically available to each person, whether disabled or non-disabled or black or white or male or female or young or old. There are really four crucial dimensions to this: that's opportunities and choices for personal autonomy, independence, self-respect, and freedom from caretakers; opportunities and choices for economic self-sufficiency through sustained integrated and compensated employment; social integration and participation; and opportunities and choices for life styles, and family and peer associations. Of course these are perfectly good and perhaps the best set of policies for people in general. I think what's happened in the evolution of disability policy is that it has arrived at the point where it has become the inclusive policy. In other words, it started as the "exceptions" policy and through its evolution it's established itself as the policy for everyone, just as the basic principles of special education are the basic principles of education for everyone.

But what about government action, given these individual policies? What are the goals for government action at any level - federal, state, or local? Here I would like to suggest five principles: (1) to maximize the economic, social, and political productivity of all citizens as an interest of government; (2) to maximize the choices for personal freedom and independence of all citizens; (3) to assure the integration and participation of all citizens within the social, economic, and political fabric of communities; (4) to ensure fairness and equity, meaning justice, within the operation of social, economic, and political institutions of the community and of the society; and (5) to permit citizen involvement in governmental decision making to the greatest extent consistent with fairness and equity goals.

It is also important to take a look at where we are in terms of social policy goals. What about the outcomes of special education programs, for example, in the United States? The picture is not very bright. We have a drop-out rate for students with disabilities which is substantially higher than for other students. We know that socioeconomic status is measured by household income and that head-of-household education is strongly related to that drop-out rate. In other words, we have a relationship between resources, disability, and dropping out of school.

We know that 78% of all special education graduates are not employed on a full-time basis during the first three years following school departure. We know that 23% of these young people with disabilities who have been out of school less than one year work part-time for pay and only 22% work full time.

We know that employment levels for youth with disabilities nationally are markedly below employment rates for non-disabled youths. We know that over 95% of special education graduates with moderate to severe disabilities are unemployed during the first three years following school departure. We know that even after that, there is a significant wage differential in terms of the average hourly wage between youth with milder handicaps and those who are more severely disabled.

We know that 21% of young persons with disabilities out of school more than one year have been arrested. We know that rate is 44% for young persons with emotional problems.

For young adults, that is people who have been out of school for a few more years, you have to take a look at the Social Security Program, one of the programs administered by our Department. For example, there are over 500,000 persons under the age of 21 and 1.2 million persons under the age of 35 with moderate and severe disabilities who receive Social Security Insurance (SSI) and Social Security Disability Insurance (SSDI) benefits. The total population enrolled in these programs is 6 million.

The SSDI population, and therefore the nature of the Disability Insurance Program, is rapidly and dramatically changing. Over 33% of the persons newly entering the SSDI program during the last several years have been 35 years of age or younger and have almost all been reported with mental impairments. That probably has something to do with the drug problem in our society, among other reasons.

Now, what about the programs we have in place for transition, the social security and vocational rehabilitation transition programs? I think it's clear that the vocational rehabilitation system is still unable to assist many persons with moderate and severe disabilities to enter and to sustain gainful employment. Despite statutory priority, the effectiveness of vocational rehabilitation services with respect to persons with moderate and severe disabilities has actually decreased during the last decade. That is, the program is less successful than it was 10 years ago. You can speculate on why. Perhaps the reason is it's actually serving more severely disabled people.

We have a system, the Social Security Vocational Rehabilitation Referral (VRR) system which is financed by our Department that has been extraordinarily ineffective. Less than 2% of all of our applicants ever receive VRR services and few are under age 25. In other words, it doesn't serve anybody.

Now, what about the current and future economic consequences of the patterns of unemployment I spoke of earlier? Let me make a few points here. First, there are serious economic consequences of this failure. We are literally squandering billions of dollars on life-long total dependency because of our social inability to expend a fragment of that amount of money to improve the quality of education, transition, and employment support services. SSI and SSDI beneficiaries receive assistance at sub-poverty levels, but average yearly expenditures for cash and medical assistance from state and local money of over $15,000. Taking the population of people right now who are under the age of 30 and projecting ahead using the current return to work rate which is less than 1/2 of 1%, the current long-term risk exposure for the United States for this population of about 900,000 people exceeds $1 trillion.

This is larger than the national debt of the United States and that is without adjustment for inflation. So if you want to look at what it's going to cost the society just in terms of outlays to continue this pattern of excluding 900,000 from the labor market during their lifetimes, I think $1 trillion turns out to be quite a conservative figure.

This extravagance is going to come home to haunt us most vividly in the next 15 to 20 years as the labor force availability in the United States shrinks and the demand for new employees rises. We are going to confront a generation of young people with disabilities who are systematically unprepared for the demands of integrated competitive employment.

Moreover, the curve pattern of unemployment will threaten our ability to sustain our current gross national product. The economic security of the United States will be affected if we do not significantly alter the pattern of participation in the labor force for people in the United States. In other words, we will be unable to maintain the gross national product as it now is.

Also, the current level of unemployment will begin to directly threaten the fiscal integrity of the Social Security trust fund that is expected to support programs for millions of middle-class Americans, many of whom are constantly voting down things like bond issues for schools. Today there are roughly 5.5 workers earning for every two beneficiaries who receive retirement benefits. This ratio will drop to approximately 3 to 2 by 1995 and reach the equilibrium, that is 2 to 2, by the year 2005. So if the current labor force participation of disabled people remains where it is, the Social Security trust fund will be in jeopardy because there simply won't be people paying in the benefits for the people who now, for the most part, are fairly unconcerned about the problem.

What are the implications of all this for this symposium? First it's clear from all of the research that we've done - and the Office of Special Education and Rehabilitation Services has published quite an excellent study in their last year's report to Congress - that for students with disabilities there seems to be a very clear relationship between having paid employment during secondary school and the ability to obtain a paying job upon leaving school. In other words, there are some significant things going on in countries like Denmark and Sweden and Italy related to training and jobs and schools that we need to take a look at.

Secondly, it's clear that we need to forge new relationships among parents and schools, among state agencies, including the mental retardation/developmental disabilities system, and with unions and employers. Again, there are lessons to be learned from European experiences and successes.

We also have to expand the use of SSI and of Medicaid as a funding source for some of these changes. It's simply not fair and it's not possible to expect the public school systems, for example, to bear the increasing costs of transition and to expect that the local tax revenue base is going to provide the kind of ongoing support services that we need, because for some people we need to provide a system that creates reasonable accommodation day after day after day to support people in an equitable environment within which to work.

The demands of school-based transitional support, it seems, lead to two or three issues that we'll be talking about. I think in Italy, remarkably innovative things have been done based on the concept that the psycho-social environment in which people work has a tremendous influence on their success; the attitudes of employers and coworkers may be much more important than the training of the disabled person.

A fairly radical concept for the United States, but one that I think we have to pay increasing attention to is the necessity of building the relationships between unions and other labor representation organizations and employers around this work. I think we have to look at the trial work contract concept. Much has been done in Italy to demonstrate the wisdom of getting people actually in jobs even if that involves paying for the salary for the first year of work and then transferring people from that program to competitive employment. This demonstrates the wisdom of an investment very well made.

Finally, I think we have to really take a look at the development of ongoing financing systems that will provide the financial support for employment and community living support networks. We have many outstanding examples and models in the United States, but we have not changed the system as yet. We're still looking at good models and talking about innovation but we really haven't figured out how to institutionalize these concepts and change the system. Most of the people who have been innovative and creative have done so, by their own words, "despite the system," as opposed to because of it. In fact, many are just now trying to come back to see if there's anything they can get from the system, having figured out for years how to finance what they were doing around it. I think we have to be ready for their return with something more than the same structure that they faced in the first place.

This conference is of tremendous importance to our Department and, in fact, to the Administration as a whole. The transition of young people with disabilities from school to work is a high priority of the President and his Administration. We have the opportunity to share the key ideas that some of you have learned from hard experience and successful models.

I certainly appreciate the opportunity to address all of you this morning and I can tell you that our Department will pay great heed to the results of this conference. We are prepared to launch model demonstration programs to support some of the technical insights that are gained here. The only way we're going to do anything with the benefits of this conference is to provide the financial support necessary for state and local government to actually try these programs out in the real world.

TOWARDS AN ADULT WORKING LIFE

PRESENTED BY JOHN FISH,
CONSULTANT TO THE ORGANIZATION FOR ECONOMIC COOPERATION AND DEVELOPMENT

I would like to start by expressing my appreciation of the opportunities provided by the transition program. One of its most notable features has been the international teamwork and friendship it has generated.

When the transition initiative was first started, in the late 1970s, there were two themes: integration and transition. Dr. Martin Gerry and David Thomas began the program which concentrated on the adolescent phase.

In those days youth unemployment was high and open employment received less emphasis, but three threads, evident then, have become increasingly important. One was the recognition of an adult status for persons with disabilities which moved away from the "eternal childhood" model of long term dependency. The second was the contribution of parents to the transition process and the very difficult issues, arising during the process, which face them. The final thread was concern for those with severe and profound disabilities and whether or not they would be offered real work. Until recently the serious consideration of these issues was not common.

Individuals make many transitions in their lives, for example from home to school, from elementary to secondary education, from work to retirement. Each transition has common features which include the establishment of personal space and worth in new groups and settings.

By far the most important transition is that from school through adolescence to adult and working life. This establishes a basis for relationships, rewards, and recognition in adult life. A successful transition should result in a satisfactory life style, a sense of personal worth, a valued place in the family, and a recognized contribution to the neighborhood and community.

Aims, expectations, and objectives for transition are set by the cultural values, policies, and practices in individual countries. Although independent living, work, developing family responsibilities, and community participation through leisure and recreational activities should be accepted as objectives for all young people, it is the aims, expectations, and objectives of different professionals and agencies which are crucial to their achievement.

When the OECD's Center for Educational Research and Innovation (OECD/CERI) began, it was evident that bits of transition were being tackled. There were very good normalization, independent living initiatives in Scandinavia and in parts of the United Kingdom and the United States. People would fund preparation for work without any attention to transport to and from work. We needed a conceptual framework for transition because of this fragmentation. The Americans with Disabilities Act is heartening because it looks at all the important bits of a person's life at the same time.

Transition is something which, after a person leaves school, becomes divided administratively into further education, social welfare, employment, and health interests with no guarantee that people in those sectors will talk to each other. The buck is passed, like a baton in a relay race, from one department or agency to another. It is left to the young people, and particularly their parents, to fight their way through a maze of different programs and responsibilities.

Even where there is one agency, for example for intellectual disability as in parts of Scandinavia or the United States, it may be very paternalistic. It may see people through from the cradle to the grave but not necessarily in an integrated way.

Throughout the work on disability there were pressures to describe handicaps, to give figures for the size of different categories and to specify precisely the total size of the group concerned. It soon became clear that definitions varied so widely between countries, and between government departments within countries, particularly during transition, that few meaningful statistics could be collected.

The distinction between a disability or significant difficulty and its handicapping effects for the individual has become increasingly important. It took five years to move OECD/CERI from talking about handicapped adolescents to thinking about young people with disabilities. This distinction has profound implications for policies and practices.

Two conclusions are clear. First, handicaps are individual and relative to particular situations. Secondly, they are socially and administratively defined. The incompatibility between developing individual programs and the categorical thinking often demanded by those funding facilities and services is not always recognized or resolved in practice.

Martin Gerry had mentioned the aims of transition which have been teased out as the CERI program has developed. We need a coherent policy to achieve these aims. Martin and I had the privilege of looking at the policies in three OECD member countries in 1986. We found that in two of the three, one branch of government was putting millions into preparing young people for employment while at the same time another department was putting millions into giving people pensions for life as long as they were unemployable and unable to live independently. The incompatibility between these two policies was not recognized.

In one of the countries they are now looking at financing individual transition. One of the important messages from the study is that it is necessary to seek ways to delay a final statement of the long term effects of disabilities until the individual has been through a decently financed transition program that maximizes independence and employment potential. Coherence is also necessary in the relationship between employment and disability.

An OECD Panel has been looking at employment practices for those who are disabled. Each country concerned submitted a paper in an agreed form. One of the sections was "Disability in Youth" and this was the least well developed. The country papers for the panel concentrated almost exclusively on wartime and adult injury and the re-employment of those disabled at work. The entry of young people with disabilities to work was almost completely ignored. At the same time the OECD report "Labor Market Policies for the 1990s" stresses the need to employ those who are disabled.

It is now possible to identify a number of criteria and standards which characterize successful transition. Effective practices demonstrate that appropriate training technologies, longer periods of training (involving direct experience), and positive expectations can enable even the most severely disabled young adult to achieve much higher levels of competence in employment and independent living.

Some procedures at the beginning of transition may limit opportunities rather than open them up. Assumptions are often based on school performance, and opportunities for exposure to open employment and independent living are not offered.

Assessment procedures should be positive and include evaluating performance in real life situations outside school, identifying individual transition needs, and developing an individual program to which all concerned, including parents, contribute.

Do young people and their families get sufficient information in a form they can understand? Young people do not always know where to look for the information they need. They and their families should receive clear and accurate information about all the options available to them.

The OECD work has identified three phases of transition: a) the final school years, b) the intermediate years of further education and training, and c) support in the early years of independent living and employment. Very often these phases are arbitrary, and administratively, divisions cause people to pass from one agency to another without a continuity of concern.

Professionals working in different phases of transition do not always talk to each other and work towards continuity in the curriculum. They should work with each other to ensure progression, continuity, and coherence in what is offered in an individual program. There is also a need to provide a single point of reference for the individual and the family over the whole of transition.

Much has been done to involve parents in transition in the United States. Two studies of the development of self-advocacy in the United Kingdom have identified the stresses and strains of this process experienced by parents. Parents have a great deal to contribute to transition but they need help to set reasonable goals for their children and often to let go of their young people as they move into adult life.

The issue of family involvement is one that has not been tackled effectively in many transition programs. Effective transition involves a new tripartite relationship, with agreed goals for transition between young people, their parents, and professionals.

Professional practices should change from leadership, through partnership with the young person, to providing services chosen by the adult. Special education is full of people who feel that a disabled person's performance is a measure of their own effectiveness and not the individual's. Growing independence and adult status require a greater equality in participation and decision making. A changing pattern of professional practice should result in the recognition of the disabled person as a responsible adult making as many decisions as possible.

Are services flexible during transition? Do all the services in any one area or neighborhood know what they want to achieve by the time their clients have reached their middle twenties? Even if these services cannot coordinate their efforts they can at least work to agreed aims.

Have we solved the problem of transferring financial management from professionals and parents to the young person, thereby giving some degree of economic independence?

Looking at the overall orientation in relation to these criteria, we can ask the following questions: are policies and practices integrative or segregative? are they "dependent care" or independence oriented? do they recognize individuality and choice? are they inward looking or do they reach out to cooperate with other agencies? are they staff or client oriented?

Technology has been mentioned but one important aspect is consumer opinion. The United Kingdom contribution, "New Technology, Disability and Special Educational Needs," is a very interesting study of consumer response. Young people with disabilities have recorded their response to using technology in schools and colleges and the way it has affected their lives. In many instances after they've gotten used to using technology in education it is not available to them at home or at work.

Another important aspect of OECD work has been the establishment of indicators of quality. These indicators include looking at the extent to which students are empowered and enabled to make choices, parents are involved in planning transition, programs focus on the functional skills necessary to live independently and to work, transition programs promote continuous interaction with non-disabled contemporaries, and services have a coherent plan.

We need a concept of transition as a united whole happening to a person and not something where different agencies are responsible for separate bits. We need to have agreed aims and agreed criteria for the quality and effectiveness of services.

We also have to recognize that whatever professional agency we come from, we cannot manage transition alone. It is a responsibility shared with other agencies. Even more importantly it is a responsibility shared with the young people concerned as they realize their own adulthood.

The OECD/CERI transition program is now being concluded, although some studies will continue. This U.S. Conference is an important occasion for disseminating outstanding transition practice. It is also a unique opportunity to share the international experience gained by many of those present who have contributed to the OECD/CERI transition work.

PART THREE

DISCUSSIONS

PERSONAL CHOICE

A SMALL GROUP DISCUSSION MODERATED BY PHILIP J. BURKE,
UNIVERSITY OF MARYLAND AT COLLEGE PARK, U. S. A.
JORGEN HANSEN, MINISTRY OF EDUCATION, DENMARK

INTRODUCTION

This discussion group focused on issues related to choice for persons with disabilities. Participants from the OECD presented information about programs, practices, and research in their respective countries. These presentations were followed by a general discussion of the issues raised and an exchange of views, ideas, and policy options. Participants also identified barriers to choice, strategies for overcoming the barriers identified, and the implications of implementing such strategies.

UNITED KINGDOM

In England, government funded colleges of further education have been established to support vocational and technical education for students over 16 years of age. Many of these colleges operate discrete courses for students with special needs. This phase of education focuses on preparing young people for employment. The OECD supported a feasibility study to determine the needs of students with special needs relative to interagency collaboration based on the concept of personal choice for the individual.

Three areas were looked at in terms of choice: the role of new technology, support of young people and their employers during their initial employment period, and the changing role of parents during this transition. These areas were related to other areas of field research, drawing on the experience of practitioners and individuals. The project was called "Working Together." The principles that guided this work were: all young people have a right to adult status; the impairment of young people with disabilities and their families must be at the heart of all transition programs; professionals should work for the person with an impairment, not for the professionals who are deciding the programs; and the voice of the individual with an impairment should be heard.

"Working Together" looked at transition as a process that involved interrelated objectives: employment, useful work and value activity, personal autonomy, independence, adult status, choice, social interaction, community participation, leisure and recreation, and roles within the family. These are the same objectives that apply to all young people. Whatever is done for people with disabilities should be an extended support of what is done for everybody else, not something separate or different.

Three major studies were undertaken. They focused on: a) technology, supported employment, and self advocacy; b) how parents are affected by the developing independence of their children; and c) self-advocacy skills with disabled adults using a system of portfolio preparation. Although this work originated in education, other agencies have supported these efforts in recognition of the need to work together and coordinate efforts to pursue programs and common goals, to drop professional barriers and share experience.

DENMARK

By the 1980s Denmark had developed a professional system based on the principle that all things must be provided for a person with a disability. In some agencies there were more professionals than clients. This was explained as the risk in a rich country: that a long standing service delivery system becomes over protective and free choice (particularly for those with severe cognitive disabilities) is limited. In the 1980s policy makers began to discuss the term "client" and its implication that the service provider has the knowledge and knows what is good for the clients who should not be allowed to decide very much for themselves.

Subsequent legislation and statutory rules empowered parents and persons with disabilities to make decisions about what they wanted of a service. For example, parents can now choose between special and ordinary schools. Of course, with choice comes responsibility, and responsibility for a decision clearly rests with the person making the decision.

Although everyone agrees that persons with disabilities should have free choice, it is important to recognize that persons with disabilities represent a very heterogeneous group. In Denmark one in eight students has been referred to special education. Of this group of 100,000, 75% are categorized by social problems (low social ability, learning difficulties, problems with language, etc.). People with physical impairments do not constitute a problem in "our rich countries." The problems concern a growing group of youngsters with social problems. It is very difficult for them to make choices.

Counseling is required. Therefore, a comprehensive counseling system needs to be in place so that the individual can seek advice from a variety of sources and so that the service is readily and naturally available.

Choice also requires opportunities. It is false to give a person with a disability choice if it means that the person only has one option from which to choose. Currently in Denmark, efforts are aimed at developing counseling systems and establishing different opportunities within the education system, the labor market, and so forth.

Three main principles guide the development of this counseling system: normalization - everyone must be part of the same system; decentralization - community-based decision-making; and integration - placement in settings with persons who are not disabled. A counselor, called a kurator, is part of a professional team in the local area. There are 135 kurators covering 180 municipalities in Denmark. The kurators' job is to support the school as to the education of the student with a disability so that he or she is better able to leave school. Kurators set up contact with the local labor market and further educational institutions as well as advise the family. They also follow the child with a disability from the secondary school until he or she is satisfactorily placed in the labor market.

An important element in assisting pupils with special needs in choosing a career is work practice. Work practice is a mixture of work experience and actual employment. It begins in the ninth grade, and the amount of time spent in on-the-job training increases from several weeks to half of the school year in the tenth grade. The student gains insight into the working world, and the school has a chance to judge the student's future possibilities. The kurator works with the student and the family throughout this time so that everyone has a good idea of what the student will do when he or she finishes school. Unlike the situation in the U.S. where the parent is faced with the problems of high staff turnover, the Danish kurator works with the student through the grades and for several years after school.

Kurators are trained special educators who are released from teaching a certain number of hours each week to function in the role of kurator and work with families and students. The case load for a kurator is about 35 students in grades eight through ten and that many again who have left school and are working or are in further education. Kurators can follow students for two years after school or until the students turn 19. Experience has shown that the kurators should take the initiative in follow up; however many former students maintain contact with their kurators for several years on their own initiative after turning 19. Many kurators want to follow students until they are 21 although the legal age in Denmark is 18.

Kurators approach local employers and solicit positions for their pupils. They also make special agreements with trade unions in arranging work practice. The kurator is always a member of the community as it is important to know the community well in order to find suitable places for work practice.

Although there is not much data on the kurator system, one thing that is known is that the employment rate of young people who have a kurator is better than it is for those who do not get this service. This situation is true for women and men. There are no differences in Denmark between jobs in which men are placed and jobs in which women are placed.

In addition to the kurator system, another issue related to choice is the unemployment situation. High unemployment is a disadvantage for persons with disabilities; improvement in the employment situation improves the possibility for free choice. A new policy in Denmark says that if an unemployed man is offered a job and he refuses it, then he is turned out of social welfare or other cash benefits. In this way, a precondition for having a real choice situation is an improvement in the employment situation.

AMERICAN BUSINESS-EDUCATION PARTNERSHIP MODELS

Many segments of industry are interested in the educational process because of concern about job applicants who are illiterate. Often applicants have bad work habits or poor discipline.

As a result, some businesses are forming partnerships with educators. For example, Martin Marietta operates a partnership in one of its companies whereby business people sit down with educators (junior college personnel, vocational institutions, etc.) in an effort to jointly review the curriculum so that the outcome is a person with skills desired of employees of the company. Business gets an opportunity to help set standards for the graduates of the program and groom potential employees. The employers help design the courses and graduates who successfully complete the program have jobs when they are done. Notable examples in the United States include: Disney World, AT&T, Westinghouse, Sun Bank, and Martin Marietta.

Volunteer networking programs involve experts who volunteer their time to give some service to people who have problems. For example, at one national laboratory in the United States, scientists and technicians volunteer their time to help persons with disabilities with assistive technology devices.

Some industries offer sign language courses which enable persons who are not hearing impaired to interact with hearing impaired colleagues on the job as well as in restaurants, churches, libraries, and other places of public accommodation.

DISCUSSION

The discussion initially centered on gender differences and the socialization of women in many cultures as homemakers rather than wage earners. The problems associated with such views are exacerbated for women with disabilities particularly in matters pertaining to personal choice. For example, in cultures where the expectation for women is to be dependent, to stay at home, and be cared for, it will be difficult in the face of historical attitudes to educate women with disabilities to become self-sufficient decision-makers and to empower them to control their own lives.

One major problem is pay equity. Many counselors in schools are counseling young women to opt for training that will only lead to low paying jobs with no opportunity for promotion or moving up a career ladder. Another problem relates to the attitudes of parents. Everyone involved in the process of dealing with young women needs to acknowledge options other than minimum paying jobs.

In the United Kingdom and in the United States, even in entry level positions which normally have more women than men, employers request young men with disabilities when they have a choice. Sadly, people are so content to merely place a person with a disability into a job, any job, that there is no thought given to career prospects, promotion, or the special problems confronted by women with disabilities.

There is a need for the total networking of service providers, of educators, and employers so that individuals can understand the alternatives and make informed decisions. One must know the consequences of the choices made. Models must be provided. If a woman with a mobility impairment, for example, can observe another woman with a similar disability who is employed in a professional job earning $35,000 per year then the consequence of her choice is clear. She has a career path and economic self-sufficiency. This process must begin early in education.

The discussion then turned to determinations of competency relative to job requirements. In Denmark, students participate in job exploration programs in the tenth grade. In the United States, the employer is required to make reasonable accommodations so that a person with a disability can do a job. In the United Kingdom the approach to employers often involves educating them about how they can change. There is new legislation requiring accommodations for persons with disabilities.

Businesses are looking for the most qualified persons to fill given jobs. Business is in business to make money and there is some acknowledgement that in order to obtain and retain qualified and necessary employees, business must look outside of traditional sources. However, business cannot replace the roles of other service providers. They are still necessary, but there is a role for business in assisting individuals to understand the opportunities available and the consequences of a particular choice. In other words, there are many prerequisite steps involved before one can be encouraged to make a personal choice.

Moreover, people with cognitive and language disorders need to actually experience certain alternatives in order to make meaningful choices. This has implications for secondary education and transition, a time when people need to spend a few weeks in different settings and different living situations.

In the United Kingdom, there is an effort to educate not only parents of children with disabilities, but also parents of all young people. There is a recognition that one must not do things just for people with disabilities but to make sure that all programs are broad enough to cover everyone because the need to make informed personal choices is common to everyone, not just one group. To achieve this, educators are working on a curriculum which is based on equal opportunity. There is a commitment that everyone should have access to certain aspects of the curriculum.

This new curriculum is designed to counteract the traditional curriculum where the girls do home economics and the boys do mathematics. The new national curriculum is available to all. There is a belief that this policy will help to overcome many of the prejudices which exist in the United Kingdom.

There is also an effort to work with persons who have been institutionalized and are now part of a "care in the community" movement in the United Kingdom. The question is how to work with people who have had no opportunity for choice and enable them to control their own lives and make decisions. Experience in the United Kingdom shows that lack of choice underlies the failure of community-based programs.

One self-advocacy project involves people putting together a portfolio of their lives, looking at their lives, and looking at when they ever had the chance to make a decision. Some people find they have been denied choice and decision-making almost all of their lives. Experience shows that decision-making skills can be learned.

Caretaking is a major role for parents of children with severe disabilities. Ideas of independence can be threatening for these parents because independence for their child represents a change in their major role. Consequently, programs for persons with disabilities must be accompanied by programs that help parents accept their children's independence.

However, some parents find that their roles as caretakers continue but in a different form. For example, because the staff turnover in many group homes is high, parents find that they continue to perform tasks such as helping with shopping.

This situation makes employers wonder if they are hiring the person with a disability or his or her parents. Yet parents possess valuable information that employers and job coaches can benefit from.

Counselors and vocational specialists need to remember that the employer is hiring someone on the basis of his or her ability, not disability. The point was made that in the United States, the concept of real work for people with disabilities has not been fully accepted by professionals, despite advances in public policy. One major problem involves the territorial attitudes held by professionals in various agencies. Another is the lack of knowledge about the kinds of jobs persons with disabilities can do and the career choices they may make.

There was some discussion about the balance between the right to have support from society and the duty to do something for society. It was noted that employment is not a right within society in Denmark or America, despite enabling legislation. In both countries, unemployed persons who refuse legitimate job offers may face loss of or reductions in benefits.

The unemployment rate in Denmark is 10% despite public policies which state that all young persons have a right to further education or a job. It appears that there are limitations to the extent to which a government can provide a job guarantee. Influences within market economies make it impractical to guarantee jobs because the economy is dominated by the private sector. The government can create some opportunity and ensure equal opportunity for everyone to participate in the labor market, given the state of the labor market at any given time.

BARRIERS TO CHOICE AND APPROACHES TO CHANGE

The group discussed barriers to equal opportunity, including stereotyping, unclear definitions of equality, and the persistence of traditional roles. Even in countries with progressive equal opportunity legislation, such as Sweden, Denmark, and Norway, problems exist. For example, in Sweden, eight out of ten women work, but often in low paying or part-time jobs. Legislation provides for up to 18 months of parental leave for a mother or father, but fathers seldom take the leave.

There are barriers in both the public and private sectors. Disincentives to work are embedded in public policy, including loss of government benefits, fear or lack of knowledge about various disabilities, lack of accessible transportation, lack of technological resources, and a social service bureaucracy based upon the medical model. Most countries do not have national policies governing the employment of persons with disabilities. The success of many programs depends on the goodwill that results from relationships between advocates for the employment of persons with disabilities and employers.

A major barrier to choice in employment is the lack of a universal health care system. In the United States, a person with a disability who accepts a job may lose his or her government health benefits. Moreover, the same person may not be eligible for the insurance package offered by the employer. Thus, choice is severely limited.

Strategies for overcoming lack of equal opportunity include: research, model program development, teacher training, dissemination of information on equity in general and sex equity in particular, leadership training for members of minority groups, and more awareness of the need to plan for transition services. A reexamination of traditional roles and gender stereotypes may enable more people to enter the workforce and may diminish the stereotyping applied to women with disabilities.

Individuals with disabilities can be prepared to make choices about work. Parents should be encouraged to model work-related behavior, and parents and service providers can do more outreach with business. They must facilitate the employers' involvement.

Efforts should be made to make the curriculum more relevant. This could be achieved by bringing people from business into the schools to teach courses or to operate exchange programs with teachers. More integrated relationships between school and work can result in more choices for a person with disabilities and a better match between an individual and an employer.

Strategies to approach barriers in the public and private sectors include eliminating the disincentives to work currently embedded in public policy, and improving dissemination of information about technological advances and about the nature of handicapping conditions. Such information would dispel myths and fears about disabilities.

In addition, the government should facilitate private sector initiatives to encourage the employment of persons with disabilities. Some countries use quota systems. In Great Britain there is a quota system but no method of enforcing it. In France, a unique policy has been established. When an employer does not meet a quota, he or she must pay a fine. The money that is collected is used to promote the employment of persons with disabilities. Companies voluntarily pay the fine with very little government enforcement.

Finally, all advocates, including parents, professionals, and persons with disabilities, should actively work to eliminate barriers to choice.

SUMMARY

Participants in the discussion agreed that persons with disabilities are entitled to free choice and that they do not have it. There are prerequisites for personal choice: individuals must feel they are able, and they must be advised of the consequences of their choices. These prerequisites apply to all people, not only those with disabilities. Sometimes, experts feel it is not advisable to offer free choice to individuals who will not be able to exercise it.

The concept of work was discussed in a broader than usual context. Much consideration was given to work as part of the socialization process, as part of the process in which an identity and sense of worth are formed. The issue of how to prepare people for decision making and choice in the workplace has not been adequately addressed as part of the general education program for everyone.

EFFECTIVE INTEGRATION AND SUPPORT IN THE WORKPLACE

A SMALL GROUP DISCUSSION MODERATED BY
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MICHAEL HARDMAN, UNIVERSITY OF UTAH, U. S. A.

INTRODUCTION

The focus of this small group discussion was to identify issues and barriers related to effective integration and support in the workplace for persons with disabilities. There was also a discussion of recommendations to promote effective support strategies in the workplace and the community. Representatives from various OECD member countries briefly described strategies or models of employment for persons with disabilities in the workplace. The discussions centered around a description of the Genoa approach in Italy, the supported employment model in the United States, support strategies in Norway, and a review of some of the issues associated with advocacy identified in the U.K. studies.

Major issues included (a) the provision of comprehensive and coordinated services to individuals throughout the lifespan, (b) the advantages and disadvantages of various support strategies that promote integration at the worksite including financial support (e.g., quota systems, wage subsidies) versus the "human" support of job coaching, and (c) the importance of balancing advocacy and empowerment between human service providers and individuals with disabilities.

OVERVIEW OF TWO MODELS FOR INTEGRATED COMMUNITY EMPLOYMENT

The Genoa approach. In Genoa, a large industrial city with a population of about 800,000 the principle of integration for people with disabilities has been pursued vigorously both in community and school life. The Genoa approach to improving the transition from school to adult life for people with moderate and severe disabilities incorporates six basic constructs.

- During the compulsory school years, the focus is on providing maximal opportunities for integration of children with disabilities in regular classrooms, as well as the development of age-appropriate social and communication skills;
- There is a need for expanded and intensive services designed to assist young people with disabilities in acquiring work skills and practical work experience prior to gainful employment;
- It is important for employers and coworkers to be directly involved in the development of needed work skills and in the ongoing support of employees with disabilities;
- Trial work approaches are developed in order to create financial incentives for employers to "take a risk" in hiring and maintaining employees with more moderate and severe disabilities;
- Families must be involved in helping the individual to identify the support needed during the post-school years; and
- Support from the leaders of the community is essential if the individual with a disability is to fully benefit from the available resources.

The overall guiding principle of the Genoa approach in relationship to employment is the successful integration of workers with disabilities into community jobs. Integration is viewed as an essential component of any successful transition to adult life because of the role work plays in attaining full adult status. The Genoa approach focuses training efforts on social and "work" skills rather than technical skills because these are considered critical factors in developing and maintaining sustained employment in the community. Additionally, coworkers play an essential role in the Genoa approach. Individuals with more moderate and severe disabilities involved in the Genoa approach have demonstrated a capacity for learning that is directly associated with being a part of a team of workers in a job setting.

Supported employment in the United States. An employment model that is similar to the Genoa approach to community work has emerged in the United States over the past decade. Supported employment is defined as work in an integrated setting for individuals with severe handicaps who are expected to need continuous support services, and for whom competitive employment has traditionally not been possible. As defined in United States legislation (the 1986 amendments to the Rehabilitation Act and the Developmental Disabilities Act of 1984), supported employment placements must meet the following criteria: 1) the job must provide a minimum of 20 weekly hours of work, up to full-time employment and is consistent with the individual's stamina; 2) the individual must earn a wage either at or above minimum wage or which is commensurate with the individual's product level and based upon the prevailing wage rate for the job; 3) fringe benefits should be similar to those provided for nondisabled workers performing the same type of work; 4) employment must be community based and provide the individual with regular opportunities for integration with nondisabled workers or with the public as a regular part of working; and 5) work should take place in settings where no more than eight persons with disabilities work together. Employment then exists for persons with severe disabilities when an individual's activities create goods and services that have economic value, and when the individual receives payment for work from an employer or customer. Based upon the above criteria, the United States government has established multi-million dollar programs to fund states to initiate supported employment services through cooperative interagency services (i.e., education and vocational rehabilitation). State dollars to either match federal funds or stand alone are being allocated for supported employment services in nearly every state in the United States. As is true with the Genoa approach in Italy, supported employment in the United States has become established as a viable alternative for rehabilitation training and employment of individuals with severe handicaps.

In the United States supported employment is often discussed in the context of "supported living." Supported living is the opportunity for people with disabilities to live in a home wherever they want, and with whomever they choose, while receiving all necessary support to make the experience successful. Supported employment fits within the framework of a supported life network for people with disabilities. As would be true for all community living programs (i.e., residential living, recreation/leisure, or personal management), services are defined in terms of individual preference and need rather than by the availability of facilities. The goals for the individual within a supported life network include increased independence, community integration, and productivity. The services provided must reflect these individualized goals, which will in turn result in an increase in the quality of life for the person with a disability.

ISSUES CONCERNING SUPPORT IN THE WORKPLACE

One of the clear recommendations of the group was to define support to individuals with disabilities in a very broad sense. Support varied from financial support in the form of wage subsidies in many European countries to "human" support for individuals with disabilities in the United States. Since many of the models and strategies to provide support are still in the formative stages, caution must be exercised in defining support strategies, in training personnel to provide support, and in devising alternative systems to promote integration of individuals with disabilities in the workplace. The issue of support must also be defined in terms of support to the system (employers, unions) versus support to the individual.

Other issues included: the intensity and length of the support once an individual with a disability is placed on the job; external versus internal mechanisms for providing support on the job (for example, the use of a job coach funded by an agency or support provided by middle management or co-workers from the employment site); and the intrusiveness of the support. Do certain models of support diminish individual choice or interfere with integration at the workplace?

QUOTA SYSTEMS AND INCENTIVES TO EMPLOYERS

The use of quota systems and incentives to employers was discussed in terms of the following questions: (a) why should employers hire individuals with disabilities? (b) should a national quota system for hiring individuals with disabilities exist and how should it be enforced? and (c) what are the advantages to providing "human support" to individuals with disabilities and their employers as opposed to wage subsidy schemes.

Wage subsidy schemes were reported to be in place in many European countries. For example, in Sweden, approximately one percent of the work force receives wage subsidies in open employment (not counting another one percent in subsidized sheltered employment). In Italy there is a quota of 12% for employees with disabilities. It was reported that this is not always effective; in some instances, employers may elect to pay fines rather than meet the criteria of the quota system.

While the provision of wage subsidies may initially promote integration at the worksite, one barrier to this approach concerns the lack of support in terms of job training and retention. It was pointed out that in the United States there has been a move away from wage subsidies to competitive employment with minimum wage and job coaching and support. An approach used in Italy combines the use of a wage subsidy and support to individuals with mental retardation during their first year of employment. During this time, the individual learns the requirements of the job and interacts with employees, and the employer is not obligated to pay wages. Support is also provided to the individual with a disability during this time. At the close of the year, the support and wage subsidy are withdrawn and the employer is expected to pick up the wages; in many instances, support is provided through co-workers.

PROVIDING COMPREHENSIVE AND COORDINATED SERVICES

The provision of coordinated and comprehensive services to individuals with disabilities throughout the lifespan was a prominent area of discussion with particular emphasis directed toward coordination of services in the workplace. (e.g., in Italy, many services are coordinated through the Health System, which is decentralized into health units.) The identification of a "lead agency" eliminates some of the problems associated with identifying and accessing related services for individuals with disabilities and their families. In Italy, services are then provided through a team approach (e.g., one team assists individuals with disabilities and their families in school settings and another team assists individuals in work settings.)

An alternative strategy to identifying a "lead agency" to coordinate comprehensive services is to identify a "lead person." The kurator model in Denmark appoints a kurator to individuals with disabilities and their families. The kurator coordinates services while the individual is in the school system and into the young adult years.

A number of issues and barriers were identified concerning the provision of coordinated service and deserve further consideration. If one "lead agency" has responsibility for coordinating services to individuals with disabilities and their families throughout the lifespan, which is the most appropriate agency? In Italy, for example, the health agency acts as the coordinating unit, while in the United States, a health agency might be viewed as a "medical model" and not be well received as a "lead coordinating agency." Agencies that serve as "single points of entry" to coordinate services for individuals and their families as they make the transition from school to the community might be another mechanism for coordinating employment and related services during the adult years.

If a multidisciplinary team approach is used for coordinating services, when should the composition of the teams change? For example, if a team provides services during school years, should an alternative team be available to provide employment and related services? Local resources will be an important consideration in determining the feasibility and make up of multidisciplinary teams and in identifying "lead agencies."

If a team approach is used in the provision of services, should a separate team exist to assist individuals with disabilities at employment sites with training, employer education, social adjustment, and job retention? In Italy, a separate mediating team is used to assist individuals with disabilities and their employers in the workplace on a time-limited basis. In the United States, a job coach serves as the trainer, mediator, and coordinator in the supported employment model.

ADVOCACY AND EMPOWERMENT

Based on a series of studies carried out for the U.K. contribution to the OECD/CERI Programme on Active Life for Young People with Disabilities, advocacy was discussed in terms of (a) empowering a lead agency or team to assist individuals with disabilities and their families to access needed services, and (b) empowering individuals and their families to make informed choices. Again, the idea of an advocate, mediator, liaison, or kurator was identified as central to ensuring that individuals are able to access needed services and acquire self-advocacy skills.

An interesting viewpoint was expressed in terms of specialized administrative bodies and advocates for people with mental retardation in Norway. It was pointed out that Norway is in the process of mainstreaming services and dismantling the special organizations and institutions set up to serve and advocate for this group. One reason for this change is that the old system tended to foster dependency on the part of individuals with disabilities. Obviously the role and the power associated with an advocate must be approached cautiously as new mechanisms of support and coordination are explored in the workplace. A related issue concerned a need for rigorous evaluation systems to determine if a change in policy or a new approach is indeed more effective than the existing system of providing/coordinating services.

REPLICATION OF MODELS

Models that promote integration in the workplace for individuals with disabilities must be adapted to meet the unique needs of the community, local resources, and the population served. It was pointed out that replication of specific models, even within the same country, is often difficult. As models continue to be implemented and expanded, it is crucial that factors associated with high rates of job retention for individuals with disabilities, and acceptance on the part of employers be reported (e.g., are success factors attributed to the model itself, to the dedication of the implementors, to the type of clientele served, or to the time allotted for planning activities?).

SUMMARY

There was considerable interest among the panel members in exchanging information and learning about models of employment and support for individuals with disabilities in various countries. Regardless of the model or setting, the issue of coordinating employment, independent living, and community services for individuals with disabilities and their families remained a pressing issue. It was also evident that many models and strategies are in the formative stages, and it is important that these be evaluated in terms of effectiveness to individuals with disabilities, to employers, and to agencies coordinating services.

ORGANIZING AND FINANCING COMMUNITY SERVICES

A SMALL GROUP DISCUSSION MODERATED BY DONALD MACLEOD,
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AND MARTIN SODER, UNIVERSITY OF UPPSALA, SWEDEN

INTRODUCTION TO ISSUES AND CONCERNS

The focus for the discussion of issues and concerns was how to provide employment related services to persons with disabilities. The discussion was guided by the general knowledge that there are many ways to provide employment related services as well as to define them. Some services are "generic" or available to the entire population and others are targeted for persons with disabilities or specific disabilities. The nature of the services can vary considerably, from school-based vocational training and transition services to on-the-job supports, wage subsidies, and employer assistance plans. The institutional frameworks can also vary across countries, as well as within. Ultimately, the individual who needs the services has to be considered as the focal point for any coordination effort.

CANADIAN EXPERIENCE

In Canada, a major coordination problem involves the constitutional division of responsibility between federal and provincial departments. This division directly limits the ways in which agencies can organize, provide, and fund services. There is a constant process of negotiation and discussion. Canada is embarking on a new federal, provincial, and territorial review of services for persons with disabilities which will examine the full range of questions regarding coordination and funding.

There are two main sources of employment support for persons with disabilities in Canada. The Vocational Rehabilitation of Disabled Persons program (VRDP) provides federal cost-sharing of provincial vocational rehabilitation services. The provinces put up the first fifty cents, and the federal government supplies the additional fifty cents. These services are targeted to persons with disabilities and provide training programs, placement on the job as well as separate training, and some additional follow-up goods and services. They do not provide long-term support of employment, although the time for training and follow-up has been lengthened somewhat. In addition, the Federal Department of Employment and Immigration provides direct services to all citizens of Canada, and there are some programs which benefit persons with disabilities that can be accessed through the Canadian employment centers across the country. There is a definite trend for persons with disabilities to argue for provision of services within the mainstream.

Perhaps the single most important funding issue in Canada is the potential disincentives to movement of persons with disabilities into the work force. Due to the broad umbrella of social assistance such as income support and replacement programs and free services provided to persons on social assistance, there is risk of loss of services for persons entering competitive employment. Currently, discussions are under way regarding how persons with disabilities may move into competitive employment and continue supports.

SWEDISH PERSPECTIVE

For many years in Sweden, coordination between different authorities and between different agencies has been a high priority. There are many coordinating bodies between, for instance, social insurance, labor market authorities, schools, and medical rehabilitation, that have been institutionalized to coordinate their activities with other agencies. These bodies are often triplicated - at the local, regional, and national levels. From the individuals' perspective it is confusing because not only do they have a number of agencies to deal with, they also have the coordinating bodies.

Sweden recognized the need to coordinate services in another way so there are currently a number of experimental activities going on in different municipalities but financed by the central government. A common theme running through them is that coordination must occur from the individual point of view. In every one of the local experiments, there is a contact person (perhaps like a case manager) who is close to the individual and whose duty it is to coordinate all things for the individual. Another common theme is the concept of personal choice. Activities are organized to help persons make choices. A related third theme is the emphasis on practical work experience. The person with a disability has the opportunity to test and practice different alternatives before making a choice.

Not much is known yet about the success of these activities; they have not been evaluated or even properly documented. They do, however, represent the new thinking regarding coordinating activities for persons with disabilities. The Swedish experiments also point out the need to consider coordination at different levels. For example, it might be necessary to coordinate at different bureaucratic levels, but that is only one type of coordination. Another type requires making personal choice a reality for individuals. There is a need to consider coordination of services from every perspective and for different purposes.

AUSTRALIAN PERSPECTIVE

In Australia, disability services are funded directly by the Commonwealth Government. State governments also provide funding, and organizations providing services obtain money from donations, bequests, and fund raising activities. The Commonwealth is not, in many instances, the major funder.

The Disability Services Act was introduced in June, 1987 as a result of the Handicapped Programs Review. The Review involved extensive consultations throughout Australia with individuals with disabilities, their parents, service providers, and other involved persons to identify problems in existing disability programs. The Review found that services were often poorly funded, inadequately coordinated, demeaning to users, and that existing legislation was inadequate or inappropriate. Recommendations were made in a report to Parliament, which was tabled in 1985. Recommendations included the need for new legislation and better accountability on the part of service providers for positive outcomes for individuals with disabilities.

The emphasis in the Disability Services Act is very much on individuals, meeting their life needs across the broad areas of employment, accommodation, and community participation. The legislation prescribes nine new service types, but within each type there are a number of options. This allows for creativity on the part of service providers. Accountability for client outcomes is carried through into contracts with organizations.

In the employment area, there are two new service types. Supported employment is intended to provide meaningful employment for people with disabilities who require intensive support, and competitive employment training and placement services are designed to meet the transition needs of persons moving into open employment at award wage levels or above. The latter services are required because mainstream programs have generally not been particularly sensitive to needs of persons with disabilities and are not able to provide the specialized assistance available through competitive employment training and placement services.

One of the current difficulties is getting employers to accept that people with disabilities can work and produce high quality goods and services. There is also some concern on the part of parents that their sons and daughters will be exposed to great risks if they move from sheltered employment into open employment. Australia is also examining the issue of disincentives to work caused by invalid pensions or welfare payments. There are payments, equivalent to invalid pensions, for persons in sheltered or supported employment which are called Supported Employment Allowances. Recent legislative amendments that have been adopted will allow persons who move from sheltered or supported employment into open employment to continue to receive health care entitlements, transportation concessions, and so forth for up to 12 months.

The Commonwealth government has also created a task force to examine eligibility criteria for invalid pensions. Currently, persons receiving invalid pensions must demonstrate that they have an 85% medical incapacity. The task force is charged with recommending assessment procedures that will look more at the abilities and levels of function of people with disabilities to determine what supports they need to move into competitive employment. People who are assessed as too severely impaired to participate in the workforce would continue to be eligible for the pension.

The Department of Community Services and Health has just finalized a major study of disability and work force issues. It examines, in some detail, the disincentives and barriers to employment, including the income security system. The report will be broadly circulated and feedback will be obtained before any recommendations are implemented.

There are numerous problems related to interagency collaboration in Australia. A pilot program involving the Departments of Community Services and Health; Employment, Education, and Training; and Social Security is operating in certain metropolitan areas to manage assessment and assistance for individual cases on a collaborative basis. In rural or isolated areas, one of the agencies assumes case management responsibilities and ensures that programs are coordinated through the three principal agencies. The program, which is being evaluated, has run into early problems due to the difficulty of achieving full interagency coordination, and these problems are being addressed. The purpose of the pilot program is to attempt to integrate the assessment of individuals and to refer them to appropriate employment assistance activities. The approach is intended to focus on the specific needs of the individual.

MODEL DEVELOPMENT IN THE UNITED KINGDOM

Representatives from the United Kingdom provided a brief overview of the work done in that country under OECD sponsorship. The programs, which resulted in a number of publications, were guided by three common themes: the right to adult status; preparing young people with disabilities and their families (the heart of transition); and getting professionals to work together. The program was funded with a £20,000 government grant with additional money from the Further Education Unit, a research and development agency funded by the Department of Education and Science. Three publications resulted from the program. One focused on the role of new technology in helping individuals with disabilities access the workplace. Another publication focused on identifying the basic skills and competencies needed to access employment. The third publication concerned self advocacy and work with parents.

From the publications come some observations concerning coordination of services and the transition process. First, there is a paradox; if young people are empowered, someone has to relinquish power. That shift in power is extremely difficult. Related to that notion is how to support parents and families in the transition process and yet untie the knot of support. Young adults still need family support, but in a different way. A final observation is the need for continuity in the transition process. There are huge discontinuities in terms of information, service, and even shared objectives.

In the United Kindgom's experience there are, as noted in other countries, problems in coordination. There are also deficiencies in the programs. For example, there is a lack of appropriate assessment that determines both strengths and weaknesses and also determines long term potential. Another problem in the United Kingdom is that people with disabilities often get the least amount of time in the education system when actually they need more time. There are points when support ends, such as at a particular age, and this is a problem in helping people access adult systems or in supporting them as adults in the workplace.

The main message from the United Kingdom work was that this had to be an interagency effort. The project was an attempt to get different agencies to share common objectives and to realize that no one agency can "deliver adult status" on its own. It requires collaboration. There are a number of pockets of legislation, including the Disabled Persons Act. There is a new educational format and legislation addressing the transition of persons with mental handicaps from long-stay institutions into the community. The United Kingdom was working to show that the strategic planning to implement the legislation can be done on a collaborative basis.

DANISH PERSPECTIVES ON COORDINATION

Denmark is a small country with about 5 million inhabitants and with the advantage of being extremely homogeneous. Coordination is not a very important problem in Denmark's social policy administration because, since the late 1960s, the overall responsibility for services to the disadvantaged, including persons with disabilities, has been placed with the municipal social administration. Therefore, there are not a lot of different people involved in the services. However, Denmark has not had much better success with increasing employment among persons with disabilities. The reasons are not due to coordination but rather to the high unemployment rate which makes it harder for the disadvantaged to get into the open labor market, and to local financing of services. That is, the state funds 50% of the activities related to rehabilitation or similar employment support. The local municipality must provide the remaining 50%. At the same time, the state will provide 100% of a disability pension so that, during times of high unemployment, there is pressure from local authorities to grant as many of these pensions as possible. As there are lines of able-bodied persons ready to be employed without training, it becomes easier to provide a pension to the disadvantaged individual.

GENERAL COMMENTS AND DISCUSSION

There was an overwhelming consensus that the need for better coordination remains critical. However, as one participant said, "We need to examine why we don't achieve it." Some of the problems have to do with the different meanings attached to coordination. The original Kennedy study panel on mental retardation, in 1962, addressed coordination, but said that it should mean coordination around the service objective as opposed to coordination around an administrative need or objective. Many individuals in administrative positions tend to think of establishing ties with other organizations that have a relationship to duties and responsibilities similar to their own. However, those who confront the issue from a clinical or direct service point of view would like to think about service coordination around the needs of a particular individual.

However, if coordination is done around the needs of the individual and the individual truly defines what services ought to be provided, there is the inherent problem of what happens when financial resources are insufficient to meet all of the identified needs. This problem is inevitable with services that are publicly funded, and it is necessary to face up to the fact that, many times, the needs are not going to match up with the political reality of fiscal limitations.

In response to the above limitation, others noted that the fiscal problems are real, but there is also the professional territoriality and desire to preserve one's own resources. Yet, one cannot accept the fact that existing resources will not change. There is a need for more resources and for coordination or sharing of those resources. Also noted is the amount of money that is spent the wrong way because there is a lack of a clear social policy and a common set of objectives. People and agencies continue to do things and spend money in an old way that is expensive and not very effective. Another financial drain is the disincentives to work.

Another problem is that resources tend to come in packages and it is difficult to disentangle them. That is, the resources follow a label or provide a specific service and it is impossible to separate them to allow the resources to be spent in a more flexible manner. In Canada, this issue is resulting in suggestions for individual funding. This involves giving the individual or someone operating on his/her behalf a check for an amount of money to pay for certain services. The decision of where those services are to come from is left to the individual. There are some pilot programs that are exploring this alternative. In another Canadian example, the British Columbia provincial government has given a community agency the authority to establish a professional brokerage system. This allows the parents or the broker to go to individual agencies and purchase specific services. The money comes from multiple agencies but is channeled through one office, which can differ from one locale to the next. The evaluations of these programs is just beginning so there is no indication of the costs nor of the effectiveness of the programs.

In the United States, there are a number of attempts to force more coordination. One noted was the requirement under the Job Training Partnership Act (JTPA) that local agencies collaborate in funding. Also, there are instances where one organization, such as the Association for Retarded Citizens (ARC), in several cities will obtain funds and services from different sources through issuing Requests for Proposals that require coordination among service providers. However, these efforts work better in some states than others and usually depend upon the availability of fiscal resources. If there is more money, agencies are less likely to want to coordinate funding. Also, the services in the United States still are very disability specific. While many individuals may go to the rehabilitation agencies, fewer will access the ARCs or Administration on Developmental Disabilities.

Other countries do have such disability specific provisions, but mostly for the voluntary agencies. The state-supported services are for all disabled. The possible exception is France, where most of the services that are provided through social security funded agencies are for particular disabilities. There have been debates in other countries about the merits of providing such disability specific services. In countries which provide generic social services, there is still reported lobbying on behalf of specific disability groups for special services or extra attention. Voluntary agencies for individuals with specific disabilities are rarely effective service providers, except in the United States.

BARRIERS TO COORDINATION AND GOALS FOR CHANGE

There was common agreement that the goals for coordinating services were to promote competitive employment, independence, and freedom of choice among persons with disabilities. Barriers to better service coordination included the following:

- Duplication of services and effort: many agencies are providing versions of the same service, resulting in inefficient use of resources and confusion to the clients.

- Lack of personal action plan: there is a poor process for working with individuals to determine what they want, how much independence they want, and where they want to go. Assessment is a process that should go through several stages and should provide a map which then determines the service needs at each stage or "sign post."

- Differing legal and policy frameworks which create different financing of services: goals are not necessarily the same, each may have a different target group, and they may all have incompatible rules and funding arrangements. These differing frameworks result in separate bureaucracies that then spend time guarding their turfs and maintaining their status quo. There is also a real problem with changing priorities among the different agencies as a result of political fadism. Without common goals, cooperation is impossible because one agency will always be changing its priorities or goals.

- Lack of defined outcomes for individuals with disabilities, such as a job or a place to live: these outcomes should be reflected in the goals for every service agency as opposed to the goal to simply provide specific services. However, there is a conflict sometimes between fulfilling the needs of the client and assuring that the service organization is sustained within the structure of publicly supported systems. The needs for accountability and the strictures of law frequently dictate why a specific service cannot be provided. How to turn that top-down control on its head to allow for decision-making to filter up is the question.

- Turf guarding and maintenance of the caregiver community which consists of multiple agencies and multiple professions: the various agencies which have been created by the different pieces of legislation guard their staffs and their own bureaucracies. They are resistant to a move toward generic service provision because it will mean loss of resources and status. At the same time, it is important to recognize the need for high quality specialized services. Total mainstreaming of services is desirable only with the guarantee that generic service providers can provide the full range of services that are required. There is no substitute for having the capable resources in place before any reorganization or reconceptualization can take place.

- Lack of joint professional training: different professions should work together early in their training, share common knowledge and understanding, and thus diminish separateness from the grass roots upward, at the same time that they work to foster cooperation at the top policy levels.

- Lack of communication among agencies and service systems: communication at the service site/community level can result in a coherent local approach to service delivery. However, communication alone is insufficient to promote cooperation. Each profession and each agency has its own theories and approaches to what should be done and how to do it.

- Financial disincentives: there is a system for supporting, through disability pensions and other income supports, non-employment. The loss of such benefits is a substantial threat to individuals and discourages independence. There is a tension between providing income assistance and encouraging work and independence.

APPROACHES TO ADDRESSING THE BARRIERS

One way to address the barriers is to empower the individual. There needs to be a profound change in attitude regarding how services should be provided. Professionals need to assist the individual in selecting services not in dictating what services are provided. In the current protected market, agencies hold the power; individuals must accept what the agencies provide in the manner in which they provide it. Under a new philosophy of personal choice, individuals should be able to choose what they need, when they need it. To do this, the individual with a disability needs to have a comprehensive "assessment" resulting in a personal plan and goals. Empowerment also comes with a tremendous responsibility, and some individuals will need assistance to make the best choices. This assistance must be part of the services, but not vested in one approach or agency.

A second approach to barriers would establish or identify models of service that are multi-disciplinary and multi-agency as well as client directed. In order to capitalize on existing local or model efforts underway in several countries, it is necessary for some single authority to assess the infrastructure of the service system and to determine where there are adequate services, where there are needs, and which entity could provide for those needs. This central authority could be time-limited (as in a special disability commission) an established Office of Disability or other centralized authority which has the power to draw on resources across agencies to fulfill service needs. All segments of the service providers, including industry and the private sector, should be brought into the process. The outcome should be a comprehensive picture of the current service structure from birth through old age. Overlapping authorities could be documented as could the differing orientations and goals that currently govern the separate agencies. The key to the success of this effort, however, must lie in how comprehensive it is. For, as a number of individuals indicated, small topical commissions and task forces have been created and meeting for years, and the situation has not improved significantly.

SUMMARY

In summary, discussion over the two days revealed that the problems of cooperation and coordination of services that support employment of persons with disabilities exist in many nations. Likewise, many nations have developed or are experimenting with different models or bureaucratic approaches that promote better coordination as well as allow for greater choice and control by individuals with disabilities. As was apparent in the discussions, none of the approaches were without problems. In part, all solutions present certain dilemmas. For example, there is a conflict between the desire for total integration of the services within existing generic employment programs and the need to ensure that specialized services are available; there is a need for financial supports that do not serve as disincentives to employment; and there is a need to establish some unifying, and perhaps, universal goals that can guide the delivery of services across all service sectors. Beyond these rather global recommendations, no one model emerged as clearly superior to others, nor does it appear that a single approach will suffice. For, as noted in the discussion of barriers, local constraints including economic downturns and high unemployment can subvert even the most perfect plan.

PART FOUR

SUMMARY

SUMMARY

SUMMARY OF THE INTERNATIONAL SYMPOSIUM ON EMPLOYMENT OF PERSONS WITH DISABILITIES

JOHN FISH, CONSULTANT TO THE
ORGANIZATION FOR ECONOMIC COOPERATION AND DEVELOPMENT

The International Symposium of Employment of Persons with Disabilities was held to disseminate information about OECD studies and innovations in the field of employment, and to share information about American disability policy and programs. The conference began with presentations by OECD experts and United States government officials, followed by group discussions on employment-related issues.

INDIVIDUAL PRESENTATIONS

On the subject of labor market trends, speakers indicated that smaller numbers of young people are entering the work force, while the need for workers is increasing. This creates an opportunity in the next decade to make the employment of persons with disabilities a natural rather than a special outcome of education and training. The appropriate use of technology could help bring this about.

However, not enough is being done to move young people with disabilities into the job market. In the United States, only 1/3 of the 43 million people with disabilities are currently in the labor force. Of all special education students leaving school, 90% remain dependent. An OECD study of its member countries found that employment departments and agencies focus on the re-employment of people who became disabled later in life, rather than on the employment of young persons with disabilities.

In the United States, economic priorities have been determining social policies, and there is an increasing need for clear social priorities. The financial risk to the economy of dependency for those with disabilities is great, and lifetime care for the 900,000 people under 30 years of age who have disabilities will exceed $1 trillion. Government action must be directed to reducing this burden and maximizing social and economic productivity.

The Job Training Partnership Act and the Americans with Disabilities Act, together with other initiatives, are attempts to remove barriers to employment for people with disabilities. The Americans with Disabilities Act is a major milestone in civil rights legislation. It protects people with disabilities from discrimination in employment, transportation, public accommodations, activities of state and local government, and telecommunications.

Private programs sponsored by business in the United States are proving effective. Among these initiatives are employment training in school, on-the-job training with employment guarantees, parent/school/employer relationships centered around the transition from school to work, and business-financed programs to encourage employment.

The OECD/CERI has developed a conceptual framework for the process of transition from school to the work, and formulated criteria for effective transition programs. Transition programs should be based on a tripartite relationship among the young person, his or her family, and professionals. Each young person with disabilities should have a needs assessment leading to an individual transition plan. In addition, individuals should have increased financial independence, and be enrolled in education and training programs which emphasize self-advocacy and decision making. Coordination and continuity are essential elements of successful transition. Professionals need to change ineffective practices that do not support the independence of the individual.

GROUP DISCUSSIONS

Following the speakers' presentations, each participant in the conference attended two of three discussion groups. The first group's theme was personal choice and the roles of the consumer, family, and advocates in the coordination of support services. The second group discussed effective integration and support in the work place, including a view of strategies in the support of young adults with severe disabilities in integrated employment. The third group focused on organizing and financing community services, including a review of problems surrounding interagency collaboration, co-funding, and service delivery.

The group discussing personal choice found that during transition, a guide or facilitator was important for young people with disabilities and their families. Participants examined the Danish kurator system which gives special education teachers the time and responsibility to inform students about post-school opportunities, including employment. Kurators offer information and support for up to two years after students leave school.

The group talked about equity and gender as these issues relate to personal choice. Discussions of disability commonly leave out gender, but the handicapping effects of disabilities are not always the same for men and women. Should choices for both sexes be the same?

Group members felt that choice, independence, and employment should be promoted by health and social support systems. When approaching prospective employers, professionals and other advocates should emphasize an individual's abilities rather than disabilities. Giving individuals the opportunity to work is more important than giving them the right to work.

The second discussion group, which focused on integration and support in the work place, looked at examples of supported employment in Italy and the United States. Successful models depended on clear integration policies in schools and in transitional programs. To replace dependency, individuals with disabilities need flexible individualized support based on assessed needs. The support can take the form of subsidized lifelong help, partial subsidies, and temporary forms of assistance. A tripartite relationship between the individual with the disability, a co-worker, and the agency with training on-the-job is necessary to support employment. The principle of normalization is important. Human support is as valuable as financial support.

The group raised questions for further exploration: How can support and choice be made available together? How does one explain why persons with disabilities should be hired? How can conflicts between agencies who feel they "own" their clients be resolved?

The third discussion group's theme was financing and coordinating services. Participants identified four dilemmas underlying the philosophy of service: Should services be specific or generic? Should financing be earmarked or given as block grants? Does coordination serve the individual or facilitate administration? Is empowerment consistent with the professional management of resources?

Coordination, if too effective, can limit choice since efficiency is not always sensitive to individual needs. Barriers to successful coordination of services include professional "turf-guarding," the lack of individual transition plans, conflicts between clients' and agencies' goals, the tendency to adopt currently popular solutions, poor communication between agencies and professionals, the vested interests of the "care industry," and disagreements over control of resources and funding.

The group agreed that additional resources for those with disabilities are justified to ensure equality of choice. Persons with disabilities should have more control of resources, perhaps in the form of vouchers for education and training. Case managers, with interdisciplinary training, can coordinate transition with the individual.

CONCLUSIONS

After the discussion group sessions, all conference participants met to share findings and develop the following recommendations and conclusions:

- There is little accurate information about how resources are used. Audits are needed to establish data bases on resources devoted to disability;
- It is important to achieve an appropriate balance between government and private sector funding of programs for persons with disabilities;

- Employment is particularly significant for young people with disabilities, since it offers regular social interaction in an integrated setting;
- Advocates should present a more positive picture of the employment attributes of persons with disabilities, putting emphasis on abilities;
- Persons with disabilities should have the opportunity to progress in employment, rather than remain in low-level jobs;
- Competition between agencies for the ownership of clients is not in clients' best interests. Solutions to problems should be individual and the coordination of services should take place at a local level. This demands delegation and effective local government;
- A benefit system should be established which encourages and supports individuals as they move in and out of the workforce. Support services should be flexible, comprehensive, and readily available. They should allow individuals to make choices.

Effective practices demonstrate that a very high percentage of young people with severe disabilities are capable of employment and independent living when given appropriate education and training into their twenties and continued support when needed. In practice, however, only a small percentage of them achieve these objectives, and many remain dependent throughout adulthood. Responsibility for providing support to individuals and families is often fragmented among numerous national, regional, and local agencies. Young people should be given the education, training, and support they need, and the transition from school to work should be recognized as a personal process requiring consistent support. This symposium offered participants an opportunity to discuss these issues and to exchange information about legislation, policies, and programs that may help young people with disabilities better achieve their goals.

APPENDICES

FACT SHEET
AMERICANS WITH DISABILITIES ACT (ADA)
(Public Law 101-336)

The ADA will protect people with disabilities from discrimination in employment, transportation, public accommodations, activities of state and local government, and telecommunications; giving protection which is comparable to that afforded other groups on the basis of race, sex, national origin, age, and religion. Most provisions go into effect two years after enactment, other than fixed-route publicly-funded transit vehicles (see below).

EMPLOYMENT

All places of employment with 25 or more employees are covered for the first 2 years; after that, employers with 15 or more employees ore more are covered. Provisions are similar to Section 504 of the Rehabilitation Act of 1973. For example, application procedures must be non-discriminatory, reasonable accommodations are required unless it would pose an undue hardship, and employment criteria must be substantially related to essential functions of the job.

TRANSPORTATION (PUBLICLY AND PRIVATELY OWNED)

New purchased and leased bus and rail vehicles must be accessible. For publicly-funded systems, this requirement goes into effect 30 days after passage. Comparable paratransit service must be provided unless it would pose an undue hardship.

All demand-response service which is provided to the general public, and privately-funded fixed-route service, may purchase only accessible vehicles unless it can be demonstrated that the service is accessible when viewed in its entirety. The exception is privately-funded fixed route service which uses vehicles carrying over 16 passengers, in which case new vehicles must be accessible.

Over-the-road coaches (Greyhound-type buses) are exempted for six years in the case of large providers and seven years for small providers; after that, newly-purchased vehicles must be accessible. The president can extend this for one year further. The bill commissions a three-year study to determine the best way to provide access to over-the-road coaches.

New bus and rail terminals must be accessible. Key rails stations must be accessible in no more than 3 years, with exemptions available for up to 20 years. Amtrak stations must be accessible within 20 years. One car per train must be accessible in no more than five years.

PUBLIC ACCOMMODATIONS

Public accommodations includes hotels, restaurants, theaters, halls, stores, offices, transit stations, museums, parks, schools, social service agencies, gyms, and any entity licensed to do business with or serve the public.

Existing facilities must remove barriers when such removal is readily achievable. If not, they must provide alternative methods of making goods and services available. Altered facilities and altered areas must be accessible to the maximum extent feasible. In major structural alternations, a path of travel to the altered area and restrooms serving the altered area must be accessible. New facilities must be accessible. Elevators need not be provided in buildings under three floors or with less than 30,000 square feet per floor, other than in shopping centers and health care facilities.

Furthermore, eligibility criteria for services cannot discriminate. Auxiliary aids and services are required unless they result in an undue burden or fundamentally alter the nature of the goods and services.

STATE AND LOCAL GOVERNMENT

State and local governments may not discriminate against qualified individuals with a disability.

TELECOMMUNICATIONS RELAY SERVICES

Telephone carriers offering services to the general public (interstate and intrastate) must provide TDD relay services on a 24-hour basis at no extra charge by three years after enactment.

ENFORCEMENT

Administrative remedies and the right to sue in Federal Court are available. Attorney's fees are available; punitive damages are not. The Attorney General can file suits and seek penalties. States can be sued.

DISABILITY DEFINED

Anyone with a physical or mental impairment substantially limiting one or more major life activities; has a record of such impairment; or is regarded as having such an impairment, is considered a person with a disability.

In terms of employment, the law defines a "qualified individual with a disability" as a person with a disability who can perform the essential functions of the job with or without reasonable accommodation.

This information was obtained from a fact sheet on ADA prepared by the President's Committee Employment of People with Disabilities (July 1, 1991).

FOR ADDITIONAL GENERAL INFORMATION

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All public documents produced by the President's Committee on Employment of People with Disabilities are available on cassette tape, Braille and large print.

SELECTED PUBLICATIONS AVAILABLE FROM THE ORGANIZATION FOR ECONOMIC COOPERATION AND DEVELOPMENT

Handicapped youth at work: Personal experiences of school-leavers (1985).

The Integration of the handicapped in secondary schools: Five case studies (1985).

Young people with handicaps: The road to adulthood (1986).

Disabled youth: The right to adult status (1988).

Disabled youth: From school to work (1991).

Labour market policies for the 1990's (1990).

MONOGRAPHS:

Wayne Sailor. Transition of disabled youth from school to working life (1991).

Martin Gerry. Transition of disabled youth from school to working life. The Genoa experience. (forthcoming)

To obtain copies of these publications, write:
OECD Publications Service,
2 rue Andre-Pascal, 75775 PARIS CEDEX 16, France, or
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TRANSITIONS TO EMPLOYMENT

Transitions to Employment presents the results of a unique international symposium that brought together policymakers, researchers, and program administrators from many nations to examine the critical issues related to full employment of persons with disabilities. The presentations herein represent the thinking of many individuals who are pioneering new programs and new concepts in this area.

Presentations of these concepts are followed by rich summaries of how individual countries are approaching this challenging area.

Summaries are organized within the following categories:

- Personal Choice
- Integration in the Workplace
- Organizing and Financing Community Services

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