Understanding the Needs of Individuals with Profound and Multiple Learning Disabilities.

Reading Material

Level 2 & 3
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Section 1 Definition and Needs

Covers learning outcome 1 & 2
Definition and Needs

Section 1

In section 1 you will learn what is meant by the term Profound and Multiple Learning Disabilities. You will also find out about disabilities and syndromes you may encounter. Further links are provided should you wish to look up more detailed information.

What does PMLD mean?

PMLD is a familiar term used within the field of learning disabilities. This word is an abbreviation for Profound and Multiple Learning Disabilities. This term may also be known as Profound Intellectual and multiple learning disabilities (PIMD) however, it means the same.

Profound - extreme
Intellectual - The mental process of thinking
Multiple - several
Learning Disability - A condition that significantly hinders someone from learning a basic skill.

There are many definitions however Jim Mansell (2010) offers the following:

‘People with profound intellectual and multiple disabilities are among the most disabled individuals in our community. They have a profound intellectual disability, which means that their intelligence quotient is estimated to be under 20 and therefore they have severely limited understanding. In addition, they have multiple disabilities, which may include impairments of vision, hearing and movement as well as other problems like epilepsy and autism. Most people in this group are unable to walk unaided and many people have complex health needs requiring extensive help. People with profound intellectual and multiple disabilities have great difficulty communicating; they typically have very limited understanding and express themselves through non-verbal means, or at most through using a few words or symbols. They often show limited evidence of intention. Some people have, in addition, problems of challenging behaviour such as self-injury’.
Whilst labelling a person is not always a positive thing as labels tend to focus on a person’s disability not their capabilities, for the purpose of this course we need to identify the group of people we are working with. Historically many people with profound and multiple learning disabilities (PMLD) would be living in long stay institutions.

**Needs**

Every person is unique and will have different capabilities but in general people with PMLD will generally have two or more serious impairments which include a profound learning disability. There may also be complex health needs associated with a person’s disability. An individual may need support in most aspects of everyday life including:

- Communication
- Eat and drinking
- Continence
- Mobilisation
- Making choices
- Life skills
- Travelling
- Accessing the community

The majority of people described as having profound and multiple learning disabilities vary greatly, some people are fully mobile but others may use a wheelchair. Others may have difficulty with movement and are unable to control or vary their posture efficiently. Specialised equipment will be required for these individuals to help assist mobility, support posture and help protect and maintain body shape, muscle tone and quality of life. Specialist services such as physiotherapy, occupational therapy and hydrotherapy are vital to ensure an individual’s physical needs are being met.

**Postural Support**

Postural care is about protecting someone’s body shape. People who find it hard to move for example, those with multiple disabilities - are most at risk of developing body shape distortions. This is because they often sit and lie in limited positions. (Mencap 2012) People will require time out of their wheelchairs during the day, the risks of sitting or lying in any position for too long can have a detrimental effect on a person’s health and well being, for example pressure formation, stiff joints/contractures, spinal deformities, respiratory infection. For more information www.posturalcareskills.com.
12 Hot tips for the everyday needs of a person with a profound learning disability.

- Basic health needs must be met; example the administration of daily medication.
- It is important to recognise when someone with PMLD is in pain; by knowing and recognising non verbal cues.
- Daily personal care routines are essential; like washing, changing pads and dental hygiene.
- Monitor the integrity of the skin for the early treatment of pressure sores.
- If the person is immobile, change their positions during the day. Example move from wheel chair to bean bag, or floor mat or bed.
- Ensure communication and social interaction is accessible in a format they can understand. Example Photos, objects of reference, signs and communication aids.
- Use sensory stories to encourage interaction.
- Ensure that adequate drinks are supplied during the day.
- Food may need to be cut into small pieces or pureed.
- Support good posture during meal times.
- Ensure plates and crockery are adapted to meet individual needs, use slip mats to secure plates.
- Maintain appropriate exercise routine to keep their range of mobility. Training and guidelines must be from a physiotherapist or other trained medical staff.

Individuals with profound learning disabilities require the good things of life to nurture their well being. This include home and family; friendship; being treated with dignity, respect and being accepted; a sense of belonging; an education, and self development ; a voice in the affairs of one's community and society; opportunities to participate; a decent material standard of living; a place to live; and opportunities to be involved in their lives (Osburn 1998).

**Complex health needs**

It is well documented that People with learning disabilities have poorer health than the general population and are less likely to access healthcare, subsequently these health inequalities have been highlighted in reports such as:-
People with learning disabilities have a shorter life expectancy compared to the general population. Whilst life expectancy is increasing with people with mild learning disabilities approaching that of the general population, the mortality rates among people with moderate to severe learning disabilities are three times higher than in the general population. (Tyrer, 2009)

People with Profound and multiple learning disabilities have greater health needs than the general population. They are more likely to experience respiratory disease, Epilepsy, Coronary heart disease, Gastrointestinal reflux, Diabetes, Helicobacter pylori, osteoporosis. (NHS, 2012) There is also a prevalence of epilepsy, pressure sores and respiratory infections (Hutchinson, 1988).

Individuals with a learning disabilities and complex health conditions must be supported to attend annual GP health checks and an annual health action plan should be devised. A hospital passport must be completed.

**Gastro-Oesophageal reflex disease (GORD)**

GORD is a very common digestive condition. It is estimated that 48% of people with a learning disability will have GORD. This is significantly higher than the general population. 70% of people with PMLD have GORD (Pamis). GORD occurs when stomach acid leaks back up the oesophagus. This is known as acid reflux and it can be very painful and can go unnoticed in service users who cannot demonstrate pain. GORD can damage the oesophagus and can lead to oesophageal cancer. Management of GORD can include medications to improve gut mobility, positioning, modification of food and drink and some people may require surgery -GORD and significant swallowing difficulties (Dysphagia) could
indicate the need for external feeding (Insertion of Gastrostomy tube) GORD can also cause tooth decay.

**Osteoporosis**

Osteoporosis is a condition that affects bone strength. The bones become less dense and less strong. People with osteoporosis have **weak and fragile** bones and will be more susceptible to fractures. Individuals with decreased or limited immobility and people with PMLD are at high risk of developing Osteoporosis. There have been a number of studies that suggest that there is a link between the long-term use of medications (anti-convulsants) and decreased bone density leading to osteoporosis.

**Respiratory Disease**

Reoccurring chest infections and or aspiration pneumonia can cause scarring on the lungs leading to chronic Respiratory disease. People with PMLD are at high risk of respiratory infections due to lack of mobility, aspiration caused by dysphagia or gastro-oesophageal reflux and asthma. Some people may require management techniques such as chest physio and postural drainage, nebulisers and oral suctioning to manage secretions. Postural support is vital for those who are at high risk of respiratory infections use of sleep systems and specialist seating can assist breathing and minimise risk of reflux.

**Malnutrition and Dysphagia**

Malnutrition is often present as people with PMLD can have difficulties in swallowing and rely on others to support them with eating and drinking. Over 60% of people with PMLD have swallowing difficulties either dealing with food and drink in the mouth or the process of swallowing (Pamis 2011). The medical term is known as Dysphagia. It can lead to aspiration (Inhalation of food/liquid into the lungs) and aspiration can cause serious lung infections. Good oral hygiene is paramount for people who are at risk of aspiration. A speech and language therapist and dietician can provide guidance on managing Dysphagia and malnutrition.

Individuals may need their food cut up into small pieces or to be fed. Drinks may require thickening agents to prevent coughing and choking. Beakers, feeders and in some cases tube feeding is required. Drinking in between finishing mouthfuls of food may be important to prevent the individuals aspirating.
Epilepsy
A proportion of people with PMLD may develop epilepsy and may need medication to try and control seizures. Strict protocols are required to manage seizures safely. These protocols are the timing of the duration of seizures, how they present themselves (Clonic tonic or Petite mal) and an action plan that can reduce risks. Some individuals walk around the room in a robotic motion and need to be eased to a sitting position. Emergency services may be called or buccul medication may be administered. In extreme cases diazepam suppositories may be used while awaiting paramedics but staff must be trained and have permission to do this and it would be written up in the protocol. Removing objects or furniture from the path of an individual during their seizure is essential so are calm words of reassurance and rest once it is over.

Other health needs
Some adults with profound and multiple learning disabilities may have complex health needs such as those who are described as being ‘technology dependent’. This mean an individual may need oxygen, tube feeding or suctioning equipment. Others have conditions that are said to be ‘life-limiting’ an example of this would be Batten disease which is a progressive disease. Over time affected children suffer seizures, and progressive loss of sight, cognitive ability and motor skills. Eventually, children with Batten disease become blind, bedridden and have profound learning disabilities. Batten disease is often fatal by the late teens or twenties.

A high proportion of individuals with PMLD have additional mental health issues. This is often overlooked as their overall disability can disguise that something is not right. Signals may include unusual passive behaviours as this may indicate depression.

The range of signals of health issues are self harm, loss of appetite and a decrease in interaction. These indicators are often subtle and need investigation as they present changes in physical and emotional well being. Continuity of support with health care staff is essential for these issues to be highlighted as you need to know an individual and build rapport with them to notice subtle changes. Also well person’s health checks are essential to treat undetected treatable conditions.

References
The impact of poor health on individuals with PMLD varies as each individual is unique however below are some suggestions of how an illness might affect a person.

- May not be able to communicate pain - being in pain may make it hard for a person to concentrate
- May present challenging behaviour as a form of communication
- May miss large amounts of school/college/attendance at day service
- May lose some of the skills already learnt
- May become ill very quickly and need medical intervention

Risks
There are hazards to both children and adults with PMLD and staff. Individuals may experience muscle spasms and uncontrolled body movement. Thought and consideration is required to prevent possible injury to staff entering their personal space.

Some individuals may be tactile defensive and strike out if touched or some may gag or vomit on strong smells. There may be challenging behaviour as an individual may have issues surrounding food, or require lots of personal space.

Individuals may be unable to control their arousal level and become over stimulated or they are unable to move on until they have completed routines or rituals.

The correct handling of chemical waste is required when handling nappies or pads to ensure infection control. Consideration must be given to protecting yourself against diseases such as hepatitis B.

Challenging behaviour
Often individuals with PLMD may display challenging behaviour. The range of behaviours may vary from self injury by hitting or biting to harming others by striking out at the people around them. Difficulties in expressing their needs may be a trigger, or being in situations that are unfamiliar to them or they don’t understand. We can only surmise the reasons behind the behaviour, however we know it is a form of expressive communication that is unique to each individual.
Understanding the triggers to challenging behaviour is important. Always look at meeting the basic human needs of the individual, look for undetected health problems, such as tooth ache, sore gums, and pain and consider medication and their side effects. Health problems must be reported to the wider professional network.

Guidelines need to be put into place to manage the behaviour to ensure a consistent approach and to lower risk.

Different syndromes and disabilities
In this section you will find out about disabilities and syndromes that you may encounter. Further links are provided should you wish to look up more detailed information.

The descriptions below are only a guide to what you may encounter however it is important to remember that every person is unique. People will have different needs and preferences and should be treated as individuals.

Sensory impairment
Individuals who have a degree of difficulty with sight and/or hearing could be described as having a sensory impairment. 40-90% of individuals with a learning disability are thought to have some level of visual impairment. Almost 40% of adults with a learning disability will have a hearing loss although it is often undiagnosed. This group need to explore and understand the world through a sensory environment. This would include touch, smell, taste, audio and visual.

Retts Syndrome
Retts syndrome is a disorder affecting the nervous system and is more common in girls. This disorder starts to appear at one year old where a child starts to lose the skills they have learnt. All people with Retts Syndrome have profound and multiple learning disabilities. This syndrome includes physical disabilities such as curvature of the spine, breathing and feeding difficulties, Epilepsy, mobility problems and the loss of speech. People with this condition may live to 50 years and beyond.
For more information about this Syndrome please see the link below.

Angelmans Syndrome
Angelman syndrome is a chromosome disorder. All people with this syndrome display jerky movements, hand flapping and a puppet like gait. They appear to have a happy demeanour often laughing and smiling. They have severe learning difficulties and a very short attention span. About 80% will also have epilepsy. http://www.angelmanuk.org/angelman Syndrome.html

**Autism.**

Autism has a very wide spectrum. On the autistic scale some individuals are high functioning others have severe learning difficulties. Autism is not physically recognisable as it is displayed in behaviours. However, communication and recognising social cues may be a problem across the spectrum. This is commonly called the 'triad of impairments'. Which means they have:

- **Problems with communicating socially** - Individuals with autism may need encouragement to respond to communication, they find maintaining eye contact difficult. From experience they are able to speak but they sometimes choose not to.
- **Problems with interacting socially** - this means they may be very isolated within a group. They find reading unspoken social cues difficult an example not knowing how to start a conversation or not responding to people
- **Problems with social imagination** - this means not understanding the world for example being apprehensive with the everyday situations that they may encounter out of their normal routines.

People with Autism have difficulty understanding and relating to other people, and taking part in everyday life.

Sounds, touch, tastes, smells, light and colours may be over or under exaggerated causing sensitivity. When a person enters an environment they are not able to take in the whole picture. They focus on one particular detail and become absorbed with it and find it hard to relate to anything else in that environment. It could be described as looking through a tube where the person is unaware of anything else going on.

Some people will lead fairly independent lives whilst others will need lifelong specialist support. More information can be found using the links below.

Down's Syndrome

Down’s syndrome is a chromosome disorder that causes moderate to severe learning disabilities. Individuals with Down's Syndrome may lead independent lives with minimal support. They may display extrovert personalities and be seen as very sociable. Often they like creative activities such as dance and drama as this can be used as a form of expression.

The more common characteristics may include slanting eyes, flat nose, shorter limbs and protruding tongue. This may be combined with health issues such as heart defects, vision problems and early onset of dementia in adulthood. People with Down's Syndrome may have difficulty communicating and will often use Makaton to support their communication.


Cerebral Palsy

Cerebral Palsy is a disability that affects different parts of the brain and may cause muscle spasms, mobility issues and in some cases a learning disability. This can be caused by abnormalities in the womb. Other causes may be an infection in the early part of pregnancy, oxygen deprivation to the brain or premature birth.


Developmental Delay and Global Developmental delay

Development Delay is a general term for children who have not reached one or two typical milestones such as walking, talking etc. Global Developmental delay is more far reaching and encompasses a range of unachieved milestones such as sitting up, picking up small objects, communicating verbally and non verbally. The ability to learn new things is reduced and they may require more processing time. This may affect a person’s ability to express their needs and make clear choices.

Fragile X syndrome
Fragile X Syndrome is an inherited chromosome disorder and is said to be one of the most common causes of learning disability. The X chromosome is abnormal and under a microscope looks like the tip is breaking off but is not quite separated and very fragile. It appears to affect boys more than girls as they only have one X chromosome which will be fragile whereas girls have two X chromosomes so the good one can compensate for the fragile one.

The degree of learning disability varies and up to 2/3 of girls will have average intelligence however they will still have other features relating to Fragile X. Many children and adults show autistic like tendencies such as difficulty relating to others, becoming anxious in social settings. They may have communication difficulties and some people also have epilepsy.

Adults with Fragile X have similar distinctive physical features although it is said male features may show more obvious signs than female. These features include a long narrow face with prominent jaw bones and wider longer eyes that project away from the head. They can also have loose connective tissue which can make them double jointed and flat footed.

http://fragilex.org.uk/LinkClick.aspx?fileticket=eXjLFrSN%2fQk%3d&tabid=57
Section 2 Communication & Sensory Exercises

Covers learning outcome 2, 3, 4 & 5
Communication

Section 2

In this section you will learn some simple rules to remember when communicating with people with PMLD. You will also gain an understanding of some of the communication methods that individuals may use and the different stages of communication. This section also looks at how to develop sensory exercises and explores different types of sensory activities that can be used when working with people with PMLD and suggests ways of adapting activities to meet individual needs. At the end of this section there will be a multiple choice quiz followed by a short video clip and some more questions.

Communication

Many people with PMLD cannot communicate using formal speech - they use different forms of communication which can be very unique to them. They will require staff to interpret their communication needs. This includes their feelings and emotions. People with PMLD may use a number of methods to support effective communication such as:-

- Objects of reference or sounds Cues
- Sensory referencing
- Eye contact/Body language/vocalisations
- Augmentative and alternative communication (Big Mac Switch, GO 4 etc)
- Communication passports
- Talking Mats
- Symbols - widget, rebus, Bliss
- Signing/body cues
- Story boards
- Massage stories and sensory stories
- Movement to music
- Multi media

As individuals may not communicate using words it is important to get to know a person by reading their facial expression, body language, vocalisations, eye movements and body contact. Careful observation of these and other communication methods will help you understand how an individual communicates.

When communicating with a person with PMLD please remember
- They are people first try to look beyond their disability
• Just because they cannot speak do not assume they cannot understand
• Do not ignore the person and talk to their carer
• Always include the person in the conversation
• Look directly at the person so they know you are communicating with them and you can observe their communication methods
• Give the person time to respond
• Use simple language
• Make sure you have their attention before speaking
• Name the person you are speaking to and give clear instructions
• Give reassurance and praise

**The Pre stage of communication**

There are different communication development stages prior to a child using spoken language, for some people with PMLD they may never progress beyond the Pre Stage of Communication. These stages are broken down into Pre Intentional and Intentional and are as follows.

**Pre Intentional**

**Level 1: Reflexive** - The person has a limited repertoire of behaviours which can be interpreted by familiar people. They will be predominantly reflex responses to internal as much as external stimuli. They may respond to light and dark, hot and cold or show a startled reflex if a loud noise is made. This communication level is similar to new born baby.

**Level 2: Reactive** - The person responds with a wider range of voluntary behaviours which are assigned social significance by caregivers. The range of likely interpretations widens a little and the person will be more responsive to affective messages from the caregiver.

**Level 3: Proactive** - The person’s behaviours are now goal directed and these behaviours function as signals to others who assign both communicative intent and meaning to them. Meaning is extracted from other peoples' intonation and facial expression.

**Intentional**

**Level 4: Primitive** - The person has learned that they can affect the environment by acting on another person. Thus they can be seen as intentional communicators. Other people rely heavily on the context to interpret these ‘primitive’ communicative acts. The person understands other people’s nonverbal communication and is starting to show situation cued understanding.

**Level 5: Conventional** - The person has acquired a range of semantic roles which can now be communicated to others using more conventional forms,
including single signs, symbols and words. These are easier for others to understand and less dependent on their context. The person uses these early meanings for a wider range of functions and will comprehend many single words. (Coupe-O’Kane & Goldbart, 1998)

Methods of Communication

TaSSeLs (Tactile Signing for Sensory Learners)
Touch is a vital channel of communication for learners at the earliest developmental levels. The TaSSeLs system uses touch to promote effective communication with people who have profound and complex learning disabilities, a number of whom may have visual impairment. Signs have been developed from Makaton but they are based on touch. The person communicating with a person with PMLD will either deliver the signs placing their hands under the hands of the person they are communicating to or if that is not possible they will adapt the method depending on the person’s physical limitation. If it is not possible to adapt the signs using hand under hand the communicator will use an on the body method whereby they do the sign on a person’s body. For example brush hair - the communicator will take their hand up to the hair and gently perform a brushing movement with their hand.

Body Cues
These are similar to the TaSSeLs method of communication because the body is being touched to give people with PMLD messages to show what is about to happen. They are gentle touch cues to give specific information, the actions is always paired with consistent key words for example stand up. Some examples of touch cues are:

- Work is starting - Person’s hands bought to midline
- Work is finishing - Person’s hands moved apart and out
- Starting to move - upper arm moved forward
- Stopping movement - press back on shoulder
- Stand up - move bent elbow upwards
- Sit down - tap lightly on shoulder

Makaton
Makaton is a programme that uses hand signs, symbols and speech to help with language development for children and adults that may have communication difficulties. The signs have been developed from British Sign Language (BSL) so some of the signs are the same however some have been adapted to make them simpler. Unlike BSL the words are signed in spoken English order and only key
words in the sentence are usually signed. People with PMLD may only know some basic signs and sometimes they adapt the sign themselves. It would be important to know how a person signs so you are able to communicate with them. Makaton vocabulary has been developed in stages from 1 to 8, stage 1 and 2 focus on immediate needs such as food and drink the higher stages focus more on ideas and concepts.

To find out more about Makaton watch the following clip
http://www.youtube.com/watch?v=MASkfzYf_9w

Makaton symbols are sometimes used to support communication. Autistic people may wish to use these instead of signs. The symbols can be used in many ways in communication passports, on the computer, with communication boards in books and education resources. However, they do need to have some meaning to the person involved and symbols used need to be consistent. Here is an example of a symbol.

![Symbol](image)

What do you think this means?
1. Happy
2. Friend
3. Name
4. Home

**Symbols/Pictures/Photographs**
As well as Makaton symbols, there are other symbols such as rebus (Widgit).

![Symbol](image)

The symbol above comes from Rebus Widgit and it means name.

Whatever symbols are used must have meaning to the person and be used consistently. It would be very confusing if different symbols were used at home and college.
Some people find symbols hard to understand but prefer to use pictures of the real thing. When telling someone they are going to college the person is shown a photograph. This could be a photo of the building or a photo of the staff who teach them. Whichever has the most meaning to an individual. When making resources using symbols it is important to only use symbols for the key words as using symbols for every word would be overwhelming and difficult to understand.

When using photos make sure the photo
- Has a plain background as too much information could distract a person
- Is of good quality, not blurry, too light or dark
- Is of an individual not of a group of people that the person will find hard to identify

**Picture exchange communication system**
Picture exchange system is a communication tool used mainly with individuals with autism. Pictures are exchanged to indicate choices. An example of this is a person would select and give a picture of orange juice to their carer and in return would receive the juice. Pictures are attached with Velcro in booklets. It is important that the pictures are significant to the person and their lifestyle. Pictures of daily routines give the individual time to adjust to what is going to be happening soon.

**Objects of reference**
An object can be used to show the person what activity is about to happen for example use a swimming costume to show the person is about to go swimming. The idea is that the person starts to associate that object with a certain activity. Once this connection has been developed the person will be able to make choices about which activity they would like to choose.

**Sounds of reference**
This is the same as objects of reference but sounds are used instead of objects for example a bell may mean it is lunch time.

**Personal Identifiers**
These can be used to communicate that a person is coming - it may be the smell of someone’s perfume and a picture to show the person who will be arriving. It could be a whistle that the PE teacher wears or a scarf that is worn by a certain person. The personal identifier will be unique to the person so will be different for each person. The personal identifier must be used consistently and kept the same.
Communication Passports
A communication passport is information about a person's preferred communication methods. It can be in a form of a book, DVD or a box of objects and will display their likes, dislikes, people and things that are important to them. They are very helpful tools especially when meeting someone for the first time. This communication passport stays with the person at all times as a communication tool for new people meeting them or as reminder for those who already know the person.

Switches and Devices
Speech and Language therapists assess individuals for electronic/digital communication aids. They are very individualised and adapted to suit a person's needs. Some devices have automated voices these can be activated by pressing buttons, pictures and switches.

Vocalisation
Often people with PMLD will be unable to speak but that does not mean they cannot communicate. Most pre-verbal and non-verbal children and adults appear able to express emotions such as pain and anger with sounds like crying, screaming or shouting and happiness with laughing, tittering and other happy sounds. It is therefore very important to get to know the range of tones a person can make as they will be able to communicate their likes and dislikes.

Eye pointing and body language
Eye pointing and body language is another way of communicating. Eye pointing can be described as the way of communicating where the person uses their eyes to look in the direction of a particular item or symbol to indicate choice. A person might look at an object they want or look away when they dislike something. It is therefore important to read any signs of eye movement and respond positively.

Reading body language and gestures is another method of communication. Defensive body language such as turning, pushing and facing away may indicate a negative preference. Facing something or someone, touching, eye contact and grasping may indicate a positive preference. Always use positive open body language when communicating with individuals with PMLD and create a calm safe environment.
Developing communication
In order to develop the pre stage of communication it is important to focus on activities that help the individual to develop the skills listed below:

- Enjoy being with others
- Learning what makes someone tick
- Concentration and attention span
- Learning a sequence of activities with other people
- Taking turns in exchanges of behaviour
- Sharing personal space
- Using and understanding eye contact
- Using and understanding facial expressions
- Using and understanding physical contacts
- Using and understanding non-verbal communication
- Using vocalisation with meaning
- Learning to regulate and control arousal levels

Intensive interaction
This process is recommended for people who are hard to reach and are not motivated to be with others.

Intensive interaction develops the fundamentals of communication prior to speech. An example of this is developing eye contact and turn taking. The process is totally led by the individual. Intensive interaction is an informal method of communication between two people, where they share moments or sequences of enjoyable interaction. The person interacting will be very sensitive to the way individuals behave or vocalise. Sessions will often be frequent and short in duration increasing as time goes by.

See the following link to watch intensive interaction in practice http://www.youtube.com/watch?v=OhnaPJw_Wh8

Communication strategies for individuals with PMLD
Coupe O’Kane and Goldbart (1998) suggest the following strategies in communication.

- When communicating get close to your communication partner, facing them if possible and be within arm’s length. (Note extended personal space may be needed for some individuals).
- Respond to their vocalisations by saying their name, singing or whispering.
- Initiate smiling or react to their facial expressions to get a response.
- Encourage eye contact with yourself or an object by making sure it is in their eye line.
- Using touch body cues to inform your communication partner of your intentions (note some individuals may be tactile defensive and this may not be appropriate).
- The communication partner can imitate their actions and sounds.
- The communication partner give time to respond and then gives feedback.

Nind & Hewett (1994) suggest the following communication strategies for individuals with PMLD.

- Touch, rock or hold your partner.
- Share the control of an activity.
- Allow yourself to be controlled by your partner.
- Use visual regards and mutual gaze.
- Exaggerate facial expressions.
- Use motherese – slower simple speech.
- Verbalise in short burst allowing time for response.
- Use games and playful ritualised routines.
- Adopt the tempo of communication partner.
- Keep their level of arousal and involvement within optimum limits.
- Respond to your communication partner being sensitive to their signals and feedback.

Individuals with profound and complex needs spend most of their time in the presence of others, but very little time communicating with them. Opportunities to develop pre-communicate skills should not be missed. Routines and sequences that encourage security and control prevent the individual from developing learnt passivity or learnt helplessness. Responding to their needs is vital to developing their skills and it must not be seen as "giving in to them".

Communication partners

It is essential to have a good communication partner to make communication effective.

The skills and qualities of a good communication partner are

- Willing to listen
- Patience
- Desire to support individuals
- Good eye contact
- Desire to listen to the individual
- Able to take quite a lot of eye contact
- Having an expressive face
- Lack of self consciousness
- Comfortable being tactile
- Responsive
- Observant
- Relaxed and calm demeanour
- Be able to sign
- Awareness of individual’s communication needs
- Engage with individual at their level

If communication is not encouraged a person with PMLD is not seen, their courses and preferences become disregarded as no one is listening to them. They are denied the opportunity to maintain existing communication skills or develop new skills. This may lead to challenging behaviour as a person becomes frustrated that no one is listening.

**Sensory exercises/activities**

The brain requires high levels of sensory stimulation to support neurotypical development of the brain. Stimulating the senses develops the emergent part of the brain and nurtures the brain stem (Bolles,M).

Seven sensory channels have been identified.

- Auditory (hearing) - listening to sounds or music.
- Visual (seeing) - looking at vibrant colours, shiny reflective surfaces and moving pictures.
- Tactile (touch) - touching a range of surfaces from rough, smooth soft, slippery, feathery etc.
- Olfactory (smell) smelling sweet, fruity or pungent fragrances.
- Gustatory (taste) Tasting on lips sour, sweet, sharp, etc.
- Vestibular (balance, speed and direction) balancing objects in the hand, moving and turning etc.
- Proprioceptive (a sense of body positioning) Rocking, moving, hands, arms up, down, tapping or body patting and body pressure etc.

Sensory activities can be any activity that involves a sense and includes the following:
• Aquatic therapy formerly known as Hydrotherapy
• Sensory rooms
• Rebound therapy
• Animal therapy
• Intensive Interaction
• Sensory stories
• TAC PAC
• Massage and Aromatherapy
• Sensory Art
• Sensory Cookery
• Sensory activities embedded in care routines
• Music therapy
• Sensory gardens

Sensory exercise can be planned in many creative ways, for olfactory a smell can be introduced to symbolise a day of the week. An example of this is as follows peppermint for Monday, citrus orange for Tuesday, and lavender for Wednesday etc. Actions songs can be used to encourage movements and body patting routines to percussive music.

Themed corners/displays/tents or Gazebos can be used to illustrate a season or the weather with the use of sensory materials and visual backdrops.

Sensory art- the use of foam and paints or food where lemon curd is used to paint the sun and cream is the moon. These exercises are about the process and not the end results.

Massage stories where touch and pressure is used on the individual’s back to stimulate the story line and effects. An example of this is a hand can be used to represent a boat that is sailing in a heavy storm or arms can be used on the back to represent rolling our dough to make a pizza.
Watch the following clip for an example of a massage story 
http://www.youtube.com/watch?v=WuQZOLT5pvI

To prevent sensory overload during sensory activities or exercises use just one or two senses. An example of one sense is taking off a sock running warm sand over their foot. An example two senses is listening to classic music and stroking a feather.
What are sensory stories?
Sensory stories involve individuals with profound and multiple learning disabilities experiencing stories through their senses. This is through vision, touch, smell, taste and sound. They work by engaging all of the senses.
An example of this is the story Handa’s Surprise.
Handa is from an African village and she is going to visit her friend and bring her a gift of exotic fruits. It’s a long way to the village and Handa has to stop and rest on several occasions. Whenever she stops different bush animals come and steal one of her fruits. She does not notice they have all been taken from the basket which she carries on her head. When she is near her friend’s village a goat rams the trunk of a Satsuma tree just as Handa is passing close by. The fruit from the tree fall into her basket. When she gives her gift to her friend she is surprised to find the Satsumas, and nothing else.

Handa’s surprise……….Author……Eileen Brown 1999
When planning a story it is good to consider all the senses and it helps to use a planning document like the one below as this will help to identify what resources are used to cater for each sense.

<table>
<thead>
<tr>
<th>Sensory Modality</th>
<th>Resource</th>
</tr>
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</table>
| Auditory         | Utube African drum music
                 | Animal sound effects. |
| Gustatory        | Kiwi, mango, banana, pineapple |
| Olfactory        | Satsumas |
| Visual           | Interactive whiteboard presentation
                 | Handa’s surprise |
| Touch            | Fur fabric of zebra pattern and giraffe feather from parrot. |
Sensory story books can be bought commercially or they can be improvised. These stories can further engage individuals if they are encouraged to become interactive by joining in and playing a small part in the story line.

To make Handa’s surprise interactive ask if anyone wants to put the fruit basket on their head or wear Handa’s brightly patterned skirt.

**Adaptation of sensory exercise and activities**

Care and adaptation is required for individuals with profound and complex needs, for some may find it difficult to respond to stimuli through competing channels. This is known as sensory overload for example an individual may not be able to explore and respond to a tactile resource if music is being played or someone is talking.

To avoid sensory overload use simple communication strategies at the appropriate level to meet the needs of each individual person. Sensory rooms with lighting equipment should be used with care with a clear focus on the purpose of the activity. Other sensory resources such as sound to light, wind machines and bubble tubes should not be used randomly as appropriate sensory exercises should also be selective and themed.

Changing the position of an individual is an important factor, the individual may benefit from being hoisted on to a mat or bean bag for sensory activities to become more accessible.

Sensory resources may become personalised to meet the complex needs of an individual. At the early stages of development sucking and putting objects in the mouth is a neurotypical stage of development, this indicates small objects may be inappropriate and will cause a health and safety issue.

When creating a sensory activity a flexible outcome should be planned to make the experience accessible to all. Adaptation is important for individuals who have different sensory impairments and motor disorders and a holistic approach ensures individuals can interact and engage in the experience.

Strategies may involve moving individuals in wheelchairs or frames into the centre of the room to prevent marginalisation and encourage inclusion. Adapting resources for individuals with degrees of sight impairment include using contrasting colours for example yellow on black. An example may be if you are using black hats tie a yellow ribbon around the base. When using shapes
some individuals may be able to hold small cuboids shapes in their hands while others can be supported to touch the outline of a large flat shape and others may touch the image of shapes on the interactive white board.

“Bodies have no limits” if the expectation or outcome of a physical activity is adapted to suit the motor disorders and physical and sensory impairments of individuals. When using music and dance an outcome for a movement for an individual may be to blink their eyes, for another it may be moving a finger or a one hand. For another individual it may be their rotating their arms or tapping a foot.

**Case study - example**
Individuals with PMLD benefit from their involvement in creative projects. The activity leader has planned a music and movement session. The music for this session is the sound track from a science fiction film and creates the sounds of explosion from a space ray gun.

The staff ratio is one to one and the session is fully integrated. The task at hand is to work in pairs to create ideas for movements to interpret an explosion. The group have complex needs and all have different ranges of mobility and the task needs to be adapted so all of the group can participate.

**Participant 1:** Is able to move their facial muscles.
Adaption: Opening and closing their mouth with a facial expression of an explosion.

**Participant 2:** Is able to use their right hand.
Adaption: To flick their finger to express a hand exploding.

**Participant 3:** Is able to use their upper limbs.
Adaption: To throw both their arms in the air from a seated position to give an upper body explosion.

**Participant 4:** Has full mobility.
Adaption: To jump and throw their arms in the air for a full body explosion.
Section 3

Values, Attitudes, Assumptions and Legislation

Covers learning outcome 6
Values, Attitudes and Assumptions

Section 3
This section will explore attitudes and assumptions and look at ways to overcome these barriers. Legislation is also explored looking at the changes that have been made to improve the lives of people with learning disabilities.

Attitudes and Assumptions
There is a growing population of individuals with profound learning disabilities. This is because NHS health services have increased the survival rate of premature births. New medical technology has decreased infant mortality rates and increased the life expectancy of individuals born with profound learning disabilities.

Valuing people with profound and complex needs requires specific initiatives to identify them as a group and focus on their individual needs. Some families feel their sons and daughters born with PMLD may be de-valued by the general population who do not understand the meaning and the quality of their lives. Those with complex needs engage with the world in many different ways and their lives can be enriched by things we all share. Like music, the company of friends, family get togethers and good food. Their contribution to society is not always acknowledged and they can be marginalised. Some people do not realise they even exist and very few services have been created to meet their needs. Although they may lack mental capacity this does not prevent them from having input into their daily life style decisions. “As a result many people with high support needs experience considerable social isolation and low expectations about having a place in the community” (McIntosh 2000).

The PMLD Network recommends that children and adults with profound and complex needs should be high on the government’s agenda and should be represented by advocates. We should all recognise that individuals with PMLD can make choices when given the right support.

To find out more follow the link
http://86.54.121.34/complexneeds/modules/Module-4.2-Safeguarding---privacy,-dignity-and-personal-care/All/downloads/m14p050c/valuing_people_with_pmld.pdf

Mencap feel that communication must be prioritised and staff supporting individuals with PMLD should have specialised training to meet all their needs. The status of those working with disabled children and young people should be
raised and their increased skills should be reflected in their pay. Good support should be person centred to enable the person with profound and multiple learning disabilities to reach their full potential.

www.pmldnetwork.org/.../Mencap_response_2020_Children
http://www.education.gov.uk/complexneeds/

Often words like choice, control, respect, rights, dignity and quality are used to describe the core values that underpin services for people with learning disabilities. These words probably describe what most of us working in the field of learning disability recognise as a clear intention to value people with learning disabilities but does this happen in reality? Government reform has changed the way people with learning disabilities are treated, from being locked away in large institutions to living in local communities but how far changes in attitudes and the value placed on the lives of people with learning disabilities has changed is still a hot topic.

Negative attitudes towards individuals with PMLD even among other practitioners within the field of learning disabilities are evident. Communication is often a problem area; individuals appear to feel uncomfortable as they just do not know how to approach individuals or are alarmed by loud vocalisation and hand flapping and feel this may be aggression. Training in this area is an obvious key issue to elevate needless fears and support other professionals to cope.

The general public may stare or move away from an individual with PMLD and this may be disconcerting for support staff. Comments may be made within ear shot and this is upsetting and may cause anger. A positive attitude and a directional approach will help to overcome these situations.

Discrimination is painful and unjust, but in society today individuals with PMLD are no longer marginalised by living in secluded institutional settings, they are cared for and educated in the community, attending mainstream primary, secondary and further education service providers like the rest of the population.

It is essential that all practitioners have a genuine commitment and belief that individuals with PMLD can and do achieve. If you don’t have this commitment this may be classed as a form of indirect discrimination. All their rights need to be acknowledged or their life chances will be limited.

Proactive ways of overcoming negative attitudes and assumptions can be achieved by raising awareness of the general population at local government
level through campaigns and projects, hoping to remove fears and increase the knowledge of the public. By preserving the rights and dignity of individuals with learning disabilities and developing an equal and diverse culture at work, school, college and in the community. Make changes by example and create your own culture that treats individuals uniquely. Make it known that any discrimination will be reported as a vulnerable adults issue. Embrace Whistle blowing policies “Reporting bad practice is good practice”.

If an assumption is made that an individual cannot progress and stimulating activities to meet their needs are not provided they may lose skills they have already acquired. They may develop routines that are self stimulating, such as hand flapping, repetitive movements and be hard to reach.

Using terms like “I am a non judgemental professional” or “I am a non discriminatory practitioner” are in fact incorrect as everyone makes judgements to some degree. If we are truly to attempt to value people for who they are, we first need to understand the extent to which we do discriminate and make judgements before we can change our action. Mee (2012) states that ‘in order to value a group of people we first need to able to be truthful about the extent to which we de-value them, and this requires deep reflection. Then of course we need to change our behaviour accordingly’. Mee (2012:178).

Here are a few things for us to consider if we are to truly value people with learning disabilities (a sample taken from Mee2012, his list is much longer)

- Be conscious of negative attribution we hold - the first response to challenging behaviour should be- “I assume the person has a completely valid reason for behaving like that”.
- Be aware of any bigger personal values such as political and religious belief and consider any conflicts in values
- Consider the person with a learning disability worthy of sharing the same cutlery, crockery and toilets
- Be happy to share space with a person with learning disability - this may be in a restaurant, theatre, hospital ward or Jacuzzi
- Consider the person with LD worthy of the same dreams and aspirations as ourselves
- Be conscious of significantly lower power status a person with LD has
- Learn to truly listen - this requires an in depth understanding of the person’s linguistic development, communicating at a level beyond that point is actively disabling them.
- Consider what we do professionally as a duty not as a gift
- Understand that working in a valuing way may require a more tentative approach for example reflecting on your practice, letting the control go, be open and transparent
- Be aware that humour is only a positive thing if the person with LD gets the joke
- Challenge bad practice and report abuse
- Act with moral courage by doing the right thing rather than the prescribed thing - if the prescribed thing seems unethical
- Take any opportunity to challenge others if they devalue people with LD

**Care Value Base**

The Care Value Base is a range of standards for health and social care, which should be followed by all professionals working with individuals with PMLD. The overall aim of the standards is to improve service user's quality of life, by ensuring that each person gets the care that is most appropriate to them as an individual.

The main features of the care value base are as follows:

<table>
<thead>
<tr>
<th>Care Base Value</th>
<th>Examples of how this relates to practice</th>
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<tbody>
<tr>
<td>Promoting and supporting the individual's right to</td>
<td>The choice to receive information and support, to make decisions and to take risks. Consulting people so they can tell us what they think and want. Respect to enjoy private time away from others and be treated as an individual. To gain personal satisfaction through independence, social, learning and work opportunities. Supporting individuals to choose their own lifestyle and helping them to accept the consequences. Follow safe practice and report problems with resources (health and safety). Report unsafe practices of colleagues. Help service users to make complaints. Ensure others are informed about risk assessments and follow these.</td>
</tr>
<tr>
<td>dignity, independence, choice and safety</td>
<td></td>
</tr>
<tr>
<td>Acknowledging people's</td>
<td>Respecting and supporting the diversity of people’s experiences, life styles and backgrounds.</td>
</tr>
<tr>
<td>beliefs and identities</td>
<td>Allowing them to go to a place of worship if this is important to them. The role of family and community networks needs to be taken into consideration when planning services for the individual. We must ensure that we meet cultural needs as well as personal care needs.</td>
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<tr>
<td>Maintaining confidentiality</td>
<td>Right to expect confidentiality of all information, whether it is verbal, electronic or written. Care needs to be taken where we discuss individuals and who might overhear that information and who has access to files. (Data Protection Act 1998) Individuals and their families must know they can trust carers. Do not abuse the trust of others in relation to confidentiality. Service user’s safety may be put at risk if personal details are shared publicly.</td>
</tr>
<tr>
<td>Promoting anti discriminatory practice</td>
<td>Carers need to recognise discriminatory practice, stereotypes and assumptions. Carers need to ensure that discrimination does not damage the quality of client care. The right to use mainstream services and be involved in the community. Treating everyone as an individual, taking into account their beliefs, abilities, likes and dislikes. Do not condone discrimination or allow it to go unchallenged. Discrimination can cause, depression, low self esteem, loss of confidence, withdrawal and a lack of belonging.</td>
</tr>
<tr>
<td>Providing effective communication and relationships</td>
<td>Communication used needs to be in the individual's preferred method or methods. Ensure it is accurate and straightforward. We also need to consider if it is in their preferred language i.e. the one they use at home.</td>
</tr>
<tr>
<td>Providing individualised care</td>
<td>Recognising and supporting individual needs. To</td>
</tr>
</tbody>
</table>
receive person centred support to achieve quality of life.

| Protecting individuals from abuse | Respect the rights of service users, whilst seeking to ensure that their behaviour does not harm themselves or other people. Report inappropriate behaviour of other staff (whistle blowing). Do not form inappropriate relationships with service users. |

Legislation
Over the last 40 years legislation and government reports have helped to improve the lives of people with learning disabilities. However some legislation and government reports in the early 20th century had a detrimental impact on the lives of people with learning Disabilities. The Wood Report (1929) suggested it would be better to put people with mental health problems and learning disabilities into self sufficient colonies away from local communities. Large hospital institutions were developed all over the country and people with learning disabilities became invisible. There are many negative elements to living in an institution
- lack of privacy
- no personal possessions
- in many cases devoid of affection
- stories of neglect and abuse
- no choices
- punishments for not conforming
- no stimulation

Most people who experienced this type of care still find the memories painful and find it hard to develop relationships. For a small minority of people living in an institution enabled them to make good friendship with other ‘inmates’ and staff. Some of those people are now living together in the community. Positive changes started in 1970 with the introduction of The Education (Handicapped Children) Act as this recognised that all children had a right to education, including those with the severest of learning difficulties and disabilities thus putting an end to the practice of classifying children unsuitable for education at school.
Community Care

The white paper Better Services for Mentally Handicapped was introduced in 1971 and this advocated a 50% reduction in hospital places by 1991, putting the emphasis on developing local authority residential and day care. The problem with this report was that it carried no power as it had no legislative backing so little changed until the Jay Committee’s report in 1979 re-emphasised the need for local authority provision and more importantly a service based on the principles of normalisation.

Normalisation is a term used to describe patterns and conditions of living that are similar to an ordinary person. The UK adopted five main principles of Normalisation (O’Brien and Thomas 1981 cited by Emerson 1992)

- Community presence - services located in local communities
- Choice - supporting people to make choices
- Competence - developing skills to help a person become more independent
- Respect - promote a positive concept of people with learning disabilities as developing citizens
- Community participation - encouraging participation in the life of the community

Since the introduction of the five main principles of Normalisation there have been many policies and legislative documents that have shaped and changed services for people with a learning disability. The 1989 White paper Caring for People (DOH) emphasised the government’s commitment to developing local service for people with a learning disability. In 1990 the government created the NHS and Community Care Act introducing the notion of a service that would meet individual needs which would involve Social Services with the help of health care professional completing community care assessments. In turn this would help providers develop provision that would enable people to stay in their own homes by increasing domiciliary, respite and day care. Other policies that have helped shaped services for people with a learning disability are:

- Moving into Mainstream (DOH 1998b) - examined the range and quality of services provided for people with a learning disability.
- Signposts for Success (1998a) - set standards for delivery to access for health care
- Once a day (DOH 1999) - set standards for delivery to access for health care
There have been other more generic policies and legislation that still have affected people with a learning disability which include:

The **Disability Discrimination Act 1995** - made it unlawful to discriminate against a person with regard to their attainment of goods and services, buying and renting of land or property and employment. This has now been replaced by the **Equality Act 2010** which has the same duties but also includes functions of public bodies for example the issuing of licences. The Equality Act also provides rights for people not to be directly discriminated against or harassed because they have an association with a disabled person. This can apply to a carer or parent of a disabled person. In addition, people must not be directly discriminated against or be harassed because they are wrongly perceived to be disabled.

The **Social Care institute (2011)** says: “The Equality Act 2010 provides a legal framework which can support personalisation in adult social care. It is about ensuring individuals receive services that are respectful, effective and accessible.” This can only be a good thing as personalisation starts with the person as an individual with characteristics, preferences and hopes, putting them at the centre of the process where their needs are identified and allowing them to make choice about how and when they are supported. This means that everyone should be geared up to put people with PMLD first.

**Human Rights Act 1998** - aims to protect all people by ensuring their rights to freedom of expression, liberty and security, respect for private life, marriage, education, prohibition of discrimination and torture, and life itself.

**The Mental Capacity Act 2005** is a statutory (legally binding) framework for ‘empowering’ vulnerable people to have more control over their own decisions. It is often used when important decisions need to made about a person’s life. If it is deemed that the individual does not have the capacity to understand what is being proposed and how they will be affected then professionals, Parents and Carers may be involved in making the decision on their behalf ensuring the best interest of the individual remaining the most important factor of any decision made.

**Valuing People 2001**
The Valuing People white paper was primarily set out on a five-year action plan from 2001. By publishing this white paper, the UK Government were clearly setting out their intentions to improve services and support for the learning
disabled from birth through to old age. The basic goal of the initiative published reinforces four main beliefs of the UK Government:

- That people with learning disabilities should have equal legal and civil rights
- That people with learning disabilities should be given the chance and the means to lead more independent lives
- That people with learning disabilities should have more choice and be able to express and achieve their preferences
- That people with learning disabilities should be included in mainstream society

The government hoped to achieve these goals by improving and modernising transport, education, health and care services, and providing people with learning disabilities with more choice for housing arrangements, and greater support for finding employment and making their own choices. They set aside money in the form of the Learning Disability Development Fund to help fund the changes that they deemed necessary.

The UK Government believed that by making it easier for people with learning disabilities to be active, seen and heard within their local communities, they wouldn’t be so ostracised or marginalised. The hope was that society’s attitudes on some level would also change.

**Putting 'Valuing People' Into Action**

Valuing People hoped to firstly bring together two major services - social services and health services, to work better together and provide greater support and opportunities for people with learning disabilities. This in turn involved local authorities setting up Learning Disability Partnership Boards throughout England and Wales. Between 2002 and 2003 these partnership boards then had to write proposals detailing just how they intended to make the Valuing People initiative work in their local area. Since that time, each local authority should have been putting their proposals into action.

The UK Government was, however, clear that the goals set out in this white paper, although initially set out over a five-year period, would take quite some time to come into fruition. There have been criticisms by some groups for people with learning disabilities who believe that despite the good intentions of the white paper, little change has occurred since the paper was published. The Government set up the Learning Disability Task Force so that they could review the progress of these Valuing People initiatives in action. They also put together a Valuing People Support Team that would operate on a national scale, assisting where required.
It is thought that although progress is slower than perhaps anticipated, there is now at least some action being taken to address the issues faced by people with learning disabilities, and the goals remain the same – equal rights, self-centred planning and social inclusion.

Valuing people now (2009) - This was set up as the government felt that targets identified in Valuing People (2001) were not being reached and they wanted to put more emphasis on equal rights, enable people with learning disabilities to have greater control over their lives, be included in their local communities and get appropriate healthcare to allow them to live a healthy live. Valuing people now (2009) says people with learning disabilities and their families should

- have the same rights as everyone
- be treated with dignity and respect
- have the same chances and responsibilities
- have the right to the same hopes and choices as other families do

The main summary

All benefit from Valuing People but Now:-

- have greater control over their life and have support to make person centred plan
- have a choice about where they live and who they live with.
- get the healthcare they need and the support needed to live a healthy life
- have a good life with chances to work, study, and enjoy leisure and social activities
- be supported into paid work - this includes people with more complex needs
- have the choice to have relationships, become parents and carry on being parents, with the appropriate support
- be treated as equal
- be able to speak up about what they want from life. Appropriate support should be provided to achieve this
- be able to use public transport safely and easily
- feel confident that their right to live in safety is supported by the law, police and prison service

Since 2009 services for people with learning disabilities have been changing and there is a far greater emphasis on self directed payments allowing people to have more control of the services they buy and a move towards supported living as opposed to residential homes. In theory these changes allow people to be
more in control of their lives but in reality funding restraints still restrict people’s choices.

Valuing People has improved health service and care of individuals with PMLD in the following way:

- The implementations of annual “Well Persons” health checks at GP’s surgeries are in place. Doctors are now proactive in checking patients for undetected conditions.

- “Health Action Plan” supports Key Workers to have action plans for individuals with PMLD and informs support staff of guidelines to deliver intensive daily care routines. The Health Action Plans include dental health to dietary requirements, weight gain or loss; detailed records of appointment, attendance and outcomes to psychologist, speech therapist and hospital consultants.

- “The Hospital Passport” is a document now in place for individuals with learning disabilities. This passport improves access to health services by informing health professionals and emergency services of essential information about their patient. Information is graded on a traffic light system, from red, amber and green depending on its priority.

For more information on Valuing People (2001) go to: www.valuingpeople.gov.uk/
For Valuing people Now (2009) go to:

Every Child Matters 2003
Every Child matters 2003 is the biggest initiative that has been implemented to support children to develop and achieve. This was a green paper launched by the UK government in September 2003 in response to the death of Victoria Climbié, who unfortunately died of neglect without support from child care professionals.
Victoria Climbié was tortured and murdered by her guardians in 2001. She was only eight years old; this led to a public enquiry and major social reforms in child protection.

To prevent this from happening again "Every Child Matters " is funded to protect children and is extended to young adults up to the age of 19 to 24 who have disabilities. Ofsted promote the values of this initiative in schools and colleges in Great Britain to protect children and promote their development and growth into adulthood.

The five main aims are for every child and young adult, whatever their cultural background or financial circumstances to:
- Be healthy
- Stay safe
- Enjoy and achieve
- Make a positive contribution
- Achieve economic well-being

<table>
<thead>
<tr>
<th>Every Child matters</th>
<th>Relevance to individuals with PMLD</th>
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<tbody>
<tr>
<td><strong>Being healthy</strong> - this outcome deals with the extent to which providers contribute to the development of healthy lifestyles in children. Evidence will include ways in which providers promote the following: physical, mental, emotional and sexual health; participation in sport and exercise; healthy eating and the drinking of water; the ability to recognise and combat personal stress; having self-esteem; and the avoidance of drug taking including smoking and alcohol. There should also be</td>
<td>To be involved in best interest decisions regarding food choices and exercise. Developing self advocacy skills. Learning to express choices and preferences and be involved in lifestyle decisions. Staff to support individuals to have an impact on their own environment.</td>
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an assessment of the extent to which appropriate support is available for both students and staff to help achieve these positive outcomes.

**Staying safe** - this outcome is principally about the extent to which providers contribute to ensuring that ‘children’ stay safe from harm. Evidence includes complying with child protection legislation, undertaking CRB checks, protecting young people and vulnerable adults from bullying, harassment and other forms of maltreatment, discrimination, crime, anti-social behaviour, sexual exploitation, exposure to violence and other dangers. Ensuring that all relevant staff are appropriately trained.

| Trained support staff for manual handling and personal care routines. | Robust procedure for risk assessments and implementing control measure. Reporting of vulnerable adult issues appropriately. Policies and procedures in place. To understanding and deal with challenging behaviour. |

**Enjoying and achieving** - this outcome includes attending and enjoying education and training, and the extent to which learners make progress with regard to their learning and their personal development. Evidence to evaluate this includes arrangements to assess and monitor learners’ progress, support learners with poor attendance and behaviour, and meet the needs of potentially underachieving groups. Also relevant will be the extent and effectiveness of the ‘enrichment’ of provision by promoting social, cultural, sporting and recreational activities. Learners’ views about the degree to which they enjoy their ‘learning life’ are taken into account here.

| Assessments to plan routes for learning and track progression. The need for realistic and challenging lesson planning. Taking account of personal needs and preferences. Family and cultural values and background. |

**Making a positive contribution** - this outcome includes the development of self-confidence and enterprising behaviour in learners, together with their understanding of rights and

| Being involved in your personal care routines and becoming more independent. Accessing the facilities and being a part of the community. Personal centred planning and being involved in major decision. |
responsibilities, and their active participation in community life. Evidence includes measures to ensure understanding of rights and responsibilities, the extent to which learners are consulted about key decisions, and the provision of opportunities for learners to develop and lead provider and community activities. There should also be a focus on enabling young people to develop appropriate independent behaviour and to avoid engaging in antisocial behaviour.

**Achieve economic well-being** - this outcome includes the effectiveness of the ways in which the provider prepares learners for the acquisition of the skills and knowledge needed for employment and for economically independent living. Evidence includes arrangements for developing self-confidence, enterprise and teamwork, the provision of good careers advice and training for financial competence, and the accessibility of opportunities for work experience and work-based learning.

Develop communication skills to support individuals to access curriculum. To achieve numbered steps to increase the neuro typical development of the brain. To react and respond to stimuli through sensory activities and exercises.

The Children Act 2004

The Children Act 2004 aims to further improve children’s lives and gives the legal underpinning to ‘Every Child Matters. The act places a duty on Local Authorities to make arrangements to promote co-operation between agencies in order to improve children’s well being, defined to the five outcomes of Every Child Matters. It also required Local Authorities to set up statutory Local Safeguarding Children Boards and that the key partners take part. This is to ensure children do not slip through the net.
**Improving the Life chances of Disabled people 2005** (taken directly from the report) Prime Minister's Strategy Unit

This report sets out an ambitious programme of action that will bring disabled people fully within the scope of the “opportunity society”.

The report proposes that the Government should set an ambitious vision for improving the life chances of disabled people. ‘By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society’.

It has four key elements

- Helping disabled people to achieve independent living by moving progressively to individual budgets for disabled people, drawing together the services to which they are entitled and giving them greater choice over the mix of support they receive in the form of cash and/or direct provision of services.

- Improving support for families with young disabled children by ensuring families of disabled children benefit from childcare and early education provided to all children; meeting the extra needs of families with disabled children; and ensuring services are centred on disabled children and their families, not on processes and funding streams.

- Facilitating a smooth transition into adulthood by putting in place improved mechanisms for effective planning for the transition to adulthood and the support that goes with this; removing “cliff edges” in service provision; and giving disabled young people access to a more transparent and more appropriate menu of opportunities and choices.

- Improving support and incentives for getting and staying in employment by ensuring that support is available well before a benefit claim is made; reforming the gateway onto entitlements; providing effective work-focused training for disabled people; and improving Access to Work and other in-work support - all of which will see more disabled people in work, contributing to the Government’s overall targets for employment.

Some measures have been put in place for disabled people to receive direct payment giving them greater control of their lives and where people with PMLD have control of direct payments they are able to buy in the services they need within their limited budgets.
Funding for education in Further Education is in the process of changing and is referred to under The Special Education Bill 2012

For more information

The Health and Social Care Act 2008
This Act impacts on those with PMLD who live in residential homes, supported living homes, receive personal care support in their own home and also access health services. This sets out the minimum level of care and support they should expect to receive and how this should be delivered. The Care Quality Commission inspect under this legislation and if the standards are not being met will set requirements or if they could be improved on set recommendations. This means that the individuals with PMLD should be experiencing a high level of care and support.

Autism Act 2009
The Autism Act 2009 was the first ever disability-specific law in England. The Act did two key things.
The first was to put a duty on the Government to produce a strategy for adults with autism, which was published on 2 March 2010.
The second was a duty on the Government to produce statutory guidance for local councils and local health bodies on implementing the adult autism strategy by the end of 2010. This guidance was published on 17 December 2010.
This should make sure that more people understand autism and how this impacts on their daily life. In the strategy the government have highlighted that local councils and health services need to write plans so that the adults with autism who live in their area get the help that they need. This is a massive step forward for people with autism as, up to now, adults with autism have struggled to get the services and support they need. There should be training for staff which can only create greater awareness of the issues

Funding for Further Education provision
Under the Equality Act 2010 in England and Wales the Local Authority has a duty to secure suitable education to meet the reasonable needs of all learners under the age of 19 and in England the Local Authority also has this duty to learners under the age of 25 if they have a Section 139a assessment. This may include a placement at a residential college if local provision cannot meet the learner needs. A place at specialist colleges will be funded by the Young People’s Learning Agency (YPLA) if you are from England or DCELLS in Wales.
• *The YPLA will change to the Education Funding Agency (EFA) in April 2012.*

This is all set to change with the introduction of the Special Education Bill (2012)

**Children and Families ACT (2014)**

A single assessment system, leading to an education, health and care plan that stays in place from birth to the age of 25, is intended to replace the 'cliff edge' with a seamless pathway. It will extend the statutory protections of the statement all the way through college. You won't have that transition at 16, it will stick with them. It should be simpler

**What will happen?**

- Introduce a new assessment system
- It will merge three different budgets which (former FE funding body) the Learning and Skills Council couldn’t: the budgets for sixth forms, the budget for independent specialist providers and then the money that goes for high-cost students in colleges, higher-level additional learning support.
- It will save money - Colleges are able to support students with profound and multiple learning difficulties for an average of £30,000, compared with £68,000 in residential colleges, making some savings possible. But the Department for Education denied that cost was a motive.

**Flaws in the Act**

- The ministers want to define education after school narrowly. University education will not be included nor are apprenticeships.
- If students leave education and return, they need to be reassessed and may have to fight to regain their previously agreed level of support.
- The education provision is guaranteed by law however the health and social care provisions are not. Last year, an estimated 3,600 people went to tribunals to ensure that they received the right education support. But if the health or social care aspect of the plan fails, families have no recourse, and it may derail students’ education.

The Act replaces the Statement of SEN and Learning Difficulty Assessments (LDAs) for those over the age of 16 with Education, Health and Care (EHC) Plans. If following assessment, special educational provision is required, local authorities must secure that
an EHC Plan is prepared and subsequently maintained for a child or young person

What is an Education, Health and Care (EHC) Plan?

An EHC Plan looks at all the needs that a child or young person has within education, health and care and sets out a plan of to meet these needs

How is the EHC Plan Developed?

Professionals and the family together consider what outcomes they would like to see for the child or young person. This plan identifies what is needed to achieve those outcomes.

Who will have an EHC Plan?

The Department for Education has stated that a child or young person who currently has a Statement of SEN will have an EHC Plan. EHC Plans will be issued when the special educational needs of a child cannot be reasonably provided for with resources normally available to mainstream early year’s provision, school and post 16 institutions.

Winterbourne View Hospital – A Serious Case Review by Margaret Flynn 2012

Winterbourne View Hospital was a private hospital for adults with learning disabilities and autism, mostly accommodating patients who were detained under the provisions of the Mental Health Act 1983.

An undercover reporter secured employment as a support worker at Winterbourne View Hospital. During his five weeks as a Castlebeck Ltd employee he filmed colleagues tormenting, bullying and assaulting patients. Fundamental principles of healthcare ethics such as respect for autonomy beneficence and justice were absent at Winterbourne View Hospital

Some recommendations from the report

- Best place to care for people with learning disabilities and Autism is in their homes and local community
- There should be a condition of employment on all health and social care practitioners (registered and unregistered) to report operational
concerns to (i) the Chief Executives and Boards of hospitals, (ii) the regulator

- Accident and Emergency can detect instances of reattendance from the same location as well as by any individual.
- Reducing the use of anti-psychotic medication with adults with learning disabilities and autism requires attention. An outcome of the National Dementia Strategy (Department of Health, 2009) was an investment in reducing anti-psychotic medication for patients with dementia (Banerjee, 2009). Adults with learning disabilities require no less
- Discontinuing the practice of supine restraint i.e. restraint that results in people being placed on the ground with staff using their body weight to subdue them

To read more in depth information about this report go to:
Reference and Links


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Mansell, J. (2010) Raising our sights: services for adults with profound intellectual and multiple disabilities, London,


NHS (2012) *Top tips for supporting and meeting the needs of people with profound and multiple learning difficulties*. Midlands and East: National Health Service


PAMIS (2011) *Top tips for supporting and meeting the needs of people with PMLD*


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