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Family Carer Support Service news

Supporting carers: everyone's responsibility

In June this year, following wide consultation with carers themselves, the Government published its new 168 page Carers' Strategy. At the time of preparing the Digest, no hard copies of *Carers at the heart of 21st century families and communities: the new carers strategy* were available, so we give a full account of what the executive summary says overleaf.

A previous report, *Valuing Carers - calculating the value of unpaid care*, (published in 2007) estimated that carers save the state £87 billion a year. This was a 52% increase on the figure calculated in 2002 and is more than the annual budget of the NHS.

The joint Carers UK, ACE National and Leeds University research included 7 recommendations. These were: robust economic costing to find out the risk to the economy if insufficient care is provided in future, a significant investment in social care including stimulation of the care market, new legislation to make it illegal to discriminate against carers (in the same way that it is for disabled people), a full scale review of carers' benefits (including exploration of tax breaks and tax credits), sound policies around maximising independence and choice for people being cared for and carers, new legislation that treats carers as partners in care, plus clarity about the "social contract" for carers - what the state, employers, and others will provide and what individuals have to contribute.

Many of the Valuing Carers report's recommendations are recognisable in the 2008 strategy, but not necessarily in the form suggested in 2007. Although the Department of Work and Pensions review of carers' benefits calls for change, no immediate increases are announced.

The new Carers' Strategy is to be used as guidance for policy over the next 10 years, so carers themselves and all those concerned nationally, regionally and locally with carers' issues should have easy access to the full document.

A source within the Department of Health has assured us that copies are now available (details inside!).

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Carers at the heart of 21st-century families and communities

Subtitled “A caring system on your side. A life of your own”, the new National Carers Strategy acknowledges that carers need more help and support than has been available in the past and sets out a framework for developing support for carers over the next 10 years. This article is based on the Executive Summary of the new Carers’ Strategy.

The Government’s vision is that by 2018, carers will be “universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals’ needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen.”

- Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role;
- Carers will be able to have a life of their own alongside their caring role
- Carers will be supported so that they are not forced into financial hardship by their caring role
- Carers will be supported to stay mentally and physically well and treated with dignity
- Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the *Every Child Matters* outcomes.

The strategy recognises that improving the support for the person being cared for is vital to improve the life of the carer.

Government support for carers since 1999

Since *Caring about Carers*, the Prime Minister’s Strategy on Carers in 1999, the Carers Grant has provided over £1 billion additional support to councils in England so they could increase support for carers, particularly through providing planned breaks.

Legislation

Legislation has given carers new rights, including the right to an assessment of their own needs, independent of the person they care for. When assessing carers, councils should bear in mind carers’ need or wish to work, study or undertake leisure opportunities outside their caring responsibilities.

The Employment Act 2002 gave the right to request flexible working to parents of children under 6 (or 18 if the child is disabled). The Work and Families Act 2006 extended this right to employees who care for an adult. In addition legislation on equalities and the Disability Discrimination Act(s) recognise the right of people in society to equal citizenship, which will be of benefit to both carers and the people they care for and support.

The New Deal for Carers

In 2006 the White Paper *Our Health, our care, our say* announced a New Deal for Carers with four parts - one of which was to update the last carers strategy:

- i) A national information helpline and website to be launched in spring 2009;
- ii) A training programme for carers, called Caring with Confidence, which will inform carers of their rights and the services available to them, and help to develop their advocacy and networking skills - to be available face to face in August this year and on a distance learning basis from December;
- iii) £25 million additional funding per year made available to councils in England to provide emergency care cover;
- iv) A major review of the 1999 Carers’ Strategy.

Standing Commission on Carers

A Standing Commission on Carers was established in 2007 to advise the Government on developing the strategy and on other matters it felt were relevant to improving support for carers in the longer term.

The roles of family, Government and wider society

The strategy aims to support people and their carers in their own homes and communities where possible, one's family being the traditional source of care and support, and home usually being the best environment. The Government's role in improving the health and well-being of carers is seen as giving leadership, overseeing implementation, setting objectives and helping to join up services.

Wider society must recognise the vital role of carers and the invaluable support they give to individuals and society as a whole.

Six sections address key areas that emerged during consultations.

1. Integrated and personalised services

In the short term:

Services for carers need to be co-ordinated and based on what they need and want. The Government believes the state should help people to get services that are tailored to their individual need and aims to deliver such support through personalised social care.

In future everyone using social care will have a personal budget - an upfront clear allocation of social care resources - and may choose to take that as cash instead of social services.

Personal budgets can be used, for example, to provide practical support for the carer (through purchasing services such as window cleaning, gardening or doing the ironing) or to provide a break for the carer.

Meeting carers' information needs is seen as an important part of ensuring people can receive personalised services - hence the New Deal's information service, which should provide a full and easy access to information through a single national help-line and website from next spring. The Caring with Confidence programme aims to help carers work better with professionals.

To examine how the NHS, social services and carers can work better together, pilot sites will involve carers actively in diagnosis, care and

discharge planning. The sites will also see how best to make sure carers get better support at GP practices and hospitals, and closer working between councils and voluntary organisations will be established. There will be investment to expand the capacity and reach of the voluntary sector.

For carers and the people they support to get the services and support they need, the workforce is vital. The Government is funding a new training and awareness raising programme for key professionals, from health to housing, to support carers.

In the longer term:

The Government says it will consider access to specialist services in every community, possible new flexibilities for personal budgets; offering carers a lead professional and sharing best practice with primary care trusts based on the NHS pilots.

2. A life of their own

A further £150 million will be invested over the next two years to fund more planned breaks for carers. This money will be made available to the NHS so it is ring fenced and will be in addition to the Carers Grant of £224 million provided to councils to support carers in 2008/9.

Technology, housing, leisure and transport are all recognised as making a contribution to the value and effectiveness of the health and social care system.

3. Income and employment

During consultations improving the financial position of carers was a strong theme: carers also said they want opportunities to combine paid work with their caring role.

Income and benefits

Carers entitled to carer's Allowance accrue a National Insurance credit for each week that they meet the Carer's Allowance entitlement conditions. From 2010 the Government is introducing a National Insurance carer's credit for carers who are providing at least 20 hours

of weekly care to recognise their need to protect their rights to State Pension.

It is acknowledged that in long term the current structure of carers' benefits will need to be reviewed, but this will be done within the context of wider welfare reform and the review of the care and support system.

Employment

The Work and Families Act 2006 extended the right to request flexible working to employees who care for an adult. There will be an awareness raising campaign for employers and carers to ensure more of them know about the right to request flexible working. Currently this right includes people who care for a spouse, partner, civil partner or relative that lives in the same home as the person they care for: in future more carers may come within the scope of the law.

A carer-specific programme will be introduced at Jobcentre Plus that will improve the help and advice available to carers who wish to re-enter the job market by

- Improving information about flexible job vacancies;
- Introducing Care Partnership Managers in every Jobcentre Plus district;
- Introducing specialist training for Jobcentre Plus advisers who work with carers;
- Funding replacement care for those participating in approved training;
- Ensuring carers have access to appropriate employment programmes &
- Investigating the feasibility of providing return to work support through voluntary organisations.

Employers

The Government is working with business to produce a good practice guide that will emphasise the business case for employing carers so more carers are welcomed to combine paid employment with caring.

Training and skills

There is a Government commitment to ensuring training is provided in a flexible way

so it can be fitted around caring responsibilities. In addition the Government is developing an adult advancement and careers service to offer advice and guidance as well as a Skills Health Check, which will form the basis of an action plan to help individuals progress into learning and paid work.

4. Health and well being

Annual health checks for carers

Currently many carers find their own personal health needs are neglected. The new Carers' Strategy says that annual health checks for carers will be piloted in the hope that emerging health problems will be detected.

Emotional Support

Because carers are more likely to experience high levels of psychological distress (such as anxiety, depression, loss of confidence) than non-carers, the Government is considering giving priority to funding national projects that provide emotional support to carers.

Training for GPs

The Princess Royal Trust for Carers, in partnership with the Royal College of General Practitioners, has published a good practice working guide highlighting the needs of carers and their health. There will be work to build on this, by developing, piloting and evaluating a training programme for GPs. Pilots could lead to a national training programme.

Expert partners in care

The Strategy refers to carers being treated as "expert partners in care" who will be equipped with information that is relevant to the care and needs of the person they support in the form of "information prescriptions".

5. Young carers

Targeted support for young carers

Young carers should not have to take on inappropriate levels and types of caring. The Government will assess the types of project-based support available to young

carers and identify best practice, then invest in a new programme to make sure local areas strengthen the range and quality of support they give them.

Universal services

The Government's new Healthy Schools Programme will include actions to raise further awareness of young carers and their support needs. There will also be new training materials tailored for GPs and hospital discharge teams.

Whole family support

An Extended Family Pathfinder programme for young carers, which aims to build better, more preventative forms of support around families who might be at risk of relying on the care of a child, will be expanded.

6. Implementation

The final part of the Strategy focuses on implementation. In the short term the Government is establishing a cross-departmental programme board to work with national, regional and local partners to ensure the Strategy is delivered at all levels. The Standing Commission on Carers will play a key advisory role, over-viewing progress on implementation and advising the Government on ways that carers are supported as society evolves and changes.

Maintaining a regional and local overview

Regional and local progress will be monitored via performance frameworks which include actively encouraging stronger multi-agency working.

Surveying carers' experiences

Local councils will be assessing carers' experiences and this year a national "omnibus survey" will include a section on carers. There is a recommendation to Parliament that the 2011 census includes a question on carers. In the longer term it is also possible that performance measures for councils will focus on carers' experiences.

Next steps for implementing Carers at the Heart of 21st Century Families

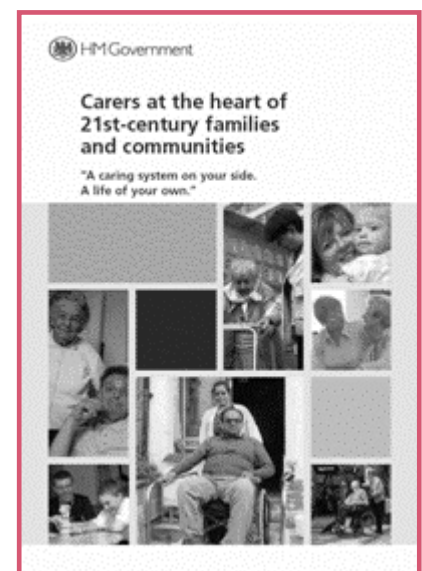
The Department of Health held 9 regional events between 8th September and 17th October, to help create a common sense of purpose and foster collective responsibility to ensure carers have the services they need.

The aim of the events was to bring together senior managers and commissioners from a range of services, employers and strategic third sector representatives (ie from voluntary organisations) to help establish the networks needed to ensure the Strategy is implemented to maximum effect.

The full guidance and executive summaries of 'Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own', can be viewed online at www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_085345168

Hard copies of the document (refs 286149) are available from DH Publications, PO Box 777, London, SE1 6XH, by email dh@prolog.uk.com or telephone 0300 123 1002.

Summaries are available in Arabic, Bengali, French, Gujarati, Polish, Portugese, Punjabi, Somali, Turkish and Urdu.



Carers Access to Education and Training

Under the Carers Equal Opportunities Act 2004 carers have a right to have their learning and work needs assessed as part of the carers' needs assessment process.

With the support of the European Social Fund, NIACE (the National Institute of Adult Continuing Education) is running a campaign to promote the key importance that learning can have on carers lives.

Education and training can provide carers with the opportunity to develop knowledge and skills whether they are in employment or want to return to paid work. Whether the course is at college, a day centre or a carers group, access to learning gives people a break from caring and a chance to step out of role.

Further education colleges can access 12% uplift in their Learning and Skills council (LSC) funding for adult carers who are family carers. This can then be used to provide additional support and help make services more flexible.

A booklet "Carers: Access to Education and Training: Information for managers and practitioners working in the post16 education and training sector" has been produced to raise awareness of the importance of accessing learning and the barriers faced by carers. This features carers' stories and good practice.

Copies are available from NIACE, Room 2-3, The Resource Centre, 356 Holloway Road, London, N7 6PA telephone 020 7700 8233 email enquiries@niace.org.uk.

Challenging Behaviour Support Line

Families caring for sons / daughters with severe learning disabilities can now receive individual telephone support around understanding and managing challenging behaviour for the cost of a local call, from the Challenging Behaviour Foundation.

Some children and adults with severe learning disabilities display behaviour which may put themselves or others at risk, or which may prevent the use of community facilities or an ordinary home life. This behaviour may be in the form of aggression, self injury, stereotyped behaviour or disruptive and destructive behaviours.

Whilst anyone may at times display challenging behaviour, the work of the Challenging Behaviour Foundation is aimed at helping those with severe learning disabilities. Severe learning disability is a developmental disability and refers to individuals who have either no speech or limited communication and require support with daily living skills such as dressing and eating.

Family carers experiencing these issues can now access individual information and support from the Challenging Behaviour Foundation Family Support Worker on 0845 602 7885.

STOP PRESS: Publication of Valuing People Now, the Government's new three year strategy for Learning Disability has been delayed until early 2009.

News from the National Family Carer Network

I am delighted to tell you all that National Family Carer Network has become a charity. This is a very important step in the organisation's development. As an independent charitable company, the Network hopes to access more sources of financial support to sustain its development and to provide for its future security.

We have also redesigned and relaunched our Network website at www.familycarers.org.uk. The new site is more accessible and offers greater opportunities for sharing local, regional and national information, for sharing good practice relating to family carers, and for consulting with family carers on national policy issues.

We hope the website will be as useful to family carers as to family carer workers and groups. The "In your Area" section lists groups and organisations supporting family carers who are already part of the Network, and gives information about the types of support they offer and the group's contact details.

In the "Resources" section you can download our popular information sheets:

- When things go wrong
- Circles of Support
- Getting help and support in your caring role
- Self-directed support: Direct payments, individual budgets and In Control
- Making Decisions: An introduction to the Mental Capacity Act

and in the "News" section you'll find recent developments, government policy and other issues of interest to family carers, as well as opportunities to engage in current consultations.

We would like the Network and related information on the website to be as comprehensive as possible, and welcome groups and organisations working at national, regional and local levels, whether large, small,

formal or informal. Supporting families that include an adult with a learning disability could form all, or part, of their activities. Family carer representatives on local partnership boards and other forums are also welcome.

Please do check out our website and keep in touch.

Joan Cox
Director

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5/6 Brook Business Park
Folly Brook Road
Emersons Green
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Healthcare for all

Healthcare for All: Sir John Michael's Report on the independent inquiry into access to healthcare for people with learning disabilities.

The Inquiry found that people with learning disabilities have higher levels of unmet needs and receive less effective treatment, despite the fact that the Disability Discrimination Act and Mental Capacity Act set out a clear legal framework for the delivery of equal treatment. The research evidence, the responses to consultation, and the information provided by witnesses demonstrated that:

- People with learning disabilities find it much harder than other people to access assessment and treatment for general health problems that have nothing directly to do with their disability.
- There is insufficient attention given to making reasonable adjustments to support the delivery of equal treatment, as required by the Disability Discrimination Act (e.g. for communication problems, difficulty in understanding or the anxieties and preferences of individuals concerning their treatment).
- Family carers of adults and children with learning disabilities frequently find their opinions and assessments are ignored by healthcare professionals, even though they often have the best information about, and understanding of, the people they support. They struggle to be accepted as effective partners in care by those involved in providing general healthcare; their complaints are not heard; they are expected to do too much of the care that should be provided by the health system and are often required to provide care beyond their personal resources.
- Health service staff, particularly those working in general healthcare, have very limited knowledge about learning disability. They are unfamiliar with the legislative framework, and commonly fail to

understand that a right to equal treatment does not mean treatment should be the same. The health needs, communication problems, and cognitive impairment characteristics of learning disability in particular are poorly understood. Staff are not familiar with what help they should provide or from whom to get expert advice.

- Partnership working and communication (between agencies providing care, between services for different age groups, and across NHS primary, secondary and tertiary boundaries) is poor in relation to services for adults with learning disabilities.
- Although there are examples of good practice, which the report highlights, witnesses described some appalling examples of discrimination, abuse and neglect across the range of health services.

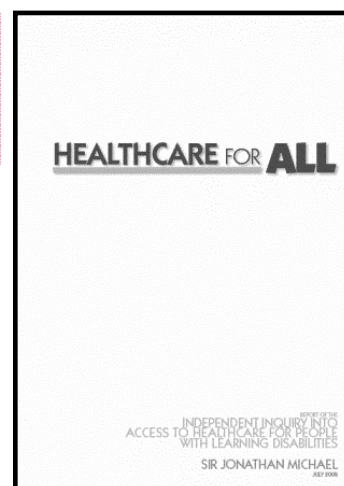
Recommendations

There are ten key recommendations of the report which concern the 'reasonable adjustments' that are needed to make health care services as accessible to people with learning disabilities as they are to other people. An annual health check; support when a visit to hospital is needed; help to communicate; better information; and tighter inspection and regulation will all work to reduce inequalities in access to and outcomes from healthcare services.

1. Those with responsibility for undergraduate and postgraduate clinical training, must ensure that curricula include mandatory training in learning disabilities. It should be competence based and involve people with learning disabilities and their carers/trainers.
2. All healthcare organisations, including the Department of Health should ensure that they collect the data and information necessary to allow people with learning disability to be identified by the health service and their pathways of care tracked.

3. Family and other carers should be involved as a matter of course as partners in the provision of treatment and care, unless good reason is given not to, and Trust Boards should ensure that reasonable adjustments are made to enable them to do this effectively. This will include the provision of information, but may also involve practical support and service co-ordination.
4. Primary care trusts should identify and assess the needs of people with learning disabilities and their carers as part of their Joint Strategic Needs Assessment. They should consult with their Local Strategic Partnership, their Learning Disability Partnership Boards and relevant voluntary user-led learning disability organisations and use the information to inform the development of Local Area Agreements.
5. To raise awareness in the health service of the risk of premature avoidable death, and to promote sustainable good practice in local assessment, management and evaluation of services, the Department of Health should establish a learning disabilities Public Health Observatory.
6. The Department of Health should immediately amend Core Standards for Better Health, to include the requirement to make 'reasonable adjustments' to the provision and delivery of services for vulnerable groups, in accordance with the disability equality legislation.
7. Inspectors and regulators of the health service should develop and extend their monitoring of the standard of general health services provided for people with learning disabilities, in both the hospital sector and in the community where primary care providers are located. The aim is to support appropriate, reasonable adjustments to general health services for adults and children with learning disabilities and their families and to ensure compliance with and enforcement of all aspects of the Disability Discrimination Act. Healthcare regulators and inspectors (and the Care Quality Commission, once established) should strengthen their work in partnership with each other and with the Commission for Equality and Human Rights, the National Patient Safety Agency and Office for Disability issues).
8. The Department of Health should direct primary care trusts (PCTs) to secure general health services that make 'reasonable adjustments' for people with learning disabilities through enhanced services. These should include regular health checks provided by GP practices and improved data, communication and cross-boundary partnership working. There should be liaison staff who work with primary care services to improve the over-all quality of health care for people with learning disabilities.
9. All Trust boards should ensure that the views and interests of people with learning disabilities and their carers are included.
10. All Trust Boards should demonstrate that they have effective systems in place to deliver effective 'reasonably adjusted' health services for those people who happen to have a learning disability. This 'adjustment' should include arrangements to provide advocacy for all those who need it, and arrangements to secure effective representation on PALS from all client groups including people with learning disabilities.

For a copy of the full report see www.iahpld.org.uk



The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care

This national framework was published in October 2007 in order to clarify the process for deciding whether the NHS or Social Services should pay for someone's care and support.

The Foundation for People with Learning Disabilities has produced a 10 page guide with an easy to read summary, information in plain English and some Frequently Asked Questions. Though the guide was primarily written for learning disability partnership boards it serves as a very useful introduction to the

framework for anyone concerned about decisions related to funding continuing healthcare and nursing care.

'Information for Learning Disability Partnership Boards about the National Framework for NHS Continuing Healthcare and NHS funded Nursing Care' is downloadable from the Valuing People website www.valuingpeople.gov.uk, click on 'News', then see February 2008 for 'Continuing Care'.

Taking blood for people with learning disabilities

As we know that many people with learning disabilities dislike having their blood taken for medical tests, we thought readers would be interested in three contributions to the Foundation for People with Learning Disabilities' online forum, the UK Health and Learning Disability network, earlier this year.

1) Allyson.Kent@humber.nhs.uk, Head of Profession Learning Disability Nursing, explained that her team has written accessible information about having your blood taken, which mentions using anaesthetic creams, and could be used to help someone make a decision about the procedure.

2) A posting mentioned that anti convulsant levels can be taken using saliva samples, so avoiding the need for a blood test - see <http://tinyurl.com/5baeex> (National Society for Epilepsy website).

3) An Independent Nurse Consultant explained: "Consent is only required from those persons who have capacity to give it. Non compliance should not be considered the same as withholding consent - a person who

lacks capacity to give consent also lacks capacity to withhold it.

It is a matter for the practitioner to decide whether or not the proposed course of action is in the 'best interests' of the individual, and act accordingly.

If the taking of blood is considered to be important, and would be important for a person without a learning disability, then it is just as important for the person with learning disability. To decide not to carry out the procedure might be considered negligent, particularly if problems occur later that could have been identified and avoided if blood had been taken, especially if professional opinion holds that it is always in the best interests of any individual to have blood taken in those circumstances."

To join the UK Health and Learning Disability network log on to www.learningdisabilities.org/ldhn

The Benefits System: Valuing and Supporting carers

The Work and Pensions Select Committee has called for the replacement of the current “outdated” system of benefits for carers in its August report entitled “Valuing and supporting carers”.

In March the National Family Carer Network (NFCN) made a 10 page submission on behalf of family carers to the inquiry into the effectiveness of the Department of Work and Pension (DWP’s) existing approach to carers. (Copies of the NFCN report, which collates responses to the NFCN’s request for family carer views are available from Joan Cox c/o HFT.)

Recommendations of Select Committee

Launched at the end of August, the Select Committee report points out that those who provide unpaid care for relatives and friends save the public purse an estimated £87 billion each year. The press release said

“The care they provide is not only of enormous value to those they care for, but also to society in general.

However, most informal carers are of working age, and sustaining their ability to remain in work, or to return to work after a period of caring, is essential both to the Government’s target of reaching an 80% employment rate and to employers who can not afford to lose their valued skills.

The Committee believes the current system of benefits for carers is outdated and recommends the introduction of two distinctive ‘tiers’ of support for carers, offering:

- (i) income replacement support for carers unable to work, or working only part-time: and
- (ii) compensation for the additional costs of caring for all carers in intensive caring roles.

The Report notes that many carers face financial pressure due to the additional costs of caring and from either reducing working hours, moving into lower paid work, or giving up paid work. Carers who give up work may also feel that their skills become rusty or out of date, and over time they may also lose confidence and feel out of touch with the world of work. When caring ends, carers who have spent a long time in demanding caring roles need sensitive, tailored support to re-enter employment, supported by advisers who understand their circumstances and particular needs.

As part of its inquiry, the Committee visited independent and third sector Carers’ Centres and saw that they can offer an effective ‘first stop shop’ for signposting carers to local organisations, services and benefits, and for providing ongoing support as carers’ circumstances change. The Report recommends that the Government takes a more strategic approach to UK Carers’ Centres, with the objective of there being a national network of such Centres.”

Copies of the House of Commons Work and Pensions Committee report ‘Valuing and Supporting Carers’ (HC 485-1) are available from the Stationary Office Ltd priced £17.50.

See www.tso.co.uk or ring 0870 6000 5522 for more information

Incapacity benefit replaced by Employment and Support Allowance

From October this year, all new and repeat claimants of Incapacity Benefit (IB) will undergo the Work Capability Assessment (WCA) - a new medical test designed to see what people can do rather than what they cannot. Employment and Support Allowance (ESA) claimants will then be split into two groups, depending on the outcome of the assessment.

The “Work-related activity group”

Those claimants who pass the assessment and are identified as capable of taking part in some form of work-related activity will be entitled to claim ESA at a rate of £84.50 a week. They will be required to attend work-focused interviews through Pathways to Work, to help them overcome their barriers to work and support them into long-term substantial employment. Those who don't fulfil these conditions without good reason could have their ESA partially cut.

The “Support Group”

Those identified as not able to take part in any work-related activity (the most severely

disabled group) will not be expected to take part in work-focused activities unless they want to, but will not face any sanctions. The Department of Work and Pensions are targeting more resources to the poorest in this group with a guaranteed income of £102.10 a week (£17.60 more than the long-term rate of Incapacity Benefit). Everyone else in this category will receive a minimum of £89.50 a week.

All people claiming ESA may also continue to be eligible for other benefits, such as Disability Living Allowance and Housing and Council Tax Benefit. Those who do not qualify for ESA can instead apply for Jobseeker's Allowance and will be expected to take part in the work-focused interviews and programmes to help them get back to work.

For more information go to www.jobcentreplus.gov.uk/JCP/customers/WorkingAgeBenefits the select **Employment and Support Allowance** on the A to Z of Benefits and Allowances.

Disabled Facilities Grant

Following consultation some changes to the Disabled Facilities Grant (DFG) came in to force from April this year.

Parents' income is not now taken into account for adaptations for disabled children. The maximum amount of grant available is raised to £30,000.

For an application to be approved the local housing authority must be satisfied that works are 'necessary and appropriate' for the needs of the disabled person and 'reasonable and practicable' in relation to the property.

After a formal application has been submitted there is a six month time limit in which the local authority has to give a decision. Payment of a DFG should take no longer than 12 months from when an application was made.

Anyone applying for a DFG, especially if it entails large works or amounts of money should consider seeking legal advice before committing to any payments or contributions.

There are lots of other considerations to be taken in to account and Housing Departments do have some discretionary powers which they do not always tell people about, for example regarding paying towards administrative costs.

For useful information on the DFG see guidance on the Department of Communities and Local Government website at www.communities.gov.uk.

You can also download factsheets from the Disability Alliance website at www.disabilityalliance.org/fact.htm Factsheets 49 and 51 both have information on the Disabled Facilities Grant.

National Autism Strategy

There is to be a new National Strategy designed to ensure adults with autism and Aspergers Syndrome are supported to have full lives.

According to a study by Professor Baird in 2006 the number of children with autism is as high as 1 in 100 but we don't currently know how many adults have the condition.

In May the Department of Health announced research into the number of adults with autism and the specific support needs of young people with autism as they make the transition

into adult life. The work will inform the first ever Government Strategy on adults with autism and Aspergers Syndrome due to be published in 2009.

When the Strategy and research were announced Ivan Lewis (the Care Services Minister) acknowledged "Adults with autism and Aspergers Syndrome are too often abandoned by services and their families left to struggle alone. Equally people are frequently misappropriately referred to either health or learning disability services."

SOCIAL CARE

Fair Care; Better Now; Fairer Tomorrow Campaign

The Local Government Association which represents over 400 councils in England and Wales, has launched a Fair Care Campaign. This calls for the Government to develop a simplified care and support system that is adequately funded.

The Local Government Association wants the government to bring together the different types of care and support into a simple system so people have more control over how they receive support. Currently inflexibilities can stop councils and local health services working together effectively.

They also recognise the care system needs to be simplified so vulnerable people don't miss

out on care because the application process is so complicated that it results in people feeling they are fighting the system to get support.

The LGA recognises that Government proposals for financial products, such as insurance, could be a way of funding social care in the future but points out that urgent action needs to be taken so that those needing vital care and support now get their needs met.

See www.lga.gov.uk, select 'Our work', 'Campaigns' then 'Fair Care Campaign'

Tell it like it is

The Learning Disability Coalition has published the results of its survey of people with learning disability and their carers.

'*Tell it like it is*' reports that 34% of people with learning disabilities say their day time activities have been cut; 37% of people whose college courses were cut were forced by lack of provision to stay at home and 77% who commented on their transport services had a negative experience of them. Even where cuts

were not made reductions in quality were experienced.

The report provides ample evidence that the demand for social care is outstripping the available resources.

The Government is consulting on the future funding of social care (see www.careandsupport.direct.gov.uk). It plans to publish a Green Paper on adult social care in 2009.

Forced Marriages

The Forced Marriage Civil Protection Act 2007 will come into force in November this year. It will give courts discretion to deal flexibly with individual cases using civil remedies to protect victims without criminalising family members.

In May the All Parliamentary Group on Learning Disability held a meeting on forced marriages of people with learning disability at the House of Commons.

Although there is a lack of hard data on the prevalence of forced marriages of people with learning disabilities it is likely that more than 80 of the 400 cases the unit dealt with in 2007 involved people with learning disability.

Reasons why some people with learning disabilities are forced into marriages were put forward:

- Family Carers, particularly as they get older may view marriage as a means of ensuring that their relative will be taken care of and a way to ensure continuing support.
- Marriage can be seen as a means of improving the chances of getting a visa to the UK. (A person with learning disabilities may be seen as easier to exploit and can act as a visiting sponsor. The Director of UK Visas said in 2007 that the Pakistan Consul dealt with 250 cases where a UK citizen was a 'reluctant sponsor' of a visa. Of those cases 86 involved adults with

severe learning disabilities who were somehow involved in marital cases).

- Families might think that marriage will 'cure' the person of their learning disability and will allow them to lead a 'normal' life.

The home office representative was careful to point out that a forced marriage is not the same as an arranged marriage nor that arranged marriages, many of which are successful, are bad. Neither are they saying that people with learning disabilities shouldn't marry. The issue is one of informed consent.

Marriage is a contract. Those involved need to understand fully what they are agreeing to and all that marriage involves e.g. sexual relations, the possibility of children. Both parties have to be in agreement and that agreement has to have been given freely without force or pressure.

The Forced Marriage Unit has a booklet available that gives information about Forced Marriages, where to get help, how to stop someone from being taken out of the country and how to assist those abroad. The Unit also has comprehensive advice and guidance for social workers, the Police, education and Health Professionals.

To find out more about the work of the forced marriage unit visit www.fco.gov.uk/forcedmarriage.

LEGAL

Sharon Coleman case: 'Discrimination by Association'

The European Court of Justice has upheld the decision that Sharon Coleman was a victim of 'discrimination by association' when she was unable to return to her previous job after maternity leave and denied the same flexible working opportunities as colleagues.

The ruling clarifies that those "associated with a disabled person", like disabled people themselves, must not be discriminated against.

A right to be safe

In May Hounslow Council was asked to pay £100,000 compensation to a couple who both have learning disability and were subjected to abuse by their neighbours.

The landmark ruling is the first to hold a local authority responsible for protecting vulnerable adults from 'third parties'. Frances Swaine, partner at Leigh Day and Co and the solicitor acting for the couple said

“The onus is now on local authorities to those adults with a learning disability living in the community to ensure, very carefully, that they are fully supported, and not to ignore any early warning signs of abuse. If they do not, they could be found liable if abuse does take place and could have been prevented.”

Easy Guide to Human Rights Act 1998

Subtitled 'An essential guide for staff, carers and relatives', this outlines key elements of the Act and shows how they can be applied to protect the rights of people with learning disabilities.

The Guide, which was published by the British Institute of Learning Disabilities in 2001, includes real stories to illustrate various

abuses of human rights as well as suggestions for good practice.

The 'Easy Guide to Human Rights Act' costs £10. Contact 01562 723 010 or www.bild.org.uk for more information.

Community Legal Advice

Community Legal Advice is the new name for Community Legal Service Direct - the free, confidential legal advice service, for people on a low income or benefits, paid for by legal aid. It is likely that your learning disabled relative will qualify even if you do not.

The service has a new website www.communitylegaladvice.org.uk which allows people to:

- Download leaflets and factsheets
- Use the legal aid calculator
- Search for advice or browse by topic
- Find out about local and national organisations that could help with legal problems.

Staff on Community Legal Advice's helpline (0845 345 4345) will help advise on who qualifies for their help which includes high quality legal advice on debt, housing, employment, welfare benefits and education.

The helpline is open from 9:00 - 6:30 Monday to Friday and calls cost no more than 4p per minute from a BT landline. Messages can be left outside office hours and clients can request to be called back within 24 hours.

Using Intermediaries to Help Vulnerable Witnesses

Under the Youth and Criminal Justice Act 1999 a “vulnerable witness” is someone less than 17 years old or whose evidence would be diminished in quality because they have a learning disability, mental disorder or physical disability.

An intermediary can help a “vulnerable witness” at each stage of the criminal justice system, from police investigations and interviews, through pre trial preparations, to court.

Intermediaries have been used successfully in police investigations and trials around the country.

They come from a range of professional backgrounds including speech and language therapy, occupational therapy, psychology, education and social work.

Registered intermediaries, who have completed a rigorous assessment process and agreed to abide by a code of practice and a code of ethics, are periodically reassessed to make sure they meet the required standard.

Intermediaries in action

Example 1

In a case where a witness was a 64 year old man with severe learning disabilities, he first gave evidence using a video statement. However, when he was asked to give evidence before the court in person, an intermediary was used to help him give his account clearly and with the least upset to him.

The intermediary produced a report on the witness for the judge and both the prosecuting and defence counsel. This explained the witness’s difficulties and how he needed to be treated.

When the defence counsel asked the type of questions the intermediary had reported the

witness would not be able to answer, the Judge challenged this inappropriate questioning. Without the intermediary’s input the questioning would have gone unchallenged, giving the jury the impression that the witness was unsure of his account and was therefore unreliable.

Example 2

In another case a young woman who reported she had been raped was initially considered unable to be a witness because of her communication difficulties.

The police engaged an intermediary. During their interviews the intermediary was able to identify questions that were too complex for the witness and repeated some of her answers so that the police understood them.

In court the intermediary told the judge and lawyers how to be aware of the witness’s communication difficulties, and helped her use pictures to identify rooms where the alleged offence had taken place. The case resulted in a conviction and the defendant was sentenced to ten years in prison.

For more information about intermediaries contact the Intermediary Registration Board (IRB) on 020 7035 8461, 020 7035 8449 or 020 7035 8476 or email intermediaries@cjs.gsi.gov.uk.

“What’s my story? A guide to using intermediaries to help vulnerable witnesses” is produced by the Criminal Justice System (CJS). This includes two CD’s and is available by e-mailing homeoffice@prolog.uk.com, downloading from the website www.frontline.cjsonline.gov.uk or by calling 0870 241 4786.

The British Institute of Learning Disabilities

The British Institute of Learning Disabilities runs events, learning opportunities and conferences for anyone working to improve the quality of life for children and adults with learning disability.

Some free, as well as discounted, places will be available to family carers for a major conference in Manchester on December 8th. "Challenges for the workforce; Choice, control and self-directed support" will feature presentations from two family carers as well as Skills for Care and the Valuing People Support Team.

Bild's programme for 2008 include many other opportunities. These are arranged under the following headings

- Behaviour Support
- Autistic Spectrum Disorder
- Advocacy, Choice and Empowerment
- Person Centred approaches to better lives
- Supporting and Developing the Workforce

Fees for the events / learning opportunities are £47 for family carers, enablers, unwaged or small voluntary organisations. Otherwise £141 per person.

For more details telephone 01562 723 010, visit www.bild.org.uk or write to BILD, Campion House, Green Street, Kidderminster, DY10 1JL.

Planning for the Future

If someone in your family or someone you care for has a learning disability you can take steps now to ensure their finances are well looked after when you are no longer around.

Mencap have organised some FREE information sessions where you can find out more about setting up wills and trusts for the benefit of someone with a learning disability.

Sessions will be held on:

Thursday 20th November, 12:30pm - 2:30pm at The Banqueting Suite, Lancaster Town Hall, Dalton Square, **Lancaster**, LA1 1PJ

Friday 21st November, 12:30pm - 2:30pm at Main Hall, Quakers Friends Meeting House, 6 Mount Street, **Manchester**, M2 5NS

Monday 24th November, 12:30pm - 2:30pm at Room B, Macclesfield Library, 2 Jordangate, **Macclesfield**, Cheshire, SK10 1EE

Wednesday 26th November, 12:30pm - 2:30pm at The Eden Suite, The Sands Centre, The Sands, **Carlisle**, CA1 1JQ

Thursday 27th November, 12:30pm - 2:30pm at The Lounge & Seminar Room, Neuro Support Centre, Norton Street, **Liverpool**, L3 8LR

Friday 28th November, 12:30pm - 2:30pm at Eagle Rooms 1 & 2, All Saints Church Centre, Vicarage Road, Hoole, **Chester**, CH2 3HZ

A local solicitor, who has experience of drafting wills for the benefit of people with a learning disability will speak. Places at these seminars are always popular so book your place(s) immediately by contacting Gina Collins, (Mencap Wills & Trusts Team) on 020 7696 6925

Sibs

Sibs, the charity for brothers and sisters of disabled children and adults is running workshops for professionals.

Forthcoming Sibs events include

11th November: Adult sibling conference in London (Working with adult siblings of disabled people)

Workshops for professionals working with disabled children will be held on 18th November in Perth and on 27th November in Crewe and Nantwich.

The aim of these workshops is to increase staff's knowledge of the needs of siblings, explore what professional services can do to support siblings, build a network of people discussing what can be done locally and explain what Sibs can do to support any proposed developments.

For more details about Sibs or the workshops and training they provide ring 01535 645 453 or visit www.sibs.org.uk.

RESOURCES

Extending Inclusion: access for disabled children and young people to extended schools and children's centres: a developmental manual

Funded by the Department for Children, Schools and Families, this guide identifies practice that promotes inclusion, taking into account the views of disabled children and their families. It comes with a CD that includes case studies, training materials and resources.

You can find out more information, download or order the document from www.publications.teachernet.gov.uk/eorderlinedownload/CDC or by calling 0845 600 9506.

Asperger meets Girl (2008) Jonathan Griffiths

This book demystifies the enigma of 'relationships' by explaining everything in Asperger-friendly terms with witty cartoons to provide visual supports. Jonathan provides hope for all hopeless wooers by offering a choice of three inter-related abstract models for understanding boy-girl relationships. To make life easier, these models are also presented in graphic form where possible.

The book also gives valuable practical tips for maximising one's chances of successfully developing a relationship, such as how to start a conversation without scaring the other person off. Serious, yet seriously funny, this book will help bring happy endings to Asperger boys and make them laugh in the process. The amusing cartoons emphasise Jonathan's light-hearted style.

See www.jkp.com/catalogue/book.php/isbn/9781843106302 for more details.

If you would like any further information on the subjects covered or would like to join our Database to receive regular mailings please contact a member of the team on 0117 9061751 or by emailing familycarersupport@hft.org.uk

Message in the fridge: Message in a Bottle

The message in a Bottle / Fridge scheme enables you to record key information about any vulnerable members of the household, so that Ambulance, Police, Fire and Rescue Services (or an emergency doctor) entering your house will get essential details quickly.

You simply collect a bottle, form and two stickers from your local chemist, doctor or emergency services, fill in the form, put the form in the bottle and put the bottle in the door of the fridge. One sticker goes on the door of the fridge, the other on the inside of your front door at eye level to alert emergency staff that

they should look for the bottle.

A Message in a Bottle identifies any special medication or allergies plus emergency contacts and if kept updated about repeat prescriptions can be a potential life saver. Family carers have told us the scheme gives them peace of mind.

If you are unable to find a bottle locally visit www.lions.org.uk/health/miab to find the nearest source.

Mobile phone location service

ChildLocate, a UK-based company, are offering a service that allows parents to locate their children using the child's mobile phone. This technology has been around for a while and uses triangulation between phone masts to locate the handset. This is less accurate than GPS (Global Positioning System) but cheaper. Permission is required to track a particular handset from its owner. Similar services are offered by other companies such as MST Locate.

For more information look at their websites www.childlocate.co.uk and www.mstlocate.co.uk.

Best of Both Voices

HFT has commissioned a booklet entitled "Best of Both Voices". The booklet contains a series of tools to help advocates ensure that the voice of the person with learning disabilities they are advocating for is heard. It is the first such publication in this country – and is especially useful with implementation of the Mental Capacity Act.

To obtain a hard copy email kate.walton@hft.org.uk. It costs £4.50. To download the book as a PDF go to <http://www.hft.org.uk/data/asset/file87.pdf>

Bullying Involving Children with Special Education Needs and Disabilities Safe to Learn: Embedding anti-bullying work in schools (2008) Department of Schools and Families

This guidance was produced jointly by the Council for Disabled Children and Young Voice working in partnership with the Anti-Bullying Alliance.

Bullying is one of the most damaging forms of discrimination. This guidance provides advice on dealing with bullying involving children with

special educational needs (SEN) and disabilities.

Visit www.teachernet.gov.uk/docbank/index.cfm?id=12626 to order a copy or for more information.

Easy Health - Online Accessible Health Information

This website was developed to make it easier for people with learning disabilities to find health information that is easy to understand.

Over 40 organisations from across the country have put their information on to the website, so that people understand what is happening with their health, to help them feel more confident in taking control of it. Most of this information can be downloaded at no cost.

The website is for all people who want to understand their own health. It's also to help health professionals like doctors and nurses to give a better service. Easyhealth.org.uk will help people who like their information to:

- be eye-catching
- use simple words
- have photos, symbols and pictures

Visit www.easyhealth.org.uk for more info.

Banking for people who lack capacity to make decisions (2007)

The British Banking Association has published a 'Help guide for managing finances'. This guidance will help if someone is managing the financial and property affairs of a person who may lack capacity to look after some or all aspects of their own financial affairs. It gives advice on how a bank account can be opened and money managed on behalf of someone else, it applies to England and Wales.

There are a number of ways in which someone can be given the authority to make decisions about money matters on behalf of an individual who may lack the capacity to make certain decisions for themselves or where they want someone to make such decisions even when they have the capacity. Depending on how it is done, the person acting on someone else's behalf could be:

- an attorney appointed under an Enduring Power of Attorney or Lasting Power of Attorney
- a deputy appointed by the Court of Protection
- as someone acting under a court order

- an appointee of the Department of Work and Pensions (DWP).

The information provided in this document explains the differences between managing a bank account as an attorney, a receiver, a deputy or an appointee.

Benefit Enquiry Line gives advice about benefits for people with disabilities and their helpers and can tell you how to apply to be an appointee to manage banking for someone who lacks mental capacity.

Telephone: 0800 88 22 00
Textphone: 0800 24 33

The 'Help Guide for managing finances' is available from:

British Bankers' Association
Pinnars Hall
105-108 Old Broad Street
London EC2N 1EX
T: +44 (0) 207 216 8800

Technology that supports people with learning disabilities

Tunstall have published a free 16 page book describing how telecare equipment is being used to support individuals in a range of ways each tailored to their needs and situation.

Learning disabilities, solutions for independent living is available from Tunstall Group Ltd. Tel 01977 661 234 or email enquiries@tunstall.co.uk