



ESSENTIAL KNOWLEDGE

MEADOW COURT

LEARNING DISABILITIES

RELATIONSHIPS



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18 Words that inform and signify-RELATIONSHIPS

Definition of learning Disability

A learning disability affects the way a person understands information and how they communicate. This means they can have difficulty: understanding new or complex information, learning new skills and coping independently

RIVALRY

EMPATHY

LOVE

ANGUISH

TRUST

IMPATIENCE

OPENNESS

NOURISHMENT

SUSTAINABILITY

HONESTY

INTENSITY

PERCEPTION

SIMILARITY



RELATIONSHIPS

1. Relationships

1.1 Understand how to agree with an individual the level of support they want to develop or maintain their relationships

People with learning disabilities are entitled to lives which are as full as anyone else's. Although every one of us differs, there are some core things we all have in common. It is important for most people to:

- be part of a community
- have good relationships with friends and family
- have relationships that last
- have opportunities to develop experience and learn new skills
- have choices and control over life
- be afforded status and respect ... and ...
- be treated as an individual

Making friends, dating and forming long-term, meaningful relationships is just as important for adults with learning disabilities as it is for anyone else. Yet, a lack of awareness and understanding of this amongst the media and general public can lead to the view that people with learning disabilities don't need relationships.

Far from being an 'added bonus', building and sustaining meaningful bonds, whether they are friendships or romantic relationships, is an important need and a fundamental right. The chance to explore friendships and meaningful relationships has a dramatic impact on a person's quality of life, emotional support network and daily activities, and can result in better health and mental wellbeing.

Support workers have an important role to play in countering prejudice and helping people with learning disabilities to develop significant relationships. By taking time to understand how people communicate, listening to and understanding them, social care workers can help people to live happier, more fulfilling lives characterised by independence, social interests, friendships and relationships. They see first-hand how people can suffer from isolation and frustration when they're not given the right opportunities.

This is part of a much wider issue: the right to choose how to live, and the lack of choice and individuality that still affects the 1.14 million people living with learning disabilities in England. However, improving opportunities to meet, socialise with, get to know and build lasting, meaningful relationships with others is an important step and one that support workers can have a huge impact on.

Duty of care

It is often tricky for support workers to know how far they can, or even should, be involved in monitoring the new friendships and relationships those in their care are forming. The line between respecting privacy and failing to prevent harm is a fine line, and knowing when to cross it is vital in all care settings.

To deal with these issues, all organisations with a duty of care should provide appropriate training and support for social workers and support workers in how to navigate this blurred line and ensure that people's rights are fully protected. With regards to identifying potential threats, there should be clear guidelines and training given to carers and families on how to spot 'false friends' or possibly exploitative situations, and how they can be prevented or sensitively handled if they should arise.

Time for change

Increasing independence for adults with learning disabilities relies on longer-term care planning, promoting a better quality of life at all levels of the social care system and changing public perceptions. The shift away from institutionalised care settings towards more independent living arrangements has helped this and encourages greater social interactions. Yet, this is still only happening on a small scale and hasn't gained the political support it needs.

As part of this shift, it's vital for support workers to understand their wider role in aiding people with learning disabilities to form and sustain fruitful and safe relationships, knowing when to raise the alarm when needed but also when to simply respect their need to form and develop relationships without the added pressure of public stigma

1.2 Understand how to enable the individuals you support to engage in different types of relationships of their choosing

Engagement in a full range of typical activities is part and parcel of such a lifestyle. Basic requirements for a full life are the opportunities to:

- participate in the full range of activities that everybody else does
- be involved and share interests with other people ... and ...
- develop relationships, skills, and experience.

When a person is not able enough to do typical activities independently, he or she will need support to do them.

Active Support is required to make sure that people who need support have the chance to be fully involved in their lives and receive the right range and level of support to be successful.

Interaction to Promote Participation. People who support the individual learn how to give him or her the right level of assistance so that he or she can do all the typical daily activities that arise in life.

Activity Support Plans. These provide a way to organise household tasks, personal self-care, hobbies, social arrangements and other activities which individuals need or want to do each day and to work out the availability of support so that activities can be accomplished successfully.

Keeping Track. A way of simply recording the opportunities people have each day that enables the quality of what is being arranged to be monitored and improvements to be made on the basis of evidence.

Each component has a system for keeping track of progress, which gives feedback to the staff team and informs regular reviews.

1.3 Know how to support individuals to maintain their chosen relationships

What are the things that people with learning disabilities may need support for?

Each person will need different support for the things that are important to them in their life and central to this will be:

- leading an ordinary life
- having friends and a social life
- being independent
- spending time doing worthwhile things
- staying healthy and safe
- finding and keeping a job or volunteering
- keeping a home
- being supported with tenancy rights and responsibilities

Families' situations

Every family is different. You may have other people to support (e.g. elderly relatives); your extended family may live a long way away or close by; they may be helpful or not so helpful. But you can adjust this

Guide to own situation: the idea of personalised support and personal budgets is that they fit around peoples circumstances.

As a family member, they are always trying to strike a balance between leading their own life and being there for your relative. The balance varies from each individual to the next – but you need to feel comfortable about the decisions made.

Whoever provides paid support is replacing support formerly provided not only by care services (respite, residential, etc.), but also by family members. It is likely that families will remain an important part of the individuals support network even when they move into their own house or flat. This means individuals need support staff who share your values

1.4 Know how to support individuals to make choices in their relationships

If a care staff member or professional has a query regarding a personal or sexual relationship for an adult who has a learning disability, it is important that they document their thought processes and everything they observe. For instance in making choices, these issues must be clarified:

- Is the person safe to be left where they are?
- Why is the care staff member or professional querying the situation?
- Who is involved?
- Is this the first time that this query has been raised?
- What are the risks?
- Is consent clear?
- Is capacity an issue?
- What are the future implications for the situation (for example, pregnancy, sexually transmitted disease)?
- Are there any signs of distress, changes in personality or any physical marks indicating struggle?

Some learning disabilities are diagnosed at birth, such as Down's syndrome. Others might not be discovered until the child is old enough to talk or walk.

Once the individual is diagnosed with a learning disability, their GP can refer to any specialist support the individual may need. The individual will begin to get to know the team of professionals who will be involved in their care.

Support from professionals – including GPs, paediatricians, speech and language therapists, physiotherapists and educational and clinical psychologists – is available to help individuals live as full and independent a life as possible

1.5 Know where to access specialist advice and information to support an individual in their relationships

An **individual** is someone requiring care or support

Others may include:

- family
- advocates
- professionals
- others important to the individual's well-being

CHILDREN

If you think a child is being bullied but they won't talk to you about it, you could suggest they speak to another relative or a teacher at school that they trust. They can also contact a confidential helpline or visit Bullying Online, who also offer help to parents, pupils and teachers.

- **Childline**
- **Kidscape**

SEX AND RELATIONSHIPS

For many parents, talking to their son or daughter about sex and relationships can be difficult, and even embarrassing.

It can be very hard to let go of a young person and let them get involved in an adult relationship – and if a young person has a learning disability, you may be especially concerned about how they will cope with the emotional and physical aspects of a romantic relationship.

However, even with support, many people with a learning disability will face obstacles in their relationships. Things other couples take for granted, such as going out on dates, spending time alone and living together may be difficult, and your son or daughter may require extra help from the people that support them. If you think your child would like to get more information on sex and contraception, they can get free confidential advice from Brook. The **Family Planning Association (FPA)** also has information on sex and sexual health, and runs Speakeasy training courses for parents and carers on how to talk to young people about sex and sexuality.

FPA sexual health training programme

FPA delivers a training programme to support adults and young people with learning disabilities to understand sexual health issues.

MARRAGE

Someone with a learning disability who has met someone they care about, or been involved in a long-term relationship, may want to consider getting married and having a family at some stage in their life.

Legally, someone with a learning disability has the same rights as anyone else to live with someone and get married, provided they are over 16, able to give their consent and understand what marriage is.

Married life can bring with it lots of happiness, companionship and shared experiences. However, it can also bring a lot of pressure for someone with a learning disability. Couples may need extra

support if they decide to live together, and getting married may have a financial impact on the benefits they receive.

They may also need extra emotional support and advice, particularly to do with issues surrounding contraception and pregnancy, and starting a family. Many people with a learning disability are capable of raising children and becoming good parents, providing they receive the right help and advice

RELATIONSHIP GUIDANCE

What can be expected in Relationship Counselling?

Counselling can take place in a number of ways at a time to fit in with your life. Face-to-face counselling is available. It may be decided to come to counselling with together or alone. Or it might have a combination of solo and couple sessions.

How can Relationship Counselling help?

It really depends what is wanted out of it, but it's rare that people leave counselling without feeling a positive change. For some people, a transformation in their relationships and their lives; for others we help them solve a specific problem and move forward with more confidence and less anxiety.

1.6 Understand your role in supporting individuals through experiences of loss

Learning Disabilities and Bereavement

Introduction

If you are caring for someone who has learning disability, they will need extra support should they experience a major personal loss, such as bereavement. As with most of us, such a loss will have an impact on their lives, and it is important that it is handled sensitively. The extent of the impact of the loss could be missed because of a limited ability to express feelings. They will need help to express their feelings and emotions and to come to terms with their loss. How we mourn will often depend on how close we were to the one who has died. For the person with learning disability, the extent and expression of grief will also relate to the extent of their dependence and their personality. A past history of depression, or other losses can make someone particularly vulnerable.

Understandably, you may want to protect them from experiencing the pain of their grief. However, it is important to recognise and acknowledge their feelings and not underestimate their capacity to mourn. Clear communication, giving all the available information and not concealing anything through fear of disturbed behaviour is important. If there are addition

physical special needs or disability such as blindness, lack of speech or paralysis, then they will be even more dependent on whoever is caring for them. The death of the carer could mean that they may have to move and be subjected to living in alien surroundings, with strange smells, textures, lights, with strangers feeding them, hearing unfamiliar voices and being touched by unknown hands.

Clues to Unresolved Grief

There are several aspects of behaviour, which may be a pointer towards unresolved grief. These include sudden changes in mood and behaviour. They may be unable to speak of their loss without intense emotional reactions such as crying or shouting, or other indications of anger, such as verbal or physical aggression. The theme of loss may tend to recur frequently in conversation, and minor events can trigger a fresh grief reaction. Some people may cling to the possessions of the person they have lost and be distressed if they are taken away. They may isolate themselves socially and stop joining in activities, which they usually enjoy. They may show a personality change and develop depression, anxiety, or lose touch with reality. Challenging behaviour in the form of verbal or physical aggression, apathy or regression (like bedwetting, soiling, smearing of faeces) can occur. Some symptoms of unresolved grief require specialist help. These include self-injury, severe eating or sleeping problems or becoming mute. Should you be concerned about such behaviour, then it would be wise to get some help.

General Principles

S Be *sensitive* and supportive

H Be *honest* with yourself and the person with the learning disability

A Be *aware* of, and acknowledge and individual's emotions

R *Respect* the individual's wishes

E *Empathy*

Practical Recommendations

What can families do?

- Try to communicate clearly and honestly about the impending loss. It can be hard to deal with your own painful emotions, and as a result it can be difficult to talk.
- If possible try to arrange visits to the dying person. This will allow some preparation for the impending death and can help them start to come to terms with their loss.
- When opportunities arise, try to encourage discussions about life and death. The way a death is handled in TV soaps can prove a useful talking point in helping someone to understand the meaning of loss and the painful emotions that accompany it.

- Find out what they know or understand, and offer the opportunity for their questions to be answered.

What can staff do?

There are things that staff in day and residential settings should do in addition to the recommendations listed above for families.

- Be aware when a resident is about to lose a loved one and try to anticipate his or her reaction to the loss.
- Communicate clearly and truthfully with the resident about the impending death, with the help and permission of the family.
- Recognise that people get attached to one another in group homes or at day centres. Any impending loss of a friend should be communicated as soon as the information is common knowledge.
- If staff are worried about a resident's ability to cope with bad news, seek support from colleagues.
- Staff should be aware of their own feelings, and seek advice at an early stage from colleagues. This will help staff who are supporting a resident who is facing an impending loss.

During Bereavement and Loss

What can Families and Staff do?

- Bereavement and loss within a family is a very traumatic period for everyone. A person with learning disability will sense this loss and the accompanying emotions.
- Communicate clearly and honestly about the loss of the loved one or any other significant person in their life. Sometimes inappropriate links can be made with a long-term problem and excessive pressure brought to change behaviour, i.e. 'Now mum has died you must not wet your bed anymore'; or 'Now mum has died, you must learn to feed yourself/dress yourself.' 'Now dad has died, you must be the man of the house and help your mother'. These sorts of pressures will add to their unhappiness and worries.
- Use clear language when giving the news of a loss. Try to avoid euphemisms like 'He has gone to a better place', or 'She has gone to sleep'. This adds to confusion and delays the mourning process. Be aware that they may think that the disappearance of their loved one may be as a result of them being difficult.

- Do not withhold news of death for fear of difficulties in managing emotional expressions of anger or sadness. Neither should the truth be withheld because of a fear that they will not understand.
- Respect, comfort and listen. Encourage them to cry and to show appropriate emotions openly. Like anyone else who is grieving, they will want to talk over again and again about what has happened and how they feel.
- Do not try to jolly them along in an effort to make them feel better.
- If possible allow them to be involved from the very beginning when funeral arrangements are made. If possible make arrangements for them to attend the funeral and partake in the rituals. Being able to experience what happens; to see other people showing emotions; to touch the coffin; take flowers and to say goodbye can greatly help them mourn.
- If they are left alone in the family home by the death of the main carer, try to support that person at home in the early stages of grief, even if he or she will be resettling in new surroundings later. This can be achieved by health and social services staff and relatives liaising closely. Helping a person to stay on at home provides space and time to start the grieving process in his or her own surroundings.

After Bereavement and Loss

What can Families Do?

- Be aware of a grieving person's feelings at birthdays, Christmas or the anniversary of a death. One way to respect and acknowledge these feelings is by arranging visits to a cemetery or other place associated with the loved one.
- Watch for signs of delayed or prolonged mourning. If these signs are detected, approach your general practitioner or social services. Unresolved grief needs specialist help.
- If your husband, wife or partner dies and you are now caring alone for someone with learning disability and experiencing difficulties approach your GP. They can help in finding respite care, and/or day care tailored to the needs of the family.
- There is a tendency for persons with learning disability to blame himself or herself for the loss of the loved one. This may manifest itself in depression, guilt, anger or problem behaviours. Be aware of this and help them through by comforting them, listening and offering reassurance. If you experience difficulties handling this situation approach professional or staff at Day Centres.

- They may cling to other family members for fear of losing them after the loss of a loved one. Be aware of this possibility and help the person to express their feelings so that you can reassure them.
- Whenever possible, try to talk about the loss to the bereaved individual. Photographs and videos and books like *When Dad Died* or *When Mum Died* are extremely useful in helping people to express their emotions. Other methods are making a life book and personal album using photographs, drawings and cuttings.
- Helping someone who is grieving can pose a major problem when they have multiple physical and sensory handicaps. Profound physical and sensory disability may make it difficult for them to understand verbal explanations of loss. Physical touch and cuddles can be extremely comforting. The touch or smell of items, such as blankets, rings or watches used by the person who died, may help to bring them back to mind and these should be made accessible.

What Can Staff Do?

- Follow all recommendations to the families in the previous section.
- Be aware of any sudden change in mood, behaviour, eating and sleeping habits. These could all relate to grief reaction. If these symptoms are prolonged, delayed or intense, contact professionals for advice and management.
- Try to arrange a group of fellow residents who have suffered a similar loss. This may help them to express their feelings. Involve carers and friends in what you are doing, as this will give them the opportunity to discuss any issues raised between the group sessions.
- Arrange visits to the dead person's family on anniversaries and birthdays, or invite family members in on these occasions. Encourage them to talk about the dead person.
- Be aware that mourning is not a brief process. It may take a long time for the person with learning disability to work through feelings of loss.

Try to maintain a normal lifestyle for the bereaved person during the mourning process, as this helps to minimise feelings of loss.

1.7 Recognise the risks and feelings created by power imbalances in your and other relationships with the individuals you support

A consistent theme in the literature is the value of identifying factors that indicate an increased risk of abuse among adults at risk in the interests of prevention; Identifying risk factors can help to prevent abuse by raising awareness among staff and service managers of the people in their care who may be most at risk of abuse. If staff are aware of risk factors, they can use these insights to develop effective risk assessments and prevention strategies.

The worker–client relationship is professional and therapeutic. It ensures the client’s needs are first and foremost. It exists to meet the needs of the client, not the needs of the worker. It is always the worker who is responsible for establishing and maintaining boundaries with clients, regardless of how the patient behaves.

There are five components to the worker–client relationship: trust, respect, professional intimacy, empathy and power. Regardless of the context, length of interaction and whether a worker is the primary or secondary care provider, these components are always present.

Trust. Trust is critical in the worker–client relationship because the client is in a vulnerable position. Initially, trust in a relationship is fragile, so it’s especially important that a worker keep promises to a client. If trust is breached, it becomes difficult to re–establish.

Respect. Respect is the recognition of the inherent dignity, worth and uniqueness of every individual, regardless of socio–economic status, personal attributes and the nature of the health problem. Professional intimacy. Professional intimacy is inherent in the type of care and services that workers provide. It may relate to the physical activities, such as bathing, that workers perform for, and with, the client that creates closeness. Professional intimacy can also involve psychological, spiritual and social elements that are identified in the plan of care. Access to the client’s personal information also contributes to professional intimacy.

Empathy. Empathy is the expression of understanding, validating and resonating with the meaning that the health care experience holds for the client. In nursing, empathy includes appropriate emotional distance from the client to ensure objectivity and an appropriate professional response.

Power. The worker–client relationship is one of unequal power. Although the worker may not immediately perceive it, the worker has more power than the client. The worker has more authority and influence in the health care system, specialized knowledge, access to privileged information, and the ability to advocate for the client and the client’s significant others. The appropriate use of power, in a caring manner, enables the worker to partner with the client to meet the client’s needs. A misuse of power is considered abuse.

1.8 Understand how to enable individuals you support to recognise potentially or actually abusive behaviour in any of their relationships

Recognising adult abuse

Abuse of vulnerable adults can occur in many different forms in our society. The information on this page will help you to recognise the signs of abuse. If you suspect someone is being abused, you should report it as soon as possible.

Who is a vulnerable adult?

A vulnerable adult is any person aged 18 years or over, who is, or may be, unable to take care of themselves or are unable to protect themselves against significant harm or exploitation. This may be because they have a mental health problem, a disability, visual or hearing problems, are old and frail or have some form of illness.

Why do we need to protect vulnerable adults?

Vulnerable adults have the right to live their lives free from abuse. Everyone should treat vulnerable people with respect and dignity. They should be able to choose how to live their lives independently, and receive support in doing this.

What is adult abuse?

Abuse is a violation of a person's human and civil rights by any other person. Abuse can take many forms:

- Physical abuse:
- hitting
- slapping
- pushing
- kicking
- burning
- giving medication that may harm
- disciplining in an inappropriate way

Possible signs:

- fractures
- bruising
- burns
- pain

- marks
- not wanting to be touched

Psychological abuse:

- emotional abuse
- verbal abuse
- humiliation
- bullying
- the use of threats

Possible signs:

- being withdrawn
- too eager to do everything they are asked
- showing compulsive behaviour
- not being able to do things they used to
- not being able to concentrate or focus

Financial or material abuse:

- stealing from the person
- cheating them
- using them for financial gain
- putting pressure on them about wills, property, inheritance or financial transactions
- misusing or stealing their property, possessions or benefits

Possible signs:

- having unusual difficulty with finances
- not having enough money
- being too protective of money and things they own
- not paying bills
- not having normal home comforts

Sexual abuse:

- direct or indirect sexual activity where the vulnerable adult cannot or does not agree to it

Possible signs:

- genital itching, soreness or having a sexually transmitted disease
- using bad language
- not wanting to be touched
- behaving in a sexually inappropriate way
- changes in appearance

Neglect or acts of omission including:

- withdrawing or not giving the help that a vulnerable adult needs, so causing them to suffer

Possible signs:

- having pain or discomfort
- being very hungry, thirsty or untidy
- failing health

Discriminatory abuse including:

- abusing a person because of their ethnic origin, religion, language, age, sexuality, gender or disability

Possible signs:

- the person is not receiving the care they require
- their carer is over critical or makes insulting remarks about the person
- the person is made to dress differently from how they wish

Institutional abuse:

- abuse or mistreatment by an organisation or by any individual within a building where the the person is living or receiving care

Possible signs:

- the person has no personal clothing or possessions
- there is no care plan for them
- he or she is often admitted to hospital
- there are instances of professionals having treated them badly or unsatisfactorily or acting in a way that cause harm to the person

**The above is only a guide and you should not consider it a complete list of forms or signs of abuse*

Guidance for members of the public and staff working with vulnerable adults is available to download at the following links.

- Guidance for members of the public on recognising adult abuse (PDF 3.4 MB)
- Guidance on recognising adult abuse for staff working with vulnerable adults (PDF 2.5 MB)
- Help with PDF files

Standards and guidance for organisations working with vulnerable adults in the voluntary, community and independent sectors is also available to download from the Volunteer Now website.

How might you become aware of abuse?

- you may see or hear something
- a vulnerable adult may tell you about apparent abuse
- a friend, family member or somebody else may tell you something that causes you concern
- you may notice injuries or physical signs that cause you concern
- you may notice either the victim or abuser behaving in a way that alerts you that something may be wrong

Who do you contact if you suspect abuse?

- if you ever feel in immediate danger or think someone else may be in immediate danger, dial 999
- if you suspect abuse it is important that you report your concerns to your local social services office or the police

1.9 Where abusive behaviour has been identified, understand how to support an individual to access or use services designed to keep them safe

Providing Community Care Services – Local Authority, NHS and Independent Care Organisations
Numerous organisations will be involved in the provision of direct support services to help people with daily life. This support includes residential and day services, supported living schemes and individual personal assistants secured through self-directed care packages or Direct Payments.

Each organisation has a responsibility to ensure that they provide a fear free environment, which ensures the safety and well-being of those using the service. Their responsibilities also include investigating any complaints and reporting concerns or allegations about abuse to social services. Each provider organisation is expected to have its own internal guidelines on adult protection and these guidelines should be consistent with local multi-agency safeguarding or vulnerable adults' policies and procedures (see below). • Providing Specialist Health and Social Care Support and Advice

This specialist provision encompasses professional groups such as social workers, nurses, care managers, psychologists, speech and language therapists, occupational therapists and physiotherapists. Their roles are to provide services, both directly or through the care management processes of assessment, care planning and reviewing. Such services promote the health and well-being of people with learning disabilities.

With regard to adult protection, health and social care practitioners are well placed to identify individuals who may be at risk or who are at risk of harming others and to recognise failing services and uncover evidence of actual abuse. They then have a responsibility to report these issues and seek protective responses where necessary

1.10 Understand how power can be used as a positive or negative influence in a relationship

Cultivating a positive attitude

Is the glass half empty or half full? Research has shown that having a positive attitude affects our overall health and success. Developing a positive attitude takes time, practice and commitment. How you view your disability can influence your self-esteem and self-confidence. People with disabilities may have negative experiences going through school, mainly from individuals who do not understand their learning needs. It is important to take time to talk with professionals, family and friends about your initial and ongoing feelings about having a disability. Others may help to address any negative feelings you may have, affirm your strengths, value your differences and identify some positive aspects of having a disability.

One important skill to develop involves rethinking any negative labels that you have come to believe about yourself. This involves teaching yourself to focus on the positive or look at things more optimistically. Successful people with disabilities are able to restate negative qualities or characteristics related to their disability in positive ways. Here are some examples of how that can be done.

NEGATIVE LABELS	POSITIVE RETHINKING
Bossy	Leader
Strong-willed	Tenacious
Failure	Learns from mistakes
Questions authority	Independent thinker
Day dreamer	Imaginative
Hyperactive	High energy

Successful people with disabilities also build a resilient and perseverant attitude in overcoming obstacles. Using a different method to get a job done is perfectly acceptable and often necessary when you have a disability. Solving potential problems takes personal creativity and sometimes connecting with professionals who have knowledge in specific areas. Being resourceful and

Negative difficulties of people with learning disabilities

Shame

People growing up with a learning disability often feel a sense of shame. For some, it is a great relief to receive the diagnosis while for others the label only serves to further stigmatize them. For many adults, especially older adults, an accurate diagnosis was unavailable. These individuals were frequently labelled as mentally retarded, written off

as being unable to learn, and most passed through the school system without acquiring basic academic skills.

Sadly, these feelings of shame often cause the individual to hide their difficulties. Rather than risk being labelled as stupid or accused of being lazy, some adults deny their learning disability as a defence mechanism. Internalized negative labels of stupidity and incompetence usually result in a poor self-concept and lack of confidence. Some adults feel ashamed of the type of difficulties they are struggling to cope with such as basic literacy skills, slow processing, attention difficulties, chronic forgetfulness, organizational difficulties, etc.

The following myths about learning disabilities have perpetuated the general public's negative perception about learning disabilities:

Fact

People with learning disabilities have average to above average intelligence. In fact, studies indicate that as many as 33% of students with learning disability are gifted.. With proper recognition, intervention and lots of hard work, children and adults with learning disabilities can learn and succeed!

Myth

Learning disabilities are just an excuse for irresponsible, unmotivated or lazy people.

Fact

Learning disabilities are caused by neurological impairments not character flaws. In fact, the national information centre for adults and youth with disabilities makes a point of saying that people with learning disabilities are not lazy or unmotivated

Myth

Learning disabilities only affect children. Adults grow out of learning disabilities.

Fact

It is now known that learning disability continues throughout the individual's lifespan and may even intensify in adulthood as tasks and environmental demands change. Sadly, many adults, especially older adults, have never been diagnosed with a learning disability. In fact, the majority of people with learning disabilities are not diagnosed until they reach adulthood.

Myth

Dyslexia and learning disability are the same thing.

Fact

Dyslexia is a type of learning disability. It is not another term for learning disability. It is a specific language based disorder affecting a person's ability to read, write and verbally express themselves. Unfortunately, careless use of the term has expanded it so that it has become, for some, an equivalent for "learning disability".

Myth

Learning disabilities are only academic in nature. They do not affect other areas of a person's life.

Fact

Some people with learning disabilities have isolated difficulties in reading, writing or mathematics. However, most people with learning disabilities have more than one area of difficulty. It is asserted that "learning disabilities are life disabilities", the same disabilities that interfere with reading, writing, and arithmetic also will interfere with sports and other a learning disability have other major difficulties in one or more of the following areas:

- Motor coordination
- Time management
- Attention
- Organizational skills
- Processing speed
- social skills needed to make friends and maintaining relationships
- emotional maturation
- verbal expression
- memory

Many adults with learning disabilities have difficulty in performing basic everyday living tasks such as shopping, budgeting, filling out a job application form or reading a recipe. They may also have difficulty with making friends and maintaining relationships. Vocational and job demands create additional challenges for young people with learning disabilities.

Myth

Adults with learning disabilities cannot succeed in higher education.

Fact

More and more adults with learning disabilities are going to college or university and succeeding. With the proper accommodations and support, adults with learning disabilities can be successful at higher education.

2. Fear

Another emotional difficulty for adults with learning disabilities is fear. This emotion is often masked by anger or anxiety. Tapping into the fear behind the anger and/or the anxiety response is often the key for adults to cope with the emotional fallout of learning disabilities.

Feelings of fear may be related one or more of the following issues:

- Fear of being found out
- Fear of failure
- Fear of judgment or criticism
- Fear of rejection

Fear of being found out

Many adults with learning disabilities live with fear of being found out. They develop coping strategies to hide their disability. For example, an adult who can hardly read might pretend to read a newspaper. Other adults may develop gregarious personalities to hide their difficulties or focus on other abilities that do not present learning barriers. Unfortunately some adults will have developed negative strategies such as quitting their job rather than risking the humiliation of being terminated because their learning disability makes it difficult for them to keep up with work demands.

The fear of being found out is particularly troublesome for many older adults who have never been diagnosed with a learning disability or those who received inappropriate support. Such adults were frequently misdiagnosed with mental retardation, inappropriately placed in programs for the mentally disabled, and/or stigmatized by teachers and classmates. In later life, these adults often return to learning through adult literacy programs in order make up for lost educational opportunities. Seeking help is a difficult step forward for these adults because it requires them to stop hiding their disability. The simple act of entering a classroom can be an anxiety producing

experience for adults who have been wrongly labelled and/or mistreated by the educational system. For these adults, returning to a learning environment is truly an act of courage!

Low literacy skills and academic difficulties are not the only type of learning disabilities adults try to hide. Adults with social skill difficulties may live in constant fear of revealing social inadequacies. For example, an adult who has trouble understanding humour, may pretend to laugh at a joke even though they don't understand it. They may also hide their social difficulties by appearing to be shy and withdrawn. On the other hand, hyperactive adults may cover up their attention difficulties by using a gregarious personality to entertain people.

Fear of failure

The national adult literacy survey, 1992, found that 58% of adult with self-reported learning disabilities lacked the basic functional reading and writing skills needed to experience job and academic success. Most of these adults have not graduated high school due to the failure of the school system to recognise and/or accommodate their learning disability. Needless to say, adult literacy programs are a second chance to learn the basic academic skills missed out in public school. As mentioned above, going back into an educational environment is often a fearful experience for adults with learning disabilities. One of the main reasons for this is the fear of failure. Many adults reason that, if they have failed before, what is to stop them failing again and, if they do fail again, then this failure must mean they, themselves, are failures.. The tendency for adults with learning disabilities to personalize failure (i.e. Failure makes me a failure) is perhaps the biggest self-esteem buster for adult learners. Educators need to be aware of these fears to help learner's understand that failure does not make them a failure and making mistakes is a part of the learning process.

For most people, anxiety about failing is what motivates them to succeed, but for people with learning disabilities this anxiety can be paralyzing. Fear of failure may prevent adults with learning disabilities from taking on new learning opportunities. It might prevent them from participating in social activities, taking on a new job opportunity or enrolling in an adult education course.

One positive characteristic that often helps adults overcome their fear of failure is their ability to come up with innovative strategies to learn and solve problems. These strategies are often attributed to the "learned creativity" that many adults with learning disabilities develop in order to cope with the vocational, social and educational demands in their everyday lives.

Fear of ridicule

Adults with learning disabilities frequently fear the ridicule of others. Sadly, these fears often develop after the individual has been routinely ridiculed by teachers, classmates or even family members. The most crushing of these criticisms usually relates to a perceived lack of intelligence or unfair judgments about the person's degree of motivation or ability to succeed. For example, comments such as you'll never amount to anything, you could do it if you only tried harder, or the taunting of classmates about being in the mental retard class have enormous emotional effects on individuals with learning disabilities. For many of these adults, especially those with unidentified learning disabilities, these and other negative criticisms, continue to affect their emotional well-being into their adult years. It is not uncommon for adults to internalize the negative criticisms and view themselves as dumb, stupid, lazy, and/or incompetent. Such negative criticisms often fuel the fear adults with

Fear of rejection

learning disabilities have about being found out.

Adults with learning disabilities frequently fear rejection if they are not seen to be as capable as others. If they come from a middle to upper class family where academic achievement is a basic expectation for its members, fear of rejection may be a very real concern. They may also fear that their social skill deficits will preclude them from building meaningful relationships with others and may lead to social rejection. Prior experiences of rejection will likely intensify this sense of fear.

3. Environmental and emotional sensitivity

Environmental sensitivities

Adults are often overwhelmed by too much environmental stimuli (e.g. Background noise, more than one person talking at a time, side conversations, reading and listening at the same time). Many people with Id and add have specific sensitivities to their environment such as certain fabrics they cannot wear, foods they cannot tolerate, etc.

Emotional sensitivity

Many adults with learning disabilities see themselves as more emotionally sensitive than other people in its most extreme form, high levels of emotional sensitivity are both a blessing and a weakness. The positive features of this trait helps adults with learning disabilities build meaningful relationships with others. For example, they are often very intuitive and in-tune with both their own and other people's emotions. Sometimes they are actually

able to perceive other's thoughts and feelings. However, this strength also serves as weakness due to its propensity to overwhelm the individuals. Emotional difficulties occur when they are unable to cope with the onslaught of emotions they are feeling. Highly sensitive adults with Id may be moved to tears more easily or feel their own and other people's pain more deeply.

4. Emotional regulation

Difficulties with regulating emotions are common for highly sensitive adults with learning disabilities. It has been described as the connection between learning disabilities and self-regulation problems in her paper "self-regulation and sensory processing for learning, attention and attachment. "She asserts that self-regulation problems frequently occur in those with learning disabilities, in its most extreme form, individual may easily shift from one emotion to the next. Others may experience difficulty regulating impulsive thoughts or actions.

Fortunately, most adults have learned to handle their emotional sensitivity to avoid becoming overwhelmed or engaging in negative social interactions. Nevertheless, some adults may be so deeply affected that they become depressed or suffer from anxiety. A lack of school, job and/or social success will likely add to this emotional burden. Some adults with Id, especially those who have been ridiculed by their family members, teachers and/or peers, may be more apt to take criticism to heart because of their experiences and/or their ultra-sensitive nature. Emotional wounds from childhood and youth may cause heightened emotional responses to rejection. In turn, social anxiety and social phobia may result

5. Difficulty adjusting to change

Change is scary for everyone, but for people with learning disabilities and other neurological disabilities, change may be particularly difficult. Children with learning disabilities may prefer procedures to stay the same and have a hard time moving from one activity to another. Usually this difficulty becomes less of an issue as the child matures. However, adults with learning disabilities may still experience difficulty adjusting to change in more subtle ways. For example, some adults will have trouble moving from one work task to another without completely finishing the first task before moving on to the next one. Adults with learning disabilities are frequently described as inflexible when it comes to considering another person's view point or a different way of doing something.

Adjustment to change is difficult for adults with Id because change brings the unexpected. In general, people with learning disabilities are less prepared for the unexpected. The unexpected may bring new learning hurdles, new job demands or new

social challenges. Since all these areas can be affected by learning disabilities, it is no wonder why change can produce so much anxiety for adults with learning disabilities.

To avoid the tendency to blame the person for their lack of flexibility, it is important to understand the neurological basis for this difficulty with adjusting to change. With this said, through social skills practice, adults with learning disabilities can improve their ability to tolerate change. In addition, parents, instructors, and other professionals can help adults with learning disabilities by making transition processes easier through understanding and accommodating the adults' needs.

1.11 Understand your responsibilities and role within the local safeguarding systems

Purpose

- To ensure that abuse of Service Users rights is avoided.
- To comply with the Independent Safeguarding Authority (ISA) requirements.
- To comply with the guidelines contained in the publication “No Secrets.”
- To comply with the Protection of Children (Scotland) Act 2003 (PoCSA).
- To comply with Regulation 18 of the CQC (Registration) Regulations 2009
- Ensure awareness of wider safeguarding powers

Scope

- All workers.

Important note: Where reference is made to the Independent Safeguarding Authority (ISA) reporting processes and requirements, be aware that the following policy and procedure is generic, and intended to set out general principles and courses of action where no local guidelines apply. If your Local Authority area publishes a local set of guidelines on Adult Abuse Reporting, those local guidelines must take precedence over this policy. You should obtain a copy of the local guidelines and attach a copy to this policy in the manual. The contact details for your local Adult Protection team is as follows: Somerset County Council County Hall TAUNTON Somerset TA1 4DY

You should contact this number if you need to report any actual or suspected case of abuse.

Policy for preventing persons barred from working in the care sector from being offered employment as a support worker:

REFERRAL PROCEDURE

The first priority should always be to ensure the safety and protection of vulnerable adults and if medical attention is required this must be sought immediately.

- **Report**

- ÷ It is the responsibility of everyone to act on suspicion or evidence of abuse or neglect (see Public Interest Disclosure Act 1998 and in-house procedures) and refer to the local Social Services Adult Protection Team.

- **Lead Responsibility**

- ÷ The local Social Services Adult Protection Team will take the lead and be responsible for managing the process by establishing the facts of the case, identify those that need to be involved and coordinate the response.

- **Consult with the Police**

- ÷ When complaints about alleged abuse suggest that a criminal offence may have been committed it is imperative that reference should be made to the police as a matter of urgency. The CQC must also be notified. Early referral or consultation with the police will enable them to establish whether a criminal act has been committed and this will give them the opportunity of determining if, and at what stage they need to become involved. Early involvement of the police will help ensure that forensic evidence is not lost or contaminated and this may prevent the abused adult being interviewed unnecessarily on subsequent occasions. Notification of the Police may be done either by the referring individual/agency or by the local Social Services Area Team. This will be dependent upon the information received at the initial point of concern and following any subsequent preliminary enquiry, and at what point the lead agency was alerted. To prevent any possibility of failure to alert the police at the proper time the person/agency making the referral should identify whether or not the police have been informed. When Social Services receive the initial referral they will identify and record whether or not the police have been informed. Constabularies have Family Protection officers whose role it is to investigate allegations of the abuse of Vulnerable Adults where the person responsible is a family member or in a position of care. Where the person responsible is not a family member or Support Worker or Carer or where the reported incident is one of financial abuse, then the matter will be investigated by local officers. Criminal investigation by the police takes priority over all other lines of enquiry; however, police investigations may proceed alongside those dealing with health and social care issues.

- **Notes:**

- In some areas the Police have determined that Providers must carry out an initial investigation before referral, in order to avoid the Police becoming involved in large numbers of investigations of reports which prove to be groundless. Check your local policy.
- In some areas, the Police demand that their investigation takes precedence over internal disciplinary procedures of the employer. However, the employer is entitled, indeed obliged, to take such action as may be necessary to safeguard the wellbeing of Service Users, wherever they may be being cared for. This may include dismissal and referral to appropriate agencies for banning from working with vulnerable people. It is unlikely that this responsibility is discharged simply by referral of the case to the Police.

- **Inform Inspection Unit**
 - By regulatory law service providers must notify the CQC without delay incidents of abuse and allegations of abuse, as well as any incident which is reported to or investigated by the police.
 - Service providers must notify the CQC about abuse or alleged abuse involving a person(s) using the service, whether the person(s) are the victim(s), the abuser(s), or both. Please refer to the Essential standards of quality and safety for information about what must be notified in relation to abuse.
 - Service providers must also alert the relevant local safeguarding authority when notification is made to the CQC about abuse or alleged abuse,
 - The forms are available on the CQC website.
 - The execution of the statutory responsibilities of the CQC relies on timely and considered intervention by their officers. It is therefore essential that enquiries into allegations involving residential, nursing or domiciliary care services are undertaken in collaboration with the appropriate inspectorate. The CQC must satisfy themselves that the local Social Services District Team is aware of incidents or allegations of abuse which come to the attention of the CQC from other sources.

- ÷ **Establish Working Arrangements**
 - ÷ The enquiry must take account of other agencies and identify those who need to be involved. Where there is a joint interest or responsibility an early agreement regarding lead responsibility and on working arrangements must be clarified. Where agreement cannot be reached or where difficulties are being experienced, the Social Services District Team Manager should be asked to obtain clarification at a senior level with the agencies involved.
- ÷ **Involve the Alleged Victim**
 - ÷ The process of the enquiries should be carefully explained to the allegedly abused person and their consent to proceed with the enquiry obtained if possible. Arrangements should be made to have a relative, friend or independent advocate present if the person so desires. The relative, friend or independent advocate should not be a person suspected of being in any way involved or implicated in the abuse.
 - ÷ A review of a service users Care Plan should be undertaken to ensure that they are properly supported following the alleged abuse incident and they should be supported by the service to take part in the safeguarding process to the extent to which they want or are able to do, or to which the process allows, and they are kept informed of progress.
- ÷ **Contact Advocacy Services**
 - ÷ See Advocacy Policy and Procedure, and the Complaints section of the Service User's Handbook for advocacy contacts.
 - **Bring in Specialist Skills**
 - ÷ Consideration must be given to enlisting the services or advice or personnel with specific skills or knowledge, particularly where people involved have limited communication skills, or where English is not their first language.

- **Coordinate**

- ÷ The Social Services District Team, as the lead agency, coordinating the response, must notify other agencies and identify those who need to be involved and ensure the following processes are addressed:
- ÷ Investigation of the incident using the guidance;
- ÷ Action to ensure immediate safety of the alleged victim;
- ÷ Early involvement of key agencies through a strategy meeting or discussion (by telephone if appropriate);
- ÷ Agreement with other agencies who should take the lead in the investigation;
- ÷ Assessment and Care Planning for the vulnerable person who has been abused;
- ÷ Action with regard to criminal proceedings;
- ÷ Action by employers, such as, suspension, disciplinary proceedings, use of complaints and grievance procedures and action to remove the perpetrator from the professional register;
- ÷ Arrangements for treatment or care of the abuser, if appropriate;
- ÷ Consideration of implications relating to regulation, inspection and contract monitoring;
- ÷ Appropriate measures to reassure and support carers and in keeping them informed;
- ÷ Development, implementation and monitoring of a Care Plan;
- ÷ Maintain appropriate records.

- **Investigation**

- ÷ For a variety of reasons, agencies other than the Police may need to conduct investigations into incidents of alleged abuse. This is because absence of (or insufficient evidence to substantiate) criminal activity cannot be taken as confirmation that abuse has not taken place. Investigation is a process that focuses on gathering “good evidence” that can be used as a basis for the decision whether or not abuse has occurred. It must be a rigorous process and the evidence must be capable of withstanding close scrutiny, as it may later be required for formal proceedings. Such proceedings may be against the perpetrator of the abuse or against other individuals or organisations in positions of responsibility and accountability. In these circumstances any decision made on the facts that arise from the investigation is made on the civil standards of proof i.e. on the balance of probabilities.

- **Case Conference**

- ÷ Following the investigation or if deemed necessary at any time during the process; it may be necessary to call a case conference involving all relevant agencies and parties. One of the purposes of the case conference would be to make multi agency decisions about future action to address the needs of the individual. An agency involved in the case may ask for a case conference to be held, although the final decision to call a conference rests with the Social Services District Team Manager.

- **Confidentiality**

- ÷ Reporting incidences of alleged abuse may involve disclosing confidential personal information. Organisations and their workers will need to make reference to their organisation’s information sharing policies to ensure they are aware in what circumstances information sharing with other agencies may be appropriate.

- ÷ The Data Protection Act makes important requirements about how information about individuals is stored 'processed' and shared, appropriate measure must be taken by the service to protect personal data. Notifications about individuals must not include their name or other details that a third party could use to identify them. Advice is to use codes instead of names, even where codes are used, they should not easily identify an individual such as room number or date of birth. A record of agreed codes should be established and kept secure, should the CQC require more information regarding an incident.
 - **Feedback**
- ÷ The accepted good practice concerning recording, minuting and circulation will be observed and The Social Services District Team Manager must ensure that feedback is given to the referring organisation and family as appropriate.
 - **General procedures for the prevention of abuse during employment:**
- ÷ The whistle blowing policy will be drawn to the attention of all employees during induction.
- ÷ Managers will ensure that they have a clear understanding of the contents of "No Secrets", the relevant documents published by the Dept. of Health.
- ÷ During induction training, all employees will complete the "Understanding Abuse" workbook, and have an opportunity to read "No Secrets".
- ÷ The person responsible for training new employees will verify that they have a clear understanding of the possible forms of abuse based on "No Secrets", their responsibility to prevent and report such abuse, and the avenues open to them for reporting.
- ÷ Allegations of abuse will be dealt with according to the procedures set out in "No Secrets".
- ÷ The Service Users' Finances Policy and Procedure will be made available to all employees during induction.
- ÷ All Service Users will receive a copy of the Service Users Handbook.
- ÷ Refer to the organisation's Complaints Policy and Procedure, Whistle-blowing Policy and Procedure and "No Secrets" for detailed procedures if allegations of abuse are made.
- ÷ Formal supervisions will take place at least every two months, and the results recorded (see Employee Supervision Policy and Procedure). The supervision format will ensure that employees are asked, at every instance of supervision, whether they have received a criminal conviction or warning, or notice of referral to the ISA register, which has not yet been declared to the employer.
- ÷ Complete the ISA Referral Form,
- ÷ A copy can also be found in the Abuse Reporting section of Useful Documents on your

REFERRAL TO THE INDEPENDENT SAFEGUARDING AUTHORITY

Ensure Safety Procedure for reporting suspected cases of abuse.

Implications for recruitment procedures:

OTHER SAFEGUARDING POWERS:

- The Mental Capacity Act 2005 provides a framework for adults who lack capacity.

- Safeguarding Vulnerable Groups Act 2006. The Sexual Offences Act 2003 outlines a number of offences where a person's choices about sexual activity may be affected by their mental disorder.
- The Law Commission has undertaken a consultation exercise on adult social care law including safeguarding powers.
- They are likely to recommend clarification of the existing legal position and establish a duty to make enquiries and take appropriate action in adult protection cases. Practitioners should be aware of possible changes to the law later in 2011.

2. Sexual relationships

2.1 Understand that sexual expression and privacy are rights of all adults

The term 'sexuality' means (in the broadest sense) 'the capacity for sexual feelings.'

The subject raises so many strong feelings in the context of people with Learning Disabilities Professional responsibility includes avoiding conflict between staff 'morality' and service users' needs

Human sexuality is the capacity to have erotic experiences and responses. A person's sexual orientation may influence their sexual interest and attraction for another person.^[1] Sexuality may be experienced and expressed in a variety of ways, including through thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships,^[2] which may manifest by way of biological, physical, emotional, or spiritual aspects. The biological and physical aspects of sexuality largely concern the reproductive functions of the sexes (including the human sexual response cycle),^[3] and the basic biological drive that exists in all species. Physical, as well as emotional, aspects of sexuality also include the bond that exists between individuals, and is expressed through profound feelings or physical manifestations of emotions of love, trust, and caring. Spiritual aspects of sexuality concern an individual's spiritual connection with others. Sexuality additionally impacts and is impacted by cultural, political, legal, and philosophical aspects of life. It can refer to issues of morality, ethics and theology, or religion.

Sexuality is a human need

Sexuality gives the individual self-esteem and intimacy

It is good practice to support service users in a range of sexuality related issues including:

- Same sex relationships
- Contraception
- Pregnancy
- Termination
- STI's
- Safer sex
- Marriage/partnerships
- Menstruation

- Cross dressing
- Personal intimate care
- Sexual Dysfunction
- Physical disabilities
- Medical conditions etc.

Common challenges include:

- Inappropriate touch
- Masturbation in public
- The use of Pornography
- Sex aids/toys
- Services of Sex Workers/Surrogates
- Offending behaviour
- ex tourism etc.

2.2 Understand your role and your boundaries in supporting individuals to develop sexual relationships if they choose to do so

The individual may have these questions:

WHO DO YOU ASK ABOUT SEX AND RELATIONSHIPS?

You can ask your support worker about sex and relationships. If they can't answer all your questions, they will find someone else to help.

WHAT ARE YOUR RIGHTS?

You have

- The same rights as people without learning disabilities of the same age
- The right to be treated with respect
- The right to find out about your body
- The right to a private and family life
- The right to get information about your body, your feelings, and the way to behave
- The right to make and break relationships
- The right not to be sexually abused
- The right to marry and start a family
- The right to explore your sexuality to decide if you are attracted to people of the same sex or of the opposite sex

GETTING THE INFORMATION YOU NEED

If you have any problems about sex and relationships, your worker should make sure you get the right help. Your worker may need help from other people to do this. When you get information, it should be given to you in a way you can understand. This may mean getting it on tape or on video or getting someone to spend extra time explaining things to you.

You should also know how to complain about things and have help to complain.

There is a list of places you can go to for help and more information at the back of this booklet.

You may need help to decide whether you want to have sex with someone and your worker should find the best person to help you with this decision.

KEEPING THINGS PRIVATE

Some things must be kept private.

You need to know what things can be kept private and what things can't. The person working with you must talk to you about this. If the person working with you has to tell someone about your private business, it will be because they are worried that you could be hurt. Your support worker must make sure that you know they are going to tell someone.

If you are unhappy about what your worker says to other people, you can complain. Ask your worker or someone you can trust about how to complain. If you don't live with your family you should be able to lock the door to your room and your worker should not come into your room without asking you if they can. Your worker should help you to have your friends round in private if you want to. If you have sex it must be in a private place. It is against the law to have sex in the street or somewhere like your work place. You could speak with your worker to find a private space if you need to find one. You may need help to decide whether you want to have sex with someone and your worker should find the best person to help you with this decision

KEEPING SAFE

Everyone has the right to feel safe. You may need to learn how to keep safe. Your worker will help you do this if you wish. If you don't feel safe you must have someone you trust to talk to. If someone is hurting you or you don't feel safe you must tell a worker. They must listen to you and respect what you say.

WHAT ABOUT YOUR FAMILY?

It is important that your worker listens to what your family says and makes sure they can get information and help if they feel they need it. However, remember you have the right to keep some things private from your family. If your worker thinks you might be harmed they have to tell someone. But they will always tell you that they are going to do this first.

If you are a woman you may need to find out about:

- Getting a smear test
- Finding out about having a baby
- Finding out how not to have a baby
- Checking your breasts for unusual lumps or bumps

If you are a man you may need to find out about:

- Checking your testicles for unusual lumps or bump
- How to have a baby with someone
- How not to have a baby with someone

Both men and women may need:

- Information about infections such as HIV, AIDS or Chlamydia, that can be caught by having sex with someone
- Help if they have sexual problems

INTIMATE CARE

If someone has to help you bath or help you when you go to the toilet, this should be done in private. If you have any special needs this can be written into your support plan which staff will follow

PORNOGRAPHY AND SEXUALLY EXPLICIT MATERIALS

If a book or dvd about sex can be bought or hired from a shop, you can ask for help to get them. Some people do not like pictures or videos about sex, so you will need to look at some things only at home in private.

You may need to ask your worker about looking for things on the Internet. You will only be able to do this on a computer and internet account that you own. Both of you will need to ask your worker's manager for advice about this as it is important to make sure you are safe on the Internet.

Some books, DVD's, and internet sites about sex are not allowed by law. Your worker will explain this to you and will not help you access them.

VERY IMPORTANT RULES

The person working with you must not be your girlfriend or boyfriend and they must not have sex with you. If you are having problems with the person working with you, it is very important to tell someone you trust. They will then make sure there is an investigation. Your worker cannot help you do anything that is against the law.

2.3 Know how to access advice on sexual safety

Talking to children about sex is a discussion most parents find difficult. Tricky at the best of times, embarrassing and disastrous at the worst. But when your child has learning disabilities, the subject can be even more of a minefield. Will they understand? Will they be safe? Do they really need to know?

Vulnerable people's sexual health

Who is a vulnerable person? It's a person who is in receipt of, may be in need of, community care services by reason of mental or other disability, age or illness, and who may be unable to take care of or protect themselves from significant harm or exploitation.

This covers a lot of people – many of whom have a learning disability – a term which again, covers a lot of different types of disability. For instance, Down's syndrome, cerebral palsy, Asperger's, autism, dyslexia, foetal alcohol syndrome, fragile X syndrome, Tourettes. Are just a

few you may have heard of. Each person and syndrome has different characteristics and we must remember to treat vulnerable people as unique individuals whose needs may not fit into a checklist or standardised guidelines. There is more recognition today of the human right of people with a learning disability to form relationships and express their sexuality, as stipulated in Article 8 of the Human Rights Act (Liberty, 2009). It is a qualified right which means that the right to respect in these areas can sometimes be infringed.

How you can help

In health care we always need to keep people's human rights in mind. When supporting vulnerable people, we need to be particularly mindful that we pay due regard to:

- Bodily integrity – a breach of human rights may occur if someone is forced to have medical treatment or is forcibly restrained.
- Personal autonomy – our right to make our own decisions.
- Sexuality – a right to express ourselves as a sexual being.
- Personal identity – for instance the new gender of a transgendered person – if this is not recognised it breaches Article 8.
- Personal information – holding, using or disclosing personal information about someone is covered in Article 8.

People with learning disabilities are often stereotyped and this can affect their sexual wellbeing. For instance, they are described as always remaining childlike, asexual and unable to understand their sexual desires or control their sex drive – they are potential deviants, don't encourage them with sex education! However, people with learning disabilities have the same sexual needs and desires as those without disabilities, and 60 to 90% of young people want to marry and have children in the future. At the same time they can be vulnerable to abuse or exploitation.

How can I support the sexual health needs of a person with a learning disability?

In Alice's case, she maybe presenting with a health problem associated with a urine infection or sexual activity. She may go on to need an intimate examination, or may, at a later date, be invited for a smear. Here are some of the things that are essential or helpful:

- Every health care worker should have child protection and vulnerable person training – is your knowledge up to date?
- Find out who the support worker is – or the person who knows your patient or client well. He or she may be able to provide important relevant information, e.g. about capacity to consent, how to communicate effectively. In Alice's case, provide more information about the nature of her relationship with 'Jimmy'.

- Find out what words this person uses for parts of their body – speak the same language, and assess their communication skills – check their glasses or hearing aid are available if needed.
- Keep explanations simple and repeat key messages.
- How friendly does the clinical environment you work in appear to a person with a learning or other disability? Think about the need for privacy, toilet facilities and large, bright signs. But minimise distractions during the consultation, e.g. interruptions.
- Provide information such as easy to read leaflets with pictures and large print, and an accompanying leaflet for carers.
- Other audio or visual resources will aid teaching or explaining things – use diagrams, photos, and anatomical models.
- Do appointment times suit the patient/client? Would a double appointment prevent rushing and allow for communication which needs to be at a pace to suit the client?
- Do policies and protocols reflect the needs of people with learning disabilities or other special needs?

2.4 Understand your role and boundaries in providing sex related advice

There is no comprehensive picture of how those responsible for providing SRE and sexual health services for young people with learning disabilities are trained for and supported in their role. The literature review and the promising practice report indicate that: many staff lack confidence and feel ill-equipped to provide SRE and services that are in keeping with recent thinking about sexual health and learning disability there can be tensions between protection and lack of training and back-up compromises their abilities to support young people

There is a need for training for all staff with a role in supporting young people with learning disabilities, including those providing direct everyday care, such as key workers and other carers.

The latter are sometimes neglected as most education and training opportunities are directed at those working in management or professional capacities (

This is particularly significant given the findings on the importance of key workers as confidantes for young people. Some specific areas in which staff need support were identified. For example, staff can be concerned about negative parental reactions to the provision of SRE and sexual health services for young people, and this can inhibit them. The literature review also found that staff were particularly concerned about tackling lesbian, gay and bisexual issues with young people with learning disabilities.

Safe boundaries include advice such as:

Safe environment

Create a safe environment when explaining the facts about sex to people with learning disabilities. Make sure you are in a place where you won't be interrupted or disturbed. A 'Private' sign could be placed on the door if this makes the person you are talking to feel more comfortable and relaxed in discussing subjects they may find difficult.

Take it slowly

Be prepared to explain things bit by bit instead of bombarding people with a lot of information all at once. Conduct a needs assessment. If you are working with a group, is the group made up of people who will learn at a similar pace?

Reinforcing information

Use as much accessible information as possible. If you are working with a group, try role play, re-capping and asking direct questions, for eg at the start of a new session, ask each individual, "Can you tell me one thing we talked about last week?" This will help to understand if the people you are working with are retaining information, and if you are working at the right pace.

Appropriate behaviour

Discuss the difference between a public place and a private place, and talk about what kind of behaviour is appropriate in both. For eg, "Is it OK to kiss and hug your boyfriend during a lesson at college?"

Just say 'No!'

Make sure the person with learning disabilities understands they don't need to kiss, cuddle or have sex with someone if they don't feel ready. Remind them they are in control of their body and no one else has the right to kiss/touch them unless they agree to it. Talk about consent. Do they feel confident enough to say 'No' if they are not ready? Practice saying 'No!' using assertive body language and eye contact.

Talk about intimacy

If you feel the person you are supporting is ready, do they know about birth control? Do they know about where to get it and how to use it? Do they understand when/where it is appropriate to be intimate with their partner? (This can be particularly significant if living in a shared house). Again, talk about public vs private places, respect and consent.

Three's company

It can be helpful for a person with learning disabilities to be accompanied by a friend or support worker in the early stages of a new relationship. Explain to the person with a learning disability that this doesn't mean they will sit in between them on a romantic date, but could sit in the same cafe reading a book whilst the date takes place, so still be close at hand for support when needed.

That's private

If a person with learning disabilities is going on a date with someone new, make sure they don't divulge lots of personal details, such as address, mobile number, bank or passport details. Talk about the importance of privacy.

2.5 Understand the potential barriers and conflicts faced by the individuals you support in developing and expressing themselves sexually

Access to sexual expression is increasingly regarded as a human right, even though it is not part of the original Universal Declaration of Human Rights set out in 1948,

Capacity and consent

The common law test of capacity to consent to sexual relations is that the person concerned must be capable of understanding what is proposed and its implications, and must be able to exercise choice. Doctors may be asked to give a view on the capacity of patients to embark on a close relationship. Under these circumstances, each person should be seen privately for assessment and advice. The implementation during 2007 of the Mental Capacity Act 2005 will have implications for decisions about capacity for consent.

Another issue in relation to people with intellectual disability is the fine line to be drawn between the protection of those who are vulnerable to exploitation and abuse and the protection of their right to fulfilment of their sexuality. It is a fact that those with intellectual disability show sexual development and interest at approximately the same age as the normal population. Where there is little opportunity to understand and explore their sexuality, they can easily become the target of abuse and exploitation.

Sexuality and sexual expression have become increasingly central to people's identity and personality. The link between sexuality and identity, as well as the acknowledgement that sexual expression can provide emotional and physical benefits, provide some of the key arguments to why disability activists are campaigning for the rights of disabled people to express their sexuality in an equal way to the non-disabled population.

Sexual expression and intimate relationships can aid self-esteem, emotional wellbeing, and therefore the overall quality of life, as well as helping to rebuke society's message that disabled people are not sexually attractive.

This link between disability and a lack of sexual well-being is well known, and a study found that people with more severe physical impairments had lower levels of sexual esteem and sexual satisfaction and higher levels of sexual depression than either people who experienced mild impairments or the able-bodied population.

It has been identified that the idea of sexuality as a human right has grown out of a history of disabled people's relative isolation from the social arenas where prospective partners are met and social skills are learnt, which has led to the label of many disabled people as asexual.

This undermining of many disabled people's autonomy and capability of expressing their sexuality, as well as the belief that sexual expression can have beneficial effects, has caused many disability activists to challenge this view.

Society defines sexual health as the capacity to enjoy and express sexuality without exploitation, oppression, or physical or emotional harm. We believe that it is crucial that sex and relationships education (SRE) and sexual health services address the needs of people with physical impairments or learning disabilities to ensure that they are able to express their sexuality and to develop and enjoy positive relationships and good sexual health and wellbeing throughout their lives.

Professionals have a duty to acknowledge that disabled people have a right to sexual health and wellbeing and to be sensitive to difficulties that they may have in freely expressing their sexuality.

It is believed that, whilst the autonomy of individuals must be respected, there are circumstances in which disabled people may be vulnerable to, or may subject others to, exploitative situations. Sexual health services should balance the individual's right to be a sexual being with the necessity to assess the risks for disabled people and those around them.

Society believes that an individual's consent to sex is crucial to his or her sexual wellbeing and to the formation of positive relationships. However, it must be acknowledged that some people with physical impairments or learning disabilities may experience problems in communicating their needs and desires, which does not necessarily imply a lack of capacity to consent.

3. Role in the community

3.1 Recognise the contribution individuals you support can and do make to their community

Personalisation for community learning disability staff means:

- all staff work to develop a partnership between themselves and those who want a personal budget
- staff perform an enabling role which gives people with learning disabilities choice and control
- work to support users to undertake a self assessment, make best use of the Resource Allocation System to secure funding and help people to develop a support plan
- ensuring people have the right information about what they can purchase
- collating unmet needs and giving this information to commissioners to help them develop greater choice in the market

- the task includes the development of community and natural supports to promote people's independence, autonomy and active citizenship
- all staff should have good training, support and development opportunities to enable

What does being in the community mean?

People are described as part of a community when they are:

- doing things that have a purpose and are meaningful for them
- doing things in ordinary places, that most members of the community would be doing
- doing things that are uniquely right for them, with support that meets their individual and specific requirements
- meeting local people, developing friendships and connections and building a sense of belonging.

This includes

- working to earn money
- learning, by attending classes or going on training
- volunteering or helping others
- doing leisure activities and hobbies that you enjoy
- socialising with friends
- enjoying the company of a loving partner
- caring for children
- campaigning
- relaxing
- following religious activities
- looking after your home
- gathering information
- travelling around from place to place.

Individuals have different things in the evenings and at weekends than in the day from Monday to Friday. They go to a range of different places to do things, and do you encounter many different people in the course of a week

Individuals with learning disabilities locally lives look similar and follow similar patterns to local people of the same age

Helping people with learning disabilities to achieve such 'ordinary' daily lives has been national policy for more than 30 years, and significant progress has been made. But there's much more to do. Now, many people still have a pattern of life that revolves around:

- using a day service operating from a building specifically for people with learning disabilities from Monday to Friday
- being in groups all day with other people who have learning disabilities

- doing a small number of activities based on going out to community facilities (but which may be fairly irregular)
- doing things that are about what the service can offer
- being transported on service vehicles in large groups
- being at home with parents most evenings and at weekends.

Adapting to fit

There is no one way to achieve improved community services and support so that people get to 'have a good day'. Development is affected by the local needs profile and the social, political, economic, geographical and demographic context. Developments have to fit the local area. To get the best from this guide you will need to think about how the lessons within it can be tailored to your local context, with all the constraints and opportunities you encounter.

3.2 Understand that individuals you support may face barriers in being accepted as a member of their community

The underlying barriers prevent equity, inclusion and empowerment. The barriers prevent individuals achieving their potential. Someone with a learning disability may be perceived as not being worthy of:

- having the same human value and human rights as anyone else
- having the right to live a fulfilling life, and to contribute to community life wherever possible
- being seen as an individual with individual needs like anyone else.
- having help with communication, as required.
- being consulted about her needs and be involved in decisions about the services she receives
- receiving services that meet her individual needs and help her to achieve her potential.
- using mainstream local services that meet her needs wherever possible.
- having specialist services available if she has not additional special needs.
- having specialists services should not enhance and not replace mainstream services.
- receiving services which are non-segregated and age appropriate.
- exercising choice, wherever possible.
- receiving the least restrictive services possible
- entitled to be discriminated against, and
- family being informed and consulted about the services available

3.3 Understand how to support individuals to develop their place in their community if they so choose

Learning to successfully interact with others is one of the most important aspects of an individuals development, with far-reaching implications. Although most individuals acquire social skills by example, and possibly osmosis, research clearly suggests individuals with learning

disabilities (LD) may have difficulty making and keeping friends. Adolescents with LD have also been shown to interact less with their peers and to spend more leisure time alone, addicted to TV, computer games and the Internet. Certainly not all young people with learning disabilities experience social problems. Typically, the good athlete, class comedian, resident artist, or owner of the most magic cards, is likely to be accepted regardless of his learning issues. Then, too, some children, with or without LD, seem born to make life easy for parents—and for themselves as well. They appear to develop social awareness early in life and, as they grow, display innately good “people skills”—a sense of humour, a positive attitude toward life, and empathy for others, qualities guaranteed to win friends.

But for many individuals with LD, the lack of peer acceptance can become the most painful of their problems. Computers and calculators can help with writing and arithmetic, but there is no similar technology to help them handle a lonely recess at work, a family outing, or a date. These require social competence. “Social competence” in this context refers to those skills necessary for effective interpersonal functioning. They include both verbal and nonverbal behaviours that are socially valued and are likely to elicit a positive response from others.

Individuals with social disabilities frequently are less able than others their age to figure out how to behave in social situations and less aware of how others respond to them. Therefore, they act without knowledge or regard for social consequences. Most, though, tend to be unaware of their role, perceiving themselves as the victims of others’ mistreatment. Therefore, they take little responsibility for their actions, blaming others or simply “bad luck” for events in their lives. What they do feel, though, is an overdose of criticism from peers and adults alike.

To help individuals with social problems, it is important to understand on what level they are having trouble and how their social disabilities relate to their learning disabilities. The immaturity of many individuals with LD transcends academic areas, affecting their social adjustment as well. Communication skills, both verbal and nonverbal, also have social implications. Individuals who don’t “read” body language and facial expressions well are likely to miss important signals in life that are apparent to others.

To help individuals develop social skills and promote social acceptance, parents might consider these techniques

- Listen to individuals with the “third ear,” i.e., active listening, not only to the words they say, but the feelings they are expressing.
- Initiate and practice pro-social skills at home, including:
 - How to initiate, maintain, and end a conversation
 - The art of negotiation—how to get what you want appropriately
 - How to be appropriately assertive without being overly aggressive
 - How to give and receive compliments
 - How to respond to teasing by peers
 - Practice how to accept constructive criticism

Although not all individuals with learning disabilities have social difficulties, those who do require special understanding, not only in terms of their current functioning, but for the people they are capable of becoming. Although each person is unique, all have the same needs—acceptance, approval and a sense of belonging.

3.4 Understand the importance of networks to the individuals you support

A **social network** is a social structure made up of a set of social individuals or organisations and a set of the ties between these services.

Netbuddy is a free online community for anyone connected with special needs. It is a place to share practical tips and solutions for supporting people with learning disabilities and autism. –

In addition to the website, Netbuddy has a large social network following, and we have people linking up and offering great ideas –

Since the site launched in September 2010 it has grown and developed, and we have now joined with the equally fabulous national charity Scope. As well as running a range of services for disabled people and their families, Scope is all about raising awareness, influencing change, and providing advice and information

Some major networks for learning Disability includes:

British Dyslexia Association

British Institute of Learning Disabilities

The Disabilities Trust

Mencap (Royal Society for M H Children & Adults)

3.5 Understand what tools and approaches you could use to promote wider networks for the individuals you support

Types of services include:

Advocacy

Advocacy is the process of helping someone to express what they want to say.

Childcare

Some parents may be interested in finding childcare services in their area, either because they are working or studying or because they would like some time to themselves.

Short breaks

Short breaks are designed for people with a learning disability and their families, to give them a break and a change from their daily routine.

Day services

Day service facilities offer a range of supported activities in the local community.

Finding a job

Finding a job that you enjoy can bring with it many benefits.

Housing

Find out more about how to access housing services for the person you care for.

Leisure

Leisure is the time we spend doing the things we enjoy. It includes a wide range of different activities, from getting involved with a sports team and visiting an art gallery to reading a book.

Personalisation

Personalisation is a way of describing how support for vulnerable people will be provided in the future. It will affect social care services as well as other public services.

Carer's assessments

Carers have a legal right to an assessment of their needs. If you provide regular, unpaid care for your son or daughter, you may be entitled to a carer's assessment.

Community care assessments

Community care is help that is provided to people in need to help them live as independently as possible.

Money and benefits

If you have a child with a learning disability you may be entitled to claim certain benefits for yourself, or on their behalf.

In Control and Me

Mencap has been working in partnership with In Control to produce advice and information about self-directed support.

Direct payments: choosing your services

Direct payments allow people to receive money directly from their local authority, so they can pay for their own services and live more independently.

Health

People with a learning disability often experience poorer health and poorer healthcare than the general population.

Communication

The following resources and organisations are available to help you learn more about communicating with people with a learning disability, and how to make your existing communication materials more accessible.

PMLD (profound and multiple learning disabilities)

This section is aimed at professionals who work with or support people with profound and multiple learning disabilities (PMLD).

Employment

Only 1 in 10 people with a learning disability are in employment.

Working with black and minority ethnic (BME) communities

Families from BME communities who are caring for someone with a learning disability face the same difficulties as other people – but these problems are often compounded by additional factors.

Personalisation

The personalisation agenda is leading some of the changes happening in social care today.

Person-centred approaches

The essence of being person-centred is that it is individual to, and owned by, the person being supported.

3.6 Recognise that individuals you support may also be carers

Your rights and legislation

- What are my rights as a carer?
- What is the mental capacity act and how does it relate to the person I care for and me?
- Where can I go to get legal support?

What are my rights as a carer?

There are some pieces of legislation which can be useful for all carers to know about when trying to speak up for or get the rights and services they are entitled to by law. These are:

- Your right to an assessment
- Your right to request flexible working
- Your right to not be discriminated against

For a comprehensive account of carers rights and the law download this pdf from Carers UK.

Carers and their rights

Your right to an assessment

All carers have the right in law to have an assessment of their needs even if the person they care

for refuses services. This assessment is potentially the gateway to accessing services from your local authority for you as a carer and goes alongside the Community Care Assessment, for services for the person you care for.

Your right to request flexible working

The Work and Families Act extends the right to request flexible working hours to carers of adult partners or relatives, or an adult living at the same address. Your employer has to consider this request but is not obligated to accept it.

Your right to not be discriminated against

The Equalities Act recognises the concept of 'associative' discrimination in relation to carers of disabled people. This means that it is illegal to be discriminated against because of your caring role, not only in relation to employment, but also in relation to goods, services, housing and other fields.

What is the mental capacity act and how does it relate to the person I care for and me?

The ability to make decisions is sometimes called mental capacity. There is a law – the Mental Capacity Act 2005 – which sets out what should happen in England and Wales if someone is unable to make a decision for themselves. As a carer of someone with a learning difficulty it is important for you to understand how the Mental Capacity Act applies to you when:

- you want to support a member of their family to make a decision
- you need to make a decision or act on your relative's behalf
- someone else (a paid worker or organisation) makes a decision or acts on behalf of your relative.

To find out what should happen in these situations see the download below: 'Using the Mental Capacity Act – a resource guide for families and friends of people with learning difficulties'. This is a really useful information pack designed to help the family carers of people with learning disabilities understand how the Mental Capacity Act applies to them.

THERE are five key points of good practice:

1. Communicating with parents in a way that is clear and easy to understand.
2. Services working well together.
3. Good support based on what people can do and where they need support to do things
4. Giving long term support to parents
5. Parents being able to get independent advocacy.

Everyone must work together to make sure parents with learning disabilities are treated equally

Communicating with parents in a way that is clear and easy to understand

Services should make their information accessible by:

- Using easy words and pictures. Using audio tape, CD or DVD.
- Making their websites accessible. Talking to people about services that are available.

- People need information in plenty of time.
- Parents should be able to get support from an independent advocate to help them understand information.
- Good communication with schools is very important.
- Parents need to know what their responsibilities are.
- Teachers and schools should make their information and communication accessible, so that parents know what they have to do.
- Talking to people about services that are available
- Parents should be able to get support from an independent advocate to help them understand information
- Good communication with schools is very important.
- Parents need to know what their responsibilities are
- All services should let parents and parents-to-be know what support is available. This information should be accessible.
- Children and Families Teams and adult services should give parents with learning disabilities
 - accessible information about support that is available to parents. This should include
 - information about the responsibilities that parents have.
- People with learning disabilities have the right to an assessment of their needs. Learning disability services should give accessible information to parents about this.
- Parents should get accessible information about why an assessment is being done. It should say how it will be done and what will happen afterwards.
- Good communication with services is very important.
- Parents need to know what their responsibilities are.
- Teachers and schools should make their information and communication accessible, so that parents know what they have to do.
- All services should let parents and parents-to-be know what support is available. This information should be accessible.
- Children and Families Teams and adult services should give parents with learning disabilities accessible information about support that is available to parents.
- This should include information about the responsibilities that parents have.