ABOUT THIS FOLDER

The content of this folder is based on the information family carers of adults with a learning disability said they needed. It is meant to be used in a "pick & mix" way and there is no expectation that carers need to read all of the information sheets!

The folder is designed to be easily updated and additional information sheets can be added as new information needs are identified. Carers of people with a learning disability, including those on the autistic spectrum, are probably experts on a whole range of issues by the time the young person reaches adulthood.

The information in this folder does not cover in detail the transition from children's to adult services, but attempts to give information on a range of issues that will be encountered by carers as both they and the person with a learning disability grow older.

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Carers Information Project
March 2004

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WHAT IS IN THIS FOLDER

1 ACCESSING HEALTH SERVICES

People with a learning disability have to overcome additional problems when accessing health services. These range from practical problems such as transport through to the accessibility and appropriateness of services. Carers play an important role in supporting the person to overcome these barriers.

Like everyone else, people with a learning disability need to have regular health checks and some 60% are likely to need medical intervention for an ongoing health condition. Health services, therefore, play a very important part in people's lives. This information sheet explains what support there is locally to help someone with a learning disability get the health care they need.

Currently, health care services for people with a learning disability are the responsibility of the Isle of Wight Healthcare NHS Trust and social care services are delivered by the Isle of Wight Council's Social Services Department. The two services have always worked very closely together and are likely to become more fully integrated in the future.

Most people initially contact their GP if they have a health problem. National research has highlighted a number of potential problems for carers and people with learning disabilities when they go to the doctor's surgery. These range from access, unhelpful receptionists and long waiting times to doctors not having enough time to listen. Not everyone experiences these problems and there are some things you as a carer can do to get the most out of a visit to the GP.

- Explaining your particular situation to the receptionist helps; they can advise you on the best time to book an appointment to avoid a lengthy wait and perhaps advise the doctor to book a double appointment if more time is needed.
- If you are visiting the doctor with the person you care for, write down in advance anything you both need to ask, noting important points that you don't want to forget.
- Ask for an explanation of any words you don't understand – including illnesses, medicines, symptoms or treatments.
- Ask what results can be expected from any drugs, therapies or medications given. Should you expect only a little or more significant changes? When should these changes occur?
- Ask about any other options available and their advantages/disadvantages.
- Ask about what side effects there may be from any drugs or therapies prescribed.
- Ask about any follow-up procedures. When and on what basis will there be another appointment?
- Note down important points arising from your discussions with your doctor as soon as possible. This will help you both remember the main points.
- Keep a diary of important events or issues between visits to the doctor, so that these can be discussed at the next visit.
- The doctor may refer to the Community Learning Disability Nurse Team if they are the best people to deal with the health problem.

MEDICATION

Carers need to know about the medication prescribed; pharmacists are a very helpful source of information about correct dosage, potential side effects and interactions. If you have to organise complicated medication, your local pharmacists can advise on how best to do this. So called 'compliance packs' are useful – these packs have the days of the week and times of the day that the medicines have to be taken clearly printed on them, with separate compartments for the pills that have to be taken at a particular time. Another useful source of information is the Health & Medicines Information Guide & Directory, available free from Ask About Medicines; telephone 020 7747 1446.

COMMUNITY LEARNING DISABILITY NURSE TEAM

This team is now based at the Arthur Webster Clinic in Shanklin (telephone number 01983 866179) and they take referrals from across the Island of people with a learning disability who need support to maintain their health and well-being. The team has an open referral system so parents and individuals can self-refer if they wish. The team have skills in working with people with complex health care needs, including challenging behaviour.

- After receiving a referral, contact will be made - usually by phone – to do an INITIAL ASSESSMENT to get more information and to determine the urgency. The team is very busy and a referral that is not urgent is likely to be put on a waiting list.

- When a learning disability nurse visits, they will assess the problem. If it is a problem with physical health, the nurse may complete a full health assessment. If this assessment picks up problems around hearing, sight or oral health, for example, the nurse will refer to the appropriate health specialist.

- The newly developed HEALTH ACTION PLAN (HAP) will be completed by the person with a learning disability with the help of a 'health facilitator', such as a support or care worker. This plan will be theirs to keep with them and will help them maintain their health and well-being.

- The specialist CONSULTANT PSYCHIATRIST has clinics one day a month and she links closely with the learning disability team.

- The PSYCHOLOGY SERVICE for people with a learning disability can provide assessment advice and therapeutic interventions. A specialist psychologist is based with the nursing team at the Arthur Webster Clinic; telephone 01983 866179.

- Should a person with a learning disability be admitted to hospital, a new initiative called HOSPITAL INPATIENT LEARNING DISABILITY ADMISSION (HILDA) should help overcome problems that might otherwise occur. If the admission is pre-planned, then a referral form will be sent in advance that gives detailed information about the individual, their likes, dislikes, communication and dietary needs, preferences, etc. In the event of an emergency admission, the nursing team or care worker would send in the form as quickly as possible.

- The SPEECH THERAPY SERVICE is based at St Mary's Hospital. One of the team specialises in working with people with learning disabilities and has good links with the nursing team. The Speech Therapy phone number is 01983 534502.

TRANSPORT

Getting to outpatient appointments and clinics can be a problem. A community support worker from Social Services can often assist with transport. The local branch of CARERS UK has published a useful handbook called *'How Can I Get There?'*, giving general information on transport to hospital and other appointments. Telephone 01983 533173 to get a copy.

2 ADVOCACY

WHAT IS ADVOCACY?

Advocacy is about speaking up and being heard. Effective advocacy can transform the lives of people with a learning disability by enabling them to express their wishes and aspirations and make real choices.

Self-advocacy has been described as speaking up for and representing your own interests. It is what most of us do most of the time. People with learning disabilities will often work in self-advocacy groups in order to provide support and help. Examples of such groups are People First, Taking Part and Speaking Up. The names of these groups indicate what they are about.

Citizen advocacy has developed as a way of supporting one-to-one relationships with vulnerable people who need more help to have their voice heard. A citizen advocate is an ordinary person prepared to commit to such a one-to-one advocacy relationship and speak up for and represent an advocacy partner's interests.

WHAT IS AN ADVOCATE?

Advocates are 'ordinary' people from a variety of backgrounds and interests who are willing and able to make a voluntary commitment to speaking up and supporting the wishes of vulnerable adults. A partnership is formed between an advocate and an adult with a learning disability who has requested support. The aim of this partnership is to develop:

- Self confidence;
- Sense of empowerment;
- To identify personal goals;
- Establish a sense of direction.

Advocates can be a support to both parents and the person with a learning disability; most parents aim to give their adult son or daughter the confidence to express themselves and take control of their lives. Advocacy can also contribute to the strengthening of self-esteem and openness, an important issue as adult children move towards greater independence. Self and citizen advocacy can also enable people with a learning disability to take an active part in planning more responsive services that benefit everyone, both carers and users.

LOCAL ADVOCACY

The Government sees a thriving self-advocacy and citizen advocacy network as a way of helping to empower people with learning disabilities to gain control over their lives and be more fully involved in decision-making.

There is a newly established organisation on the Island called the **Isle of Wight Advocacy Trust**. This independent charity aims to offer volunteer advocates to adults with a learning disability to enable them to speak up for themselves and exercise choice. The Trust is based at Quay House, The Quay, Newport, Isle of Wight PO30 2QR; telephone Jan Gavin on 01983 822209 extension 203.

101 Per Cent Advocacy and Appropriate Adult Service is a long established charity that provides independent advocacy in a number of situations, such as complaints, housing and financial issues, benefit appeals, etc. The Isle of Wight office is at Parklands Resource Centre, Park Road, Cowes, Isle of Wight PO31 7LZ; telephone 01983 209710.

3 ASSESSMENT & PERSON CENTRED PLANNING

WHAT IS THE LEGAL BASIS FOR THE RIGHT TO AN ASSESSMENT?

Section 47 of the NHS & Community Care Act 1990 gives the right to an individual assessment of needs. An individual should receive a package of care in line with their Care Plan and have their needs reviewed over a period of time. Care Managers are responsible for an individual's assessment and for delivering flexible packages of care. These are supported by Community Care Plans based on an assessment of need within the whole community. The completed assessment should be the basis on which services are offered.

Local Authority Social Services departments are responsible for the provision of community care services. Social Services departments have a duty to provide some services and a power to provide others. Where they are under a duty to provide a service, they MUST do so. Where they have a power to provide a service, they MAY do.

WHAT ARE MY ENTITLEMENTS?

The user of services, or the carer, is entitled to the following:
- An assessment of need for community care services.
- A statement of the services to be provided. This should not be restricted to services that the Local Authority can provide.
- To receive the support specified in the assessment when a need is recognised.
- To be told the reasons for any refusal or failure to assess or provide services.
- Participation in the assessment process.
- Agreed criteria for bringing in the support of an advocate for users unable to participate in their own assessment.
- To request a full review of all services (though focusing on a specific need will often get a quicker response).

WHEN SHOULD AN ASSESSMENT BE REQUESTED?

An assessment should be requested if:
- There is a need for social care and support;
- There is a need for an individual plan;
- There is a major life change, such as moving from home to residential care, from education to community services or moving to a different area.

A review or reassessment should be requested if:
- You are unhappy about a particular aspect of the individual Community Care Plan;
- You or the service user feels different or additional services are needed.

CAN AN ASSESSMENT BE REFUSED?

Yes, although it is rare. Local Authorities must consider every request for an assessment of community care needs. A decision not to make an assessment must be reasonable and the disabled person or carer must be given reasons for this. If a satisfactory reason is not given, you can make a complaint.

WHAT SHOULD THE ASSESSMENT INCLUDE?

It should consider all of the needs, including:

- Accommodation – short and long term;
- Health care – including nursing and psychiatric needs;
- Personal care;
- Social needs, e.g. social work support, daytime activity and leisure;
- Employment;
- Education;
- Finance.

The Local Authority is obliged by law to produce information about how it assesses people, the services they need and what is actually provided. It must also have information on how people can get what they need. If there is a need identified for an individual, the Local Authority must provide a Care Plan.

HOW LONG AFTER REQUESTING AN ASSESSMENT WILL IT TAKE PLACE?

Social Services have the following care management standards for assessment and service delivery. Obviously, sometimes it may not be possible to meet these timescales and you should be kept informed about any delays.

- If the need is URGENT the assessment will be done within 24 hours.
- If the need is LESS URGENT but the risk is high, it should be done within 2 to 10 days.
- A request that is NOT URGENT may well wait for more than two weeks, but the speed of the response will depend upon the particular circumstances.

HOW IS THE ASSESSMENT CONDUCTED?

The assessment is undertaken by a designated officer who may be a Care Manager, nurse or therapist. They liaise with all the people concerned. The information is recorded on an assessment form. The assessment may take place over a number of sessions. It usually takes place at the disabled person's home. The person being assessed will have appropriate support to enable them to play a full role in the assessment procedure.

CAN A CARER REQUEST AN ASSESSMENT OF THEIR NEEDS?

Yes – the Carers (Recognition & Services) Act 1995 and the Carers & Disabled Children's Bill 2000 give all carers of people with special needs the right to an assessment of their needs.

The Carers & Disabled Children Act 2000 will allow services to be specifically provided for the carer. In any event, the provision of these services to a person with a learning disability may also help the carer, for example, by providing a break away from caring. (See Information Sheet 7 Carer Support Services and the second part of this information sheet for advice on things you need to think about before an assessment. The Act also gives the Local Authority the power to charge carers for services that are delivered directly to them. You should ask about any charges before you commit yourself to receive any service.

HOW DO I GO ABOUT GETTING AN ASSESSMENT?

Simply contact the Social Services Learning Disability Team, currently based at the Social Services Centre, Lind Street, Ryde (telephone 01983 566011). As the aim is to more fully integrate Social Services with Health, the working base for teams may change in the near future. Any change will be well publicised.

It should not be necessary for you to ask for an assessment for the person with a learning disability unless they are potentially new service users or their needs have changed and a reassessment is needed. There should be some support and planning for the transition from children's to adult services and an assessment of need will take place as young person reaches 18.

IS THERE A RIGHT TO SERVICES?

You are only entitled to the services that are specified as necessary to meet your needs following an assessment. The Local Authority must decide whether there is a need to provide community care services. This is not the same as a duty to provide services. If there is no statutory duty to provide a service but a person with a learning disability is assessed as needing it, it would be at the authority's discretion whether to provide it or not. The authority should abide by its own published criteria for eligibility to the service. Ask for a copy of the eligibility criteria from the Care Manager if you have any queries.

WHAT HAPPENS WHEN THE ASSESSMENT IS COMPLETED?

The Local Authority is not obliged to provide copies of completed assessment forms but local good practice is to do so. You should always ask for a copy of the assessment. If this is refused, write to the Care Manager to clarify the reason for the refusal.

The next stage of the process of care management is the care planning stage. Information from the assessment is used as the basis for an individual Care Plan. The meeting is usually attended by all the interested parties: client, carer, Care Manager, etc. It is essential that service users and advocates attending this meeting are well prepared. Make a note of the points you need to make. The disabled person concerned should be involved as much as possible. The Care Manager will draw up the final Care Plan following the assessment and the meeting.

Guidance states that individuals are entitled to a copy of the Care Plan and you should always ask for a copy. In the future, PERSON CENTRED PLANNING will lead to a Personal Life Plan rather than a Care Plan. This is outlined in more detail later.

HOW IS THE CARE PLAN IMPLEMENTED?

The responsibility lies with the Care Manager to ensure that this happens. Service providers may be private or voluntary organisations, as well as the local authority itself.

The period between the formulation of the plan and implementation can vary greatly, from as little as a week right up to several months if the needs are complex. Don't be afraid to ask about the reasons for a delay.

Once a plan is fully implemented, it is up to the Care Manager to monitor it and review the assessment regularly. Reviews should be carried out at set times to discuss the effectiveness of the plan. If the review doesn't take place within the agreed timescale, contact the Care Manager for a new date.

CAN THE LOCAL AUTHORITY REDUCE A SERVICE?

Following an individual reassessment, a Local Authority can reduce community care services to people, either because of a change in their needs or because of a change in the Authority's policies and/or eligibility criteria. A Local Authority may review a service following changes in its criteria for providing a service, for instance, due to lack of resources. You should remind them that your needs must be fully reassessed. If they have not changed, you should argue that the service should not be withdrawn.

An Authority cannot withdraw a service because someone is refusing or is unable to pay for it. (There is further information on charging in Information Sheet 8 Community Care Services.)

PERSON CENTRED PLANNING

In 2001, the Government published their new strategy for learning disability called *'Valuing People'.* This set the four key principles of Rights, Choice, Independence and Inclusion and the Government's objectives for learning disability services. One of these is *"to enable people with learning disabilities to have as much choice and control as possible over their lives through advocacy and a PERSON CENTRED approach to planning the services and support they need".* Locally, the development of Person Centred Planning is at an early stage but it is important that carers of people with learning disabilities know about this new development, as they will be very much involved in the process.

WHAT IS PERSON CENTRED PLANNING?

Person Centred Planning is **about**:

- Putting the person at the centre of planning their lives;
- Listening to what people want and need in their lives;
- Helping people to think about how they want to lead their lives now and in the future;
- Families, friends, professionals and services all working together to make a person's plan happen;
- For everyone who wants one;
- A person's life changing for the better.

Person Centred Planning is **not**:

- The same as Assessment, Care Planning or Reviews;
- Owned by services;
- A new type of meeting;
- A form-filling exercise;
- Only for people who are easy to communicate with.

WHAT IS A PERSON CENTRED PLAN?

Increasingly, through Person Centred Planning, people with a learning disability will have a personal Life Plan, which is much broader than a Care Plan. A Life Plan will be developed over a period of time and will describe how the person, their family and professionals will work together to help that person lead a fuller life.

The Life Plan should include health care needs, any special support that is required and set out the assessed care needs, including:

- Short breaks for the person or their carers;
- Meaningful work or other opportunities during the day;
- Further education;
- Housing and transport needs;
- How each of these should be met.

A Life Plan should look at what is in the best interests of the person with a learning disability in an in-depth way, focusing on needs and what is available.

HOW COULD IT BE DONE?

There are a number of ways, but it always starts with the person and continues to include the person throughout. Each method combines a number of elements, for example, questions that facilitate understanding of the person and his/her situation, processes for engaging people and processes for bringing people together to share and make decisions. Parents may find it helpful to have some idea of the approaches that may be used.

MAPS (Making Action Plans): these are tools designed to help individuals, organisations and families think about their futures and make effective and creative plans.

PATH (Planning Alternative Tomorrows with Hope) evolved from the MAPS process. It was designed and developed in 1991. Like MAPS, it is a graphical model for helping people to address long and short range planning.

PFP (Personal Futures Planning) is a flexible set of questions and graphical maps for building a sense of the individual's strengths and gifts and how they could be better utilised.

ELP (Essential Lifestyle Planning) is a powerful way of gathering information about what is important to people with learning disabilities in their day-to-day lives. It is especially useful in working with people who do not speak or use signing.

Circle of Friends/Support: this is an ancient concept – historically, groups of people have often formed a support network around a person who is vulnerable in society. A Circle is a group of people who come together voluntarily and at the invitation of the individual to offer support. The focus of the group is to concentrate on positives, as opposed to being preoccupied with negatives and problems.

HOW DOES IT HELP?

There are lots of positive things to say about Person Centred Planning. For example, Person Centred Planning:

- Helps a person to think about their life, dreams and wishes;
- Helps a person to think about who is in their life and to develop friendships and relationships;
- Helps a person to live life as they want to now and in the future;
- Boosts confidence;
- Changes attitudes;
- Helps a person to be part of the community;
- Helps services understand how they can support a person to lead their life the way they want to;
- Helps a person to make changes to their life;
- Recognises a person's talents;
- Recognises what a person can contribute to their community.

HOW WILL THIS WORK WITH PEOPLE WITH COMPLEX NEEDS?

There are many ways to do this. They often involve finding out about the individual's unique communication skills in order to really listen to them. Sometimes the worker will need to learn new skills in order to really listen to the person. *"The more we listen, the more we learn. The more we really listen, the more the person speaks."* The worker will need to think creatively and imaginatively in order to help the person communicate. Creative, innovative and imaginative thinking are essential to person centred planning.

Person Centred Planning requires person centred thinking. Person centred thinking, however, shouldn't necessarily have to wait until Person Centred Planning takes place. It should be the way everyone thinks when supporting a person with a learning disability.

Person Centred Plans are about helping people to get the lives that they want and need. Those who support and develop plans with people who have disabilities should be able to answer seven questions:

1. What is important to the person?
2. What is important for the person?
3. Is what is important to the person being addressed in the context of what is important for the person?
4. Is there a good balance between what is important to the person and what is important for the person?
5. What does the person want to learn and what else does the person need to learn?
6. What needs to stay the same (be maintained or enhanced)?
7. What needs to change?

The key principles of Person Centred Planning are:

- The person is at the centre;
- Family members and friends are partners in planning;
- The plan reflects what is important to the person, their capacities and what support they require;
- The plan results in ongoing listening, learning and further action.

Source: MENCAP – A Guide to Community Care Law
Person Centred Planning: Sue McSwiggan, Independent Practitioner

GETTING A CARER'S ASSESSMENT – WHAT DO I NEED TO THINK ABOUT?

- If you decide to have an assessment, it is important to think about what you want to get out of it before it happens.
- Remember: no-one can force you to provide care even though, at times, you may feel you have no choice.
- You need to think about what is best for the person you care for and consider the impact that being a carer will have on you and those around you, both now and in the future.
- It is important not to forget that many illnesses and disabilities will get worse over time and, even if you feel able to cope right now, you may not always be able to.
- Read through the local Carers Handbook (available from Social Services and the Carers UK branch on 01983 533173) and, if possible, talk though all the options with the person you care for.

We have put together a list of things to think about as you are preparing for the assessment. Everyone's situation is different and so not all the questions may seem relevant to you. Focus on the ones that you think are important and remember that you must think about ***your needs*** as you answer them – the person you care for will have their own assessment.

Your role
- Do you think you have a choice?
- How much time does caring take up and are there things involved that you can't do or just don't want to do?
- Are you feeling constantly stressed?
- Does caring stop you doing things that are important to you?

Yourself
- What would you like to do that you can't?
- Do you have a past hobby, sport or interest that you would like to do again?
- Do you see the friends and relatives you would like to?
- Can you get out when you want to?
- Do you have someone you can talk to or confide in?

Your time
- How much time do you get to do the things you want to do for yourself?
- How much time do you spend doing practical things for the person you care for that they can't do for themselves?
- What are these things?
- Do you have to spend time 'just being there' for the person you care for or supervising them as they do things?
- Can the person you care for be left alone?
- Do you have to provide help at night and, if so, what?

Your work
- Do you have a job or would you like to get one?
- What help do you need to keep or get that job?
- Can your employer change your hours or change your job so that you can stay in work?
- Do you need training to help you get a job?

Money

- Are you sure you have claimed all the benefits and allowances you are entitled to?
- Can the person you care for manage their own money?
- Do they help you with the expenses of living?

Health

- Do you understand all the health needs of the person you care for?
- Do you know who to contact in an emergency?
- Do you have any health problems of your own, either now or that you think may get worse in the future?
- Do you get enough sleep?
- Are you able to rest and switch off?

Housing

- Do you and the person you care for live together or apart?
- Is the arrangement satisfactory?
- Who owns the house and who has the right to live in it?
- Is the house suitable for the physical needs of the person you care for?
- Is the house suitable for the needs of everyone else who lives there?
- Is there easy access to facilities you need in your community, such as the doctor, the post office, shops and the chemist?

The future

- What would happen to the person you care for if you were unable to provide the care you do?
- What will happen when you no longer have to provide care?

Hopefully, the answers you have come up with will give you an idea of the sort of help you need. Don't be embarrassed to ask for that help – you are entitled to it. Your task at the assessment is to try and establish, with the help of the Social Services Department, where you can best get the help you need.

Don't decide what you think an organisation can do before you have spoken to them. Go to the assessment with an open mind – you may be surprised at what is on offer.

When you feel ready for your carers assessment, call the Social Services office on 01983 566011 and ask to speak to the Care Manager for the person you care for.

It may take time to get what you need, but remember you are entitled to help. Don't give up. Try to think ahead and don't wait until a crisis occurs. The right sort of help, at the right time, may help you to care more effectively and also give you more opportunities to do the things you want to do for yourself or other members of your family.

This information folder should provide you with most of the information and contact numbers to get the help you need.

4 BENEFITS

PART 1: BENEFITS FOR CARERS

CLAIMING BENEFITS

The benefits system changes frequently and it might be worth contacting either the Benefits Agency or your key worker to make sure that you know what you can or can't claim for. Every year, millions of pounds of benefits are left unclaimed.

A confidential telephone service giving general advice on benefits is available for people with disabilities and their carers. Ring the Benefit Enquiry Line (BEL) on Freephone 0800 882200.

Some benefits are 'means tested', so depend on your family's net income and any savings you or your partner may have. Other benefits depend on the amount of National Insurance (NI) contributions you may have made. Rates of payment normally change once a year. This leaflet gives general guidance only – it is not an authoritative statement of the law.

The benefits listed in this section may be available to you and to the person for whom you care.

ATTENDANCE ALLOWANCE

This weekly cash benefit is for people aged 65 years or over who need help with personal care because of an illness or disability. It is:

- Tax free
- Not dependent on NI contributions
- Not usually affected by any savings or income you or your partner may have

Attendance Allowance is one of the key benefits for people over pensionable age with a disability. This benefit is payable to the disabled person and is based on an assessment of the care they actually need. They do not have to be getting the care in order to get the benefit.

The money is intended to enable the carer to buy in whatever they feel they need to help them. It is paid at two levels: the lower rate for help during either the day or the night, and the higher rate for both day and night.

If the person is under pensionable age, the equivalent benefit is Disability Living Allowance, which also contains an extra mobility component (replacing the old Mobility Allowance).

DISABILITY LIVING ALLOWANCE

This is for people under 65 years old who need help with personal care, getting around or both. It is:

- Tax free
- Not dependent on NI contributions
- Not usually affected by any savings or income you or your partner may have

INCAPACITY BENEFIT (formerly known as SICKNESS BENEFIT and INVALIDITY BENEFIT)

This is for people who:

- Cannot work because of illness or disability
- Cannot get Statutory Sick Pay from their employer or are self-employed
- Have not retired

Incapacity Benefit:

- Depends on NI contributions
- Is not affected by any savings you or your partner may have
- Requires regular medical certificates (sick notes) to say the person is still unable to work
- Is subject to regular checks by the Benefits Agency

HOUSING BENEFIT

This is paid by local councils to people who need help to pay their rent. It is:

- Means tested
- Tax free
- Does not depend on NI contributions

However, it does not cover:

- Some service charges, e.g. water
- Fuel costs
- Meals
- Mortgage interest payments

COUNCIL TAX BENEFIT

This benefit helps people on a low income who find it hard to pay their Council Tax. It has similar rules to Housing Benefit.

NB. A person with a learning disability who is in receipt of Attendance Allowance is also entitled to a reduction in Council Tax. Application forms are available on request at the local Council office.

INCOME SUPPORT

This is a social security benefit to help people aged 16 years old and over whose income is below a certain level. This benefit varies according to circumstances and may be paid:

- To top up earnings or other benefits
- To a person who has no income at all

Income Support is not related to NI contributions. Sometimes payments, such as mortgage interest payments, may be included or be paid directly to the lender or building society.

SOCIAL FUND

Payments from the Social Fund are extra payments made to people on certain benefits for expenses that are difficult to meet out of their regular income. Examples include:

- Maternity payments
- Funeral payment
- Cold weather payment
- Community care grant
- Budgeting loans (interest-free, repayable loans)
- Crisis loans (interest-free, repayable loans)

Payments from the Social Fund are not related to NI contributions.

The following benefit is available to carers:

CARERS ALLOWANCE (formerly known as INVALID CARE ALLOWANCE or ICA)

This is a taxable weekly benefit for people who:

- Are of working age
- And have to look after someone who is getting Attendance Allowance (AA) or Disability Living Allowance (DLA) care component at the middle or high rate.

The carer must:

- Be 16 to 65 years old
- Spend at least 35 hours per week as a carer
- Be earning less than £77 per week (2004)
- Not be in full time education

Carers Allowance is not dependent on NI contributions.
Receiving Carers Allowance can reduce certain benefits received by the person being cared for.

THE PENSION CREDIT

The new pension credit guarantees everyone aged 60 and over an income of at least £102.10 a week for single people or £155.80 a week for those who have a partner (October 2003 figures). The person who applies for the pension credit must be at least 60; it doesn't matter if their partner is under 60.

There will be higher amounts for some disabled people, carers and homeowners with certain housing costs. For the first time, people aged 65 and over will be rewarded for having income and savings by being given extra money.

The pension credit has two parts: the guarantee credit and the savings credit.

- The guarantee credit replaces the Minimum Income Guarantee (MIG – Income Support for people over 60) and will work in the same way, by topping up a person's income to a set level.
- The savings credit is extra money for people aged 65 or over who have an income above basic retirement pension level or who have savings or investments. It is based on the total amount of income a person has, including income from private or occupational pensions.

People who are already receiving MIG/Income Support do not need to make a claim for pension credit – they will automatically be transferred. Those who do not receive MIG will need to claim. Between April 2003 and June 2004 the pension service is writing to all people aged and over to help them decide whether to apply for the pension credit. Those who have not yet claimed will not lose out as long as they claim before October 2004; their pension credit will be backdated to October 2003.

People can provide the details needed to work out their pension credit claim over the phone. The pensions service will send them a statement of the details given, which should be signed and returned to confirm they are correct.

To apply for pension credit, ring the pensions service on 0800 99 1234 (Monday to Friday, 8.00am to 8.00pm and Saturday 9.00am to 1.00pm). The textphone number is 0800 169 0133.

You will need the following details for both yourself and your partner when you phone:

- Your National Insurance (NI) number. You can get this from your pension book, payslips, tax papers or letters from the Benefits Agency.
- Information about any income you have.
- Information about any savings and investments you have, including bank/building society details.

VAT

Disabled people are exempt from VAT on certain supplies and equipment specifically bought for their needs. Contact a specialist supplier of equipment for disabled people for further information.

NHS COSTS

Help can be given with NHS costs. Under certain circumstances, you can get free:

- NHS prescriptions and hospital medicine
- Dental treatment
- Eyesight tests
- Other costs

PART 2: EARNINGS AND BENEFITS

INTRODUCTION

It is generally thought that less than 10% of people with severe learning disabilities are in paid employment and that at least half of those who are doing paid jobs are in part time work. Nearly all are in low paid work. Many people are involved in various kinds of (unpaid) voluntary work.

People with severe disabilities should not be under pressure to work but should be given the opportunity and support to work if they wish. For the most severely disabled people, work will not be a realistic option. People with severe learning disabilities who do paid work will usually be combining social security benefits and earnings.

The Benefits Agency and the Employment Service merged in April 2002 and the combined service is now called Jobcentre Plus.

This fact sheet explains the relationship between benefits and earnings.

INCAPACITY BENEFIT/SEVERE DISABLEMENT ALLOWANCE

Permitted Work Rule

In April 2002, the Permitted Work rule replaced the Therapeutic Earnings rule. In contrast to the Therapeutic Earnings rule, under the Permitted Work rule it is not necessary to get a doctor's approval in order to work. It is, however, still necessary to notify Jobcentre Plus about starting any work and in some situations to get their permission. Making contact before starting work is advisable.

People with disabilities can work for 26 weeks for less than 16 hours a week and earn up to £72 a week on minimum wage rates (this figure tends to change in October each year) without affecting their Incapacity Benefit or Severe Disablement Allowance. Some people will have this extended for a further 26 weeks if they seem to be getting closer to full time work. People with disabilities can work for less than 16 hours a week and earn up to £72 a week on an ongoing basis without their Incapacity Benefit or Severe Disablement Allowance being affected if they are doing Supported Permitted Work. This means that they are supervised at work by someone whose job it is to find work for people with disabilities and that the support is ongoing and regular. The person giving the support must be someone who is working for a local or public authority or voluntary organisation (Pathway support would count).

All claimants can work and earn £20 without it affecting their Incapacity Benefit or Severe Disablement Allowance. At this level, means-tested benefits will not be affected either.

INCOME SUPPORT

Income Support is paid to a wide range of people who are not in full time work. It either gives them their whole income or else it tops up other income to a prescribed level.

Disabled people who are doing some work while receiving Income Support on grounds of being incapable of full time work are allowed to earn £20 a week without cutting into their Income Support. Above £20, Income Support is reduced by £1 for each £1 of earnings. Usually, working hours are limited to under 16 hours week, though people in residential care can work without an hours limit – progressively cutting into their Income Support.

People receiving Income Support to top up their Incapacity Benefit or Severe Disablement Allowance are subject to both the Incapacity Benefit/Severe Disablement Allowance permitted work rules and the Income Support earnings rule. They can earn up to £72 under the permitted work rule without affecting their Incapacity Benefit or Severe Disablement Allowance, but any earnings above £20 will reduce their Income Support.

A range of additional help is available to people receiving Income Support, such as hospital travel costs and free prescriptions. Much of this help is also available to disabled low earners who get alternative financial help through the Working Tax Credit to replace their Income Support when they start full time work.

CALCULATING EARNINGS

Earnings are normally taken as the earnings you receive once tax and contributions have been taken off, net of work-related expenses.

WORKING TAX CREDIT

This benefit is claimed from the Inland Revenue. It can be claimed by people with disabilities on low earnings who are working 16 hours or more a week. Higher amounts are payable to those working more than 30 hours, those with children, those over 50 and those who are paying for certain types of child care. People earning a gross income of above £5060 (April 2003 figure) will have their personal Working Tax Credit reduced by 37% of the excess income.

CHILD TAX CREDIT

This benefit is paid to people with children. It is paid at different rates depending on the age of the child and whether or not the child is disabled. People earning a gross annual income of over £13,230 (April 2003) have their Child Tax Credit reduced.

HOUSING BENEFIT and COUNCIL TAX BENEFIT

These are income-related benefits designed to help people without earnings or with low earnings to meet housing costs or Council Tax costs. The two benefits are very similar. (Some people have both rent and a mortgage to pay on their home and need both Income Support and Housing Benefit to help meet their housing costs.) Some housing related costs that were met by Housing Benefit are now being separately identified and met under the separate heading of Supporting People funding.

For disabled people getting Housing Benefit, the earnings disregard before benefit is affected is £20, as for Income Support.

Note that people with severe learning disability may not be required to pay Council Tax. For those who do, Council Tax Benefit takes account of income, including earned income, in much the same way as Housing Benefit.

DISABILITY LIVING ALLOWANCE

The Care and Mobility Components of Disability Living Allowance (and Attendance Allowance for those claiming once they are over pension age) are paid to people whether they are working or not. There is no income test, so earnings make no difference. Entitlement to this benefit should not be reviewed simply because someone starts work - and Department of Work guidance says this.

THE INDEPENDENT LIVING FUND

This fund provides financial help for severely disabled people to help them meet the costs of personal care. People are expected to contribute from their benefits towards their support costs, but earnings are not taken into account.

JOB SEEKERS ALLOWANCE

This is paid to people, including disabled people, who are capable of work but unemployed and looking for work. In the shorter term, the first six months benefit is based on contributions, if these have accrued, with means-tested additions. After six months, the benefit is means-tested. Voluntary work is possible if it does not prevent someone responding promptly to a paid job opportunity. The earnings disregard is normally limited to £5 a week.

CARERS ALLOWANCE

This is the benefit paid to those who are prevented from working normally by having to care for a disabled person receiving middle or higher rate Disability Living Allowance Care Component or Attendance Allowance. Caring must be for 35 hours a week or more. Paid work outside this period is permissable but earnings must not exceed the National Insurance lower earnings limit, i.e. £77 a week (as from April 2003).

ACCESS TO WORK

This is an employment support programme that offers financial and other help to disabled people in work or seeking work. Establishing entitlement can be a lengthy process and, if possible, negotiations should start early with the help of an employment adviser or other person.

VOLUNTARY WORK

Voluntary work (unpaid) will probably have no impact on anyone claiming Incapacity Benefit, Severe Disablement Allowance or Income Support for reasons of disability, or any combination of these benefits. The Department for Work & Pensions is entitled to review an individual's capacity for work and might do so if the voluntary work suggests that the beneficiary could do a paid job. Those claiming Job Seekers Allowance and doing voluntary work have to be prepared to leave this work within 48 hours to take up paid employment.

WHAT ARE THE OPTIONS FOR WORK AND EARNINGS?

- A person with disabilities may do voluntary, unpaid work where expenses such as travel and food are met, but no other payment is received. This should not affect disability benefits at all, though if they are doing work for which other people are getting paid, they should let the Jobcentre Plus know (or Benefits Agency in Northern Ireland). People getting Job Seekers Allowance normally must be available for paid work if they are doing voluntary work.

- A person with disabilities may do a limited amount of paid work under the Income Support disregard of £5, £10 or £20. The £20 allows them to work for up to 4 hours on the minimum wage. They must tell the Jobcentre Plus.

- A person with disabilities may do a certain amount of work without affecting Incapacity Benefit or Severe Disablement Allowance if that work meets the permitted work rule. They may earn up to £67.50 per week and work for up to 16 hours per week. Some people will only be permitted to do this for a period of 26 weeks; some will get an extension for a further 26 weeks. Some people can do this on a permanent basis. In all cases, they must tell the Jobcentre Plus (or Benefits Agency in Northern Ireland) before starting.

- A person with disabilities may, in any case, earn £20 a week without it affecting their Incapacity Benefit.

- A person with disabilities may decide, with help, that with work available it is better to come off Incapacity Benefit and Income Support and rely on earnings and Working Tax Credit. They should make sure that housing costs will be covered by some means.

MORE INFORMATION

If you want further information, try contacting:
- Citizens Advice Bureau (CAB) – telephone 0845 120 2959
- The Disability Alliance Rights Advice Line – telephone 020 7247 8763
- Tax Credit Help Line (Great Britain) – telephone 0845 300 3900
- Benefits Enquiry Line for Disabled People and their Carers (Great Britain) – telephone 0800 882 200
- See Information Sheet 10: Employment and Training

Source: MENCAP Fact Sheet, updated January 2004

5 BULLYING AND ABUSE – WHAT TO DO

People with a learning disability remain, in general, a vulnerable group in society, although most now live and work in ordinary communities, leading increasingly independent lives. Research shows that society has not moved on or adapted to this change and a substantial number of people with a learning disability may be the target for physical and verbal abuse as they go about their daily lives. Some may also be subjected to other forms of abuse, such as financial and sexual abuse.

Abuse, especially physical and sexual abuse, has emerged from the "it doesn't happen" stage, through the "it sometimes happens in a few bad services and it is always perpetrated by men" stage, to the painful recognition that vulnerable people, adults and children, male and female, may be at risk in services, in families and in public places, and at risk from men and women, and from other people with learning disabilities.

The honest recognition of a painful truth is not a reason for denying people the right to grow up and take planned risks – that is itself a form of abuse that has been all too common. The aim is:

- To make people themselves and advocates and carers more aware of the risks;
- To reduce the risks as far as possible;
- To enable people with a learning disability to have an awareness about what constitutes abuse and to be more able to assert themselves;
- To ensure that good systems are in place to both reduce the possibility of abuse and deal with situations that occur.

This information sheet aims to raise awareness of the possibility of abuse and advise carers on what steps they can take if they suspect that someone is being bullied or abused.

WHAT IS ABUSE?

Abuse is the violation of an individual's human or civil rights by any other person or persons. It can occur as a single incident or as part of a repeated pattern. It can be spontaneous or premeditated. The person acting in an abusive way may not even be aware of it.

THERE ARE DIFFERENT KINDS OF ABUSE

Abuse covers a wide range of behaviours and situations.

- **Physical abuse:** such as pushing, shaking, pinching, slapping, restraint, withholding care or medication.
- **Neglect:** such as failure to meet someone's care needs, either deliberately or unintentionally. This results in risk to the well-being of the vulnerable adult.
- **Emotional abuse:** such as verbal threats, offensive or belittling remarks or other behaviour that causes distress or concern to another person.
- **Financial abuse and exploitation:** another person uses the resources of the vulnerable person for their own advantage. This can range from not getting change from their shopping to property transfer.
- **Institutional abuse:** abuse is not expected in such settings and abusive practices are often unintentional but could include – stark living areas, lack of stimulation, inappropriate confinement or restriction, over-use of sanctions by staff, over-restraint including the use of drugs.

- **Sexual abuse:** this means unwanted sexual or 'touching' behaviour without consent and any sexual act that someone has not consented to and doesn't understand. An individual can be pressurised into consenting and it is not uncommon for emotional abuse in the form of threats and intimidation to be perpetrated alongside sexual abuse.
- **Bullying and harassment:** can involve any of the following behaviours – kicking, biting, name-calling, teasing, stealing, pushing, threatening, having things thrown at you, being told to leave a building, hitting, being shouted at, swearing, demanding money, hair-pulling, throwing stones, spitting, poking, being punched, being beaten up, having one's head banged against the wall. Many of these would also be seen as examples of financial, physical and psychological/emotional abuse.

WHO AND WHERE?

Any vulnerable person may be abused, anyone may be an abuser and abuse can occur on a bus, at a sports centre, college or day centre, at a club or even at home – in other words, anywhere at any time.

WHAT CAN YOU AS A PARENT DO?

Parents can be alert to what is going on, aware of what behaviour should arouse suspicion and be able to act promptly. Being aware of dangers means that you can be prepared so that if you are concerned you can act quickly and effectively and help to prevent abuse. You can also help prevent abuse by supporting your son and daughter in understanding what constitutes abuse and giving them the confidence to say 'No'. Useful booklets and guides are listed at the end of this information sheet, as is information about the local People First self-advocacy group.

You need to be:

AWARE
- Of your rights and those of your adult son or daughter
- Of the standards you should expect in services
- Of the actual services being provided
- Of what behaviour should arouse suspicion

ALERT
- To what is happening
- To what is being said
- To the behaviour of your adult son or daughter and any possible change

ABLE
- To listen
- To understand
- To ask questions
- To ask for help
- To take action

RIGHTS OF PARENTS AND ADULT CHILDREN

People with learning disabilities are adults, not children, but their parents will always have an interest and concern about their welfare, particularly if they live with them. This interest and concern does not disappear even if the person with learning disability goes into residential care. Parents should be told of any abuse or suspected abuse and if they have worries these should be acknowledged and responded to by staff.

Sometimes staff refuse to reply to parents' questions or give them information because they say the person is an adult and that parents have no right to information. Many parents are made to feel that because their son or daughter is chronologically an adult they have not legitimate interest in their welfare and they are expected to be completely independent. Parents are likely to be the most constant factor in the life of their son or daughter and should be kept informed.

People with learning disabilities are individuals with a wide range of abilities. Trying to protect them from abuse does not deny their individual rights to form appropriate relationships if they wish to do so. However, it must always be remembered that almost all people with learning disabilities do not have full control over their lives. They can be exploited and vulnerable to abuse.

WHAT TO BE ALERT TO

Changes in behaviour: becoming withdrawn and depressed, agitation, refusal to go to a centre or club.

What is said to you: you may be told "X did so and so" but communication may well be a mixture of words and gestures. However, do not necessarily expect to be told, no matter how good your relationship with your son/daughter. They may actually more easily confide in someone else whom they trust too.

Medical/physical problems: such as bruising or scratches. Sudden difficulty in walking/sitting, genital infections, discharges and menstrual problems can be symptomatic of sexual abuse.

People react to trauma in different ways and their disabilities may affect the way it shows. Parents will know that 'something is different' or 'is not right'. They can then look for causes. These may not be abuse at all. There may be a number of reasons why people don't want to do something, become depressed or anxious. Parents need to find out what is going on and realise that one possibility is sexual abuse.

WHAT TO DO ABOUT IT

Your first concern will be for your son/daughter. If he or she has said something that indicates abuse of any kind, listen calmly, take time, comfort them and believe them. If there are signs of abuse, try to find out gently what has happened. If evidence is available, keep it. You will want to make certain your son or daughter is safe and protected from further abuse. If the evidence is very strong this may mean withdrawing them from a centre, home or club or changing travel arrangements.

Immediate action will depend on what has raised suspicion, where it is happening and who is involved. Something is wrong; it may not be sexual abuse but parents need to find out what is going on. They may wonder, for example, about the disappearance of their daughter's radio and that of her friend. Why is their son bruised so often? Is he really falling down every day or fighting? Why is their daughter refusing to go to the club? These concerns should be raised with managers. If no satisfactory response is received senior managers should be informed. Other parents may have similar worries and it can be helpful to talk to them. When parents are uneasy they should be on the alert and talk to staff, volunteers and advocates as well as other parents.

Residential units and community services should have a Policy on Adult Protection, which should spell out the steps that should be taken and the people who should be involved in the investigations. Insist that this is carried out.

Abuse may arise within the person's social network. If a voluntary society is involved, the manager should be told. If it is in a less formal setting, it is more difficult.

- If the problem needs immediate attention (for example, the person is at imminent risk of harm), the Police should be called. Telephone either 999 or the local Police number at 0845 045 4545.

- Phone the Social Services Duty Team Help Desk on 01983 823340 and ask to speak to the Duty Officer. Whilst you do not have to give your name, it is helpful to have a name and contact number in case they need to contact you. They may need to act on the information you give and contact other relevant services.

- If you need help with talking about what has happened and want someone to advise you or act on your behalf, contact 101 Per Cent Advocacy on 01983 209710 or Isle of Wight Advocacy Trust on 01983 822209 extension 203.

- If you need assistance outside of office hours, please phone Wightcare on 01983 821105 and ask for the Duty Social Worker.

WHAT WILL HAPPEN NEXT?

In response to your referral, trained staff will carry out a careful and sensitive enquiry. What needs to happen will depend on the wishes of the person or the seriousness of the situation. If they are in physical danger, ensuring their safety will be of the utmost importance. Remember that every adult has the right to:

- A life free from fear;
- Be treated with dignity;
- Have their choices respected and not be forced to do anything against their will.

WHAT SUPPORT IS AVAILABLE?

Action must be taken when abuse is suspected and taking action is not a matter for blame, although many parents feel that they should have, in some way, prevented the abuse – that it is their fault. It is the abuser, a powerful person in relation to the person with disabilities, who is responsible. Parents may have feelings of guilt, failure and anger. It is important to share these feelings with someone who can help, such as the Care Manager, nurse, psychiatrist or another parent who has 'been there'.

Respond: national help line provides information and support for parents and carers who are concerned about the disclosure and effects of any kind of abuse, Mon-Fri, 1.30pm-5.00pm. Telephone: 0808 808 0700

ARC (Association for Real Change): have some helpful publications. Telephone 01246 555043

MENCAP Help Line and Information Service: Telephone 020 7696 6900/6979

VIA (Values Into Action): produce some pocket-sized guides for people with a learning disability called *'A-Z Let's Keep Safe and Let's Report It'*. Telephone 020 7729 5436

VOICE UK: publish a booklet in an accessible format for people with a learning disability called *'Stop! No More Abuse'*. Telephone 0870 013 3965

Royal College of Psychiatry: Books Beyond Words series - *'Mugged'*. Telephone 020 7235 2351

People First: an organisation that exists to help people with a learning disability to take responsibility for and better manage their own lives. Members learn about assertiveness and how to deal with bullying and abuse, as well as other issues. There are social events and they also have fun. Contact Dave Downer on 01983 520795 or John Phillips on 01983 864891.

6 CONSENT AND DECISION MAKING

Carers often want to know who is legally entitled to make decisions on behalf of their adult sons and daughters with a learning disability.

In most circumstances, people with a learning disability who are aged 18 or over have the same legal rights and freedoms as any other adult. In most situations, no one has a formal right to make decisions on behalf of a person with a learning disability who is aged 18 or over.

Relatives do not have any legal right to make decisions on behalf of their adult relatives with a learning disability. Relatives cannot become the legal guardian of an adult with a learning disability. A term such as 'guardian' carries no legal meaning in respect of adults with learning disabilities.

There are two main exceptions where the law allows another adult to make a decision on behalf of an adult with a learning disability. These are:

- **Medical treatment:** In some cases where treatment is needed, a health professional can give medical treatment to an adult with a learning disability who is unable to consent.

- **Financial issues:** In some circumstances, a relative or friend can go through specific procedures to take control of the finances of an adult with a learning disability who is not able to look after their own affairs even with support.

These areas are explained in detail in this information sheet.

Most adults with a learning disability are capable of making their own decisions, particularly when clear, accessible information is provided. It is important that adults with a learning disability are encouraged to make their own decisions.

However, some adults with a learning disability do not have the mental capacity to make certain decisions. For these people, relatives and carers will of course make everyday decisions on their behalf on a daily basis, such as what someone is going to wear or eat, although choice should always be encouraged. However, there is nothing in the law that gives relatives decision-making rights, other than in certain financial situations as explained in this information sheet.

MAKING DECISIONS AND MEDICAL TREATMENT

Adults with a learning disability have a right to make their own decisions on health care and treatment decisions. Everyone has the right to make decisions on their own bodies and a health professional must seek a person's consent before starting treatment or providing personal care to an adult with a learning disability.

It is presumed that an adult has the capacity to make a decision for him/herself and that every step should be taken to explain the options to that person. Health professionals should help people with a learning disability find ways to understand what is wrong with them, what treatment is being proposed and why, the effects of the treatment and whether there are any alternatives.

Where there is doubt about the ability of a person to make a decision, an assessment of capacity should be carried out by a doctor. Good practice suggests that those close to the patient will be consulted on this.

But, in the end, it is the doctor who will take the final decision. An adult with a learning disability will need to understand what is involved in the treatment. This means that they will need to understand (and retain) information relevant to the decision, the consequences of not having the treatment and be able to use and weigh up the information provided. Capacity should not be confused with the reasonableness of a decision. A patient can make a decision, even if it appears irrational, as long as they understand what is entailed in that decision. An individual may also be able to consent to some forms of treatment but not others. In some cases, it may be important for an individual to have the support and help of an advocate in order to make decisions.

No one can give or withhold consent to medical treatment on behalf of another adult. Families and carers cannot make decisions on behalf of adult patients who cannot decide for themselves. Health professionals are generally allowed to provide treatment to someone who does not have the capacity to consent, when they believe it is in the patient's "best interests". Best interests are not limited to physical health. It also includes the patient's values and preferences, well being and psychological health. It is good practice for the health team to consult with those close to the patient such as families and carers.

There may be difficulties in balancing the views of best interests as seen by health care professionals, people with a learning disability, families and carers. It is hoped that everyone involved will be able to agree what is best. Occasionally they do not.

If you are unhappy with the process with regard to seeking the consent of a person with a learning disability, you are entitled to complain. Information Sheet 14 gives information about how to make a complaint and it has all the local contact numbers.

If there is a dispute with regard to the appropriateness of treatment for a serious medical matter which cannot be resolved, in the absence of consent, you or the person providing health care can ask the Court to intervene and decide what is in the patient's best interests. Certain types of irreversible treatment such as sterilisation or withdrawal of life support can only be carried out if a court has authorised it.

Where someone is making their own decisions, it is very important to ensure that the person's decision is truly their own. People should not be forced into making decisions that they are not happy with because of pressure from others or simply out of a desire to agree with a person in authority.

There has been considerable guidance drawn up by the Department of Health in consultation with others, including Mencap, on seeking consent to medical treatment based on case law. This can be found on www.doh.gov.uk/consent

FINANCIAL MATTERS

Money matters can be difficult for many of us. They are even more difficult for people with learning disabilities. Someone with a learning disability may be competent to draw weekly benefits, take responsibility (with help where necessary) for personal spending and make a valid will.

Many people with learning disabilities live full and independent lives in the community, making their own choices with varying levels of support. Many people with learning disabilities are perfectly capable of handling their current and savings accounts. Money is a key factor in a person's self-determination, giving an individual an opportunity for choice and control. Many simple contracts should be open to people with a learning disability, including payment for goods in a shop or booking a holiday. The Disability Discrimination Act reinforces this right.

Bank accounts

A person with a learning disability has the same right to open a bank account as the rest of the population, which means they are subject to the same obligations. A learning disabled customer must be capable of entering into a legally enforceable agreement and give informed consent to transactions such as opening a bank account. For card-based accounts, customers need to understand the use of cashpoints and have the ability to remember a PIN number and to keep it secret. They need to understand the security consequences of failing to do so. Difficulties can sometimes be solved by explaining a bank account in very clear terms to a person with learning disabilities and offering a simple account. If the person does not have the capacity to have their own account, it is sometimes possible to open a joint account with a staff member or relative.

Mortgages and tenancies

People with learning disabilities live in a variety of different accommodation. Some live in shared homes and others alone. The issue of capacity arises in taking a tenancy, buying a property or taking out a mortgage. To make a contract a person will need to understand the nature of the contract, want to enter into a contract and understand the obligations of the contract (for example, in the case of rented housing that they will have to pay money regularly).

Home ownership is an increasingly possible option. Adults with a learning disability can take out a tenancy or buy a property outright or take out a mortgage. They will need to understand the contract they are entering into. People with learning disabilities who are on Income Support can get a mortgage providing certain criteria are met.

The official Solicitor has confirmed the view that the grant of a tenancy (for the basic necessity of having a roof over your head) is perfectly proper, even where the tenant’s capacity is limited.

Wills

People with learning disabilities can make valid wills if they have the capacity to do so. The capacity required is the ability to understand the will and what they are leaving and to whom. If they have capacity they should consult solicitors in the usual way. If they do not, there is a procedure for drawing up a Will on their behalf through the Court of Protection.

Making financial decisions on behalf of people with a learning disability

There are a number of situations in which it may be necessary to take over the management of someone else’s money. It is important that control is never taken away from people against their wishes if they are still able to manage for themselves.

In trying to identify when people are no longer mentally capable of managing their own affairs, it should be assumed they are capable unless they demonstrate otherwise. Focus should be on the actual ability to understand and to function in making particular decisions; for example, whether they can go shopping, whether they can pay their bills and whether they know what income they have.

A person is unable to make a decision if, at the time when the decision is made, the person is:

- unable to understand or retain information relevant to the decision, or
- unable to make a decision based on that information.

A carer may have a friend or family member who cannot manage their own financial affairs and may be concerned about what action should be taken to protect the vulnerable person's money and property. There are a number of ways of administering the financial affairs of those who are not able to do so themselves. A person could act as an **appointee** with the Department for Work & Pensions and have responsibility for everything in relation to social security benefits. In some instances, a person could be registered as having **Power of Attorney** with the Public Guardianship Office or be appointed as a **Receiver** by the Court of Protection to manage their affairs.

Court of Protection

An application may be made to the Court of Protection for a Receiver to be appointed for a person who does not have the legal capacity to deal with his or her money and property and does not have the capacity to make a Power of Attorney (see below). A Receiver may be a friend or paid professional and must produce annual accounts for the Court of Protection. The Court selects the Receiver by considering the "patient's" wishes, the nature or complexity of the person's financial affairs, whether a family member or carer could be appointed as a Receiver and the person's best interests.

The Receiver must get the Court's approval for spending large amounts of money or unusual expenses. A Receiver handles collecting pensions and income, paying bills and looking after the "patient's" property. Receivers are paid for their expenses and a professional may charge for their services. Annual and transaction fees are also paid to the Trust Division of the Public Guardianship Office for their services.

To apply to the Court of Protection for a Receivership, you should contact the Receivership Division of the Public Guardianship Office (telephone 020 7664 7300).

Short orders from the Court of Protection

Short orders usually deal with sums of money under £16,000. An applicant is appointed on a one-off basis to deal with a financial situation that has arisen, for instance, to pay bills, receive money into someone's bank account or receive money on behalf of someone who does not have the mental capacity to have their own account. An applicant can be a relative in the same way as a Receiver from the Court of Protection. Each time an applicant is appointed for a short order, there is a cost of £230.

Appointeeships

An appointee is a named person who acts on behalf of another person in relation to claims for and payments of social security benefits. An appointee has to apply to the Department for Work & Pensions for appointment and this usually requires medical evidence that a disabled person is unable to manage their own affairs. Appointeeships are only appropriate when someone is unable to look after their own affairs, because of disability. If it is only a question of difficulty in picking up their payments, alternative arrangements can be made. (An agent can be appointed to collect the benefits on the beneficiary's behalf. Direct payments into a bank account and banking arrangements with the post office mean other arrangements are increasingly rare.)

The appointee does not have to be a relative or carer, or live with the disabled person. They are responsible for everything relating to a person's benefits. For example, they are responsible for claiming benefits in good time and for reporting changes that could affect benefit entitlement.

If someone is living in residential care, the provider should make sure there is an appropriate appointee. If a parent is the appointee and bills are not being paid, or the son or daughter is regularly without spending money, the appointeeship can be challenged and can be withdrawn.

It should be noted that it is common for residential care providers to want to manage the funds themselves. Some have had bad experiences of relatives being reluctant to spend the money and of the disabled person always being short of both money and goods. However, some parents wish to maintain a stake in the life of a son or daughter who cannot manage their own money and there is no legal bar to them doing so.

If someone suspects that the appointee is not using the person's benefits in the disabled person's best interests, they can challenge the appointeeship by informing the Department for Work & Pensions of their concerns.

To become an appointee, telephone the Benefits Enquiry Line for people with disabilities: Freephone 0800 882200.

Powers of Attorney

A Power of Attorney is never an option for someone who has never had mental capacity. A Power of Attorney allows a person with a learning disability to choose a person to assume control of his or her financial and property affairs for reasons of convenience, such as going abroad. This does not enable someone to give consent on that person's behalf for medical or welfare matters. It enables the attorney to enter into legal commitments on behalf of that person in certain situations.

The person appointing a Power of Attorney needs to be capable of understanding the meaning and nature of the powers their attorney would have over their financial and property affairs.

There are two types of attorney. An individual may appoint someone under an Ordinary Power of Attorney. This can be general (relate to all donor's property) or specific, only in relation to one property. It is automatically revoked by law when the donor loses capacity to manage and administer his/her property affairs.

An Enduring Power of Attorney will enable someone to manage a person's financial and property affairs with legal authority, if that individual becomes unable to manage them or communicate their wishes. There will be some people with a severe learning disability who will not have the capacity to appoint an attorney. This Power of Attorney is more use to someone who is originally competent and then loses the competency through mental illness or old age. It continues in force after the donor has lost his or her mental capacity to manage and administer his/her financial affairs. Registration with the Public Guardianship Office is required when an Enduring Power of Attorney starts to act on behalf of the individual granting the power. This does not affect the role and responsibility of the attorney's powers, but it means that attorneys are accountable to the Court of Protection if their actions are called into question. It also means that the attorney cannot be terminated by the donor or the attorney without the consent of the Court or the Public Guardian Office.

Information Sheet 17 has further information relating to Wills and Trusts.
Source: Mencap Factsheet (7/5/03)

7 CARER SUPPORT SERVICES

In April 1999, the Government introduced a three-year Carers Grant, now extended to 2006. This grant is specifically for local authorities to provide services that will allow carers to take breaks from caring. Social Services have produced a Carers Plan that specifies what services they will provide from this grant. Before drawing up the plan and introducing options, Social Services worked with the local branch of Carers UK and consulted widely across the Island. Services now available as a result are as follows:

- A free sitting service makes provision for two hours 'sitting' each week by trained staff, allowing carers to go out knowing the person they care for is safe at home.

- A carers' assessment: when planning a care package for a person, the local authority has a duty – through the Carers Act – to take into account the individual needs of the carer. Care Managers offer this service and undertake a separate assessment on request. Information Sheet 3 also has information about carers assessments.

- Free therapy courses for carers: a short course of six sessions in alternative therapy can be made available to carers by the therapists of Watchbell House. Contact the Carers Office on 01983 533173 for more information. There is a big demand for this service and there is often a waiting list.

Emergency Alert Card

Carers can carry one of these in case they have an accident or an emergency whilst away from home. They register with Wightcare, giving confidential details of what should be done in their absence to ensure the well-being of the person they care for. No details appear on the card, just a registration number and the Wightcare telephone number. There is also a card for the cared for person to carry with them. This service is provided free of charge. Ring Wightcare on 01983 533772 for details.

Respite care

Respite care is provided at Westminster House, a 10-bedded short stay unit in Newport. The frequency of the respite care is based on assessed need and the level of support is flexible, matching that available to the individual at home.

White Lodge, a specialist assessment and treatment unit for adults with a learning disability who have more complex needs also has some respite provision. Placement is based on assessed need and will be arranged through the Care Manager or nurse.

Direct Payments

This is a scheme run by Social Services whereby the disabled person and, in certain situations, you as a carer, can be paid an agreed amount of money to buy their/your own care. This only applies once there has been an assessment and it is clear that they/you qualify for help. The scheme does allow greater flexibility in finding and paying for the right kind of care, which may include breaks for you as a carer. Support and advice can be given on how to manage Direct Payments – contact Elizabeth Martin on 01983 522823.

Crossroads

Crossroads UK is a national charity offering practical support services to carers, such as a 'sitting service' to enable carers to have a break. Support is focused on carer need and is flexible so that the support is acceptable to both carer and the cared for. The funding for Crossroads largely comes through Social Services and although carers can refer themselves, a carers' assessment should be completed first. Crossroads has recently established a scheme on the Island and can be contacted on 01983 822200.

OTHER CARER SUPPORT

Carers UK: The local branch of Carers UK is based at the Riverside Centre, The Quay, Newport and they can be contacted on 01983 533173. There is someone in the office every weekday between 10.00am and 12.00 noon and there is an answerphone outside of these times which is checked regularly for messages. There are 8 carer support groups around the Island that meet on a monthly basis.

Young Carers: Sometimes, younger brothers or sisters can be very involved in the care of the person with a learning disability and contact with a young carers group can be a support to them. There is a project on the Island – contact Heidi Kurowska on 01983 521590 (24-hour answerphone after office hours). Address: Spurgeons Young Carers Project IOW, 1 St John's Place, Newport, Isle of Wight PO30 1LH.

MENCAP: There is a local MENCAP branch on the Island. Contact Robin Goodfellow on 01983 868443 (mobile 07971 817373) for more information.

The local **CARERS HANDBOOK** has information about services, support and help for carers. It is available from Social Services offices or the Carers Office, The Riverside Centre, Newport; telephone 01983 533173.

8 COMMUNITY CARE SERVICES

This sheet provides information about the different services available to support adults with a learning disability in the community. The services range from support to people in their homes, enabling independence, the provision of basic skills and day services, through to respite and residential care. Many of the services cannot accept direct referrals, so talk to the Care Manager, support worker or nurse for more information. The second part of this information sheet has details of the charges for these services.

PART 1: SERVICES

Social Services Learning Disability Team
Social Services Centre, Lind Street, Ryde, Isle of Wight (telephone 01983 566011)
This team consists of specialist Care Managers and support workers who work with adults with a learning disability from the age of 18 upwards. Care Managers are responsible for the assessment of the needs of both the person with a learning disability and their carers, and putting together the care plans and support services to meet those needs. They will also give advice and information on the available options. The team works closely with the health services and it is anticipated that both the learning disability team and the nursing team will be working together from the same base in the near future.

Community Nursing Learning Disability Team
Arthur Webster Clinic, Landguard Manor Road, Shanklin, Isle of Wight (telephone 01983 866179)
This specialist nursing team supports people with a learning disability who also have health care needs. See Information Sheet 1 for information about this and other specialist health services.

Day Services
Local day services offer a range of activities, such as craft work, basic skills and support to help people with learning disabilities access their local community and develop their independence. Some day services provide skills training and have a more work-based focus. Most day services are open weekdays 9.00am to 4.00pm.

Medina Centre
School Lane, Newport, Isle of Wight (telephone 01983 523090)
The Medina Centre has a wide range of activities for people from 18 to retirement age, both Centre and community based. Activities include arts and crafts, horticulture, cooking, swimming, horse riding and work experience. The Centre also has a special needs unit for people with more profound and multiple disabilities where they can receive sensory stimulation and an individual programme of support and activities.

Meadowbrook in Ryde is another day centre offering similar activities to the Medina Centre.

Riverside Centre
The Quay, Newport, Isle of Wight (telephone 01983 822209)
The Riverside Centre's purpose is to provide equality of opportunity in all that it does. The Centre provides day services, craft workshops, music, carpentry and restaurant and catering services. The Centre also provides skills and vocational training, work experience and supported work. People can self-refer to the Centre.

Haylands Farm
Salters Road, Ryde, Isle of Wight (telephone 01983 566038)
Haylands Farm offers both day services and work experience to people with a learning disability. Training is given in animal care, growing vegetables and poultry care. Referral can be made direct or via Social Services.

Osel Enterprises, including **Sunnycrest Nursery**, also provide day services as well as work experience. See Information Sheet 10 for more information on these services.

Social Services also purchase day care services on an individual basis from **Ryde House in Binstead** and **Weston Manor in Freshwater**.

ASK THE CARE MANAGER ABOUT ALL THESE DAY SERVICES BEFORE A DECISION IS MADE ABOUT WHICH ONE OFFERS THE BEST OPTION.

Home care services
Home care services provide the practical and person care support necessary for someone to continue living at home. This can include support to carers by enabling them to have a break (see Information Sheet 7). These services are provided either by Social Services, Wightcare Services or by Care Managers arranging for the support to be provided through private home care providers working under a contract to Social Services.

Direct payments
A Direct Payment is money given to an individual by Social Services so that they can purchase for themselves the home care support they have been assessed as needing. This might seem too complicated for a person with a learning disability, but having a Direct Payment can make all the difference between having the only service available and one which they actually choose to meet their individual needs. Support is available to enable this to happen. Contact Lizzie Martin at the Riverside Centre on 01983 522823 for more information.

Housing and Supporting People
Supported housing and independent living options are covered in Information Sheet 11. The Government's Supporting People programme provides the practical support people who receive Housing Benefit need to successfully maintain tenancies in both Housing Association and private rented accommodation. This covers general counselling and support and can include support with budgeting, nutrition, hygiene, using other services and other practical tasks.

Specialist advice and equipment for people with visual and hearing difficulties is available from Sight Concern (telephone 01983 522205) and Sound Advice (telephone 01983 529533).

Occupational Therapy services
Social Services Occupational Therapy services (OTs) can advise on any activity of daily living, such as cooking, dressing, bathing and toileting, equipment to help independence and adaptations to property. The OT service can be contacted through the Care Manager or the Social Services Duty Team on 01983 823340.

Wightcare 'Lifeline' service
This 'lifeline' telephone scheme operated by the Council's Wightcare Services provides 24-hour emergency cover. The Lifeline telephone, with a personal pendant, is linked to a call centre where a trained operator is always available to answer a call for help. The user simply presses a button on the personal pendant if help is required. If the user is not able to speak, the operator will still know where the call has come from and help

will automatically be sent. For further information or to arrange a free demonstration, call Wightcare Services on 01983 821105.

Respite care

Respite care is about having a break. Carers can do this in different ways, for example, either by having a home carer take over the care for a few hours to enable them to go out or for the cared for person to have short stay care somewhere like **Westminster House** or **White Lodge**, the specialist unit for people with complex health care needs. Referral for these services is made through the Care Manager or nurse.

Blue Badge scheme

The Disabled Persons Parking Badge Scheme provides a national scheme of parking concessions for people who have permanent severe walking difficulties and who travel as drivers or passengers. Badges have to be renewed every three years and there is a small administration fee. Some people will have an automatic entitlement to a badge and others may be eligible under discretionary criteria. The Social Services leaflet *'The Disabled Persons Parking Badge'* covers this in more detail.

Disabled toilet key (RADAR national key scheme)

The keys cost £2.50 and are available from Tourist Information offices, Social Services offices and the Riverside Centre in Newport. This facility is very useful if you need to assist with toileting.

PART 2: CHARGES FOR SERVICES

"Fairer Charging"

In 2002 the Government introduced new rules about the way Social Services charges for home care and other non-residential services. These rules gave Councils the choice of whether to charge for services. The Isle of Wight Council decided to make a charge as the Government reduces the amount of money given to Councils on the assumption that they will charge! Charges (or not charging for certain services) are always kept under review so the information in this sheet may change in the future.

Who pays for what and how much can be complicated and this sheet will give general, not detailed, information. Leaflets and advice sheets on charges are available at all the Social Services offices.

No charge is made until the service user has been told how much they have to pay based on the assessment of their particular financial situation. There will be written confirmation of the charge, an explanation of how it has been worked out and information on how to ask for the charge to be renewed. A service cannot be withdrawn because someone is refusing or unable to pay for it.

Home care services

Many adults with a learning disability will have a limited income. Those who only receive Income Support will have to pay a charge, but if they also receive other benefits such as the Care Element of the Disability Living Allowance (DLA), these may be counted as income and an assessed charge will be made.

Day services

There is currently no charge for day services or transport to them. There is a small charge made for meals and drinks (currently £1.50 and 50p respectively) and service users will be asked to pay for certain activities, such as swimming.

Supporting People services

Most people with a learning disability who are receiving this form of support are likely to need it in the long term. If they are in receipt of Housing Benefit, the support costs are met in full by the Supporting People system. Anyone **not** receiving Housing Benefit will be assessed to make a contribution under the 'Fairer Charging' process.

Occupational Therapy services

There is currently no charge for this service.

Wightcare Alarm

£25.31 installation charge and £4.00 per week rental (these charges will increase later in 2004).

Respite care

This is charged at a flat rate of £59.95 per week (April 2004).

Residential care and group homes

Under current legislation, residents must either pay the full cost of their accommodation or contribute towards the cost of it, based on their financial situation. The contribution residents make towards the fees is calculated in the way set out in the national regulations. Care Managers will usually be involved in helping to choose a suitable home and they will advise on which homes have accommodation at the Social Services 'contract' price. A resident with more than £20,000 capital (April 2004) is liable to pay the full amount of the fees; capital of over £12,250 is disregarded. If someone is already receiving Income Support this will continue, but the amount may vary. Personal expenses have to be met from the Personal Allowance of £18.10 per week.

Nursing care

The charging system is the same as that for residential care but people now going into a nursing home are eligible for NHS funding for that part of their care provided by a Registered Nurse. The level of payment is based on an NHS assessment of their nursing care needs and there are three bands: low, medium and high. This makes a difference to the amount paid by people who meet the full cost of their care, but doesn't affect the contribution made by people whose fees are paid for by Social Services. Further information is available from Sandra Haskett at the Isle of Wight Primary Care Trust on 01983 535445. There is also a Department of Health Booklet, *'NHS Funded Nursing Care in Nursing Homes – What it means for you: a guide for people living in or going into nursing homes, their families and carers'.*
Website: www.doh.gov.uk/jointunit/freenursingcare

9 FURTHER EDUCATION

Further education is the term used to describe any education or training after compulsory school age. Everyone is entitled to a free education until the age of 19.

A young person between the age of 16 and 18 with a learning difficulty should have a transitional worker who will help with the information and support necessary to ease the transition from childhood to adulthood. The starting point for planning a young person's further education should ideally be a transition plan, which will provide the young person with a clear understanding of their educational choices and opportunities when they leave school. This is only applicable if the child has a Special Educational Needs (SEN) Statement.

As the young person reaches the age of 18, the responsibility for support moves to the Adult Services of the local Social Services Department. An assessment of needs at this point should indicate how those needs could be met and the young person will be encouraged to look at the various opportunities available, including further education courses. The College will invite the student for interview to discuss their individual learning needs and to establish that the College can meet them.

LOCAL FURTHER EDUCATION SERVICES

The Isle of Wight College runs several courses for young people with a learning difficulty.

The **INDEPENDENT LIVING SKILLS COURSE** is a one-year course with the opportunity on completion to return to College to follow one or additional years. The course runs on a three-year cycle, with a different theme each year. This and the Life Skills course (outlined below) are designed for students with considerable learning difficulties and/or a physical or sensory disability. The course content covers: the Arts, Community, Leisure & Personal Lifestyle, and Practical & Vocational & Personal Lifestyle. Referral is usually made through a Care Manager or residential home manager but direct referrals can be made to the College.

Classes can be accessed in the College and at an outreach class at the Ventnor Youth Club. The outreach class is designed as an introduction to College life. Students are offered learning experiences both in and out of College that will progress them towards their long term plans. Students can choose from just one class per week, up to a maximum of four classes a week, subject to availability. Enrichment activities may be offered during the year as well as a residential during the summer term. On successful completion of the course the student will be awarded an Isle of Wight College certificate.

The **LIFE SKILLS COURSE** is a two-year course and students will be given support to access mainstream qualifications and/or classes on an individual basis. The course content covers: Daily Living Skills, Personal Presentation, Community & Leisure, Practical & Work-related Skills, Confidence Building and Independent Travel programmes.

If students achieve, they will be awarded an Isle of Wight College certificate. In addition, they may be able to gain other qualifications, for example, OCN Library Skills, Basic Food Hygiene Certificate, City & Guilds Entry Level Qualifications in Literacy or Numeracy. Students leaving the course may obtain sheltered employment (such as Osel Enterprises) or continue work experience through the No Barriers supported employment scheme. Others may progress on to other College courses.

Further information about these and other courses can be obtained from Sandie Munt, Course Co-ordinator at the Isle of Wight College; telephone 01983 526631.

Cost: These further education courses are funded by the Learning & Skills Council. The only costs will be a one-off £20 materials charge, for practical activities or visits and lunch.

Transport: Currently, Social Services fund transport to the College and students can use the Wightbus service, a taxi if that is the most appropriate form of transport or can be issued with a bus pass. Social Services have a 'bus programme' of training where a support worker will travel with a student until they are able to undertake the journey to college independently. More information can be obtained from Mrs J Taylor at Ryde Social Services Centre; telephone 01983 566011.

SPECIALIST COLLEGES

These are usually residential colleges for students with disabilities that are experienced in providing additional support as well as running educational programmes. The Connexions service will be able to advise you on the procedures for applying to these colleges. You do not have to be turned down by your local further education college before you apply to a specialist residential further education college. There is a list of specialist colleges in the NATSPEC Directory: ask your Connexions advisor for a copy or ring NATSPEC direct on 0121 544 9003 and they will send you a copy.

FUNDING FOR STUDENTS IN FURTHER EDUCATION

In England, students are entitled to free education up to the age of 19. A student over the age of 19 does not have to pay tuition fees if:

- They are receiving Job Seekers Allowance (JSA);
- They are receiving a means-tested state benefit, for example, Income Support or Housing Benefit;
- They are not receiving a wage and are dependent on someone who receives any of the benefits above;
- They are taking a course that teaches basic skills or the course is English for Speakers of Other Languages (ESOL).

The Learning & Skills Council has a duty to fund a specialist place for a student under the age of 19 whose needs cannot be met in the local 'sector' college or school. Social Services may contribute towards a place at a local residential college in cases where the provision includes a strong care component. The LSC also has the power to fund a specialist place for a student between the ages of 19 and 25 whose needs cannot be met elsewhere. However, if a student's disability-related needs can be met a local 'sector' college or school, it is unlikely that they will receive Government funding for a place at a specialist college.

OTHER SOURCES OF INFORMATION

CONNEXIONS

68a Upper St James Street, Newport, Isle of Wight PO30 1LQ
Telephone 01983 527565 www.connexions.gov.uk

Connexions provides information, advice, guidance and personal development opportunities for young people aged 13 to 19, or aged up to 25 years for those with special needs. Connexions have a local network of Personal Advisors who will work with students on a one-to-one basis.

LEARN DIRECT
Freephone 0800 100 900 (have a pen and paper ready) http://www.learndirect.co.uk

Learn Direct is a free confidential advice and information service about adult learning opportunities. This is a database (a list) of hundreds of thousands of courses available around the country. They will ask you where you live and what kind of course your son or daughter would like to do. They will tell you what is available and give you the contact details for the people in charge of the class or course. They do not send out any written information.

SKILL: NATIONAL BUREAU FOR STUDENTS WITH DISABILITIES
Chapter House, 18-20 Crucifix Lane, London SE1 3JW
Information service 0800 328 5050 Minicom 0800 068 2422 www.skill.org.uk

SKILL promotes opportunities for young people and adults with any kind of disability in post-16 education, training and employment across the UK. They provide individual support to disabled people, their families or people working with disabled people. SKILL offers an information service by phone and minicom and produces booklets and information sheets.

STEPPING STONES TO WORK

A local employment and training directory for disabled people.
This booklet is available from: Elaine Garrett, Public Health Partnerships Manager, IW Primary Care Trust, Whitecroft, Sandy Lane, Newport, Isle of Wight PO30 3ED Telephone 01983 535437

10 EMPLOYMENT AND TRAINING

"Everybody has the right to contribute to society through work if they are able to do so. Employment is a crucial aspect of reversing social exclusion; it enables people with a learning disability to achieve aspirations of financial independence and personal growth that they share with the rest of the population." So said the then Minister for Disabled People in 2002.

Very few people with a severe learning disability currently work – less than 10% of people with a severe learning disability are in paid employment.

Not everyone is able to work and for some severely disabled people earning a living will never be an option. However, it may be possible for them to try voluntary work or take part in a work placement that may provide them with a limited income and, more importantly, more social contact with others. Many people with a learning disability do, however, work in the open labour market, competing with others for the jobs available, perhaps with support through a specialist agency. This information sheet sets out the local employment and training options open to people with a learning disability and the support available to help them to take an employment opportunity.

Many people with a learning disability rely on a combination of earnings and 'in work' benefits, which are designed to make sure that people are financially better off by working. You will find information on earnings and benefits in Information Sheet 4 and on further education and skills training in Information Sheet 9. Detailed information on local supported employment and training resources, including information for people with sight and hearing problems, can be found in the booklet *'Stepping Stones to Work'*, available from Elaine Garrett on 01983 535437.

TYPES OF WORK AVAILABLE

Open employment

The most common route to employment for most people with a learning disability is through competition in the open jobs market. People apply for the vacancies they see in the newspaper, at the Job Centre or on the Internet. They may be supported by a specialist agency, such as the local MENCAP Pathway Employment Service (details of this are in the section 'Support for Employment'). The support can vary for each individual from a weekly monitoring visit to liaise with employee and employer or to act as an advocate for benefit issue, to training or coaching the individual in their work. This support can last for as long as the individual needs and would slowly be withdrawn as and when appropriate to reach a goal of independence. The employer appoints the best person for the job. People are paid the going rate for the job.

Supported employment/Workstep

Supported employment is provided by a variety of agencies, including the voluntary sector, local authorities and health authorities and through the Government's Supported Employment Programme, Workstep. Supported employment has traditionally been the main route to open employment for people with a learning disability.

The Supported Employment Scheme is work undertaken in the open job market but with financial support made available to the employer to pay some of the wage if the person they employ receives certain welfare benefits. This enables employers to pay a person with learning disability the going rate for the job, even if the particular individual's output is below that of other employees. The Government insists that, as far as possible, this programme should be transitional – until people can earn the going rate for the job they do without a subsidy.

The Government has recently modernised supported employment. Changes to the scheme have included placing an emphasis on progression through the scheme to open employment over a specified period and changing the name to Workstep. All potential participants for the scheme will undergo a vocational assessment to determine the best support package available to them.

To find out whether supported employment is available, you need to speak to the Employment Advisor at your local Job Centre (details appear later in this information sheet).

New Deal

Government programmes called New Deal benefit disadvantaged groups in the labour market. There are a number of different New Deals, including New Deal for Disabled People and New Deal for Young People (those under the age of 25). People can qualify for one New Deal scheme or another but not more than one.

The New Deal for Disabled People is designed to support disabled people in gaining work and training. It is open to people claiming Incapacity Benefit, Severe Disablement Allowance and Income Support. The programme involves a job brokering service to help disabled people find lasting employment. The intention is to place and keep people in work and ensure that it is practical to try out jobs without losing benefits. It can also access equipment and services as people move into work.

The New Deal for Young People and New Deal for people aged 25 and over both provide participants with an option of subsidised employment. A person between 18 and 24 years of age will have access to this option after six months of unemployment. People who are 25 years and over can access the subsidy after eighteen months of unemployment. (New Deal 25 Plus offers the subsidy after eighteen months of unemployment.)

New Deal gives employers of people on the programme a Government grant in order to subsidise the individual's income. In order to receive the New Deal grant, employers must provide training for employees towards a nationally recognised qualification. Again, the Job Centre can give further information on this programme.

Sheltered placements

These are environments where disabled people work in a specially designed or separate environment. Examples locally would be OSEL Enterprises and the No Barriers scheme. The work often involves production of goods that are then sold on to a business or administration work supporting a business or charity. The organisations listed here also offer skills training.

> OSEL has six enterprises based at Newchurch, Newport and Shanklin, including Sunnycrest Nurseries, Island Images Pot Pourri and the Wight Crystal bottling plant. These enterprises provide work experience, training and employment in occupational areas such as: warehousing, delivery, manufacturing, packaging and processing; horticulture and gardening services; catering and kitchen portering; retail and customer services; administration, sales and accounts. The emphasis is to provide real working situations and to develop an individual's ability to adapt to the working environment, build

team and individual skills necessary for work, improve confidence and self-esteem, and acquire knowledge and skills related to the job.

OSEL Training Unit, Sunnycrest Nursery	Telephone 01983 866218
Wacklands Lane, Newchurch	Fax 01983 866218
Isle of Wight PO36 0NB	Email osel@oseliw.fsnet.co.uk

Disability Employment Advisers refer individuals to various programmes for work experience, job search skills and supported employment. Care Managers refer individuals for work tasters, work experience, training and development of work/social interaction skills. Careers and Social Liaison Officers refer for work experience. Clients can also self-refer for work experience and training.

No Barriers offers people with learning disabilities vocational guidance, work experience, support into employment and continuing support in sheltered/supported, open or volunteer employment. The service includes action planning, career guidance, job coaching, employer and employee support. Clients can access this service through their Care Manager or the Duty Team at Social Services (telephone 01983 823340).

No Barriers, Social Services Centre	Telephone 01983 566011
Lind Street, Ryde	Fax 01983 612918
Isle of Wight PO33 2NQ	Email jan.taylor@iow.gov.uk

Social firms

These are similar in structure to sheltered placements but their workforce combines disabled and non-disabled people. A social firm is a business that brings together the best of business practice and social support. Employees are paid a standard rate or salaries that are appropriate to the work, whatever their productive capacity. The Riverside Centre is an example of a social firm.

The Centre is a charity and a company limited by guarantee, as well as operating a training company (Riverside Ventures), which provides catering and ancillary services. The Riverside Centre has over 50 member organisations, such as Age Concern, Arthritis Care, etc. and its purpose is to provide equality of opportunity in all that it does, within a physically accessible environment and within an inclusive operational structure. Activities include the provision of day care, music and carpentry workshops, recording studios, conferencing and functions, and restaurant and catering services. Over 50% of the employees are disabled, some under SEPACS, Disability Working Allowance, Therapeutic Earnings or similar schemes. Clients can be referred by GPs, Social Workers, Care Managers or No Barriers.

Riverside Centre	Telephone 01983 822209
The Quay	Fax 01983 822411
Newport	Email lizzie@riversidecentre.org.uk
Isle of Wight PO30 2QR	Website www.riversidecentre.org.uk

Permitted work

This is limited work (of any kind) that allows people to retain their entitlement to Incapacity Benefit or Severe Disablement Allowance. Such work must not exceed 16 hours per week. It is in place to enable individuals to benefit from the positive effects that working can bring, whilst ensuring that they do not lose their welfare benefits. Earnings must not exceed £72 in any case and are limited to £20 a week after an initial period if work is unsupported. People receiving Income Support can earn up to £20 a week without losing any of their benefit.

Work experience

A time-limited period of work experience with a host employer; a 'taste bite' of employment allows an individual to sample employment and to try out its suitability to their needs. This also gives a prospective employer the chance to see an individual's capability without commitment from either side, therefore breaking down some barriers to employment.

There are a number of local opportunities for people with a learning disability to get work experience. These are all set out in the booklet *'Stepping Stones to Work'*. The Social Services Care Manager can also advise and refer to the appropriate organisation for both work experience and voluntary work.

Voluntary work

Voluntary work is unpaid work, although some expenses may be provided to cover travel or lunch costs. Voluntary work can sometimes be a stepping stone to paid work. Ongoing voluntary work can only be undertaken with a non-profit-making organisation. The Benefits Agency or Job Centre Plus should always be informed before a period of voluntary work is agreed upon. A local organisation called Changing Faces is one example of an organisation that arranges voluntary work placements.

> Changing Faces offers supported volunteering to people with learning disabilities, physical disabilities, mental health problems or alcohol abuse problems. The aim is to match the personal interests and skills of the individual to an appropriate volunteer placement. Volunteers achieve a sense of purpose and increased confidence, as well as making social contacts and learning/regaining skills.
>
> Changing Faces personally introduces volunteers to their placements. There is a month's trial at the start of the placement. If the volunteer ever decides they wish to try something different, they can let the co-ordinator know. Free training programmes are also available in basic skills, IT and communication/confidence.

Changing Faces
117 St James Street, Newport
Isle of Wight PO30 5HB

Telephone 01983 539500
Fax 01983 539526
Email Margaret.ivg@btconnect.com

SUPPORT FOR EMPLOYMENT

JOB CENTRE PLUS (DEPARTMENT OF WORK & PENSIONS

Job Centre Plus is the Government's new organisation that deals with all clients of working age who wish to access work or benefits.

- There is a new telephone service for people who want to claim benefit. The operators will assess the client's needs, refer them to the right office and send the appropriate claim forms. The number is 0845 602 6710.
- The existing Job Seeker Direct phone service is for those who want to seek work. The operators will search the database of vacancies and match clients to jobs according to the criteria they give. The number is 0845 6060 234. All vacancies held by Job Centre Plus can be accessed through the Worktrain website. Everyone of working age is welcome to visit Job Centre Plus to talk to an adviser or use our touch-screen job search terminals.

Disability Employment Advisers provide specialist support to disabled job seekers or disabled people already in work. They also provide help and advice to employers about employing and retaining disabled people. DEAs have a caseload of keen, job-ready applicants looking for work and are looking for employers to employ them.

Assistance may be given under one of the following specialist schemes. Clients can self-refer via the Job Centre or directly, or they can be referred by any other linked organisation.

Access to Work: Provision of grants to overcome the effects of disability on employment towards:

- Purchase of specialist equipment
- Adaptation of premises or equipment
- Vehicle adaptation
- Travel to work or within work
- Support worker provision
- Disability awareness training for work colleagues
- Interpreter support for interviews

Job Introduction Scheme (JIS): Provides help towards employment costs for a disabled person during the first few weeks of the job. The current allowance is £75 a week and usually lasts for six weeks.

Workstep: Designed for disabled people facing complex barriers to finding or keeping a job. It provides support to an individual to help them realise their full work potential.

Work Preparation: Provides the opportunity to develop skills and confidence and try out tasks in a supportive environment. Provision of work placements with supervision and support. Help with business planning and provision of grants and loans to help disabled people to start self-employment.

NEWPORT
Ground Floor, Broadlands House, Staplers Road
Newport, Isle of Wight PO30 2HX
Phone 01983 273134 (Jane Mitchell)
Fax 01983 273007
Email j.mitchell@jobcentreplus.gov.uk

RYDE
150 High Street, Ryde
ISLE OF WIGHT PO33 2RE
Phone 01983 276810 (Dave Mursell)
Fax 01983 276830
Email dave.mursell@jobcentreplus.gov.uk

SHANKLIN
1 Steephill Road, Shanklin
ISLE OF WIGHT PO37 6NH
Phone 01983 276716 (Di Graham)

MENCAP EDUCATION & BUSINESS UNIT – PATHWAY EMPLOYMENT SERVICE

MENCAP Pathway offers a variety of services to help people find paid employment. This can be by assisting with job searching, application and interview techniques or via work experience placement. The service provided includes:

- An initial interview to assess skills and support required
- Assistance with job applications and interviews
- Contacting local employers
- Job coach support in the workplace during work experience and when clients enter paid employment, for as long as it is required
- Benefits 'better off' calculations when moving into paid employment
- Promoting the positive aspects of employing people with a disability

Listed overleaf are the schemes offered.

Work experience: 6-13 week work experience placements under MENCAP's Work Preparation Contract, where they have a 60% success rate in people moving through to paid employment.

Job Coach support in the workplace: Support in the workplace from a Job Coach to help people to settle into a new job, overcoming the initial period of moving from benefits into paid employment. This includes helping people to talk over any issues and problems with their employer and providing mentor support through this.

Work placement and training: In partnership with Community Solutions, MENCAP offers a 26-week work placement with an employer where clients can undertake training towards a qualification.

New Deal for Disabled People: The Job Broker can help people find work if they are on a qualifying benefit, including Incapacity Benefit, Severe Disabled Allowance or Income Support with a Disability Premium and would like to work a minimum of 8 hours a week. Guidance on working under the 'Permitted Work' rules can be provided and extensions to this programme can be approved if anyone wishes to work towards moving on to 16 hours or more paid work per week.

Workstep: As part of MENCAP's national partnerships with mainland organisations The Shaw Trust and Remploy, they can offer support in the workplace if someone is working 16 hours or more. This can be in the form of job coaching, access to training or helping to break down other barriers that people may come across.

Referrals are welcome from Disability Employment Advisers, Careers Service, Connexions, schools and colleges, and other agencies. Clients can also self-refer. Access to the schemes is determined by eligibility, e.g. welfare benefits claimed, age, etc. The team of project co-ordinators can advise which schemes a client would be able to undertake and would be most beneficial. Clients can telephone, email or request an information leaflet, or have an informal chat.

MENCAP Education & Employment Business Unit
Pathway Employment Service
26 Carisbrooke Road
Newport, Isle of Wight PO30 1BW

Phone 01983 529461
Fax 01983 530108
Email iow.pathway@mencap.org.uk
Website www.mencap.co.uk

Source: MENCAP fact sheet 'Employment – Making It Work'
'Stepping Stones to Work', January 2004

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INDEPENDENCE & LEARNING DISABILITY: LETTING GO

Each new stage of a child's and then adolescent's life sees changes in the parent's role until the point where young adults take responsibility for themselves. This process of growing up usually brings its own mixture of anxiety and then relief and pleasure as independence is achieved.

For the parents of someone with a learning disability, the situation can be particularly painful and the 'letting go' much more complex. For some parents, letting go and encouraging growing independence will not be an option if their child is severely disabled and will never be capable of independently managing life. Some parents will feel stuck in the parenting role whilst other parents have gradually gained more freedom. Some parents, facing growing older themselves, would happily share or even give up the caring role if there were local options of a standard they were happy with.

The majority of adults with a severe or profound learning disability – estimated to be 60%, the same proportion as 30 years ago – live at home with their parents or, more commonly in later life, with one parent, usually their mother. Adults with a learning disability now live much longer, with the result that there is an ever-growing number of elderly parents who are continuing to care for a son or daughter well into old age. These parents often become increasingly anxious about what will happen if they become ill or their children outlive them. This information sheet notes some of the dilemmas parents face as their adult offspring move towards independence, supported living or full time care and some of the housing and care options available locally.

DILEMMAS

- Parents may, to varying degrees, have difficulty in coming to terms with their son or daughter leaving home. It can help to share these feelings with other parents who have 'been there', through the local MENCAP group, carers or parents involved with the Fairhaven Housing Trust. Contact numbers can be found in Information Sheet 16.

- When adult children leave home, it takes considerable adjustment on both sides. When the adult has lived with parents perhaps for 30 or 40 years, these adjustments will be greater. Give yourselves time.

- Young people leaving home will often change, freed from parental constraints and support. Someone with a learning disability moving into supported accommodation or residential care is likely to react in the same way – testing out new freedoms and choices and learning what they can and cannot do.

- Support and care staff cannot and should not replace the role of parents. Their role is that of adviser, mentor and advocate, enabling choice and decision making, with support when needed.

- People with a learning disability are often not very good at placing new relationships in the right context. They may think that the support/care worker is taking a special interest in them; especially, they may try to copy dress and hairstyles or exaggerate the degree of familiarity. Parents can naturally feel a little jealous of this new and all-important person when they have cared for so many years without comment. See it for what it is – it adds rather than detracts from the experience of positive relationships parents want their offspring to have. You will still have an important role in their lives.

- The possibility of adult children with a learning disability having a sexual relationship is difficult for parents to come to terms with. Sex is a normal and natural part of development. When any young person moves towards adulthood and greater independence or leaves home, it is likely that they will want to experiment with sex and people with a learning disability are no exception. There is plenty of evidence that many people with a learning disability can enjoy sexual relationships, which also increase their confidence and well-being. Information Sheet 15 looks at how parents can play their part in enabling their offspring to take this step.

- Be prepared for the changes in your son or daughter when they leave home – these may consist of their friendships, their hobbies, style of dress or even their attitude to you, which can be hurtful. Again, talking to other parents who have had similar experiences can help.

- After years of caring, their departure may leave a big gap in your life. You may have time just for yourself for the first time in years. Use the time if you can to do all those things you've wanted to do if only you had the time.

HOUSING AND CARE OPTIONS

The majority of family carers of adults are committed to caring for their family member at home until they are no longer able to do so. Some want to put off the inevitable but should not be criticised for being overprotective as, in the past, there has been little encouragement for them to plan ahead, little help for their sons or daughters to gain independence and insufficient housing or care options. Parents of any age may have sympathy with this view; parents will want to plan ahead in a way that involves their son or daughter with a learning disability in ***their*** choice for ***their*** future.

Choice has been limited in the past by a lack of awareness about the options. The information here should help to widen choice and, as Person Centred Planning develops, help by planning early to get the clearest possible picture of what the person concerned is likely to need and want. Start planning ahead and think about the following questions – the answers will help when looking together at the available options.

Questions

- What timescale do you have in mind for a planned move? Two to three years is probably realistic.

- Who needs to be involved in the thinking process? When do you need specialist advice (e.g. financial or legal) and should an advocate be involved?

- What people and activities, including the family, is the disabled person going to want to stay in touch with?

- If the disabled person's circle of friends is small and range of activities fairly narrow, is it possible to begin building these up now?

- Is the disabled person most likely to be happy (provided they get all the support they need) living on their own, with a friend, with a small number of other people, as part of a bigger group, with another family or in some sort of community with other people with learning disabilities?

- What are the preferences in terms of part of the country, rural or town, close to facilities and therefore busy or quieter and therefore perhaps further away?

- What about travelling and can travelling skills be developed?

- Is it expected that the disabled person will want to spend regular or occasional periods staying with family members or friends and is this mutual?

- Is the disabled person already used to staying away from the family home? If not, can short breaks or staying with other family members or friends be arranged?

- Are there more things that the disabled person could learn to do for themselves? If so, can this learning best be done at home, at college, at a training centre or in a special training flat if there is one available?

- What, if any, resources of cash, time or expertise would I/we like to put into whatever arrangements are made?

- What support is needed in the house; ranging from someone available for advice, through occasional or regular prompting to some tasks having to be taken over, and full 24-hour supervision or supervision and physical care?

TYPES OF ACCOMMODATION AND SUPPORT

Where people live, with whom and how they are supported are each different but linked issues. The following are examples of accommodation and support arrangements.

- Living as a tenant in a flat, either Housing Association or privately rented, with support from workers under the Supporting People programme.

- Supported accommodation – this can be a self-contained bedsit in a unit with shared lounge, kitchen and other communal facilities, with non-resident support staff through to a staffed group home shared with a number of other people with a learning disability.

- Staying on in the family home as home owner or tenant once you have gone, perhaps with someone else as a friend, with support coming into the home.

- A self-contained property in the grounds of the family home, let to or sold to the disabled person, with family and paid staff sharing the support.

- Residential care for those more severely disabled people for whom independent or supported living is not an option and nursing care for those with predominantly health needs. There are a number of specialist care homes on the Island. The Care Manager can advise on these and the range of accommodation and support available locally. The local guide to residential care and nursing homes is available from Social Services offices and it contains a useful checklist of things to look for when choosing a care home.

- Specialist residential placements for people with very challenging behaviour. These placements will most probably be on the mainland and are likely to be the most expensive option at in excess of £200,000 a year. It would have to be demonstrated that the care needs of the individual could not appropriately be met locally before such a placement would be considered.

A HOME FOR LIFE?

For parents, the start of insecurity is the knowledge that they cannot guarantee a home for life for a son or daughter, even if they wanted to. One day they will die. There is therefore a perfectly natural desire to see in place alternative arrangements that will guarantee a home for life.

Parents can be confident that someone with a severe learning disability who needs lifelong accommodation and support will get it. Such a person is very unlikely simply to be abandoned. The best guarantee of having a particular home for life is to own it; however, even the owner occupier may want to move or may have to go into hospital or a nursing home because of deteriorating health.

Any other arrangement amounts to a guarantee of ***a*** home for life, rather than ***that*** home for life – though we are as a society getting much better at supporting people in their own homes as their needs change. Someone's needs may come to exceed the resources that can be put into that home or incompatible with meeting the needs of other people living in the home and this may mean that a move to a home more suited to their needs is inevitable.

WHO PAYS?

The funding for tenancies and charging for care is quite complex and is set out in more detail in Information Sheet 8. The information here summarises the different types of funding available.

Rented property – Housing Association or private: the rent payable is covered by Housing Benefit for those whose capital is less than £16,000.

Support costs in rented accommodation: Supporting People funding, Disability Living Allowance (DLA) or Attendance Allowance, Direct Payments (see Information Sheet 8), Social Services Community Care funding and sometimes NHS funding where there are health-related support needs.

Group homes and residential care: the fees are funded mainly through social security benefits (Income Support) and Social Services Community Care budget. Residents have a small personal allowance of £18.10 per week (from April 2004).

WHERE TO GET MORE INFORMATION

- Talk to your Care Manager, support worker or nurse.
- Talk to other parents through the local MENCAP group (telephone 01983 868443) or Fairhaven Housing Trust (telephone 01983 855345).
- Contact a local Housing Association that provides supported accommodation and go to look at the various housing options. The Isle of Wight Housing Association welcome such contact – telephone 01983 528275.

Source: MENCAP Fact Sheet 'Housing Choices'

12 LEARNING DISABILITIES, MENTAL HEALTH ISSUES AND AUTISM

DEMENTIA IN PEOPLE WITH A LEARNING DISABILITY

Advances in medical and social care have led to a significant increase in the life expectancy of people with learning disabilities. The changes that happen as we age have therefore taken on a new importance. One of these changes is the increased risk of developing dementia. This information sheet outlines some of the important issues concerning people with learning disability who develop dementia.

People with learning disabilities are those whose intellectual ability is lower than that of the average person. This group is diverse, as are the causes of learning disability, which include specific genetic disorders such as Down's syndrome, pre- or post-natal infections, brain injury and general individual differences.

WHAT IS DEMENTIA?

Dementia is a general term used to describe a group of diseases that affect the brain. Alzheimer's disease is the most common form of dementia. The damage caused by all types of dementia leads to a progressive loss of brain tissue. As brain tissue cannot be replaced, symptoms become worse over time. These generally reflect a loss of skills and may include:

- Loss of memory;
- An inability to concentrate;
- Difficulty in finding the right words or understanding what other people are saying;
- A poor sense of time and place;
- Difficulty in completing self-care and domestic tasks and solving minor problems;
- Mood changes;
- Behavioural changes.

There is no evidence that dementia affects people with learning disabilities differently from other people. However, the early stages are more likely to be missed or misinterpreted, particularly if several professionals are involved in the person's care. In addition, the person themselves may find it hard to express how they feel their abilities have deteriorated and problems with communication may make it more difficult for others to assess change.

WHAT ARE THE RISKS?

Down's syndrome and Alzheimer's disease: About 20% of people with a learning disability have Down's syndrome. People with Down's syndrome are at particular risk of developing dementia. Figures from one major study suggest that the following percentages of people with Down's syndrome have dementia:

30 – 39 years	2%
40 – 49 years	9.4%
50 – 59 years	36.1%
60 – 69 years	54.5%

Different figures have been suggested by other studies.

Studies have also shown that virtually all people with Down's syndrome develop the plaques and tangles in the brain associated with Alzheimer's disease, although not all will develop the symptoms of Alzheimer's disease. The reason for this has not been fully explained. However, research has shown that amyloid protein found in these plaques and tangles is linked to a gene on chromosome 21. People with Down's syndrome have an extra copy of chromosome 21, which may explain their increased risk of developing Alzheimer's disease.

Other learning disabilities and dementia: The prevalence of dementia in people with other forms of learning disability is also higher than in the general population. Figures suggest that the following percentages of people with learning disabilities *not* due to Down's syndrome have dementia:

50+ years	13%
65+ years	22%

This is about four times higher than the general population.

It is only possible to speculate at this stage why this might be. Further research is needed. People with learning disabilities are vulnerable to the same risk factors as the general population. It may be that genetic factors are involved or that a particular type of brain damage associated with a learning disability is implicated.

HOW CAN YOU TELL IF SOMEONE IS DEVELOPING DEMENTIA?

Carers play an important part in helping to identify dementia by recognising changes in behaviour or personality. It is not possible to diagnose dementia definitely from a simple assessment. A diagnosis is made by excluding other possible causes and comparing a person's performance over time. The process should include:

- **A detailed personal history:** This is vital to establish the nature of any changes that have taken place. It will almost certainly include a discussion with the main carer and any care service staff.

- **A full health assessment:** It is important to exclude any physical causes that could account for changes taking place. There are a number of other conditions that have similar symptoms to dementia but are treatable, for example, hypothyroidism and depression. It is important not to assume that a person has dementia simply because they fall into a high-risk group. A review of medication, vision and hearing should also be included. Input from the Learning Disability Nurse and the new individual Health Action Plan (HAP) could help with this assessment.

- **Psychological and mental state assessment:** It is equally important to exclude any other psychological or psychiatric causes of memory loss. Standard tests that measure cognitive ability are not generally applicable as people with learning disabilities already have cognitive impairment and the tests are not designed for people without verbal language skills. New tests are being developed for people with learning disabilities.

- **Special investigations:** Brain scans are not essential in the diagnosis of dementia, although they can be useful in excluding other conditions or in aiding diagnosis when other assessments have been inconclusive.

WHAT CAN BE DONE IF IT IS DEMENTIA?

Although dementia is a progressive condition, the person will be able to continue with many activities for some time. It is important that the person's skills and abilities are maintained and supported for as long as possible and that they are given the opportunity to fulfil their potential. However, the experience of failure can be frustrating and upsetting, so it is important to find a balance between encouraging independence and ensuring that the person's self esteem and dignity are not undermined.

At present, there is no cure for dementia. People progress from mild to moderate to more severe dementia over a period of years. New drug treatments seek to slow down or delay the progression of the disease and it is hoped that treatments will become more effective in the future.

STRATEGIES FOR SUPPORTING THE PERSON WITH DEMENTIA

People who develop dementia are, first and foremost, human beings with individual personalities, life histories, likes and dislikes. Dementia affects a person's ability to communicate, so they may develop alternative ways of expressing their feelings. By understanding something of a person's past and personality we can begin to understand what they might be feeling and why they respond in the way they do.

There are many practical ways in which a carer can support a person with dementia and many of these are outlined in a local information book called *"What If? a handbook for carers of people with memory problems"*. This book is available from the local Alzheimer's Support Group on 01983 612043 or Carers UK branch on 01983 533173 or Social Services offices.

USEFUL ORGANISATIONS

The Foundation for People with Learning Disabilities
20/21 Cornwall Terrace, London NW1 4QL
Telephone 020 7535 7400 Email mhf@mentalhealth.org.uk
Website www.mentalhealth.org.uk

Down's Syndrome Association
155 Mitcham Road, London SW17 9PG
Telephone 020 8682 4001 Email informationdepartment@downs-syndrome.org.uk
Website www.downs-syndrome.org.uk

Alzheimer's Society
Gordon House, 10 Greencoat Place, London SW1P 1PH
Telephone 020 7306 0606
Website www.alzheimers.org.uk

Source: Alzheimer's Society Information Sheet 430

DEPRESSION IN PEOPLE WITH A LEARNING DISABILITY

Many people will get depressed at some time in their lives, including people with learning disability. Bereavement, disappointment, stress or illness are some possible causes, but depression may also occur for no apparent reason. Generally, periods of depression are short by sometimes they last much longer, when special help is needed.

Because depression is so common, it is usually easy to spot. As well as obvious feelings of sadness or misery, symptoms may include a loss of interest in previously enjoyed activities, agitation and restlessness, disturbances of eating and sleeping, lack of motivation and a loss of self confidence and self esteem. People who are depressed may be able to talk about their feelings to their family, friends or workmates and to their GP. Talking is an important part of getting better.

The problem for many people with learning disabilities is that they are not able to express their feelings easily in words. So their actions may have to speak for them. Sudden changes in behaviour or mood, or not being able to do things they could previously do may all be important signs of depression. These changes in behaviour are often mistakenly viewed as just a phase and so the right help may not be given.

HOW TO RECOGNISE DEPRESSION

Feeling low or sad is not the only sign of depressive illness. Other common symptoms include:

- Less interest in activities which are usually enjoyed;
- Feeling tired all the time;
- No get up and go;
- Eating too little or too much;
- Losing weight;
- Inability to sleep or waking up too early;
- Sleeping all the time;
- Avoiding other people;
- Inability to relax or restlessness;
- Being snappy or irritable;
- Feeling bad, guilty or worthless;
- Loss of confidence;
- Thinking life isn't worth living.

People with learning disabilities are just as likely to get depressed as other people. But the way they show it can sometimes be different from the picture painted above, especially when there are communication problems. Other signs to look out for are:

- Sudden or gradual changes in usual behaviour;
- Seeking reassurance;
- Loss of skills;
- Loss of bowel or bladder control;
- Loss of ability to communicate;
- Outbursts of anger, destructiveness or self harm;
- Physical illness;
- Complaining about aches and pains;
- Wandering or searching.

CAUSES

People looking after someone with learning disability who is depressed usually want to know why. The reasons differ from one person the next and often there is more than one cause.

Loss

Although depression sometimes strikes out of the blue, it is often triggered by some unhappy event, such as bereavement or a favourite carer leaving. These events affect most people with learning disability at some time, although not everyone gets depressed. Sometimes one loss can then lead on to other major changes: for example, after parents have died people with learning disability are often moved to emergency residential care. This means they lose their home, their familiar possessions and routines, as well as their parent and carer.

Many people with learning disability find change difficult to cope with. Routine can be important but often other people make decisions that affect their lives without any warning or any personal choice or control.

Usually people can work through their feelings about an unhappy event and come to terms with it. People with learning disability will probably need help to do this. Sometimes a more serious and persistent depression develops. This is a particular risk for people with learning disability because carers often miss the early signs of depression.

Health problems

Physical illness or simply the presence of a long-term disability may trigger depression. Often it is a combination of illnesses that take their toll over a number of years. Although this may make the depression more understandable, it doesn't mean that treating any associated depression is a waste of time!

Sometimes depression may be provoked by the body's chemistry being affected by a physical illness, such as an under-active thyroid gland. Sometimes drugs prescribed to treat another condition can make a person depressed. The GP is well placed to check these things out.

Abuse

People with learning disability are at risk of being neglected and physically or sexually abused, because they cannot easily protect themselves or may not be able to tell other people what has happened. Abuse may lead to depression. (See Information Sheet 5.)

OTHER FACTORS RELATED TO DEPRESSION

Personality may play a part in depression, with some people seeming to be more vulnerable than others, perhaps because of the way they were raised or because they were born with a depressive tendency. Generally speaking, women get depressed more often than men. Hormones probably play a part, as with monthly mood changes before each period. Some people who get depressed will also have times when they are elated and overactive. This form of depression – known as manic depression – tends to run in families.

GETTING HELP

First, you have to be aware that the person you care for may be depressed. The time to get help is when any changes in behaviour, withdrawal or gloom have gone on for some weeks. Then you should seek professional help.

Most family doctors are quite used to dealing with emotional problems, but very few doctors will have had training in how to recognise depression in people with learning disabilities. So, don't forget that you are the expert when it comes to telling the doctor about the changes you have noticed in the person you are worried about. You may have to explain that the depression is not part of the condition that caused the learning disability, but is something new and different. The doctor will probably appreciate your being present to help explain what is happening. It may be necessary for the psychiatrist who has special training in working with people with learning disability to be consulted. It would also be helpful to share your concerns with the care manager or support worker as they will be able to involve the Specialist Learning Disability Nurse.

In severe depression, most people feel that life is not worth living. Thoughts or actions suggesting that people may want to harm or even kill themselves should always be taken seriously – they mean help is definitely needed. However, changes in mood or behaviour may be caused by problems other than depression, so it is wise to have a careful health check by the GP before deciding that any changes are due to depression. Physical illness and chronic pain are themselves causes of depression in some people with learning disabilities and both physical as well as emotional illness will need attention. The GP may also refer to the Learning Disability Nursing Team for specialist support (see Information Sheet 1: Accessing Health Services).

PREVENTION

Bereavement or other major changes in life are probably the most common causes of depression. Although it is not possible to protect people with learning disability from events of this kind, proper preparation and explanation can help to prevent them from becoming too distressed. Moving from home to live in the community, separation from families, siblings leaving home, the of a favourite care worker, the need to adapt to frequent staff changes or the moves of other residents are familiar experiences for people with learning disability. Often, greater stability could be achieved through better planning or organisation of resources to make as few changes as possible. If this is not possible, more attention to explaining (in whatever way is most suitable) why, what, when or where changes will take place and who they will involve can greatly reduce stress and anxiety. Helping people to express their worries and feelings at the level that suits them best can also help to reduce or even avoid many problems.

TREATMENT

Psychological approaches

Psychological approaches play an important role in the treatment of anyone who is depressed. The opportunity to talk about problems and finding practical ways of dealing with them are essential parts of treatment. Counselling and psychotherapy can be very successful with people with learning disability too, as long as they are adapted to their levels of communication and understanding. A specialist psychologist is based with the local Learning Disability Nursing Team.

Psychological approaches need not rule out other methods, such as medical treatment. There is no point in trying to do without drugs if they are needed.

Drug treatment

When depression is severe, for example, when there is loss of weight and poor sleep, an antidepressant drug will be needed. These tablets are not addictive and most side effects generally pass or lessen after a few days.

The doctor who prescribes the antidepressant drug will warn the person with learning disability or carer about common side effects such as a dry mouth or feeling a bit drowsy or dizzy. The doctor will also want to know about any other medications (including any from the chemist) that the depressed person is already taking.

Antidepressants may take up to 4 weeks before taking full effect. They should be taken for some months after the depression has lifted, for it may reappear if the tablets are stopped too soon. The prescribing doctor, usually the GP, will see how treatment is going with regular appointments and will advise on when to stop the tablets.

Social support

Loneliness or lack of anything interesting to do during the day may be a cause of depression or can make depression worse. Help from Social Services, voluntary organisations, parent groups and other support groups will be needed to deal with such problems. Some of the other information sheets in this folder will help you find out what other support is available locally.

WHAT YOU CAN DO TO HELP

- Do ask for help. It's not normal for someone to feel depressed just because they have a disability.
- Do be patient and remember that depression is an illness and that most people get better.
- Do make sure they keep taking any tablets they are on, but watch out for any side effects and report these to the doctor or nurse immediately.
- Do listen to how they feel and if they are having counselling help them to keep their appointment.
- Do encourage eating and drinking properly – the right nourishment and enough of it. People with depression often lose weight.
- Do encourage going out and joining in activities they have previously enjoyed, but don't bully them into doing things.
- Don't forget your own needs – it can be very wearing living with a depressed person. Talking to other carers can be helpful, as can having regular breaks.
- Don't think depression is a slur on your family or on your care. Be clear that it is not a form of madness.
- Don't make decisions about a change of home when someone is depressed. It is much harder to cope with a move at such a time.

Information Sheet 16 has a list of useful contact numbers and other sources of information.

Source: Royal College of Psychiatrists leaflet 'Help is at Hand'

LEARNING DISABILITY AND AUTISM

WHAT IS A LEARNING DISABILITY?

People usually have a learning disability from birth and sometimes from early childhood. Some people have severe learning disabilities and need a lot of day-to-day support. Others have moderate learning disabilities and can live independently with less support from other people. Usually, someone with a learning disability has an IQ (Intelligence Quotient) of 70 or less, which leads to an impairment of their functioning in learning, social and communication skills.

AUTISM

Autism is a term that was first used by an American, Dr Kanner, to describe children who had a particular difficulty in relating emotionally to people. Autistic children also have difficulty understanding spoken and gestural language and in developing normal and gestural speech. They may have rigid patterns of behaviour, strongly resist change and have difficulty in understanding their visual perceptions.

DO ALL AUTISTIC PEOPLE ALSO HAVE LEARNING DISABILITIES?

Just as a learning disability can range from severe through moderate to 'mild', so the so-called Autistic Spectrum includes a condition called Asperger Syndrome, which describes people who show characteristics of autism but are of above average intelligence and have good communication skills. People with Asperger Syndrome are therefore not seen as having a specific learning disability and many of the services and support for people with a learning disability are not appropriate for those with Asperger Syndrome.

WHAT SUPPORT IS AVAILABLE?

Local specialist services are not well developed but Social Services have recently appointed a specialist worker to support young people with autism. This worker is based with the Learning Disability team in Ryde. Although there are no 'autistic specific' services on the Island, local services are geared to meet need and great care is taken to 'match' the individual to the available support.

Support is also available through the Specialist Learning Disability community health and social services, which are covered in various information sheets in this folder. Other services geared to the needs of autistic people are:

- CONNEXIONS: which provides information, advice and guidance to young people. Connexions should be represented at the Year 9 review and the service will support young people with special needs up to the age of 25.

- MENCAP PATHWAY EMPLOYMENT SERVICE also supports people with autism. More information about education and employment services can be found in Information Sheets 9 and 10.

SPECIALIST PLACEMENTS

Wherever possible, the needs of a person with autism and a learning disability will be met locally, using the available services as flexibly as possible. However, someone with particular complex needs and challenging behaviour who cannot be supported through local services may need a specialist mainland residential placement. In this event, all options will be explored and discussed by health and social services staff.

FURTHER INFORMATION

The National Autistic Society publishes a number of books and has a helpline. AUTISM HELPLINE: 0870 600 8585, 10.00am to 4.00pm, Monday to Friday. AUTISM SUPPORT GROUP: telephone 01983 868443.

13 LEISURE AND SOCIAL ACTIVITIES

Most adults with a learning disability want to do the same things that other adults would do in their leisure time – go to a club, enjoy a sporting activity or just socialise with other people. Some will be able to do just that without support; others may need help to access social activities and prefer to meet up with friends in a supported setting. The clubs, groups and sports listed here all depend on parent/volunteer support and activities may be restricted if the group is unable to recruit enough volunteers.

Unless the clubs have a contract with Social Services or similar sources of funding, it is not a requirement for volunteers to be vetted. Ask what their procedures are for recruiting and vetting both paid staff and volunteers.

All the clubs have a small subscription charge.

BREAKAWAY is a small group run by parents and volunteers during school holiday periods. The group currently has 32 member families and caters for the over-16s. Activities include swimming, bowling, skating, discos and holidays. Contact Margaret Green on 01983 294884 for further information.

GATEWAY CLUB is a club run by volunteers for people 16+ upwards – the oldest member currently is 82! The club has 160 members, is based at Shanklin Youth Club and is open 6.30pm to 8.30pm Thursday and Sunday evenings. Activities include table tennis, pool, badminton, disco and live music. Contact John Phillips on 01983 864891 for details.

PhAB – this group has a very small number of people with a learning disability as members. It is run by parents and volunteers and is based at Wootton Youth Club, New Road, Wootton. It is open on a Wednesday evening 7.15pm to 10.00pm during school term times. The club provides a range of activities, games and opportunities for socialising. Contact Barbara Bailey on 01983 884092 for information about membership.

RYDE SPEAKING OUT GROUP – this group for adults meets at the Simeon Arms in Ryde on the third Tuesday of every month from 7.00pm onwards. The group is member-led and provides an opportunity for socialising. Contact Dennis O'Hearn on 01983 565964 to find out more.

SATURDAY SPECIALS YOUTH CLUB (SSYC) is run by Island Volunteers. It is based at Newport Youth Club in St James Street, takes members aged 13 to 25 and is open from 10.00am to 2.00pm (lunch is included). Telephone Island Volunteers Social Care Group on 01983 539500 for more information.

SPECIAL OLYMPICS is a worldwide organisation providing sports training and athletic competitions in 23 Olympic-style sports for people with severe learning disabilities. The Island's Special Olympics provides opportunities for local people with learning disabilities to interact with their peers and integrate in the wider community. Individuals and teams compete both nationally and locally but there is no pressure for individuals to do so! The training programmes include:

- MULTISPORT (soccer, athletics and sports hall, table tennis, kwik cricket, badminton, uni-hoc, keep fit, basketball and volleyball): Multisport meets at Carisbrooke High School on a Monday between 5.00pm adn 6.30pm. Some of the multisports are very popular and have a waiting list. Contact Celia Jordan on 01983 526009.
- BOWLS: meet at Ryde Indoor Bowls Club. Contact Fred Rylands on 01983 529589.

- SWIMMING: this group is called the 'Kingfishers' and meets at West Wight Swimming Pool, Freshwater on Thursday evenings between 6.00pm and 7.00pm. Members currently range in age from 9 to 38 and the group can take a maximum of 20 people. Membership is Island-wide; the Wightbus picks people up at the Medina Centre to take them to the pool and club members each pay for a shared taxi home. Contact Marion Heming on 01983 760221.

VECTIS SUPPORT GROUP provides learning, training and leisure time activities for adults with a learning disability. Activities include basic skills training, literacy, numeracy, keeping healthy, cooking, discussion and crafts. The group has a minibus and is able to take members out and about. Membership is limited to between 10 and 12 people. The clubs run at the Handi-Centre, 22 Acorn Gardens, East Cowes on Monday mornings, Wednesdays and Wednesday evenings. The Monday Group for older, more disabled people, meets between 9.30am and 12.00 noon, the Wednesday Group between 10.00am and 3.30pm (lunch provided) and the Wednesday Evening club meets between 7.00pm and 9.15pm. This is very much a social evening with theme nights, music, disco and karaoke. Contact Sandra Leppard on 01983 529504 for more information.

WEDNESDAY CLUB – many of the members of this club also have links with the Westminster House respite care facility. This club for adults meets every Wednesday at Parklands, Park Road, Cowes between 4.00pm and 8.00pm. Activities include quizzes, games nights, etc. People interested in joining are welcome to call in or contact Jeremy Baker at Westminster House on 01983 526310 for information.

HOLIDAYS

BREAKAWAY (listed on previous page page) organise holidays for families and HAYLANDS FARM (day centre) include 'non members' in their holiday activities. Contact Charles Cook on 01983 566038 for more information. The GATEWAY CLUB (listed on previous page) also organises holidays for members – they do one main holiday and several weekend and day trips to the mainland during the year.

National organisations:
Holiday Care Services – telephone 0845 124 9971
Winged Fellowship – telephone 020 7833 2594

14

MAKING A COMPLAINT

Don't be afraid to complain about things if they are not right for you and the person you care for. If you have a complaint you should, in the first instance, talk to the person you are in contact with or their care manager. If your complaint is about health service treatment or care and you would rather talk to someone who is not directly involved, contact the Patient Advice & Liaison Service (PALS). The telephone number is listed on this advice sheet. The majority of complaints can be quickly resolved in this way but if you feel this approach hasn't helped, then ask for the organisation's formal complaints procedure.

If you feel you would like some help in making a complaint, speak to your local Carers Centre, Citizen's Advice Bureau or the Advocacy Service. Don't forget that if your complaint is not resolved properly, you can contact your MP, County Councillor, Ombudsman or even take advice about legal proceedings. If you feel you need to use the law, you should be aware that it can be a costly process for all concerned, with uncertain outcomes, so make sure you get good advice before you start.

Useful contacts

101% Advocacy
Parklands Resource Centre, Park Road
Cowes, Isle of Wight PO31 7LZ
Telephone 01983 209710
www.101percent.org

Carers UK (Isle of Wight Branch)
Riverside Centre, The Quay
Newport, Isle of Wight PO30 2QR
Telephone 01983 533173
www.carersonline.org.uk

Citizen's Advice Bureau
Exchange House, St Cross Lane
Newport, Isle of Wight
Telephone 0845 120 2959

Isle of Wight Primary Care Trust
Complaints Manager
Whitecroft, Sandy Lane
Newport, Isle of Wight PO30 3ED
Telephone 01983 535455

Isle of Wight Advocacy Trust
Quay House, Riverside Centre,The Quay
Newport, Isle of Wight PO30 2QR
Telephone 01983 822209 ext 203 (Jan Gavin)
Email: jangavin2002@yahoo.com

IW Council Social Services & Housing Directorate
Mr D Carmichael, Complaints Manager
46 Sea Street, Newport, Isle of Wight PO30 5BL
Telephone 01983 533289

Isle of Wight Healthcare NHS Trust
Patricia Gent, Patient Advisor/Complaints Manager
St Mary's Hospital, Parkhurst Road
Newport, Isle of Wight PO30 5TG
Telephone 01983 534420

Patient Advice & Liaison Service (PALS)
Isle of Wight Healthcare NHS Trust
Cathy Brown, PALS Facilitator, St Mary's Hospital
Parkhurst Road, Newport, Isle of Wight PO30 5TG
Telephone 01983 534850

Local Government Ombudsman
The Oaks No. 2, Westwood Way
Westwood Business Park, Coventry CV4 8JB
Telephone 024 7669 5999
www.lgo.org.uk

Health Service Commissioner (Ombudsman)
11th Floor, Millbank Tower, Millbank
London SW1P 4QP
Telephone 0845 015 4033

MENCAP
123 Golden Lane, London EC1Y 0RT
Telephone 020 7454 0454
www.mencap.org.uk/helpline

15 RELATIONSHIPS

All parents find it hard when their teenagers approach the age of sexual maturity, but it is even harder when those young people have a disability. It is natural to worry about vulnerability and the possibility of exploitation and abuse. Parents may believe their children will never form a sexual relationship and worry about what will happen if they do.

Whatever a person's abilities or disabilities, most people develop sexual feelings that may be shown in a variety of ways, in different sorts of relationships or in marriage. This gives parents a tough task in helping their son or daughter to understand these feelings and express them in a way that increases their well-being and does no harm to themselves or others. Growing independence is also a challenge for parents, many of whom have spent years caring. This experience gives parents a perspective that takes time to change.

All people share the same basic rights to be independent, treated with dignity and respect, to be able to exercise basic human rights, to be accepted by the community in which we live and to be able to choose how to lead individual lives and lifestyles. Rights also carry risks and it is essential that parents are involved in any assessment of these risks, which may be undertaken within the services used by the person with a disability. The sexual rights of people with a learning disability should be recognised and respected as part of these overall rights. This is also reflected in the Valuing People document.

VALUING PEOPLE

'Valuing People: a new strategy for learning disabilities for the 21st century' is a White Paper introduced by the Government in 2001.

The four key principles underpinning the White Paper are:

- **Legal and civil rights:** people with learning disabilities have the right to a decent education, to grow up, to vote, to marry and have a family, to express opinions, with support as necessary.

- **Independence:** the starting presumption should be of independence rather than dependence, with public services providing the support needed to maximise this.

- **Choice:** like other people, people with learning disabilities want a real say in where they live, what work they should do and who looks after them.

- **Inclusion:** this means enabling people with learning disabilities to carry out day-to-day activities, make use of mainstream services and be fully included in local communities.

The implication of this is that people with learning disabilities should have the opportunity to gain information about contraception, pregnancy, parenthood, sexual orientation and sexual activity. People with learning disabilities will need help with developing decision making skills, understanding and using information, communicating about sex and relationships, and recognising and dealing with abusive situations. Parents have a role in this, along with the people working in the learning disability and other services.

WHAT CAN PARENTS DO TO HELP?

Sources of support and information are listed at the end of the information sheet.

- Help increase self-esteem and confidence in meeting other people.
- Encourage friendships and peer group activities.
- Prepare YOURSELF – work out what your response will be to risk taking, contraceptive advice and sexual relationships.
- Make a distinction between what is in the best interests of the person with a learning disability or your own best interests as a parent/relative.
- Encourage practice in choice and decision-making through clothes, music, food and friends.
- Help with an understanding of how bodies and feelings can change, about changes that happen to the opposite sex too.
- Help them to be realistic about the choices that lie ahead and support the choices that are possible.
- Encourage positive sexual health and relationships and respect relationship choices and preferences.
- Help with learning about sexuality and relationships, the rights of others and the right to say 'No'.

SOURCES OF INFORMATION AND SUPPORT

Information Sheet 5 also has relevant information.

The Community Learning Disability Nursing Team, Care Managers, Residential and Support Staff can all be useful sources of advice and support in dealing with concerns about sex and relationships. See Information Sheet 16 for contact numbers.

People First self-advocacy group – see Information Sheet 5 for details.

Publications:

Holding on, letting go – sex, sexuality and people with learning disabilities
John Drury, Lynne Hutchinson and Jon Wright, Souvenir Press, 2000
A book for parents and carers to help them feel more comfortable and confident when thinking about sex and sexuality in relation to their son, daughter or caree. Available from all bookshops.

Talking together.... about growing up
Scott & Kerr Edwards, fpa, 1999
A workbook for parents of children with learning disabilities.
Available from: fpa direct, PO Box 1078, E.Oxford DO, Oxon, OX 4 5JE (Phone 01865 719418)

Talking together.... about sex and relationships
Scott & Kerr Edwards, fpa, 2003
The second in the Talking Together series for parents.
Available from: fpa direct, PO Box 1078, E.Oxford DO, Oxon, OX 4 5JE (Phone 01865 719418)

Everything you ever wanted to know about safer sex – but nobody bothered to tell you
Nigel Bull with Camden People First, 1993
Contains information about having safe sex and the prevention of HIV and AIDS.
Available from: People First, 207/215 Kings Cross Road, London WCIX 9DB (Phone 020 7485 6660)

Books beyond words
Collins, 1993
Illustrated booklets designed to enable people to understand health issues and personal relationships.
Available from: Royal College of Psychiatrists, 17 Belgrave Square, London SW1X 8PG
Website: www.rcpsych.ac.uk/publications (Phone 020 7235 2351 extension 146)

Learning to love
Brook Publications
A set of five booklets including sex, contraception and health, and infection.
Available from: Brook Publications, PO Box 1239, Coventry CV8 3ZB (Phone 024 7654 5557)

16 USEFUL CONTACT NUMBERS

Advocacy (101%)	01983 209710
Advocacy Trust	01983 822209 extension 203
Autism Helpline	0870 600 8585
Citizens Advice Bureau	0845 120 2959
Carers UK (IW)	01983 533173
Community Learning Disability Team	01983 566011
Community Learning Disability Nurses	01983 866179
Connexions	01983 527565
Day services:	
Medina Centre	01983 523090
Haylands Farm	01983 566038
Riverside Centre	01983 822209
Crossroads (Care for Carers)	01983 822200
DIAL (Disability Advice Line)	01983 522823
Fairhaven Housing Trust	01983 855345
MENCAP (Isle of Wight)	01983 868443
MENCAP Pathway Employment Service	01983 529461
MENCAP Helpline & Information Service	020 769 6900/6979 *(9.00am to 5.30pm, Mon to Fri)*
NHS Direct	0845 4647
No Barriers	01983 566011
Osel Enterprises	01983 866218
Primary Care Trust	01983 535455
Social Services:	
Headquarters	01983 520600
Ryde Social Services Centre	01983 566011
Housing	01983 823040
Duty Team & Occupational Therapists	01983 823340
Supporting People	01983 550477
Westminster House	01983 526310
Wightcare	01983 821105
Young Carers Project	01983 521590

INFORMATION SOURCES AND WEBSITES

Organisation	**What it does**	**Contact details**
Association for Residential Care (ARC)	ARC is an umbrella organisation that brings together those who provide for people with learning disabilities	ARC House, Marsden Street, Chesterfield, Derbyshire S40 1JY Telephone: 01246 555043 Email: contact.us@arcuk.org.uk Website: www.arcuk.org.uk
British Institute for Learning Disabilities (BILD)	Committed to improving the quality of life of all people with learning disabilities	BILD, Campion House, Green Street Kidderminster, Worcestershire DY10 1JL Telephone: 01562 723029 (Publication sales: 01752 202301) Fax: 01562 723029 Email: enquiries@bild.org.uk Website: www.bild.org.uk
Carers National Association	To help anyone who is caring for a sick, disabled or elderly frail friend or relative at home	Carers National Association Ruth Pitter House 20-25 Glasshouse Yard London EC1A 4JT Telephone: 020 7490 8818 Fax: 020 7490 8824 Email: internet@ukcarers.org Helpline: 0808 808 7777 (Mon to Fri, 10.00am to 12.00 noon and 2.00pm to 4.00pm)
CHANGE	Fights for the rights of learning disabled people, especially people with learning disabilities who are deaf or blind	CHANGE Unity Business Centre, Units 19 & 20 26 Roundhay Road, Leeds LS7 1AB Telephone: 0113 243 0202 Fax: 0113 243 0220 Email: changepeople@btconnect.com
Department of Health	To improve the health and well being of people in England	The Department of Health Richmond House, 79 Whitehall London SW1A 2NS Telephone: 020 7972 4499 Email: dhmail@doh.gsi.gov.uk Website: www.doh.gov.uk
Down's Syndrome Association	National organisation concerned with all aspects of Down's Syndrome	The Down's Syndrome Association 155 Mitcham Road London SW17 9PG Telephone: 020 8682 4001 Fax: 020 8682 4012 Email: info@downs-syndrome.org.uk Website: www.dsa-uk.com

Organisation	What it does	Contact details
Foundation for people with learning disabilities	Aims to improve the quality of life for people with learning disabilities by conducting research and sharing the findings with other people	UK Office, 7th Floor, 83 Victoria Street, London SW1H 0HW Telephone: 020 7802 0300 Fax: 020 7802 0301 Email: fpld@fpld.org.uk Website: www.learningdisabilities.org.uk
Image in Action	Creative work with young people and adults with learning disabilities	Chinnor Road, Bledlow Bridge, High Wycombe, Bucks HP14 4AJ Telephone: 01494 481 632 Email: iia@nascr.net
LDUK	Web-based site containing latest news and events information in the UK	Email: LDUK@learningdisabilitiesuk.org.uk Website: www.learningdisabilitiesuk.org.uk
MENCAP	To provide support for people with learning disabilities in all aspects of their lives	MENCAP National Centre, 123 Golden Lane, London EC1Y 0RT Telephone: 020 7454 0454 Fax: 020 7608 3254 Email: information@mencap.org.uk Website: www.mencap.org.uk
National Autistic Society	Aims to encourage better understanding of autism and to pioneer specialist services	393 City Road, London EC1V 1NG Telephone: 020 7833 2299 Fax: 020 7833 9666 Email: nas@nas.org.uk Website: www.nas.org.uk
Respond	National organisation working with people with learning disabilities who have been sexually abused	3rd Floor, 24-32 Stephenson Way, London NW1 2HD Telephone: 020 7383 0700 Fax: 020 7387 1222 Helpline: 0845 606 1503 Email: admin@respond.org.uk Website: www.respond.org.uk
Values into Action	UK-wide campaign with people with learning disabilities	Oxford House, Derbyshire Street, Bethnal Green, London E2 6HG Telephone: 020 7729 5436 Email: general@viauk.org Website: www.viauk.org
Working with Words	Produce information and literature for people with learning disabilities	St Mary's Gallery, Greenlaw Street, London SE18 5AR Telephone: 020 8855 6644 Fax: 020 8855 3393 Email: workingwith@words01.fsnet.co.uk

17 WILLS AND TRUSTS

Parents of people with a learning disability often ask for advice on how they should provide by Will for their children's future. In consultation, many carers identified this an information need. This information sheet gives general guidance only and it is essential that expert advice is sought from a specialist solicitor on the options and the possible tax implications. A list of local specialist solicitors is included in the information sheet.

WHY MAKE A WILL?

A Will is the only way to ensure that your wishes are carried out after your death. A Will allows you to appoint a person of your choice to administer your estate according to your wishes and to leave money in a special trust for children or adults with a learning disability. If you have already made a Will, make sure you keep it up to date as your circumstances may have changed, through divorce or remarriage, for example, and this can invalidate a previous Will.

TRUSTS FOR ADULTS

When it is possible or certain that an adult with a learning disability will be unable to handle money left to him/her, parents should consider setting up a Trust, which will become operational on their deaths and last for the adult's lifetime.

In simple terms, a Trust is a binding agreement between an owner of property/money and another person or persons, to the effect that the other person or persons will hold the property/money, invest it as specified and make payments out of it or its income to named individuals. The persons who are placed under an obligation to hold the property/money and invest it are called the trustees. They may be placed under a duty to make certain payments to certain persons at various points in time or may be given a discretion as to when or to whom payments should be made. The arrangements themselves will usually be set out in either a Trust Deed or Will.

A Trust is a useful way to provide for an adult with a learning disability, as it relieves that adult of the task of investment. A Trust can also give the trustees power to make payments to third parties such as carers and to purchase items. Money does not need to be paid directly to the adult concerned if this would not be appropriate, but can be used to buy items or pay for services for them.

Trusts can take many different forms. The two most common are:

Life Interest Trusts or **Interest in Possession Trusts**
The Trust will have a specific beneficiary who is legally entitled to receive the income of the Trust or to use its assets (e.g. life in a house rent free). The capital is held for the benefit of another person/s. They become entitled to the whole Trust fund when the person who is entitled to the income dies.

Discretionary Trusts
The common feature of these Trusts is that no one beneficiary is legally entitled to receive the income or the capital of the Trust fund. It is left to the trustees to decide who is to benefit and how and when. It is possible and usual to give the trustees directions as to the desired distribution, although this can be changed, to avoid tax, for example.

OUTRIGHT GIFTS TO ADULTS

If money or property is left by Will directly to an adult with insufficient capacity to deal with it, he/she will be unable to give a valid receipt for it (which would normally discharge the administrators of the estate from further liability). The administrators might, therefore, be advised by their solicitors to seek the appointment of a Receiver by the Court of Protection. A Receiver appointed by the court has power to receive money or property and to deal with it on behalf of someone who is mentally disordered (within the meaning of the Mental Health Act 1983) and is unable to manage his/her property or affairs. A Receiver will, therefore, have power to give a valid receipt to an administrator of an estate. The Receiver's management role may, however, be subject to restrictions imposed by the court on the use of the money or property concerned.

Once in receipt of money or property, a Receiver's role is similar to that of a trustee in some ways. However, as a receivership appointment will occur after a parent's death, the ways in which the money or property should be invested or used for the adult with a learning disability will not have been decided in advance by the parent, nor will he/she have any say in the question of who should be appointed as Receiver. The Receiver must also declare the funds they hold when applying for state funding. Their existence may well result in withdrawal of such funding.

TRUSTS AND STATE FUNDING

People with a learning disability are likely to be in receipt of one or more of three main categories of means tested funding:

- Income Support;
- Local Authority funding of residential care placements;
- Housing Benefit.

The usual aim in making provision is to make payments that won't affect such funding.

The methods currently used by the Benefits Agency for Income Support, Social Services departments for funding of residential care and district councils, city councils or metropolitan boroughs for Housing Benefit are very similar. All three apply general criteria to assess eligibility in principle, then consider the amount of funding that can be paid, given the individual's personal circumstances. They then apply deductions to this amount, taking the individual's income from other sources and/or savings levels into account.

Individuals who have relevant capital, as defined by these systems, above certain amounts are not entitled to Income Support, Local Authority funding of residential care or Housing Benefit. Capital held in certain types of Trusts is not, however, defined as relevant capital by the three agencies involved in means testing for these forms of funding. These are Trusts where the person receiving state funding has no absolute right to the capital from the Trust. Such Trusts include ones where only the income arising from the investment of the capital is released under the terms of the Trust or where capital is released to the recipient of state funding solely at the discretion of the trustees. These are called DISCRETIONARY TRUSTS.

Sums actually paid from the capital of Trusts, at the discretion of the trustee(s), to a person in receipt of one or more of the three forms of state funding will be taken into account. In such circumstances, any payments actually made to him or her will be treated as charitable or voluntary payments in his or her hands. They will, therefore, be considered part of the recipient's capital, if made irregularly. If made regularly, they will be treated as part of the income of the recipient and their effect will depend on whether payments are in excess of the disregarded weekly amount of £20 and, if so, the purposes for which the sums are paid and used.

Sums actually paid from the income of any type of Trust fund will also be taken into account. However, they are only deducted in full from applicable amounts as income of the recipient of state funding if he or she has a right to the Trust income.

If income is paid out to him or her solely as the discretion of the trustees, the payments made are treated a charitable or voluntary payments, the effect of which depends, as usual, on whether they are made regularly, the amounts paid and the purposes for which they are paid. This is the case even if the terms of the Trust provide that only the individual in receipt of state funding can be considered by the trustee(s) as a potential recipient of Trust income.

There are, however, advantages in naming more than one potential recipient of such income in the Trust document. Firstly, this action makes absolutely clear the discretionary nature of the Trust. Secondly, income can be paid out solely to individuals who are not in receipt of state funding when any time limits imposed by Trust law on holding onto income and adding it to the capital of a Trust fund expire.

When payments of either capital or income are made to third parties for the individual in receipt of funding, at the discretion of the trustees, these are usually wholly ignored if made for purposes outside the scope of Income Support. Otherwise, they are treated as capital if made irregularly and as income if made regularly.

A specialist solicitor will give you more detailed advice on type of Trust, the most appropriate people to name as trustees and what constitutes 'reasonable provision' in your particular case. MENCAP publish an informative booklet titled *'Leaving Money by Will'* and Age Concern have a helpful advice sheet called *'Making Your Will'* – see Information Sheet 16 for contact details. Local specialist solicitors are listed below

SPECIALIST SOLICITORS

Careless & Kemp Solicitors (Specialist Solicitor: Mr Tony Careless)
Old Bank Chambers, 19 Church Street, Ventnor, Isle of Wight PO38 1SN
Telephone 01983 852626

Glanvilles (Specialist Solicitors: Mr E Giles and Mr G Lambie)
The Courtyard, St Cross Business Park, Newport, Isle of Wight PO30 5BF
Telephone 01983 523663

Eldridges Solicitors (Specialist Solicitor: Mr Peter Smith)
36 St James Street, Newport, Isle of Wight PO30 1LF
Telephone 01983 524741

Robinson, Jarvis & Rolf Solicitors (Specialist Solicitor: Mr Ian Pratt)
19-21 Quay Street, Newport, Isle of Wight
Telephone 01983 526924

Walter Gray & Co (Specialist Solicitor: Mary Blake)
27a High Street, Newport, Isle of Wight
Telephone 01983 526625

Walter Gray & Co (Specialist Solicitor: Cathy Powe)
27 High Street, Shanklin, Isle of Wight
Telephone 01983 862655

Source: MENCAP updated January 2004

INDEPENDENT LIVING TRUSTS are a legal entity but have very different aims to other Trust funds. An Independent Living Trust enables a person with a learning disability who has high support needs to be in control of their money and their life. They link very closely with both the Social Services development of Direct Payments (see Information Sheet 8) and Person Centred Planning (see Information Sheet 3) and are sometimes called 'User Controlled Trust Funds'.

An Independent Living Trust is a legally constituted body that enables the receipt and spending of money for a specific purpose. It has to follow clear rules set out in a Trust deed. A number of trustees agree the spending of the money to met the purpose of the Trust, in this case, independent living. Trusts can employ people and meet employer responsibilities. Trusts can also be registered for VAT purposes. This can be particularly useful if contracting with an agency that charges VAT.

The money managed by the Trust can come from a variety of sources; inheritances, Direct Payments or Independent Living Fund money, for example. It belongs to the individual and is managed with them and for them by the trustees, usually to pay for support staff. Trustees are usually drawn from a so-called 'circle of friends', which can include family and other close contacts.

Independent Living Trusts can be a useful tool in making independent living a possibility for people who may not otherwise have this opportunity. Values Into Action (VIA) and Community Living have published a practical guide to these Trusts, called *'Trusting Independence'*. Contact details are in Information Sheet 16.