

UROLINK **AGE**

**AGE AND DISABILITY
A
CHALLENGE FOR EUROPE**

Incorporating
A EUROPEAN CODE OF GOOD PRACTICE
in meeting the needs
of
DISABILITY AND AGEING

April 1990

**LA VIEILLESSE ET L'INVALIDITE
UN
DEFI POUR L'EUROPE**

Comprenant
UN CODE EUROPEEN DE BONNE PROCEDURE
pour faire face aux besoins
de
L'INVALIDITE ET LA VIEILLESSE

Avril 1990



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AGE AND DISABILITY

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CHALLENGE FOR EUROPE

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EUROLINK AGE SEMINAR ON AGE AND DISABILITY

Florence, 15-17 March 1990

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FINAL REPORT

Incorporating

A EUROPEAN CODE OF GOOD PRACTICE

in meeting the needs

of

DISABILITY AND AGEING

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Seminar organised with the support of the Commission of the European Communities, as part of the Helios programme to promote the economic and social integration and independent living of disabled people.

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April 1990

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PART I: A EUROPEAN CODE OF GOOD PRACTICE IN MEETING THE NEEDS OF DISABILITY AND AGEING

A The aim of policy

The aim of European, national, regional and local policies and measures concerned with disability and ageing should be to secure and maintain for all elderly disabled people a good quality of life, and to strive always to improve this. A 'good quality of life' can be conceived as comprising:

Autonomy: the freedom to choose a preferred way of life.

Independence: the opportunity to make one's own practical decisions; encouragement not to be over dependent in everyday matters.

Integration: acceptance by society as a fellow citizen and member of the community, with full political as well as social rights; freedom from marginalisation.

Respect: recognition of the value of one's identity and role, and of one's contribution to the lives of others.

Ownership: the possibility to keep one's own personal possessions and retain control of one's own finances.

Social Involvement and Communication: access to regular, free social contact and communication with others, including family and peers; freedom from isolation.

Activity and Mobility: access to a range of useful and interesting occupations, of educational experiences and of cultural, leisure and self-help activities; encouragement and support in undertaking these; availability of a physically accessible environment, including transport.

Privacy

Tranquillity: freedom from noise and disruption; continuity of place and environment.

The detailed Code which follows consists first of a set of **General Operational Principles** which apply to all sectors. There then follow the recommended **Practical Measures** which cover the three essential sectors: **Incomes and Benefits, Home, Health and Care, and A Full and Active Life.** All the measures recommended are directed at the achievement of the **Aim of Policy.**

B Measures in pursuit of the aim

1 General Operational Principles

a) Rights, redress and participation

(i) The rights of elderly disabled people as consumers should be clearly stated in policy documents and respected; they should include :-

- the right to equal opportunity, without discrimination, for access to employment, education and public facilities;
- the right to the financial support, and to the services of rehabilitation, care, advice and information, which respond to their needs;
- the right to objective assessment of their needs, and to regular reviews based both on an evaluation of the degree to which services have responded to those needs and on a recognition of any changes in the needs themselves;
- the right to choose their own place and life-style, and to contest relocation where this is proposed for financial or administrative reasons;
- the right to benefit from flexible retirement schemes.

(ii) Elderly disabled people should have access to legal redress against acts of injustice and discrimination, and to conciliation services when decisions are contested.

(iii) Elderly disabled people or their representatives should be able to participate both in the making of decisions and adoption of measures which directly affect them, and in the implementation of these. This principle should apply at all levels - European, national, regional and local.

(iv) Encouragement and practical support should be given to local associations of elderly disabled people and self-help groups, and to national and European federations of these.

b) Delivery of services

(i) Services should be readily available and accessible, and decentralised wherever that is appropriate. They should 'reach out' to the elderly disabled people who need them.

(ii) Services should be coordinated and the responsibility for ensuring this clearly assigned; those which specialise in the needs of disability should be harmonised with those concerned with elderly people as a whole. Cooperation between the public, voluntary and commercial sectors should be promoted, and collaboration between associations of elderly and of disabled people encouraged. These actions should be given priority above all at local level and in the management of services offered to individuals.

(iii) In order to respond to individual needs and to changes in these, benefit systems and services should be flexible as well

as comprehensive, housing should be adaptable and residential establishments able to modify their levels of care.

(iv) At all times of decision the principles of involving the client in the process and of promoting free choice should be observed.

(v) With the aid of research, national authorities should publish guidelines and models in order to help local authorities address the complexities of management demanded of them. These guidelines should include consideration of the various categories and degrees of disability, of the distinction between 'long-term' and 'new' disability, of different age-bands (50-65, 65-80, 80+), of anomalies among benefit systems, and of socio-economic, cultural and environmental differences (including those between social classes and between urban and rural situations). They should also take account of the fact that broad categories of people cannot simply be matched to broad categories of solution, and of the need to predict and to plan for generally rising expectations and other modifications of demand.

c) Training, counselling and information

(i) Elderly disabled people should be afforded training on the nature of their disability, on how to cope with it, on how to develop self-confidence and self-advocacy and on the skills of independence. Special training should be offered to enable those with mental disabilities to express their point of view. Counselling should be readily accessible, and should include preparation for retirement, for increasing age and for other aspects of the future. Information about disability, rights and services should be delivered and interpreted to individuals as well as to centres and associations, and elderly people themselves should be consulted about their training, counselling and information needs.

(ii) Public authorities should ensure that specific information and training are provided for professionals and voluntary workers so as to enable them to meet the new and changing needs of elderly disabled people. Training programmes should include multi-disciplinary courses and offer opportunities for senior professionals to work together with others. Included should be providers of primary health and social care; rehabilitation staff and the staff of residential establishments; administrators, planners and architects; teachers of adult education; and transport staff and others working in key positions in facilities provided for the public.

(iii) Opportunities should be encouraged for professionals and family members to share joint training sessions.

(iv) Local authorities should establish resource centres where training, advice and information are available to professional and voluntary workers, to informal carers and to elderly disabled people themselves.

(v) There should be national and local campaigns aimed at informing the general public about the realities of ageing and disability (including the recognition of hidden disabilities and of the positive potential of elderly disabled people), and at diminishing ignorance, disinterest, prejudice and discrimination.

d) **Research**

(i) National programmes of research in the health and social fields should include as a priority the problems of disability and ageing, and national authorities should encourage the creation of institutes specialising in this domain. Specific measures should be undertaken to ensure that research results are disseminated and applied.

(ii) Elderly disabled people or their representatives should be involved in the framing of research policy, in the planning of projects and in the application of results.

(iii) Research priorities should include the study of everyday functioning and of the effects of the social and physical environment, as well as the evaluation of the system of provision as a whole.

e) **Coherence of measures**

(i) Those responsible for the preparation, implementation and monitoring of policy concerning ageing and disability should oversee the coherence, consistency and comprehensiveness of the measures undertaken in pursuit of the general aim, notably over the three areas of incomes and benefits, accommodation and care, and active life. The three sections of the Code which now follow are concerned with practical measures in these three areas.

2 **Practical Measures**

a) **Incomes and Benefits**

(i) Elderly disabled people should be assured either of a full state pension, or (if, under national regulations applying to everybody, they have no entitlement) of the alternative support necessary to ensure a secure and adequate income, together with all allowances or benefits (including financial support to care in the home) accorded to similarly disabled people who are not elderly in order to meet the additional costs incurred as a result of their disability.

(ii) Concerning the special allowances mentioned in (i), the level and range of benefits received by people with long-term disabilities should not be reduced when they attain old age, whether or not they are receiving a full state old-age pension. Nor should anyone's entitlement to any of the benefits to which their disability would otherwise entitle them be disallowed on grounds of the age when disability was first incurred.

(iii) Financial benefits or assistance deriving from the medical and social sectors should be coordinated in such a way as to maximise choice of life-style for individual elderly disabled people, and to ensure that no one 'falls through gaps' in the system or has to grapple with confusing formalities.

(iv) For elderly people, in view of the liability to change in their circumstances (including sometimes deterioration), the frequency of assessments to establish eligibility for benefits on grounds of disability should be increased.

(v) The right of elderly people who have learning difficulties or are subject to mental illness to retain as much control as possible over their own money should be guaranteed by law. Regulations should require that help in the exercise of this control should always be available when needed, and that the circumstances in which the right may be removed should be precisely defined.

(vi) Allowances to meet the costs of care and attendance in the home should wherever possible be paid to and managed by the elderly disabled people themselves, and systems of 'client-linked budgets' should be available if preferred. When this is either not possible or not desired, the clients themselves should be enabled to choose whether the allowance is paid to a family member, a personal friend or a professional, and there should be a statutory responsibility to ensure that the client is not exploited.

(vii) Vocational rehabilitation, with financial support, should be available to workers who incur a disability (whether or not as a result of industrial accident) late in their working career. Financial incentives should be available to employers who take on older workers with disabilities, also when the employment is part time. Disabled people who undertake employment later in life should not forfeit their right to allowances which compensate the extra costs of their disability, and the financial security of those who work part time should be fully protected.

(viii) Elderly people who need an adapted car as a result of disability, whether or not they intend to drive the car themselves, should have the same right to financial aid towards the purchase and running of the car as anyone else with a similar disability.

(ix) People who encounter disability late in life should have the same level of financial support for the acquisition of technical aids to independent living as do long-term disabled people. This right should cover all essential basic aids but also extend to advanced aids where necessary. In any case, the best aid available should be provided wherever possible.

(x) In assessing the cost to the public of benefits accorded to elderly people with disabilities, account should be taken of the substantial savings to public expenditure which result from the successful promotion of independent living.

b) Home, Health and Care

(i) National policies should encourage elderly disabled people to live for as long as possible in the 'open community', whether that means staying in their family, living with a partner or in a small group, or setting up independently on their own.

(ii) Policy makers should nonetheless take into account the fact that some elderly disabled people may not be able, or may not choose, to live in the open community, or may lose this possibility. Priority should be given to improving the consistent quality of residential care and increasing the extent to which individual people are offered provision which matches their needs. Programmes should be initiated for the general availability of flexible 'half-way' accommodation, such as sheltered or 'very sheltered' housing, small group homes, self-help schemes etc. Particular attention should be paid to the need to ensure both physical accessibility to all disabilities and financial accessibility to those on low incomes. These solutions should avoid large-scale inhuman arrangements, be adaptable to the changing needs of the clients and be sited within a friendly and accessible environment. National standards for such provision should be laid down, and codes of practice published and made available to the clients themselves.

(iii) Where elderly disabled people have to spend the rest of their lives in large institutions for want of an alternative, national criteria which guarantee their quality of life must be vigorously applied in both the public and private sector so as to ensure that there is opportunity and encouragement for varied occupation and social activity, that contacts with the outside world (including family) are fostered, and that dignity and privacy are respected.

(iv) Elderly disabled people already living in large institutions should not be excluded from opportunities to restart life in the open community simply on the grounds that it is too late to endeavour this 'at their age'. Equally, they need special protection from removal out of an institution on grounds of administrative necessity or financial retrenchment, if this is against their will or if adequate care and support outside are not available.

(v) Disabled people whose housing has been linked to sheltered employment should not on retirement be required to leave that housing until there is alternative accommodation offered which meets their preference as far as is practicable.

(vi) National housing policies should promote 'macro' projects which aim at designing normal housing so as to be adaptable at small cost to the individual needs of disabled people.

(vii) Those responsible for delivering and coordinating services should ensure that all aspects of adequate care and support are afforded to elderly disabled people living in the open community, whether or not they are in that situation as a result of a

decision taken by public authority. For each client a care manager should be appointed, responsible for ensuring (as appropriate) cooperation between professionals working in the statutory services, in voluntary organisations or in commercial agencies, as well as voluntary workers and 'informal carers' (friends or family) Supporting services from outside the home should be designed in response to actual realities (for example the different needs of those living alone and those living with a spouse who acts as informal carer) Equally, it should be part of the responsibility of the care manager to see that an unfair burden of this cooperative task does not fall on the informal carers, and to guard against the particular danger of the exploitation of women in this context.

(viii) In addition to primary services of care, support and information, care managers should foster the development of the client's social networks and activities, and help the client to identify individuals or groups able to promote and where necessary defend his interests.

(ix) The principle of remuneration of informal carers should be developed, especially when the carer is worse off financially through loss of employment. Authorities and voluntary organisations should cooperate to ensure that informal carers are afforded periods of respite without financial loss, whether by means of a temporary relief carer coming into the home or through the offer of a short-term residential place for the elderly person. Carers should be encouraged to form associations, and able to benefit from the services of training, advice and information provided both for the professionals and for the elderly disabled clients themselves. The importance of a carer or friend as advocate should be stressed.

(x) Assessment should be multi-disciplinary and followed up by regular visiting. The objectives should be not only to evaluate life-style, accommodation, care and treatment, and make decisions about the future of these, but also to prevent the onset or deterioration of disability, of whatever kind or however caused. Decisions should be guided by the recognition of the positive relation between independence and health and of the danger of underestimating the potential of elderly disabled people.

(xi) Special professional training should focus on the prevention of disability and of the aggravation of disability among elderly people, and on the diagnosis of conditions (such as depression or mental incapacity) which are difficult to recognise in old age.

(xii) Active medical and functional rehabilitation should be made available to elderly disabled people, whatever their disability, on the same terms as they are provided for the younger disabled. The notion that rehabilitation is not appropriate to certain disabilities, or to disabilities newly incurred in old age, should be discarded. The contribution which family members and other informal carers can make to rehabilitation should be recognised.

(xiii) Special efforts should be made to reduce waiting lists for common operations on which a good quality of life depends, such as cataract and hip replacement.

c) **A Full and Active Life**

(i) The principle should be established that encouragement and support towards the most autonomous situation possible and the most active life desired should be extended as a matter of course to all elderly disabled people, whatever the kind or degree of their disability.

(ii) Elderly disabled people should be encouraged and supported in developing to the full their preferred social, cultural, affective and political life. Practical support should be given to the costs of setting up and running clubs for them.

(iii) Elderly people with disabilities should be assisted in obtaining advanced aids to communication, such as security systems, visual aids, adapted telephones and electronic mail, and in benefiting from information technology (for example, telework and teleshopping).

(iv) In addition to specific training for independent living (see 1c) above), elderly disabled people should have the opportunity to choose from a range of educational experiences, regardless of the extent to which they are living independently. This means that suitable courses and activities must be available, the buildings in which they take place accessible and encouragement to participate ensured.

(v) Positive encouragement should also be given to elderly disabled people, whatever their circumstances or the severity of their disability, to undertake work, whether voluntary or remunerated; caring for other elderly disabled people should be among the options encouraged. Suitable retraining courses should be available and flexible retirement schemes facilitated. Special help in finding new gainful occupation should be afforded to disabled people obliged to retire from sheltered workshops.

(vi) For those elderly disabled people not able to undertake paid or voluntary work, day centres should be available which offer a variety of interesting occupations as well as social and leisure facilities.

(vii) Within a framework of national policy, local authorities should ensure that there is a concerted set of measures and facilities to encourage the mobility of elderly disabled people. These should include improvements in the accessibility of both urban and rural transport, and the development of special transport systems for those with more severe disabilities.

(viii) Urban planning should ensure that streets, precincts and crossings are safe and negotiable for all elderly disabled people, including those with serious visual disabilities or in wheelchairs.

(ix) Administrative offices (social security, post offices etc), commercial premises (banks, shops etc) and cultural and leisure facilities of all kinds should be fully accessible, and it should be forbidden to exclude elderly people from any of these on principle because of a disability of any sort.

(x) In all public places signs should be simple, clear and uniform, conforming to international standards where these exist. Wherever appropriate, signals should be both visible and audible.

(xi) Guides and other information documents on the accessibility of transport and other facilities should be readily available and clear.

PART II - THE SEMINAR PAPERS

A Report on the work of the Eurolink Age seminar on Age and Disability, Florence, 15-17 March 1990

1 The objectives and methods of the seminar

The seminar followed the example of the European Commission by respecting the definitions of disability set down by the World Health Organisation, even though they are now subject to review and even though they may cause difficulties in some languages (including French)

This means that the term 'impairment' was used to refer to the primary condition, which can be medically defined; 'disability' to describe the loss of basic function, of whatever kind, that results from this; and 'handicap' to mean the loss of freedom to act which results from the interaction between the disability and an unresponsive environment.

It also means that the theme of the seminar was taken to be inclusive as to kind and level of disability. While some Community actions (the European Social Fund, for example) are in effect closed to many of those with severe disabilities, this limitation does not apply to the current Helios programme and did not apply to the first disability action programme which preceded it.

Nor was any kind of physical or mental disability to be excluded from the agenda. The term 'physical' was taken to include therefore not only all motor disabilities however caused and the sensory disabilities of sight or hearing, but also those 'hidden' disabling conditions, sometimes called 'medical' or 'physiological', such as diabetes and pulmonary or cardiac diseases. Similarly on the non-physical side, discussion covered the needs both of those who have mental or intellectual disabilities and also of those suffering from mental illness or with a history of this.

The discussion paper prepared by the rapporteur drew attention to the fact that the seminar was the first significant endeavour to tackle at European level questions which are of vital importance to many thousands of Community citizens. It was pointed out that for the majority of elderly disabled people now life is far less enjoyable than it could or should be, and for a considerable number barely tolerable. Moreover the general situation is likely to get worse unless a vigorous and sustained effort is made to improve it.

Yet if the seminar was to be really seminal, a creative and realistic optimism would be more appropriate than pessimism. One objective should be to promote a positive image of disability in age. Those who have experienced serious disability for all or much of their lives have in this a unique and crucial contribution to make, since they know what it means not only to come to terms with disability but to overcome it.

The work of the seminar was founded on a working document, which introduced the members to the working method of the seminar. It comprised a first draft of a Code of Good Practice, an analysis of the importance and neglect of the subject and of the situation of the elderly disabled and the disabled elderly, and a set of proposals for the contribution which action at European level could make to the national effort. This final report is therefore derived from the working paper, much modified and enriched as a result of the seminar discussions. Every effort has been made to include in this final version all the points raised during discussion.

Three half-day sessions were each introduced by a Resource Person who assisted the rapporteur. Dr Hana Hermanova of the World Health Organisation's European Regional Office stressed the extent to which the problems of disability and ageing had been neglected world-wide. Revision of the International Classification of Diseases however was taking into account social and environmental factors; review also of the International Classification of Impairments, Disabilities and Handicaps should ensure that there would be more emphasis on functional capacities in the future. Dr Hermanova presented a matrix definition of disability seen as a deficit between health status and environment, setting out the relation between levels of disability and needs, problems and solutions. She also warned against the notion that there would be no future place for residential institutions.

Ms Mary Kyriasopoulou, member of the Helios experts' team responsible for the Local Model Projects on Independent Living, presented the results both of a specific study on disability and independent living which she has undertaken in three countries and of her experience of Community-wide local projects in the first (1982-7) disability action programme and in Helios. Community living makes both technical and psychological demands, - the provision of care facilities, the breaking down of physical and psychological barriers and changes of attitude. Disabled people need financial, psychological and practical security; family links are usually important and avoidance of isolation always so. Ms Kyriasopoulou gave examples of good practice in the three key domains of housing, transport and accessibility.

Ms Pascale Roussel, CLEIRPPA, introduced the third half-day session, focusing on the needs of the long-term disabled, particularly those with mental handicaps. After describing how CLEIRPPA's concern for older disabled people had developed, and the results of their enquiries into premature ageing, Ms Roussel presented findings on the differences between the problems of those elderly people who were disabled and those who were not in respect of incomes, care services, housing, and activity including employment. There then followed an analysis of the mismatches and conflicts which are characteristic of the domain: placements are too often determined by what happens to be available rather than what would be suitable; the client wants

to stay in the familiar surroundings, whereas institutions are commonly good in so far as they are specialised; the client may be seeking independence in a family context which is over protective; institutions may actually offer more accessible activity than does independent living; adult education systems are geared to improvement and not equipped to respond sensitively to decline. There are no simple solutions and types of solution cannot be directly matched to kinds or levels of disability. Financial and other provision must therefore be modified to make individual solutions possible.

3 The 'Output'

The last half-day session of the seminar brought together the conclusions of the seminar by means of a systematic review of the working paper in the light of the preceding free-ranging discussions. This final report reflects the total impact of the seminar on that original input; while covering much the same fundamental content it diverges in one important point of structure, in that the Code of Good Practice has been given pride of place in the belief that it is the element of the work most likely to arouse interest and form the basis of further action at European and national levels.

This report is then the principal physical output of the seminar. Its dynamic output will of course be the new initiatives which will now be undertaken and which would not have happened if the seminar had not taken place. Agents of change will include all participant organisations plus all those throughout the Community who are elderly and disabled or who work in the field of age and disability and who in reading this report or hearing of the seminar find new points of departure or inspiration for their professional or personal lives.

B Analysis of problems and needs concerning disability and ageing

1. The 'state of the art'

Whoever makes a fresh approach to the topic of age and disability is likely to be struck at once by its obvious importance, and very soon afterwards made aware of the comparative neglect which is generally accorded to it. Let us therefore focus on this anomaly before attempting to identify the characteristics of the disabled elderly population, their typical needs and the measures that have been or should be taken to meet these.

a) The importance of the subject

To consider first the quantitative aspect: it is common knowledge that the majority of disabled people in our society are elderly and a significant proportion of the elderly disabled; moreover no one doubts that the certain increase in the number and percentage of elderly persons in our population will be

accompanied by a growth in the prevalence of disability among them.

On no criteria do estimates of the proportion of disabled people who are over 60 years of age fall below 70%. That this percentage will increase significantly in the next thirty years is a certain implication both of the general increase in the percentage of elderly people (and especially of the older elderly) who will incur disability in association with ageing, and of the participation in that greater longevity of people with long-standing disabilities.

The figures for the percentage of elderly people who are disabled are less high but hardly less dramatic in their implications. Estimates in one Member State show, by criteria which reveal a disability prevalence of 12% in the whole population, figures of 35% for those in their 70s and 50% for those over 80; prevalence of severe disability is 12 times higher among over 80s than it is generally. A recent major survey in another large Community country has given a significant disability prevalence of 14.2% for the whole population, compared with 24% for those aged 60-70, 40.8% for those aged 70-80 and 71.4% for those over 80; the respective percentages for severe disability are 6.2, 8.4, 16.9 and 43.8, while the chance that someone over 80 will be profoundly disabled is 11 times greater than for the population as a whole.

Striking as these figures are, their implications are greatly aggravated by qualitative factors. The increasing longevity resulting from improvements in medical care, diet and housing has already created demands for care and support which cannot adequately be met either in institutions or in the open community; many of these demands are specific to disability. What is more, the problems are not only increasing in number - so much is generally admitted - but also in severity, owing to the accumulation and deterioration of disabling conditions.

The effect of this trend on a context of determined policies in all our Member States to reduce or close long-stay institutions has been to increase the extent to which authorities are looking to the 'informal carers' - that is above all the families' - to save the situation. Yet this is only to shift responsibility from one scene of crisis to another. People with disabilities which in the past would have rarely allowed them to outlive their parents now do this commonly; the increase in the number of broken homes reduces the availability of family support; caring spouses may break down under the triple burden of their own age and of the age and disability of their partner; a significant number of long-term disabled people do not have children; smaller families can offer less by way of sibling support.

As a consequence systems are unprepared to meet the combination of problems, some of them fortuitous, others resulting from the effect of new measures. In spite therefore of the main policy thrust, demand for long-stay places continues; so criteria for reception tend to become more severe and delays more grievous.

And in the community, though there are many references to service support of high quality, the general picture is one of provision which is often meagre and at best uneven. Again and again in the seminar it was stressed that care services are generally undeveloped and fail to respond to the needs. Moreover, ambiguity pervades the motivation underlying the move towards community care: is the true aim to offer the client a better way of life or to cut costs? In so far as the latter figures significantly among the aims, there is the certainty of a direct conflict of objectives, since for disabled elderly people community living - so professionals are agreed - can only save money if standards of care are lowered.

It should be noted that elderly women are likely to undergo more than an equal share of the inadequacies in services whether official or voluntary. This is not only due to their greater longevity and higher liability to impairment: because of the general assumption that women are better able to look after themselves it is often the case that their disability has to be more severe than that of men before additional support is forthcoming. Elderly disabled women are exceptionally at risk of isolation and neglect.

These troubles belong, as is well known, to old age as such, especially to those who comprise 'the older elderly'. They are heightened by unfavourable trends in the organised environment - reductions in rural public transport services, for example, and the planning of urban facilities designed to suit car drivers who are also agile pedestrians. What disability does is both aggravate the difficulties and superimpose on them problems which are specific to particular impairments.

Nonetheless, it would be quite wrong to end with the impression that the importance of this subject depends entirely on its problematic character and the difficulties which surround it. Everywhere we see a growing awareness of disabled people's and elderly people's high potential for leading a happy life and contributing to the happiness of others; this is proved by the countless examples of successful independence, some expressing a traditional culture, others resulting from new measures to promote living in the community. What is true both of disabled people and of elderly people can certainly also be true of people who are both disabled and elderly. Indeed, recognition of the overall savings to the economy which come whenever dependency is reduced and the effect of declining birthrates on the labour market will offer over the next twenty years a context for the social emancipation of elderly disabled people which is in some ways more favourable than ever before. The importance of the subject manifests itself through positive factors such as these as well as in terms of predicament.

b) The neglect of the subject

Complaints of the comparative neglect with which the problems of elderly disabled people have been treated are a frequent feature of what literature there is concerned with it; the sparseness of

the literature itself is even more compelling evidence. Perhaps this neglect is, inspite of the subject's importance, not altogether surprising. It is the classical problem of a 'mixed' population defined by the intersection of two established categories familiar to researchers, policy makers and those responsible for the delivery of services. To subsume the elderly disabled simply either in the category of the disabled or in that of the elderly would lead to falsifications of reality and misjudgments of need; not to do this leaves them permanently on the margin of two sectors, without a power base or any guarantee of constant attention to their requirements.

This effect is heightened by a certain reluctance to afford to the problems of elderly and disabled people the attention and priority they call for. Western culture since the war has tended to favour the manifestations of growth, success, youthfulness, activity and speed, sometimes evidently to idolize these. It is often complacently assumed that elderly and disabled people in general do not have the same range of needs as others and are therefore - or should be - content with restricted opportunities and facilities. The persistence of a traditional concentration on exclusively medical models can widen the gap between the theory and practice of independent living. And the mere size of the problem, with its menace of increasing demand on resources, means that it is a convenient one to put aside in the hope that it might somehow go away. Ageing itself, the harassed administrator may be tempted to reflect, is enough of a problem without the aggravation of disability superimposed.

To this we must add all those hesitations which derive from the very nature of disability itself and society's response to it. Much of the vocabulary still in use is stigmatising, so that what are presented as objective statements are loaded with negative implications. Ignorance about disability is still profound and widespread. Fear and even hostility characterise the popular response to some disabilities more than to others, of course - those which affect understanding and relationships may be most likely to be associated with difficulties. But all disability is vulnerable to negative response and many people who (for example) are in wheel-chairs or who have hearing impairments will attest this.

Least surprising of all, perhaps, is the fact that the European Community institutions themselves have not yet focused on these questions. Establishing any sort of position for disabled people in the Community's social policy has been hard enough, and that position is still a precarious one; it is little wonder that the Commission has taken the strongest ground it can find and concentrated its efforts on the those disabled people who are young or in the mature prime of life and whose needs are more in harmony with the economic preoccupations of the Treaty. This problem is obviously of crucial importance to all those who are striving to put age and disability in the European 'map'.

At European level too the Non-governmental Organisations whose activities in the disability field are supported by the

Commission, although they are under less constraints as to choice of topics than the Commission itself, have so far shown little or no interest in the special needs of those disabled people who are also elderly. Indeed, the European dimension of the subject can barely be said to exist: it is significant that the bibliographies of relevant works of all kinds in the English language typically include abundant American references and not a single one from the European mainland. A prominent exception is the initiative of the Hester Adrian Research Centre in Manchester in launching a network of European researchers concerned with ageing and mental retardation.

While at national level the subject has not of course been totally neglected, what evidence I have been able to find suggests a lack of coherent policy, of coordination of services and of appropriate provision. Nor do there appear to be effective lobbies or pressure groups able to identify and articulate the special needs of this population, let alone bring them forcibly to the attention of the authorities. Partly, no doubt, this is due to the fact that militancy and advocacy are themselves as yet young phenomena; we may see a big change when the first generation of those people who have acquired motor or sensory disabilities and who have championed the cause of equal opportunity themselves encounter the realities of ageing. Again, with a number of the congenital disabilities (mental retardation, for example, or cerebral palsy) the lead in campaigning and working for better services and fairer life chances has often been taken by parents, who are simply no longer there when the problems of ageing are added to those of disability.

As we did for the previous section, so here we can end on a more positive note. The mere fact that this seminar has been organised is a guarantee that the comparative silence which has enclosed this topic is now to be broken. During the seminar too new evidence came to light of European and international initiatives relevant to the question of ageing and disability; these will be mentioned in section C, 'The European Contribution' below.

2 The elderly disabled and the disabled elderly

a) **The two groups**

The population we are considering is made up of two groups with different personal histories. First we have those who come to the experience of ageing having encountered disability earlier in their lives or even lived with it since birth or early childhood. These are the elderly disabled ('les handicapés âgés'); for convenience here, and for want of a better term, this group can be called the 'long-term disabled' - even it must include those who have not incurred a disability until well into the middle stage of their lives. But also our population includes those who confront disability for the first time relatively late in life and in association with ageing, the disabled elderly ('les âgés handicapés'); this group can be called the 'new disabled'.

Naturally there are experiences and problems which are common to both these groups, and some of these will be noticed in d) below. In many respects however the form which disability takes for the two groups and the way it presents itself are different, so that to avoid vagueness and confusion we need to be aware of the most prominent sorts of disability characteristic of each.

The dangers of categorisation have been frequently and forcibly stressed in recent times; if, as has been said, there is a risk that elderly people come to be thought of as 'a class apart', that probability must be all the greater for those who are disabled as well as elderly. Nonetheless, it is true (for example) that all deaf people have a common set of problems because they cannot hear, and similarly all blind people because they cannot see. It is also true that in asserting this we may be led to underestimate the extent to which individuals have problems which are unique to themselves, as well as their own special potentials and aspirations, or fail to see that they require different solutions even to those problems which are indeed common. Yet it does not follow that we must ban all use of categories from our discourse in order to make sure that we do not lose sight of the individual; to deny the truth and relevance of the valid generalisations leads to damaging confusions and in the end to hopeless absurdities. We need the courage to distinguish between the use of categories and the misuse of them, accepting therefore the responsibility to be vigilant and self-critical on this question.

There are of course a number of disabling conditions which characterise both our groups since they may quite commonly be either lifelong or first incurred in old age, even though the nature of the impairment and the exact form which the disability typically takes may differ. This is true of such widely distinct conditions as the sensory disabilities of sight and hearing, the various forms of arthritis (less uncommon in mid-life than is sometimes supposed), depression and diabetes.

Among the many disabilities which are usually congenital or encountered relatively early in life are mental retardation, most mental illnesses (for example, schizophrenia) and special conditions such as epilepsy and autism. A number of impairments causing paralysis are congenital, while young people are more often than others the victims of paralysing accidents. Some of the most severe multi-disabilities are also acquired at or about birth; these include spina bifida with hydrocephalus, cerebral palsy involving mental retardation and deaf-blindness linked to rubella. It should be noticed that deterioration is a characteristic of some conditions (such as multiple sclerosis) in themselves without being specifically associated with ageing.

There appear to be fewer disabilities which are rarely encountered except in the context of ageing. Of these dementia and the consequences of stroke or heart attack are among the most common and serious. Mention should also be made of Parkinson's disease and of osteoporosis, the weak bone disease which most often affects women in late middle age or later.

It is obviously not possible in a report of this kind to follow through the characteristics of these many conditions in any detail. It will however be useful for our purpose to explore some of the differences we are likely to find between the ways in which our two groups - the new and the long-term disabled - experience ageing and disability.

b) Some characteristics of the long-term disabled - -

For the long-term disabled, success in coping with age will depend to a large extent on the level of independence they have been able to develop and maintain during their adolescent and adult life; this is a factor of prime importance for almost all disabled people, and is particularly stressed by those who work in the field of mental retardation.

Long-term disabled people who have succeeded in establishing an autonomous and active way of life will actually find themselves at an advantage over new disabled in a number of important respects. Typically they will have overcome the sense of stigma, at least to a large extent; very often they will be settled into housing which is adapted for their needs; they will have acquired a battery of coping skills which enable them to get the best out of technical aids and to grapple more or less successfully with the problems of transport and access to facilities; and they will have developed social habits and strategies that suit their desires and constraints.

Clearly too the long-term disabled have the possibility to prepare and plan for their old age with a full knowledge of their disability and its implications; the seminar could however offer little evidence that the systems of care were reliably offering help or support in this process.

If on the other hand the long-term disabled person has been cared for at home he runs a high risk of institutionalisation when, as often happens, that care is no longer available. He will indeed be fortunate if the institution to which he is 'relocated' is one that is designed to respond to his individual needs; he may have to face an accumulation of traumas, the bewilderment and fear of a new and perhaps insensitive environment being added to the shock of lost security and love. Many older people may have to suffer this or something like it, but for those with disabilities there is added all the isolation and frustrations which come from reduced mobility and limited communication.

For those who have already been living in large institutions for some time before ageing the prospects may be no better. Life skills which they may have developed in their youth have most likely been weakened or lost; it is striking that older mentally retarded people can remember how this has happened to them. Even therefore if legal provision makes them eligible as elderly persons for independent or semi-independent housing to which they were not entitled as disabled ones, it is likely that the opportunity comes too late for them to be able to accept it. The danger of decline into increasing isolation and apathy in the

institution is a real one; so is the risk that those who are resettled in the open community may become simply 'abandonnati', their needs less well understood by non-specialised professionals working in the open community than they were by the specialists in the institution. There are fine examples of the successful resettlement of elderly people with a history of mental illness and of long residence in hospital, but the cost in personnel looks high.

On the brighter side, it should be borne in mind that though this last problem is both grave and widespread throughout the Community it should be a declining one. In so far as the deinstitutionalising measures being applied everywhere are successful we may expect that an increasing number of the long-term disabled will come to ageing with a solid experience of more or less independent living behind them. Continuing improvements in medical care and in the effectiveness and availability of aids should mean too that the degree of autonomy achieved will be steadily enhanced.

On the other hand, one of the most severe afflictions which ageing can impose on long-term disabled people is the addition of a contrasting disability to the one with which they have learnt to live. The consequences of this are likely to be profound whatever the previous history of the disabled person may be; indeed those who have established a pattern of independent living may in one respect suffer most, in so far as they have the most to lose. A mentally retarded person who incurs a physical disability may find that his carefully constructed life-style collapses because the accommodation he has settled into is no longer accessible. A paraplegic person who encounters dementia may lose control of all the elaborate coping systems which he has so laboriously constructed throughout his life.

There is no need to spell out the consequences for a deaf person when faced with a deteriorating visual disability or for a blind person with an auditory one. In one study, nearly 80% of elderly blind people were found to have another disability; another research project has revealed a link between the combination of hearing loss with another disability and depression. There may even be examples of a direct connection between certain long-term disabilities and the onset of quite different ones with ageing; the incidence of dementia among people with Down's Syndrome may be an instance of this, and mental retardation has been associated with an abnormal incidence of sensory disability later in life. There is besides some evidence of premature ageing among mentally retarded people and those with a number of specific physical impairments such as spina bifida.

There are other difficulties too to which the long-term disabled may be prone whatever their earlier life-style. For example, the nature and even existence of a long-term disability may simply not be recognised by professionals because its effects are hidden among more general losses of function in old age.

To conclude this section, it is evident that the problems which ageing presents to the long-term disabled may often be severe, and are likely to be profound wherever relocation or accumulation of disability are involved. The key to generalised progress is the launching in youth and the maintenance throughout adulthood of an active independent life; this will release the rich fund of courage, positivism and resourcefulness which disabled people, more than any others, are able to bring to ageing. It should also be observed that the more severe the problems which confront the long-term disabled as they become older, the more idiosyncratic they are likely to be and the greater therefore the degree of individualisation which will be required of the service providers.

Finally, it must not be forgotten that for this group there may be specific dangers in the matter of income support as well as special needs of personal care and an appropriate environment.

c) Some characteristics of the new disabled

What we are calling here the 'new disabled' have the advantage that when they first encounter disability as an accompaniment of ageing they do so from a background of more or less well developed life-long independence. On the other hand they may be faced with both psychological and technical difficulties which are typically more severe than those the long-term disabled have to face.

On the psychological side, the social difficulties resulting from a deteriorating sensory disability, from speech loss or from incipient dementia may be severe, as may the shock, and consequent danger of depression and withdrawal, resulting from suddenly acquired disability after a stroke or heart attack. The new disabled have a most understandable difficulty in recognising or coming to terms with their own disability. They may be acutely vulnerable to the fear of stigma; however specific and severe the disability that has fallen on them, it may be a priority for them not to think of themselves as disabled and to regard being called this as virtually an insult. Naturally therefore they may not wish to be identified with the long-term disabled, to associate with them in a planned way or to join their associations. But in this way they cut themselves off from the most accessible and relevant source of information and advice which they vitally need - on how to choose and obtain aids, for example, or how to relate to services and overcome environmental handicaps.

This probability of isolation from the 'community' of disabled people is all the more detrimental given that the new disabled, at a time of life when learning and adjusting to new demands is generally not easy, will be faced with a whole set of moral and technical problems which are unfamiliar to them and for which they have had no preparation. Meanwhile the belief that sadness is part of the natural condition of age may contribute to failures in diagnosis of clinical depression. The sense that 'life has become a burden' may be particularly common among the new disabled, leading to self-neglect and even self-destruction,

partly therefore accounting for the high rate of suicide among elderly people. At the same time carers are subject to acute sensations of guilt whether in the face of sudden changes, for example as a result of stroke, or of more usually gradual but irremediable declines such as dementia.

Quite apart from any psychological impediments, the new disabled will have to face formidable practical problems for which they will have had no preparation. They will have no knowledge of what technical aids are relevant to their needs and available, of how to obtain them or of how they are paid for. At their stage of life it is likely that a number of the most effective aids or systems will be inaccessible - braille or guide-dogs for example, for those acquiring visual disabilities, the use of sign-language or a facility with subtitling for those who become deaf, or, in the case of many various disabilities, the capacity to master sophisticated aids to communication and environmental control. Many ageing people have also established themselves in old housing which may be particularly difficult to adapt in response to new physical infirmities. It cannot be said to be likely that the new disabled will encounter services of advice and information adequate to compensate for these deficits; it is even doubtful if policies for the provision of such services commonly exist.

These difficulties in basic functioning will also be found when encountering the external environment. The new disabled have to learn, when new learning is the last thing to be welcome, all the infuriating details of possibility and impossibility in public transport and in access to the administrative, commercial and cultural facilities on which a life worth living partly depends. More important still, they may have to find a new home, an experience which may involve either the elimination of that concept from their lives or a new and alien meaning for the word.

Although this paper is not essentially addressed to the medical sector, there are three sets of specifically health-care problems of such crucial importance for the elderly new disabled that they must be mentioned here. First, the immediate availability of certain surgical operations, notably those concerned with hip replacement and cataract, is an essential prerequisite to the establishment of a new active way of life for a large number of people confronting disability for the first time as they age. Delays in this provision, which may be excessive, can undermine the building up of a new life programme at its most critical and sensitive stage.

Secondly, the importance of medical and functional rehabilitation is so familiar in discussion of the needs of young disabled people that its relevance to the problems of disability and ageing is easily overlooked. Yet the need is paramount. Since some 70% of people who experience a stroke recover from it, the number of those who survive with serious new disabilities in urgent need of rehabilitation is considerable; as to survivors of heart attack, a recent survey in the United Kingdom suggests that only one third of them in need of rehabilitation are

receiving it. Rehabilitation is equally essential when new sensory disabilities occur.

Lastly, the new disabled may suffer from a failure of the professional services to distinguish the onset of a new disability - which may have a good prognosis, but only if its specific needs are addressed - from what are considered the general declines of function associated with ageing. The earlier stages of the onset of dementia are perhaps the most obvious example. Researchers however have noted also the failure to diagnose depression, for which useful treatment may be available but is not even thought of; similarly, deafness may be confused with incipient senility or mental retardation. Weaknesses in the effective transfer of personal records between different institutions or systems are mentioned as a common cause of such errors, which may evidently have profoundly harmful implications for the individual. Late onset of diabetes may also be hard to recognise, with sometimes serious consequences.

For the new disabled therefore what stand out in conclusion are their own difficulties in accepting and adjusting to their disability. To this however must be added the specially intractable and indeed tragic circumstances created as a result of dementia, brought on most often (in about 50% of cases) by Alzheimer's disease or by a series of minor strokes. Though a good educational background is thought to be some protection against its worst effects, seminar members agreed that dementia created exceptionally severe problems for those trying to live independently. Over and above the many practical difficulties which ensue, the hardest aspect of deteriorating dementia for carers to bear is probably the breakdown of communication, affection and even personal recognition.

It is obvious from what has been said about the problems of the new disabled that in addressing them primacy must be given to services of information, guidance and advice, and to the training of both professional and informal carers. Also, as with the long disabled but in a different way, there will be dangers to anticipate and avert on the side of income support and allowances.

d) **Some common problems**

There are naturally also many factors which are common to the situation of both the long-term and the new disabled; the majority of the most important of these have already been identified in section 1 above. There are a few however that need stressing here. First, whatever the history of the onset of their impairment, all elderly disabled people are vulnerable to deterioration of an existing disability or acquisition of an additional one; for all therefore sensitive and reliable services of diagnosis and prevention will be among the highest priorities.

Secondly, the seminar noted that significant progress in the planning and delivery of services cannot be made as long as people's conditions are expressed only in terms of medical causes

and definitions. New systems should be devised for describing needs according to functional disability, and the recent initiative of the World Health Organisation in this direction is to be welcomed.

Thirdly, stress was laid on specific difficulties which occur when elderly disabled people are, perhaps quite rightly, relocated. For one thing, medical and other records are sometimes not available or not transferred. Separation from the informal networks of friends and relatives can also be a serious problem.

Finally an interesting point was made about the effects of economic and social progress. New generations of both the long-term and the new elderly disabled will have different and generally higher expectations of what life should offer them. It is not therefore enough to plan for the future simply on the basis of those services and facilities which are thought to be acceptable at the present time.

3 Establishing policy aims

Any discussion of the measures required to meet the needs of elderly people who are disabled must be preceded by a statement of policy aims. Without this there is the almost certain danger that needs will be underestimated since they will be conceived as 'needs as now perceived' in a general situation where it is still true that many elderly and many disabled people are trapped in under achievement so that they and their carers - even the professionals - undervalue their potential.

'The Grey Agenda', published by Eurolink Age at the time of the 1989 European Parliament elections, refers to the need for 'integrated and comprehensive' policies. This is particularly important as soon as we have to take disability into account as well as ageing: 'integrated', for the obvious reason that ageing and disability policies will have to be coordinated and made coherent; 'comprehensive', since the demands of disability, both on the physical environment and on medical and personal services, go wide and deep. Yet it must be observed that these ideas are generally unpopular with governments (not least when they meet together in the framework of the Council of the European Communities); disability, like ageing, is an embarrassingly cross-sectoral domain and the means for effective transverse operations do not as a rule exist in Member States.

In the same document, as well as elsewhere, there is reference to the rights of elderly people. This also is a concept which will be welcome to disabled people, and which must not be abandoned - whatever the United Kingdom may do to try to have it eliminated from the texts.

The 'Grey Agenda' specifies first those rights which should be listed under the heading 'social protection': a minimum guaranteed income is included, together with a warm well-lit home, adequate and nutritious diet, health and social services, a safe and accessible living environment and four intensely

personal requirements - 'dignity, choice, independence, privacy'. The Eurolink Age document continues: '.....(a Community initiative)..must also make reference to income provision, health and care services, economic and social participation, discrimination, representation, access to information, education and training'.

It is important to stress, what may not be obvious, that for disabled people the more positive and active elements in these excellent lists will be even more welcome than the rather passive and protective ones. Choice and independence (autonomy, to be more precise) are fundamental elements of enlightened disability policy; so also is representation. Economic participation is something which one might have felt was merely a polite hope only a few years ago. Now all that has changed: elderly people have an exciting future on the labour market and elderly disabled people will want to be among those benefiting from this. Social participation is also an essential positive element and should include all aspects of cultural life and leisure, and political life too.

Finally, the importance of the inclusion on the second list, of education and training should not be underestimated. Theoretically it would be hard to set any limit to the expansion of educational activity on the part of the elderly people of Europe in the next two decades; the existence of an international association of universities of the third age is one witness to this. The full participation of elderly people who have disabilities in this new flowering of opportunity is something we must fight for. That includes of course all those intelligent elderly people who have to contend with the effects of motor or sensory or psychological impairments; equally important candidates are those people who have throughout their lives experienced learning difficulties, including those whose disabilities are severe or profound, who are sharing in the general phenomenon of increased longevity and whose educational needs in third age present a new and welcome challenge.

There are two other points of a general character which need to be borne in mind if the right approach to these goals is to be found. The first is that everything possible should be done to harmonise regulations and service provision aimed at elderly and at disabled people in such a way that those who are both disabled and elderly do not suffer disadvantage as a result of confusions or anomalies. The other is that, without detracting from any special provision (for example in favour of war veterans) already in force, rights and services should in future be allocated in response to the consequences of a disability not to its cause.

It is with these goals and approaches in mind that the Code of Good Practice which constitutes Part I of this document has been drawn up.

C The European Contribution

1 Community Possibilities

It is often said that the purpose of Community activity in the social field is to 'reinforce the efforts of the Member States'. This is diplomatic language and as such we may have to make do with it, provided it is understood that in reality the Community should and will often give the lead both in establishing principles, goals and standards and (at the practical level) demonstrating good practice and fostering innovation. We should moreover never forget that the once orthodox notion that the term 'European Community policy' could only be applied to a very few fields such as agriculture is now dead.

Equally, we should be clear that the principal criterion of success for any Community initiative in the social field is the extent to which it is an effective agent of change in the Member States - in all Member States, and at local and regional as well as national levels. For the elderly disabled this means policy development covering a number of profound issues: the notion of a national Charter of Rights for elderly disabled people and for their carers was among those stressed during the discussion. Others were the elimination of discrimination; reform of systems of taxation, social security and pensions; opportunities for education, training and work; and support for advocacy. 'Putting human energy into policy development' was identified during the seminar as one of the most fruitful roles the Commission can undertake.

Policy initiatives (including Community legislation) are indeed one of the three principal kinds of action which the Community undertakes in the domain of social affairs; the others are major funding operations (such as the European Social Fund), and multi-faceted action programmes (such as Helios, the current action programme to promote the economic and social integration, and the independent living, of disabled people) It should be stressed that the first of these is not the only one which can bear on national policy. Technical and financial interventions of the Community can also be used as means for learning how to determine policy aims and select the most effective measures; if national governments are not always quick to act in this way, pressure groups can use the European experience to persuade them to do so.

Of the three kinds of action, the chance that a scheme of major Community funding in favour of elderly disabled people might be introduced in the foreseeable future can be put aside. There could be no legal basis for intervention on such a scale without an amendment to the Treaty, and, although we must not say that such a thing could never happen, it would be unrealistic not to admit that a great deal of progress over quite a considerable time would have to be made before it could even be contemplated.

The ideas of an action programme and also of a policy initiative (or a series of these) concerned - not necessarily exclusively

- with the needs of the elderly disabled are on the other hand real possibilities. Indeed the best strategy of all is to integrate work at policy level with the more technical activity typical of an action programme. In this way, those who are preparing a proposal for policy development can draw easily and directly on Community-wide up-to-date evidence about problems and solutions; equally, once a Community policy instrument is adopted, the action programme can supply situations in which its implementation can be pioneered and demonstrated.

The value of this integrated approach can be seen in a number of the components of the Commission's social action programme to date, and above all in the promotion of equal opportunity for women where it was first consistently adopted. In the fields of education and free movement it has been less prominent except where they intersect, that is on the question of the education of the children of migrant workers. It was consciously brought into play in the first (1981-1987) action programme on disability, by means of the 1984 Recommendation on the Employment of Disabled People. In addition, the Commission is currently preparing a draft Directive on Mobility and Transport for disabled people. In order to find a dependable legal basis for this Directive it may well be necessary to found it on the new (Single European Act) article 118A of the Treaty which concerns the health and safety of workers. Nonetheless many of the improvements in transport and related facilities achieved as a result of the Directive would effectively benefit all disabled people, including those who are elderly.

The two kinds of action at European level which we shall now briefly explore, technical cooperation and stimulation by means of a diverse action programme, and the development of Community policy by means of recommendatory or constraining instruments, should therefore be understood as being complementary and interdependent. The importance of strategy design is obvious when it is remembered that what the Community has to offer is unique, literally unobtainable elsewhere.

But first one other preliminary word: we must remember that Commission action, in addition to its impact on Member States, may also be of interest and benefit beyond the frontiers of the Community itself; indeed, there is clearly a responsibility for the Community to share its experience and above all to support similar initiatives in other including developing countries. Non-governmental Organisations are important partners in this endeavour, while cooperation with European organisations (such as the European Conference of Ministers of Transport and the Council of Europe) is seen by the Commission as another essential part of its task, as also with the International Organisations, notably the United Nations and its agencies.

Furthermore professional training strategies and modules developed in the Community could be adapted for use in developing countries. Cooperation entails mutual benefit: in the voluntary sector, the work of the recently formed World Association of Home Care will certainly be of interest at European level, while the

contribution of the UN Institute on Ageing in Malta and the new level of attention given to these questions by the World Health Organisation ensure that the Community will benefit from international cooperation as well as contributing to it.

2 The idea of an Action Programme

In March 1990, the European Commission published proposals for an action programme for elderly people to start in 1991 and to run for three years. These proposals are currently under consideration and it is hoped will reach a Council of Ministers decision by the end of the year. As well as being an invaluable complement to Community policy development in the way that has just been described, an action programme brings a number of other precious advantages. It is an enormous encouragement to its primary clients and to those who work with and for them, since it enables them to perceive that their needs are formally recognised at the European level and that the Community is committed to at least some practical effort to meet these needs. And of course the cooperation and exchange have immediate practical effects: professionals and others do in fact learn from good results elsewhere and adjust their practice accordingly.

At least as important, the adoption of a recognised action programme means that the interests of those concerned have really 'arrived' on the Brussels and Strasbourg scenes and that their affairs and the progress of the Community response to their needs will continually be before the notice of the Community Institutions. It is also worth recording that once a moderate budget for the implementation of an action programme has been voted, very reasonable levels of flexibility may be permitted in the use of it, and the chances of developing it in the light of the increased demand which the process of exchange inevitably excites are also not at all bad.

There is ample experience at Community level of the kinds of activity which are worth considering for inclusion as elements in an action programme in the social field. These will include activities which the Community has already entered into on behalf of elderly people; in that case a first official action programme would offer the chance of intensifying and extending them, while also making it possible to do for the first time things that had not before been attempted. A list of actions to think about when planning should include:

- studies as a basis for operations and policy development
- encounters aimed at consultation, 'brainstorming', consensus reports, dissemination etc
- study visit schemes and other exchanges
- joint training courses
- networks of model projects
- grants to the European activities of Non-governmental Organisations
- publications and data bases
- setting up of a clearing house for information exchange and cooperation between researchers.

Unfortunately, the Commission's current proposals are limited, and include information exchange, studies and seminars, and preparation for networking of innovative experiences. They stop short at substantial proposals for an action programme including innovative local and pilot projects.

Looking to the future, however, it would of course, not make sense to propose the adoption of a separate action programme devoted to elderly disabled people alone. Instead, a new programme for the benefit of all elderly people could contain a commitment to include within it a special concern for the particular needs of elderly people who are disabled, and would include some specific activities focusing on these. On the other hand the contribution which the Helios programme is making to the needs of the elderly disabled should not be ignored - rather its extension in the future should be fostered. A rationale for sharing the responsibility between the two domains and for coordinating the whole will be suggested in 4 below.

The seminar identified a number of specific contents to which such an action programme could give priority. Research could include comparison at Community level of the results of various measures; databases should establish uniform means for categorising the day-to-day functional needs and problems of elderly disabled people and develop statistics revealing the percentages of those in institutions and of those living in the community whether independently or cared for.

Most valuable of all, perhaps, is the identification and dissemination of models of good practice, most often derived from project networks. Numerous important contents for this treatment were mentioned. They included strategies for making accessible to elderly disabled people and to carers information about rights and services and about the environment to independent living; examples of good residential institutions, of effective coordination, of how local projects can be set up and how research results are best disseminated; of successful measures in the fields of assessment, prevention and advocacy.

Before leaving the idea of an action programme, we need to stress again the vital importance of the part to be played by Non-governmental Organisations (NGOs). Their potential value has recently been highlighted by the extra 1.2 million ecus which the European Parliament has voted for the Helios programme. Equally important is the help which NGOs can give to the Commission in the design of programmes and the preparation of policy proposals; this support is not marginal but essential.

There are three points concerning NGOs which will need vigilance in the future. The first concerns the notion of **solidarity**, one of the principal themes action programme proposal for elderly people; this could be an important breakthrough in view of the apparent lack of this or any equivalent concept in the vocabulary of the organisations for disability. While it will ultimately depend on the NGOs whether or not it is carried forward, the

likelihood that the Commission will support its development in the second Helios programme is to be welcomed.

Secondly, it must be observed that although Eurolink Age is a member of the Commission's Liaison Group for the Helios disability programme, it is there under the present rules not as one of the six permanent member organisations but among the three temporary ones. This is unsatisfactory as things are; it will become very much less acceptable once an action programme on ageing is under way, for reasons which are evident throughout this section of the report. It may not be possible to change the rules within the current Helios programme; but 'Helios II' will be on the drawing board next year, so that an opportunity to put this right which should not be missed is not far off.

Thirdly, there is the question of the direct participation of the clients themselves in European discussions and activities which concern them. There will be the need for a new involvement of men and women who are both disabled and elderly - and that will mean representation of both the 'long-term' and the 'new' groups. Their effective presence at European level will depend on the extent of their active participation in the daily work and decision making of the national voluntary bodies.

3 Action at policy level

It is possible that a successful action programme might be able to engender sufficient political will for the Commission to bring forward one or more policy instruments, at least at the level of Recommendations, on specific issues whose importance the action programme itself had highlighted. A more fruitful strategy might however be to carry through a general framework initiative, covering among other things all the needs of elderly people, including those with disabilities, on the basis of which a series of specific policy instruments could be introduced. Such a framework proposal could well take the form of a Declaration, the formula which was used for the recently adopted Social Charter.

It is evident that the Social Charter which exists will not serve the purpose. What in May 1989 was entitled a 'Charter of Fundamental Social Rights' had become by November a 'Charter of Basic Social Rights for Workers'. However optimistic we may be about the positive effects of demography on the chances that in the future elderly people who wish to do so will be able to find paid employment - and we must hope soon to see more open recognition of this possibility in Community documents - it is obvious that a Workers' Charter is not a basis for the main thrust of initiatives in favour of elderly people in general or of elderly people who are also disabled.

This reality can be seen even more clearly if we look at the specific texts of the present Charter and of the Commission's proposed action programme in implementation of it. Indeed in some measure it goes back to the Single European Act itself in which the new Article 118 A of the Treaty mandates the Commission to bring forward directives on the 'health and safety of workers,

especially in the working environment'. One had always supposed that 'especially' was a word detested by jurists: the expression pretends to mean something more generous than '(exclusively) in the working environment', while in reality no proposal extending beyond that environment will ever receive serious consideration. This is precisely what has happened in the Charter and its action programme, in both of which only 'health and safety at the work place' is even mentioned. This outcome is little short of calamitous for all disabled people of whatever age: it is evident that, uniquely for disabled people, the offer of work or training is quite useless if there is no suitable housing within reasonable distance, no accessible means of transport to the work place and no way of entering the building on arrival. Similarly, what is called the 'improvement of living and working conditions' in both the Charter and the programme deals only with terms of employment.

Our main concern however should be not with what the Community has achieved but with what it could achieve; recent history has taught that we should be ambitious in our vision of what is possible, not dismayed by the sceptics and the legalists who have been proved wrong so often now that it would be merely feeble not to ignore them. The reservations in what the Commission has to say about elderly people in the current Social Charter action programme should be taken as a challenge not a dismissal; the proposed designation of 1993 as the Year of the European Community for the Elderly corroborates this view.

We should start now laying the foundations of a campaign for a new Social Charter which would establish a European Bill of Rights - a solid social guarantee for all those adult citizens (children would need something of their own) excluded from the Workers' Charter. The constituency is large and politically formidable: it includes not only most elderly people but all housewives and other full-time home-makers or informal carers, many severely and multi-disabled people and the members of the 'fourth world'. An alliance of these interests would constitute a politically powerful grouping and the preparation of a New Community Social Charter focused on their needs within three or four years would not be beyond possibility.

This would seem both a more solid and a more dynamic approach than the promotion of a Charter for elderly people alone; it could be linked to the general attack on the distorted view of the Community as nothing more than a labour market, a view which owes much to the undue importance of the structural funds. That does not mean that the specific needs of elderly people, and of elderly disabled people, would not be accommodated. On the contrary, the New Charter would be the basis for many instruments - which might be Recommendations or where legally possible Directives - on particular issues of priority concern to the various groups whose needs the Charter addressed.

Which priority issues in the field of disability and ageing should be selected as the content of policy instruments could no doubt emerge from the learning experiences of the action

programmes on disability and ageing. It is too early now to try to identify them; one could guess however that the need for harmony and fairness for all concerning income and benefits is likely to be one of the first to command attention. At all events the Code of Good Practice which occupies the first part of this report offers a comprehensive check-list for this purpose.

4 Coordination and responsibility

Critics of Community endeavour, particularly those who are enamoured of inaction, often speak of the dangers of 'double emploi'. In reality, the danger that 'frontier' issues will be neglected or misrepresented is much greater.

It would seem reasonable that official responsibility for guarding and promoting the interests of elderly disabled people at Community level should be jointly undertaken by means of a collaborative and coordinated action on the part of the Division in the services of the Commission responsible for the Helios disability programme and the unit responsible for the problems of ageing. The Commission's officials present at the seminar themselves pointed out that the success of such cooperation is virtually ensured by the fact that the two units are located in the same Directorate. The interest shown by the Commission's representatives in the seminar, and the support they afforded to its organisation and objectives, are a further guarantee of this.

The first task in this regard will be to set up a means for monitoring the inclusion of elderly disabled people and their needs in all Commission proposals whether for action programmes or for new Community policy. This will apply of course first to all proposals about elderly people, and secondly all those concerned with disabled people; but action in the fields of equality for women, the rights of migrants and poverty will need to be monitored too. Also important for elderly disabled people are developments in the field of new technology, and therefore many of the Community research and development activities in that domain will need to be followed. The programme of Directorate General XII on medical research - one of whose experts informed the seminar of the importance now being attached to the questions of ageing in that framework - and the work in the context of the Cooperation in Science and Technology should also not be ignored.

The decisions which have to be made if mistakes are to be avoided may be difficult and finely balanced. For example, it could be enough if any future proposal on the employment of disabled people were to include a carefully prepared specific reference to elderly disabled people; whereas there is a strong case for arguing that all future initiatives concerned with transport, access or housing should in the first place be designed not for disabled people alone but for disabled and elderly people together. Proposals concerning incomes and benefits for elderly and disabled people, on the other hand, might need to be entirely separate, in view of their different legal structures in the Member States; if so there would need to be separate provision

yet again at Community level for those who are both elderly and disabled.

For some projects coordination may have to lead to close active cooperation or even assimilation. This could be the case for the development of data bases, if, that is, it is decided to follow for ageing the same technical approach as the Commission has adopted for disability by means of the Handynet project. This activity, on the point now of becoming fully operational, could certainly accommodate some of the information needs of those disabled people who are also elderly and of the professionals who work with them. It would seem unlikely however that Handynet will be able to cover all those needs; for this it will be necessary to coordinate a number of initiatives, among them no doubt the Commission's data base on family problems.

Mention has already been made of the Commission's draft Directive on the mobility and transport of disabled people. It is possible that this may include a practical proposal for the institution of a European Travel Card for Disabled People, and if so there will be an urgent need to optimise the relationship of this with the Recommendation for a 'European Seniors Pass' put forward by the Commission in June 1989.

Other examples of activities which will require close coordination will no doubt present themselves as the new action programme gets under way and again when Helios II is being actively prepared. In that connection, it was suggested that the problems of disability and ageing should be one of the explicit priority themes of the Local Model Activities under the second Helios programme. In the meantime, a new initiative from the Commission, in the form of a major statistical and definitional study on disability is now being launched within Helios I with the collaboration of the Commission's Statistical Office in Luxembourg, aimed at covering all age-ranges, including the elderly and the very elderly.

5 Conclusion

This report has already drawn attention to the support, personal as well as financial, which the Directorate-General for Employment, Industrial Relations and Social Affairs afforded to the seminar. In addition, a joint meeting (April 1990) of the European Parliament's Inter-groups on disablement and ageing discussed the Code of Good Practice included in this report. It is hoped this will lead to a Parliament Resolution on age and disability, or at least some particular attention to this theme in the Resolution which will be adopted in response to the Commission's action programme proposal on ageing.

We should mention also here the very active and positive contributions made to the seminar by the representatives of the Economic and Social Committee and the Dublin Foundation on Living and Working Conditions. The seminar welcomed both the information on the Dublin Foundation's current work on care and supporting

services for elderly people, and the suggestion that ECOSOC might undertake an 'own-initiative' report on disability and ageing.

Eurolink Age is encouraged, as it addresses this new, certainly formidable theme, by the reflection that it will be able to call on powerful allies.

Annex I

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