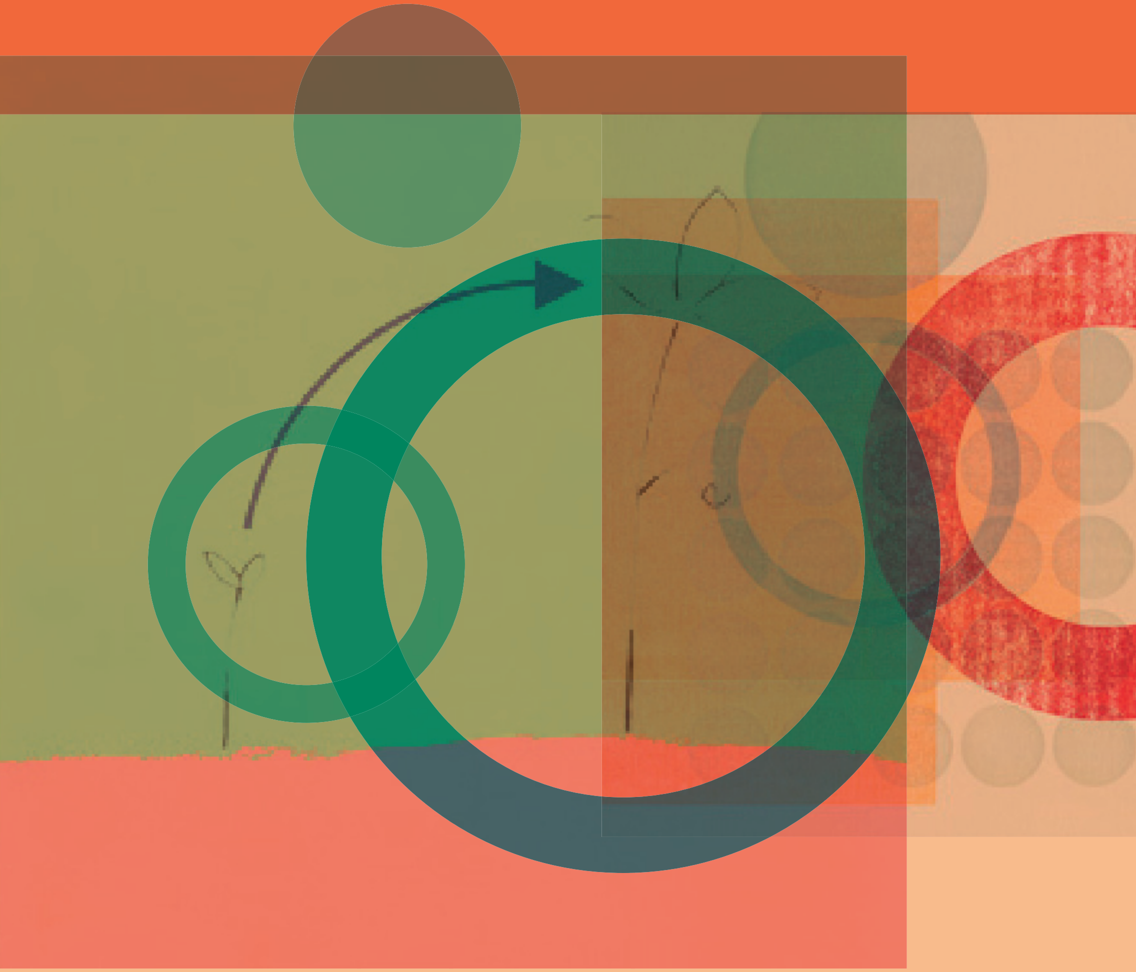
Citizens not patients: developing innovative approaches to meet the needs of disabled people



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Citizens not patients: developing innovative approaches to meet the needs of disabled people

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in co-operation with the Drafting Group
on community living for people with disabilities
in need of a high level of support (P-RR-COLI)

Committee on the Rehabilitation and Integration
of People with Disabilities (CD-P-RR)

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Preface

The Council of Europe

The Council of Europe is a political organisation which was founded on 5 May 1949 by ten European countries in order to promote greater unity between its members. It now numbers 46 member states.[1]

The main aims of the Organisation are to reinforce democracy, human rights and the rule of law and to develop common responses to political, social, cultural and legal challenges in its member states. Since 1989 the Council of Europe has integrated most of the countries of central and eastern Europe into its structures and supported them in their efforts to implement and consolidate their political, legal and administrative reforms.

The Council of Europe has its permanent headquarters in Strasbourg (France). By Statute, it has two constituent organs: the Committee of Ministers, composed of the Ministers of Foreign Affairs of the 46 member states, and the Parliamentary Assembly, comprising delegations from the 46 national parliaments. The Congress of Local and Regional Authorities of the Council of Europe represents the entities of local and regional self-government within the member states.

The European Court of Human Rights is the judicial body competent to adjudicate complaints brought against a state by individuals, associations or other contracting states on grounds of violation of the European Convention on Human Rights.

Partial Agreement in the Social and Public Health Field

Where a lesser number of member states of the Council of Europe wish to engage in some action in which not all their European partners

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[1] Albania, Andorra, Armenia, Austria, Azerbaijan, Belgium, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Georgia, Germany, Greece, Hungary, Iceland, Ireland, Italy, Latvia, Liechtenstein, Lithuania, Luxembourg, Malta, Moldova, Monaco, the Netherlands, Norway, Poland, Portugal, Romania, Russian Federation, San Marino, Serbia and Montenegro, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, “the former Yugoslav Republic of Macedonia”, Turkey, Ukraine, United Kingdom of Great Britain and Northern Ireland.

desire to join, they can conclude a ‘Partial Agreement’ which is binding on themselves alone.

The Partial Agreement in the social and public health field was concluded on this basis in 1959. At present, the Partial Agreement in the Social and Public Health Field has 18 member states.[2]

The principal areas of activity are:

- rehabilitation and integration of people with disabilities
- protection of public health and especially the health of the consumer.

The activities in the sphere of rehabilitation are supervised by the Committee on the Rehabilitation and Integration of People with disabilities and guided by the Coherent policy for people with disabilities, adopted by the Committee of Ministers of the Council of Europe in 1992 as Recommendation No. R (92) 6. The Partial Agreement is committed to upholding the rights of people with disabilities and advocates for their integration and full participation in society. Such a commitment should also be seen against the background of the European Convention on Human Rights and the European Social Charter, both major instruments of the Council of Europe.

The present report has been prepared by Professor Hilary Brown, consultant, in co-operation with the Drafting Group on community living for people with disabilities in need of a high level of support, a sub-group of the Committee on the Rehabilitation and Integration of People with disabilities. Special thanks are due to the Salomons Centre for Applied Social & Psychological Development, Canterbury University College, United Kingdom, for having made Professor Brown available for this project.

The report was presented at the Second European Conference of Ministers responsible for integration policies for people with disabilities, Malaga, Spain, 7-8 May 2003, entitled: “Improving the quality of life of people with disabilities: enhancing a coherent policy for and through

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[2] Austria, Belgium, Cyprus, Denmark, Finland, France, Germany, Ireland, Italy, Luxembourg, the Netherlands, Norway, Portugal, Slovenia, Spain, Sweden, Switzerland, United Kingdom of Great Britain and Northern Ireland.

full participation”. It provided the background for the discussion of the sub-theme “Developing innovative approaches to meet the needs of disabled people”.

Further information on the Ministerial Conference is available on www.coe.int/soc-sp

Abstract

This report restates earlier commitments to people with disabilities[3] and invites member states to adopt policies which are underpinned by anti-discrimination and human rights frameworks. Progress requires the active removal of barriers and the adoption of the universal design principle to ensure that new barriers are not created and at the same time the development of local service models which take full account of individual needs, preferences, entitlements and circumstances. To achieve this, governments should consolidate measures already in place and strengthen elements of the infrastructure necessary to underpin high quality service provision. The goal is that persons with disabilities should be empowered so that they can take their place as citizens and play a full part in our communities.

Governments should:

- work within anti-discriminatory and human rights frameworks, improving access to all public facilities through the use of the universal design principle, and strengthening co-ordination across and between government departments, with a particular commitment to promoting equity in mainstream service provision, health care and the legal system as well as improving accountability between local, regional and national areas of responsibility;
- provide high-quality, tailor-made services, which are accessed via published eligibility criteria, based on thorough, but equitable assessment, shaped by the disabled person's own choices, autonomy, welfare and representation, with proper safeguards, regulation and access to independent adjudication of complaints;
- refocus their policies to take full account of the needs of children and older people with disabilities without detracting from the current commitments to disabled adults of working age, whether or not they are in employment, noting that employment cannot be allowed to stand as the only measure of citizenship, arena for participation and route to human dignity;

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[3] As set out in the European Social Charter, the Revised European Social Charter (Article 15), and the Council of Europe's Recommendation No. R (92) 6 on a Coherent Policy for People with Disabilities.

- act to champion the inclusion of disabled people in all walks of life through public education and by making a visible commitment to them as citizens with agency in, and over, their private lives and use of public services.

1. A principled approach

This report restates the commitment of states to the Council of Europe's Recommendation No. R (92) 6 on a Coherent Policy for people with disabilities, adopted by the Committee of Ministers of all Council of Europe member states on 9 April 1992, that all disabled people should be helped to lead independent lives and given whatever assistance they need in order to participate in the social, economic and political affairs of their communities.

These commitments are rooted in a human rights approach to disability that guarantees important freedoms including liberty of movement and freedom to choose where to live; respect for private and family life, home and correspondence; and protection from incarceration or detention; torture, inhuman or degrading treatment or punishment. Specifically Article 15 of the Revised European Social Charter guarantees "persons with disabilities, irrespective of age and the nature and origin of their disabilities the effective exercise of the right to independence, social integration and participation in the life of the community".

A country which is well managed will promote solidarity with, and empathy for, disabled people as fellow human beings, and there is a broad consensus that respect for human rights, integration and equal citizenship form the core of morally coherent policies. Universal rights and entitlements, such as to health care and benefits are one cornerstone of this commitment but service provision should then be designed to meet the needs of individual disabled people and their families and shaped by demand rather than offered as monopoly provision to everyone regardless of their needs or wants.

2. Progress in a changing society

Disabled people and their families have legitimately campaigned for measures to be put in place which assure their place in the mainstream of our communities and which uphold their rights to live valued lives of their own choice.

Nevertheless progress is taking place against a dynamic but unstable backdrop for all countries, in which important factors are affecting social and economic policy, including:

- changing demographic patterns, with age and family structures changing, a greater preponderance of older people, more single person households, fewer children per family, higher rates of divorce and more single parent families;
- changing patterns of employment with women entering the workforce in greater numbers and households becoming increasingly reliant on dual incomes in certain countries, with greater inequality between, as well as within, countries in terms of economic resources and security of employment;
- new models of governance and accountability in public service departments and agencies in which there has been a breaking down of traditional local and central government monopolies when it comes to service provision leading to a "mix and match" of services provided by independent, (for-profit and not-for-profit), agencies as well as more traditional NGOs, religious and charitable organisations;
- shifts in contractual arrangements and managerial relationships which have knock-on effects for employers, and employees and for the balance between professional and low skill (low-paid) workers;
- better assistive technologies and access to the Internet[4] which provide solutions to issues of mobility, sensory and communication impairments;
- greater technological sophistication providing some answers for disabled people in terms of more accurate diagnoses and potential treatments but this also generates new demand, decisions about rationing of scarce resources and raises disturbing questions, such as in the context of genetic screening and selective abortion. These new technologies give rise to complex and critical ethical dilemmas; they also risk inadvertently providing a new discourse for the dehumanisation of disabled people which has unwelcome echoes of earlier eugenic ideologies;[5]

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4. Council of Europe Resolution Res AP (2001) 3 'Towards full citizenship of persons with disabilities through inclusive new technologies', Council of Europe, Strasbourg 2001.
5. Ward, L. (2001) Considered Choices: the new genetics, prenatal testing and people with learning disabilities, Routledge London.

- war and economic instability that have caused increased migration with concomitant social upheaval and mental distress: the Council of Europe underlines principled respect for the human rights of disabled people and their families living in war-torn countries and in regions that are struggling to provide a decent standard of living for all their citizens;
- continued reliance for many disabled people on services provided in segregated or institutional settings in which their rights, privacy, safety and even basic requirements such as food and hygiene may be routinely compromised.

Most governments are making good progress towards service provision that empowers users, promotes integration and is tailored to individual need in nature and intensity, but they are starting from a different baseline and have varying levels of resources. Where countries are stressed and communities fragmented and/or under-resourced it is understandable that services are offered in more centralised and institutional settings, designed to meet basic needs in uniform ways, but as soon as it is feasible to provide choice and differentiated assistance this should be the goal. Steps towards this include the development of access/outreach services to identify those individuals and families in need of support; assessment to assure equitable access to service provision; innovation in funding and the provision of a range of local services. No country, starting from scratch, should invest in institutionally-based services but in those countries where resources are tied up in such provision, standards must be maintained. Even while resources are being transferred from institutional to community-based services, governments should uphold the human rights of disabled people living in institutions and guarantee the quality of their basic care.

Despite these challenges countries within the Council of Europe remain committed to policies that emphasise citizenship and anti-discrimination as set out in Recommendation No. R (92) 6 on a Coherent Policy for People with disabilities and the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

While disabled people were traditionally seen as “patients” or passive recipients of services, modern societies increasingly promote active participation of the individual as citizen and consumer in expressing his/her needs and contributing to the design of the services he/she receives. The empowerment of the person with a disability as the user of the service is an important step towards the achievement of full citizenship and may be supported in some places by direct payments or other forms of alternative service provision.[6] If disabled people are to be empowered to make valid choices as informed consumers they need to have viable alternatives, information about what is available and indicators of how services perform against agreed standards.

3. A changing population of disabled people

Countries also face new demands including changing demography and a growing number of people with high support needs. Demographic change is sometimes hidden behind changes in service usage; nevertheless the population of disabled people is changing and this presents new challenges to governments and service providers. Trends may not be easy to discern because countries have different ways of defining and assessing eligibility for services and benefits, using a range of ordinal scales (BAREMA's)[7] traditionally based on the WHO International Classification of Impairments, Disabilities and Handicaps (ICIDH 1980) and soon to be based on the new WHO International Classification of Functioning, Disability and Health (ICF)[8] which will allow for more accurate comparative studies of incidence and service usage[9] and of the relationship between actual and administrative "incidence" figures.[10]

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[6] Glasby, J. and Littlechild, R. (2002) Social Work and Direct Payments, Policy Press, Bristol UK.

[7] Council of Europe (2002) Assessing disability in Europe:- similarities and differences, Strasbourg, Council of Europe Publishing.

[8] World Health Organization (2002) International Classification of Functioning, Disability and Health (ICF). The revised manual has shifted the emphasis from negative descriptions to more neutral descriptions of body structure and function, activities and participation and also includes a section on environmental factors in either facilitating or creating barriers for people with disabilities.

[9] International co-operation could be spearheaded by the European network within the International Society for the Scientific Study of Intellectual Disabilities (IASSID), representing the academic community and the European Disability Forum (EDF) which represents a user and carer viewpoint.

[10] See Appendix 1 for a worked example from the United Kingdom to show how actual incidence figures vary from those which record various forms of service usage.

Despite methodological difficulties a changing profile can be discerned. Until now disability policy in Europe has been predominantly concerned with the needs of disabled people of working age in relation to rehabilitation and employment but there is growing concern about the increasing prevalence and severity of disability in childhood and older age.

3.1. Disability in older people

It is clear that longevity brings increasing impairment, including age related increases in mental illness and dementias.[11] According to the United Nations, mental health problems are a leading cause of disability and reduced quality of life worldwide.

3.2. Disability amongst children and young people

Meanwhile the technology available to care for premature babies has improved dramatically in recent years, but babies born before 24 weeks are at increased risk of developing cerebral palsy, sensory impairments and physical disabilities, particularly those associated with heart and lung problems (Alberman et al 1992).[12] Prevalence figures for mental health and behavioural disorders are particularly variable[13] but rising in relation to emotional disorders, conduct disorders, hyperactivity, autism[14] and eating disorders.

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11. The Select Committee on Science and Technology (2000) Equal (Extend Quality of Life). www.parliament.the-stationary-office.co.uk, accessed 9.6.02, which categorised people with disabilities according to the severity of their disability, using the WHO International Classification of Impairments, Disabilities and Handicaps (ICIDH).

12. Alberman, E., Nicholson, A. and Wald, A. (1992). Severe Learning Disability in Young Children: Likely Future Trends. Wolfson Institute of Preventative Medicine, Department of Health, London.

13. One large county in the United Kingdom produced local estimates that suggested 40% of children and adolescents have a diagnosable mental health disorder with a more conservative estimate of 2.1% in whom this is severe enough to be disabling.

14. Wing, L. (1993) The definition and prevalence of autism: a review. *European Child and Adolescent Psychiatry,* Vol 2 (2), 61-74. There has been a seven-fold increase in children diagnosed with an autistic spectrum disorder from 0.3% per 10k in 1988 to 2.1% per 10k in 1999 (Kaye et al 2000). As yet there is no consensus about the cause(s) of this increase, although a publicised link with MMR immunisation has been discredited.

3.3. Different causes of impairment

The predominant causes of disability have also changed as a result of improved and more intensive health care. Disabilities caused by common infections have reduced to be replaced by non-communicable diseases and genetic or neurological disorders and malformation as leading causes of impairment.[15] Sometimes advanced technical interventions create their own dilemmas such as those that arise in the context of persistent vegetative state (PVS) or other conditions that lead the person to be continually dependent on medical technology for their survival; although individuals are helped to survive by intensive medical interventions the ongoing support they need may not match this technological input.

Disability may also increasingly be influenced by environmental factors as is the case with asthma[16] and allergies, acquired brain injury due to road traffic accidents, physical and mental impairments caused or exacerbated by social exclusion, economic stress, war and migration.[17]

Taken together these figures suggest increased, as well as changing, need for services and social intervention amongst children and young people, as well as increased demand from older people amongst whom disability is likely to be most frequent and severe. But these changes need to be addressed without jeopardising the gains that have been made for disabled adults of working age. This highlights the importance of valuing diverse citizenship and not allowing employability to be the only measure of worth or arena for participation.

4. Current policies and aspirations

There is also wide variation across member states in the mix of public/private service delivery, issues of quality control and financing, boundaries between professionals, basic care staff, family carers and volunteers; the balance of provision devoted to prevention, cure and

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15. See for example the case of visual impairment (*www.seeability.org*.uk).

16. According to the World Health Organization (WHO) asthma is the No. 1 disease in children worldwide.

17. See for example Roberts, K. and Harris, J. (2002) Disabled People in Refugee and Asylum seeking communities, Policy Press, and the work of the Social Policy Research Unit, University of York.

rehabilitation; the proper balance between specialist as opposed to mainstream provision and, last but not least, new forms of effective service management and consultation with disabled people and their families.

But although the practice, organisation and location of service provision varies from one country to another, there is considerable consensus about the aspirations of macro- and micro-policy in this arena, including the need to:

- maintain an emphasis on independence, autonomy, protection and representation, building services around the commitment to disabled persons as having agency in their own lives and acting in the role of autonomous citizens and consumers in relation to their private lives and usage of public services wherever this is possible;
- facilitate social inclusion through universal design and improved access;
- implement anti-discrimination legislation in relation to employment, access, education and equitable access to mainstream benefits and entitlements including health care, housing, employment and justice;
- create opportunities for integration and mainstreaming by moving from large segregated facilities to smaller, more homely, community-based service provision, although it is acknowledged that in developing countries it may not be possible or desirable to “leap-frog” from institutional provision to a total reliance on community services until these are properly established and meanwhile that resources have to be sustained to assure basic human rights are upheld in any institutional provision;[18]
- provide safe and sensitive mechanisms for making decisions on behalf of persons who are unable to represent themselves, in relation to any intervention which risks breaching their human rights; such as, for example, restraint or detention, so that

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[18] Schick, A.(1998) Why most developing countries should not try New Zealand reforms, The World Bank Research Observer, Vol. 13, No. 1, February 1998, pp. 123-131.

these decisions are made transparently, using the principle of proportionality, and are open both to public scrutiny and judicial review;

- provide services that are tailored to the expressed and/or assessed needs of disabled people and their families, using transparent, published eligibility criteria, and aggregate data to feed long-term planning and funding strategies;
- provide services which have appropriate forms of governance, accountability, regulation and audit, and which have mechanisms in place to ensure that resources set aside for disabled people are properly applied on their behalf without conflicts of interest between profit and provision;
- create and sustain professional and research networks to underpin evidence-based practice, tested through professional debate and impartial evaluation;
- provide mechanisms for disabled people, their families and representative organisations to influence the principles and priorities of provision in this field.

Implementing such a complex policy agenda demands co-ordination at, and between, every level.

At *individual* level good service provision is likely to be achieved through prompt and accurate diagnosis; sensitive multidisciplinary assessment and care planning (wherever possible a unified rather than multiple assessment should emerge from this process), agreed care pathways, with regular reviews, transition planning, feedback and evaluation. The investment in assessment should be proportional to the level of service that is being sought: some individuals require limited input and should not be subjected to complicated assessment to access these specific supports. It is likely that individuals will need graduated help which varies over time according to their needs and that advocacy will play an important part in helping disabled individuals and their families to articulate their aspirations and needs. Flexible funding including direct payments may be a means of providing person-centred services but only with safeguards in place. These should ensure that public money is used for the purposes to which it has been allocated and also that there are mechanisms which protect disabled people from financial abuse. Protection should be in place for the disabled person, (whether or not he/she is the direct employer) and for the worker as employee with rights to proper working conditions and considerations.

At *local* level, multidisciplinary teams need to work to agreed protocols and assessment formats, mechanisms to be in place for appropriate sharing of information and expertise across disciplines and agencies, person-centred planning and flexible commissioning of service provision, resource centre models to service independent and flexible placements, joint investment planning and partnership arrangements to facilitate pooled budgets and arrangements for audit of interagency working.

At *regional* level it requires cross-agency funding to sustain high quality, multidisciplinary centres of excellence linking research institutes, training and education establishments with service providers to ensure an adequate evidence base for practice, evaluation and innovation. Action plans, and cross departmental agreements are likely to be needed at all these levels, for example to secure adequate accessible housing or planning for residential care placements. Where disabled people are still living in institutions, funding should be incrementally shifted to support the development of community-based alternatives leading to the development of affordable and sustainable options. Where the maintenance of institutional services in the short term is unavoidable then independent advocacy must be put in place to assure that basic standards are maintained and that the human rights of disabled people who remain there are respected. In the first instance wards can be downsized and made to be more homely and informal; day programmes, normal leisure activities and better community links should be developed. In tandem, local and more integrated services should be built up. The goal should be to gradually shift from a supply-led system in which disabled people have to fit in with what is on offer to a demand-led system, shaped and developed in response to individual needs.

At *national* level delivery requires proper resourcing and regulation; the goal of national policies should be to ensure that regional autonomy does not result in disabled people receiving very different levels of support and assistance depending on where they live. National governments are also responsible for screening and regulating the workforce; commissioning and accreditation of appropriate training and protecting the rights of workers in terms of their working conditions, adherence to minimum wage regulations, holidays and family friendly working arrangements, and protection from discrimination, violence, or harassment at work. There need to be arrangements in place for cross-cutting initiatives that span relevant ministries and for the auditing of generic legislation for its impact on disabled people and their families. Equity and safeguards are also needed throughout other arenas of government responsibility such as health care and the criminal justice system.

At *Europe-wide level* consistency in provision would benefit disabled people and their families who move within, and between, countries. Where migration is forced, occasioned by war, persecution and/or economic necessity, host governments should make, and publicise, special efforts to provide for disabled refugees and asylum seekers. Harmonising measures and definitions and promoting strong research networks across national borders will assist in comparative studies and make it possible to pool data and learn from the experience of other countries and service systems.

Between these layers of administrative responsibility, local and central governments should sponsor public awareness campaigns on disability issues amongst the population at large and champion the inclusion of disabled people at all levels in public life. Provision and legislation is needed to address decision-making on behalf of persons who cannot make their own decisions. Measures need to be in place to uphold the rights of vulnerable children and adults and to protect them from abuse. Such arrangements are necessarily a responsibility of governments that cannot be devolved to democratically unaccountable agencies.[19] Links between research and training institutes should be established at national, regional and local levels to ensure that appropriate research is commissioned and disseminated and that new service models are developed.

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[19] Council of Europe (2002) Safeguarding disabled children and adults against abuse, Council of Europe Publishing, Strasbourg.

5. Balancing these priorities

Although these aspirations are not in dispute there are undoubtedly dilemmas in achieving the right balance between sometimes conflicting ideals. Governments will need to achieve an appropriate balance between:

- *local variation and equitable access*
  Setting and monitoring appropriate thresholds for eligibility to various elements of service provision and benefits is a government responsibility and requires a view to be taken about how much variation can be tolerated without this leading to arbitrary inequalities and unfair access based on geographical and political boundaries;
- *decentralised service provision and the maintenance of centres of excellence*
  Encouraging local service provision and devolving education, training and research funding to regional or local level may inadvertently lead to the dispersal and sometimes dissolution of centres of excellence and dilution of specialist expertise. This means that staff working directly with disabled people may not have access to appropriate knowledge on which to base their practice. Important skills such as assisting persons with severe communication disabilities and managing challenging behaviours, or knowledge about rarer syndromes or specific impairments, may be lost in the transfer of provision from institutional to community-based services unless centres of excellence and a proper research infrastructure are maintained;
- *professional expertise and generic support*
  Unobtrusive assistance may be deceptively difficult and require more expertise than is currently acknowledged. Over-emphasis on generic support leads to complex demands being made on low-paid (often women) workers whose tasks are implicitly, if not explicitly, defined in terms of domiciliary or practical assistance when successful integration rests on recognition of differentiated needs; for example supporting individuals with autistic spectrum disorders to achieve successful community living is not only a matter of shopping and cooking but of managing

difficult social interactions. An over-reliance on a minimum wage, low skill workforce may lead to resentment and abuse;

- *social and medical models of assistance*
  Bringing different disciplines and professions together is necessary in order to ensure that provision based on social models of disability work alongside, but do not replace, or set themselves in opposition to, sensitive and expert medical input, both in relation to any specific needs arising from the person's impairment and in relation to the generic health care needs of disabled people, including screening and preventative therapies such as would be accessed by the general population;

- *regulation and flexibility*
  Governments need to regulate settings and workers to protect disabled people and their families from abuse or poor practice, without restricting the scope for agencies or individuals to respond flexibly and informally to the disabled person's needs and situation. This can be hard to achieve uniformly across the whole range of employing organisations from large state, charity or religious bodies to new community-based agencies and independent living arrangements. More traditional or institutionally-based workforces may be supervised by an internal hierarchy but resist outside scrutiny whereas staff employed by smaller free-standing agencies or individual disabled people may be able to work more autonomously but do so without scrutiny and may move between employers without proper references or checks. Where families provide most of the care to persons with disabilities it is even more difficult to strike the right balance between privacy and surveillance and to manage any conflicts of interest between the disabled person and the caring relative;

- *regional and national funding*
  There are probably as many different models of funding as there are countries within the Council of Europe, most of which balance national and regional funding (for example where health care is funded from the national budget and social services locally or where institutions are funded nationally and community support locally which may set up disincentives to the development of community-based provision). Regional or municipal funding

means that levels of service provision can be decided close to local electorates and that support for high quality service provision for disabled people and their families can be built into the political process. On the other hand local funding may lead to unacceptable discrepancies, under-funding, or to rigid rules which undermine innovation and bolster institutional solutions. If separate budgets cannot be pooled, demarcation disputes may occur on a regular basis, and local authorities may be unwilling to maintain arrangements for disabled people who move. If there is tension between different budget holders scarce resources can be diverted by spending time shifting monies from one budget to another instead of increasing the total investment in services for disabled people and managing an incremental transition to flexible, community-based service provision.

6. Recommendations

This report restates the commitments set out in the European Social Charter and the Revised European Social Charter (Article 15) and the Council of Europe's Recommendation No. R (92) 6 on a Coherent Policy for People with Disabilities, and invites member states to adopt disability policies which are underpinned by anti-discrimination and human rights frameworks. Governments should promote services that are based on choice, autonomy, protection and representation. Disabled people want to take up their place as citizens and as consumers alongside their peers, colleagues, neighbours and friends. To achieve this, governments should consolidate measures already in place and strengthen elements of the infrastructure necessary to underpin such high quality service provision.

Real progress requires both the removal of barriers and at the same time, proactive service development.

<u>Removal of barriers</u> requires foresight in planning using principles of universal design to improve access and accessibility. The term universal design is used to convey the idea that public amenities should be designed to be inclusive from the outset and not adapted for disabled people as an afterthought. According to the Council of Europe ResAP (2001) 1 ("The Tomar Resolution"), "Universal design is a strategy, which aims to make the design and composition of

different environments and products accessible and understandable to, as well as usable by, everyone, to the greatest extent in the most independent and natural manner possible, without the need for adaptation or specialised design solutions".

Proactive service development needs to develop out of proper consultation and user involvement and a focus on providing assistance which is targeted to specific individual needs and which is delivered on an equitable basis. Disabled people and their families want to be able to access services without jeopardising their autonomy or rights to privacy, relationships and status within their communities.

In order to address this complex agenda the following recommendations have been set out:

- Firstly, to spell out a clear picture of the scope of assistance which may be required by disabled people and their families and of the mechanisms for assessment and co-ordination necessary to ensure that people receive a service which is tailored to their specific needs and circumstances, (micro level) and
- Secondly, to clarify the responsibilities of governments to strengthen the infrastructure underpinning service provision for disabled people (macro level).

Individually-designed services

Instead of providing a uniform service to everyone, regardless of their needs and/or of their own priorities and preferences, governments should develop mechanisms for consultation, assessment, co-ordination and service delivery which respect these differences. Individuals require very different forms, and very different levels of assistance in any or all of the following domains:[20]

- *health care* to address needs arising out of specific impairments or conditions but also generic preventative and curative treatment for illness or injury, including appropriate sexual health and reproductive health care;

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[20] Within and between these domains there is clearly a hierarchy so that ambitious goals for self-determination must not be allowed to deflect from the importance of meeting basic needs and ensuring elementary safeguards are in place.

- *education and employment* to ensure that disabled people are helped to acquire skills and knowledge which will help them to enter the workforce and participate to as full an extent as possible in the political, social and cultural life of their communities;
- *access* to a full range of amenities including housing, transport, public buildings, sports, culture and leisure facilities;
- *resources* including help in accessing benefits and entitlements;
- *social care* to address functional disability including help in carrying out everyday activities, such as eating, drinking or personal hygiene whether as a result of physical, psychological or intellectual difficulties;
- *technical equipment and aids* (assistive technology)[21] which are accessible, affordable and designed to be easy to use, which ameliorate functional disabilities or sensory impairment, particularly mobility or communication aids, and enhance opportunities for integration;
- *psychological input* to assist in the management of challenging behaviour or to address particular mental health problems;
- *decision-making and advocacy* for people who are not able to manage their own lives, act in their own best interests, represent themselves or initiate access to mainstream service provision as a result of cognitive impairments or mental illness;
- *social inclusion* especially where disability is exacerbated by public hostility, misrepresentation or lack of understanding or compounded by other forms of prejudice and discrimination.

In order to provide such individually tailored services governments should prioritise at the *micro* level:

- providing individual disabled people and their families with a prompt and accurate diagnosis, sensitively shared, and accompanied by appropriate emotional and financial support;

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[21] See Council of Europe Resolution Res AP (2001) 3 “Towards full citizenship of persons with disabilities through inclusive new technologies”.

- creating a sound method of individual, person-centred planning with full participation of the person and their family, and multi-disciplinary input leading to a unified assessment which is regularly reviewed to ensure that services of the right type and extent are provided within acknowledged resource constraints;
- making information available about services with indicators of how each service is performing against agreed standards and providing viable alternatives so that individual disabled people and their families can make genuine choices without pressure or stigma;
- providing safe and sensitive mechanisms for decision-making and a framework for appeal and ethical scrutiny on behalf of persons who cannot make their own decisions or who are at risk of undue pressure, conflicts of interest or exploitation, providing safeguards through such mechanisms as complaints procedures, access to an independent ombudsman and advocacy;
- developing user involvement and independent advocacy to support disabled people and their families in articulating their needs and negotiating appropriate provision;
- assuring that sensitive and dignified assistance is provided to individuals who require basic personal care whether they live at home, in hospitals or other health care settings or in more institutional forms of provision;
- maintaining a preference for mainstream solutions augmented by expert assistance which is backed up by input from centres of excellence.

Strengthening the infrastructure

Governments should strengthen co-ordination at the *macro* level and prioritise:

- enacting and enforcing strong anti-discrimination legislation and frameworks in employment, mainstream service provision and public life;

- the introduction of universal design principles in environmental planning, including transport and the built environment, including housing, sporting, leisure, cultural and transport facilities;
- co-ordination across government departments laterally by auditing equity for disabled people in relation to other government departments such as health and criminal justice systems and vertically by improving collaboration between the administrative divisions of local and regional authorities and national ministries;
- co-ordinating proper national, regional and local planning with investment and funding of disability services which is adequate, steady, guaranteed and flexible and ensuring that services have appropriate forms of governance, accountability, regulation and audit so that resources allocated to disabled people and their families are used properly on their behalf;
- gradually shifting resources which are locked up in the provision of institutional services to more flexible, local and homely services and to create or sustain nationally funded centres of excellence;
- ensuring equity in access to, and availability of, services by publishing eligibility criteria, setting up mechanisms for monitoring and evaluating service usage and quality with links into, and output from, high quality research centres, taking steps to provide a proper infrastructure for research and the dissemination of the existing knowledge and evidence base and generating data about disability to inform planning and research which furthers the interests of disabled people across all member states;
- creating formal and informal opportunities for feedback and consultation with disabled people, their families and through their organisations so that they can influence broader policies as well as the ways in which their own support is structured;
- supporting a well-trained, properly remunerated and regulated workforce, including screening out of individuals who are unsuitable by reason of prior criminal convictions or professional misconduct and underpinning partnership arrangements across different disciplines and professions, and between professionally affiliated and unqualified staff;

- setting up mechanisms to protect individuals from abuse and neglect and to safeguard their human rights, including the provision of comprehensive and accessible support to disabled asylum seekers and refugees.

Many countries have already made progress towards implementing these recommendations, while others have greater barriers to overcome. All should recommit to this agenda and renew their investment in universal design, individually tailored assistance and high quality service provision. Demographic data suggests that service needs are changing as well as increasing and that governments should refocus their policies to take proper account of the needs of children and older people with disabilities. This should not be allowed to detract from the current commitment to disabled adults of working age, irrespective of whether or not they have employment, or are likely to take part in the world of work. Employment is important but it cannot be allowed to stand as the only measure of citizenship, arena for participation or route to human dignity.

Appendix 1

Demographic change and service usage: illustrative figures from the United Kingdom

In the United Kingdom a baseline figure for the incidence of disability was established by the Office of Population and Census Survey (Martin et al 1988)[22] at 14.2%, a total of approximately 6 million disabled people. But recent statistics collated in relation to service usage produced an estimate of around 1 million people (Department of Health 2000),[23] which roughly corresponds with the top four severity categories in the OPCS survey and is indicative of the threshold at which disabled people become eligible for services. So in the United Kingdom for every 1000 of the general population, 140 will be deemed to have a disability, 24 will be in receipt of residential or domiciliary care services and 1-2 will be classified as having high support needs.[24]

The United Kingdom OPCS survey also found that almost 70% of disabled adults were aged 60 or over and nearly half were aged 70 or over. Older people also predominate in the most severely disabled groups, with 64% of adults in the two most severe categories being over the age of 70. This means that of the 140 disabled people per 1 000 of the general population 30 will be over 60 and a further 70 aged 70+ meaning that 100 out of the 140 disabled people fall within the 60+ age group.

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[22] Martin, J., Meltzer, H. & Elliot, D. (1988) *The prevalence of disability among adults,* London: Office of Population and Census Surveys, HMSO.

[23] Department of Health (2000a) Community Care Statistics 2000: Residential personal social services for adults, England. www.doh.gov.ukaccessed 21.12.01
Department of Health (2000b) *Community Care Statistics 2000: Home help/home care services, England.* www.doh.gov.uk accessed 21.12.01 according to which the total number of beds in residential social services was estimated to be around 539k and the total number of households receiving home care in one survey week to be 398k.

[24] Using an estimate that countries tend to register as multiply handicapped approximately 0.5 to 2.5 per 1 000 taken from EDF (2000) Excluded among the excluded : people with complex dependency needs, EDF Brussels.

Appendix 2

Members of the Drafting Group on community living for people with disabilities in need of a high level of support (P-RR-COLI)

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