

*transforming* **DIS**[ABILITY] *into* **ABILITY**

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Summaries of Presentations

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*Statements by  
Political Representatives*



## *Transforming Disability into Ability*

*W. Roy Grizzard*

Thank you for the kind invitation to present at this event sponsored by the OECD and the European Centre for Social Welfare Policy and Research. The U. S. Department of Labor appreciates the important role of both organizations, the diversity of OECD membership, and the role of research to advance policy options across various important areas of activity.

I especially commend the leadership of both organizations for recognizing the importance of new knowledge informing the development of new disability policy.

I will look forward to learning from all of you as the conference unfolds. The diverse states of Europe harbor valuable lessons, as do the 50 states and 4 territories of the United States of America. Our countries will share valuable information that will hopefully lead to the most effective employment policies for people with disabilities.

The sovereign states on both sides of the Atlantic face a jobs and skills gap in the coming years of the 21st Century. Our collective challenge is to match employer demand in the various labor market sectors with skilled supply. Working age people with disabilities can help greatly to fill the gap.

We in America and in the United States Department of Labor place the highest value on the premise that people with disabilities are able to work. We agree with you, as stated in the OECD policy conclusions, that the term “disabled” should no longer be automatically equated with “unable to work.”

We applaud the policy conclusion that disability and benefit receipt should be unbundled. I will later provide examples of work programs meeting individual’s needs in different work situations.

We further believe that the individual worker with a disability should be afforded the right to choose what type of work to do, have technical assistance to perform essential functions of a job, and have the chance to advance and progress in work

of choice. As such, individual worker needs must be embedded in policies and comprehensively addressed in practical implementations.

I want to speak about the opportunity we all have to create meaningful policy regarding people with disabilities. The word “opportunity” has an especially important meaning to me, for I have retinitis pigmentosa, and have been declared legally blind.

But that did not stop me from earning three degrees, or from serving in the field of education for over 25 years. It did not keep me from running a large state agency, or from being appointed as the first Assistant Secretary on disability employment issues in the history of the United States.

A large part of my success continues because I have come in contact with people who focus on my abilities – not on my disability. They give me opportunities to succeed, and I rise to the challenges.

Public policy, and the structures and systems which emanate from such policy, are in many ways a reflection of societal beliefs and values.

The key value on which the United States of America was founded is that of freedom. And one of the key definitions of freedom is: “the right of enjoying all of the privileges of membership or citizenship.” The best form of economic security, the best pathway to full participation in citizenship, is employment.

The history of U.S. policy impacting people with disabilities is a long and winding road — moving from isolation and segregation to inclusion, empowerment and disability rights. History tells us that, as a group, people with disabilities were hidden from society, and viewed as a class of dependent people who would always require segregation, protection, charity and care.

But American policies have helped change this view. They have shaped the movement of people with disabilities from segregation to integration – from being hidden away to becoming full participants of an inclusive community, including the employment community. United States policy now clearly recognizes that people with disabilities can work and should be afforded the services and supports they choose to make that happen.

The Americans with Disabilities Act (ADA), signed into law July 26, 1990, is the “lens” for disability policy in the United States. Enactment of this landmark civil rights legislation struck a statutory and regulatory blow to discrimination against individuals with disabilities in employment, state and local government services, public accommodation, and telecommunications.

The ADA serves as the framework for government-wide actions to end discrimination against people with disabilities in the United States.

As with any significant civil rights legislation, later questions raised as to the scope and intent of this Act are further defined through implementation. An American freedom is the opportunity to raise questions. We have an environment of checks and balances established by our founding fathers to ensure refinement of policy and practices.

We are fortunate to have a President who is fully committed to extending the opportunity to succeed to people with disabilities. He believes that the ADA has been an integral component of the movement toward full integration of people with disabilities into every aspect of American life. But he also recognizes that there is far more to be done to integrate people with disabilities into the workforce.

Two weeks after taking office, President George W. Bush launched the New Freedom Initiative, or NFI, as we call it. This Presidential Administration understands well the integration and synergies across government.

The President charged federal agencies in February 2001 to assess their programs and policies relating to people with disabilities, and to identify how they would support the objectives of the NFI. The objectives include:

- Increasing access to assistive technologies
- Expanding educational opportunities
- Promoting increased access into the community, and
- Increasing access to employment.

The NFI promotes federal interagency coordination to solve the complex social policy issues that impact employment for people with disabilities. The NFI recognizes that many aspects influence the ability of people with disabilities to seek and keep meaningful employment. These issues are broad-based, and involve many government entities.

For instance, the Department of Transportation needs to ensure that people with disabilities have a way to get to work. The Department of Education needs to ensure that people with disabilities have the requisite education and effective processes to transition from school to work. The Department of Health and Human Services needs to ensure that people with disabilities have access to health care. And the Social Security Administration needs to ensure that social security programs provide the flexibility and incentive for people with disabilities to leave the public assistance roles and participate in the workplace.

The Department of Labor is charged with preparing the American workforce for new and better jobs, and ensuring the adequacy of America's workplaces. The Department is responsible for the administration and enforcement of over 180 federal statutes. DOL programs, services and benefits are intended for all employers and workers across the nation, including individuals with disabilities.

Under the strong leadership of Labor Secretary Elaine L. Chao, the Department of Labor, through the Office of Disability Employment Policy, has been given a significant share of the responsibility for fulfilling the promise of the President's New Freedom Initiative.

Established just two years ago, ODEP has committed millions of dollars to fund various experimental programs to eliminate employment barriers in the public and private sector.

The workforce development system, which links people looking for jobs with available jobs, does its work in nationwide programs named One Stop Career Centers. ODEP's funds help these one stop centers to use effective methods to link people with disabilities and jobs. Such methods benefit both young people and adults with disabilities coming from all ethnic and racial backgrounds.

ODEP funds are focused on finding ways to better link employer demand with skilled labor supply. I offer you several examples of our work.

### **JAN – the Job Accommodation Network**

- Provides free telephone and Internet technical assistance on making workplace accommodations.
- Is used both by employers and employees to determine effective accommodations.

- Provides personalized attention to approximately 32,000 workplace accommodations in any given year.

### **EARN – the Employer Assistance Referral Network**

- Provides free telephone and electronic assistance to employers seeking to hire people with disabilities.
- Connects employers to local resources that have qualified job candidates with disabilities.
- Worked with some 2,000 employers in its first year.

The President and the Secretary of Labor recognize and reward those organizations, businesses and individuals who establish the most effective policies and practices increasing the employment of people with disabilities. For the first time in November 2002, the Secretary of Labor saluted winners of the New Freedom Initiative Award.

Our work includes refining methods of supplying skilled labor to the workplace. I again offer you several examples.

### **Telework/Telecommuting Research**

- This project is intended to test and assess the feasibility of telework or telecommuting for persons with severe disabilities. The research is using federal agencies as pilot sites.

### **Customized Employment**

- Customized employment means individualizing the employment relationship between employees and employers based on a determination of the strengths, needs, and interests of the person with a disability. It may include job development or restructuring strategies. Customization of employment is especially important for people with severe disabilities.

### **Youth**

- We support programs that develop effective school to work strategies. In addition, we help launch and expand programs that provide mentoring and work experience for young people with disabilities interested in technology fields.

## Technical Assistance

- ODEP also funds three national technical assistance centers. Two provide technical assistance to One Stop Career Centers in order to assist them to serve youth and adults with disabilities more effectively. Another center provides technical assistance to community rehabilitation providers.

## Collaborative Efforts

- One promising approach finds the Department of Labor collaborating with the Social Security Administration and the Department of Health and Human Services. We established a position named a “navigator” in the One Stop Career Centers to help people with disabilities to find their way through the maze of state and local services essential to living independently in the community.

Perhaps you have heard of Social Security’s “Ticket to Work.” It provides incentives for people with disabilities to return to work by:

Allowing people with disabilities to choose their own support services, including vocational education and rehabilitation

Extending health coverage for Social Security pension beneficiaries (people with a former workforce attachment) so they can return to work without the fear of losing health benefits, and

Expanding health coverage for certain people with severe disabilities who decide to go to work. They will continue to receive health benefits at the same time income rises or medical condition improves.

Improving the employment results of people with disabilities requires the cooperation of the federal government, state and local governments, the private sector, service providers, and advocacy organizations.

The President has said, “Government likes to begin things — to declare grand new programs and causes. But good beginnings are not the measure of success. What matters in the end is completion. Performance. Results.”

We must work together to develop strategies for success. We must determine what barriers act as roadblocks—and we must remove them.

As we move further into the 21st century, we are faced with new challenges. New opportunities for employment are opening as scientific and technological advances give rise to new industries and occupations unheard of only a few decades ago. At the same time, many traditional job opportunities are disappearing as industrial operations become increasingly automated and the nation's economy as a whole becomes increasingly globalized.

The transformation we are currently undergoing creates a great opportunity in terms of employment for people with disabilities. Together we must make sure that the result is a society — a world — that affords opportunity for employment and community participation to all people.

## *Exposé*

*Jean-Yves Hocquet*

Année après année, la situation des personnes handicapées et de leur famille s'impose comme un véritable enjeu de société. Une société, se juge notamment à l'attention qu'elle porte aux plus fragiles et à la place qu'elle réserve par conséquent aux personnes qui souffrent d'un handicap.

Il y a un peu plus de vingt-cinq ans, la loi du 30 juin 1975 a engagé une étape importante. Pour la première fois, la question du handicap a été abordée de manière globale et en termes de droits. La Nation a placé le handicap dans le champ de la responsabilité collective et de la protection sociale. Elle a affirmé une obligation nationale de solidarité et elle a défini la nature de l'engagement des pouvoirs publics. Les personnes handicapées ont pu bénéficier d'allocations qui ont été régulièrement revalorisées. Les villes, les transports en commun, le grand commerce ont dû commencer, commencer à s'adapter. Même si elle reste encore à imposer, l'éducation des enfants et des adolescents handicapés a été reconnue comme une nécessité,

La loi du 10 juillet 1987 est venue compléter cet ensemble en faisant obligation à l'Etat et aux entreprises d'employer des personnes handicapées.

Aujourd'hui nous devons d'abord remédier aux situations d'urgence que les personnes handicapées et leur famille affrontent trop souvent dans la solitude et parfois dans la détresse. Nous devons aussi revoir les fondements mêmes de notre politique, en passant d'un système d'aide uniforme à une logique qui prenne pleinement en compte les besoins particuliers de chaque cas individuel.

Ce qui est en jeu, en effet, c'est en réalité le principe même de l'égalité des chances.

C'est pourquoi le Président de la République a souhaité faire de la politique pour les personnes handicapées l'un des grands chantiers du quinquennat. Cette action s'inscrit dans une ambition visant à renforcer notre cohésion nationale par davantage de justice et donc par davantage d'attention aux plus vulnérables.

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D'abord en commençant à rattraper notre retard en matière d'accueil :

3 000 places supplémentaires en centres d'aide par le travail et plus de 2 000 places en maisons d'accueil spécialisées seront créées l'an prochain, ce qui est un doublement par rapport au rythme prévu. Trop de personnes, c'est évident, polyhandicapées, autistes, traumatisées crâniennes, handicapées psychiques sont aujourd'hui sans solution. L'effort engagé cette année devra donc être poursuivi et si nécessaire amplifié.

L'impératif d'intégration scolaire ne doit naturellement pas être oublié. C'est l'un des soucis du gouvernement et dans cet esprit, le nombre d'auxiliaires de vie scolaire sera porté à 6 000 à la rentrée prochaine, soit trois fois plus qu'en 2002.

Le gouvernement vient aussi de mettre en place un dispositif spécifique pour apporter une aide immédiate à des personnes très lourdement handicapées qui ont fait le choix de vivre à domicile. Cet effort sera accru en 2003. D'ici douze mois, 5 000 postes d'auxiliaires de vie auront été créés. Enfin, la réforme des tutelles, maintes fois repoussée, et il est vrai délicate, a été engagée.

Ces mesures doivent s'accompagner d'une réforme en profondeur.

Les orientations seront présentées au Conseil des ministres avant l'été prochain en vue d'un examen par le Parlement à l'automne.

Chaque année, une Conférence des handicaps sera réunie afin d'évaluer tous les effets de la politique pour les personnes handicapées, notamment du point de vue de leur intégration dans la société.

Cette réforme permettra de construire un véritable système d'aides personnalisées et de donner la priorité à l'intégration professionnelle et sociale des personnes handicapées.

En consolidant le système de protection sociale mis en place au cours des vingt dernières années, il faut maintenant personnaliser le soutien apporté à chaque personne handicapée en tenant compte de ses caractéristiques et de son projet de vie.

Personnaliser, c'est d'abord évaluer les aptitudes, les potentialités et les besoins de la personne handicapée dans l'environnement qui est le sien. Personnaliser, c'est aussi, dans le cadre d'un nouveau droit à la compensation, s'attacher à compenser les conséquences - et notamment les surcoûts- qu'implique le handicap.

Personnaliser, c'est simplifier considérablement les aides, regrouper les dispositifs actuels, sans rien perdre de leurs avantages, mais en les rendant plus accessibles et donc plus efficaces. Personnaliser, c'est enfin prendre en compte l'évolution du handicap tout au long de la vie et cela d'abord évidemment en reconnaissant qu'une personne handicapée ne cesse pas de l'être au-delà de 60 ans et doit continuer à bénéficier d'aides spécifiques.

La solidarité nationale doit permettre aux personnes handicapées et à leur famille de construire un véritable projet d'intégration et de réussite personnel.

Pour parvenir à cet objectif, plusieurs actions peuvent être envisagées. Toutes devront être examinées. Les personnes handicapées pourraient s'adresser à un interlocuteur unique pour définir les réponses adaptées à leurs besoins. Un réseau de maisons des personnes handicapées pourrait ainsi être implanté sur tout le territoire. Elles pourraient être coordonnées par une agence nationale des handicaps.

Ces maisons mettraient à la disposition des personnes handicapées et de leur famille toutes les informations nécessaires. Elles pourraient aussi établir, avec les personnes handicapées, leur famille et grâce à une équipe pluridisciplinaire de professionnels, un projet personnalisé, couvrant tous les aspects de la vie quotidienne : scolarité, formation, logement, vie professionnelle, aides humaines, techniques ou animales. Les aides apportées aux personnes handicapées seront au service de la réalisation de leur projet. Elles devront évidemment tenir compte des capacités contributives des personnes.

Cela suppose aussi que dès l'enseignement, et notamment pour tout ce qui concerne les techniciens de la société : les architectes, les ingénieurs, on explique et on donne conscience aux étudiants de l'exigence des adaptations qu'ils doivent spontanément mettre dans leur projet pour qu'il s'applique à tout le monde.

Il faut aussi renforcer la professionnalisation des fonctions d'accompagnement comme celles qu'assurent les auxiliaires de vie, dont le métier doit être mieux reconnu et reposer sur des formations qualifiantes.

Enfin, les aides techniques restent encore trop difficiles à obtenir et à financer. Il faut faire évoluer cette situation qui est le premier obstacle à l'autonomie. En élargissant la gamme des équipements dont le coût peut être pris en charge par la collectivité. En permettant aussi aux personnes handicapées de mieux accéder aux aides que leur offre aujourd'hui le progrès technologique qui ne cessera de se développer..

A côté de cette personnalisation de notre système d'aides, la réforme devrait poursuivre, un deuxième objectif : donner aux personnes handicapées les moyens de construire un véritable parcours professionnel. C'est à notre société de s'adapter à leurs besoins.

Cela commence par l'enseignement et la formation, indispensables pour trouver sa place dans la société. Le principe de non-discrimination fait obligation à l'Education nationale d'accueillir en son sein tous les enfants handicapés qui peuvent l'être et de nouer avec l'éducation spécialisée, dont le rôle est également fondamental, les liens qui s'imposent. Cette obligation doit être respectée, scrupuleusement respectée. Nous devons nous en donner les moyens en développant l'accueil des personnes handicapées, de la crèche jusqu'à l'université, en mobilisant les enseignants qui y sont prêts, en les formant et en recourant davantage aux aides humaines et techniques.

Il faut faciliter ensuite l'insertion professionnelle en renforçant les dispositifs existants, que ce soit en milieu ordinaire ou en milieu protégé.

Les pouvoirs publics doivent, c'est une priorité, créer davantage de places en structures protégées, consolider l'activité de ces établissements, conforter les droits des personnes en leur sein et favoriser les projets innovants. Cela permettra de construire de véritables parcours professionnels. Il faut avoir l'ambition humaine de faire évoluer celles et ceux qui le peuvent des centres d'aide par le travail vers les ateliers protégés ou vers les entreprises, tout en veillant à leur conserver un droit au retour.

S'agissant maintenant de l'insertion professionnelle en milieu ordinaire, l'objectif fixé par la loi de 1987 est, chacun le sait, très loin d'être atteint, notamment dans l'administration. La transposition de la directive emploi permettra aux partenaires sociaux de négocier les voies et moyens d'un meilleur accueil des personnes handicapées dans l'entreprise. Les possibilités de cumul entre des revenus professionnels et des allocations soient élargies pour favoriser l'accès au travail.

Les fonctions publiques devraient être exemplaires. Dans ce domaine prioritaire, l'Etat et les employeurs publics doivent respecter leurs obligations. Personnalisation des aides, accès au monde du travail : ces deux axes de réforme paraissent prioritaires.

Au-delà de la nécessité de faire évoluer nos lois et nos pratiques, nous devons toujours être particulièrement attentifs au respect des droits des plus vulnérables. Elles sont encore beaucoup trop souvent les victimes, des difficultés qu'elles peuvent aussi rencontrer pour simplement faire valoir leurs droits. Enfin, nous devons être particulièrement vigilants pour que la recherche soit mise au service de la prévention, du dépistage et de la prise en charge précoce du handicap et, chaque fois que c'est possible, de la guérison des maladies qui en sont la cause.

*Introduction:  
Main Findings and Conclusions  
of the OECD Report*



## *Transforming Disability into Ability – Results and Conclusions from the OECD Study of Disability Policies for the Working-age Population in 20 Member Countries*

*Berglind Ásgeirsdóttir*

The paper presents the main results and conclusions of the first comprehensive analysis of disability policies for the working-age population in the OECD. The first part includes some interesting facts and numbers about disability in OECD countries. The second part includes the policy conclusions and proposes a radically new approach to disability, which places employment, rather than income support, at the heart of disability policy.

The results of the OECD study suggests that disability benefits systems and their rules strongly influence the number of people on disability benefits. In other words, policy matters – there is no “natural” rate of disability. It matters how countries define and assess disability, how they define entitlement to benefits, how they award benefits and, especially, how generous disability benefits are. The availability of other social benefits also has an impact on disability benefit rates. The less accessible other out-of-work programmes are, the more heavily disability programmes are used. In the United States and the United Kingdom, for example, disability benefit rates increased as entry to unemployment and early retirement programmes became more restricted.

The OECD study shows that different policy approaches by different countries had little or no effect on outcomes. The most striking commonality was that there is no outflow from disability programmes to jobs.

A new policy approach that emphasises the economic and social integration of persons with disabilities is proposed. It has *five* key features:

- it recognises the status of disability independent of the work and income situation;
- it emphasises activation;
- it proposes a new structure for benefit systems;
- it introduces a culture of mutual obligations; and
- it gives a more important role to employers.

Disability policies must be seen primarily as activation programmes rather than passive income support programmes. Many countries are already moving in this direction but much remains to be done. The OECD would like to support this process by conducting in-depth country reviews of disability policy from this perspective.

## *Transforming Disability into Ability. A Commentary Based on Recent European Research*

*Deborah Mabbett\**

The OECD report makes a major contribution to the cross-national policy debate on promoting employment among people with disabilities. The report provides a comprehensive overview of data on receipt of income maintenance disability benefits, including analyses of inflow and outflow rates and the incidence of reciprocity by age and gender. These data are accompanied by concise and insightful explanations of the great variety of institutional and administrative factors that can influence income maintenance disability benefit receipt, including availability of other benefits, linkages between sickness and disability benefits, partial awards, rules on severity of disablement and the impact of contribution requirements and means tests.

The report also contains a number of policy recommendations, particularly about measures which might be adopted to promote employment among people receiving disability income maintenance benefits. In chapter 2, the report defines what it sees as a consensus around the desirability of promoting paid employment among people with disabilities, invoking developments in OECD countries (paragraph 39) as well as supra-national agreements (40) in support of this position.

### **Policy and Evidence**

When there is broad agreement on policy goals, the task of the social scientist is straightforward: it is to explore the empirical evidence in order to map out the relationships between different policies and the outcomes or goals that have been agreed. Of course it is always difficult to come up with firm results in social science. The difficulty that the OECD study faces, and to its credit acknowledges, is that the data do not permit any strong conclusions to be drawn about the effectiveness of particular policies to promote employment among disabled people. Some of the policies favoured in some countries are evidently felt to be successful by national policy-makers, but comparative data on employment rates do not provide

evidence for the success of these policies. The basic reason is that the contextual factors are extremely varied and complex. A particular problem is that disability is defined and assessed differently in different contexts, making comparative statistical analysis very difficult.

The absence of empirical evidence for the effectiveness of particular policies does not diminish the value of the report. On the contrary, the report helps us to understand why the evidence cannot be found, by explaining the multitude of factors which impinge on benefit recipiency and employment rates. However, the lack of empirical evidence means that the policy recommendations, of which there are a number, must be based on something else, and it is quite difficult to identify their basis. For a start, it is easy to be misled by the abundance of data into thinking that the recommendations are based on the data, even though the text of the report makes it clear that this is not so.

### **The Independence Axiom**

The policy recommendations are derived deductively, on the basis of axioms which are not clearly stated, but can be inferred. A key axiom is as follows:

There exists a group of truly disabled people. True disability is a state of affairs which is independent of a person's employment, income, insurance and benefit status (384).

This 'independence axiom' provides a basis for the proposition that disability categorisation and income maintenance benefit receipt could be 'unbundled'. In other words, a truly disabled person could be recognised as such independently of the process of seeking access to particular benefits and services. Furthermore, given the agreed policy goal of promoting paid employment, it is possible to argue that unbundling not only could but should be done. Unbundling is advocated in order to provide a basis for wider access to employment measures for disabled people and to allow benefits to be structured more flexibly for those moving into and out of employment.

The report recognises that unbundling would involve a substantial change in the way disability is currently assessed. There is no single common idea of what disability is, or what it entails, embodied in the legislation of developed welfare states. Understandings of what constitutes disability, and methods of assessment, vary according to a person's employment, insurance (and work history) and benefit sta-

tus, as well as being affected by other factors such as age. Different assessments are done for different social policy purposes. Furthermore, some commentators have argued that this diversity is desirable if social policy categories are to be relevant to their purposes (see e.g. Mashaw and Reno, 1996). In our research for the European Commission, we made relevance a central criterion for evaluating definitions of disability, and argued that relevant definitions would be different for different purposes. This argument was based on a detailed study of how disability was assessed for various purposes in the EU states, but the general reasons for our conclusion can be briefly stated. The fundamental problem is that the environment affects a person's degree of disability. Impairment may be seen as an inherent or person-level attribute, but the extent to which people are disabled by their impairments depends on the environments in which they endeavour to participate.

### **True Disability**

The OECD report acknowledges the difficulty of identifying who is disabled and who is not, and the heterogeneity of the group (394). However, this does not lead to reconsideration of the independence axiom, even though two rather different views are taken about the nature of the true group. First, in chapter 3, survey measures of disability are reported. Right at the start, it is noted that it would be desirable to use objective measures rather than self-reported disability. The definition of disability is of those reporting a health problem which limits general activities of daily life, and this is used because it is available from surveys in a number of countries. It seems that the OECD does not propose the survey measure as the true measure of disability. However, the data are still used to establish certain key propositions about employment and welfare among disabled people. More problematically, the data on surveyed disability are contrasted with data on disability benefit receipt, and discrepancies are found which are described as 'quite alarming' (84). Disability benefit schemes are characterised as suffering from both inclusion and exclusion error, and much of the commentary assumes that surveys have less error: they might not capture the group of truly disabled people perfectly, but they are assumed to give a truer picture than the administrative data.

The second main set of ideas about true disability are most clearly stated in chapter 8, where it is argued that disability assessment should be done in two steps which clearly differentiate biological difference (impairment and functional limitations) from limitations in activities and participation (401). The first step, assessing biological difference, should be done by medical specialists and based on medical grounds. The second step should determine the extent to which the disabling con-

dition affects a person's ability to work (402). Disability status determined in this way would be unaffected by the person's employment status, unless the medical condition changes (403). In this sense, the medical step is seen as the fundamental and stable component of the disability assessment.

The OECD report notes that there are some examples of disability assessments which are independent of employment status and income maintenance benefit receipt. For example, a number of countries use impairment rubrics for administering their employment quota systems. As the report notes, these systems generally create a registered disability status which is kept irrespective of work status (406). However, registered disability status does not bring with it entitlement to income maintenance benefits: it does not provide a unified disability category which is referred to both for employment service provision and for benefit administration. The OECD suggests that it could be extended in this way (fn 66).

The EC study shows that there are some important reasons why the use of impairment-based assessments is restricted, and why states impose further and/or different disability tests in their income maintenance systems. The oldest-established impairment rubrics assess the degree of disability directly from the description of a person's medical condition in terms of impairment. For example, degrees of loss of sight or hearing, measured using accepted technical equipment, may be translated directly into a degree of disability. This 'direct measurement' approach is appealingly simple, but it is hard to sustain because of the difficulty of explaining why one impairment is more severe than another without referring to its disabling effects. As a result, the ratings in these impairment rubrics can seem rather arbitrary. The ratings are not widely used for benefit administration because they are not seen as relevant to the purposes of benefit provision.

This example suggests that the OECD-proposed approach to disability assessment may also fail the test of relevance. Social policy categories which are not sufficiently relevant are unsustainable. Irrelevant exclusions may mean that there will be a group of people whose needs and circumstances are suitable for the policy (e.g. the income maintenance benefit) who are denied access. Irrelevant inclusions may mean that people are offered employment-related services (for example) which they do not want and cannot utilise.

These criticisms do not mean that the OECD is wrong to advocate some form of unbundling of disability status from benefit receipt. To the extent that existing rules and benefit structures make transitions into work difficult for disabled people, it

would be desirable to reform them. Few would dissent from the idea that ‘disability should not be equated with inability to work’, although they might question whether this designation is, in itself, an explanation for low outflows from disability benefits (131). However, the report does not explain why a medically-based assessment of work capacity should be determinative, or why a single definition is necessary. (One might argue for a single definition to reduce administrative costs and intrusion, but this argument is not made by the OECD, which advocates more frequent reassessment than is currently done.)

### **Employment neutrality and employment promotion**

The report notes that benefits to compensate for extra costs of care or mobility may be paid independently of employment status and income maintenance benefit receipt (408). However, it is puzzlingly dismissive of the potential role of extra costs benefits in providing a structure for the types of reforms it envisages, asserting that these benefits are ‘often not adequately integrated with any other policy component’. While the discussion is rather brief, I think that the point is that extra costs assessments do not involve any work capacity assessment or evaluation of the potential for vocational rehabilitation or other employment measures. In other words, extra costs benefits are (broadly) neutral with respect to a person’s employment status, but they are not employment-promoting in the way that vocational assessments might be.

Benefits to compensate for extra costs may be paid to disabled people without designating them as unable to work. There are two different implications which might follow from this. One implication is that non-working disabled people might be able or unable to work but the social security administration would not endeavour to determine this question. The other is that a person who is not unable to work would be seen as able to work. The former implication is employment-neutral; the latter is employment-promoting. The OECD report chooses the latter.

The report argues against the use of a disability category to exempt certain people from labour market participation requirements (such as requirements to seek and be available for work) which are applied to unemployed people. However, it recognises that it would be pernicious to impose participation requirements on all disabled people, and therefore advocates a discretionary approach to these requirements rather than the use of a categorical criterion. Administrators should have flexibility in assembling benefit packages and developing return-to-work plans for disabled people (410).

The rejection of a categorical approach to participation could be explained logically as follows. From the independence axiom, we can deduce that a group of truly disabled people exists, and the true meaning of disability does not equate with inability to work. If it is further assumed that the disability categories used in social policy should correspond to the true meaning of disability, it follows that there is no valid disability category which could be used to exempt a group of people from labour market participation requirements. Therefore a discretionary rather than a categorical approach to these requirements should be adopted.

Clearly it is possible to avoid this conclusion by rejecting the postulate that the disability categories used in social policy should correspond to the true meaning of disability, in favour of the relevance criterion. This suggests instead that social policy categories are constructed for particular purposes: in particular, to facilitate the efficient allocation of resources while avoiding intrusive and burdensome administrative enquiries. We can note that one of the purposes for which disability categories have been constructed in social policy is to exempt certain people from labour market participation requirements. It is arguable that the notion of disability has, in the past, given legitimacy to this exemption. However, the use of the exemption has, in practice, raised a lot of issues about the meaning of disability: in particular, the extent to which age, labour market conditions and other social factors should be taken into account in exempting people from participation. It is clear that governments have manipulated the disability category for political and financial reasons, seeking sometimes to allow more exemptions and, at other times, wanting to extend participation.

It would be possible to detach disability from its problematic connection with participation exemptions in several ways, of which the OECD proposal (expectation of participation with discretion) is one. Another approach would be to base participation exemptions on other grounds. An obvious candidate is age: people over the old age pension age are already exempt from participation, and many states do not impose participation requirements on older unemployed workers long before they reach pension age.

One objection to this is that states are generally trying to raise retirement ages, not lower them. The OECD report notes that contestation over disability classifications in social security is liable to increase rather than diminish as early retirement provisions are eliminated and access to old age pensions is delayed (448). The report argues that the appropriate policy response is to adopt employment-promoting policies and participation requirements, backed by the clear delineation of the dis-

ability category on medical grounds. Clearly, it is possible to draw the opposite implication: that disability classification will become even more of a minefield in the future than it is today, and that other approaches which do not rely on contentious distinctions need to be found.

One approach is to try to promote employment through choice rather than through administrative intervention. The report points out that benefit structures often deter employment, whether because of the difficulty of earning more than the out-of-work benefit entitlement, or because of high in-work costs, or because of the risk of losing future entitlement by giving up a hard-won disability classification. These deterrents could be removed by changing benefit structures: in particular, by allowing the income maintenance component of benefits for older workers to operate like a basic income. For people with disabilities that impose extra costs, additional benefits to meet these costs could be paid regardless of employment status (as noted above).

A number of states have old age pensions which, with the easing of retirement (labour force exit) conditions, provide something very like a basic income to people over pension age. It would be possible to de-link policies on the pension age and the retirement age, allowing the age of access to a basic income to be lowered while also promoting extension of working lives by allowing work and benefit receipt to be combined.

One possible objection to paying unconditional income maintenance to older people is that it is desirable to establish an expectation of participation in order to motivate the search for effective employment-promoting policies and to encourage governments to provide adequate resources for them. The problem with this argument is that there is a risk that the expectation of participation could have adverse consequences for the fair and consistent treatment of social policy clients. In particular, hard-pressed administrators may develop their own low-level categories of disability based on clients' employment prospects, without these categories being subject to explicit definition and public and political scrutiny.

## **Conclusion**

Implicit in the OECD policy recommendations is a view that there is a 'true' cohort of disabled people who should rightly be the target of social security and employment policy, while current measures have constructed a partially 'false' cohort whose presence on the benefit rolls is due to the adverse labour market

conditions facing older workers and to policy decisions to promote exit among those workers. This discussion has shown that there are considerable problems in characterising the ‘true’ disabled. The OECD proposes a medical and work capacity-oriented approach to disability. The findings of research done for the European Commission raise questions about whether this approach is consistent with the criterion of relevance which, in our view, should guide the construction of social policy categories.

Zola (1989) famously put forward the case for a ‘necessary universalising’ of disability policy. He argued that the different disabling effects of different environments resulted in contingent and ever-changing experiences of disability. While his analysis did not rule out using disability categories in social policy to identify particular groups with relevant needs, it highlighted a number of possible problems. Many disabling conditions have complex patterns of progression and remission, implying frequent reassessment and adjustment of provision. Zola advocated more flexible universal policies. These might include not only changes to building and transport design, but also workplace policies allowing flexibility in hours and productivity, provision of benefits which would function as a non-categorical basic income, and so on. The OECD has advocated an approach which is flexible in the sense of being favourable to employment, but the policies it proposes leave little to individual choice and envisage a high level of administrative engagement which could be both costly and intrusive.

## Note

- \* Brunel University recently hosted a research project on Definitions of Disability, funded by the European Commission and involving national reporters from all the EU member states except Luxembourg, along with Norway. The project report will shortly be published by the European Commission. Information about the project is available from its website: <http://www.brunel.ac.uk/depts/govn/research/disability.htm>.

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## OECD Key Issues and Policy Conclusions

### *Theme 1: What Do We Mean by “Being Disabled”?*

#### **Key issues**

Whether a person is disabled or not can mean various things. Assessments, involving both medical and vocational judgements, have several different but related objectives: to define needs, to determine eligibility for services, and to regulate access to transfer payments.

Assessment problems and cross-country differences in assessment procedures and eligibility criteria are reflected in often high and dissimilar benefit rejection rates.

There is a striking lack of permeability between being disabled and not being disabled, which fosters benefit dependence. People avoid risking the loss of their benefit through attempting to work, which contributes to very low outflow rates from disability benefits. Not being entitled to disability benefits can exclude people from receipt of necessary services.

To distinguish full from partial and permanent from temporary disability is notoriously difficult, and there is no uniform response to these two problems across countries.

Different procedures, medical and occupational requirements are applied to assess shorter-term sickness and longer-term disability. The result can be confusion and injustice. There are also different responsible authorities in most countries.

## **OECD policy conclusions**

“Disabled” can refer to a medical condition, labour market prospects or benefit receipt. These should be determined independently.

The term “disabled” should no longer be automatically equated with “unable to work”. Disability should be recognised as a condition but it should be distinct from eligibility for and receipt of benefits, just as it should not automatically mean an obstacle to work.

This approach would allow beneficiaries to “risk” taking up work even if they are not sure to be fit for work. The disability status itself should be the basis for certain benefits that are designed to compensate the extra costs of the disabling condition, e.g. for medication, care, or mobility. Benefits for these purposes should not be related to the work status of the disabled person, should not be means-tested, and should be paid as long as the costs arise.

The disability assessment should be repeated at regular intervals. If a review finds considerable health improvement or if the vocational outcome of a stable health condition is judged differently, intervention strategies should be re-adapted.

This “unbundling” of disability and benefit receipt would help to ensure that the full range of disability-related benefits and services is available to every person with a disability, according to individual needs but regardless of the work situation, the insurance status or benefit receipt.

## *Ability Assessment in Pre-pension and Flex Job Schemes*

*Steen Bengtsson*

The reformation of the Danish system of pre-pension (disability pension) originated in the research on disability pension (with the 1984 reform called pre-pension) that took place on the Institute of Social Research in Copenhagen from the sixties. In this decade the labour market participation of physically disabled persons was surveyed and the results used as basis for a legislation of vocational rehabilitation. In the seventies the problem of a growing number of disability pensioners inspired to a research on this pension. In the eighties a reform had united disability pension with some social pensions under the name of pre-pension.

The research on regional differences in the award of pre-pension discovered by pure incidence that the municipal administration of pre-pensions and other provisional benefits had a significance for how many pensions there were awarded. By then such a result was anything than expected, because a number of state boards had the authority of awarding these pensions and the municipalities had no influence in that connection. Disability was widely considered a fact that should be evaluated by medical experts. How could it be then that the municipal casework had an influence on people's disability?

The discovery of the significance of the municipality and its casework and attitudes lead to a quite new politics on the area. In the nineties the municipalities little by little got the responsibility for awarding pre-pensions, and in return had to pay a steadily greater share of them. In 1992 they came to pay 50% of pre-pension and all other maintenance benefits as well, so that the municipalities no longer had any gain of placing people on pre-pension. In 1998 they came to pay 65% of these pensions, whereas provisional maintenance benefits were paid with 50% and wage support to the new flex jobs by 35%. So the system had become active-oriented with incentives for the municipalities to chose the most active possibility.

At the same time the municipalities acquired more instruments for vocational rehabilitation and activation of their clients on sick pay, unemployment benefit, rehabilitation benefit and social assistance. In 1990 rehabilitation benefit was re-

formed, in 1994 unemployment benefit and during the nineties social assistance was gradually replaced more or less by activation. The flex job scheme from 1998 has already been mentioned, and the same year the possibilities of coming in job for disabled people was enhanced by a special law including a supported entrance in job and possibility to get personal assistance. So the municipalities got a number of new instruments to administer the cases in a more active direction.

With the 1998 legislation the new ability assessment was introduced, not yet directly formulated in law texts but in an indirect way. This was effected by making the application of pre-pension something that could not simply be done by the citizen himself or herself, but should be decided by the municipality and only so if all possibilities of vocational rehabilitation or flex jobs had been exhausted. So the person who could be rehabilitated to a job or a flex job could not come to apply for a pre-pension, even if he or she should be medically “bad enough” to get it. With the pre-pension reform of 2003 the new principle is made official, and its application had been prepared by courses for caseworkers all over the country.

We do not yet know for sure if this is the background for the decline of awards of prepension during the nineties. I am preparing a project to throw light over this. Another possibility is that the persons who would earlier have got a pre-pension now are “parked” on social assistance. But, anyhow, the number of awards of prepension has declined drastically in the period 1994-2000, from around 28.000 in the beginning of this period to 13-15.000 in the end. So there has been a decline of about 50%. If this is a genuine activation policy it so far (2003 included) has saved the country for some 200.000 pension years, which is some 4 billion euro. Even if activation is costly too, one can at least conclude that we get more value for the money in this way because we know from research that nearly all persons prefer flex jobs or other supported employment for pre-pension. If the persons are just parked on social assistance, however, there has not been any gain of this policy.

It is too early to say if the 2003 reform of pre-pension making ability assessment official and explicit will change anything. It is possible that we have already gained what can be gained by this new principle because it in fact has been applied for the last five years in this indirect way as I have mentioned. It is furthermore possible that the reform makes casework more bureaucratic because a certain formal procedure is demanded by the new law. This procedure is described in a manual and has been taught to all caseworkers. Our latest research shows that municipalities who administer in a rule-oriented and formal way are awarding more pre-pensions, whereas municipalities that administer in a concrete way and are using networks

to employers, education places and medical doctors are awarding less pensions. Perhaps the reform will install a bureaucracy which draws in passive direction.

The Danish pre-pension reform with its orientation towards integration on local level and a less medical disability concept is rather unique in Europe. Other countries who try to limit awarding of disability pensions often will centralise the control and restrict the pensions to strict medical diagnosis. Here the local and near authority has been developed into an organisation who works through local partnerships to integrate people if possible in employment. Especially deserve the so-called local coordination committees to be mentioned. They were established in 1999 in every municipality, and include representatives from municipality, employment office, the social partners, local medical doctors and organisations of disabled people. Research has shown that some of the is making a great difference whereas others are achieving less.

Municipalities too are different. Quite a number are pensioning the double amount of what should be expected from population composition, unemployment and other relevant background variables, and quite a number are pensioning half the expected number. Even if the expected numbers have been calculated on the basis of research and published since 1995, the municipalities have not used this statistics to become more similar. The development goes in fact in the opposite direction. It seems that local differences – for the time being at least – is the price for decentralisation of the authority of awarding pre-pensions.

## *What Do We Mean by Being Disabled?*

*Adele Furrie*

What do we mean by the phrase “being disabled”? For the last 18 years, my primary research has revolved around this phrase so that I could design questions or assist with the design of questions that operationalize the phrase and that could be used to collect statistics on disability. For 18 years, I have listened to people describing what “being disabled” means to them, and what I heard depends on the perspective of who was speaking. Let me describe some of what I have heard and then we can move on to how I think my experience can inform your work.

I’ve listened to persons with disabilities enumerate what being disabled means to them. To them, it means limitations imposed by their community in the form of barriers that prevent or impede their full participation. It means physical barriers – not being able to get into the building to see job postings because you’re in a wheelchair and there are steps into the building and no ramps. It means attitudinal barriers – your opinion is ignored because you use a walker – and your speech patterns are different – and saliva may gather in the corner of your mouth. It means barriers to working because you can’t afford to take a low-paying job or short-term employment because the supports that you need to live independently and that you have struggled to get out of the bureaucracy will be withdrawn if you go to work. It means listening as politicians receive accolades for their progressive disability policy but seeing no real change to your everyday life as a result of that policy.

When pushed to respond to the question “but how do I first identify who you are so that I can then ask about barriers”, I have consistently received reluctant agreement that the functional model of disability could be used - provided that those questions are followed by the nature and severity of the barriers encountered.

I’ve listened to organizations representing persons with disabilities as a result of a particular condition or health problem – the Arthritis Society is interested in the issues facing people with disabilities who report arthritis; the Mental Health Association is interested in the issues facing people with disabilities who report a mental health condition.

So, when asked the question “how do I identify your population”, the response for these types of organizations is “ask about the condition, then ask about barriers”. When pushed to acknowledge that not everyone who has a particular health problem has a disability, there usually is reluctant agreement to use the functional model of disability followed by a question on underlying health problem or condition that causes the limitation in activity.

I’ve listened to employers who have legislation imposed on them. The Canadian Employment Equity Act, for example, states that employers must have representation in their labour force of persons with disabilities at least equal to or more than their representation in the population. So, to employers, being disabled means compliance with legislation and with the definition that is imbedded in that legislation. That definition includes a reference to limitation in the workplace. So, from an employer’s perspective, it’s a two-edged sword. Firstly, there is the concern that additional expenses will have to be incurred to accommodate persons with disabilities æ such as widening doorways to accommodate wheelchairs and providing technical devices to accommodate persons with low vision or who are blind and sign language interpreters for persons who are deaf. And, the other side of the coin is that accommodated persons will no longer identify as having a disability in employer surveys because they no longer experience any limitation in the workplace æ thus the resulting counts of employees with disabilities will be lower than they should be.

Finally, I’ve listened to bureaucrats who have responsibility for particular program or services. To each one of them, the phrase “being disabled” means operationalizing the definition that is imbedded in the particular program or service. In my experience, each program has a different definition æ the differences may take the form of inclusions based on a particular health condition or health problem æ it may include exclusions based on location or age but, in most instances, the definition is functional in nature. However, in most instances, there is also a requirement that a member of the medical profession certifies that the individual meets the definition.

So, with all of these perspectives, I had the task of designing a set of questions that operationalized all of the various perspectives on “being disabled”. What was consistent across most perspectives was the use of the functional model of disability. Thank goodness for the work of the OECD in the early 80s! A working group developed and tested a set of questions that operationalized the functional model of dis-

ability. And thank goodness that my initial task was made simpler by the choice of the survey vehicle that would be used to collect the data. For the two disability surveys in Canada and the one in New Zealand, I had the opportunity to use a set of 28 questions to identify the population with disabilities æ the original questions developed by the OECD augmented by questions to identify persons with limitations in activity as a result of a learning disability, a mental health condition or discrimination because of a mental health problem. These 28 questions encompassed all functional limitations as a result of a health problem or condition. With the use of follow-up questions, we were able to identify persons who had particular health problems and we include a number of barriers and accommodations questions as well. Because the survey vehicle was a specially designed disability survey, there was no constraint with respect to the number of questions used.

Life was easy then; it's not so easy today. Today, I'm working with a team of bureaucrats in the United States to provide technical advice with respect to establishing a small set of questions æ the emphasis on small æ that can be used in their monthly labour force survey æ the Current Population Survey æ to identify the employment characteristics of American adults with disabilities. Space on the Current Population Survey is limited because it is important to maintain a high response rate and to achieve this means a limitation in the number of questions that can be asked. However, the task is easier because the questions have to operationalize only an interpretation of the phrase "being disabled". The American with Disabilities Act provides the definition and the task is to find a set of questions that operationalizes that definition. Their population of interest is anyone aged 15 and older æ slightly different from your population of interest, but it poses a similar challenge. My background paper describes the steps that we have and are undertaking to achieve this goal. Of particular interest to me is the use of the Delphi methodology that utilizes the expert opinion of individuals who are active in the disability movement æ academics, program administrators, disability advocates and most importantly, persons with disabilities themselves. The goal of this exercise is to have this panel of experts independently provide their opinion as to the disability status of a sample of individuals who has answered a longer set of disability screening questions. Based on their opinions æ and assuming that we can achieve a convergence in their opinions æ we will conduct an analysis of the larger database to determine the minimum set of questions that would identify the population with disabilities.

Employment is the primary focus for my American work. The impact of lack of employment and the disincentives to employment imbedded in many of the income

support programs in Canada was also a primary focus of the 1991 Health and Activity Limitation Survey.

In the US, the focus is on getting numbers æ the number of adults with disabilities and the number who are employed, unemployed and no longer in the labour force. These three numbers were very important in the 1991 Canadian survey as well since they formed the basis for the availability data that were used to monitor employer's compliance with the relatively new Employment Equity Act.

As important was the in-depth questioning that we included about disincentives to employment. In 1986, the participation rate for persons with disabilities aged 15 – 64 was 47.5, as compared to 77.9 for the non-disabled population. What was missing from the 1986 survey was an answer to why so many persons with disabilities had opted out of the labour force. Through consultations with disability organizations, service providers and adults with disabilities, we developed a series of questions that examined the barriers encountered when employment was being sought. We also included questions on the nature and extent of accommodations that would be required that would enable adults with disabilities to obtain employment. Examples of the barriers questions included a Yes or No response to a series of statements such as “you would lose some or all of your current income if you went to work” and “you would lose some or all of your current additional supports such as your drug plan or housing if you went to work”. These same questions were repeated in the 2001 Participation and Activity Limitation Survey.

So, what does the phrase “being disabled” mean to me after these 18 years of listening? A consistent message received from persons with disabilities, organizations of and for persons with disabilities, employers, and bureaucrats is support æ albeit reluctant on the part of persons with disabilities æ for the functional model of disability. Operationalizing the definition for surveys was made easier by the work done by an OECD working group in the 1980s. Identifying a small set of questions is a task that remains to be done.

How can my experience facilitate the objectives of this gathering? I've learned that measuring the population with disabilities is not an easy task. It can only be done effectively if one has the support of the population with disabilities and their advocates. It can only be done effectively if one has a thorough understanding of the definitions that are imbedded in the disability policy of the country and the various programs and services provided for persons with disabilities. And, in hindsight, I believe that it is a worthwhile exercise to contemplate only if change is viewed as

a possibility. Persons with disabilities æ to quote a disability activist from the US æ have been surveyed to death. Persons with disabilities have been consulted and consulted. They have listened to politicians announcing new and exciting changes to disability policies and disability programs and persons with disabilities have seen no change to their social and economic position with their community.

And here we are today æ looking at policies to promote work and income security for disabled people. The goal is commendable, but the way in which it is expressed causes me some concern. Quoting directly from the report: “The report concludes that a promising new disability policy approach should move closer to the philosophy of unemployment programs by emphasizing activation, promoting tailored early intervention, removing disincentives to work, introducing a culture of mutual obligations, and involving employers.”

I’m now going to step outside the position that I have had to take when I am facilitating the development of questions for disability surveys. As you can probably recognize through the way that I have presented the facts, I am very much an advocate for disability rights. So – based on my experience, I believe that the new disability policy approach should have two distinct parts: employment programs for those who are able to work that include income support programs to cover out-of-pocket expenses related to supports – be they technical or personal, and the second part, income security for those who are unable to work. The employment programs and related income support programs would include incentives to work through personalized interventions that accommodate the heterogeneity of the population with disabilities and involve ALL three partners in its development: the government, the employers and persons with disabilities. The income security programs would include personalized interventions that accommodate the heterogeneity of the population with disabilities and involve two partners in its development: the government and persons with disabilities.

And only when these new disability policies are in place and only when all of the other barriers to full participation are removed, then and only then will persons with disabilities be on a level playing field with their peers and the phrase “being disabled” will no longer have any relevance – and I’ll no longer have to be concerned with how to operationalize the definition.

## *What Do We Mean By Being Disabled?*

*Irene Hoskins*

The theme of this conference is how can we transform “disability” into “ability” and, very rightly, the first question that is asked within this context is “What do we mean by being disabled?” In response to this question, I would like to give a brief overview of how disability is being viewed, defined and measured at WHO. More specifically, within the context of looking at how “disability” can be turned into “ability”, this means:

- Viewing disability from a “health” rather than a “disease” perspective
- Rejecting the view that disability is a defining feature of a separate minority of people
- Being able to measure the different components of disability and their consequences
- Creating an enabling environment based on the principle of inclusion rather than exclusion, derived from the diagnosis of a medical condition
- Analysing the primary reasons for disability at various stages of the life course and how they can be prevented.

Further, I would like to expand this discussion by adding two additional points which are important to the discussion on the future occurrence of disability in our societies:

- Beyond the focus on policies for the management of disabilities and the administration of disability benefits, we need to determine the risk factors and primary causes that contribute to disease and disabilities. More specifically, what policies are necessary to prevent disabilities or the worsening of disabilities? In this connection, the question needs to be raised: Is it possible to link disability policies to the larger efforts of health promotion and prevention?
- What are the linkages between population ageing and disability? As populations age, chronic diseases are significant and costly causes of disability. Societies in OECD countries continue to age rapidly. How can this challenge be met?

## Defining and Measuring Disabilities

According to the Preamble of WHO's Constitution adopted in 1946, "health" is defined as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." Based on this broad understanding of health, it is vital to recognise that disablement is not simply a defining attribute of a minority of people but rather a universal feature of humanity, manifested for everyone in different levels of functioning and at different stages of life.

Quoting WHO's Director General, Dr Gro Harlem Brundtland, "improving the health of an individual, or the population as a whole, is not merely a matter of reducing premature death due to disease and injury. Health is also about human functioning, the capacity of individuals to live a full life as an individual and as a member of society."

It was not until the 1990s that WHO tried to capture this important paradigm shift which eventually led to a biopsychosocial understanding of human functioning and disablement. It has resulted in several revisions of the ICDH (International Classification of Impairments, Disabilities and Handicaps), a classification of human functioning at the physical, personal, and societal levels that goes beyond a mere medical diagnosis and takes into account the social and environmental context within which people live. Finally, this led to the publication in 2001 of a new international standard that describes and measures health and disability, the ICF (the International Classification of Functioning, Health and Disability). The ICF provides, notably, operational tools for both measurement and comparison.

ICF describes disability as an overarching term covering the experience of functional limitation at the level of the body or organ system as well as the person in society. Disability is the outcome of the interaction between a person's health condition and the context within which he or she finds him or herself. The "context" is made up of personal factors (e.g age, sex, race and education) and external environmental factors (e.g attitudes, physical environment, assistive technology, policies, services, environmental and personal support).

Disability is described from three different perspectives or levels:

- Body functions and structures where the experience of a disability is termed an *impairment*, e.g. the lack of muscle tone, lack of speech or intellectual impairment;

- Personal activities where the experience of a disability is called an *activity limitation* (e.g. inability to walk, to communicate or to care for oneself)
- Societal (or person within society) where an experience of a disability is called a *participation restriction* (e.g. not working because the work environment is inaccessible or not communicating because people do not engage in communications with the individual concerned). In other words, a person may be unable to do certain things but can still participate because the environment facilitates participation. On the other hand, he or she may have the ability to do something but be prevented from doing it because of a lack of opportunities, an enabling environment or negative attitudes towards disabilities.

Currently, common clinical usage of the word disability refers to something close to activity limitation and tends to also include some elements of participation restriction.

These measurements are extremely important not only for documenting the prevalence of chronic disability but also for forecasting current and future needs for long-term care and health system planning.

### **Global Increase in Chronic Diseases**

WHO regularly undertakes studies on what is called the *Global Burden of Disease* to determine the age and sex-specific prevalences of a large number of disease diagnoses by geographic regions or country groupings. For example, the Global Burden of Disease projections have clearly demonstrated the so-called “epidemiological transition”, that is the move from infectious to non-communicable diseases which is currently underway in the developing world — a world where chronic illnesses, such as heart disease, cancer and depression, are quickly becoming the leading causes of morbidity and disability. For example, in 1990, 51 percent of the global burden of disease in developing and newly industrialised countries was caused by non-communicable diseases, mental health disorders and injuries. By 2020, the burden of the non-communicable diseases in these countries will rise to approximately 78 percent.

Established market economies, i.e. OECD countries, have already undergone the epidemiological transition and chronic non-communicable diseases and injuries continue to be significant and costly causes of disability.

This leads to the urgent question of how policy makers can transform disability into ability, i.e. how can they address and eliminate some of the risk factors contributing to disability and morbidity in the first instance? These risk factors relate to *environmental* risks, such as sanitation, hygiene and air pollution; *occupational hazards*, such as industrial accidents, ergonomic stressors causing, for example, lower-back pain, a major cause of absence from work; work-related noise, one of the most common occupational hazards causing hearing loss; and finally the *behavioural* risk factors.

With regard to the latter, behavioural risk factors, WHO estimates that in the developed countries of North America, Europe and Asia Pacific, at least one-third of the disease burden is attributable to the following five risk factors: tobacco, alcohol, blood pressure, cholesterol, and obesity. The tobacco epidemic alone kills about 2.4 million people every year in industrialised countries and disables many more through respiratory diseases. The risks arising from high blood pressure and cholesterol, strongly linked to heart attacks and strokes, each cause millions of deaths annually and are closely related to the excessive consumption of fatty, sugary and salty foods. They become even more dangerous when combined with tobacco and excessive alcohol consumption.

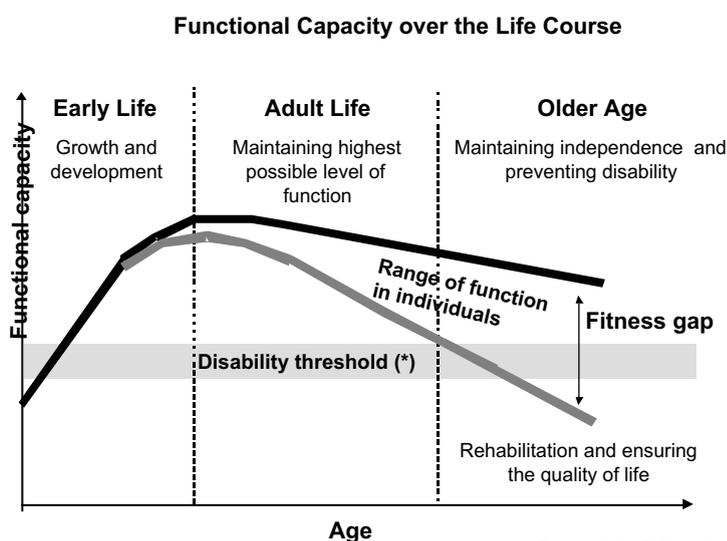
The lack of physical activity, a growing phenomenon in the age of the automobile and the computer, is in itself a serious health risk. While it is easy to blame behaviour on the individual it would in most cases be more appropriate and effective to promote population-wide prevention strategies aimed at reducing these risks to health. Governments should seek a more joined-up approach, including concerted action by many different agencies across society, for policies that promote health and prevent disability.

### **Disability – a Challenge for Ageing Societies**

Last, but certainly not least, when discussing disabilities, we need to refer to the ageing of populations which brings with it an increased risk of developing disabilities, including mobility and cognitive impairments that often occur at older ages. An older person's independence is threatened when physical or mental disabilities make it difficult to carry out the activities of daily living. Furthermore, people with disabilities, as they grow older, are likely to encounter new and additional barriers related to the ageing process. But, in fact, the disabilities related to the wear and tear of the ageing process could in many instances have been prevented in the first place.

The good news is that, as longevity increases in OECD countries, there is evidence of a decline in severe disability among the older population. Biotechnologies offer earlier diagnoses and new treatments, including the replacement of lost functions. Among such promising developments has been the actual decline in disabilities among older Americans between 1982 and 1999, compared to the projected rates if disabilities had remained stable over the same time period. England, Sweden and some other countries have shown similar trends. The critical question is therefore not only whether these trends will continue, in spite of increasing numbers of nonagenarians and centenarians, but also whether the increasing numbers of persons 60 plus will remain active and whether, at the same time, working life can be extended and age discrimination can be attenuated. Clearly, age discrimination and discrimination against the disabled remain powerful deterrents to participation and inclusion and thus continue to contribute to the rising social cost of disability.

To counter such negative developments, WHO advocates the life course perspective on ageing and the decline in functional capacity. The life course approach underpins all multi-sectoral actions on active ageing. Functional capacity (such as ventilatory capacity, muscular strength and cardiovascular output) increases in childhood, peaks in early adulthood and is eventually followed by a decline. The rate of decline, however, is largely determined by factors related to lifestyle — such as smoking, alcohol consumption, levels of physical activity and nutrition — as well as external and environmental factors. The gradient of the decline may



Source: WHO/NMH/HPS, 2000

become so steep as to result in premature disability. However, the rate of the decline can be influenced and may even be reversible through individual or public policy measures at critical junctures of the life course. Moreover, it has to be realised that the disability threshold is not stationary but rather moves up or down depending on the interaction of the individual with his/her environment. Thus, making the environment more friendly and manageable for older persons and persons with disabilities will inevitably decrease the number of disabled persons and increase personal and societal well-being.

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## *What Do We Mean by Being Disabled?*

*Vladimir Kosic*

In April last year, in Trieste, Italy, the World Health Organization (WHO), in conjunction with the Ministry of Health of Italy and the Regional Government of the Regione Autonoma Friuli-Venezia Giulia, held the International Conference on Health and Disability. I quote this event not for geographical reasons but, according to me, because during the Trieste Conference a milestone was marked on how disability should be considered. Let's try to understand why.

### **A scientific approach**

During the Trieste Conference, which lasted from the 17<sup>th</sup> till the 20<sup>th</sup> of April 2002, a new World Health Organization publication was presented to classify the functioning, health and disability of people across the world which challenges mainstream ideas on how we consider health and disability. ICF (International Classification of Functioning, Disability and Health) is the name given to this classification, and it changes our understanding of disability for many reasons. The most important are:

- 1) While traditional health indicators are based on the mortality (i.e. death) rates of populations, the ICF shifts focus to "life", i.e., how people live with their health conditions and how these can be improved to achieve a productive, fulfilling life. It has implications for medical practice; for law and social policy to improve access and treatment; and for the protection of the rights of individuals and groups.
- 2) Disability is not presented as a problem of a minority group, nor just of people with a visible impairment or in a wheelchair. For example, a person living with HIV/AIDS could be disabled in terms of his/her ability to participate actively in a profession. In that case, the ICF provides different perspectives as to how measures can be targeted to optimize that person's ability to remain in the workforce and live a full life in the community.

- 3) The ICF takes into account the social aspects of disability and provides a mechanism to document the impact of the social and physical environment on a person's functioning. For instance, when a person with a serious disability finds it difficult to work in a particular building because it does not provide ramps or elevators, the ICF identifies the needed focus of an intervention, i.e. that the building should include those facilities and not that the person be forced out of the job because of an inability to work.
- 4) ICF puts all disease and health conditions on an equal footing irrespective of their cause. A person may not be able to attend work because of a cold or angina, but also because of depression. This neutral approach puts mental disorders on a par with physical illness and has contributed to the recognition and documentation of the world-wide burden of depressive disorders, which is currently the leading cause, world-wide, of life years lost due to disability.

In other words, for the person involved, disability is conceptualised as a multi-dimensional experience that can be related to organs or body parts, such as impairment of the mobility of joints or bones, or the function of muscles. There may be effects on certain activities, for instance lifting or gripping objects with the hand. There may be consequences for a person's participation in aspects of life, such as education, work or leisure. Participation can be facilitated in various ways; for instance, by the provision of assistive technology or environmental modifications. What must be stressed is the fact that physical and social environmental factors play a significant role in the "creation" of disability.

Put in this way, the word disability is used as an umbrella term which includes:

- Impairments;
- Activity limitations;
- Participation restrictions.

In order to understand better what should change by adopting the ICF to classify disability and which are the new fields and topics involved I think a comparison with the traditional way of considering disability might help.

<b>DISABILITY</b>	<i>Old paradigm</i>	<i>New paradigm</i>
<b>Definition</b>	A personal problem caused by functional limitations due to psychical or physical impairments.	The result of <i>psychical or physical impairments</i> and of the social and cultural obstacles which hinder the process of integration and which may concern any citizen.
<b>Strategies for intervention</b>	Limit or eliminate the functional deficit by active intervention on the individual.	Remove barriers, facilitate the access to services, promote the well-being and health of citizens
<b>Methodology for intervention</b>	Take care that there are medical services, rehabilitation, school, work and psychogical support for disabled people.	Overcome a sectorial vision of the needs and support both the persons involved and their families by offering different instruments and services, promoting, at the same time, processes of social change.
<b>Subjects involved</b>	Doctors, rehabilitation and social professionals.	The participation of professionals involved both in social and health fields is a component which must be added to the participation of other disabled people, other consultants who can offer information, and new subjects we are able to involve.
<b>Reasons to act</b>	The disabled citizen benefits grants and services in order to the seriousness and to the cause of his/her impairment.	Services and grants are justified as the necessary condition for the disabled person in order to benefit of the complete rights of his citizenship.
<b>Role of the disabled person</b>	Object of intervention, patient, a person who benefits of something, object of research.	A liable and active subject in taking decision involved in research, client.

The choice to consider disability as one of the main problems in social policy, in medical practice and in law, in order to improve access to services and treatment, and for the protection of the rights of individuals and groups, means that we both recognize the extent of the consequences due to disability and the required attention we must pay to face it properly. We are not anymore interested neither with

the cause nor with the type of disability or the cycles of life. To act in order to overcome the consequences of disability so that the disabled person might benefit of his/her citizenship rights, as we have shown in the table above, implies an idea of planning the society which involves all, or nearly all, the fields in which the public administration acts. But the value of a unitary approach towards disability gives us the possibility to propose shared models of intervention, to develop services and invest shared resources, trying to improve the whole organization of the society we live in, stressing the fact that we are not dealing with a problem of a minority group but that we are pursuing a general interest. For the future development of health and social services to evaluate properly the consequences of disability is fundamental as the “burden of disease” is much more linked to the disabling consequences than to its treatment in the acute phase. This way of considering the problem implies, as we like to stress again, a multi dimensional vision, as the answers to disability cannot be given only by the health-social-system, but housing, transport and even leisure might assume, sometimes, even a greater relevance not only to improve the quality of life but even to spend the financial resources properly.

### **The Regional Consulting Committee of the Associations of Disabled people of Friuli-Venzia Giulia**

It might be useful, at this point, to explain the role and the activities of the Steering Committee I am heading. It has been founded in 1985 but it was legally recognized as the representative of all disabled people of the region, with a specific law, in 2001. We can say that it expresses a kind of a third level of democracy, as in our region, which is divided in four provinces, in each province there is a Committee which includes the associations of that area. The four Committees choose two delegates each who are the components of the Regional Steering Committee, so we have eight members plus the president.

What we are trying to ensure to the disabled people of our region are the so-called four rights:

- 1) The right to have an autonomous life;
- 2) The right to a healthy life (prevention, treatment and rehabilitation for each specific disability);
- 3) The right to education;
- 4) The right to work.

We are trying to ensure the same standard of services on the whole regional area, which is not so simple, though the region has the same laws and financial resources. An important role is played by the local committees and the most active associations which are able to check the situations more directly. For this reason we have about ten meetings each year of our Steering Committee. Every local Committee expresses the problems of the area and we try to support the most difficult situations. One of the main goals is to link and to strengthen the collaboration and comparison among the four committees so that the Steering committee is able to make shared proposals to the Councillor who plans the health and social policies. We are also trying to affirm that every disabled person should have a life-project, as it is provided by a regional law already approved in 1996.

Our office-headquarters is in the same building where the Councillor for health and social policy of our region resides, better to say, my office is next to his. We collaborate with the Councillor trying to plan the regional health and social policy most of all. We have succeeded to realize some of the goals we had planned even in other fields. The collaboration with the public and private institutions dealing with disability, including problems of housing, school, work et alia, is daily routine and we have to face new challenges quite often. We are consulted when new bills are proposed and discussed at the regional parliament and I must say that our proposals are always considered and often accepted. We have succeeded in convincing our politicians that if we want to face the problems of disabled persons wisely we must invest both financial resources and intelligence. It is not worthwhile to keep people closed in hospitals or in old folk's homes, as it would cost us more with no satisfaction for the people. I am sure that if we try to remove disability from the society, from our life, we waste money, time and happiness. Disability means being alive with some problems we have to share with the community we live in, because by giving the proper answers to disabled people we improve the standard of the society and we give values for a worthy existence. Disability can be accepted if we alleviate it, if it is shared by the community and if we succeed to give it a meaning .

## *What Do We Mean by ‘Being Disabled’?*

*Bruno Nydegger Lory*

I was invited to make a short presentation about a new element in the system of the federal invalidity insurance – as the disability insurance is called in Switzerland. The Introduction of this element (a new protagonist providing a service) is planned for the beginning of next year. For better understanding of the considerations and expected improvements of this reform I’ll explain in just some words the actual situation and related problems.

Entitlements to benefits from the invalidity insurance presuppose three conditions:

- 1) a medically judged permanent or lasting health problem
- 2) a limitation of earning capacity / ability (in fact, the Swiss invalidity insurance not only insures economically active but the inactive population as well. Therefore also a limitation in the usual field of activity, i.e. in the household or going to school/university is assessed.)
- 3) a causal link between the two above mentioned conditions: the health problem and the limitation.

Because of this specification the insurance uses the term ‘invalidity’ instead of ‘disability’. I’ll come back to this point later.

The Swiss invalidity insurance is enforced by 26 cantonal offices. In consequence there are 26 divided territories implementing and executing a nationwide system. Looking at the experience registered in the statistics, we see that the prevalence of various categories of benefits differs strongly between the cantons. This may be explained through different external determinants as e.g. the socio-demographic structure of the population or the economic environment (i.e. in respect of the industrial sectors). The roles of these and other external determinants have been or are currently analysed in several studies. Already accomplished studies – but also various experiences – come to the conclusion that with a high probability the actors involved in the assessment process apply their degrees of freedom – which are inherent in this topic – in different ways.

One of the most delicate challenges in the assessment process is to be seen in the third condition mentioned above – the causal link between health problem and limitation, and in particular in the quantification of the limitation.

Until now treating doctors – mostly general practitioners – still take an important role in the process of medical assessment. The medical services in cantonal offices have to decide about the health problem related limitation of earning capacity on the basis of written reports on diagnostics of the health problem including also judgements or opinions about the limitation of functioning in the (professional) activity done so far.

In addition to this during the last decade the diagnosis by treating doctors got increasingly multiple and therefore more complex and difficult to decide upon. Furthermore it has to be said that medical services in the cantonal offices are until now not allowed to examine the applicant themselves. If they find necessary to carry out further or specific medical examinations, they may commission external experts.

The government now proposes so-called regional medical services under the supervision of the federal authority. Each of these services should provide support for several cantonal offices, and these services will be allowed to examine the applicants.

With this new service a critical size would be achieved which ensures a constant supply of pluridisciplinary medical know-how (i.e. different specialised knowledge including industrial medicine and (social) insurance medicine) for better handling of multiple diagnoses and provide better answers to the problem of disability caused limitation. This should lead to a better harmonization or standardization of the medical assessment – and in consequence have preventive effects on potential legal inequality.

Increasing multiple diagnoses raise the probability of an appeal against a negative decision with arguments of lack of taking in consideration one (or several) element(s) of the diagnosis. As a consequence often time intensive legal procedures with risk of aggravation of the (remaining) earning capacity are caused. So, as an additional goal the new services should accelerate the assessment and keep the chance of re-integration as high as possible. The acceleration is expected because of time winning through pluridisciplinarity and direct examination on the one side, but also through more comprehensive assessments.

Finally the staff of these regional medical services will explicitly be assigned to network with general practitioners in order to spread specific medical knowledge required for the assessment of disability caused limitation. This (goal) focuses on a “*unité de doctrine*” (which finally leads to “*unité de pratique*”).

So far my presentation and comments on the performance goals and the improvements expected by implementing the new regional medical services in the Swiss invalidity insurance.

For the time left I’d like to discuss this new element in the light of the policy conclusions formulated in the OECD report.

The Swiss invalidity insurance requires a causal link between health problems and limitation in earning capacity. This reflects the purpose of this social insurance: The invalidity insurance protects from the economic consequences of health problems.

As we know an insurance does not protect against the risk in the true sense of the word, but grants benefits in case the risk is occurred. The invalidity insurance grants individual benefits for working aged insured on the principle of ‘integration before benefit payments’. Therefore the assessment starts by deciding about measures for medical, educational or vocational rehabilitation and handing over aid or remedy for (re-)integration. During the time this measures take place the insured person gets daily allowance. Only if (re-)integration is fruitless, has failed or was only partly successful a claim for benefit payments will be justified.

- Being disabled means not automatically being invalid, and the status of being invalid doesn’t primarily mean to have a claim for benefit payments.
- Claim for benefit (re-integration measures or payments) requires a casual link of disability and limitation.

The Swiss invalidity insurance is focused upon economic consequences of health problems and not on the problems themselves. That’s why the term ‘invalidity’ instead of ‘disability’ is used (being dependent on a wheelchair doesn’t lead to the same earning limitations for a lawyer as for a construction worker; the consequences of loosing a finger differ for a professional violinist and a professional football player; the last-named will surely get no benefit from the invalidity insurance).

This is no argument against the necessity of further legally legitimized accounts for other benefits or non-discrimination of disabled in other spheres or subsystems of the society. But ‘being disabled’ doesn’t serve as a diagnosis or term per. Especially in the context of – social or not social – insurances we always have to decide about claims being justified or not. Whenever we define and apply the notion ‘being disabled’ for limitation of entitlements we talk about a distribution struggle for scarce resources.

At the same time one should be carefully by labelling people ‘being disabled’ as a notion without purpose or goal. This involves several risks. Some are e.g. profoundly described by Erving Goffman, when he discusses stigmatisation and self-identification; others could be seen by fostering the tendency of standardizing the *Homo sapiens sapiens*, which is already to be observed in several political – sometimes ethical – discourses.

I hope it was understandable that – at least in my opinion – the Swiss system tries to prevent the equation between “health conditions / health problems” and “ability to work”. But as the experience – especially in the last decade – shows, the diagnostics of the health problems considered more and more various aspects; mainly social aspects. Reacting to this development with a pluridisciplinary medical service is probably not enough; there must also be a (permanent) discussion about the changing understanding of health problems.

One might argue that with the International Classification of Functioning, Disability and Health (ICF) an instrument exists that treats ‘disability’ in a comprehensive way and does not only focus on the physical subject. But doesn’t this just shift the problem to the question, what ICF components are relevant according to different benefits or rights? What kind of improvements can we expect from ICF? Aren’t the central points for judgments on claims still left open? What degree, what kind of disability must be fulfilled? Interpretation processes seems still needed in which the interpreters still have degrees of freedom.



## OECD Key Issues and Policy Conclusions

### *Theme 2: What Rights and Responsibilities for Society and for Persons with Disabilities?*

#### **Key issues**

Most societies accept their responsibility to offer special support to persons with disabilities. But too little effort is made to (re)integrate or keep disabled workers, in particular older disabled workers, in the labour market. Instead, income-replacing cash benefits are deemed sufficient.

Not everybody who is fully and permanently disabled receives adequate disability benefits. Many of those who have never been integrated into the labour market or who have been out of the labour market for too long are not entitled to any (or only to a relatively low minimum) benefit, or maybe to a household means-tested non-contributory disability benefit.

Disabled people are treated as if they were unable to work. Hence, little is expected from them in terms of contributing to their successful labour market integration. In some countries, certain groups of (insured) disabled people are obliged to go through vocational rehabilitation or training before any benefit could be awarded. However, age-specific data on programme participants suggest that this obligation is only applied for people below age 45.

While disabled people tend to have few obligations, they also have few rights e.g. to get their workplace accommodated. Anti-discrimination legislation, which is spreading quickly, has yet to prove its effectiveness in this context.

Too often, disability benefit programmes have become a “catch-all” benefit replacing long-term unemployment, social assistance, or early retirement payments. Governments have tightened eligibility criteria, introduced “mutual obligations” and sometimes reduced benefit levels for these other benefits.

### **OECD policy conclusions**

The focus of policy should not in the first place be on granting entitlement to income-replacing benefits but on providing individually-tailored assistance aiming at reintegration into the labour market.

Income support should be provided to the extent necessary while these efforts are underway, unless integration measures are inappropriate due to the severity of the disability.

If society obliges authorities to make efforts to reintegrate people, so should cooperation be expected from the disabled person. Failure to make an effort to participate in the (re)employment process should result in sanctions in the same way that failure of society to provide work should result in an obligation to pay the disabled person a cash transfer. Such “mutual obligations” should be handled sensitively; there should be no question of people being forced to accept inappropriate work.

Introducing the notion of mutual obligations of both society and the disabled person would move disability policy closer to the philosophy of unemployment programmes, which also expect an active contribution and effort from beneficiaries. Lessons should be drawn from recent changes in unemployment and social assistance programmes.

In means-tested disability schemes the method of household income testing may have to be reconsidered if such an approach of mutual obligations is applied. A disabled person not entitled to any transfer payment because of other household income sources cannot easily be obliged to participate in integration programmes.

## *Panel on Rights and Responsibilities*

*Kenneth S. Apfel*

I want to commend OECD for its continued efforts over the years to focus attention on the need for enhanced policies to promote work for persons with disabilities. This new OECD report provides valuable new information on this issue, and I deeply appreciate the opportunity to comment on OECD's policy conclusions. I agree strongly with the central OECD conclusion that far too little is being done to (re)integrate or keep disabled workers in the labor market. I also agree that efforts in particular fall short for older workers and that disability assistance programs have to some extent replaced other social assistance and early retirement programs.

The key question before us is not whether we need to expand efforts to promote work but how to expand efforts, and in particular, what are the responsibilities of government, employers, and persons with disabilities in this process.

The central OECD policy recommendation is to promote work through the establishment of a system of "mutual obligations" for both society and for person with disabilities—somewhat similar to systems established for persons receiving unemployment or social assistance payments. While the report makes a compelling case in this area and while I have been a longstanding supporter of many efforts to strengthen "mutual obligations", I have serious reservations about establishing stronger sanctions mechanisms on individuals with disabilities. Until assistance has first been vastly strengthened and shown to produce solid and sustained results, a system of "mutual obligations" is — at best — premature.

Persons with disabilities in the United States still face enormous obstacles in their efforts to work. My deep fear is that a "mutual obligations" strategy that includes individual sanctions *in practice* would end up combining (1) modest government efforts to reduce barriers and/or encourage work, (2) minimal efforts to expand the responsibilities of employers and (3) tough sanctions on persons with disabilities who too often cannot overcome the barriers and return to work. Such a strategy sets the stage for a set of unacceptable outcomes: a reduction in government income support for the disabled, a shift to more individual responsibility to meet work and income needs and a new paradigm that blames persons with disabilities for the absence of work.

## US Experience With Welfare Reform

The US experience with welfare reform provides some useful lessons and gives us reasons to be both somewhat optimistic as well as very cautious about a system of “mutual obligations”. What are our “mutual obligations” in this area of social policy?

The US has established very tough work requirements and sanctions for the vast majority of welfare beneficiaries, and the culture of welfare offices has significantly changed to promote work rather than welfare. The majority of states (37) have established “full family” sanctions, meaning that the entire cash assistance grant can be eliminated for failure to work. Caseloads have dropped by half, food stamps participation by almost a third, and about 5% of families are receiving sanctions in any given month.

What about employers? The use of “employer obligations” in the US to assist former welfare beneficiaries is virtually non-existent. There are no requirements and only very modest incentives to provide jobs, and working poor families and people leaving welfare to work receive vastly less employer provided health coverage, pension benefits, and other worker benefits than the general population. For example, three-quarters of the working poor do not have access to employer provided sick leave, compared to only 40% of workers with income above 200% of poverty. Large proportions of working poor families who leave welfare and government provided health insurance do not receive employer-provided health insurance.

What about “government obligations”? Government support for work support programs has been vastly increased in recent years. Work supports amounted to only \$6 billion per year in the late 1980s and now amount to about \$50 billion a year. The key expansions are in the earned income tax credit, child-care assistance and health insurance coverage for families losing welfare and returning to work. While major gaps still exist for many, many families, it is clear that US policy has taken substantial steps to try to “make work pay”. If it wasn’t for this dramatic increase in support that mostly predated welfare reform, I would have been very opposed to the imposition of the work requirements and individual sanctions in this area.

But even with this significant increase in support, the case for tough sanctions is debatable. On the positive side, the move to a system of tough work requirements, sanctions and added government support for work has greatly increased work, and modestly reduced poverty (by about 10%) for single parent mothers. However, even

with these new levels of work support, some very needy families have been hurt by the sanctions policies and work requirements. Studies show that a third to a half of welfare “leavers” found no work, and only a fifth to a half of sanctioned families found work. Many sanctioned families still face multiple barriers to work, including health difficulties. I should point out that these sanction policies cover many persons with some level of disabilities, since over 40% of TANF recipients report having some level of physical or mental impairment, a proportion almost three times the level of the general population.

### **A Similar System for Disability?**

The OECD report concludes that a sanctions system makes sense within the context of a much stronger societal support system. What do these support systems look like now in the USA and what is the potential for change?

**Employers** – The centerpiece of employer responsibilities in this area revolves around the Americans With Disabilities Act of 1990. The ADA, a very important civil rights law, has broadened access in a variety of ways. The remedies in the ADA banning discrimination and requiring reasonable accommodation in the workforce have been somewhat effective for higher skilled workers, particularly those connected to employers; but employers by and large have avoided employment for lower skilled persons with disabilities, which are the vast majority of federal disability beneficiaries. Currently, employers receive very modest tax incentives to help them comply with ADA barriers and a very modest tax credit to help subsidize the wages of individuals on disability insurance or persons referred from vocational rehabilitation agencies.

What would a system of mutual obligations mean for US employers? As is the case with welfare, I believe the answer would end up being “very little”. Discrimination-based enforcement has yet to show major results, and a government system of numerical targets for hiring the disabled would have no chance of enactment in the US. Employers will continue to resist hiring disabled persons for a variety of reasons. While it’s possible that a much greater regime of tax incentives would help somewhat, I fear that pervasive discrimination against hiring the disabled will be hard to overcome. *And without broad access to jobs, I question the moral basis for imposing a sanctions system on persons with disabilities.*

**Government** – What about added government responsibilities in this area? Later in this conference, my colleagues from the US Social Security Administration will

discuss the progress being made in expanding the government's commitment to assist the disabled in returning to work. I will not take time here to review these initiatives except to say that these very important actions quite frankly will take years to fully materialize. And even after implementation of these important initiatives, substantially more comprehensive steps are needed in at least four areas—creating a “culture” of work, establishing comprehensive assessment measures, developing major expansions in early intervention strategies, and vastly expanding efforts to “make work pay” for persons with disabilities. *All need considerable increases in government commitments if we want a system that transforms disability into ability.*

**1) Organization Culture** – The primary work of Social Security offices in the US is to determine eligibility for benefits; up until recent years, this was also the primary work of local welfare offices. In the case of welfare, the shift to work necessitated a shift of roles in the local offices—in effect, the “culture” of local welfare offices had to change. As part of a comprehensive effort to shift more focus on work and reintegration for persons with disabilities, the culture of Social Security offices must also change somewhat. As a first step, substantial numbers of work incentive specialists are needed to work with persons with disabilities and with other public and private organizations to encourage integration activities.

**2) Assessment** – The OECD Report makes abundantly clear the difficulties in assessing what constitutes disability *and* work incapacity. In practice, we all know that it is exceedingly difficult to distinguish those who are able to work from those who are not. Virtually everyone in the disability field believes that more disability beneficiaries can and should work. While medical and technological advances give us a somewhat better understanding of how medical conditions affect the ability to work, we don't possess the supreme knowledge to be able to say who can or can't work. And no consensus exists on the overall proportions of persons with disabilities who should or can work or be subject to sanctions. Better assessment measures are clearly essential in this area.

We are quite a ways away from having these measures. And without much more comprehensive assessment measures, what moral basis would we have to establish a system of individual sanctions? Which persons, for example, with schizophrenia would we sanction—and who would be exempt? Which persons with substantial mobility impairments? *Until we establish a much more comprehensive assessment system, I strongly question the moral basis for imposing a sanctions system on persons with disabilities.*

**3) Early Intervention** – The OECD Report also makes abundantly clear the importance of expanding early intervention initiatives, even before people become eligible for disability benefits. This will require new government resources, but is well worth the outlay of resources. And as we move forward with efforts to strengthen the government role in early intervention and (re)integration, I recommend that extra efforts be targeted towards two groups-older teenagers and older workers. Both are at very high risk of a lifetime of income assistance if targeted efforts are not instituted.

There are currently 1 million children on the disability rolls in the USA. As these youth move from childhood to early adulthood, their expectations of themselves and their future links to the labor market-are being formed. Unless we invest heavily in integration activities at this stage, those expectations will likely solidify around a life of income assistance and little or no work. We let these young people down if we do not dramatically increase government responsibilities in this area.

The second group is made up of older disabled workers. I believe we let these individuals down in two ways. First, many older persons who are not on the disability rolls should be on the rolls, and those who are on the rolls receive no real assistance to return to work. There are real unmet needs. About 10% of early retirees would likely qualify for larger disability benefits if they applied, and many more individuals with major disabilities are screened out because they either do not meet current rigid disability eligibility guidelines or have no recent work experience. We need policies to help more of these individuals receive income support. Moreover, as the OECD Report makes painfully clear, there is a striking age bias in integration programs. We need to vastly step up assistance in this area or most of these individuals will never work again.

**4) Make Work Pay** – While we have made some progress in “making work pay” for welfare families, only smaller steps have been instituted for disabled beneficiaries, particularly older individuals. We need substantially greater efforts to make work pay through a combination of partial benefits when coupled with some work, the establishment of a sizeable disabled workers tax credit similar to the earned income tax credit and possibly immediate access to health insurance for disabled individuals who work and are nearing the retirement age.

## **Role of Disability Insurance in Income Support**

One final reason for caution in the area of individual sanctions relates the growing importance of the disability system — and the diminishing role of a variety of other assistance programs — in providing income support for the working age population, particularly workers with less education and lower skills. The US unemployment insurance system, which provides only short-term (6-9 months) assistance, provides benefits to a dwindling share of unemployed workers. During the 1990s, only a third of unemployed workers actually received unemployment benefits, down about 20% from the levels in the 1960s and early 1970s. Currently, only one-third of less skilled men and only 15% of less skilled women separated from their jobs qualify for unemployment assistance. In addition, the proportion of families eligible for traditional US cash welfare assistance and food stamps has declined by a third to a half in recent years. Disability beneficiaries face numerous obstacles to securing jobs - obstacles above and beyond their disabling conditions. Indeed, about two-thirds of disability beneficiaries have no more than a high school degree and will find diminishing opportunities in the US labor market. Disability benefits are often the only potential source of support for relatively low skilled working age individuals with impairments, and this is especially true for older workers. We need to be very careful before we impose benefit reductions in the disability programs.

## **Conclusion**

Some day, a system of strong individual sanctions *may* make sense for the United States — but not today, and not for some time into the future. First, let us take down more of the barriers and encourage work. And let us create some real incentives to make work pay for persons with disabilities. And let us create real job opportunities by at least reducing the barriers for employers to hire persons with disabilities. And let us see some real success for our efforts. We should not even consider establishing a framework of “mutual obligations” through a system of individual sanctions for persons with disabilities until we have truly changed government and employer responsibilities in this area. Without the establishment of strong and viable societal systems, I believe that we would be establishing a new paradigm—one that blames persons with disabilities for the absence of work. That would be very, very wrong for society *and* for persons with disabilities.

## *Disability, the Organization of Work, and the Need for Change*

*Colin Barnes*

There is considerable historical and anthropological evidence that impairment is a human constant and that cultural responses to perceived abnormalities of the body and mind vary across time, culture and place.

It is equally evident too that throughout recorded history western society has systematically discriminated against or excluded various groups of people on the basis of perceived biological inferiority, and that this exclusion became systematic following the material and ideological changes associated with capitalist development.

The combination of industrialisation, urbanisation, and associate ideologies, such as liberal utilitarianism, Social Darwinism, and Eugenics, provided ‘scientific’ legitimacy to ancient myths, fears and prejudices, and the gradual but intensifying commodification of every day life. .

As a result ‘work’ became almost exclusively associated with wage labour and paid employment. This precipitated the development of an employment infrastructure geared to the needs of those deemed ‘capable’ of this type of labour.

Hence, those considered incapable of work, and labelled ‘disabled’ were, apart from times of war, excluded from the workplace. This legacy remains with us today. Discrimination against disabled people is institutionalised in the very fabric of western society; consequently, disabled people encounter a whole range of material, political and cultural barriers to meaningful mainstream employment and social activity.

Moreover, despite the introduction of a range of measures said to address this unfortunate and unacceptable situation, including in some states such as the USA and Britain, anti-discrimination legislation, these barriers remain largely unchecked. Hence, unemployment and underemployment are a constant feature of the overwhelming majority of disabled people’s lives.

This has obvious and well-documented negative economic, social and psychological implications for disabled people themselves, their families and, indeed, society as a whole.

This is especially important given that the more technically and society sophisticated a society becomes the more impairment and disability it creates. There are more disabled people today than there ever were in the past, and the numbers are likely to increase substantially over the coming decades due to a variety of factors including medical advances and ageing populations.

The barriers remain because, hitherto, legislation has been weak and piecemeal and, without exception, is founded in, one way or another, on an individualistic rather than a holistic approach to the problem of disability.

Furthermore, to-date, the overwhelming bulk of the policies introduced to address the problems encountered by disabled workers in the workplace have, in the main centred on the supply side of labour: disabled workers. In the form of training schemes, subsidised wages and so on. All of which, to varying degrees, reinforce rather than undermine, the traditional assumption that disabled workers are somehow not equal to non-disabled peers.

It is evident therefore that if Governments are serious about addressing the employment problems experienced by disabled people then anti-discrimination policies must adopt a more holistic approach and be strengthened and rigorously enforced.

Barrier removal in the workplace is only possible by the development and adoption of policies with a clear and unambiguous focus on the demand side of labour - the social organisation of work - and the economic and social infrastructures that support it. This will inevitably mean deep-rooted structural and cultural change involving the systematic redistribution and allocation of resources, and the generation of a culture that celebrates rather than rejects human diversity in all its forms..

As we move further into the twenty first century the reality of this insight becomes ever more obvious.

## Further Reading

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# *What Rights and Responsibilities for Society and for Persons with Disabilities*

*Peter Scherer*

## **Introduction**

The OECD Report Transforming Disability into Ability took its current form because its authors were confronted with a fundamental paradox in policies in many member countries:

- Disability support is awarded on the basis of demonstrated inability to work
- Disabled people want to be enabled to participate in society, which includes in particular access to work.

This implies that income support is granted provided disabled people demonstrate they cannot work. That is, they are given support for demonstrating they cannot work, not for finding out how they can. The Report documents at length the result of these policies: very small rates of outflow from disability benefit, despite wide-ranging programmes to encourage it.

In looking for a way out of this dilemma, we have drawn on the growing experience with policies directed at other groups, and particularly at the unemployed.

## **Unemployment Policies**

Historically, policy for the unemployed was based on a similar (but different) dilemma. Unemployed people were seen as victims of the labour market, and policies which required action on their part were condemned as “blaming the victims”. Yet the whole basis of unemployment insurance was that it was there to subsidise job search: that is, actions to find a new place in the labour market.

The persistence of unemployment at times when overall employment rates have grown has led to a revision of policy in most countries – a revision which the OECD encouraged in its “job strategy” published in 1996. The unemployed are now increasingly *required* to make “active” steps to find work as a condition for receiving

ing income support. This applies whether they are receiving such support on the basis on unemployment insurance, and also if they have become reliant on means tested social assistance.

No one claims such policies are a panacea. Our own analysis shows that some “active” policies – such as classroom training of unemployed people for particular vocations – do not help much in actually getting into the labour market. Some types of employment – such as fixed term public sector jobs – can isolate participants from looking for more permanent jobs in the “regular” labour market, so those emerging from such work can be worse off – in terms of employment access—than those who were searching more widely during the same period.

While it is sometimes alleged that these new policies amount to ‘blaming the victims’ of malfunctioning labour markets, this need not be the case. Some countries which have been most fervent in implementing such policies – such as Australia and the UK – base most income support on assistance principles, and put no time limit on receipt. However, this income support, while potentially unlimited in time, is not unconditional. It is based on the obligation to take up opportunities as they arise, and not to wait until the “perfect” job is on offer.

### **Disabled People and Employment**

Disabled people who try to find a place in modern labour markets operate at a double disadvantage. They face the same challenges of structural change and job insecurity as other labour market participants. And their disability makes it more difficult to find a place.

Hence it is important to admit at the start that it would be foolish to pretend that there a magic formula which will enable disabled people to have just the same access to the labour market as others. But this is not the same a saying that there is nothing that works. On the contrary, the Report we are discussing contains some very strong clues in this regard.

In particular, a number of countries have succeeded in achieving an relative employment rate of over 80% on the part of those *under age 50* who identify themselves as having a disability which hampers their daily activities. (Table 3.4) In general, these are European countries (such as Germany) which require applicants for disability benefits to participate in rehabilitation efforts, and only allow them to access once disability benefits (which assume that they cannot work) if those

efforts have failed. Quotas for employers to employ a certain percentage of disabled people seem to contribute. There is, then, an implicit mutual obligation in these cases: society will provide income support for those who cannot work, but will require those who apply for such help to test stringently whether this inability is really the case. And it works: relative employment rates are not perfect, but they are much higher than would happen if disability benefits were awarded on the basis of nothing but “objective: medical evidence.

In the overall picture, however, many of these countries do poorly by disabled people. This is because of the other feature of their policy which is documented at length in the report: above age 50, the disability benefit programme has been converted into an early retirement route, and all efforts to rehabilitate are abandoned. This is a part of a broader attitude to older people under which, in return for income support, they are encouraged to regard themselves as obsolescent and to get out of the way of labour market. Income support systems underwrite this attitude, but they do not cause it: similar attitudes to older workers can be observed in countries (such as the UK and Australia) with much more meagre levels of public income support in retirement. A counter example is Sweden, where income support is generous, but has resisted (while not completely avoiding) this drift to treating older workers as expendable. It would be better to explicitly put in place explicit early retirement programmes and recognise their cost than to use disability programmes for this purpose, as it can easily result in all disability beneficiaries being treated as people who have prematurely aged.

But this poor performance overall should not be allowed to hide the lesson that the experience of these countries shows: that a policy of mutual obligations can work, and is effective improving employment rates of disabled people.

### **The Insurance Principle**

When this principle was first proposed by the OECD, a number of countries reacted by saying that it violated the basic principle on which social insurance is based: in return for paying a premium, those covered by social insurance are entitled to unconditional recompense if the condition against which they are socially insured occurs. Making receipt of disability benefits conditional on fulfilling further mutual obligations is, it was argued, a violation of this contract. It is fair to say that this attitude is not confined to countries which rely on contribution-based social insurance models (“Bismarckian” systems – though I am not sure that is universally accepted label, at least in Austria!) People with a disability are recognised as

requiring protection even where there has been no opportunity to contribute, or where (as in Australia) social protection does not rely on contribution records.

On this point I would argue that the analogy that is implied with an ordinary insurance contract is not valid. Social insurance is of its nature compulsory, and so the design of the system has to take account of the social and economic externalities which the system design involves. An individual or even group contract with an insurance company for (for example) compensation in the case of certain defined accidents does not need to be subject to such scrutiny. But social insurance cannot escape it.

The issue I have in mind here is the social consequence of signalling that disabled people are not expected (unlike the unemployed) to make a contribution to society. The implication is that they have little of economic value to contribute, and so society need is better off without their services. But it is not their fault, so we should compensate them.

It is sometime agued that this issue can best be addressed by making opportunities available to disabled people, forbidding discrimination against them by employers, but in neither case imposing compulsion. By such an approach, it is argued, the insurance principle can be honoured and opportunities for disabled people can still be created.

The basic problem with this approach is that it fails to recognise the basic facts of labour market economics. Most jobs are not particularly enjoyable. Individuals undertake them in return for the compensation they receive. If disabled people are to be integrated into society, they face the same challenge. On this understanding, the income support disabled people receive is not a “compensation” for their condition. It is their wage for social participation. Their participation in integration activities is therefore the counterpart for that compensation, just as work is the counterpart of a wage.

### **The Mutuality of the Obligation**

I pass now to the other side of the bargain. The “integration” principle discussed in Chapter 6 (alongside the compensation principle) is (with the exceptions mentioned above) is largely observed in the breach. Almost nothing is done to integrate older disabled people into the labour market, and even for younger people the offers are often few and inadequate.

Clearly disabled people only have an “obligation” to participate if an activity is offered to which they can realistically respond: one which builds on their talents and adjusts for their disability. Failure to offer such an opportunity is not a ground for denying the income support which is necessary. Unemployment insurance programmes do use the time limited nature of income support as an incentive to push recipients into taking their job search obligations seriously. In the case of severe disability, a threat that such support is withheld is clearly unacceptable.

Of course, many disability benefit schemes do include compensation for “partial” disability, or include partial disability in an overall guarantee. It is clear that in such cases, providing participation opportunities will be less costly – and requiring beneficiaries to take them up will be even more appropriate. In practical terms, this is clearly the place to start.

For those who are severely disabled, voluntary participation will always be the only real option: compulsion will be counter-productive. But here the mutual obligation principle operates on the side of the beneficiary. Proper implementation of this proposal would require a large expansion of support resources beyond those currently on offer. If there are some people for whom it is indeed the case that the cost of support completely outweighs the contribution they could make, it will be necessary to formulate clear criteria for making that judgement.

### **Transforming Disability into Ability**

It follows from these considerations that the transformation of disability programs into labour market programmes will require a fundamental change in their nature, and often in the legislation on which they are based. It will be necessary to abandon the idea that only those who “cannot work” are entitled to compensation. This approach, common to many countries, is self defeating, since it essentially sends signals to medical practitioners and to potential applicants that they should commit labour market euthanasia and suicide (respectively) to get the compensation they need.

Instead, the object of the screening must become the determination of the degree and nature of integration support and compensation each client needs. Society may then decide that some integration support is too expensive, and rely on compensation alone. But unless we change direction, the tendency will continue to be to make this judgement for *all* disabled people.

## *Outline of the OECD Panel Presentation*

*Philip de Jong*

The OECD study advocates ‘mutual obligations’ as a critical element in the design of disability policy. This concept should guide the design of the relationship between disabled citizens and the state as well as between employers and disabled employees.

Both relationships have been the subject of recent changes in Dutch disability policy. These changes have reinforced the responsibility of both the state and employers to promote (re)-employment of disabled workers. Since 1996 employers bear a large financial responsibility when their employees fall ill. The effect was a 15 per cent reduction in sickness absenteeism. Since 1998 premium rates for disability insurance differ according to the disability risk at the level of the individual firm. These employers’ incentives were not matched by equally strong incentives for employees. In that sense ‘mutuality’ was, until recently, absent.

Stressing the responsibilities of the disabled is a new concept in Dutch disability legislation, which used to be biased towards income security as opposed to job security. In April 2002 a new regime was introduced defining the actions to be taken by employers and employees during the first months of sickness. These actions aim at early intervention, and prevention of avoidable disability benefit dependency. The adequacy and sufficiency of the actions are tested by the Social Insurance Institute, when a disability claim is filed. If the actions are judged insufficient the claim will not be processed. Employees who refuse to cooperate with reasonable efforts of employers to help them back to work, can be fired.

This policy direction is underscored by the so-called Donner proposals for a new disability insurance scheme. The proposed scheme puts even more emphasis on the mutual obligations of employers and employees with respect to each other.

In my presentation I’ll place these (proposed and enacted) changes against the long-standing disability problem in the Netherlands, where ten percent of the labor force is on disability benefits. A background paper will be available at the conference.

## *What Rights and Responsibilities for Society and for Persons with Disabilities*

*Stanislawa Golinowska*

1) The serious problem of the state social policy pertaining to disability and the reaction of society in this respect in the transformation countries is a phenomenon of the so called “escape to disability”, which is especially observed in difficult life situations and intensification of social changes. Analyzed from the time perspective, the problem in question has two different causes. First cause is the heritage of the past and the second one is the transformation of labour market during the transition period.

The post-communist countries are still bearing the consequences of socio-economical policy from the previous system. The policy of full employment or even “compulsory labour” or perhaps stating it more delicately “compulsion to a determined kind of labour often resulted in a reverse reaction- looking for the possibility of avoiding this pressure, at the same time assuring oneself another source of income, different from regular work salary. Such a possibility has been created by the system of disability pensions. Escape into disability instead of undertaking a job or remaining in the labour market is a typical for Poland phenomenon, which has lasted for over a quarter of a century (70ies, 80ies and half of the 90ies decade).

What elements of the socio-economical system contributed to this situation?

- Low and poorly differentiated remuneration system, limiting motivation to work.
- Control of labour relations by political authorities.
- Limited possibilities of changing the career path in case of life problems.
- Underdevelopment of educational care and nursing institutions (for children and the elderly) motivating women to take advantage of disability pensions faced with necessity to provide nursing and educational care in family.

What elements of the social security system contributed to the easy access to disability pension?

- Liberal medical certification (medical assessment) of a disability level, using only medical definition of disability – health impairment (instead of inability to work) faced with the lack of disability standards and any accountability (medical, financial, social) of a commission (collective) body responsible for the medical certification for the effects of undertaken decisions.
- Similar level of disability pension to work remunerations and the old-age pension.
- Insufficient system of control and verification of the ability state of people who get the disability pension.

On the other hand the pressing on the system of disability pensions during the transformation period was mainly connected with a bad labour market situation:

- Outbreak of transition unemployment, related to the introduction of market economy and the changes of economical system confronted with the changes of trends and principles of international collaboration and modernization of industry ( decline of old industries and dynamic increase of labour productivity in branches using modern technologies).
- Underdevelopment of educational and adaptation programs allowing for the change of profession or additional training.
- Barriers to the mobility, allowing for the change of workplace such as: underdevelopment of contractor, housing market and transport and communication infrastructure.

At the same time social insurance system was still in place offering the disability pensions allowing for easy access to the system ( reform of the pension system was carried out in 1996). What elements of the disability pension system during transformation period contributed to the pressure of entering the system?

- Introduction of automatic indexing of long-term social benefits ( in high inflation conditions) with a sharp decrease remunerations level.
- Separating the social security institution for farmers under the supervision of the Ministry of Agriculture with the internal disability certification system, allowing for easing a difficult social situation in the country by the system of disability pensions.

- Lack of control of the farm work safety system with the high accident rate in the agriculture sector.
- No undertaking of the reform of social insurance system, in which disability pensions played the role of earlier old-age pensions, what allowed the older workers go through the change of the system and introduction of market economy in a less shocking way.

2) In the conditions of introducing the market mechanism, promotion of competition and effectiveness and the existence of a large scale unemployment rate, work for the disabled treated as an alternative solution for pension benefit is not sufficiently understood in the transition countries. The disabled are not able to find vacancies in open market, despite the introduction of motivation instruments for employers. On the other hand the development of disability protection work places is very expensive and requires reimbursement from public funds. It results in the approach which is limited only to income support.

3) Although disability pension benefits are more attractive than unemployment or pre-old-age pension benefits they loose in relation to wages due to the changes in the indexing rules introduced in the second half of the 90's (price indexing instead of wage indexing). Such a situation is conducive to undertaking work in the so called gray sphere by some pensioners which does not result in the decrease of benefit due to undertaking of job. The employer is also interested in employing a pensioner because he/she does not need the social insurance and agrees to be unofficially employed. In view of this fact a number of pensioners is *de facto* employed and such a phenomenon is socially tolerated.

4) The social policy with respect to the disabled has the elements of policy which has problems to leave the "magic circle" of difficulties. Its next steps will include:

- Limiting the easy access to the system of disability pensions by changes in the medical certification system (one-person certification instead of commission, change of the definition – giving up the medical definition and introducing the definition which reflects the fact of ability/disability to work).
- Introducing the system of pre-pension prevention system ( compulsory medical rehabilitation, occupational rehabilitation together with granting the training before getting a decision on disability pension).
- Developing different forms of activities for the disabled, which supports the professional and social rehabilitation process and especially the so called sheltered workshops and rehabilitation groupings.

- Analyzing the effectiveness of the current employment solutions for the disabled on the open labour market and looking for the possibilities of increasing of this kind of employment.
- Introducing the changes in the in the employment system of the disabled in the “sheltered” institutions by supporting different forms of such employment (the legislature on social employment is being developed in Poland).

5) The introduction of social policy changes pertaining to disability is carried out on the basis of the dialogue with the organizations of the disabled, which has the following characteristics:

- Putting high priority to securing the income for the disabled who are outside the social insurance system (the born disabled, disabled from childhood and early adolescence) and subsidizing their families in the system of social assistance.
- Avoiding the problem of employing the disabled by the employers organisations owing to a great number of problems connected with restructuring of economy and strong social pressure on the job creation in general and even more for the young than any “special” participants of labour market (if prioritizing).
- Strong defense of protected (sheltered) work places by the lobby of the disabled organizations even if only monitoring of functioning such firms is involved for the better transparency connected with the flow of public funds.

6) The subject of mutual obligation of society and the disabled has a lot of aspects. One of them is the scale of redistribution of income for the social benefits for the disabled, another one is the relationship between benefits in cash and services and subsidies for education and institutions to facilitate the employment of the disabled (the policy of active and passive support analogically, as it is in case of supporting the unemployed).

- The opinion polls in Poland show the social acceptance for the redistribution of income for the benefits for the disabled under the condition of limiting the access to the pension system.
- The change of social policy with respect to employing the disabled in the direction of differentiated and individually tailored programs of social inclusion requires some promotional and educational work. That is why not only bigger public sources are needed but also openness of the disabled to the changes. Since a strong attachment to the existent solutions can be observed.



## OECD Key Issues and Policy Conclusions

### *Theme 3: Who Needs Activation, How, and When?*

#### **Key issues**

Expenditure on activation programmes for disabled people is on the rise but is still very low as a proportion of total expenditure on disability-related programmes.

Vocational rehabilitation and training is often used too little and initiated too late. Average costs for such interventions are low compared to average costs of a disability benefit.

While segregation of disabled people in special forms of employment is increasingly seen as inappropriate and in need of being replaced by initiatives aimed at integration into the open labour market, empirically the protected sector remains as important as ever. Tailored and individualised programmes spread only slowly – often due to a lack of qualified personnel. Average public costs of usually permanent jobs in special, sheltered employment often exceed those of an average disability benefit.

There is a striking age bias in all types of integration programmes. This is especially true for vocational rehabilitation and training programmes for which people seem to be selected primarily on the basis of age.

Several countries use different eligibility criteria for access to different types of integration programmes, and lack coherent administration and co-ordination of those services.

## **OECD policy conclusions**

Each disabled person should be entitled to an “individual participation package”, depending on needs and capacities. This package could contain various work and rehabilitation elements, and also cash and in kind benefits.

Tailoring integration packages will only be possible with small-scale, focussed programmes. More permanent on-the-job support, such as individual job coaches or personal help for work-related and social activities, appears to have strong potential.

This individual approach will place a wide range of new demands on disability gate-keepers. Case workers will need extensive knowledge of the range of available instruments. Doctors must be enabled to fulfil their role as medical assessors. A one-stop philosophy can promote equality of access to all programmes for all people, and would help gate-keepers to manage the full menu of available interventions.

The timing of activation plays an important role. The longer a disabled person stays out of work, the lower the chances of reintegration will be. An effective measure against long-term benefit dependence appears to be a focus on early intervention. In many countries the period of sickness absence is “lost”, because vocational intervention starts only when a person is potentially entitled to or already paid a disability benefit.

As all these measures are potentially expensive, adequate longer-term evaluation of new programmes will be required.

## *Building New Pathways to Work. The Background to Change*

*Rebecca Endean*

Since 1997 the UK Government has helped deliver a strong and stable economy and created the Department for Work and Pensions, Jobcentre Plus, the New Deals (for the unemployed, lone parents and people with disabilities) and given better in-work support through tax credits. The significant reductions in the numbers of unemployed and lone parents on benefit, and the fact that well over 1 million more people are now in work, are a testimony to the success of this strategy.

However there are currently 2.7 million people of working age receiving incapacity benefits because of a health condition or disability. This is 7.5% of the working age population (rising to 15% in the most affected local authority areas in the North West and South Wales). This number has more than trebled since the 1970s, despite improvements in most objective measures of health since that time, and has continued to increase [albeit at a slower rate] since the mid 1990s.

People do not have to be incapable of all forms of work in order to get an incapacity benefit. Instead entitlement is based on whether a person has a level of incapacity at which it is felt unreasonable to require them to seek work. It is not set at a level of incapacity at which doing any form of work is impossible. The clear evidence is that the vast majority of people who start a claim to an incapacity benefit expect to get back to work and that, for most, a return should be a real possibility if the right help is offered at the right time. For example:

- Around three quarters of new claimants have more manageable medical conditions such as back pain, depression and mild circulatory disorders rather than a severe disability such as Parkinson's disease, schizophrenia or severe learning difficulties
- Best medical evidence suggests that for the main conditions reported by claimants, a return to normal activity including work is likely to enhance well being and improve long term recovery<sup>1</sup>. The outlook for a return to work should also be positive.

- Surprisingly high numbers (up to 40%) of claimants in the early stage of their claim do not see their health as a key obstacle to them finding work at all.
- People coming onto incapacity benefits do report a wide range of obstacles to work that are unrelated to health. These include low confidence about finding a job, poor skills, little or no financial incentive to get a job, employer discrimination and a belief that they cannot work with their health condition.

Yet the longer claimants remain on incapacity benefits the more likely that they will find it difficult to make a successful return to work. So later work-focused interventions risk being less effective because of declining health, compounded by a declining attachment to the labour, and worsening skills. Out of every hundred people claiming an incapacity benefit, over 40 will still be there one year later. By this point their prospects for getting back to work are very poor, whatever condition they report. Once people have been on incapacity benefits for a year, the average duration of their claim will be eight years.

### **So What Should We Do ?**

In order for the Government to achieve its overall welfare to work objectives it is imperative that we attempt to find an integrated package or measures that helps people remain in contact with the labour market and move back into work. However, hard evaluation evidence on “what works” in terms of an integrated package, both in the UK and across the world, is limited. Therefore the UK is proposing to pilot a package of measures for people coming onto incapacity benefits much in roughly 8 per cent of the country. The pilots will be subject to an extensive programme of evaluation and it will be the findings from this that will determine what should be rolled out nationally.

### **Detailed Proposals Offered in the Recent UK Green Paper**

#### ***1) Providing a better framework of support***

We intend to engage individuals and provide effective support through:

- Ensuring new incapacity benefits claimants maintain contact with skilled personal advisers throughout the crucial early stages of a claim through a series of mandatory work-focused interviews

- Ensuring new claimants draw up an action plan with their personal advisers to help them focus on their long-term goals and set out the steps they are willing to take to prepare for a return to work
- Developing a new team of specialist personal advisers equipped with a much broader set of skills.
- Close linking of the incapacity benefit medical assessment process and the new work-focused interviews.

## 2) *Direct access to a wider range of help*

People claiming incapacity benefits can already access a range of disability and mainstream employment programmes such as the New Deal for Disabled People, Work-Based Learning for Adults and basic skills provision. In addition the Paper recommends filling a critical gap in the provision of services at present through:

- The establishment of new joint programmes combining support to find jobs delivered by Jobcentre Plus personal advisers with health-focused rehabilitation delivered in collaboration with the NHS.

## 3) *Offering improved, visible financial incentives*

The Working Tax Credit will, from April 2003, improve incentives for many claimants. However there is still room to improve incentives further – many of those currently out of work would be worse off in work if they took a job of 16 hours a week paying the national minimum wage. To encourage people to look for jobs and improve the certainty that they will be better off moving into work the Paper recommends:

- a simple Return to Work credit, paid through Jobcentre Plus, to help all those moving off an incapacity benefit back to employment. It will be paid at £40 a week for 52 weeks where personal income in work will be less than £15,000 a year. This will significantly improve financial incentives for those returning to work.
- Provide more financial support to enable claimants to compete effectively in the job markets by enabling advisers to make discretionary awards of up to £300 to spend on anything that will help their client obtain a job (for example new clothes for an interview or work equipment) through widening access to the Advisers' Discretion Fund

By offering this support we will have created a ‘Choices Package’ for incapacity benefit claimants – balancing improved opportunities with greater responsibilities to actively consider a return to work.

The full and summary versions of the Green paper are on the DWP website at: [www.dwp.gov.uk/consultations/consult/2002/pathways](http://www.dwp.gov.uk/consultations/consult/2002/pathways)

### **Note**

- 1 Waddell G and Burton AK – Occupational Health Guidelines for the management of low back pain – Evidence Review – Faculty of Occupational Medicine, London; Jones D and West R – Cardiac Rehabilitation – BMJ Publishing Group; Acheson D (Chairman). Report. Independent Inquiry into Inequalities in Health. London. TSO 1998

## *Activation through Sheltered Work? Not IF but HOW*

*Erik Samoy*

Sheltered work became an important instrument of rehabilitation policy some fifty years ago. From the start it had a double role to play. It had to provide a temporary solution for those who were not yet ready to enter or re-enter the regular labour market but it was also a permanent resort for those people who were unable to get or hold a regular job. In the course of the years the latter function became dominant, and because few people left the workshops the total number of sheltered workers kept on growing. Once in a while there have been attempts to remind the workshops of their role as a transition-institution but the outflow to a regular job remained low. The largest transition numbers occurred in periods when the economy was going well, probably because in those times workshop-employees had faith in their chances to make more money or find more interesting jobs on the regular market. Paradoxically, in the same periods there was a large growth in the number of workers in sheltered employment. This is explained by the fact that when the economy is at a high, regular firms have a lot of sub-contracting work that is tendered to the sheltered workshops.

Over the years sheltered workshops have become an important business. In a study for the Council of Europe, in the mid-nineties, we found that they employed nearly 500.000 workers in 17 European countries.<sup>1</sup> The federation 'Workability International' says on its web-site ([www.workability-international.org](http://www.workability-international.org)) that more than a million people are employed by the workshops in 28 countries all over the world. Table 5.3 of the OECD-report 'Transforming Disability into Ability' illustrates how countries attach a different importance to sheltered employment within their employment programmes for the disabled. The table compares the number of people per 1000 of the population, in subsidised, supported or sheltered employment. The range for the total number of people in all three types of programs together goes from 0.2 (Portugal) to 16.0 (Sweden). The range for sheltered employment goes from 0.1 (Portugal) to 10.1 (Poland). The top 5 countries for all employment programmes are : Sweden (16.0), Poland (12.1), France (9.5), The Netherlands (9.2) and Norway (7.2). The top 5 for sheltered employment are : Poland (10.1), The Netherlands (9.2), Switzerland (5.6), Sweden (5.2) and Germany (3.3). Three coun-

tries, Poland, Sweden and the Netherlands appear in both lists, which means that in those countries, which all three have a high overall number of people in employment programmes, sheltered employment plays a very important role. But there are also other countries, such as Belgium, where sheltered employment has a large share, although the overall number people in programmes is no that high.

However, the diversity between the workshops is so great that it's very hazardous to talk about sheltered employment in general. What they have in common is that they all create special employment conditions to activate people with disabilities, and sometimes also other target groups. But the type of activities, the status of the employees and the position of the workshops in the economy and in the field of services for the disabled differs a lot.

The question therefore is not IF sheltered employment contributes to the activation of people with disabilities but HOW.

One is inclined to think that the answer is obvious: people in sheltered workshops are at work and are being paid for it, so they are no longer inactive and dependent on benefits. There is no doubt about their being at work, although the pace and intensity is very different, but they are not always regular workers with a normal wage. In some countries the workshop employees' income is an income from work much below a minimum-wage level, but topped up with allowances and benefits. But there are other countries where the wages paid in sheltered employment compare favourably with open-market wages. The difference in pay-levels somehow reflects the productivity of the workers, but also the amount of State-subsidies for sheltered employment.

Activation is not always exclusively activation through what we normally consider as work. There are workshops (or parts of workshops) where people spend some of their time on occupational activities and social-skills training. These workshops resemble some daycenters where occupational activities and social-skills training are dominant, but part of the time is spent on productive work. Another important activity in some workshops, is vocational training. The aim of the training is primarily to produce better workers for the workshop itself, but it may also benefit the person to find a regular job. When people enter a workshop there may be an assessment and training period which is meant to find out which employment option is suitable for the person (regular work or permanent sheltered work or referral to a day-centre). In some countries vocational training and sheltered work are intensely interwoven whereas in other countries they are institutionally quite separated.

Although in many cases the sheltered work environment provides good opportunities for the activation of people with disabilities, many people want to see it abolished on the grounds that it is a segregated form of employment which does not really lead to integration in the labour market in the sense of not only having a paid job but also of being at work amongst non-disabled people. A new type of program, called supported employment, is preferred. Supported employment contains all the same elements as sheltered work (a wage subsidy - adaptations to the workplace - personal support on the workplace), but it realises these elements in a regular work-environment, where disabled people are working with non-disabled people. Many countries do not have such programs yet, in others they are still relatively small, compared to the workshops. Sometimes they exist mainly for people, often with a mental disability, who are performing unpaid work.

The challenge for the future is to find a model of sheltered work (some people will prefer to use the term 'adapted work') that fits the needs of every single person. We are dealing with a set of components which piled onto one another produce a continuum of employment supports. The weakest form of intervention is subsidised employment, which may be limited to a wage-subsidy, but there may also be material or immaterial adaptations to the workplace. When we add personal support we end up with supported employment. And when all this is organised in a collective way, we have the traditional model of a sheltered workshop. To offer tailor-made solutions to people we may need to break barriers between organisations, administrations and regulations. In some countries we see this happening, but it's only a start and there remains a lot of resistance to change.

## Note

- 1 Samoy, E., L. Waterplas (1997) Sheltered employment in five member states of the Council of Europe : Austria, Finland, Norway, Sweden and Switzerland. Council of Europe, Strasbourg.

# *Who Needs Supported Employment and How?<sup>1</sup>*

*Charlotte Strümpel*

## **What is Supported Employment?**

Supported Employment is a perspective which involves supporting people with a severe disability to find and maintain a job on the ordinary labor market. It offers individual, tailor-made support in the job finding phase and on-the-job with the help of job coaches.

## **Who is Supported Employment for?**

The key idea of Supported Employment is to support people with a substantial disability who otherwise would not work in an ordinary work setting. It was conceived for a target group who was traditionally non-employed or employed only in sheltered work settings.

Supported Employment thus challenges a phrase which is heard often in discussions on employment of people with a disability: „those people not able to work on the ordinary labor market“. There are many examples of people were not seen as able to work on the ordinary labour market by their environment, and who through Supported Employment have succeeded in finding and maintaining such a job.

However, policy in many countries has been about defining the success of Supported Employment through the number of placements made. This can lead to the effect known as „creaming“, where Supported Employment providers choose people with less severe disabilities as clients in order to more easily fulfill quantitative placement criteria. Especially in cases where the overall labor market situation is difficult, this can lead to excluding those from Supported Employment services that they are actually meant for.

*Recommendation 1: Supported Employment must maintain its aims to cater to people in need of a vast amount of support to work on the ordinary labor market.*

## **What is the relationship between Supported Employment and Sheltered Work?**

The relationship between Sheltered Work and Supported Employment is much discussed and is also subject of other statements of this conference. In his contribution Erik Samoy states that Supported Employment and Sheltered Work is a continuum and that very much the same elements are involved in both these provisions, such as wage subsidies, adaptation to the work place and personal support. Many people active in Supported Employment would not see this as a continuum, but rather see Sheltered Work as a symbol for a segregated work setting and a job on the ordinary labor market as a symbol of an integrated work setting.

The objective of Supported Employment is to find a job on the ordinary labor market which fulfills certain criteria. These are: a valid contract of employment, adequate wages and a stable job. This also means a job that matches the employees skills and abilities including a positive atmosphere at the workplace, a satisfied employer as well as a good relationship with and support from co-workers (see also [www.quip.at](http://www.quip.at)).

Erik Samoy mentions big differences in sheltered workshops in terms of wages, working conditions, amount of support offered and level of segregation. Thus it is hard to make overall judgements on sheltered work. However, the ultimate aim of all activation measures – no matter what they are called – should be full employment in work settings that fulfill the above mentioned criteria. It should be about offering high quality jobs for people with a disability. However, in reality, people with a disability – whether in sheltered or integrated settings – are still found in low paying, low status, odd jobs that are not permanent.

Sheltered work settings should continue to develop in such a way that they fulfill aspects of the „ordinary labor market“ and the so-called „ordinary labor market“ should continue to develop in such a way as to accommodate and offer support to people with different needs. This is the idea which underlies the discussion on mainstreaming. In the whole mainstreaming debate there is of course the issue that targeted support can be missing for people with vast support needs.

“I would like to find a real and interesting job” (Job seeker, Austria)

„I want to find the job I want to do, and not just any old one“ (Job seeker, UK)

*Recommendation 2: When designing activation measures to support the integration of people with disabilities into the labor market, the main focus should be on the characteristics and the quality of the job.*

## **What makes Supported Employment work?**

### ***Tailor-made approach***

The key to the success of Supported Employment is in the tailor-made individual approach. This involves individual planning, individual support for job seekers, supported employees and employers, as well as flexible help when needed. The methods used in Supported Employment can be an impulse for other activation measures.

„I like that you are not only a number“ (Job seeker, Austria)

„As SE is an individual approach, the problem is never the same“  
(Job coach, Norway)

„They always come when we need them“ (Employer, Spain)

*Recommendation 3: Activation measures should take into account Supported Employments' tailor-made, flexible approach that encompasses the needs of the individual person with a disability and those of the employer.*

### ***Including stakeholders as partners***

A further key issue with respect to activation measures like Supported Employment, is how to involve the many actors in the provision of the service. While traditionally, the job seekers or employees with a disability, the employers as well as policy makers are seen as customers, that are offered a service by the SE provider, a stronger focus be put on involving these stakeholders as partners and co-producers and not as passive recipients of a service in the future.

A crucial role is that of the *job seekers / supported employee* with a disability. One of the main objectives of Supported Employment is to involve job seekers actively in the Supported Employment process, support them to make their own decisions and generally support their empowerment. However, this is an aspect which is not yet systematically implemented in practice. Here social service attitudes where things are done for and not by the job seekers or supported employees with a disability are still predominant in practice. There are also big differences between

different countries in self advocacy and user involvement in service provision. There is a large scope for improvement in this field.

“It is based on clients expectations and abilities, on dialogue with the client”

(Policy maker, Czech Rep.)

“We (my job coach and I) are a good team, we work together as equals”

(Job seeker, UK)

*Recommendation 4: Supported employees and job seekers should be actively involved in all levels of the Supported Employment process and user involvement in service provision should be encouraged.*

The role of the *employers and co-workers* in Supported Employment is one of the most difficult issues as is also in general the case when looking at the employment of people with a disability. It is a challenge to involve employers actively in promoting the employment of people with a disability. Another issue is involving and informing co-workers and supporting them to support the employees with a disability. This is also a field where improvements are necessary.

“The job coach was here, but we preferred to use a colleague to teach the employee the work” (Employer, Norway)

“There were no troubles with the colleagues, on the contrary they facilitated his integration” (Employer, Spain)

*Recommendation 5: Employers should be seen more as co-producers and encouraged to contribute actively to the success of Supported Employment.*

### ***The job coaches job***

The job coach has a pivotal role in Supported Employment is the job coach. The job coach is a broker and a go-between between all other stakeholders in the SE process. The job is characterized by very high expectations towards the job coach and a wide variety of key skills that the job coach is said to need. Within many Supported Employment organisations there is a high turnover among job coaches, which is especially problematic because of the importance of the personal relationship between job coach and supported employee, and job coach and employers. One reason for this can be the difficulty in negotiating and moving in the ‘two worlds’ of social service logic and business logic. Also in most countries there is no systematic training for job coaches and people from many different backgrounds work as job coaches.

“It is the variation and diversity of competence that counts in SE work”

(Job coach, Norway)

“Job coaches need fearlessness in dealing with employers” (Job seeker, Czech rep.)

*Recommendation 6: Working conditions, as well as training of job coaches need to be reviewed and improved.*

### *One service of many*

Another crucial point that is also mentioned in the OECD report “Transforming disability into ability” is how Supported Employment relates to other services. It has to work closely with other services to be able to refer people who need different kinds of support. Networking and referral between the vast variety of services to promote the integration of people with a disability needs to be improved. This is connected with the question of how people are referred to different activation services. It is still the case that access to Supported Employment is based on chance encounters or referrals rather than being the result of a systematic approach.

“Developing the process of learning from each other between different providers of services for people with a disability” (Employer, Hungary)

“I don’t like agency tennis: being hit from side to side” (Job seeker, UK)

*Recommendation 7: There is the need to improve the cooperation between labor market services, social services and providers of SE.*

### **Which role should policy have?**

We find in many countries that employment and disability policies actively promote Supported Employment measures. In some countries there is a clear legal background for Supported Employment, in others there is not. As mentioned above, there is a strong focus on quantitative placement measures to determine the success of Supported Employment providers by policy makers. This can lead to forgetting important aspects of Supported Employment like the quality of the job, opportunities for career development, targeting those people that need the service most or long-term job retention and jeopardize the main aims as well as the quality of Supported Employment.

*Recommendation 8: Supported Employment needs to be firmly embedded in national employment policies for people with a disability. Criteria for success should not only focus on quantitative placement measures but on providing good, long-term jobs for people with a disability.*

## **Note**

- 1 This statement is based on the project „QUIP- Quality in practice: Stakeholders‘ view of Supported Employment“ which was carried out in the framework of the European Commissions‘ LEONARDO-programme between from 2001-2002. It was coordinated by the European Centre for Welfare Policy and Research and involved partners from Austria, Czech Republic, Hungary, Norway, Spain and UK. For more information see [www.quip.at](http://www.quip.at).

## *Comments by the Director General of STAKES, Finland, on the Policy Conclusions*

*Vappu Taipale*

### **Some background issues: societal challenges**

There are many societal phenomena and challenges of the OECD countries which have to be met when speaking about transforming disability into ability.

#### *The development of information societies*

All the OECD countries will face the rapid societal development into information societies. The sudden leap into the information society is a most intrinsic process in all our societies. The significance of the information society is measured by the relevance of the contents it is producing through its means. Information is a commodity whose importance grows when it is being distributed. Education is a means for producing well-being and control of life. The development opportunities are tremendous. The societies can implement the idea of life-long learning; nobody is too young, too disabled or too old to learn. Technologies are available which allow us to overcome the obstacles of distance, time and disability. Through satellite connections, the most remote health centre in the midst of mountains or rain forests can get the most modern information on treatment. There exist technologies which allow people with grave disabilities to live with autonomy and dignity. The technological innovations made mostly to serve warlike conditions can be converted to be used in everyday life.

But, the challenges are even greater: to make an information society a society for all. In an information society, learning and skills become a major asset, and people with learning disorders and poor learning environments will easily face marginalisation and exclusion.

#### *The need for integrated policies*

Social policy programmes are the best way to enhance social protection and to reduce vulnerability. The present economic, environmental and social situation in the world challenges national policies; international cooperation is needed. Within national social policies a stage has been reached where there is a growing need to

replace vertical policy-making by horizontal activities and connections. The various sectors of politics have become more interdependent: agricultural policy bears an effect on health, equality policies influence competitive capabilities, transport policies influence industrial policies, employment policies affect pension schemes, and regional policies involve socio-political responsibilities. The issues of disability and ability should be consistently tackled by multisectoral, integrated policies.

### ***The importance of the civil society***

Social capital is based on inclusion, participation and promotion of an enabling environment. There are studies to show that the existence of a civil society is not only the precursor and guarantor of good governance, but also the key to sustained socioeconomic development. Social capital brings into daylight the networks between people, the confidence people feel in their transactions, and the stability and reliability of functioning in municipalities and localities. The concept addresses the economy from the social point of view and shows that important pre-conditions of economic life are social. But, everywhere the civil society needs to be strengthened. The challenges of empowering the people are the same were the societies rich or poor, developing or developed.

### ***The ageing of the population***

Ageing is a natural phenomenon, but it often brings with it multiple minor disabilities. All OECD countries are being faced with demographic, structural, social and technological changes of major importance. The ageing process will not only change the population structure of countries profoundly. The process will be intersectoral, part of everything. It will cover all policy areas. We have to develop a perspective, which enables all societies to see the population changes as positive opportunities for societies and economies. The opportunity lies in innovative social, organisational and technological responses to the rising challenges.

### **From disability to ability**

There are two points of departure

### ***The current magnitude of the issue***

Internationally, the magnitude of the issue of disability is remarkable, and the world is still rather producing disabilities than preventing their emergence. Poverty, hunger, malnutrition, wars and conflicts, infectious diseases, traffic and work accidents cause traumas, disabilities, and disease which could be prevented.

It has also to be kept in mind that neither people with disabilities nor older people are a homogeneous group, a grey mass of people. They differ greatly from each other; hard of hearing people do need different policies and aids than mentally ill people, a child with CP has different needs from an adult with diabetes.

In the Finnish context we are speaking about a population of five million people. There is no single source of valid and reliable statistics on the labor force status of people with disabilities. According to the registers of them Ministry for Labor, there are 85 000 people with disabilities in the open labor market Finland. Out of these, 67 000 are unemployed and 16 000 employed. Additionally there are 11 000 people with disabilities engaged in sheltered jobs. If we assume that there are 5% people with disabilities in the potential labor force, these figures indicate that at least every second person, rather two thirds, of the potential labor force with disabilities are not working and most of these are officially unemployed. The challenge is thus enormous. On the other hand this issue cannot be solved by sheltered jobs, either.

### ***The agreed international standard of nondiscrimination and inclusion of people with disabilities***

The United Standard Rules as well as the premises of current European legal frameworks imply that people who have disabilities should not be discriminated and each individual sector is responsible to manage disability issues in an inclusive manner. As of the labor market there is also the new ILO Code of Practice to that effect.

### ***Policy conclusions***

Solutions need to be sought primarily from the open labor market but the challenge is huge. Thus, in respect of the policy conclusions, the following issues arise:

- 1) Due to the magnitude of the issue, to “roll out” i.e. expand the idea of individual participation packages are realistic only if integrated to the basic rehabilitation process of each individual with disabilities. This is not yet a standard practice due to sector boundaries. There is a need for *designing a cross-sectoral and integrated concept of seamless services and system of rehabilitation services*.
- 2) Similarly, individual case by case coaching is difficult to expand. Rather a “resource centre” type of *job accommodation services in collaboration with e.g. the organizations of the people with disabilities* may be more feasible.
- 3) There is a serious challenge to raise the *awareness* of the gate-keepers and the intervention needs to be intense in the basic *training as well as retraining* of staff involved in gate keeping.

- 4) As of early intervention, there is a need *to review legislation* to allow flexibility between benefit eligibility and work related income.
- 5) Systematic *evaluations of the impact of alternative interventions* are indeed scarce and should be baked in to any new programme.

### ***Community Based Rehabilitation***

It is obvious that significant increase in the inclusion of people with disabilities in the open labor market will not be possible by focusing on activating people with disabilities or excluded people, themselves only. Experiments should be initiated to try out the ideas known as Community Based Rehabilitation (CBR) to activate and involve the private and public actors in the community to take part in the rehabilitation and inclusion process of its members with disabilities. This would foster shared responsibility and ownership by the community of the outcome of inclusion efforts.

### ***Design for All***

There is also a need also to elicit demand for the productive potential of people with disabilities. This implies changes in the policies as well as the knowledge, attitudes and practices of all stakeholders: the employers, the legislators and organizations of people with disabilities. At all levels the “Design for All” principle needs to be internalized and applied.

### ***Corporate Social Responsibility***

Inclusion is a public good that does not seem to be catered properly for by the market. There is a case for stronger public intervention to ensure that business needs to bear its social responsibilities for the cohesion of their communities and the society as a whole. Corporate Social Responsibility refers to manifold activities of the enterprises and allows innovative ways to meet the needs of people with disabilities.

### ***Empowerment!***

Furthermore, there is a need to reorient disability related services and social security from the traditional safety-net approach towards becoming empowering “springboards” aiming clearly towards inclusion and active participation rather than serving as passivating harbor for the already excluded.



## OECD Key Issues and Policy Conclusions

### *Theme 4: How Should Disability Benefits Be Structured?*

#### **Key issues**

Different disabilities lead to different degrees of work capacity. Half of the countries offer at least some type of benefit for partial disability, and one in four have partial disability benefits at several gradations. In the latter group, one in three awards is for partial disability.

At the same time, partial benefits may become an easy bridge into benefit dependence, because outflow from such benefits is also low. Paradoxically, some countries aim to introduce or broaden the scale of partial benefits while others are in the process of abolishing them.

Many disability benefit schemes take the applicant's age and/or the length of the insurance record into account to determine the benefit level. This may systematically discriminate against certain groups of disabled people.

Flat-rate disability benefits avoid such discrimination but will often fail to secure a disabled person's current standard of living. And household means-testing of disability benefits, that is targeting of available resources, can also be problematic.

Often, disability benefit schemes provide little incentives to work.

## **OECD policy conclusions**

Disability cash benefits should be available with sufficient flexibility to take account of both different cases of remaining work capacity and of the evolution of an individual's disability and work status over time.

Many disability schemes are centred on income-replacing benefits and tie other benefits and services to eligibility for such cash transfers, thereby discouraging disabled persons from trying to return to work. Such systems need to be dismantled so that benefits and services can be awarded independently.

Benefit entitlements should be designed in a way that the disabled person is not penalised for taking up work. After-tax income including all transfers should be higher in work than the income the person received while out of work.

Take-up of work may need to be encouraged through financial incentives. In-work top-up payments are likely to be most effective. Such top-up payments would be strictly work-related for compensation of low pay or reduced working hours.

Wage subsidies paid to the employers would play a less important role under this new approach, since beneficiaries would receive direct in-work benefits. There may, however, be a case for compensating the employers for the extra costs of workplace accommodation.

## *How Should Disability Benefits Be Structured?*

*Emily S. Andrews*

The ideal structure of disability benefits depends upon society's core values with regard to the position of persons with disabilities in the society. Over the past 100 years, these values have been changing. A key ingredient for modern disability policy in the 21<sup>st</sup> century is the concept of inclusion, with the objective of independent living and fulfilling one's potential. Disability policies based on inclusion may be quite different from those based on older concepts of assistance, which often contained an implicit assumption that persons with disabilities could only be assisted outside the community, either for their 'own good' or because society was embarrassed by their presence (for undoubtedly a long list of cultural reasons beyond our purview today). I still remember my work in Bosnia when representatives of disabled veteran's associations kept repeating that they were not 'social cases,' suggesting that other persons with disabilities were or should be.

Income support programs, such as social insurance, can still be consistent with the concept of inclusion, as are programs focused on poverty alleviation, particularly for persons without work history and those disabled from childhood. However, these benefits should be a safety net that hopefully is provided to a small proportion of the disabled population. Above and beyond cash benefits, one of the best ways to develop inclusion is through labor force participation, as work challenges individuals and provides independence.

But, I should start off by defining the term 'persons with disabilities.' I am using the disability to mean *work* disability (or activity disability) not medical condition or impairment; that is, the effect of impairment on one's ability to do tasks related to daily living, study or work. We should also remember that to some extent, we are all disabled, as none of us can do all the jobs that are available because of lack of strength, agility, or mental ability. Further, the likelihood is strong that any one of us may become disabled as we age. So disability is an issue that affects us all personally and directly.

The onset of disability may come at different times during a lifetime, and, as such may require different types of interventions to promote inclusion, independence,

and the full use of abilities. Some persons with disabilities are disabled from childhood, with assistance needed in the area of education, possibly supplemented by other interventions throughout adult life. In this case, education, care giving, and even income support may be important. Second, and more frequently, individuals may become disabled during their working lives. Here disability benefits, physical, psychological and vocational rehabilitation are appropriate interventions. Others may become disabled through an occupational illness or injury. Many countries provide separate occupational insurance, in part, as a means to improve working conditions, particularly if payroll tax rates reflect firm-specific incidence of injury or disease. Occupational insurance is also useful to restrict litigation on the part of employees, replacing individual lawsuits with a system of insurance. Other adults may become disabled before they have a job record, either because they are young or because they have worked at home raising a family. These individuals also need rehabilitation opportunities and, if necessary, cash assistance.

No one program is suitable for each type of disability or for each and every country. One size cannot fit all. Age, age of onset, type of disabling condition are all part of the set of individual characteristics that require individual solutions – or at least, solutions that are sensitive to the different circumstances of the individuals affected. Similarly, different countries may select different options either because of a tradition of benefit design or other cultural differences. For example, cash benefits come in a variety of colors – flat benefits, income-related social insurance, means-tested benefits, low benefits, high replacement rates, universal public benefits, private sector insurance or some combination of the above. There is no one good solution.

Program parameters for cash benefit programs also vary widely in both OECD and transition economies. Some countries provide benefits for full disability only, while in others cash benefits are provided for partial disability as well. Partial disability pensions can help workers with disabilities enter into the workplace, or provide serious disincentives for work, depending upon the country and the level of benefits provided. Each case needs to be evaluated independently.

The disability determination process can also influence whether a disability program will be successful or not. Certainly, the disability determination process should be designed to be consistent with international standards. Further, the process should be efficient and impartial. However, we do not necessarily know what the best mix of professionals should be. Probably, a panel of physicians, as is seen in a number of transition economies, is too many. Probably consideration should be given to

physical, psychological and rehabilitation. But what to do in a country such as Russia where there is a current undersupply of vocational and occupational experts, which hinders the implementation of forward-looking legislation?

In terms of impartiality, disability determination personnel should be independent. This means that decisions should not be left to the applicant's own doctor – as moral hazard could be great. Disability determination panels should be paid appropriately so that doctors do not look for bribes and can refuse those that are offered. In Hungary, many thought that doctors were bribed to certify persons as disabled who did not meet disability criteria. However, it could also have been the case that doctors accepted bribes to make a disability determination that was correct, just as medical services often require additional payments! Some OECD countries have experienced yet another problem. While the disability determination process is not subject to bribes, it may be subject to political demands. For example, in the Netherlands and the United States, disability determination decisions have been more or less strict, depending upon the political climate of the day

While it would be ideal if every country could establish an extensive system of proven policies to assist all categories of disabled persons with individual assistance that ensures inclusion and independence, the financial resources to do so must also be considered. This is yet another area in which programs must be designed to meet the possibilities of the country in question. For example, payroll tax rates in both the Netherlands and Poland have been higher than in many other countries. But the Netherlands is better able to sustain such a strain on its resources than is Poland, where economic growth is essential, particularly as an upcoming member of the EU. Thus, inefficiency and overprotection in the Netherlands can better be afforded than in Poland. Too often disability programs are designed with little or no concern for budgetary constraints. Programs that promise more than they can deliver are probably worse than limited programs as they can only operate in a climate of favoritism and will not serve the population well. One of my favorite examples of an unfunded mandate is the promise in more than one transition economy of personal transportation (cars) for persons who are 100 percent disabled, a promise that is primarily honored in the breach.

Independent living may be highly dependent on finding work, which provides the resources for financial self-sufficiency. One method that does not appear to work is the imposition of quotas on employers to hire the disabled. Employers tend to prefer to pay taxes than to tax their workforces with individuals they do not want to hire. The use of sheltered workshops also has serious problems either for finan-

cial abuse or because persons with disabilities are placed outside the community. Poland is one of the most problematic cases as sheltered workshops have basically sheltered employers from competition. But, sheltered workshops may be helpful in some cases, even for persons without serious mental retardation – the disability most often suggested for this type of program. For example, in countries in which transportation is poor, a community of persons with disabilities at a workplace may lead to greater independence than other alternatives. This argument was made to me in one case in Bosnia, and I cannot say it was wrong.

Another lesson I have learned by talking to persons with disabilities in Poland and Bosnia is that policies other than cash benefits are as important, and even more important than money. For example, access is crucial – access to buildings, access to transportation, and access to the workplace. Similarly, access to personal assistance devices, such as wheelchairs (comfortable ones), hearing aids, seeing-eye dogs, and many others aids that are not necessarily expensive but vital to independent living is also needed. I believe that we have far to go to determine what public funding is necessary and efficient to promote access. Similarly, we need to think outside the box in other areas. For example, a caregiver's allowances could be a better use of public funds if it allows a person to work, than poverty benefits that do not provide work incentives.

In all countries, the public still needs more education to understand that inclusion, independent living, and the development of abilities should be the goals of public policy. Persons with disabilities, themselves, may also need the same public information. I was amazed in Bosnia to find a stark difference in attitude between disabled persons who had become acquainted with examples of independent living in the United States and disabled war veterans who thought that work was not necessary but benefit eligibility was. What a waste of a young man who is not interested in achieving as much as he can. Attitudes can change through public information, through educational systems that are as inclusive, and through anti-discrimination laws such as the Americans with Disability Act in the United State.

While there is no 'ideal' disability policy, better methods of program evaluation are needed in the future to determine how effective programs are with regard to the underlying goals of disability policy. For example, a system with a high social insurance replacement rate, such as those in place in transition economies at the beginning of the 1990s, could not be considered successful measured against modern criteria of inclusion, independence, and the development of abilities. Pre-transition policies warehoused people in institutions and sheltered workshops, removed

them from the labor force and/or provided meaningless jobs within an enterprise. We should consider setting millennium development goals in the area of disability policy to promote inclusion, independent living and the maximization of abilities. Labor force participation could be one measure. The development of others should be our challenge for the future.

## *How Should Disability Benefits Be Structured?*

*David Kalisch*

### **The Australian Benefits System**

The Australian income support system differs from those of most other developed countries, with payments funded from general revenue rather than from direct contributions by individuals, are generally not time limited, and benefits provide a basic flat rate income support payment. Payments in Australia are made under specific social security legislation, which can be subject to change depending on support from both the community and Parliament.

### **Disability Payments**

Some form of disability pension has existed in Australia for around 100 years, the same time as our Age Pension. The Disability Support Pension (DSP) is a non-contributory, means tested (except for blind applicants) income support payment equivalent to 25% of male average weekly earnings for single people and is non-taxable income. It is funded by the Federal Government and administered by Centrelink. Non-cash benefits and concessions are also available.

Current eligibility criteria for DSP is as follows:

- Applicants must be aged over 16 and under Age Pension age.
- Applicants must have a medical impairment that attracts at least 20 points under the DSP impairment tables (this does not necessarily correspond with a 20 percent impairment) and a continuing inability to work 30 hours or more per week at award wages, or inability to be re-trained (through mainstream training) for such work, within two years. For those over 55, the availability of work in the local labour market can be considered.
- Special eligibility provisions apply for blind applicants who only need demonstrate that they meet required medical tests for permanent blindness.

### **Sickness benefits and workers' compensation**

Disability pensions are complemented by other arrangements for sickness benefits and workers' compensation:

- Sickness benefits in Australia are provided largely by employers. People who are not covered by their employers or private insurance (such as casual employees), those who have exhausted their private cover, or those seeking employment, may be eligible for income assistance from the Commonwealth Government.
- Assistance to people injured or killed as a result of workplace or traffic accidents is a responsibility of State/Territory Governments. The Commonwealth Government manages workers' compensation arrangements only for its own employees. People who are not covered by any of these options may be eligible for a safety net Commonwealth Government income support payment.

### **Some of the recent trends in Australian disability benefits**

#### ***The number receiving DSP has been growing strongly, and few leave for work***

The number of people receiving DSP has been doubled over the last decade, and still growing at an average rate of around 4 % per annum over the past four years. Just under 40% of new entrants to DSP transfer from unemployment payments, suggesting that a significant proportion have experienced long-term labour market disadvantage. Almost half of all people granted DSP are aged 50 years or over, providing an early retirement option for many recipients. Around 1 in 19 people of workforce age in Australia are now receiving DSP, more than in receipt of unemployment benefits.

Few DSP recipients have any contact with the labour market, despite relatively generous (by Australian standards) means testing provisions and a significant part-time employment sector that could accommodate those unable to work full-time. There has been a gradual increase in percentage of DSP customers with earnings since the DSP reforms in 1991 from 6% in 1992 to the current level of 9.7%. The majority of those who exit DSP payments do so because they have transferred to Age Pension on reaching the qualifying age or have died.

#### ***Certain conditions dominate***

Musculo-skeletal and connective tissue conditions are the most common medical condition for DSP customers (also the case for the last decade), representing approximately 33% of the total DSP population. Psychological/psychiatric conditions represent 24% and intellectual learning disabilities represent 10%. Younger DSP customers are more likely to have an intellectual or learning disability, and have

more earnings from employment. Older DSP customers are more likely to have musculo-skeletal conditions and less likely to have earnings.

### **Some key issues for design and administration of disability benefits**

*Administration makes a difference* – Design of disability benefits can be either undermined or supported by tight, consistent, appropriate administration. The practice of benefit delivery agencies can influence rates of claim for disability benefits and they play a critical role in accurately assessing claims, undertaking regular reviews of conditions, and facilitating access to assistance that can help people undertake or expand participation in work. Where medical impairment is part of the qualifying test for disability pension, expert review is important.

*Early intervention and greater focus on work capacity holds prospects for improvement* – In Australia, too many people come onto DSP long after their condition has deteriorated, either while they have been unemployed, sick, or receiving worker's compensation from State/Territory based schemes. New arrangements in Australia have a greater focus on the assessment of work capacity, to establish what people applying for DSP can do in relation to workforce participation and to identify what services and supports may help people back into work or to continue to work. These changes are part of efforts to build an integrated and responsive social support system that effectively combines income support and services for people with disabilities. We are encouraging workers' compensation schemes to expand efforts on early rehabilitation, rather than the lower cost approach (for these schemes) of providing cash support. We are looking to mainstream employment services to assist more people with disabilities, and desirably help achieve better outcomes for them.

Among the DSP population, there is a wide range of work capacities yet too few work. Some with very extreme medical impairments desperately want to work, yet others with milder conditions just want to be left alone now that they have achieved the goal of receiving a disability pension. The system needs to take a balanced approach towards enabling and encouraging people to fulfil their potential, especially if flexible employment such as part-time work is more readily available.

*The ageing of the population presents additional challenges* - In Australia, around half of the inflow to disability benefits over the past decade has been people aged

over 50 years. This could increase further over coming years, as our baby boom generation (born between 1945 and 1960) moves through the critical “pre-retirement” years. Relevant issues here include the extent to which early retirement is desired by the workforce, the extent to which older people are treated more generously in claims for disability benefits, and the broader dimension of the extent to which there are successful complementary policies and programs that assist older workers to stay and re-enter the labour market.

***Consider interplay between disability and other benefits: may need a system solution*** – In Australia, disability benefits that provide more generous assistance than unemployment benefits and expanded work requirements for unemployed people acts to encourage claims for disability benefits by those who are in a grey area and could potentially qualify for either. Some possible solutions include reducing the financial disparity between disability benefits and unemployment benefits if they exist, and considering activity requirements for those in receipt of disability benefits where they have an assessed capacity to work.

Recent experience suggests that more effective solutions may lie in broadly based reform of income support across the working age population rather than more limited reform of disability pensions. The Australian government is currently engaged in a community consultation on the future structure of income support payments for people of working age. Many issues affecting people with disabilities will be considered as part of this process, including eligibility and coverage, structure of assistance, income tests and incentives for paid work and participation requirements. The consultation paper is available at [www.facs.gov.au/welfare\\_reform](http://www.facs.gov.au/welfare_reform).

***Importance of community support*** - Any reform of the benefit system will be challenging. Community attitudes and expectations of benefits vary considerably and changes to the benefit system for people with a disability are often controversial, even if they are packaged with positive elements. In the 2002-03 Budget, new measures to change the qualification criteria for DSP were announced. These changes would have limited DSP to people with more restricted work capacity (not able to work more than 15 hours a week at award wages), allowed a broader range of interventions to be taken into account in assessing the possibility of moving back into the workforce within two years, and those aged 55 years and over would no longer have their local labour market conditions taken into account. These measures to reform DSP eligibility were not well received at the time of their release and to date have not successfully progressed through the Australian Parliament.

## *Report on a Programme for Better Health in Working Life in Sweden*

*Jan Rydh*

### **Background**

During the latest 5 years, Sweden has seen an incredible increase in people on sick leave. The increase is more than 20% a year meaning that the figures have been doubled in less than five years. With very few exceptions, all people working in Sweden are insured through the Swedish general sickness insurance scheme, financed over the state budget. For 2003, the total cost for the state (disability pensions and sickness compensation) is calculated to about 125 billion Swedish Crowns (about 13 billions Euros). This sum occupies more than 15 per cent of the total budget and is more than twice the cost of the Swedish defence system or three times the cost of the Swedish educational system. In November 1999, I was appointed by the Swedish Government to lead an Official Inquiry into the Swedish Insurance System in order to analyse this development and, based on that analysis, recommend proper actions.

### **Basic facts of the report**

At present, some 120000 people have been on sick leave for a period exceeding one year. About a third of them have been on sick leave for more than two years.

Total sickness absence, including short and long-term absence, corresponds to 400000 person years and the numbers of people financed by disability pension add another 400000 person years. Absence from work due to ill health corresponds to some 800000 person years or *14 per cent of the working-age population*.

*The short-term absence has not increased* – today there are not more persons on short-term sick leave than five years ago.

*Women count for two thirds of the increase*. However, there is no medical explanation to this overrepresentation in sick absences of women.

*The proportion of people on sick leave differs* between various sectors of the labour market. Illness related absence is extremely high among municipal and county council employees, while central government employees are at the average and the private sector employees about 20 per cent lower than the average. In towns and cities and at county councils responsible for health care in Sweden the majority of the employees are women. There are also surprisingly differences in relative sick leave figures between towns and cities, which cannot be explained by demographic factors such as age or other factors as education etc. Also between similar organisational units within a town or a city, there are differences in sick absence. These differences cannot be explained by individual differences in health status of the people employed.

Looking into the private sector you will find the same kind of distribution. The 25 per cent of companies (working places) with the lowest sick absence have an absence rate of only 1.72 per cent compared to the 25 per cent at top with an absence rate of 9.2 per cent as an average.

Another remarkable finding was that the *rate of sick leave absence increased with the size of a company*. Small and medium sized companies had a much lower rate compared to big companies and organisations.

## **Conclusions and suggestions**

The most important conclusion of the study is that there is no significant support for the generally accepted assumption that the increase in sick leave absence mainly is due to differences in individuals employed may it be medical, psychological, social or “moral” factors. With “moral” factor I mean for example willingness to work or, its opposite, willingness to “cheat” the system. Nor has there been any change during the period studied in the compensation level. To clarify, Sweden has not a more favourable compensation system than other European countries with much lower figures of people on sick leave.

The Commission presented its final report in January 2002 with a number of proposals to the Swedish Government. On a more general level, the Commission suggested that the insurance system should be changed and based on more marked oriented principles. The period during which the employer pays the sick pay should be extended to 60 days. The health insurance charge (financed as a social “tax” paid by the employers) should be reduced corresponding to the increase of sick pay costs. This suggestion created a big debate and was opposed by both employ-

ers' organisations and trade unions. However, the Government, especially the Finance Ministry, has not turned down the idea of giving the employer a more direct financial responsibility. The Government considers even "harder" alternatives. In a paper presented by the Finance Ministry, it is argued that the current system does not give enough economic incentives. It is proposed that all employers starting with the public sector should pay a considerable part (about 25 %) of the sick pay up to one year. It has been announced that a Government bill will be presented to the Swedish Parliament in March 2003.

The Commission further recommended that administrative changes should be made, stressing the importance of the employer taking the first action in order to give the employee possibilities to go back to work as soon as possible. It is extremely important that the employer adapts the working conditions in such a way that the employee could work even if he or she cannot work effectively for a shorter or longer period. The employee should of course have an appropriate medical or/and social rehabilitation but there is always a possibility to "rehabilitate" the working place, the tasks and the organisation. If the employer does what is needed there is of course a corresponding obligation for the employee to go back to work. For companies and authorities this would in the end be a "cheaper" solution compared to the current system, which creates abnormal sick leave figures and a corresponding high social tax level. For the state budget, such a system would take away a substantial burden.

The doctor plays an important role when meeting his client. The doctor certifies that his client needs to rest from work. It is a widespread assumption among the public, doctors as well as their clients, that an illness or disease certified by a doctor should be accompanied by a sick-pay period. However, current regulation says that the doctor should rather certify what type of work that could be done during a shorter or longer period of illness. Studies in Sweden show that a long passive sick leave period in the majority of cases rather prolongs the illness and makes it even more difficult to go back to work. The Commission recommended that the education of doctors should include those findings and that more regularly use of part time sick leave is a better way of rehabilitation. However, it is important that this change in attitudes and routines should be accompanied with a better accommodation of the working place.

It was also recommended that all authorities, companies or organisations should present their relative figures on sick absence in their annual reports. The Swedish Parliament has already adopted this proposal and a new law will take effect from

1 July 2003. Accordingly, in 2004, media will publish comparisons, listing for example the sick leave figures of the 10 top companies noted on The Stockholm Stock Exchange, or the ten top big cities etc. This benchmarking is expected to give interesting incentives to employers with high figures to do better in the coming years.

It would go far beyond the time frame for this presentation to comment on all proposals of the report. I have tried to concentrate on the basic facts and principles, which I hope could serve as a basis for discussions and changes of experiences at this conference.

Sweden will strengthen the emphasis on work-oriented rehabilitation. Sick benefits and disability pensions are not regarded to be part of the benefit system. It is an insurance system to cover loss of income. Personally, I agree with the policy conclusion presented for theme 5. "Existing employer-employee relationships should be utilised as much as possible, both through positive incentives and through mandated obligations." The figures of sick leave in Sweden could serve as warning. It will take some hard years for Sweden to return to a 50 per cent lower level – a goal set by the Swedish Government.

## *The New Benefit Strategy Being Implemented in Luxembourg*

*Raymond Wagener*

### **1) Why a reform?**

In 1987 the Luxembourg Pension legislation of blue- and white-collar wage earners and self-employed workers were unified into a General Pension Scheme. Only civil servants and workers assimilated to civil servants belong to other pension schemes. The reform introduced the following common definition of a disabled person:

“An insured person who, as a result of prolonged sickness or disability, has lost the working capacity to such a degree that he/ she is unable to carry on the occupation of the last post or another occupation suited to his/her capacity.”

During the first years after the 1987 unification law the disability definition was interpreted broadly as giving a right to a disability benefit to workers unable to keep their last job because of a lengthy sickness or a disability, without referring to the global situation on the labour market. As a consequence the number of beneficiaries of a disability pension increased substantially. But over the years until 1996 several court rulings determined firmly that disability has to be defined by taking into account simultaneously the two criteria stated in the law: is the concerned person unable to go on working at his or her last job and is he or she able to work at another job? Due to these rulings the number of new beneficiaries of a disability pension decreased considerably, but at the same time some persons became exposed to the risk of falling out of the social security safety net. These were workers who were no longer able to return to their last job, who lost the right to the sickness benefit that is limited to a maximum of one year, and who were unable to find a new job, or who managed only to find a job with a very low wage compared to the one they had at their previous job.

In a first approach the Government proposed to introduce a two level disability pension system with a general disability pension benefit and a professional disability pension benefit reduced to 50% of the general disability benefit. But the

main trade unions categorically refused this proposal, because they were afraid that such a two level disability benefit system would not avoid the poverty trap for workers only entitled to a professional disability pension benefit. Thereupon the Government abandoned its proposal and convened in 1999 a tripartite working group of representatives of the ministries of labour and social security, of the trade unions and the employers. The group worked out a new proposal introducing a reinsertion grant instead of the professional disability pension benefit, combined with rehabilitation and reinsertion procedures. Unfortunately the working party did not reach a common agreement among its members. Nevertheless the Government worked out a new proposal based on the discussions of the working group that was finally voted by Parliament in 2002 and is applicable since October 2002.

## 2) Description of the procedure

The new law on work disability and professional reintegration is meant to improve the social protection of the workers who have been become unable to continue working at their last job and who nevertheless are still not entitled to a disability pension, because they are not disabled according to the disability definition of 1987 which defines disability with respect to the entire labour market. The reform introduced two complementary measures to improve the social welfare of these workers:

- *Redeployment measures* within the firm or on the general labour market so that these workers may continue participating in the labour market;
- *A compensatory allowance* in the case where the new wage is less high than the former one, and for workers who are no longer entitled to the unemployment benefit and who have not been redeployed to a new job, a *waiting allowance*.

It is of course important to start the redeployment procedure as soon as possible and not to wait until the end of the sickness leave. Therefore every worker on a prolonged sickness leave is examined within the first four month of the leave to determine if he or she is still unable to work because of his or her illness. If the worker is found able to return to work, sickness benefit payments are stopped (and administrative procedures in case of contest are accelerated). If the examination shows that the sickness is likely to continue, another examination is scheduled at a later date. If the worker applies for a disability pension benefit, a medical examination will determine if he or she is disabled according to the 1987 definition. If this is the case, the work contract is dissolved and the worker is entitled to the dis-

ability pension benefit. If this is not the case, the occupational medical service will determine if he or she is able or not to continue working at the same job. The redeployment procedure is started in the case the occupational medicine examination concludes that the worker is no longer able to keep his or her job.

The redeployment of a worker may be:

- *Internal redeployment* within the same firm but at a different job or on different work conditions, or
- *External redeployment* on the general labour market.

The redeployment of a worker is decided by the *Joint Commission* composed of representatives of the insured persons, the employers, the Medical Control of Social Security, the Occupational Medicine Department of the Health Ministry, the Labour and Employment Ministry and the Employment Administration.

Internal redeployment of a worker is compulsory for companies with more than 25 workers and which have not yet fulfilled the legal measures concerning the employment of disabled persons. The employer is entitled to special support as well as special tax deductions. On the other hand sanctions (half of the social minimum wage during a maximum period of 24 months) may be imposed on employers who fail to comply with their obligation to internally reclassify their disabled workers. If the wage at the new job is less than the previous one, the Employment Fund pays a *compensatory allowance* to make up for the difference (up to five times the social minimum wage). In addition, the redeployed worker enjoys special protection from dismissal during one year.

If the internal redeployment of a worker is not possible, he or she is registered at the new Department for workers with reduced work capacity of the Employment Administration as a job seeker. If this department can find a suitable job, disabled workers and their employers are entitled to the same benefits as in the case of internally reclassified workers. Compensatory benefits are calculated according to the previous wage and regardless of the level of unemployment benefits the worker received in the interim.

A worker who could not be redeployed to an alternative employment during the legal duration of unemployment benefit payments is entitled to a waiting allowance, which corresponds to the level of a disability pension. The disabled worker, however, has to remain available for any job placement attempts and the waiting

allowance will be stopped once a suitable occupation is found. The waiting allowance is not paid by the Labour Fund, but by the pension insurance scheme.

### **3) On what depends the success or the failure of the reform?**

The implementation of the reform on work disability and professional reintegration started only in October 2002, so that it is far too early to make an evaluation of its success or failure. Nevertheless from the description of the redeployment procedure it seems obvious that it is an ambitious reform, which depends on the active collaboration of the concerned workers, the employers and various administrations. Some of the conditions of the success of the reform are the following ones:

- The role of the Joint Commission is absolutely essential for organising rehabilitation and reintegration measures and for deciding a successful redeployment of workers to new jobs adapted to their capacities.
- Of course jobs have to be available and adapted to the capacities of the concerned workers: this is only possible if it is an important social concern of the employers to foster the employment of disabled persons.
- Redeployment of workers to new jobs needs an efficient system of rehabilitation, retraining and reintegration measures.
- Occupational medical services and the Employment Administration have to play an important role in helping disabled workers to find a suitable work place.
- And of course nothing is possible without the active commitment of the workers to find a suitable job, and to prepare themselves to it through an active participation in rehabilitation and reintegration measures.

## *Reflections on Disability Based on my Comparison of 19 Countries – Rich Democracies: Political Economy, Public Policy, and Performance*

*Harold L. Wilensky*

1) *Work oriented rehabilitation vs. passive income replacements* (treating the disabled as if they are unable to work). Passive benefits are a bad idea not only for disability policies but for unemployment insurance (vs. an active labor market policy) [ALMP]) and public assistance (vs. a universal family policy including child care, parental leave, housing and transportation help and earned-income supplements). Heavy means-testing in all these programs creates political resistance to funding them at an adequate level. The distinction between divisive means-testing and simple, quiet income testing is important. By “means-testing” I mean (1) noncategorical benefits targeted to the poor via a stiff income- and/or assets-test, (2) applied by welfare administrators with substantial discretion, (3) with a high probability of stigma. “Income testing” is the opposite. It is categorical as a social right with co-payments graded by income bracket and, because it is private and invisible, has no stigma. Although the disabled are certainly not as unpopular as the nonworking, nondisabled, nonaged poor, the principle holds: Highly visible, highly targeted benefits for any handicapped population will be less adequately funded than either universal benefits or quietly income-tested work-oriented benefits. The political effects of means-testing (tax-welfare backlash) are reinforced if the visible benefits are seen as lavish or result in too many inequities as is the case for some of the disabled.

“Partial benefits may become an easy bridge into benefit dependence” (OECD themes, p. 5) only if you require nothing in rehabilitation, training/education, therapy, etc. I would not “use the philosophy of unemployment programs” (OECD, p. 3) as a model. With only a few exceptions, rich democracies are quite passive in these programs, not active; they cannot successfully tie benefits to participation in active labor-market programs because the latter are non-existent or poorly funded or poorly organized.

The problem of reintegration in the labor force and workplace, *applying sanctions without forcing the disabled into inappropriate work or into poverty. Solving this problem of the right to cash and services vs. the obligation to work highlights the interdependence of separate clusters of public policies.* Success in that balance for the disabled, as for other vulnerable populations, depends on the existence of serious support for ALMP, including job creation; and a wage structure that does not impoverish low-paid workers (e.g., ensuring a high minimum wage via laws, executive enforcement, collective bargaining, and subsidies to low-paid or short-hours workers); and fiscal and especially monetary policies that are pro-growth. Finally, without universally effective schools on which to build, no program designed to rehabilitate, train, and place the disadvantaged in a modern economy - - the chronically unemployed, the disabled - - will be very effective. Policy linkages directly affecting the disabled can best be achieved with a centralized “one-stop” service coordination agency (OECD Theme 3). If there is a strong labor-market board (Sweden, Germany) this agency can be lodged there, so maximum information about work can be readily tapped and a work orientation emphasized.

3) “Unbundling” disability status and benefits of medication, care, or transportation, another good OECD idea (p. 1), depends on the avoidance of means testing for both cash benefits and service delivery. Both cost containment and “individual participation packages” (fitting the highly diverse needs of various types and degrees of disability) are best accomplished by combining universal rights and light income tests, the simpler the better. The model might be another population that has proved popular - - working parents. The leading nations in publicly subsidized childcare generally provide childcare services categorically as a social right with graded co-payments to constrain costs and make the spending politically acceptable. The principle might be applied to the disabled: Everyone in the category should be assured of a minimum income that increases with increments of impairment. If the total cash income of the household is quite high, an income test should be applied, as with the universal right of working parents to costly daycare for their children. The income test, if any, should be applied to the household income of the disabled, not to all nonresident ascendant and descendent relatives. The package of services relevant to the condition of the recipient, however, should be separate from any income test and administered without an elaborate investigatory and surveillance apparatus. Periodic review should not degenerate into sustained harassment. (Incidentally I see no solution to the notoriously slippery definitions of “disabled”. The invalidity of clinical diagnoses is apparent everywhere - - one reason the growth in these programs seems unrelated to the incidence of real disabilities.)

4) *Country Variations* Four countries illustrate these themes of active work orientation, balancing rights and obligations, the interdependence of social, economic, and labor-market policies, and “unbundling” - - The Netherlands, Sweden, Germany, and the USA. For the cost conscious, *The Netherlands* until the mid-1990s was the symbol of what not to do: the combination of wildly loose definitions of disability, indulgent administration, and an almost exclusive focus on passive cash benefits made it tops in total disability claims and spending, with the lowest average age of first-time claimants (42 yrs. old), and the lowest labor-force participation rate of 55-64 year-old males. A high unemployment rate did not help. *Sweden* is the opposite extreme: Although it does not run up the total bill as much as the Netherlands, it is tops in interrelated work-oriented rehabilitation, ALMP, and family policies designed to facilitate work; the result is the highest rate of labor force participation for all adults - - and three times the Dutch rate for age 60-64. The *Germans* are in the middle: they combine the Swedish accent on rehabilitation for work with cost control. However, offsetting their incentives for work and rehab, they encourage early retirement by giving unemployed workers over 60 full disability. So their disability recipients/1000 60-64 year olds in 1990 was almost twice the Swedish rate. The *USA*, for various structural reasons, keeps marginally productive workers, including the disabled, at low wages in a market-driven system. There is little connection between clinical disability evaluation and job finding services (meager effort at ALMP). Periodic and erratic efforts to crack down on rising costs bring loud protests, much judicial action (adversary legalism), and a rise in spending but little rehab and job creation for the disabled.

## OECD Key Issues and Policy Conclusions

### *Theme 5: What Should and What Can Employers Do?*

#### **Key issues**

Often systems make it too easy for employers to use the disability benefit scheme as a workforce management tool. The result of this is a large number of older workers permanently leaving the labour market through such benefits.

Employers are usually not sufficiently involved in the (re)integration process of their own and other (potential) employees. In few countries are employers given any role in the process of vocational rehabilitation and training, and mandates to accommodate work or the workplace are also exceptional. Where they exist, they are rarely effectively enforced.

Obligations to pay sick leave or continue (full) wage payment during a certain period of sickness absence are more widespread, and are meant to encourage employers to invest in preventive measures.

Different employment promotion policy approaches have similar effects. Whether policy is rights-based (anti-discrimination legislation), obligations-based (employment quota) or incentives-based (voluntary action), it is predominantly current employees who receive protection, not those seeking work.

Regulations which oblige the employer to make an effort for disabled employees are difficult to enforce, despite sanctions. Most regulations contain wording that is open to interpretation, and it has to be determined from case to case what constitutes undue hardship on the employer or whether it is impossible to accommodate a person's disabling condition in the company. Fines are often so low that employers may find it easier to pay than make any effort.

## **OECD policy conclusions**

Existing employer-employee relationships should be utilised as much as possible, both through positive incentives and through mandated obligations. Involving the employers is crucial for the (re)integration of disabled persons.

The effectiveness of any measure will depend on the willingness of employers to help disabled persons stay in or enter work, and on possibilities of circumventing legislation. Proper sanctions for employers not fulfilling their obligations and adequate instruments to implement these sanctions are important. It is the existence of these two elements which could guarantee that either anti-discrimination laws or mandatory employment quotas are effective in requiring employers to satisfy their responsibilities.

To strike the balance between promotion of employment and imposing undue hardship on employers is a major policy challenge. Special attention needs to be given to the fact that retention measures can lead to discrimination of those disabled persons seeking work.

Therefore, it is essential to recognise that employers need help to fulfil their obligations. Workplace and job adjustments generally require small financial investments. More crucial are technical assistance and guidance, assessment of the problem and development of an intervention strategy for the participation plan.

Employers who make an effort to (re)employ disabled persons should not be penalised financially vis-à-vis employers who fail to make an effort.

## *Transforming Disability into Ability – What Can Employers Do? Adapting Modern Work Organizations?*

*Philippe Askenazy*

The outflow from disability benefits remains extremely low. In the same time, despite the reforms affecting benefit access, the inflow rate was stable in the last decade; in addition, the proportions of mental disability and of ex-working recipients, and the number of early retirements have increased. This evolution is consistent with trends shown by the working condition surveys (e.g. European survey, Dublin Foundation): workers report higher mental strain and also increasing physical constraints on their workplace; In European countries, the number of cumulative trauma disorders (CTD) has dramatically jumped. However, these phenomena can seem puzzling because jobs are more and more concentrated in tertiary activities and mainly because the development modern workplace practices – multitask jobs, job rotation, quality management...- should improve quality of work.

In fact, existing literature in sociology or ergonomics have stressed that these workplace changes are not necessary virtuous and can lead to an intensification of work. There are also statistical evidences.

The French working conditions survey 1998 provides unique information for a large (20,000) and representative sample of labor force: workplaces practices, working conditions, mental strain (receive contradictory orders, isolation, tensions with colleagues, hierarchy, customers, time pressure...), occupational injuries, plus age, sex, nationally, education, seniority, family etc.... It enables us to perform robust statistical treatment. Even after corrections of selection bias, innovative practices such as job rotation, quality norms, and working time flexibility are each associated with about 20% additional mental strain and occupational benign injuries.

These results on France confirm finding on specific industries (e.g. car manufacturing in Canada), or using establishment data. They suggest that it would be worthwhile to focus more on health and safety when implementing innovative organiza-

tion in order to not discourage some disability benefit recipients and to reduce the flow from work to disability.

Actually, connections between organisation and damage on safety or health should not be a fatality. First, the French survey also proves that “net” technology can improve well-being at work by facilitating communication and reducing isolation. Second, because of the pressure of insurance companies, of trade unions or of public stigmatisation, firms can be aware of this issue; the recent US experience shows rates of occupational injuries or CTD have dropped.

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## *The Decline in the Employment of People with Disabilities: A Policy Puzzle*

*Richard Burkhauser*

1) While the onset of a impairment or a serious health condition will have a significant impact on the employment of those with disabilities, the social environment the person with a disability faces at the time of onset will also significantly influence his/her subsequent employment or disability program participation.

2) In the United States the employment rates of working age men and women with disabilities, like those without disabilities, were pro-cyclical during the 1980s business cycle, falling during the years leading to the recession of 1982 and rising over the next seven years until the business cycle peak of 1989. During the 1990s the employment rates of men and women with disabilities fell between 1989 and 1992 along with the rest of the working age population. But over the next eight years of economic growth they continued to fall in contrast to the rest of the working age population and their previous experience in the 1980s. By 2000, the employment of men with disabilities was 25 percent below its business cycle high of 1989 and 20 percent below its level during the business cycle trough year of 1992.

3) Based on evidence in our book, I believe it is unlikely that this dramatic change in the employment patterns of men and women with disabilities was caused by increased severity in their impairments or health conditions. Rather it was caused by changes in the social environment they faced, most especially by changes in social policies. The main two changes in social policy were the passage of the Americans with Disabilities Act of 1990 (ADA) and the increased generosity and ease of entry onto to the Social Security Disability Insurance (SSDI) and Supplementary Security Income (SSI) programs.

4) Employers demand for all workers including those with disabilities is effected by general economic condition. Hence the employment of those with and without disabilities is sensitive to trends in economic growth and in the business cycle. But the relative level of employment of those with and without disabilities are also sensitive to how public policy impacts on their relative returns from working ver-

sus their returns from a movement onto the disability rolls and by the rules of employment under which firms hire workers including those with disabilities.

5) The Americans with Disabilities Act of 1990 which was first implemented in 1992 required firms to provide accommodations to workers with disabilities as long as they did not put an undue burden on the firm. Work I have done with several colleagues shows that before the passage of the ADA about 30 percent of workers who experienced a disability were accommodated by their employers and that these workers on average stayed longer on the job and delayed their movement onto the disability rolls. Hence any increases in accommodation by employers should have increased employment in the 1990s. But others have argued that an “unintended consequence” of this protective legislation is that employers will be less likely to hire those with disabilities to avoid the requirements to accommodate them. The evidence of the overall impact of this law on employment since its enactment is mixed. What is clear is that the ease of entry onto the disability rolls has increased (the acceptance rates of those who applied for SSDI and SSI benefits increased dramatically after 1989) and that is likely to have discouraged workers with disabilities, especially those who were unemployed from staying in the labor force.

6) Employers will voluntarily hire workers only if they believe it is in their interest to do so. In the United States, programs like the Earned Income Tax Credit which subsidize work both encourage workers with low skills who live in poor families to work and make them more competitive in the private labour market by not requiring firms to pay them more than the value of their work. This is a creative way to use the voluntary mechanisms of the private market to increase the employment of low skilled workers. Expanding this type of program to low skilled workers with disabilities is likely to increase the employment of such workers and is both an alternative for the segregated supported work of sheltered workshops (it subsidizes the worker and not the workplace) and provides an income alternative to needs tested programs like SSI that provide full benefits on the condition that those with disabilities do not work.

7) Programs that rely on employer cooperation to increase the employment of those with disability are likely to be more effective in gaining that cooperation if they use government funds to offset the additional cost to employers of employing workers with disabilities rather than imposing those costs on employers via regulation.

## *What Can Employers Do?*

*Hartmut Haines*

Newly introduced or strengthened obligations and incentives for employers towards disabled employees in Germany

- integration services in every district to support employers and employment services in „problem cases“
- benefits for necessary workplace assistance
- part time work for those who need it because of their disability
- easier administration of integration benefits
- more influence for shop floor representatives of severely disabled persons
- reduction of the quota for the employment of severely disabled persons from 6 % to 5 % if the number of unemployed severely disabled persons could be cut by 25 %
- different compensatory levy rates according to quota fulfilment
- campaign „50,000 jobs for severely disabled persons“

First experiences with those regulations

- 150,000 new jobs for severely disabled persons within 3 years, 55,000 of them with financial support
- unemployment of severely disabled persons cut by 45,305 (from 189,766, October 1999, to 144,461, October 2002)
- development of unemployment rate for severely disabled persons better than for other groups

## *How to Get Employers to Take on Greater Responsibility for the Inclusion of People with Disabilities in Working Life?*

*Bjørn Hvinden*

Briefly, the situation in Norway seems paradoxical in the sense that available evidence (e.g. the coming OECD report on Transforming Disability into Ability and OECD statistics on the labour market participation of people 55+ years) suggests that a comparatively high percentage of disabled people are in employment, while the rate of people of working age in receipt of disability pension is also higher than in most other countries. Moreover, detailed studies of the use of available policy instruments and the experiences of people with disabilities indicate that there is a substantial scope for improving employment opportunities and prospects. I think there are three important preconditions that need to be fulfilled in order to achieve this improvement.

1) *Meeting the challenge of designing, implementing and enforcing appropriate measures to make employers take on greater responsibility for workers with disabilities.* Since 1978 there have been legal provisions in Norway that appear to give the employer quite strong obligations for the practical adjustment or accommodation of working conditions for employees that have become disabled while working for this employer. On closer examination the obligations turn out to be less clear and straightforward, using formulations giving wide scope for discretionary judgments. More significantly, successive governments of different political colours have been hesitant or reluctant to provide binding regulations that stipulated more explicitly under what circumstances (e.g. in terms of financial costs involved) employers are supposed to undertake on-the-job accommodations. Given this, it is not too surprising that the body responsible for supervising on the practical follow-up of the legal provision, the Directorate of Labour Inspection, has not made very strong attempts to enforce employers' obligations in practice. To put it crudely, one may question whether this part of the act was ever implemented or enforced. Relatively few cases have been taken to court, litigants have rarely been successful, and the organizations of disabled people have generally advised members not to file complaints because of the risks for losing their case. It is possible

to draw various lessons from this situation. One is that Norwegian political authorities have not really wished to challenge the steering prerogatives of employers regarding issues internal to the firm, as these prerogatives have become understood within the Norwegian system of corporatist industrial relations and collective agreements between employers and trade unions. In other words, one is not likely to make progress unless one acknowledges that there may be conflicts of interests in this area, not only between potential or actual employers and the individual with disabilities, but also between the latter and the majority of “able-bodied” workers in the firm. If there is not will to acknowledge this conflict and adopt the appropriate legal instruments to handle it, the two remaining types of policy instruments, economic support like wage subsidies and communicative means like guidance, information and persuasion, will only be partially successful.

2) *Finding arrangements for the sharing of costs related to on-the-job accommodation between the individual employer and the government (“society”)* Under the main social security scheme in Norway there have been legal provisions to provide financial support to finance or reimburse a part of the costs involved in on-the-job accommodation for workers with disabilities. The rules are designed to complement the other legal provisions referred just a minute ago, giving the employer an obligation to accommodate the workplace to the requirements of an employee with disabilities. However, on closer examination it appears that there has clearly been an underuse of the financial support available under the national insurance scheme. This seems partly to have caused by an overzealous effort within local offices of the National Insurance Administration to prevent abuse of public funds. Partly there seems to have been a lack of co-ordination between the Directorate of Labour Inspection and the National Insurance Administration on how to promote an appropriate use of available resources, that is, facilitate on-the-job accommodation in circumstances where the full costs involved would represent an unreasonable burden for the employer. As a result, local level staff within the Labour Inspectorate appeared to lack basis knowledge about this possibility. Finally, there are reasons to assume that the weak legal obligations enforced on employers have weakened their incentive to pursue the possibility of obtaining public support that could have facilitated a return to work for employees who had become disabled.

3) *To develop our understanding of what on-the-job accommodation will imply in a working life moving towards more highly qualified services work and “greedy” work organizations.* On the basis of our study of the unsuccessful implementation of the two legal provisions outlined above we have seen a need to question the way

in which accommodation in the workplace is described and illustrated in the existing guidance from the responsible agencies. There is a very strong emphasis on physical access to buildings, physical or ergonomic adjustments in the work situation, the adoption of adjusted technical equipment, possibilities to regulate your work speed, take breaks, working shorter hours, etc. Obviously there is still a lot to do in this area before one has achieved a satisfactory situation. Yet, a growing proportion of the jobs available in the emerging working life are of a nature where these factors just mentioned are not the main barrier for allowing people with disabilities to work there. Rather, the jobs are less well-defined than traditional jobs, there are not clear boundaries within what you have to do and what you could do, while others may be depend on the results of your work, before they can get on their tasks, etc. In the future development of disability policy we need to give more attention to what reasonable on-the-job accommodation may imply in the emerging new working life, if we are to avoid that people with disabilities will be further marginalized in employment.

## *Role of Employers in Transforming Disability into Ability – The Dutch Experience<sup>1</sup>*

*Rick van der Ploeg*

The Netherlands has a relatively large number of people on disability benefits ('wao'). In the eighties there were 16.6 per 1000 insured entering the ranks of the disabled (only 8.8 in Belgium and 9.5 in Germany) and in the early nineties 5% of GDP was spent on disability benefits (2.2% of GDP average for the EU). The inactivity ratio for the population under 65 (persons on various kinds of benefit and without work divided by employment) is 0.8; average in Europe due to the relatively low unemployment rates. However, the share of sick and disabled people in total benefit years is at 61% extremely high (16% for Belgium, 30% for Germany, 26% for Great Britain, 27% for France).<sup>2</sup> The Netherlands has an excellent health system, so it seems unlikely that it is much more sick and disabled than the rest of Europe. The same comment applies to Norway, Sweden and to a lesser extent Denmark.

Many have argued that disability in the Netherlands is often disguised unemployment as a large proportion leaves the labour market permanently through such benefits. Workers prefer the higher and longer-lasting disability benefit to the unemployment benefit and firms find it an easy and cheap workforce management tool to get rid of less productive and older workers. The two most prevalent causes of disability are psychiatric and back problems, which are more difficult to diagnose and thus more open to manipulation the critics argue. Rather than slashing the duration and level of disability benefits (70% of wage but often raised through collective bargaining) attention should be focused on having and tough and just eligibility requirements and on encouraging investment in (re)integration of persons with a work handicap without imposing undue hardship on employers.

Since high incidence of sickness implies a high incidence of disability, policy to transform disability into ability must focus on preventing and reducing sickness as well. The following policies are designed to stimulate employers to take their responsibility in transforming disability into ability in the Netherlands:

## **A. Avoiding free riders**

Bargaining at a central level between employers, employees and government can play a crucial role both in preventing disability and in reintegration of disabled workers. Agreements to avoid sickness among employees and to get sick employees back to work again ('arbo-convenanten') are crucial in preventing sick people sliding into disability. Also, agreements to not under all circumstances pay sick employees the full 100% of the wage they last earned seem to help.

Extending coverage of collective bargaining outcomes between employers' federations and trade unions so far only played a marginal role, since there were few and non-measured collective agreements about reserving jobs for disabled persons, stimulating reintegration, etc. From 2003 onwards the employer is responsible for reintegration, including vocational rehabilitation and training, with other employers as well as within the own company. Extending coverage can apply to the duration of the reintegration track with other employers and contents of contracts with reintegration companies, albeit that an employers must always have a choice of reintegration company.

## **B. Sticks**

Differentiation of disability insurance premiums ('pemba') punishes employers who have a lot of employees becoming disabled. Firms have to pay for a period of 5 years a substantial part of the costs of the disability arising in their firm, so firms have a strong financial incentive to prevent disability and to re-employ disabled workers. Of course, there is an offsetting effect as firms may be more hesitant to hire job applicants who are more likely to become disabled. This policy is only in full operation from 2003 onwards, but signals so far suggest that this policy encourages firms to transform disability into ability.

Employers normally have an incentive to invest in measures preventing sickness, because they have to pay sick workers full pay for a maximum of a year. If employers do too little to reduce sickness among their employees, they can get sanctioned by having to pay the wage of sick employees for longer than a year with a maximum of two years ('Wet verbetering poortwachter'). There are stiff fines, but it is too early to tell whether this policy will be properly enforced, let alone whether it helps.

Sick employees who try to get reintegrated cannot be fired for two years. If they become fully disabled after a year, they get a disability benefit and leave the firm. Making it more difficult to fire partially disabled people encourages employers to find suitable work for them, but also makes them more hesitant in hiring new employees with a higher chance of becoming sick and disabled. To avoid this type of adverse selection, employers do not incur any financial risk if they hire registered people who are handicapped for work (registered disabled and others that are designated as such).

### **C. Carrots**

Employers who keep employees (or hire applicants) with a work handicap in service can receive a one-off reduction of 2.042 euro (or at most three yearly reductions of 2.042 euro) on their sickness and disability insurance premiums. If the adjustment costs for such employees (schooling, training, coaching, help of such employees, making the workplace suitable, etc.) are higher, they are eligible for an extra subsidy. Employers also receive half of the costs of a reintegration trajectory to another employer and the other half when the employee with a work handicap gets a job of at least half a year. Employers who take on a person with a work handicap receive a no-risk insurance contract, i.e., when such a person becomes sick or disabled during the first five years the employers does not have to continue paying their salary or to pay higher disability insurance premiums, respectively.

Employees with a work handicap are entitled to facilities to keep or return them to work (e.g., transport, communication, workplace alterations which can be moved to another employer).

### **Conclusion**

A large part of the costs of transforming disability into ability are reimbursed for employers, free rider behaviour is punished, and the coverage of collective agreements that help are extended. Policy seems to be incentive-based (anti-discrimination legislation) and incentive-based (encouraging voluntary actions) rather than obligations-based (quota). Protection seems to cover existing employees rather than those disabled seeking work. Such protection may, in fact, be counterproductive as firms become more hesitant in taking on persons with a work handicap. However, employers who are effective in transforming disability into ability have a

competitive advantage over other employers as they are entitled to various government subsidies (for training, coaching, workplace adjustments, etc.), face lower costs (less sickness pay, lower disability premiums) and enjoy better work morale. Enforcement of actions announced in collective agreements seem difficult to monitor and enforce, also as they are often imprecisely worded. Nevertheless, the role of employers and tri-partite bargaining is crucial for the (re)integration of persons with a work handicap.

## Notes

- 1 I am extremely grateful for the help and advice I have had from Michel Rovers and his colleagues of the Ministry of Social Affairs and Employment in preparing this intervention.
- 2 There is some evidence, however, that some disability is disguised as pre-pension in France, unemployment in Belgium and welfare in Great Britain.

*Special Theme:  
Barriers to Participation*



## *Le changement de mentalité nécessaire de la société vers les possibilités d'emploi des personnes handicapés*

*Luis Cayo Pérez Bueno*

- L'emploi est un des facteurs préférés de socialisation et participation ordinaire dans la vie communautaire. Pour les personnes handicapées, l'importance de l'accès au marché de travail est redoublée par rapport aux autres, puisque l'emploi signifie vie privilégiée de participation sociale. Sans avoir un poste de travail il s'avère très difficile de vivre une vie autonome et de décider par soi-même. Sans emploi, les personnes handicapées se sont mises dans une situation de dépendance, à l'arbitre de la famille ou des pouvoirs publics et toujours en permanent péril de marginalisation et exclusion sociale.
- La situation de l'emploi des personnes handicapées en Europe est loin d'être satisfaisante et indique clairement qu'il s'agit d'un groupe avec un certain risque d'exclusion. L'accès à l'emploi des personnes handicapées est plus bas que celui des non-handicapés (taux d'activité moins importants) et ils souffrent des niveaux de chômage beaucoup plus élevés. La qualification et les niveaux salariaux des encore très peu nombreuses personnes qui aboutissent à l'accès à un poste de travail sont très inférieures à la moyenne des travailleurs non handicapés.
- L'incorporation des personnes handicapées au marché de l'emploi exige la volonté décidée et l'action énergique des pouvoirs publics, les agents sociaux, la société en général, ainsi que, et très spécialement, des personnes handicapées, qui doivent convertir en les acteurs principaux, les agents de sa propre insertion.
- Dans cet état des choses, qui empêche l'écartement injustifié de presque un 10% de la population de la société à laquelle ils sont légitime pour faire partie, en égalité de devoirs et obligations, il s'avère nécessaire l'adoption des mesures actives pour promouvoir le rapprochement de ce groupe de population au marché de l'emploi, leur permettant de contribuer avec son effort à la richesse de ses pays et au développement de la communauté à laquelle ils appartiennent.
- L'ensemble de la société doit surmonter et mettre à l'écart définitivement les préjugés existants sur le handicap. La personne handicapée est **aussi** un

citoyen de la société, avec ses particularités, et son importance ne doit être que celle de se voir compensées quand ils représentent un désavantage, inégalité ou manque d'opportunités.

- Les employeurs doivent avoir pleine conscience des capacités de travail, et offrir des opportunités d'emploi aux personnes handicapées. En outre, ils doivent les encourager à avoir comme exemple aux entreprises qui ont déjà essayé ces mesures d'insertion au marché d'emploi avec des résultats positives. Il faut voir à la personne handicapée comme étant un être humain avec capacités et habilités, et non une personne limitée.
- L'inégalité de traitement, ou plus directement les actions de discrimination qui souffrent ou puissent souffrir les personnes handicapées dans le processus d'intégration dans le marché de l'emploi ou pendant sa permanence dans celui-ci doit être interdite, poursuivies et punies par la Loi et le Droit, étant donné qu'ils constituent des violations des droits reconnus à tout le monde. Il est urgent que tous les pays de l'Union Européen conforment sa législation à la Directive du 27 novembre 2002 sur l'égalité de traitement en matière d'emploi et de travail, qui doit encore être mise en oeuvre dans assez d'Etats. De cette façon que des personnes handicapées et ses organisations représentatives puissent avoir des mécanismes effectifs de défense et y tutelle contre les actions discriminatoires dans le champ de l'emploi, l'occupation et la formation.
- Il faut faire une appelle aux personnes handicapés et aux organisations représentatives pour qu'elles prêtent une attention spéciale à leur formation, provenant des pouvoirs publics, à fin d'obtenir une bonne qualification et avoir des possibilités d'intégration laborale comme les autres citoyens.
- En ce qui concerne les personnes handicapés qui ne puissent pas travailler ou ont une capacité sociale limité, les pouvoirs publiques doivent garantir la protection sociale ou des formules sociolaborales (emploi protégé) adaptés à ses circonstances.
- La célébration, en 2003, de l'Année Européenne des Personnes Handicapées, représente une opportunité formidable pour adopter des mesures ambitieuses en faveur de l'intégration au marché du travail des personnes handicapées.
- Les organisations d'entreprenneurs et les syndicats, effectuant le rôle fondamental qui ont comme agents sociaux dans la régulation du marché de travail à travers les négociations collectives, doivent s'engager sérieusement à surveiller l'accomplissement de la législation laborale et sociale pour améliorer l'accès à l'emploi des personnes handicapées..

- L'emploi protégé est une formule d'accès et insertion sociale pleinement valide, que s'occupe de la demande d'emploi de beaucoup des personnes handicapées souffrant de difficultés spéciales.
- La situation sociale des femmes handicapées, souffrant des taux de participation au marché d'emploi, ainsi que de chômage beaucoup plus négatives que ceux des hommes handicapés demande l'adoption des mesures d'action spécifiques de façon à que ce group soit un objective préféré des politiques actives d'emploi à développer à l'avenir.
- En outre, les politiques actives d'emploi développées les prochaines années doivent mettre l'accent dans la promotion de l'accès à l'emploi des personnes handicapés qui se trouvent dans une situation plus grave d'exclusion du marché de l'emploi, telles que les handicapés intellectuels, les personnes très gravement handicapées, les maladies mentaux, les personnes avec une paralysie cérébrale, etc.
- Les nouvelles technologies, utilisées d'une manière intelligente, sont un allié naturel de l'intégration sociale des personnes handicapées. Il faut absolument lutter pour empêcher que les nouvelles technologies non accessibles ou dessinées sur la base des critères d'exclusion en deviennent une brèche qui écarte encore plus aux personnes handicapées de l'emploi et des possibilités vitales et existentielles que celui-ci offre.

## *Mental Barriers in General Labour Market Policy*

*Mikael Klein*

The topic of this conference “transforming disability into ability”, puts the focus on an exciting challenge. From a labour market point of view, the challenge consists in creating opportunities for persons with disabilities, to change from being objects (targets for social welfare) to become subjects (citizens empowered by their own support).

Two years ago, the Swedish parliament adopted a national action plan for the disability policy, expressing the same ambition. This national plan is meant to influence all policy fields for the next decade, and is entitled “From Patient to Citizen”, which by its name catches the same idea as the topic of this conference.

However I would like to change focus for a moment, and instead apply the question on the labour market itself. We could start by asking ourselves about the condition of working life of today:

In Sweden we have a long political tradition of aiming for a high level of employment. Enforcing the possibility for every citizen to have a job and thereby their own support, has been a priority for all. Looking at the conditions of today, we can verify that unemployment rates of 4,3 % are quite low. Anyhow, a large number of the workforce of almost 6 million people is not participating in the job market.

For example, we have almost half a million people who are provided with early retirement pension. They are not in the labour market and do not have any impact on the unemployment rates.

In the last couple of years, we have had a rapidly increasing number of people suffering from long-term illness, which has lead to dramatically increased costs for the governmental finances. A large part of those being on sick-leave for long time, suffer from illnesses related to stress, mainly caused by their situation at work.

At the same time, we still have groups of people that are not fully allowed into the labour market, for example immigrants and persons with disabilities. As in other

parts of Europe, Sweden has the problem of an ageing population, which in a near future will create an urgent lack of labour force.

So, to sum up the analysis of the Swedish labour market of today:

We have a situation where different groups are excluded from the labour market, an increasing number of the working population getting ill because of their jobs, and at the same time a lack of working force entering the job market. From the Swedish Disability movement's point of view, we draw the conclusion that we actually have a "disabled" working life. Or at least we have a labour market that is unable to economise with the labour force.

With the challenge of transforming disability to ability, we can apply the question not only to persons with disabilities, but to the labour market itself:

How do we transform the labour market from the recent low ability into a working life capable of a healthy administration of the working force, including the ability to benefit from every single citizen's working ability?

Such a challenge demands essential changes in various fields of the working life. Our traditional understanding of working hours, working places and work organisation has to be redefined. If the labour market shall be able to safe guard the working capacity of every citizen, it has to focus on the varying conditions for individuals to carry out work. In that sense, we need a working life much more adaptable to different conditions within the manpower than today. Roughly speaking, we have had the same structure within our working life since the start of industrialisation. Even today the main idea is to get the manpower adapted to the conditions of the labour market in a much wider extent, than conversed.

Approaching the issue in such a different matter raises many questions: Is this approach really realistic or is it like reaching for Utopia? Who shall carry the responsibility for such a development? And above all, does every citizen really have a capacity to work that could be of use for society?

The last of these three questions is perhaps the most interesting, at least from an ideological point of view. The question puts our own view on people in focus.

Do we really believe that every person in our society, to some extent can carry out a job that is useful for others? If we are talking about the labour market of today, the definite answer to that question must of course be "No". Today there are many people who cannot manage a job, due to various reasons. It is hard to imagine how that would be possible for all, even with great measures of support to those who need it.

However, our belief within the Swedish Disability Movement is that each and every person actually has a capacity (and also a wish) to contribute to the benefit for the whole society, if given the chance and the right circumstances.

If we want to enclose every citizen of our society in an equal citizenship, we must guarantee equal rights for him. But not less important, every citizen must be prepared to contribute to society as well. Many people with disabilities are presently denied both their rights and duties that follow with complete citizenship. These incongruities are in the long run untenable for the prosperity and stableness of our society. Amongst the obligations for every citizen, there is the duty to work. This means that the society is obligated to create conditions for every citizen to be able to actually participate in the working life.

The United Nations Declaration of Human Rights is including the right to work besides other fundamental rights. To fulfil our obligations of the declaration, we cannot continue to create separate solutions in the labour market for people with disabilities. Neither can we do so in other fields of our society. A much better way to proceed is by trying to make the labour market itself adapted to all our citizens. In that way, we can be sure of a much more sustainable development of our working life and of society at large.

Well then, whose responsibility is it to ensure a sustainable development of the labour market? An easy answer to that would be that the responsibility lies on the employers. Of course they have an important role in the process as they are in charge of the conditions of each workplace.

But as we all carry similar cultural values and have similar views of the conditions of working life and the working capacity of people, we all have to be involved in a change of thinking. How often do we for example think about people with disabilities mainly as an asset to the workforce?

The main responsibility however lies on the power of the state. Despite everything, the state has through legislation and through the power of its authorities, the possibility to start a process of change. Our cultural values and how we look upon people with disabilities, has an impact on how policies are being designed. We shall not be naive and believe otherwise. Our common opinions, our prejudice etcetera, are shared by both politicians and employees of the governmental authorities working in this field. Our traditions and cultural values give us many benefits, but

are also creating mental barriers, both in disability policies and in labour market policies (which are of more concern in the context of this conference).

In the big political context, for example when the objectives for national or international labour market policies are being discussed, you very seldom find representatives of rare experiences involved in the process. Mainly the discussion includes different experts of that political field but lacks the variety of experiences needed to get a good result.

I would like to give you a highly topical example of this: Right now we are having a debate in Sweden about the increasing ill-health within the working life, and the government is fumbling for solutions that will straighten up the growing deficit of the national finances. They have put pressure on the parties of the labour market to find ways to prevent further increase of the problem. Unfortunately there haven't been any successes in that matter yet.

The Disability Movement haven't yet been invited into the discussion, and is probably not seen as having suggestions for feasible solutions.

And maybe we don't have the necessary solutions? We certainly don't have any hidden trump card, but the point is that our experience is not even asked for.

The issue of ill-health in the working life has now been a growing problem for the Swedish government during the past three or four years. I guess the Disability Movements experience of dealing with the issues of ill-health and working life for at least sixty years now, is considered too short a time to be worth asking for...

To end this intervention in a more positive tone I would like to conclude our point of view like this: We all have good intentions of solving different problems, but we easily focus on the matters that are different from the main stream. In matters of labour market issues, we try to find solutions for those who do not fit in. Instead we should try to find ways of broadening the labour market, making it possible for more people to actually fit in. If we could find ways to benefit from every citizens individual ability, we would get access to new experiences that we lack today. Amongst them the unique experiences that people with disabilities possess.

So, is this possible or is it like reaching for Utopia?

I think there is no objective answer to that question; we must all give ourselves the answer to that. Instead I would like to raise a counter question:

Can our society in the long run afford to abandon the diversity of knowledge and experience represented by our fellow citizens, might it be within the field of working life or in the matter of policymaking?

## *Moving towards Equality for Disabled Londoners*

*David Morris*

In 1981 I was contemplating why I was having such difficulty in getting a job and somewhere to live over a beer having just graduated and, probably emboldened by all the publicity around “the disabled”, somebody decided to engage me in conversation with my favourite chat up line of all time: “I’ve got a friend like you. He is a vegetable!” Two weeks ago probably emboldened by all the publicity around European year, while I was contemplating firefighting procedures, over a beer, somebody decided to ask whether they could borrow the ashtray on my table and then returned to the party sitting on the table behind me and loudly announced: “I’ve never talked to a cripple before. It wasn’t as scary as I thought!”

It is on these occasions when I realise that for some people I still continue to exist on another planet. The fact is when this attitude is linked into power; the amusing anecdote becomes a dangerous experience. When we move beyond the arts and access and being special and brave; When we ask questions and protest; when we want to be in control of our lives, when we start to affect other people’s “normality” the veneer starts to crack. The fact is that the experience of living as a disabled person in 2003 is still too often the experience of exclusion; the experience of humiliation; the experience of prejudice; the experience of discrimination. Disablism is alive and well and just as pernicious and damaging as racism and sexism and homophobia.

*(David Morris extract from a speech to launch GLA’s Disability Capital initiative)*

### **The Greater London Authority-what is it and what does it do?**

- The Greater London Authority (GLA) was created as a new form of strategic citywide government, consisting of an elected Mayor and a separately elected Assembly in 2000. The GLA stands apart from the London boroughs, looking at the needs of London as a whole and representing the city on a national and an international level.

- The Mayor is elected by the people of London every four years. The current Mayor is Ken Livingstone, who was elected in May 2000. The Mayor's powers and responsibilities are set out in the Greater London Authority Act 1999. the Act imposes on the Authority a duty to promote equality of opportunity for all persons irrespective of their race, sex, disability, age, sexual orientation or religion, to eliminate unlawful discrimination and to promote good relations between persons of different racial groups, religious beliefs and sexual orientation.
- The Mayor sets the budget for the Metropolitan Police Service (under the oversight of the Metropolitan Police Authority), Transport for London, the London Development Agency, the London Fire Brigade (under the oversight of The London Fire & Emergency Planning Authority) and the GLA.
- He is responsible for setting policies on transport, buildings and land use, economic development and regeneration, culture and the environment. He has a duty to promote the health of Londoners. He must ensure that all of the policies work together and that they benefit all Londoners.
- The London Assembly acts as a check and balance on the Mayor. Elected by the people of London, the Assembly consists of 25 members. Fourteen of the members are elected to represent particular areas of London. The other 11 are elected by a system of proportional representation and are known as Londonwide members. They examine the Mayor's activities, questioning him about his decisions and scrutinising his policies. They are also able to investigate other issues of importance to Londoners.

### **The Mayor's equality Vision**

To create a fair city, promoting social inclusion and tackling deprivation and discrimination

We will be an equalities champion and leader in:

- Promoting equality
- Challenging and eradicating discrimination
- Providing responsive and accessible services for Londoners
- Ensuring our workforce reflects the diverse population of London

## **The Social Model of Disability – a tool for understanding disability equality**

The GLA rejects the medical model of disability and accepts

- that disability is a social phenomenon
- that while many individuals have physical or sensory impairments or learning difficulties or are living with mental health needs, it is the way society responds to these which creates disability and not the impairment
- that disablism is a form of oppression in the same way as is for example racism, sexism and homophobia.

The medical model of disability encourages explanations for the discrimination and disadvantage experienced by disabled people in terms of the features of an individual's body. The social model, however, encourages explanations in terms of characteristics of social organisation. The social model of disability makes the important distinction between '*impairment*' and '*disability*' and is the response of the disabled people's civil rights movement to the oppression of disabled people. Disability is caused by 'barriers' or elements of social organisation that take no or little account of people who have impairments. It follows that if disabled people are to be able to join in mainstream society, which is their human right, the way society is organised must be changed. Removing the barriers that exclude (disable) people who have impairments will bring about this change.

### *Disabled Londoners-some facts*

- Disabled Londoners are twice as likely to be unemployed than non-disabled people. 11% of disabled Londoners are unemployed compared with 6% of non-disabled Londoners. Young disabled people (26%) and black disabled people (19%) are more likely to be unemployed.
- Disabled workers living in London are much more likely to be doing routine and elementary jobs. Only 38% of disabled workers were employed in managerial, professional and technical occupations compared with 53% of non-disabled workers.
- Disabled workers earn considerably less than non-disabled workers. The average hourly wage for disabled Londoners was £10.25. This is 20% lower than the average for non-disabled Londoners.
- In London, 28% of disabled people want to work but do not have a job, compared to 11% of non-disabled people

- 88% of white male non-disabled people of working age were employed, compared with 30% of ethnic minority disabled women.<sup>1</sup>
- Disabled people are less likely to have access to education. Only 39% of disabled 16-24 year-olds participate in some form of education compared with 50% of young non-disabled Londoners.
- Disabled people are generally less well qualified than non-disabled people. Only 18% of disabled people have higher-level qualifications compared with 34% of non-disabled people.
- 11 % of disabled people have degree level qualifications compared with 22% of non-disabled people.<sup>2</sup>
- 39% of disabled people have no educational qualifications compared with 19% of non-Disabled people.

### *Putting disability equality on the agenda*

Disability capital 2003 is a major initiative to make sure that London takes a lead in promoting equal rights for disabled people. In order to take the disability rights agenda forward during 2003

- We will be undertaking a major consultation exercise in direct partnership with all communities of disabled people to find out what are the major barriers to equality and how these can be overcome.
- We will be looking to use new and existing research to establish how far disabled people are excluded from mainstream life in London focusing on poverty, health, employment, education, housing, transport, crime and support services.
- We will be publishing a report to bring together the results of the consultation and research
- We will be organising a major conference in December 2003 to launch the report and provide a form for moving forwards towards equality.
- We will be developing a disability equality scheme to ensure that disability equality is mainstreamed into all aspects of the Authority's work and raise awareness of disability equality within the core GLA and functional bodies

### **Notes**

- 1 Disabled people and the labour market: an analysis of the Labour Force Survey 2001/2002 GLA (2003)
- 2 London Household Survey

## *L'emploi des personnes handicapées en France*

*Agnes Roche de la Porte des Vaux*

Dans un premier temps, je voudrai vous livrer un réflexion sur les conséquences du contexte législatif français concernant les personnes reconnues travailleurs handicapés puis dans un deuxième temps vous faire partager notre expérience de médiateur sur le marché de l'emploi.

### **La discrimination positive contribue-t-elle à dépasser les barrières psychologiques?**

La loi du 10 juillet 1987 a institué en France l'obligation d'emploi des travailleurs handicapés (quotas de 6%) pour les établissements de 20 salariés et plus. On parle alors de « discrimination positive » en faveur des travailleurs handicapés.

Discriminer, c'est de fait, reconnaître les différences de nature des publics concernés. Dans le domaine du handicap, c'est considérer que le handicap est constitutif de la personne: être handicapé, c'est ne pas être comme les autres, non pas au niveau de la difficulté à vivre dans la société mais dans ce qui fait l'essence même de l'être humain, c'est-à-dire sa qualité de sujet.

La discrimination , même positive, est antinomique de l'égalisation des chances; dans un premier temps, elle met à part et le mal est fait. Elle a même un effet plus pervers, sur la personne elle-même, qui va se persuader qu'elle peut «exiger» un emploi car elle est handicapée; d'où le discours de certaines personnes handicapées «vous devez m'embaucher , vous avez des emplois réservés» et là viennent à l'esprit des images de «réserves» ou encore la signification du qualificatif «réservé»: bien sage dans mon coin, un petit emploi qui ne gênera personne, sans exigence.

Le droit au travail n'est pas un droit à géométrie variable selon les caractéristiques de l'individu. Et faire croire à la personne que son handicap peut lui donner une identité professionnelle, c'est la leurrer et la faire aller aux devants de difficultés d'intégration dans le collectif de travail.

Le stigmatisme devient l'emblème: «mon handicap vous oblige à m'embaucher» et alors la personne handicapée peut se dispenser des obligations de tout salarié.

D'autre part, dans un contexte économique où nombre de personnes sont exclues du marché du travail, ce «passe-droit» isole les travailleurs handicapés de la communauté des chercheurs d'emploi.

Le développement important en France des dispositifs spécialisés a contribué à cette mise à l'écart; les établissements de reclassement professionnel n'ont pas toujours bénéficié des avancées du réseau de droit commun et ne sont souvent plus en prise avec le milieu économique d'où la nécessité, aujourd'hui, de développer une énergie considérable pour désenclaver les acteurs du champ du handicap.

Et pourtant, notre législation, en braquant les projecteurs sur les personnes handicapées, a permis de mettre en place des dispositifs qui ont largement contribué à démystifier le handicap, à modifier la représentation collective, à mobiliser des ressources pour compenser la déficience et à contraindre les entreprises à une politique volontariste.

Même si la France reste encore largement ancrée dans l'obligation d'emploi, les lois du 12 juillet 1990 relative à la protection des personnes contre la discrimination en raison de leur état de santé ou de leur handicap et du 16 novembre 2001 relative à la lutte contre toute forme de discrimination devraient nous obliger à proscrire ce terme de discrimination positive. Nous pourrions certainement, même, aller plus loin: ces distinctions justifiées qui se sont traduites par la mise en place de politiques volontaristes et de traitements différentiels doivent être considérées comme des entorses temporaires au principe d'égalité et nous permettre, aujourd'hui, de construire une réelle politique de non-discrimination basée sur l'engagement contractuel, un enrichissement des compétences et une protection contre toute forme de discrimination.

### **Adecco: l'accès à l'emploi des personnes handicapées par le travail temporaire.**

Depuis 17 ans, l'entreprise *Adecco* s'est investie pour développer l'insertion des personnes handicapées.

Elle a fait le choix stratégique de ne pas créer d'agences spécialisées pour les personnes handicapées mais de développer des moyens d'accompagnement, de

formation et d'expertise pour que dans ses 1000 agences en France, ses professionnels soient en capacité d'accueillir, d'évaluer, de déléguer des personnes handicapées mais aussi de sensibiliser nos clients à l'accueil de personnes handicapées. Dans cet objectif, elle a mis en place un pôle national «Handicap et Compétences» qui anime, forme et accompagne 20 chargés de missions régionaux.

Le travail temporaire est un excellent moyen de faire passer le message de la compétence des personnes handicapées; rien ne vaut l'expérience dans un contexte qui ne soit pas trop contraignant pour l'entreprise. La clef d'entrée est la qualification demandée par notre client: si nous déléguons chez lui une personne correspondant à cette demande, il nous est facile, lors du bilan de fin de mission de lui faire reconnaître que le handicap de la personne n'a pas été un obstacle et de lui permettre d'avoir un autre regard sur les personnes handicapées.

Aujourd'hui, les barrières psychologiques sont bien souvent davantage du côté des personnes handicapées qui n'osent pas pousser la porte d'une agence de travail temporaire ou qui ont une fausse image du monde professionnel. De ce fait, elles ont des difficultés à s'adapter au contexte de plus en plus mouvant et exigeant de l'entreprise. Mais plus encore que ces barrières psychologiques ce sont des barrières de niveau de qualification qui sont bien souvent rédhitoires. En France, 75% des personnes reconnues travailleurs handicapés ont un niveau V ou inférieur à V (CAP/BEP). Il y a aussi un certain nombre de personnes handicapées qui ont une formation incompatible avec leurs capacités réelles: un technicien réseau informatique qui est sourd et ne peut donc pas utiliser le téléphone, par exemple.

Je pense également que les personnes handicapées et les associations doivent mettre en avant les réussites ( l'exemplarité est un très bon moyen de faire passer des messages) et ne pas sans cesse montrer du doigt les entreprises qui ont fait beaucoup évoluer la mentalité de leur encadrement.

Il reste certainement beaucoup à faire mais nous avons la volonté de mettre notre conviction et notre professionnalisme au service des personnes handicapées et de nos entreprises clientes.

## *Speakers and Chairs*

**Andrews, Emily S.** is a Lead Economist at the World Bank. She specializes in social protection issues in transition economies, including old age and disability pensions, labor market developments, and social assistance. Her work has taken her to over a dozen countries in Europe and Asia. Earlier in her career, Ms. Andrews worked for the US government, academia, and the private sector. Immediately prior to joining the Bank, she was Senior Economist at Mathematica Policy Research, Inc. and, before that, Research Director for the Employee Benefits Research Institute. Her government work included positions at the Department of Labor and the Social Security Administration. She received her Ph.D. in Economics from the University of Pennsylvania.

**Apfel, Kenneth** holds the Sid Richardson Chair at the LBJ School of Public Affairs at the University of Texas at Austin. From 1997-2001, he served as Commissioner of the Social Security Administration. Before 1997, he served in senior capacities at the Office of Management and Budget in the Executive Office of the President and at the U.S. Department of Health and Human Services. From 1980 to 1993, Apfel worked on Capitol Hill for Senator Bill Bradley and for the U.S. Senate Budget Committee. From 1978 to 1980, he held a Presidential Management Internship at the U.S. Department of Labor.

**Ásgeirsdóttir, Berglind** an Icelandic national, is one of the four Deputy Secretaries-General of the Organisation for Economic Co-operation and Development (OECD) based in Paris. Within OECD, she is, among other things, responsible for overseeing work on the environment, education, health, labour and social policy as well as for the multidisciplinary projects on Health and on Sustainable Development which involves most OECD Directorates. Before taking her current appointment in September 2002, Ms. Ásgeirsdóttir was Secretary-General in the Ministry of Social Affairs in Iceland most recently since 1999 and between 1988 to 1996. In this capacity, Ms. Ásgeirsdóttir was responsible for the leadership of the Ministry of Social Affairs in its responsibilities in the area of employment, state/municipalities relations, social services, housing, gender equality, child welfare, migration and refugee issues. Ms. Ásgeirsdóttir was Secretary-General of the Nordic Council in Copenhagen from 1996 to 1999, which is the forum for inter-parliamentary co-operation.

**Askenazy, Philippe** Researcher at CNRS and CEPREMAP (Paris, France), and Assistant Professor at the Ecole Nationale d'Administration. Published works in, e.g. *Economic and Industrial Democracy* or *Journal of Economic Theory*, dealing with the consequences of innovative workplace organization and information and communication technology on working conditions and firm performance; growth in open economy; and dynamical optimisation. Thirty-one years old, Philippe Askenazy is the youngest economist to have received a Great Prize from the Académie des Sciences Morales et Politiques.

**Barnes, Colin** is a disability activist, writer and researcher with an international reputation in the field of disability studies and disability research. He is a member of several organisations controlled and run by disabled people and research director for the British Council of Disabled People (BCODP). He teaches disability studies and is the founder and Director of the Centre for Disability Studies, an independent publisher: The Disability Press, and the electronic Disability Archive UK. He is an executive editor, reviews editor and regular contributor to the international journal *Disability and Society* - formerly *Disability, Handicap and Society*. His most recent publications include *Disabled People in Britain and Discrimination* (1991 reprinted in 1994 and 2000); *Disabled People and Social Policy* (1998) with Mike Oliver; and *Exploring Disability: a Sociological Introduction* with Geof Mercer and Tom Shakespeare.

**Bengtsson, Steen** is Senior Researcher at the Social Research Institute in Copenhagen and Associate Professor at the University of Roskilde, Denmark. In the 1980s he conducted research on disability pensions inspiring the reform of the 1990s building on decentralisation and active orientation. From 1991-92 he was on leave to function as social policy consultant with the Danish Council of Organisations of Disabled People. He has also done research on living conditions for people with disabilities. In later years his research has mostly been concerned with the quality of social services and the relation between citizens and authorities in this connection, and recently he has also returned to his work on disability pensions.

**Burkhauser, Richard V.** is the Sarah Gibson Blanding Professor of Policy Analysis and Chair of the Department of Policy Analysis and Management at Cornell University. He is a member of the Technical Committee on Assumptions Panel for the Social Security Advisory Board and a former member of the TTWWIA Advi-

sory Board to SSA. He is the co-editor of the forthcoming book: *The Decline in Employment of Working Age People with Disabilities: A Policy Puzzle*. He has published widely on the behavioural and distributional consequences of disability policy

**Castellano, Carlo** is Chairman and Managing Director of Esaote S.p.A., one of the world's leading producers of medical diagnostic systems. Formerly Associate Professor at the University of Genoa, he is Vice-President of the Health Committee BIAC; member of the Economic Affairs Committee Cocir, the European Coordination Committee of the Radiological and Electromedical Industries; member of INFN, the Italian National Institute for Nuclear Research as well as holds a number of other positions in international bodies and societies.

**Durand, Martine** is Deputy Director of the Directorate for Employment, Labour and Social Affairs at the OECD. Prior to her appointment to this post in 2002 Ms Durand worked as the Deputy Head of OECD Secretary General's Private Office, dealing with all substantive and administrative matters requiring the Secretary General's attention as well as the preparation of the Secretary General's speeches. From 1997-2001 she was the counsellor for economic policies in the office of the OECD's chief economist. Prior to this, she occupied various positions in the OECD Economics Department. An economist and statistician by training, Ms Durand is the author and co-author of several OECD articles and publications in the area of international competitiveness, foreign trade and investment, public finances in saving and investment and analysis of macroeconomic development and policies in OECD member countries.

**Endean, Rebecca** is a Senior Economic Adviser in the Working Age and Children Strategy Directorate of the Department of Work and Pensions.

She heads a division which is responsible for analysis and evaluation of programmes to help disabled and incapacitated people engage with the labour market and find work and state benefits for disabled people. Work is currently being undertaken on the evaluation of the New Deal for Disabled People and the recently announced pilots aimed at providing an integrated package of help for incapacitated people. She has previously worked within Government on a range of social and labour market policy areas.

**Feldes, Werner** is Senior Manager at the Department of Disability Politics, Rehabilitation and Older Employees of the IGMetall Workers Union, Germany. He is responsible for policy-making, consultation, project management, organisation and team development, as well as a facilitator.

**Furrie, Adele** is President of Adele Furrie Consulting Inc., a private company that provides research and analytical services to governmental and non-governmental organizations. The company's foundation is the extensive experience that Ms. Furrie gained from her national work in disability, human rights and Aboriginal issues at Statistics Canada as well as her international work through consultancies with the United Nations Statistical Division. Since forming her company in 1995, Ms. Furrie has worked with government officials and researchers in Canada, New Zealand and the United States to provide information that informs social and economic policy development to address disability issues.

**Golinowska, Stanislaw** Professor of Economics at the Jagiellonian University in Cracow. 2002 Director of the Institute of Public Health at the Jagiellonian University, former Director of the governmental research Institute for Labour and Social Studies (IPiSS) at the Ministry of Labour and Social Policy. Since 1996 member of the Rada Strategii Spoeczno-Gospodarczej (Council of Economic and Social Strategy) as an advisor for the Polish government.

As a co-founder and vice-chairperson of the Foundation Council from 1992 she closely co-operates with CASE (Centre for Social and Economic Research), an independent Polish think tank organisation oriented towards countries in transition. Author of numerous articles and books on social aspects of economics and social policy reforms in Poland and other Central and Eastern European Countries.

**Grizzard, W. Roy** was nominated by President Bush to be the first Assistant Secretary for Disability Employment Policy and was confirmed by the Senate on July 26, 2002. Dr. Grizzard is responsible for advising the Secretary of Labor on issues related to the employment of people with disabilities. He works with all agencies within the U.S. Department of Labor to provide leadership in the Department's efforts to increase employment opportunities for adults and youth with disabilities.

Prior to joining the Department of Labor, Dr. Grizzard served for six years as Commissioner for the Virginia Department for the Blind and Vision Impaired. This

state agency provides comprehensive services to Virginia's citizens who are blind, visually impaired and deaf blind. Prior to his appointment as Commissioner, Dr. Grizzard was a teacher and administrator in Henrico County Schools.

**Haines, Hartmut**, studies in laws, economics, psychology; experience in industrial financing. Since 1971 working with the German Federal Ministry of Labour and Social Affairs (since 2002: Health and Social Security), since 1982 as senior ministerial expert in the field of rehabilitation, integration, and participation of disabled persons. Preparation of German legislation and of political reports; organization of rehabilitation research and the database REHADAT; international activities, e.g. in the ILO, Council of Europe, European Union, and OECD; counselling in this field, e.g. during the German unification process, in Western, Central and Eastern Europe, and overseas; publications in the field.

**Hocquet, Jean-Yves** is Deputy Director General of the Department for Social Welfare at the French Ministry of Social Affairs, Labour and Welfare. Before that he was Regional Delegate for Saint Gobin Development (1996-2001), Deputy Director for Professional Training and Deputy Director for Labour Relationships at the French Ministry of Labour (1991-1996), and Deputy Director of the French National Agency for the Improvement of Working Conditions (1988-1991). He studied Political Sciences, Law and Economical Sciences.

**Hoskins, Irene** has served as Senior Technical Officer in the Ageing and Life Course programme of WHO since 1998. Prior to joining WHO, she served as Senior Programme Specialist and International Representative of AARP (American Association of Retired Persons) to the United Nations and its specialised agencies. Her career spans over 20 years of professional activities devoted to international ageing issues, including policy development, publications, management of research projects and advocacy. She was educated in Germany (University of Heidelberg), Switzerland (University of Geneva) and the United States (George Washington University).

**Hvinden, Bjørn** is Professor of Sociology at the Norwegian University of Science and Technology and Scientific Advisor to the Welfare Research Programme of the Research Council of Norway. He has written and lectured about disability,

activation and employment policies, comparative welfare, self-organisation among marginal groups and the situation of Romany people in the Nordic countries. He is currently leading a Nordic project on Active Citizenship and Marginality in a European Context. He is the author of *Divided against Itself. Integration in Welfare Bureaucracy* (1994), and has co-edited and co-authored *Nordic Social Policy* (1999), *Nordic Welfare States in the European Context* (2001) and *Disability Policies in Europe* (2001).

**de Jong, Philip** is partner in APE, a research and consultancy bureau focussing on the public sector, and De Kruyff Professor of Economics of Social Security at the University of Amsterdam. Before his involvement in APE he worked at the Department of Economics of the University of Leiden (from 1977 until 1998), and was De Kruyff Professor of Economics of Social Security at Erasmus University Rotterdam (1992-1999). De Jong has published extensively (in English and in Dutch) on the micro-economic and public policy aspects of social welfare programmes. He regularly serves as a consultant to Dutch and foreign governments and international organisations (World Bank, OECD, ILO).

**Kalisch, David** is an economist, with an interest in labour markets, social policy and public policy. He has been an Executive Director in the Department of Family and Community Services, first looking after Economic and Social Participation policies and programs (including managing income support and employment services for people with a disability) and then to co-ordinate the Welfare Reform agenda. He has just moved to the position of Executive Director, Family and Children. In 1997-98, he worked at the OECD in the social policy division and was then with the Australian Permanent Delegation to the OECD in Paris between 1998 and 1999. He was Chief of Staff to a former Australian Minister for Social Security in 1996-97.

**Klein, Mikael** has the position of policy officer, responsible for labour market issues at the Swedish Disability Federation, an umbrella organisation for the main part of Disability Associations in Sweden. The main task during 2002 has been to elaborate a joint policy programme for the disability associations, targeting working life and labour market policy. His professional background is in various assignments within the Disability Movement of Sweden, mainly the youth organisations.

**Kosic, Vladimir** Head of Regional NGOs for disabled people since 2000. He has taught English literature and language until 1998. Quadriplegic since 1964 after a diving accident. In 1975 (Naples) he founded the FRI (Radical Front of Invalids), in 1977 (Caserta) the LpH (League of Handicapped People Problems), in 1978 (Rome) the League for the Right to Work of Handicapped People. Since 1985, leading roles in regional NGOs. Recently, one of the main organizers of the International Conference on Health and Disability, Trieste (17-20 April, 2002), held by WHO, the Italian Ministry of Health, and the Regional Government of Friuli-Venezia Giulia.

**Mabbett, Deborah** is an academic who has worked on a number of social policy research projects for the UK and New Zealand governments, the European Commission and the World Bank. Most recently she was project manager for the EC's "Definitions of Disability" project ([www.brunel.ac.uk/depts/govn/research/disability.htm](http://www.brunel.ac.uk/depts/govn/research/disability.htm)). She has a PhD in Economics from Oxford. Her publications include *Trade, Employment and Welfare* (Oxford University Press, 1995), and academic papers on multi-level governance, social insurance, free movement in the European Union and the comparative analysis of welfare states.

**Marin, Bernd** is Executive Director of the European Centre for Social Welfare Policy and Research, formerly Professor of Comparative Political and Social Research at the European University Institute (EUI) in Florence. He is expert and policy advisor on pension reforms, and international rapporteur to United Nations ministerial conferences on social affairs and ageing 1993-2002. His recent publications include *Facts and Figures on Disability Welfare* (2003, with C. Prinz); *the Introduction to European Disability Pension Policies* (2003, ed. C. Prinz); *Innovative Employment Initiatives* (2000, with D. Meulders and D. Snower); *Pensions-reformen* (1999, with C. Prinz); *Managing AIDS* (1997, with P. Kenis).

**Morris, David** works as Senior Coordinator Disability for the Greater London Authority (GLA). He is responsible for coordinating and developing disability equality initiatives, particularly a disability equality scheme designed to ensure that the GLA is proactive in developing a disability rights based agenda. He has worked in the disability rights movement in the UK over a number of years and has specific experience and expertise of advocacy, employment, independent living and personal assistance.

**Nydegger Lory, Bruno** since 1998 is Scientific Collaborator at the Federal Office for Social Affairs, Research and Development Unit, with the main topic of “disability”. From 1994-1998 he did research and evaluation in the field of drug policy at the Addiction Research Institute in Zurich, Switzerland.

**Palme, Joakim** is Director of the Institute for Futures Studies in Stockholm and an associate of the Swedish Institute for Social Research at Stockholm University. His research focuses on the development of welfare state institutions, and the causes and consequences of this development. He has published on the pension rights and pension reform, the public-private mix in social protection, as well as on health and social insurance. Recently, he chaired the *Welfare Commission*, a large survey of the state of welfare in Sweden. He is currently involved in research on recent welfare state transformations in a comparative perspective.

**Pearson, Mark** is Head of the Social Policy Division at the OECD, responsible for work on policy advice to governments on how best to integrate income transfers with social and employment services in order to help individuals to fulfil their potential and to support a dynamic economy. Previously, he was head of a unit which worked on employment-oriented social policy at the OECD, where he oversaw work on reform of the tax and benefit system; work incentives and policies to make work pay; social indicators; social expenditure statistics; social assistance systems; family-friendly policies; sustainable development and links between social protection, inequality and economic growth. Prior to this job, he worked at the Fiscal Affairs division of the OECD on tax policy analysis and statistics. Before moving to Paris, he was employed by the Institute for Fiscal Studies in London, looking *inter alia* at the taxation of multinational enterprises, the move by transition economies to market-based tax systems, European tax harmonisation and environmental taxes. He has been a consultant for the World Bank, the IMF and the European Commission. He was editor of the journal *Fiscal Studies* and is on a number of editorial boards, including that of *OECD Economic Studies* and the *European Journal of Social Security*.

**Pérez Bueno, Luis Cayo** is Director of the Spanish National Council of Disabled Representatives, CERMI. He holds a Degree in Law and has specialised in Juridical Philosophy. He has professional experience in the social field of disability since 1994 and held several positions in SERVIMEDIA, the ONCE Foundation and

ONCE. A publisher, writer, poet and translator, he has published a large number of works and translations, not only of literary creation but also concerning disability aspects.

**Prinz, Christopher** is the main author of the OECD report “Transforming Disability into Ability”. Degrees in statistics and demography; 1989-1994 Research Scholar in the Population Project at the International Institute for Applied Systems Analysis in Laxenburg, Austria; 1995-2000 Head of the Social Policy Modelling Unit at the European Centre for Social Welfare Policy and Research in Vienna, Austria; since April 2000 Administrator in the Social Policy Division at the OECD in Paris, France. He planned and directed several international comparative research projects in the area of demography (population ageing, family change) and social policy (pension reform, family policy, disability policy) and is the author or editor of several books on these subjects.

**Queisser, Monika** is Principal Administrator in the Social Policy Division at the OECD. She works on retirement systems, disability policies, income distribution and other social policy issues. Prior to joining the OECD, she worked in the Financial Sector Development Department of the World Bank, in the pensions and insurance group. She has worked with governments in Latin America, Eastern Europe, Asia, and Africa and has published several articles and studies on pension reform issues.

**Roche de la Porte des Vaux, Agnès** 1999-2003 Responsable Nationale Pôle Handicap et Compétences – ADECCO, 1992-1999 Directrice adjointe d’un organisme de placement pour travailleurs handicapés – Ohé Prométhée Finistère, 1985-1992 Responsable d’un organisme de formation – Atelier Pédagogique Personnalisé

**Rydh, Jan** is Chairman of various Governmental Committees, e.g. from 1999-2002 of the official Inquiry into The Swedish Insurance Scheme. Before that, he was Governor of the Swedish Province of Västmanland (1991-1999) and President of The Swedish Savings Banks Association (1979-1991).

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