

# Community living for people with disabilities in need of a high level of support



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# **Community living for people with disabilities in need of a high level of support**

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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.<sup>1</sup>

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

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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.

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.<sup>2</sup>

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.

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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.

## 1. Introduction

This report reaffirms the Council of Europe's Recommendation No. R (92) 6 on "A coherent policy for people with disabilities" and urges a greater commitment to ensuring that the aspirations set out in that policy recommendation are fully realised on behalf of adults and children with disabilities who are in need of a high level of support. The Council of Europe hereby reinforces its commitment to inclusion and full citizenship of disabled people with a specific focus on those who need the most extensive support. These are people who face, and who present their families and service providers with considerable challenges and it is to their needs that this text is addressed.

People with disabilities in need of a high level of support are the most likely group to be still living in institutional settings or they may live with their families but be equally trapped because they receive little or no contact or service provision. Sometimes they will be hidden and stigmatised members of their communities whose needs are not noted and whose voices are not heard. Outreach is needed in cases where disabled people in need of a high level of support are isolated within, as well as segregated from, their communities. Such isolation may undermine the quality of their care at the same time as it places a burden on their families and primary care-givers (often women) whose own rights to economic and social participation are in turn undermined.

In common with other disabled people, mainstreaming solutions have provided a positive route to a better quality of life for many persons with disabilities in need of a high level of support. But sometimes these may have failed for want of sufficiently expert assistance. Alternatively, mainstreaming may not have been attempted for lack of commitment, and this leaves people with disabilities in need of a high level of support, as a group and as relatively isolated individuals, at heightened risk of social exclusion, neglect, abuse and/or a return to segregated forms of care. For those few individuals for whom mainstreaming may not be the best or only solution, a range of high quality choices should be available.

This report seeks to stimulate awareness-raising by systematically drawing the special and vulnerable position of people with disabilities

in need of a high level of support to the attention of policy makers, service providers, professionals and the general public and championing their cause within organisations of, and for, people with disabilities in relation to which their needs might inadvertently be marginalized.

Member states of the Council of Europe are asked to extend and enhance their provision to ensure that persons with disabilities in need of a high level of support are accorded their full human rights and assisted so that they can participate as full citizens in their communities. The aim of this text is to highlight what it takes to make community living possible for disabled people with high support needs and to ensure adequate co-ordination, at both micro and macro levels, so that a range of service provision is appropriately accessed, based on proper assessment, and tailored to individual needs and circumstances.

Although people with disabilities in need of a high level of support often require complex medical input, this runs parallel to, and does not wholly invalidate, a social model of disability in which even significant impairments are seen to be exacerbated by discrimination and barriers in the social and physical environment, leading to further disablement. Moreover, there is a need to increase communication across these discourses and across these different traditions of service provision.

This text thereby builds on, and enhances, the commitment to anti-discrimination in employment, housing, political representation, protection and proactive upholding of human rights, and supports a model of inclusion in mainstream educational, health, justice, leisure and sporting facilities, augmented by expert help and assistance, when this is appropriate.

The quality and appropriateness of this assistance requires the setting-up of centres of excellence and will need to be monitored through regular quality assurance audits, independent inspections and review against explicit standards and individual care plans.

Member states are also urged to take note of carers and to provide mechanisms for assessing their needs independently of those of their disabled relative, including their need for sleep, time off during the day, arrangements which allow them to work and, when appropriate,

financial support to compensate them for the additional costs of caring.

The commitments set out below are based on the same human rights as those which underpin policies towards all disabled people but specifically Article 15 of the Revised European Social Charter, which refers to:

*“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, [and]...to overcome barriers to communication and mobility and enable access to transport, housing, cultural activities and leisure”.*  
(emphasis added)

They also draw on, and reiterate, the United Nations Standard Rules on the equalization of opportunities for persons with disabilities (1993), in particular:

*Rule 3 Rehabilitation, paragraph 3 “All persons with disabilities, including persons with severe and/or multiple disabilities, who require rehabilitation should have access to it.”*

*Rule 4 Support Services, paragraph 6 “States should support the development and provision of personal assistance programmes and interpretation services, especially for persons with severe and/or multiple disabilities.”*

*Rule 6 Education, paragraph 4 “In States where education is compulsory it should be provided to girls and boys with all kinds and all levels of disabilities, including the most severe.”*

These principles are sound and are not negotiable when it comes to people with disabilities in need of a high level of support and it is the view of the Drafting Group that existing policy frameworks need strengthening for those in most need, not diluting or delaying. What does require innovation is the will to uphold the commitment to these entitlements and the development and sustaining of expertise to provide assistance to disabled persons with complex and intensive support needs and to co-ordinate the different kinds of input they require.

## **2. People with disabilities in need of a high level of support**

Persons who are at the heart of this report are referred to by a range of terminology. They are sometimes labelled as having severe, complex, challenging or enduring needs. A recent report from the European Disability Forum refers to this group as “people with complex dependency needs.”<sup>3</sup> Individuals may require enhanced service provision as a result of the nature, severity, pervasiveness, duration or rarity of their condition or because they have multiple and cumulative problems which require different types of assistance. Because of the range of their situations and the ever-present risk that they will be stigmatised, our preferred term is “people with disabilities in need of a high level of support”.

Individuals whose needs would fall within the purview of this text may or may not already have diagnoses or labels. It is not the case that labels are always unhelpful and many of the individuals concerned, and their carers, express relief when they are told the reason for their problems even if the prognosis is distressing. Accurate diagnosis is going to be possible for a greater proportion of people with disabilities in need of a high level of support as a result of medical advances and increased knowledge from the human genome project but this should be communicated sensitively and used to inform those who are responsible for the person’s everyday care. Accurate diagnosis and dissemination of scientific information should also be used to dispel lingering myths that parents are “responsible” for their child’s impairment or that poor parenting is the “cause” of challenging behaviour – these beliefs compound the isolation of parents in their extended families, neighbourhoods and communities.

Accurate information is of particular concern in relation to individuals with rare and low prevalence conditions so that data can be aggregated across countries and a large enough cohort identified for proper studies to be carried out. Linking scientific research and practical experience lies at the heart of the commitment to support these individuals and uphold their rights.

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3. European Disability Forum (EDF) (2000). Excluded among the excluded: people with complex dependency needs, Brussels.

At their best, accurate and sensitive diagnostic labels will act as a gateway to targeted services and helpful information. Individuals will then be able to get expert input based on up-to-date research and backed up by active networking and support. For example parents of children with rare syndromes might be sustained by syndrome-specific parent groups and virtual networks via the Internet. Practitioners and clinicians may then work more effectively with parents and help them to become a stronger and more informed consumer group with a more effective lobbying base.

## **2.1. A needs-based definition**

The downside of labels is that they may be used to justify inaction or lead to people being seen as hopeless, or of less worth than others, and it is for this reason that the Drafting Group chose to focus on the kinds of assistance that people with disabilities in need of a high level of support require and on ways of achieving this within the frameworks set out in policies for all disabled people. A diagnostic label is not synonymous with, nor can it be a substitute for, a detailed assessment of need or a person-centred plan.

In most cases disabled people in need of a high level of support fall within the group of people often referred to as “severely disabled” but the Drafting Group believes that it is more helpful to think about their needs in relation to the following seven domains:

- persons requiring a high level of *health care* including people with life-threatening or chronic illnesses, persistent vegetative states, those requiring ventilators or tube feeding, or who have syndromes which present specific, rare or complicated health care needs;
- persons who need a considerable degree of *social care* as a result of the extent of their functional disability and who therefore require significant, long-term personal assistance or help in carrying out everyday life activities, such as eating, drinking or personal hygiene as a consequence of lack or loss of physical, psychological or intellectual independence;
- persons who require intensive and very structured *educational input* to learn ordinary skills and make sense of relationships

and experiences as is the case for some children and adults with impairments related to autism;

- persons who require a significant amount of *technical assistance*, including adaptations to their homes or specialised equipment such as special wheelchairs or communication aids, to ameliorate functional disabilities or sensory impairments – these must be provided on an equitable basis and not limited to people who have private means;
- persons who require intensive *psychological input* to manage challenging behaviour or to assist with serious mental health problems which may result in behaviour which is violent to others or self-harming and which is difficult to manage in both community and institutional settings (noting that other persons with disabilities might be disproportionately affected by their behaviour);
- persons who require enhanced assistance in *decision-making and managing their everyday lives* as a result of cognitive impairments or mental illness in that they are not able to protect their own interests, represent themselves or initiate access to mainstream service provision on their own behalf and who therefore require proactive approaches to ensure that their human rights are upheld, their welfare and protection safeguarded: for some this will require sound mechanisms for proxy decision-making and advocacy. The European Disability Forum (EDF)<sup>4</sup> has expressed particular concern for people with disabilities who are unable to represent themselves;
- persons who require particular assistance with *social inclusion, acceptance and building social networks* because as a group, and as individuals, they are at heightened risk of rejection, public hostility, misrepresentation or lack of understanding, as can be seen arises for persons with severe or enduring mental health problems, or persons with disabilities from visible but rejected social groups such as asylum seekers or refugees.

Persons with disabilities may be deemed to have high support needs in one or more of these categories. Sometimes they require extra

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4. European Disability Forum (EDF) (2000). Excluded among the excluded: people with complex dependency needs, Brussels.

service provision because of the severe or enduring nature of their needs *within* one of these domains, or because they have interacting needs *across* these domains, highlighting the need for expert co-ordination across the usual boundaries of professions or agencies.

For example, disabled people addressing serious health problems may have a need for emotional support and those with psychiatric diagnoses also encounter problems with their physical health often exacerbated by difficulties in accessing mainstream health care. Persons with challenging behaviour, or intellectual disabilities that render them unable to give consent to treatment, need active intervention to ensure that they receive routine preventative and primary health care and special protocols to maintain good physical health.

Therefore, people with disabilities may find themselves in need of a high level of support as a result of a wide range of impairments and circumstances. They will be found in groups which are denoted by other labels and which access different kinds of service provision; they include people with multiple sensory and physical impairments, people with degenerative, life-threatening or life-limiting conditions; those with severe or profound intellectual disabilities and challenging behaviours, some people with autism, those with severe and enduring mental health problems or with severe after-effects of acquired brain damage, and people with specific syndromes that affect them in multiple ways. Disabled people needing intensive support may have had their impairments from birth or find their needs changing over time, acquiring disabilities as they grow up or later in life. They include individuals whose needs fluctuate as a result of mental health disorders that lead to cyclical changes in mood or behaviour. Sometimes needs change as a result of the circumstances or deteriorating health of their next of kin or because their care giver has additional needs of their own that disrupt their support structure.

The complexity in these situations does not give rise to a uniform situation but to unique configurations of need that require individually-tailored responses and should not be allowed to rule out community-based living. Instead, what is needed is a skilled assessment that identifies these specific needs and designs support mechanisms that differentiate the type and level of help each individual needs in each

domain, without undermining their abilities to manage in other arenas of their lives. Many disabled people prefer to use the term “assistance” rather than “care” to describe these instrumental supports which allow them to live their day to lives – lives which may be rich with “care” from their informal networks and ordinary relationships.

It is also important to note that persons with disabilities in need of a high level of support are at additional risk when subjected to other forms of discrimination, economic or social exclusion, for example when they come from war-torn countries, live in poor housing or are members of overlapping disadvantaged ethnic, religious, migrant or sexual minorities.

## 2.2. Prevalence

Given the elasticity of these definitions, it is difficult to come up with an estimate of prevalence but the European Disability Forum (EDF) puts forward a figure of between 0.5 and 2.5 per 1,000.<sup>5</sup> Numerically, it is likely that the majority of people with disabilities in need of a high level of support will be older people,<sup>6</sup> but this should not dilute the support available to children and adults who are born with complex conditions, requiring lifelong assistance and often “outgrowing” their family’s resources to care for them without assistance.

In the United Kingdom, Mencap<sup>7</sup> (a large charity representing people with intellectual disabilities and their families) estimate that the number of people with profound intellectual disability has risen from 25,000 to 40,000 since 1985. Improved survival rates of very premature babies

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5. European Disability Forum (EDF) (2000). Excluded among the Excluded: People with complex dependency needs, Brussels, p. 27.

6. The UK OPCS survey 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. (Martin, J., Meltzer, H. & Elliot, D. (1988) *The prevalence of disability among adults*, London: Office of Population and Census Surveys, HMSO).

7. Mencap (2001) *No ordinary life: the support needs of families caring for children and adults with profound and multiple learning disabilities*, Mencap, London. In this study half the families received no support from outside the family and three-quarters received less than two hours per week: most said that extended families did not share in the work of caring and as family structures change, more formal support services need to step in. 37% had had contact with eight or more professionals and 80% said that they thought professionals were poorly co-ordinated.

account for part of this increase but also increased longevity as a result of better control of epilepsy and the introduction of tube feeding.

As diagnostic procedures become more sophisticated it is likely that prevalence figures for specific configurations of impairment will be available and that a larger proportion of this group will be known to services rather than cared for, and often still hidden, within the family home. Nevertheless, at the current time there is a need for more sophisticated data bases to produce accurate information and also for more consistent case finding and registration, not only to assist in service planning, but to allow for information to be gathered about present and projected incidence and both current and anticipated service needs.

### **2.3. The role of family members and informal carers**

Families play a heightened role in caring for disabled family members with complex needs in ways that impact, sometimes unacceptably on their own health and day-to-day lives. The carers' own rights may be breached if they find themselves in this situation without their consent or without access to assistance. Intensive medical care now has the capacity to help individuals survive who might otherwise have died but this leads to a continuing responsibility for care, which should remain a communal responsibility, and not be allowed to become a private burden.

Governments should not rely on family carers to meet needs that professional services cannot deliver. For example, people with challenging behaviours are sometimes excluded from service provision without any alternative arrangements in place which leaves families to step in, as if they had a magic formula enabling them to do what a service, with its greater resources, could not.

Carers in turn require services and support that recognises their own rights and needs as well as the needs of other family members, including attention to their own physical and mental health and their needs for emotional support. Family members can find themselves very isolated, without support from their own extended families or from the wider community.

A recent report by Mencap<sup>8</sup> pointed to the practicalities of caring for someone with high dependency needs. On average parents were disturbed three times each night and 60% spent more than ten hours per day on basic physical care with one third of these saying that effectively their care had to be continuous 24 hours per day and 7 days a week. This caring work is physically demanding and the pressures can lead to increased rates of depression and physical illness. Current estimates suggest that parents, (usually mothers) do the work of 4.5 full time paid staff working within the expectations of a normal job.

The consequences of this intensive care-giving role are not confined to these matters: parents of disabled children in need of a high level of support will probably sacrifice at least one income and their future financial security through interrupted pension or insurance payments. Services which provide cover for only part of a day or which are not reliable cut across the possibility of family members (re-)entering paid work which they might have expected to do in many countries:<sup>9</sup> substitute arrangements should be tailored to *their* circumstances as well as to those of the disabled person they care for, be local, flexible, reliable, safe and of high quality. Mainstream child-care services should be assisted in taking on this role. This commitment should be seen as central to upholding the rights of disabled individuals and their families and to achieving a better balance between work and family life for those affected.

Parent carers express concern that the welcome increase in longevity means that their profoundly and multiply disabled children will outlive them and they need to see that services are in place to take over the role they have played in maintaining an acceptable quality of life for their sons and daughters. Half the parents in the Mencap study wanted to plan ahead for their son or daughter to move from the family home into a high quality alternative, requiring transition planning over time and over the artificial boundary between children's and adult services.

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8. Mencap op. cit.

9. 78% of the parents in Mencap's survey had been unable to return to work as a direct result of their caring responsibilities. Caregivers may have additional responsibilities to other family members and they need to be freed up to meet these other claims on their time and interests.

### **3. Grounds for providing an enhanced level of service**

It is widely acknowledged that people with disabilities in need of a high level of support are often failed by services and that there are a number of weak links. The most basic failure is that services are not made available or that families do not know what they are entitled to ask for. Some may feel additionally stigmatised and not engage with services at all. Others may be on the receiving end of unco-ordinated inputs or contradictory advice. Service providers may assume that extended families play a greater role than is actually the case.<sup>10</sup>

Mainstreaming remains the preferred route for service provision but the more complex the needs of the disabled person the more likely it is that they will be excluded unless additional resources and expertise are made available. Mainstreaming is sometimes embarked upon from a naïve standpoint or one that loses sight of the expert input needed to support people in ordinary settings. Mainstreaming may fail if it is not informed and supported by the right level of expertise and intensity of input. Jobs may be ill-defined as “shopping” or “domestic help” when actually what is needed is sophisticated assistance to help someone engage with their environment and/or their community.

### **4. Mechanisms which need to be in place for individuals**

Hence this report recommends that the structures around people with disabilities in need of a high level of support be strengthened without departing from a model of community-based services and access to mainstream provision. For this reason the Drafting Group believes that it is appropriate to intensify planning and funding for this small but growing number of individuals who have the most needs since failure represents a waste of resource as well as a denial of their rights. Individuals require:

- *expert and sensitive diagnosis* and attention to the way this is disseminated to family carers and non-clinical staff so that they

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10. Morris, J. (1999) *Hurting into a void*, Joseph Rowntree Pavilion, Brighton.

have relevant information at their fingertips and are helped to anticipate the needs of their relative;

- *concerted outreach work* in some countries where there is a widespread failure to identify or register children or adults with disabilities in need of a high level of support, many of whom remain hidden within their families: authorities are urged to provide outreach and to conduct assessments using standardised definitions so that they can record data which allows useful comparisons to be made across regions and countries: the goal should be for administrative prevalence of different conditions to be consistent across Europe even if service provision varies;
- a *detailed support plan* to mandate and co-ordinate interventions: this should be constructed through a multidisciplinary assessment but lead to a unified care plan specifying multiple, but co-ordinated interventions, supervised and managed by a care manager with appropriate clinical expertise and seniority: families express concern that mainstreaming represents a trend away from specialisation just at the point where science is in a position to give them some answers;
- a range of *flexible service provision* available at a local level including personal assistance, transport, high quality and innovative respite care, aids for daily living;
- proper *advocacy* for individuals and for families, who cannot represent themselves in decisions made about their lives or treatment, and where human rights are at issue, access to judicial review should be guaranteed and facilitated;
- *regular reviews* to monitor and evaluate interventions and service provision and these should be frequent at points of transition or rapidly changing need including as parent-carers get older and need to put arrangements in place so that they know their son or daughter will be cared for properly when they die;
- that placement breakdowns should not be a signal for services to give up and leave the family to cope alone but should lead to *revised assessments* and service design with increased resources as required and emergency placements, if appropriate;

- *flexible and secure funding* so that as needs change, (for example, if someone with intellectual disabilities becomes ill or requires hospital treatment), agreements should be in place in advance so that individual families or service providers do not have to wait for approval to act in the person's best immediate interests, and while individualised funding is welcome this should be accompanied by support, safeguards and evaluation;
- *alertness to the possibility of abuse* and neglect with proper avenues for assessment and investigation if concerns are raised: supervision of staff, regulation and quality assurance should be in place with an ombudsman to resolve complaints;
- *structured means for consultation* between organisations of disabled people in need of a high level of support and their families and service providers and policy makers.

Placements and provision for disabled people in need of a high level of support are inevitably expensive wherever they are, so that they are a group for whom a half-hearted commitment does not mean a saving on resources but more often a wasteful failure. When community-based options fail as a result of poor planning or inadequate support, people with disabilities in need of a high level of support often end up being served in expensive but inappropriate ways, for example “bed-blocking” by taking up spaces in acute hospitals or being placed in secure settings, prisons or orphanages when with expert assistance they could be living fulfilling lives in their own communities and with assistance that is positively geared towards participation and inclusion. The goal is therefore that their service provision should be seamless and successful.

This report urges that a range of mechanisms be put in place to facilitate empowerment of disabled persons in need of a high level of support and to protect their human rights: people who are highly dependent on support are likely to be at increased risk, in a difficult position from which to complain, and less likely to have their challenges addressed. This compounded vulnerability may only come to light retrospectively when things have gone wrong. In this regard empowerment and protecting the rights of this group is a major issue and requires:

- regular independent audit and inspection against agreed standards and individual care plans;
- representation of people with disabilities in need of a high level of support and independent advocacy for those who are unable to act in their best interests;
- adequate complaint procedures, with particular assistance for people with disabilities in need of a high level of support, and access to the legal system;
- user committees and client councils in institutions or residential homes;
- upholding the rights of a client to information about the nature and seriousness of their condition and alternative treatments or support systems;
- proper protection of the privacy and ownership of medical records.

People who are empowered to have a greater say in the way they are supported can also effectively contribute to debate about more general quality standards and inspection protocols to enhance the quality of life of other disabled people as well as to evaluate their own provision.

Persons with disabilities in need of a high level of support are particularly at risk of having their human rights breached without adequate reflection or scrutiny. The European Disability Forum (EDF) has voiced particular concerns about those people with disabilities who are unable to represent themselves or advocate for their own needs. This gives rise to ethical problems in the context of everyday matters but more importantly in relation to significant interventions and decisions such as intrusive or irreversible treatments, sterilisation, abortion, end-of-life care, involvement in medical or social research, personal or sexual relationships, financial or property transactions, protection from abuse or exploitation, disagreements with or between carers and professionals.

Wherever possible, disabled children and adults should be helped to make an informed input into such decisions but where this is not possible a proper system of substitute decision-making should be in

operation, backed up by an ombudsperson who is independent of service providers or provider agencies.

Parents or carers have a legitimate voice in these matters and will usually be at the heart of any such system on the basis that are acting in the best interests of their family member. But professional views must also be represented especially in relation to their assessment of the person's ability to contribute to decisions and their knowledge of best practice and treatment options. Usually a consensus can be reached informally but in relation to very significant decisions, or to conflicts of interest between family members and professionals, a properly structured system should be in place – one that is transparent, accountable and open to appeal. Independent advocacy is important as is proper legal representation and ease of access to judicial review. Individuals and families should be helped to access such a body/person whenever contentious decisions of an ethical nature have to be made.

## **5. Robust planning and partnership at all levels**

The position taken in this report is that the needs of people with complex needs require coherent planning at several levels.

At *regional* level agencies and professions should work closely together; a proper register should be kept to identify individuals who are affected by conditions that lead to complex needs, using a standard format so that information can be aggregated at regional and national level for international comparison and research.

The text advocates the establishment and underpinning of centres of excellence to:

- pool existing expertise on severe/complex/rare disorders and disabilities;
- support regular providers of both health and social care in setting up and implementing specialised support programmes;
- enhance multidisciplinary partnership working;
- disseminate research and the evidence base for practice provided by national and international centres of excellence and university affiliated programmes;

- provide, or facilitate access to advice, information, counselling and specialist health services for people with disabilities in need of a high level of support and their families, informal carers.

At *national* level planning is required across ministries; workforce planning and training is needed to ensure that specialist expertise is developed, accredited, maintained and located appropriately (possibly through the development of university affiliated programmes which link research, clinical input to practice settings) and that expert advice is made available to, and followed by, direct service providers.

Public education campaigns are needed to counter community rejection and sensationalist stories and misinformed or stigmatising use of labels, for example in relation to persons with severe or enduring mental health problems and/or dangerous behaviours.

Research is also a priority. The integration of disabled people in need of a high level of support requires an increased level of funding for research and dissemination of existing knowledge.

Member states are asked to build this infrastructure to support research at all levels:

*at local level*

- informing and evaluating service provision and developing innovative, accredited work-based training for direct care staff and first line management;

*at regional level*

- supporting programmes of research linked to professional education through university affiliated programmes;<sup>11</sup> these programmes should support clinical services for people with disabilities in need of a high level of support, dual diagnoses and challenging behaviours: it is at this level that funding for permanent research staff, clinical and outreach programmes should be provided;

*at national level*

- analysing demographic trends and social policy, commissioning and sustaining research capacity through a network of multidisciplinary

11. See for example McGill, P. (2001) A university affiliated programme in learning disabilities, *Tizard Learning Disability Review* Vol. 6, issue 4, October 2001, pp. 4-6.

centres of excellence which contribute to the development, evaluation and dissemination of innovative service provision and the evaluation of treatment options;

*at Europe-wide level*

- funding specific programmes into rare conditions and specific syndromes especially where a condition occurs so infrequently that it is difficult to recruit a sufficiently large cohort in individual countries: it is considered that this research is best carried out through Europe-wide partnerships between national research institutes as centres of excellence and syndrome-based parent groups with funding channelled through the former but conditional on such partnership arrangements being demonstrably in place: an outcome of such research should be the publication of up to date findings and through creative use of the internet to create “virtual” communities which address the needs of those living with rare conditions or in very specific circumstances.

At each of these levels there should be dedicated ethics committees to assure and strengthen the human rights of people with disabilities and their families and to periodically publish reviews of their decisions so that precedents can be disseminated and so that there can be public scrutiny whenever decisions are taken about the involvement of people with disabilities in need of a high level of support in research, especially where those individuals are unable to make their own decisions, represent their own interests, are not likely to benefit directly from the research or are at risk of incriminating themselves through their participation.<sup>12</sup>

## **6. Conclusions**

This report sets out a commitment to enhance service provision for disabled people in need of a high level of support, drawing on the principles established in the Council of Europe Recommendation No. R (92) 6 on “A coherent policy for people with disabilities” while recognising the additional challenges that they, and their families,

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12. See for example Brown, H. and Thompson, D. (1997) *The Ethics of Research With Men who Have Learning Disabilities and Abusive Sexual Behaviour: a minefield in a vacuum. Disability and Society* 12(5) (pp. 695-707).

face. Legal and policy initiatives should put disabled people with high support needs first so that they receive excellent provision, rather than last, as is usually the case.

Without special and expert assistance people with disabilities in need of a high level of support are always at double jeopardy – at risk of losing what little specialist service provision there is, whilst also being excluded from mainstream options. Any failures in service provision are ours not theirs and neither they, nor their families should be blamed for their difficulties, nor should they be consigned to institutional and segregated facilities or left to wait on the sidelines of a better life until other easier client groups have been served.

## **7. Recommendations**

Children and adults with disabilities in need of a high level of support should not get a watered-down version of the services which others receive but provision which is geared specifically to meet their needs and which aims for excellence. Legal and policy initiatives should prioritise their requirements. Hence this report recommends that the structures around children and adults with disabilities in need of a high level of support are strengthened, without departing from a model of community-based services and equitable access to mainstream provision. This requires intensive planning and appropriate funding for the small, but growing, group of individuals who have the most needs, in case failure represents a waste of resource as well as a denial of their rights.

### **7.1. Designing individualised services for persons with disabilities in need of a high level of support**

Children and adults with disabilities may need intensive support in a number of domains: health or social care, educational development, technical assistance, psychological input, help in decision-making and managing everyday life, assistance with building social networks and overcoming social exclusion.

Children and adults with disabilities, who are deemed to have high support needs, may require intensive assistance in one or more of these categories. Sometimes they require extra service provision because of the severe or enduring nature of their needs *within* one of

these domains, or because they have interacting needs *across* these domains, highlighting the need for expert co-ordination across the usual boundaries of professions or agencies.

Mechanisms to design and co-ordinate integrated services for individuals include:

- expert and sensitive diagnosis and attention to the way this is disseminated to family carers and non clinical staff; they need relevant information at their fingertips so that they can anticipate the needs of their relative; this will require concerted outreach work especially in countries where there are difficulties in registering children or adults with disabilities in need of a high level of support many of whom remain hidden and stigmatised within their families;
- a detailed support plan to mandate and co-ordinate interventions, supervised and managed by a care manager with appropriate clinical expertise and seniority; this should be constructed through a multidisciplinary assessment but lead to a unified care plan specifying multiple, but co-ordinated interventions, and should be regularly reviewed especially at points of transition or rapidly changing need, (including crises which arise in the lives of their carers); the plan should secure access to a range of flexible service provision available at a local level including personal assistance, transport, high quality and innovative respite care, aids for daily living, all of which should be funded in ways which are flexible and secure even when needs change rapidly;
- independent advocacy for individuals and for families, especially those who cannot represent themselves, in decisions made about their lives or treatment; informal opportunities for shared decision-making should be augmented by structured means for consultation between organisations of disabled people in need of a high level of support and their families and by additional alertness to the possibility of abuse and neglect.

## **7.2. Protecting human rights and enhancing safeguards**

Because both children and adults with disabilities in need of a high level of support are particularly likely to be at increased risk,

governments should put in place a range of mechanisms to facilitate empowerment and to guarantee their human rights so that:

- wherever possible disabled children and adults are helped to make an informed input into important decisions; but where this is not possible a proper system of substitute decision-making should be in operation, backed up by an independent ombudsperson which they are helped to access whenever contentious decisions of an ethical nature have to be made;
- in relation to very significant decisions, or to conflicts of interest between family members and professionals, a properly structured system of tribunal or judicial review should be in place, which is transparent, accountable and open to appeal;
- dedicated ethics committees should be put in place to assure and strengthen the human rights of people with disabilities and their families which periodically publish reviews of their decisions so that precedents can be disseminated;
- public education campaigns are needed to counter community rejection and sensationalist stories, misinformed or stigmatising use of labels, for example in relation to persons with severe or enduring mental health problems and/or dangerous behaviours.

Carers in turn require services and support that recognises their own rights and needs as well as those of other family members, including attention to their physical and mental health, and emotional well-being. Governments should not rely on family carers to meet needs that professional services should deliver, and should work to achieve a better balance between work and family life for those affected.

### **7.3. Planning a national infrastructure for local services**

High-quality local services for people with disabilities in need of a high level of support require coherent planning at regional and national levels.<sup>13</sup>

At *regional* level it is necessary that agencies and professions work closely together, that a proper register is kept to identify those who are

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13. See for example Mansell, J. (1994) Services for people with severe learning disabilities and challenging behaviours, HMSO, London.

affected by conditions that lead to their having high support needs, and that this is kept in a standard format allowing for information to be aggregated at regional and national level for international comparison and research.

At *national* level there must be planning across ministries; workforce planning and support for training to ensure that specialist expertise is developed, accredited, maintained and located appropriately. In order to achieve the right balance of generic and expert assistance governments should establish and properly resource centres of excellence based on partnerships between service providers, NGOs, research and teaching institutes in order to:

- pool existing expertise on severe/complex/rare disorders and disabilities;
- support regular providers of both health and social care in setting up and implementing specialised support programmes;
- enhance *multidisciplinary partnership working*;
- disseminate research and the evidence base for practice provided by national and international centres of excellence and university affiliated programmes;
- provide, or facilitate, access to advice, information, counselling and specialist health services for people with high support needs and their families, as well as informal carers.

International co-operation in research and service development is to be encouraged and governments are urged to record data which allows useful comparisons to be made across regions and countries: the goal should be for administrative prevalence of different conditions to be consistent across Europe even if service provision varies.

People with disabilities in need of a high level of support are also at a high risk of being rejected by, or within, their communities: rejection has many faces: isolation, ignorance, neglect and withdrawal are just some of them. The intent of these recommendations is to provide respectful and comprehensive local services for adults and children in need of a high level of support; and in turn to support their carers and service providers with information, assistance, co-ordination and solidarity.



## **Appendix**

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