Working with People who have a Learning Disability and Complex needs

the essentials
Contents

Introduction

Module 1: A Contemporary Overview

Module 2: Understanding Complexity across the Lifespan for People with Multiple Disabilities

Module 3: Managing Physical Health and Well Being

Module 4: Complexity in Care and Communication

Module 5: Mental Health and Well Being

Module 6: Managing and Understanding Complicated Behaviours
Welcome to Working with People who have a Learning Disability and Complex needs – the essentials

This learning resource has been developed by Edinburgh Napier University, The University of Stirling and The Learning Disability Managed Care Network. The resource aims to offer workers supporting people with a learning disability and complex needs opportunities to develop their knowledge, skills and values in ways that maximise the involvement of service users and families and increase health and wellbeing. To promote the provision of support that maximises quality of life, choice, opportunity and capability.

The materials have been designed to present a contemporary picture, be engaging for learners and enable learners to apply learning in a range of practice settings. This is a work based learning resource with a focus on learners reflecting on their own practice, enabling learners to make changes in their practice that can positively impact on the experiences of service users, families and carers. The materials aim to support change by presenting key topics in relation to working with people who have a learning disability and complex needs and practical guidance to help workers develop new roles, relationships and ways of working with service users, families and wider communities.

The learning materials consist of six modules

At the start of each module we estimate the number of hours it should take to complete. The level of study involved in the modules links to the Scottish Credit and Qualifications Framework (SCQF). The module content and learning outcomes have been developed to reflect a level of learning that equates with Level 8 on the SCQF. This is equivalent to the level of study you would undertake in the second year of an ordinary degree programme.

Working with People who have a Learning Disability and Complex Needs – the essentials Modules:

1. Module 1 – A Contemporary Overview
2. Module 2 – Understanding Complexity across the Lifespan for People with Multiple Disabilities
3. Module 3 – Managing Physical health and Well Being
4. Module 4 – Complexity in Care and Communication
5. Module 5 – Managing and Understanding Complicated Behaviours
6. Module 6 – Mental Health and Well Being

How do I undertake this learning?

The learning materials have been designed so they can be studied as a self-directed learning resource, but we recommend that opportunities for facilitated group discussions should be offered to help learners put individual experiences into broader context and enhance learning. This can be achieved by:
Introduction

• Setting up a learning group
• Using existing opportunities such as supervision, team meetings or away days

Learning will be significantly enhanced by opportunities to share and discuss ideas with others and learning support and supervision should be provided for the duration of the learning. Some of the activities clearly lend themselves to group discussion.

We hope these learning materials will provide you with new knowledge, skills and values and encourage you to implement new ways of working with service users and their families. Reflecting on your practice is essential during learning. You are required to reflect deeply on yourself and your experiences and this can be a challenging experience for many. Being part of a study group will give you the opportunity to gain from mutual support, share your learning and gain insights from other people’s experiences.

There is no set timescale suggested for completing the learning resource and while the materials could be delivered as an intensive, facilitated course delivered over a block of days. We would suggest that learning will be enhanced if the materials are studied over 12-16 weeks. This will give learners time to reflect on their learning in the context of their workplace.

Learning Outcomes

On completion of the learning resource you should be able to:

1. Demonstrate understanding of the complex and multiple factors which influence the support and care of people with a learning disability and complex needs in a range of care settings
2. Critically reflect on the essential skills required to provide person-centred and evidence based support and interventions for people with a learning disability with complex needs
3. Demonstrate a respect for diversity and an understanding of the impact of discrimination on people with a learning disability and their family carers, demonstrating a commitment to challenging any equalities experienced by people with a learning disability and complex needs and their families/carers
4. Critically reflect on your own current practices and values and how these may be developed to maximise opportunities for people with a learning disability and complex needs to make choices about how people live their lives and have those choices respected and acted upon wherever possible
5. Explore the knowledge and skills required to provide person centred and outcome focused evidence based support and interventions for people with a learning disability and complex needs that can be applied in a range of care settings
Module 1: A Contemporary Overview
Module 1: A Contemporary Overview

Introduction

This module will provide a contemporary overview of the needs of people with a learning disability. We will briefly consider definitions, terms and prevalence and historical perspectives before exploring in more depth the changing picture of needs, models of care and the principles on which care is based. A number of concepts introduced in this module will be returned to throughout the learning resource such as person-centred approaches to care, interprofessional working and maximising opportunities for people with learning disabilities and complex needs.

On completion of this module you should be able to:

• Explore your understanding of what it means to have a learning disability and complex needs
• Demonstrate an understanding of the development of services for people with a learning disability and the key issues for contemporary practice
• Critically reflect on the changing picture of needs and how this may impact on your role, knowledge and skills development
• Demonstrate understanding of a range of principles of care and how your practices can be developed to maximise opportunities for people with a learning disability to direct their care and enable social inclusion

Activity: Identifying Existing Knowledge, Skills and Areas for Development

Spend a few minutes identifying your existing knowledge, skills and areas for development in relation to supporting people with learning disabilities and complex needs manage their mental health and well-being – make some notes below

Existing Knowledge:

Existing Skills:

Areas for Development:
Definitions

There are a number of different ways of defining and classifying learning disability and they are all open to different interpretations. The term *learning disability* itself can be confusing. In the USA, it means a disorder of the basic processes involved in understanding or using language, such as dyslexia. The current accepted international terms are *Intellectual Disability* or *Developmental Disability*. Other terms such as Mental Handicap, Learning Difficulty and Mental Retardation have been used in the past and still are acceptable in some places.

Activity: Identifying Existing Knowledge, Skills and Areas for Development

Now click on the link below to access the *The Same as You?* (Scottish Executive, 2000) and write down the definition they use for learning disability? Are there any differences between this one and yours?

http://www.scotland.gov.uk/ldsrdocs/tsay-00.asp

Activity: Defining Learning Disability

In the space provided below write down your definition of the term learning disability.

The term learning disability is a social construction (a social construction is an idea that appears to be natural and obvious to people who accept it but may or may not represent reality, so it remains largely an invention of a given society, in order to support meaning), the name and definition of which have changed over the years, depending partly on the way services were provided in relation to the perception of needs at any given time. It is important to remember that the term learning disability is a label, which can be convenient in ensuring a shared understanding, but this label only describes one aspect of the person. People with this label also carry a number of other labels such as brother, parent, friend, colleague, neighbour, it is important we recognise that a label does not capture the whole person (BILD, 2011).
Although there is no general consensus it is clear that whatever term is used should be positive and inclusive (BILD, 2011). For the purpose of this learning resource we shall use the term learning disability and the definition used within ‘The Same as You’ (Scottish Executive, 2000, p. 15).

‘People with learning disabilities have a significant, lifelong condition that started before adulthood, that affected their development and which means they need help to understand information, learn skills and cope independently’.

This learning resource is designed for staff who support people with a learning disability and complex needs. Complex needs can also mean different things to different people and for the purpose of clarity, when we use the term complex needs we mean a person who has a range of ‘layered’ issues.

‘Needs arising from both learning disability and from other difficulties such as physical and sensory impairment, mental health problems or behavioural difficulties’.
(Scottish Executive, 2000, p.15).

Another term you will come across in this learning resource is ‘profound and multiple learning disability’. People with profound and multiple learning disabilities are among the most disabled within our community and this term refers to people with:

‘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’.
(Mansell, 2010, p3).

**Recommended Reading & Resources:**

If you are interested in finding out more about definitions and labelling you can visit the BILD website pages below

http://www.bild.org.uk


**Prevalence**

Prevalence is the estimation of the number of people with a condition as a proportion of the general population. The number of people with a learning disability in Scotland is unknown; estimates are in the region of 20 people in every 1,000 with mild or moderate learning disabilities and 3 to 4 people in every 1,000 with severe or profound learning disabilities. About 27,671 adults with a learning disability are known to Local Authorities across Scotland (SCLD, 2009).

On a statistical basis 2.5% of the population should have learning disabilities. In fact, prevalence seems to be
lower at about 1-2%, giving a total of between 602,000 and 1,204,000 in a UK population of 60.2 million. This is thought to be due to higher mortality rates among people with more severe learning disability than in the general population. Also not all cases of mild learning disabilities are identified. We can be more accurate about the numbers of people with moderate to profound learning disabilities because they almost all use services of some kind. They are thought to represent 0.35% of the total UK population, or about 210,700 people (BILD 2011).

Activity: Prevalence

Why do you think it could be important to have an understanding of prevalence?

You may have mentioned that having an understanding of the numbers of people with a learning disability can help us plan appropriate service provision. This is important along with an understanding of what it means to have a learning disability, as this information helps services predict need and design services that are responsive to those needs. Having information about incidence and prevalence can also help us identify if patterns are changing and this too can be important in ensuring we have the best service provision and skills sets, required to appropriately provide person centred and holistic support.

A Historical Perspective

Activity: Historical Perspective

Follow the link to ‘A brief history of learning disability’ by Helen Atherton

http://www.healthcareimprovementscotland.org/home.aspx

Feel free to read all of this - but the section we want you to look at for this activity is the timeline on pp: 42-43. Once you have read this, take the statements and terms over the page and place them where you think they belong. These statements represent key moments in history, how society viewed people with a learning disability and the values and principles in services at that time.
Module 1: A Contemporary Overview

5 Accomplishments
- Adults with incapacity
- Segregation

Lunatics
- Person centred planning
- Witchcraft

Human Rights
- Community care
- Feeble minded

Darwinian theory
- Compulsory sterilisation
- NHS created

Same as You
- Health Needs report
- Imbecile

Personalisation
- Value based approaches
- Eugenics

Bleeding/Emetics
- Chaining/Whipping
- Keepers who are feared

Normalisation
- Social role valorisation
- Evidence based practice

Inclusion

Learning disability seen as distinct from mental illness

Occupation & Training

<table>
<thead>
<tr>
<th></th>
<th>1400</th>
<th>1500</th>
<th>1700</th>
<th>1800</th>
<th>1900-47</th>
<th>1947-2000</th>
<th>2000-present</th>
</tr>
</thead>
</table>

Institutional Care       An Ordinary Life
A wide number of philosophical and legislative shifts in ideology have impacted on the lives of people with a learning disability and their carers over the years. Changes in ideology over the years have seen perceptions move from people with learning disabilities being feared and dehumanised, to being seen as in need of care and protection, to a welcome and significant emphasis on people being seen as capable citizens with rights. Within the last 40 years we have moved from institutional models of care, with the closure of long-stay institutions to models of care which promote social inclusion and ordinary living. These shifts in perspectives should be celebrated and embraced as they give opportunity, choice and the potential for further positive developments.

However despite major shifts forward many people with a learning disability continue to face difficulties in living what Johnson, Whalmsley and Wofle (2010) describe as ‘a good life’. Some people with a learning disability still do not have:

- the sense of belonging to their community that they would like
- the relationships they would like
- the meaningful occupation/activity they would like or
- the choice and control over their life they would like

This learning resource has a focus on people with a learning disability and complex needs and it is worth noting that Emerson (2005) states that people with more severe learning disabilities are likely to experience a poorer quality of life than people with less severe learning disabilities.

You may have mentioned that having an understanding of the numbers of people with a learning disability can help us plan appropriate service provision. This is important along with an understanding of what it means to have a learning disability, as this information helps services predict need and design services that are responsive to those needs. Having information about incidence and prevalence can also help us identify if patterns are changing and this too can be important in ensuring we have the best service provision and skills sets, required to appropriately provide person centred and holistic support.

Recommended Reading & Resources:

If you are interested in finding out more about the history of learning disability you can visit the Webpages of the Social History of Learning Disability at

http://www.open.ac.uk/hsc/ldsite

If you are interested in reflecting further on what ‘a good life’ should mean for people with a learning disability have a look at:

A Changing Picture of Needs

The population of people with a learning disability is changing. We have a growing population due to a number of factors. Advances in care mean that pre-natal survival rates are increasing and improvements in health and social care services mean that people with a learning disability are living longer. The incidence of children and adults with a learning disability is increasing. The evidence base also indicates increases in substance abuse, foetal alcohol spectrum disorder, attention deficit disorder, and autistic spectrum disorder (Blackburn et al. 2010; MacKay et al. 2010). We have a growing population of children and young adults with profound learning and multiple disabilities (Mansell, 2010; Parrott et al. 2008). We also have a growing number of adults with a learning disability living into older age and experiencing the associated health needs of ageing (Torr & Davis, 2007). This in turn leads to an increasing population with more complex needs than previously seen, commonly comprising of multiple coexisting conditions.

We have a robust evidence base illustrating high and unmet health needs experienced by people with a learning disability (Cooper et al, 2004; NHS health Scotland, 2004; Disability Rights Commission, 2006). We know that compared to the general population people with a learning disability experience a different pattern and higher frequency of health disorders (Cooper et al. 2004), including respiratory disease, cardiovascular, gastric, neurological, haematological, musculoskeletal disorders, sensory impairment and mental illness (NHS Health Scotland, 2004). It is common for people with a learning disability to present with multiple complex physical and mental health needs, coupled with communication challenges this leads to a particularly vulnerable group in terms of accessing and receiving care and support (RCN, 2011).

In addition life expectancy is significantly lower than the general population, with mortality rates reported as three times higher than the general population (Tyler et al. 2007). People with a learning disability are frequent users of health services (Brown et al. 2010) however there is significant evidence suggesting their needs are often poorly met and many experience significant barriers to accessing appropriate health care (NHS Health Scotland, 2004; Melville et al. 2006; Noncon et al. 2008; Curtice et al, 2001). Access to both health and social care services is an increasing problem for many people with a learning disability and their families, with reports that people face prejudice, discrimination and low expectations when trying to access appropriate services (Mansell, 2010; Mansell and Wilson, 2010).
Activity: A Changing Picture of Need – what does this mean?

Reflect on what you have just read – how do you think this changing picture will impact on your role? – spend about 20 minutes on this activity

What additional knowledge will be important to you in your role?

You may have mentioned:

• Your role may change in that you may be supporting people with more complex needs and multiple presentations
• A need for you to increase your knowledge around the evidence base of the specific conditions that are increasing in incidence to ensure you continue to meet people’s needs

What skills will be important to develop?

You may need:

• a knowledge of service models and the ability to work alongside a wide range of services
• It may become more important for you to have the knowledge and skills to provide advice, education and support to people with learning disabilities and their families
• You may need to further develop your knowledge and skills in promoting person centred approaches and self-directed support particularly for people with more complex needs
• You may need to develop your knowledge and understanding to safeguard and promote the rights of people with a learning disability, especially when they are vulnerable
• You may need to develop your ability to undertake comprehensive assessments of health and social care needs
• You may need to develop skills in being able to work with people with a learning disability and complex needs and their families to promote opportunity, choice and capability
• You may need knowledge and skills to enable equality of access and reduce marginalisation within health and social cares services and the wider community
• You may need to become increasingly skilled in collaboration with people with a learning disability, families and other professionals and disciplines
• You may need to increase your knowledge and skills in promoting healthy lifestyles and choices
Activity: Changing Patterns of Needs

Follow the link below to access and read ‘Raising our Sights: services for adults with profound intellectual and multiple disabilities’ a report by Professor Jim Mansell reviewing services for adults with profound learning and multiple disabilities in England.


We suggest you download and save this report (we will be coming back to it). For the time being as you read this report, note down the information that you think is significant to you in your role.

Recommended Reading & Resources:

We will look in detail at a range of health needs in this learning resource but if you are interested in finding out more about the health needs of people with a learning disability at this point, you can access.


Provides a comprehensive and systematic review of physical and mental health conditions experienced by people with a learning disability.


Changing Models of Care

It has become apparent that current learning disability services need continuing development to provide appropriate levels of care and support to people with complex care needs. There are a small but increasing number of people who require different service models to ensure that their needs are effectively met in the future.

The current model of provision is not currently able to respond to the needs of these small numbers of people. As you have identified earlier it is apparent that the complexity of care needs within this group is increasing and at the same time the numbers of people presenting...
with these complexities is also increasing. This is evidenced in the literature and is also apparent in the information that has been gathered in a recent project being undertaken by the Learning Disability Managed Care Network.

Activity: The Learning Disability Managed Care Network

Access the Learning Disability Managed Care Network at the following
http://www.nhsforthvalley.com/LDMCN/LDMCNHomePage.html

Now answer the following questions

Who are the MCN’s partners

What groups does the MCN host?

What does the MCN do?

What is the Models of Care Project?

The models of care project are attempting to describe a full spectrum of care including models of service provision for people with a learning disability who also have complex care needs. The complex care needs that are encompassed within the project are People who have a learning disability and:

- Mental health needs
- Severe challenging behaviour
- Forensic men
- Forensic women
- Autism
- Profound and multiple learning disability.

It has been identified that services in both health and social care cannot currently cope with the rising demand from people within the above groups. In 2007, Mansell
reported that there are still community placement breakdowns and that increasingly out of area placements are used as a solution (DoH 2007). These placements are often very costly despite the fact that they are often of poor quality and may be very institutionalised (DoH 2007). It is also apparent according to Pritchard and Roy (2006) that when out of area placements are used there are difficulties with monitoring the quality of service provision and a tendency towards using congregate models of care. It should be recognised that this situation is often created in childhood when a child is placed in an out of area residential school. McGill (2008) identified that two thirds of residents in out of area placements had previously been placed in a residential school – often run by the same provider.

In the United Kingdom out of area placements often occur because there is inadequate planning and management in terms of preventing crisis’s occurring. Assessment and treatment beds within health provision are often full and there are some delayed discharges. This leads to a situation where when a crisis does occur there is no service available locally. The models of care project (Kwiatek 2011) identified the following issues for consideration.

1. Planning for the future
   • The reasons for placement breakdown need to be analysed and then used to predict future needs
   • Plans to overcome crisis and therefore prevent admission to specialist health services including proactive and reactive strategies should be developed
   • The development of robust services that support people to maintain their current placement
   • The use of telecare and telehealth care needs to be explored (Kerr et al 2010). The latter would enable us to get information on challenging behaviours into the system and would also allow for the monitoring and evaluating of interventions

Recommended Reading & Resources:

If you would like to find out more about telecare and telehealth care you should access a copy of Kerr B, Cunningham C, Martin s, Watchman K, (2010) Telecare and Learning Disability. Using telecare effectively in the support of people with learning disabilities. Edinburgh, Joint Improvement Team.

Or click on the link below to find out how the Joint Improvement Team at the Scottish government are promoting telecare

http://www.jitscotland.org.uk/action-areas/telecareinscotland/

   • There should be development of short breaks and respite services
   • There should be consistency in relation to admission across health provision and one point of entry into health should be explored
   • If admission to health is required there should be planned discharges with clear pathways out that are developed in partnership

2. Repatriation
   • Criteria for repatriation should be developed that will enable all areas to be consistent in their decision making
   • New services should be developed to meet the needs of the people who are to be repatriated
These services will need to be cost effective and there needs to be a projection of future savings.

It may be necessary because of small numbers in each area for one area to become a lead in the development of a specialist service. Other areas could then use this resource as required.

3. Improving existing provision
   - Strategic rather than reactive planning
   - Commissioners should demonstrate value for money by identifying specific outcomes for the individual receiving a service (DoH 2007)
   - At a systems level one outcome could be low number of placement breakdowns and out of area placements
   - Low value high cost services should be replaced by better alternatives
   - Continued development of specialist multi disciplinary support teams across the MCN

4. Commissioning for service development
   - Identify current expenditure on learning disability including hidden costs.
   - Audit existing services
   - Assess need
   - Develop partnerships
   - Plan services together to meet future need (all from DoH 2007)
   - Making self directed support an option for more people (Poll et al 2006)

**Recommended Reading & Resources:**

For more information on self directed support please visit the following on the Scottish governments web site:

http://www.scotland.gov.uk/Topics/Health/care/sdsbill

http://www.selfdirectedsupport.org.uk

http://www.scotland.gov.uk/Publications/2010/02/05133942/0

You will look at self directed support and personalisation in more detail later in the module.

Children who are born with complex needs now, are more likely to live into adulthood and adults with complex needs also have greater life expectancy (Emerson 2009, Emerson and Hatton 2009). This means that services are required by more and more people. This is borne out both in practice and in the literature. Indeed in the emerging literature it also suggests that this will be a continuing trend.

There are issues when these children move from child to adult services (Mittler 2007, Cheseldine 2010). It is clear that currently services cannot respond adequately. Operational managers and planners of services for people with learning disabilities who have high complex care needs recognise the need for more effective forward planning for this transition period in order to ensure that
community services across health, social care and the independent sector develop robust ways of providing care and support whilst enabling inclusive lives.

There is evidence that people with learning disabilities and complex needs are now living longer (Torr and Davis 2007). This has a dual effect in that those that are in receipt of services require this for longer and that those not previously in receipt of services may require a service as their parent or carer becomes older and frailer. It is also apparent that whilst some areas are able to provide respite care to support families that this is not consistent across the Scotland. It is apparent that services need to be developed within this area.

Supporting Health, Promoting Inclusion (SEHD 2002) used a tiered approach to identify care models at different levels. This is now nearly ten years old and requires revision with a view to re-provisioning of services to reflect the complexities identified above and to deliver effective outcomes. It is suggested that new tiers are required so that services become more flexible and responsive thus averting many of the crisis of the recent past. It is suggested therefore that services in the future therefore could be at the following tiers

<table>
<thead>
<tr>
<th>Tier</th>
<th>Type of Provision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tier 7</td>
<td>National Specialist Provision</td>
</tr>
<tr>
<td>Tier 6</td>
<td>Regional Specialist Provision</td>
</tr>
<tr>
<td>Tier 5</td>
<td>Assessment and Treatment</td>
</tr>
<tr>
<td>Tier 4</td>
<td>Joint Health / Local Authority (LA) Provision</td>
</tr>
<tr>
<td>Tier 3</td>
<td>Intensive Home Support</td>
</tr>
<tr>
<td></td>
<td>Day Support Health/social care</td>
</tr>
<tr>
<td>Tier 2</td>
<td>Local Authority Provision or Commissioned Services</td>
</tr>
<tr>
<td></td>
<td>(Voluntary/independent)</td>
</tr>
<tr>
<td>Tier 1</td>
<td>Primary care / Local Area Co-ordination / Day Time Occupation/Employment</td>
</tr>
</tbody>
</table>

Across Tiers 1 to 4 there should be an enhanced respite service and input from community learning disability teams as required. In order to meet the needs of the different populations in different areas not all areas would need to develop services or models of care at all the tiers identified.

**Activity: Tiers of Care**

Reflect on your service. What tier are you working at currently?

[Blank space for text response]
Bleasdale (2007) warns against developing models of care. It is believed that this is because he interprets the term ‘models’ very narrowly. Therefore for each of the services at each level a broad approach to the interpretation of ‘models’ should be adopted. At each tier therefore the service provision could be described using the following headings:

- Environment
- Staffing levels
- Care plans/philosophy
- Outcomes
- Skill sets

Each of these elements will now be considered – although you should note you have already done some work on skill sets required to care for people with a learning disability and complex care needs and you will do some work on care plans/philosophy when you consider values based care later in the module.

**Environment**

There are two aspects to environment first the actual building/living arrangements and second the characteristics of that building. In relation to the first aspect it should be noted that the environments expected under the new approach will be either group living with individual bedrooms or bedsits. There may according to the persons needs also be some shared living space but the people living there will still have the opportunity to be alone. This type of arrangement is sometimes referred to as core and cluster. There will not be a return to congregate living but at the same time there will be financial challenges to developing individual tenancies unless the person has very particular needs.

In relation to the second aspect it is important to think about the actual characteristics of the buildings.

**Activity: Characteristics**

What characteristics do you think the environments should have:

You may have mentioned that the environment should minimise risk to the individual whilst still enabling positive risk taking. It should also be well ventilated, have good lighting and be at the right temperature. It may be necessary to have a secure garden and to consider how a place for pacing (which may be important if the person has autism) can be incorporated into the design. It may also be necessary to think carefully about the gender mix.

**Staffing Levels**

The staffing levels should be identified with consideration for:

- Episodes of care
  Traditionally staffing levels have been described as ratios. So for example a person may require 1 to 1 or 2 to 1 support. This method of describing staffing levels can be misleading as the person may not require the full amount of support throughout a 24 hour period. It is suggested therefore that it is more accurate to describe staffing levels in term of
episodes of care. A person for example may require more support at mealtimes or when going out but may require less support at night. When described in this manner it ensures that each person’s needs are taken into account.

- **Individual need**
  Staffing levels should be matched to each person’s individual needs at all points in their day. It should also be noted that many people also require time alone and that this should be factored in.

- **Availability of drawing on more staff**
  It is important when looking at needs that for very complex people who have challenging behaviour it is important to be able to draw on more staff if reactive strategies are required.

- **Risk assessments**
  It is important when considering staffing levels that individual risk assessment is taken into account so that a safe environment can be provided. It is also important that there is a plan for constructive risk taking.

**Staff Mix**

If the model is within health all of the following may be identified within the staffing mix:

- Psychiatry
- Nursing
- Support workers
- Speech and language therapist
- Clinical psychologist
- Cognitive behaviour therapist
- Social worker

If the model is in social care all of the following may be involved

- Social worker
- Care worker
- Input from the multidisciplinary team
- Input from community learning disability team
- Input from respite services

It should be noted that in many instances there will be shared responsibility from health and social care services and partnership with voluntary/independent service providers in relation to the model of care and the staffing mix will reflect this.

**Care Plans / Philosophy**

You will consider values based care later in the module. If you would like more information about the type of care plans that can be utilised the following resources may be useful:

**Recommended Reading & Resources:**

If you are interested in learning more about legislation relevant to the care and support of people with a learning disability you can access:

“Respecting and Protecting Vulnerable Adults in Scotland – Legislation and Practice” provides a learning resource covering Adults with Incapacity (Scotland) Act 2000, the Mental Health (Care and Treatment) (Scotland) Act 2003 and, the Adult Support and Protection (Scotland) Act 2007
It is clear that person centred philosophy should underpin the care plans and this will be explored later in this module. It is also important that the care plans have an integrated approach with input from the multidisciplinary team.

Outcomes

Detailed within the care plans should be individual outcomes for each person. It is suggested that they should reflect the outcomes identified by Miller et al (2008):

- Feeling safe
- Having meaningful things to do
- Seeing people
- Staying well
- Having a meaningful assessment
- Having a robust support plan

There are also process outcomes outlined by Miller et al (2008). These are:

- Being listened to
- Having choice
- Being treated as an individual

Outlining these process outcomes and using them in practice will lead to improved confidence and skills in the individuals you are working with. You will look at the difference between service led and person centred outcomes in more detail later in the module.

Skill Sets

Earlier you looked at the new skills that are required in order to deliver effective care to people with complex needs. It may however be useful to remind you of some of the skills that you may have identified. These include being:

- Caring, compassionate, person centred (Scottish Government, 2010)
- Calm, confident, consistent
- Good oral and non verbal communication
- Good observation skills
- Good risk assessment skills
- Ability to reflect on and implement an approach to support that focuses on encouraging people’s active involvement in their own support rather than on containment and care (University of Sydney, 2004)
- Ability to use active support (Clement and Bigby 2008)
- Ability to use a positive behavioural approach including the ability to complete a functional assessment (McVilly 2002)
- Ability to react and defuse aggression
- Record keeping and report writing skills
- Ability to use reflective practice
- Ability to work in a team

Managers

Obviously the managers of the services that you work in will require all of the above but they should have additional expertise.
Activity: Managerial Skills

Think of a person whom you consider a good manager and then list all the skills that you believe contribute to this.

Clement and Bigby (2008) suggest that all of the following are required to be an effective manager. You probably have included most of these in your list above:

- Leadership skills
- Management skills
- Providing staff support
- Enhancing staff relations
- Building inclusive communities
- Leading training and developing staff
- Promoting public relations
- Protecting health and safety
- Managing financial activities
- Rostering skills
- Coordinating policies and procedures

It should be noted that the manager should also be an expert in relation to the client group that they are working with.

Principles of Care

Since 2000 we have seen the development of a range of policy and legislation guiding services for people with a learning disability across the UK, all unequivocally highlighting the importance of supporting people as individuals and promoting their human, civil and legal rights (Scottish Executive, 2000; DoH, 2001; Welsh Office, 2001; DoH SSPS, 2005; DoH, 2009).

Recommended Reading & Resources:

If you are interested in learning more about legislation relevant to the care and support of people with a learning disability you can access:

“Respecting and Protecting Vulnerable Adults in Scotland – Legislation and Practice” provides a learning resource covering Adults with Incapacity (Scotland) Act 2000, the Mental Health (Care and Treatment) (Scotland) Act 2003 and, the Adult Support and Protection (Scotland) Act 2007

The table over the page shows the seven principles from the Same as You? (Scottish Executive, 2000). There are a wide number of concepts that can impact either positively or negatively on ensuring these principles are embedded in practice including diversity, person centred approaches, stereotyping, exclusion, human rights, prejudice, values based care and equality to name but a few.
Principles of Care - Same as you?

1. People with learning disabilities should be valued. They should be asked and encouraged to contribute to the community they live in. They should not be picked on or treated differently from others.

2. People with learning disabilities are individual people.

3. People with learning disabilities should be asked about the services they need and be involved in making choices about what they want.

4. People with learning disabilities should be helped and supported to do everything they are able to.

5. People with learning disabilities should be able to use the same local services as everyone else, wherever possible.

6. People with learning disabilities should benefit from specialist social, health, and educational services.

7. People with learning disabilities should have services which take account of their age, abilities, and other needs.

Activity: Principles of Care

Part 1: For each of the principles of care reflect on your practice and try to identify one example of how you, in your role, have promoted the principle and one example of when you have not promoted the principle. We have given an example from a community learning disability nurse but you may be a support worker or a nurse working in a health or social care setting—spend about 40 minutes on this activity.

<table>
<thead>
<tr>
<th>Example</th>
<th>As part of a health assessment asked service user what they were worried about in relation to their health person wanted to lose weight so then explained range of options such as support from carers, joining weight watchers, referral to dietician and supported person to choose best option for them</th>
<th>Made a referral to a day centre without asking person if they wanted to be referred—task driven by wish to provide respite for family carers rather than service user wishes</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with learning disabilities should be asked about the services they need and be involved in making choices about what they want</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Example</td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>People with learning disabilities should be valued. They should</td>
<td></td>
<td></td>
</tr>
<tr>
<td>be asked and encouraged to contribute to the community they live in.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>They should not be picked on or treated differently from others</td>
<td></td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities are individual people.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities should be asked about the services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>they need and be involved in making choices about what they want.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities should be able to use the same</td>
<td></td>
<td></td>
</tr>
<tr>
<td>local services as everyone else, wherever possible.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities should be given the help and</td>
<td></td>
<td></td>
</tr>
<tr>
<td>support to do what they want to do</td>
<td></td>
<td></td>
</tr>
<tr>
<td>People with learning disabilities should benefit from specialist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>social, health and educational services.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Example

| People with learning disabilities should have services which take account of their age, abilities and other needs. |  |

**Part 2:** Discuss within your study group or with your supervisor each of the principles – try to answer the following questions – spend about 30 minutes on this activity

1. **How would someone coming into your service see each principle in action?**

2. **What are the gaps – in what areas could your service develop?**

3. **Can you identify why a person may need to step up a tier?**
## Activity: Managerial Skills

For this activity please visit the NHS Education for Scotland website publications pages. Here you will find The 10 Essential Shared Capabilities for Mental Health Practice Learning Materials (Scotland). You may want to come back and look at these again and perhaps complete the activities but for now have a brief look at Module 2: the 10 Essential Shared Capabilities. This introduces you to each of the capabilities. The 10 Essential Shared Capabilities are:

- Working in Partnership
- Respecting Diversity
- Practising Ethically
- Challenging Inequality
- Promoting Recovery
- Identifying People’s Needs and Strengths
- Providing Service User-Centred Care
- Making a Difference
- Promoting Safety and Positive Risk Taking
- Personal Development and Learning

By reading module 2 and gaining an overview of the 10 ESCs you will be able to consider how this framework could be applied to your setting?

What are the similarities and differences between the 10 ESCs and The Same as You Principles?

<table>
<thead>
<tr>
<th>Similarities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Differences</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>
The last two activities have allowed you to explore principles for care and reflect on how far these principles are demonstrated in your service. Principle frameworks like the two you have considered aim to make explicit the behaviours, values and delivery of services and reflect and promote the philosophical ideology and legislative policy of our time. Explicit principle frameworks can support staff development and organisational quality and guard against poor practice. Let us explore further how explicit principle frameworks can promote good practice by considering stereotyping. We are using stereotyping to illustrate how principle frameworks can promote good practice because stereotyping can lead to stigma and social exclusion, which are commonly experienced by people with a learning disability.

**Stereotyping**

A stereotype is a commonly held set of assumptions about someone, based on the perceived characteristics of a particular group to which they belong for example a religious or ethnic group. Stereotypes present an oversimplified view which does not take account of the individuality of the person. We cannot avoid using stereotypes they help us make sense of a complex world but we must be aware of their impact as they can have damaging consequences for individuals and their families. Some examples of stereotypes include:

- Women are the carers in families
- South Asian people live in extended close knit families and care for their own
- People in wheelchairs are helpless ‘poor souls’
- People with mental health problems are dangerous
- Groups of teenagers are looking for trouble

We would suggest that all the principles support good practice in relation to stereotypes but particularly:

- People with learning disabilities should be valued. They should be asked and encouraged to contribute to the community they live in. They should not be picked on or treated differently from others
- People with learning disabilities are individual people.
- People with learning disabilities should be asked about the services they need and be involved in making choices about what they want.
- People with learning disabilities should be given the help and support to do what they want to do
- People with learning disabilities should have services which take account of their age, abilities and other needs.
- Working in Partnership
- Respecting Diversity
- Challenging Inequality
- Identifying People’s Needs and Strengths
- Providing Service User-Centred Care

<table>
<thead>
<tr>
<th>Activity: Principle Frameworks to Promote Good Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify which of the Same as You principles and the 10 ESCs you think could support good practice in relation to challenging stereotyping.</td>
</tr>
</tbody>
</table>
You may have mentioned that:

- Stereotyped assumptions can lead to inadequate or inappropriate care for instance stereotypes can result in failure to consult people about the support they need resulting in help that is misdirected or inappropriate
- Stereotypes may lead to depersonalisation, removing any sense of individualism, complexities of personality are ignored and needs seen in simplistic terms, which in turn leads to the person having less control over their life
- Stereotypes can force people into expected behaviours further enforcing the preconceptions i.e. a person whose carer does everything for them because they view them as ‘a poor soul’ will often give up trying to do things for themselves and feel further disempowered
- Stereotyping may lead to workers and services being less person-centred and minimise choice and opportunities for people
- You may be less likely to see someone’s capabilities
- Stereotypes can lead to prejudice and discrimination
- Stereotypes can be a significant barrier to social inclusion

To minimise stereotypes care workers:

- Must look beyond stereotyped assumptions by developing self-awareness and reflective practice
- Should always keep an open mind, get to know the person as an individual and question any assumptions they have
- Need to develop skills in communication, listen carefully and avoid ‘talking down’ to people
- Need to be familiar with that person’s method of communication
Values Based Practice

Values-based practice is about working in a positive and constructive way with differences and diversity of values. It means putting the values, views and understanding of individual service users and carers at the centre of everything we do. It means understanding and using our own values and beliefs in a positive way. It is about respecting the values of the other people we work with and being open and receptive to their views.

Activity: Values Based Practice

For this activity we are returning to the 10 Essential Shared Capabilities (there are many examples like this of learning materials/resources from different fields such as mental health, social work and education that are applicable to learning disability services and practice and we would encourage learners to look at other areas for resources that can apply or easily be adapted).

http://www.nes.scot.nhs.uk/initiatives/mental-health/publications#values

On the NES website scroll down to Module 4: values based practice. Read through this module, once you have done this return to page 75 where you will find the values for mental health nursing. This professional value statement was written jointly by mental health nurses, people from other agencies, service users and family carers. In your study group or with your supervisor write a values statement for your service, decide what your core values are and place these in the left column and in the right column outline how these are demonstrated.

Once you have done this find your services value statement or service philosophy statement and compare this with yours. If you cannot find an explicit values statement within your service why don’t you suggest that your team develops one based on your work.
The values base for ______________________ (enter the name of your service here)

<table>
<thead>
<tr>
<th>Core Values</th>
<th>Demonstrated By</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Our values guide our decisions, values based practice relies upon practitioners having the knowledge and skills to facilitate effective decisions where different (and potentially conflicting) values are in play (Woodbridge and Fulford, 2004).

Decisions made with respect for values as well as evidence, following a process in which values have been explored, clarified and balanced, are more owned and more likely to be acted on.

Values based practice:

• Places an emphasis on the importance and differences of individual values, including the values of health and social care workers, researchers and managers as well as those of service users and carers.
• Recognises that values whether explicit or implicit guide all decisions.
• Recognises the importance of values and evidence and clinical expertise working together for optimum outcomes for people accessing health or social care.
• Is more than a theoretical stance it has a focus on processes and building skills sets to enable practitioners to work sensitively with different values and perspectives.

Activity: The Impact of Values

Read the case study and then answer the questions below. Spend about 20 minutes on this activity.

Paula is married to John and mum to Lynn and Tom. Lynn is 18 years old and her younger brother Tom is 6 years old. The family home has been adapted for Lynn’s wheelchair. Lynn attends a day centre but spends much of her time isolated as she regularly becomes distressed and will make loud vocalisations and will try to hit out and bite carers and other service users. She is often sent home early due to staffing shortages. Lynn has been waiting for a respite service for over 2 years after moving from children to adult services.

At her review meeting Mum and Dad are angry at the centre staff for regularly sending Lynn home and at their social worker for the lack of respite. Mum says

“Last week I couldn’t go to Tom’s school play because Lynn was sent home early! This is not fair. We want Lynn at home but cannot cope without support. We need to be able to rely on the day centre especially as we have no respite. Why could Jennifer not have been working on that day, Lynn is fine when Jennifer is working? Jennifer said she would work that day but was told no. I appreciate Lynn is not the only person you have to look after but I very rarely ask for anything. We cannot continue to have Lynn at home if things do not change.”
Note below what you think is important to Lynn’s mum—what are her values?

Lynn has gripped her or tried to bite her. This does cause some tension and stress for Jennifer. However Jennifer had said to James she would change her days off to be there on the day of Tom’s play but James had said no as that would be setting a precedent and Mum would then expect this all the time. Jennifer felt this was unfair but unable to challenge James.

What do you think is important to Jennifer—what are her values?

Now read on:
James the day centre manager appreciates Paula and John’s situation but has long standing issues with staff sickness. He has 3 vacant posts but has been told within the current climate he cannot fill them. He is under pressure from his manager for the increasing number of incident reports involving Lynn. James states “Jennifer is good with all the service users and is not just here for Lynn”.

What do you think is important to James—what are his values?

How are the ‘values’ demonstrated here a barrier to meeting Lynn and her family’s needs?

Jennifer works 3 days a week and is generally happy to work with Lynn as she believes she is just anxious and unsure but her boyfriend complains about her going home with marks from where
You may have mentioned that Paula recognises and values Jennifer’s ability to support Lynn and be non-judgemental. It is important to Paula that she has support with Lynn. It is also important to Paula that she is listened to and valued in her role as Mum and that the support provided is flexible and considers the needs of the whole family.

James values the collective needs of the organisation, he has all the service users’ and the staffs needs to consider and feels this is his priority rather than individual need.

Jennifer feels the service could be more flexible but believes it is not her place to question James.

James is clear that he has an overall responsibility for all staff and service users at the centre. This is true but he is not valuing flexibility and the ability of the service to respond individually rather he thinks that doing this would not be fair to everyone else and would set up expectations that would then be difficult to meet. This is a barrier to meeting Lynn and her family’s needs. Woodbridge and Fulford, (2004) explain that values are complex because:

- Values come in many varieties, for instance they can be associated with ethics, rights, virtues, wishes, desires, aesthetic values.
- Values vary with time and place; they are your perspective, fluid and changeable.
- Values also vary from person to person.

This complexity of values and how they can impact on care is demonstrated in the case study above and we have not even begun to consider what is important to Lynn! There will be a number of examples from your own practice that illustrate the complexity of situations we face on a daily basis. It can be helpful when you are faced with complex situations, where there is a number of what appear to be conflicting views to stop and reflect on what your values are and how these may impact on the decision making process. It can also be helpful to try and encourage people to explicitly state their values and to openly acknowledge that you will all have different values and that these are best explored openly to reach the best outcome.

**Recommended Reading & Resources:**

You can find out more about values based care by reading:


**Person Centred Approaches to Care**

Person centred approaches to care are embedded in current policy and legislation and include, person centred planning, involving service users and carers as partners in care, maximising participation, personalisation and self-directed care. Most services would state that they are person centred however in reality this is not always the case.
<table>
<thead>
<tr>
<th>Activity: Person Centred Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reflect on your own service – how are person centred approaches to care demonstrated in your service? Spend about 30 minutes on this activity</td>
</tr>
<tr>
<td>What areas or developments can you think of that would improve how person centred your service are?</td>
</tr>
<tr>
<td>What do you think are the barriers to person centred approaches being implemented in practice? (think about your service)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Activity: Person Centred Approaches to Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>To find out more about person centred planning, involving service users and carers as partners in care and maximising participation follow the link below and work through</td>
</tr>
<tr>
<td>Units 2-5 of Module 1: Person Centred Approaches to Care in the ‘Respecting and Protecting Vulnerable Adults in Scotland – Legislation and Practice’ learning resource</td>
</tr>
</tbody>
</table>

**Equal Citizens**

Social exclusion results from a lack of participation in society as a result of multiple factors such as unemployment, poor skills, low income, poor housing, and poor health. Social exclusion can be viewed as a process leading to a state in which it is more difficult for certain individuals and groups to achieve certain capabilities which allow an individual to lead the kind of life they want (Khan, 2009).
Activity: Supporting Inclusion

Begin by thinking about what it means to you to be included – make some notes below

You probably mentioned things like:
- Being accepted
- Talking to people
- Having friends
- Having opportunities
- Having choices

Reflect on your role – how can you promote social inclusion and equal citizenship for people with a learning disability?

What do you think can be the barriers to social inclusion for people with a learning disability?

You may have mentioned
- Abilities and skills of the person – can they travel independently, do they have behaviours that are challenging, communication and social skills
- Abilities and skills of staff
- Poor knowledge of the area
- Staff and management – e.g. person not allowed out on their own
- Where people live – number of community facilities nearby
- The community people live in – name calling and bullying or acceptance?

What can you do in your role to increase social inclusion?
You may have mentioned
Ensure all health needs are met
Consider appropriate interventions to reduce challenging behaviours and improve quality of life
Support skills development around increasing communication, social skills
Develop knowledge of community facilities
Develop relationships within the local community that enable access to community facilities for people with a learning disability and promote positive values and attitudes
Staff training to raise awareness and develop skills and attitudes

Support the person to:
• develop as wide a range of social activities as possible
• find work or training opportunities
• develop independent living skills such as travel
• increase contact with family

Self-Directed Support & Personalisation
(The information within this section has been adapted from NHS Lothian Self Directed Support Pilot further information can be accessed at http://intranet.lothian.scot.nhs.uk/NHSLothian/Corporate/A-Z/SelfDirectedSupport/Pages/default.aspx)

Personalisation is about whole system change, not about change at the margins. It is radical and requires fundamental transformation of adult social care.

Disabled people’s organisations believe that a change in the way the social care system operates is required, and that existing processes and strategies have not and will not affect the changes needed to deliver realistic self directed support options.

Personalisation has been defined as something which: Enables the individual alone, or in groups, to find the right solutions for them and to participate in the delivery of a service. From being a recipient of services, citizens can become actively involved in selecting and shaping the services they receive.

Personalisation means that people become more involved in how services are designed, and they receive support that is most suited to them. It is not just about tailoring existing services but about thinking innovatively to ensure the individual has a service that suits their requirements. Changes in the way services are delivered are fundamental to the success of the personalisation agenda. In healthcare, this means everyone having choice and control over the shape of their support, along with a greater emphasis on prevention and early intervention.

Recommended Reading & Resources:
The Scottish Consortium for Learning Disability was developed to support the implementation of The Same as You and its mission is to work in partnership with people with learning disabilities and family carers to challenge discrimination and develop and share good practice visit their website at: http://www.scld.org.uk/home
Activity: Personalisation (a)

Find out from a person with a learning disability and complex needs or a family member what services they feel would suit their requirements that they do not currently receive – make some notes below.

- Personal budgets - Personal budgets are similar to individual budgets but are made up solely of personal care funding.
- Direct payments - A direct payment is a cash payment made by a local authority to a recipient of community care services to purchase support services of choice instead of receiving community care services arranged directly by a local authority.

Direct payments were the result of a long campaign by disabled people who fought to take control of their own support.

They can also form part of an individual budget.

Self-directed support is a term that loosely describes, at present, the ways in which individuals and families can have informed choice about the way support is provided to them.

How does self-directed support work?

- Identifies care outcomes for an individual
- Gives a financial value to those outcomes
- People can choose how to spend their money to meet those outcomes

Disabled people are interested in getting on with their lives, whether ordinary or extraordinary, without having to negotiate continuous obstacles imposed by society. Yet, if you ask what personalisation means to them, most will probably wonder about the term, unless they are part of (or have had too much to do with) the professional ‘care’ community. They will mention, however, how support that they are able to direct themselves is key to achieve Independent Living.
Activity: Personalisation (b)

Building on the last activity consider how you or your organisation could collaborate with others to access/develop the service outlined by the people you talked to in activity a) to meet the person’s needs – make some notes below.

<table>
<thead>
<tr>
<th>What other organisations could help empower individuals to have their needs met through personalisation?</th>
</tr>
</thead>
</table>

Talking Points – a personal outcomes approach

An approach to working with people that focuses on outcomes involves everyone working together to achieve the best possible impact on an individual’s life. This means understanding individuals and their carers in the context of their whole lives, and working with them to identify their priorities. The philosophy of this approach is one that emphasises the strengths, capacity and resilience of individuals, and builds upon natural support systems such as family and local community.

The starting point is to get a clear understanding of the outcomes that matter to the person. This understanding is then used to inform key decision-making processes, namely assessment, support planning and review. Involving the individual in identifying and working towards their outcomes is critical to the approach and will support their independence and wellbeing. When illness or limitations prohibit the person’s ability to directly inform, family members, carers or relevant others should be involved.

Although in some ways building on good practice, a move to focus on outcomes also requires a significant ‘culture shift’. Practitioners tell us that an outcomes approach supports practice that has otherwise been undermined by the current dominance of service-driven assessment and support planning. As a result, adopting an outcomes approach requires a process of ‘unlearning’, as much for organisations as for practitioners.

Ownership and responsibility need to be taken at every level of the system. Making this culture shift requires sustained effort, and the involvement of all partner agencies. Partners need to be creative, flexible and solution-focused in developing supports and services that maximise outcomes. This may also prove more cost effective than traditional service provision. The following principles can inform and guide successful implementation of an outcomes approach in practice.
Principles underpinning organisational change

- An outcomes approach needs to be taken forward across the whole organisation. Communication between practitioners and strategic planning needs to be two-way. Staff need to know not just that they have permission to practice in a different way, but that the information they gather will influence planning and service developments.
- Adopting an outcomes approach requires significant organisational change. There will be a need to review financial, planning and reporting systems as well as how services are prioritised.
- A successful outcomes approach requires that systems for collecting and analysing data are developed around practice and should not dictate practice.
- Individual organisations and partnerships need to ensure that aggregated information is available both as a means of measuring outcomes and in order to shape service development and commissioning.
- The continuing relevance of services and supports and the extent to which the outcomes have been achieved can be revisited at review.
- An outcomes approach should support practitioners and organisations to be honest with people using services about what can and cannot be achieved with existing supports and resources, and promote creative alternative pathways as required.
- The approach relies on and restores the importance of the analytical skills of professionals in bringing together information from diverse sources, most importantly the individual, who should retain ownership of the outcome.

Talking Points – the principles underpinning practice

- Practitioners have identified that a focus on outcomes goes back to the basics of their training and professional skills.
- Adopting a conversational approach to assessment, support planning and review allows for more meaningful engagement with individuals and families, as compared to more prescriptive, tick box, question and answer approaches. The value of a relationship-centred approach is evidenced in the literature.
- Having a conversation with people with specific communication difficulties may be challenging, but flexibility and developments in person-centred care can inform this process.
- Early engagement and good listening skills with individuals should result in a support plan based on their outcomes, providing clarity and direction for everybody involved.
- The continuing relevance of services and supports and the extent to which the outcomes have been achieved can be revisited at review.
- An outcomes approach should support practitioners and organisations to be honest with people using services about what can and cannot be achieved with existing supports and resources, and promote creative alternative pathways as required.
- The approach relies on and restores the importance of the analytical skills of professionals in bringing together information from diverse sources, most importantly the individual, who should retain ownership of the outcome.
We can see what outcomes mean in practice by comparing the key features of outcomes-focused approaches with service-led approaches. The statements below summarise some of the constraints that have developed in the community care system and identify the potential for overcoming these barriers through focusing on outcomes. Have a look the statements and decide whether you think they are service led or outcomes focused.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Service Led or Outcomes Focused</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decision-making informed by semi-structured conversations with individuals in assessment, support planning and review</td>
<td></td>
</tr>
<tr>
<td>Analytical skills involved in assessment</td>
<td></td>
</tr>
<tr>
<td>Current tools encourage information gathering through standardised question and answer approaches to assessment, support planning and review</td>
<td></td>
</tr>
<tr>
<td>The person’s views and preferences are central to decision-making</td>
<td></td>
</tr>
<tr>
<td>Tick box approach to assessment</td>
<td></td>
</tr>
<tr>
<td>The person's views may be included in decision-making</td>
<td></td>
</tr>
<tr>
<td>Where needs link to strict eligibility criteria, the assessor is required to maximise individual difficulties to access services</td>
<td></td>
</tr>
<tr>
<td>The person is a citizen with rights and responsibilities</td>
<td></td>
</tr>
<tr>
<td>Involves consideration of difficulties, limitations and aspirations or goals. The priority is to identify what to work towards</td>
<td></td>
</tr>
<tr>
<td>Identifying outcomes involve considering a range of solutions and strategies, including the role of the person, family supports and community-based resources</td>
<td></td>
</tr>
<tr>
<td>If the person is deemed eligible, identified needs are matched to a limited range of block provided services, resulting in service-driven approaches</td>
<td></td>
</tr>
<tr>
<td>Where needs are tied to eligibility criteria, preventive work with people with low-level needs may be excluded</td>
<td></td>
</tr>
<tr>
<td>Statement</td>
<td>Service Led or Outcomes Focused</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>---------------------------------</td>
</tr>
<tr>
<td>Identifying outcomes involve considering a range of solutions and strategies, including the role of the person, family supports and community-based resources</td>
<td></td>
</tr>
<tr>
<td>By focusing on strengths, capacities and goals, while mindful of limitations, the role of the person is maximised. Services do things with people</td>
<td></td>
</tr>
<tr>
<td>Focusing exclusively on deficits and difficulties, and how needs are to be met, results in a focus on tasks and in services which do things to people</td>
<td></td>
</tr>
<tr>
<td>Matching needs and deficits to services tends to result in static service delivery</td>
<td></td>
</tr>
<tr>
<td>Outcomes may change in the person’s life journey and so should be revisited</td>
<td></td>
</tr>
<tr>
<td>Starting from the person’s priorities supports enabling relationships, creates clarity and identifies goals at an early stage. Being listened to, involved and respected results in better outcomes</td>
<td></td>
</tr>
<tr>
<td>Outcomes are what matter to the person, though often consistent with professional and organisational outcomes, e.g. being able to get out and about.</td>
<td></td>
</tr>
<tr>
<td>Starting from what services are currently available restricts communication and limits options</td>
<td></td>
</tr>
<tr>
<td>Where outcomes are identified, these tend to be professional or organisational outcomes, e.g. improved nutrition, or avoid delayed discharge</td>
<td></td>
</tr>
</tbody>
</table>

However, it should be remembered that outcomes-focused support planning is not in itself a magic bullet. When assessment and care management was introduced in the 1990s, the intention was to deliver ‘tailor-made’ packages based on ‘needs-led’ assessment.
<table>
<thead>
<tr>
<th>Service Led</th>
<th>Outcomes Focused</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current tools encourage information gathering through standardised question and answer approaches to assessment, support planning and review</td>
<td>Decision-making informed by semi-structured conversations with individuals in assessment, support planning and review</td>
</tr>
<tr>
<td>Tick box approach to assessment</td>
<td>Analytical skills involved in assessment</td>
</tr>
<tr>
<td>The person’s views may be included in decision-making</td>
<td>The person’s views and preferences are central to decision-making</td>
</tr>
<tr>
<td>The person is viewed as a client, service user or patient</td>
<td>The person is a citizen with rights and responsibilities</td>
</tr>
<tr>
<td>Where needs link to strict eligibility criteria, the assessor is required to maximise individual difficulties to access services</td>
<td>Involves consideration of difficulties, limitations and aspirations or goals. The priority is to identify what to work towards</td>
</tr>
<tr>
<td>If the person is deemed eligible, identified needs are matched to a limited range of block provided services, resulting in service-driven approaches</td>
<td>Identifying outcomes involve considering a range of solutions and strategies, including the role of the person, family supports and community-based resources</td>
</tr>
<tr>
<td>Where needs are tied to eligibility criteria, preventive work with people with low-level needs may be excluded</td>
<td>Outcomes allow preventive work to take place while services and resources are prioritised for those most in need</td>
</tr>
<tr>
<td>Focusing exclusively on deficits and difficulties, and how needs are to be met, results in a focus on tasks and in services which do things to people</td>
<td>By focusing on strengths, capacities and goals, while mindful of limitations, the role of the person is maximised. Services do things with people</td>
</tr>
<tr>
<td>Matching needs and deficits to services tends to result in static service delivery</td>
<td>Outcomes may change in the person’s life journey and so should be revisited</td>
</tr>
<tr>
<td>Where outcomes are identified, these tend to be professional or organisational outcomes, e.g. improved nutrition, or avoid delayed discharge</td>
<td>Outcomes are what matter to the person, though often consistent with professional and organisational outcomes, e.g. being able to get out and about.</td>
</tr>
<tr>
<td>Starting from what services are currently available restricts communication and limits options</td>
<td>Starting from the person’s priorities supports enabling relationships, creates clarity and identifies goals at an early stage. Being listened to, involved and respected results in better outcomes</td>
</tr>
</tbody>
</table>
Module 1: A Contemporary Overview

National Drivers

**Self-directed Support: A National Strategy for Scotland**

In 2010 the national strategy for self-directed support in Scotland was developed by the Scottish Government, to help take forward the personalisation of health and social care services in Scotland.

The increasing numbers of people accessing healthcare, and the range of individual needs, mean that services and supports will have to continue to become much more flexible and responsive in the future.

This strategy responds to increasing interest in reshaping healthcare and support in Scotland. It aims to set out and drive a cultural shift around the delivery of healthcare and support that views people as equal citizens with rights and responsibilities. It recognises that for consumers and providers alike, tighter financial pressures, and demographic changes mean that improved outcomes cannot be delivered with more of the same.

http://www.selfdirectedsupport.org.uk

Self-directed Support: A Draft Bill for Consultation

This document, published on 16th December 2010, together with Self-directed Support: A National Strategy for Scotland, published alongside it, presents the Scottish Government’s legislative proposals. The draft bill seeks to enshrine choice and control for the citizen, to sustain the changes outlined in the strategy and to bring the law into line with the vision that we have set.

http://www.scotland.gov.uk/Topics/Health/care/sdsbill

Recommended Reading & Resources:

**Self-directed support resources**

- A Users Guide to Self-directed Support in Scotland [PDF - 258Kb]
- Review of Self-directed Support [PDF - 746Kb]
- Self-directed Support - new national guidance [PDF - 1Mb]
- National Statistics Self-directed Support 2008 [PDF - 180Kb]

**Self-directed support organisations**

Lothian Centre for Inclusive Living

The first Centre for Inclusive Living, (CIL) to emerge in Scotland, in 1991, was the Lothian Centre for Inclusive Living, formerly known as Lothian Centre for Integrated Living. LCiL renamed itself in 2009 to reflect the changing understanding of what was meant by inclusion. Opening Hours: Monday - Friday, 10am - 4pm

Tel: 0131 475 2350

http://www.lothiancil.org.uk/
Module 1: A Contemporary Overview

Office of the Public Guardian Scotland
The Office of the Public Guardian in Scotland has a general function to supervise those individuals who have been appointed to manage the financial or property affairs of adults who lack the capacity to do so for themselves. The office is based in Falkirk and covers the whole of Scotland. Tel: 01324 678 300
http://www.publicguardian-scotland.gov.uk

Self-Directed Support Scotland
An umbrella organisation – Self-Directed Support Scotland (SDSS) is a one-stop shop for information about self-directed support for service-users and health and social support professionals alike. SDSS provides guidance on Self-Directed Support, useful links and an FAQ section for new and existing users and professionals
http://www.selfdirectedsupportscotland.org.uk

SPAEN (Scottish Personal Assistants Employers Network)
“SPAEN strives to be the authoritative voice of personal assistant employers in Scotland” SPAEN is a membership organisation and its members are all people who have made the transition from having their care needs organised by the state to taking over the management and control of their own assistance. Tel: 01698 250 280
http://www.spaen.co.uk
Reflect on your learning within this module. Identify 5 key areas where your knowledge has developed and then write one objective for each that outlines how you can implement in practice some of the ideas you have learned about to develop either yourself or your service to provide good care and support. Discuss this with your supervisor, mentor or manager.

<table>
<thead>
<tr>
<th>Key Learning - I have Learned About</th>
<th>To develop this in my area of practice I will</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
</tr>
</tbody>
</table>
References


British Institute of Learning Disabilities. Available at: http://www.bild.org.uk/


Clement T and Bigby C (2008) *Making life good in the community. As good as it gets?* Victoria, La Trobe University.


NHS Education for Scotland The 10 Essential Shared Capabilities for Mental Health Practice Learning Materials (Scotland)


Module 1: A Contemporary Overview


Recommended Reading and Resources

**Scottish Policy**

This review provides the framework for the development of supports and services for people with learning disabilities in Scotland. The review has 29 recommendations and acts as a blueprint for services over the next 10 years.

Scottish Executive (2002) Promoting Health, Supporting Inclusion - The national review of the contribution of all nurses and midwives to the care and support of people with learning disabilities
A national nursing review of the contributions required from all nurses and midwives to meet the health needs of children and adults with learning disabilities, to improve health and support inclusion.


The report looks at the progress towards the implementation of the Quality Indicators, which were published in February 2004. These reports have information on NHS services and on the progress that has been made towards the closure of learning disability long-stay hospitals.

A Ministerial Task Force report which states that NHS Board areas must ensure the fair and equitable access of people with learning disabilities.

This Action Plan places emphasis on prevention and health inequalities, particularly health inequalities experienced by people with learning disabilities.

Report of the recommendations made by the 21st Century Social Work Review Group for the future of
social services in Scotland. Services need to be open to ‘developing the aspirations of people with learning disabilities, and must protect those who may be vulnerable from bullying and challenging behaviour’.


In June 2001 the Scottish Executive set up the National Implementation Group to oversee the implementation of the 29 recommendations in ‘The same as you?’ The group decided on three priority areas which it considered would have a significant impact on quality of life for people with learning disabilities. This is the final report of the short-life working group on employment for people with learning disabilities.

Wider Policy
Module 2: Understanding Complexity across the Lifespan for People with Multiple Disabilities
Introduction

This module explores complexity across the lifespan for people with multiple disabilities. In this module you will examine the impact that meeting the needs of children, adults and older adults with learning disabilities with additional and complex health needs have on the individual, families, siblings and carers.

You will explore contemporary issues affecting people with learning disabilities and complex needs and their families and carers and reflect on your experience, attitudes and values. You will consider the impact and management of transitions throughout the lifespan and reflect on your role in supporting the health and social care needs of people with multiple disabilities.

On completion of this module you should be able to:

• Explore the impact of multiple disabilities on individuals and families across the lifespan and reflect on your role in supporting the health and social care needs of the individual and family
• Identify the processes and procedures involved during transition across the lifespan of children and young people and adults with a learning disability and complex needs
• Critically reflect on a range of key themes and contemporary issues affecting people with learning disabilities and complex needs and their families
• Identify skills, knowledge and gaps in the provision of care for individuals with complex needs and their families

Activity: Identifying Existing Knowledge, Skills and Areas for Development

Spend a few minutes identifying your existing knowledge, skills and areas for development in relation to supporting people with learning disabilities and complex needs manage their mental health and well-being – make some notes below

Existing Knowledge:

Existing Skills:

Areas for Development:
Children and Young People: The Impact of Multiple Presentations, Families, Siblings and Carers – Child Perspective

As mentioned in module 1, we have an increasing number of children with a learning disability and complex needs. Medical advances bring their own challenges; children who would previously have succumbed to extreme prematurity or serious illness are surviving through childhood and beyond. Around 7,000 children in Scotland have been identified as having “complex needs”. With this figure growing there will be an additional requirement to provide multi-agency support for their health and personal needs. Around one-third of very low birth weight babies (<1000gm) will be disabled, about half of them severely. (Scottish Government, 2007).

There are a wide number of conditions that can lead to complex needs for children with a learning disability.

Activity: Complex Needs

Using the recommended reading and resources explore the following and write down the information relating to the condition that you are finding out about that could be relevant to you in your role and identify the associated needs

Down Syndrome:

Autism Spectrum Disorder:

Fragile X:

Recommended Reading & Resources:


http://www.cafamily.org.uk/inyourarea/scotland/index.html
http://www.aboutlearningdisabilities.co.uk/types-disabilities-category.html
http://www.autism.org.uk/

Policy Context

There are many different legislative papers and national drivers that discuss the provisions that are and should be available to children and young people in Scotland who have a learning disability.
### Activity: Legislative / National Drivers

Locate 2 of these policy or legislative drivers that are specifically written for children / young people with complex needs and identify the key points in these papers:

<table>
<thead>
<tr>
<th>Paper 1:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paper 2:</td>
</tr>
</tbody>
</table>

### Recommended Reading & Resources:

- [www.scotland.gov.uk](http://www.scotland.gov.uk)
- [www.dh.gov.uk](http://www.dh.gov.uk)
- [www.education.gov.uk](http://www.education.gov.uk)

### Activity: Key Drivers

Now click on the following links to establish some of the more high profile papers – how many of them did you locate in your own search:

- [www.scotland.gov.uk/topics/People/Young-People/gettingitright](http://www.scotland.gov.uk/topics/People/Young-People/gettingitright)
- [www.scotland.gov.uk/Topics/Education/Schools/welfare/ASL](http://www.scotland.gov.uk/Topics/Education/Schools/welfare/ASL)


### Activity: Policy into Practice

Choose one of the above documents which is relevant to your area of work, and identify one aspect that is or could be implemented in your practice:
Activity: A Family Perspective

Begin by reading the following narrative:

“Caring for our son when he was very small was difficult because he had disabilities and was one of four children. When he was wee he needed a lot of care because he didn’t sleep and would go 7-10 days without a proper sleep. I felt frustrated and out of control and felt that I was a bad mum. Both dad and I were very tired. We had lots of different professionals in and out of our house; this was intrusive and seemed to take over our lives. They would all be telling us how to bring up our child and we didn’t feel like mum and dad any more.

Things became bad when he was 11 months old. I was working part time and my son was up all the time. One day I put the kids in the cot, filled the bath and tried to commit suicide. We just wanted to be mum and dad, not professional carers and it can be intimidating being told how to care for your child. We knew what our son needed but professionals told us other things. They said “Don’t give him that” but didn’t give a reason why. We were spoken to like we weren’t there. Then we started to attend meetings and finally found our voice. We told the professionals how we wanted to bring up our son but all the professionals kept talking about him needing to go into hospital.

A social worker suggested respite care for my son; I felt that they were saying I couldn’t cope.

My son had to be physically taken from me by dad and the social worker. I was screaming at the time but now admit it was the best thing that could have happened. I visited respite and felt better after showing staff how to look after my son. I became close to the staff and trusted them. It was an amazing feeling to know I could hand over my son for the first time to people who I could trust. In saying that I would still phone 5 times a day and visit frequently and this carried on for 2 years until I could finally relax.

This respite unit closed and we were transferred to another respite facility. It was difficult at the new respite place because his care plan wasn’t being adhered to and I was scared to say anything and was frightened to phone to raise my concerns. I wasn’t happy but then my son’s community nurse became his care co-ordinator and I felt easier to chat to her and arrange meetings. I felt better because we have chats and communicate better with everyone involved.

Your whole day can be taken up with his care if he isn’t at school. Catheter care, feeds, medicines, etc. What would it be like if we didn’t have respite? I know when he goes for respite we can have a rest and 48 hours not dealing with him we can take a deep breath and be ourselves for a few hours.

Transition will be scary. People are asking what happens when my son leaves respite. I see a lot of parents who have put their kids into a residential place but I can’t ever see a time when he’s not living at home. I have spoken to another mum.
about residential care. She can’t see my point of view. Dad thinks he should move on but I don’t. Sometimes I think I need my son more than he needs me. Dad won’t take him out but I go everywhere with him, it’s important that he and his sister are out and about experiencing new things. I find it difficult being away from him.

My son is frequently admitted to hospital due to the complexity of his needs. Transfer to hospital is a nightmare, and I hate every minute he is in Ward **. Ward** used to be an amazing ward but I will bring him home if he is admitted to any other ward. There is lack of communication and lack of knowledge of disabilities. It angers and frustrates me; they seem to put everyone in the same category and don’t see people as individuals. They don’t ask enough questions and don’t seek enough information from us; we do all his care when he is in hospital.

It’s hard to stay as a family with things changing all the time, and as parents we never thought that we would get to this stage. It takes my son longer to get over surgery or illness every time. I sometimes feel we are mourning for our son but he is a fantastic wee boy. The kids are all happy; we have a nice home and family. I don’t need anybody to feel pity for us.”

Now consider your experiences working with people and their families. How do the issues mentioned in the narrative fit with your experiences? Briefly describe the common themes.

Describe your role in supporting families, carers and friends.

Describe a situation from practice where you or your team have made a positive contribution to a family/carer

What skills and knowledge did you need to enable this?
Module 2: Understanding Complexity across the Lifespan for People with Multiple Disabilities

Parents, and those with parental responsibilities, enjoy a pivotal role in shaping, and even irrevocably determining, the long-term physical, mental and emotional health and wellbeing of their children. Being a parent is a complex and demanding task and parents’ ability to fulfil their role will be influenced by the information and support they receive as well as their own health, resilience and life circumstances. It is important to recognise and value that parents are the ‘experts’ in caring for their child.

Activity: Parents Concerns
Reflect on what you think the main concerns parents have in relation to having a child / young person who has learning disabilities with complex needs?

Activity: Considering the Perspective of Siblings
Reflect on what you think the main concerns siblings have in relation to having a brother / sister who has learning disabilities with complex needs?

Activity: More from Families
Access the Mencap website to hear more family perspectives
http://www.mencap.org.uk/landing.asp?id=4201

Access the PAMIS website and find out more about this organisation that that works with people with profound and multiple learning disabilities and their families and offers a family support service.
http://www.pamis.org.uk/_page.php?id=6

Recommended Reading & Resources:


Activity: Family and Service User Involvement (partnership working)

Discuss with colleagues how you involve families and service users in both day to day decision making about their care and in more strategic ways concerning how the service is delivered – make some brief notes about this discussion below.

Discuss with a service user/family member/ advocate what their perception of family and user involvement is like within the service – make some brief notes below.

Reflect on both sets of views and make recommendations as to how to improve /enhance family and service user involvement and empower individuals.

Recommended Reading & Resources:

Recommended Reading and Resources
To find out more about advocacy and empowerment you can visit:

Multi-Agency & Inter-Professional Working

Interprofessional working may be defined as: “A group of people, each of whom is responsible for making individual decisions; who hold together a common purpose; who meet together to communicate, collaborate and consolidate knowledge from which plans are made, actions determined and future decisions influenced”
Activity: Interprofessional Working

Access the link and read p188-193 in collaboration in Social Work Practice By Jenny Weinstein, Colin Whittington, Tony Leiba (2006) http://books.google.co.uk/books?id=cwyhd6t_iQEC&pg=PA188&dq=multi+disciplinary+working+in+learning+disabilities&hl=en&ei=4zlmTfiOGMSGhQf42q3-DQ&sa=X&oi=book_result&ct=result&resnum=7&ved=0CGEQ6AEwBg#v=onepage&q=multi%20disciplinary%20working%20in%20learning%20disabilities&f=false

Considering the attributes of effective multidisciplinary working discussed please identify:

From your practice a situation involving the support of someone with complex needs required the involvement of multi-disciplinary working. Clearly identify the roles and responsibilities of those involved.

From that situation describe instances of effective practice – How did a multi professional approach improve the outcomes for the person?

From the same situation describe an instance where practice was less effective and make recommendations for improving things in the future.

Recommended Reading & Resources:

Recommended Reading & Resources:
NHS Scotland’s Managed Clinical Networks http://www.mcns.nhsscotland.com

Children and Young People’s Services Managed Knowledge Network http://www.knowledge.scot.nhs.uk/child-services.aspx


National Delivery Plan: For Children and Young People Specialist Services in Scotland http://www.specialchildrensservices.scot.nhs.uk
It is equally vital that the various elements of care are delivered in a consistent and coordinated manner. Too often in the past care provided by different agencies and services has been delivered in isolation and without reference to other care providers. The introduction of an integrated assessment process should foster inter-agency working. Equally, service provision for children with complex needs should be explicitly incorporated in Integrated Children’s Service Plans. In order to achieve these goals there is a need for:

- effective inter-agency working
- sharing of information (particularly where there may be child or adult protection concerns)
- well organised discharge planning
- structured resourcing of care packages
- coordination of care through an identified key worker / lead professional
- planned multi-agency review.

Voluntary Agencies

According to Gates (2003) “The term ‘the independent sector’ developed during the late 1980’s and early 1990’s as an umbrella term to cover those services not provided by the statutory sector. It includes those residential, day and domiciliary services provided by voluntary, private and charitable organisations.”

Activity: Voluntary Agencies

In your own area, locate and discuss the different voluntary agencies that provide support for children / young people / adults with learning disabilities with a complexity of need and their families:

Activity: Multi-Agency Working

Reflect on your experiences within your own role with working with different agencies / disciplines in relation to the above goals:

Recommended Reading & Resources:

Recommended Reading & Resources:
RNIB: Supporting Blind and Partially Sighted People
www.rnib.org.uk

Kindred: Supporting Families of Children and Young People with Additional Needs
www.kindred-scotland.org

Enable: We campaign for a better life for children and adults with learning disabilities
www.enable.org.uk
Social Work

In 2006, recommendations were made by the Scottish Government with regards to the report ‘21ST Century Social Work - The Vision of the Social Worker in the 21st century’. This paper suggests that the main purpose of social work as a department is considered to be protecting and promoting the welfare and well being of children, vulnerable adults and communities across the country.

This can be further broken down by defining the work of Social Workers as identifying ways to ensure the individual's physical, psychological, emotional and spiritual integrity and well-being are promoted and maintained. This is achieved by working in a holistic manner, taking account of the needs of the individual, their family and their community. Social workers also strive to develop supportive relationships with people in order to help them manage change in their lives, and work collaboratively with other agencies, both statutory and voluntary. Throughout their careers, Social Workers are also encouraged to develop their skills, knowledge and understanding of the changing context of our local communities (Scottish Government 2006).

Integrated working

There are many examples throughout Scotland and the UK, of Social Work teams being integrated with the work of other agencies. The benefits of this approach, is that a skill mix of staff can increase the likelihood of better outcomes for service users, and an increased understanding of the roles and responsibilities of individual practitioners from different services. Examples of integrated working could include:

- Community Mental Health Teams
- Integrated Response Teams
- Integrated Community Schools Teams

It is often the Social Worker who is considered to be the 'Lead' professional, and who may be responsible for the management and co-ordination of services where there are identified complex needs.

Risk Management

With assessment being a major part of the role of the Social Worker, there is also a duty to assess 'risk' for the individual and their community. Practice in recent years appears to be driving towards risk management rather than being completely risk adverse. To achieve this, the practitioner needs to consider the rights of the individual, promoting independence whilst limiting the chance of harm. The Social Worker should work collaboratively with the individual, other professionals, families and carers to ensure all the information is available to contribute to managing the risk.

Activity: Social Work

In your local area, what assessments are currently undertaken by Social Workers during the transition from child to adult services for young people who have complex needs and learning disabilities?
Activity: Interprofessional Working

How do social workers from child services communicate with social workers from adult services?

Is there a multi-agency transition pathway involving social work to help smooth the transition for young people?

What do you consider the role of Social Work to be in the transition of ‘Looked after Children’ into adult services?

(Read about the new centre of excellence for Looked After Children in Scotland http://www.scotland.gov.uk/News/Releases/2011/02/23094433)

Read about the needs of young people who have communication impairments using the following link (In particular Chapter 2 – Barriers to communication) http://scope.org.uk/drupal-fm/41/download

Reflect upon your own practice and consider how you have helped a client with communication impairment. Having read this chapter, how would you consider changing your practice to reduce barriers to communication?
Roles and Responsibilities of Workforce

There have been many key drivers for modernising workforce across the public sector, which have impacted on the roles and responsibilities of professionals across all agencies.

Some of these include papers such as:
- Modernising Nursing Career: setting the direction (Scottish Executive, 2006)
- Delivering a Healthy Future: an action framework for children and young people’s health in Scotland (Scottish Government, 2007)
- Teaching Scotland’s Future (Scottish Government, 2011)

Activity: Modernising Workforce

You may wish to take the opportunity to discuss and obtain the perspective of colleagues from three different professions, and establish how their roles and responsibilities have changed over the last decade, or are likely to change in the coming years:

Recommended Reading & Resources:

Access the link below to find out more about multi disciplinary work and care co ordination
http://books.google.co.uk/books?id=p5oDTjf812kC&pg=PA109&dq=multi+disciplinary+working+in+learning+disabilities&hl=en&ei=4zlmTfiOGMSGhQf42q3-DQ&sa=X&oi=book_result&ct=result&resnum=1&ved=0CD0Q6AEwAA#v=onepage&q=multi%20disciplinary%20working%20in%20learning%20disabilities&f=false

Access the link below to read about ‘Looking beyond the discipline’.
http://books.google.co.uk/books?id=PLdW9HsG3tAC&pg=PA147&dq=multi+disciplinary+working+in+learning+disabilities&hl=en&ei=4zlmTfiOGMSGhQf42q3-DQ&sa=X&oi=book_result&ct=result&resnum=4&ved=0CE8Q6AEwAw#v=onepage&q&f=false

Access the link below to read more about how multi disciplinary teams work in health
http://books.google.co.uk/books?id=9f78JovnJPEC&pg=PA115&dq=how+multidisciplinary+teams+work+in+health+provision+in+learning+disabilities&hl=en&ei=cX9vTZGuFYuChQfk4fBB&sa=X&oi=book_result&ct=result&resnum=5&ved=0CEkQ6AEwBA#

Modernising Nursing Careers: setting the direction (Scottish Executive 2006)
Module 2: Understanding Complexity across the Lifespan for People with Multiple Disabilities


Delivering a Healthy Future: An Action Framework for Children and Young People’s Health in Scotland (Scottish government 2007)

Teaching Scotland’s Future (Scottish Government 2011)

Child Protection

- Safeguarding vulnerable children and young people is everyone’s responsibility. Therefore any person who has contact with a child has a duty of care to help safeguard and promote the welfare of children and young people in their care. (McDougall 2008).
- To demonstrate an understanding of child protection within your own area, please complete the following tasks:

Activity: Child Protection

Identify the 5 types of abuse and neglect according to the RCN (2007), Safeguarding children and young people – every nurse’s responsibility, London

Can you identify some of the signs / symptoms of abuse / neglect:
(Signs = what you see / Symptoms = what the child / young person feels)

Reflect on what you would do / feel if you suspected abuse or neglect?
Module 2: Understanding Complexity across the Lifespan for People with Multiple Disabilities

Identify a specific action plan and compare it with child protection guidelines (see below) is there anything you think needs reconsidered/developed in light of this exercise?

Activity: Safeguarding Vulnerable Children

In your area locate or find out about the following:
- Child Protection Training (internal + external) available
- Resources e.g. Intranet based / CD ROMs etc
- Child Protection Team / Public Support Unit, or equivalent
- Risk Assessment Tool, or equivalent
- Support Teams for children / young people with learning disabilities / complex needs

Recommended Reading & Resources:

Getting it Right for Every Child – Overview
http://www.scotland.gov.uk/Topics/People/Young-People/gettingitright

It's Everyone's Job to Make Sure I am Alright

Protecting Children & Young People: Framework for Standards
http://www.scotland.gov.uk/Publications/2004/04/19082/34410

Protecting Children & Young People: the Charter
http://www.scotland.gov.uk/Publications/2004/04/19082/34410

RCN (2007), Safeguarding children and young people – every nurse’s responsibility, London


RCN (2010), Safeguarding Children and Young People: Roles and Competencies for Health Care Staff, London
Module 2: Understanding Complexity across the Lifespan for People with Multiple Disabilities

Education

The Education (Additional Support for Learning) (Scotland) Act 2004 introduced a new framework, based on the idea of additional support needs, to provide for children and young people who require additional help with their learning. The ASL Act (2004), which has been amended to become the ASL (Scotland) Act (2009), aims to ensure that all children and young people are provided with the necessary support to help them work towards achieving their full potential. The Early Years Framework is an approach which recognises the right of all young children to high quality relationships, environments and services which offer a holistic approach to meeting their needs. (Scottish Government, 2007).

For children and young people in education in Scotland, the main strategy centres on the Curriculum for Excellence (Scottish Executive 2004). The aim was to ensure that all young people have the skills and knowledge needed for life in the 21st century, and maximising the potential capability of young people.

Activity: Educational Requirements

Think about a child you know or think back to the previous activity where you described the needs of a child with Autism or Fragile X - discuss what might be their educational requirements at different ages:

Pre-school (3 – 5 years):

Primary School (5 – 11 years):

Secondary School (11 – school leaving age):

Recommended Reading & Resources:

Additional Support for Learning
http://www.scotland.gov.uk/Topics/Education/Schools/Welfare/ASL

Schools/welfare/ASL
Early Years Framework

Pre-birth to 3 years: Positive Outcomes for Scotland’s Children and Families
Education is often the initiator of the transition process within the multi-agency context. They may introduce the concept of transition to the young people through links with the careers service, and talking to young people about post school options. School staff often have a key role in supporting and preparing parents and carers for changes which are likely to be happening during the transition from school to adult services. Some schools provide information evenings for this purpose such as Transition Fairs or events: see transition section for further information.

**Assessment Tools / Pathways**

There are many assessment tools and pathways that are used with children and young people with learning disabilities. These can be related to health or social care needs or child protection, e.g. Attention Deficit Hyperactivity Disorder or Autistic Spectrum Disorder pathway / Child Protection Assessment Tool / Wellbeing indicators SHANARRI (Safe, Healthy, Active, Nurtured, Achieving, Respected and Responsible and Included).

**Recommended Reading & Resources:**

- Scottish Autism [www.scottishautism.org](http://www.scottishautism.org)
- ADHD – Services over Scotland [www.playfieldinstitute.co.uk/information/pdfs/publications/adhd/services_over_scotland.pdf](http://www.playfieldinstitute.co.uk/information/pdfs/publications/adhd/services_over_scotland.pdf)
- Getting it Right for Every Child – Overview [http://www.scotland.gov.uk/Topics/People/YoungPeople/gettingitright](http://www.scotland.gov.uk/Topics/People/YoungPeople/gettingitright)
- RCN (2010), Safeguarding Children and Young People: Roles and Competencies for Health Care Staff, London

**Activity: Assessment Tools and Pathways**

In your own area, locate and discuss some of the assessment tools and pathways that are currently used:

**Care Planning**

There are many ways in which plans of care are organised for children / young people with learning disabilities. These may include:
- CCP (coordinated care plan – based on the SHANAARI process)
- CSP (co-ordinated support plan – used by education)
Activity: Care Plans

In your own area, locate and consider the different care plans used in the following disciplines:
Social work
Health
Education

Are the care plans that you found evaluated and how effective is the process / outcomes that are measured?

Recommended Reading & Resources:

Getting it Right for Every Child – Overview
http://www.scotland.gov.uk/Topics/People/Young-People/gettingitright

Transition charter for east midlands can be viewed on http://www.leics.gov.uk/principles_for_transition_booklet.pdf

CCP (Co-ordinated Care Plan)

Case Study: Child Perspective

This case study is based on an infant who is born with Pierre Robin Sequence who has developed absence seizures. This infant is not achieving their developmental milestones. Spend some time finding out what you can about Pierre Robin Sequence and then try and identify the services they may require during the stages of life.

Recommended Reading & Resources:

Find out more about Pierre Robin Sequence at:
http://www.patient.co.uk/doctor/Pierre-Robin-Syndrome.htm

Find out more about absence seizures at:
http://www.patient.co.uk/health/Epilepsy-Childhood-Absence-Seizures.htm
### Activity: Care Plans

Discuss the journey this infant may have till they reach school leaving age – basing stages of life on the services they may require taking into account all of the above:

<table>
<thead>
<tr>
<th>Stage</th>
<th>Health</th>
<th>Social Work</th>
<th>Education</th>
<th>Voluntary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Toddler (1 – 3 years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-school (3 – 5 years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 – 11 years</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Transition

Transition is a term that is becoming much more prominent and can be used in many contexts, from personal experience of change in our lives, to that of political changes that are happening on a national and international basis. It is often the way ‘transitions’ are considered and managed, that will have the most impact. The impact can often have profound and lasting effects on the individual and their circumstances, both positive and negative.

#### Defining Transition

The process or a period of changing from one state or condition to another

- **Transition (from something) (to something)**
  - *the transition from school to full-time work*
  - *He will remain head of state during the period of transition to democracy.*

- **Transition (between A and B)**
  - We need to ensure a smooth transition between the old system and the new one.
  - This course is useful for students who are in transition
    (= in the process of changing) from one training programme to another. Oxford University Press (2010)
Module 2: Understanding Complexity across the Lifespan for People with Multiple Disabilities

Activity: Process of Transition

Read through the article by John M Fisher which you can access at the link below:
http://www.ontrackresources.co.uk/model_transition.html

Reflect on the ‘Process of Transition’ and the ‘Transition Curve’ created by JM Fisher and relate this to a particular experience of change in your own life. Identify some of the associated emotions that you felt during this time.

In this module we will consider transition throughout the lifespan of individuals who have learning disabilities and complex needs. Transition will be considered in the context of education, health and social care. The main transition points that will be addressed will focus upon the following areas:

1. Early years
2. School years
3. Adolescence
4. Young adulthood
5. Palliative Care
6. Older People

It must be emphasised that this is not an exhaustive list of periods of transition throughout the lifespan and you may be able to identify others.

Activity: Transitions

Consider the definition of transition, and identify other specific ‘transitions’ which may occur throughout the lifespan for individuals.

Early Years

In 2002, the Scottish Executive invested in a research study to identify factors which may affect a child’s ability to cope with change. The resultant document helps us understand what some of these factors are, and how to promote the concept of ‘resilience’. The 3 main elements of resilience are considered to be:

• The Child – attributes such as social skills, personal awareness and internal locus of control
• The Family – including supportive parents and valued social role
• The Environment – the importance of friendships, successful school experiences, and supportive extended family

(Scottish Executive 2002)

Activity: Promoting Resilience

Think of someone you know who has a learning disability and complex needs and identify how some of these factors may be significant for them, commenting on how this impacts on their ‘resilience’ to cope with change. (You may wish to consider if the elements of resilience were positive or negative for the individual for example the presence or absence of a family support network).
Improving outcomes for children and young people in Scotland is a major priority for both the National and Local Government. The framework for achieving this has been developed through the Scottish strategy ‘Getting it Right for Every Child’ (Scottish Government 2008). This encourages the practitioner to consider the child’s needs as a whole, and look to improve the outcomes for children, using a multi-agency approach, and the ‘My World Triangle’ framework (Scottish Government 2008). The Scottish Executive (2006) strongly link, what we achieve in adulthood as being influenced by experiences in childhood. The following principles are the cornerstones of support for children and families and include: safety, health, achieving, nurture, active, respected, responsible and included.

Activity: Reflecting on Your Role

Spend a few minutes reflecting on your role. Which of the needs identified within the ‘My World Triangle’ do you have a role in supporting the child and family to achieve:

Are there any of these that you feel are not currently being met?

What needs to happen to change this?
School Years

In 2008, a longitudinal study by the Effective Pre-school, Primary and Secondary Education 3-14 Project (EPPSE 3-14 project) was carried out in England (Evangelou et al 2008). This was to establish what makes a successful transition from Primary to Secondary School. The study of more than 500 children and families highlights practices which can either help or hinder a successful transition. Although this report was carried out in a mainstream school setting, the review also includes the transition for children with special educational needs. Within this report, the factors affecting a positive experience of transition were considered to be:

- The opportunity to expand friendships which would result in increased self-esteem and confidence
- Settling very well into school life
- Showing a growing interest in school and work
- Getting used to new routines and organization of secondary school
- Experiencing curriculum continuity

Within the study completed by Evangelou et al. (2008), a range of practices were employed by schools which helped to support children’s transitions. These included:

- the use of ‘bridging materials’;
- the sharing of information between schools;
- visits to schools by prospective teachers, children and their parents;
- distribution of booklets;
- talks at the schools;
- taster days and other joint social events between schools.

Other findings within this study (Evangelou et al. 2008) indicated that most children (84%) said they felt prepared on entry to secondary school. Many believed that their family and/or teachers helped them to prepare by:

- Dealing with anxieties
- Offering reassurance
- Offering encouragement
- Explanations on how to cope with situations
- Explaining how secondary schools operate and differing expectations

16 per cent of children did not feel prepared when they changed schools. The research states that those who

Recommended Reading & Resources:

You may choose to read more about ‘Getting it right for Every Child’ at: http://www.scotland.gov.uk/Topics/People/Young-People/childreensservices/girfec

had experienced bullying, problems with teachers and the curriculum, or making new friends, generally had a more negative experience of transition. If interested in finding out more about this then read the following resources below.

**Recommended Reading & Resources:**


http://www.behaviour4learning.ac.uk/attachments/1aacac99-a099-4804-9d2b-00912b3a23a6.pdf

The following link is an example of good practice to support the transition from primary to secondary education:

http://www.highland.gov.uk/NR/rdonlyres/E9C71F8B-9698-4094-8C71-6F9668AFB0B9/0/buildingpositiverelationshipstransitions.doc

**Adolescence**

The term adolescence is generally used to describe the period of time between 13-18 years when there is much growth for the young person, both in terms of physical and emotional development. This is a period of time that is frequently reported as being very challenging to the young person, parents and carers.

**Activity: Understanding Adolescence**

Access and read the article by the Royal College of Psychiatry in relation to understanding adolescence:

http://www.rcpsych.ac.uk/mentalhealthinfoforall/youngpeople/adolescence.aspx

After reading this article, please summarise the main developments that are occurring during adolescence for the young person. Then discuss how this may present in someone who has learning disabilities and complex needs.

You may also wish to consider the sex and health education needs of the young person experiencing adolescence and consider sexuality and people with complex needs more generally.
It is important to note that during and after transition from children to adult services, there is a shift from health to social care provision and this can be challenging for families as services are configured differently and the expectations from children’s services may not be met in the same way in adult services.

**Activity: Key Principles of Transition**

View the transition charter from East Midlands using the following link, and identify the key principles of transition which should apply to practice.


This charter also provides examples of transition pathways – Find out if your local area have any transition protocols and pathways that are either agency specific or within the multi-agency context.

**Activity: Transition Planning**

In your local area:
Find out about the role of education during the transition for the young person who has learning disabilities and complex needs, and at what age transition planning usually starts.

Find out about how staff from the Education Department communicate with parents and carers in preparation for transition planning:

**Young Adulthood**

The physical and emotional development of the young person during adolescence is all in preparation for becoming a young adult. This period of time also brings about significant changes in support especially in relation to handing over from children to adult services. In this particular section the focus will be on the transition in a multi-agency context from the perspective of:

- Education – School to post- school activities
- Social Work – children & families support to adult support
- Health – Paediatric to Adult Health Services

**Recommended Reading & Resources:**


Health Scotland’s review on resources available for sexual health education for people with LD

Health Transition

The Department of Health (DoH 2006) developed a ‘good practice guide’ which suggests that the handover between child and adult health services should be planned and managed as a process and asks services to consider the term ‘transition’ more appropriate, than ‘transfer’. The definition of ‘transition’ used by the Department of Health (2006, p14) is:

“A purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions from child centred to adult-orientated healthcare systems’

Where possible, young people should take responsibility for their own health and make informed choices regarding their development (DoH 2006). The challenge remains for services supporting young people with learning disabilities to ensure that this is available whenever possible, and appropriate safeguards are taken, when the individual’s abilities to do this are impaired.

Models of Transition

The DoH (2006) discusses transition models in terms of the provision of service.

- Dedicated follow-up service
- Seamless clinic
- Lifelong follow-up within the paediatric service
- Transition Team
- Transition coordinators

Recommended Reading & Resources:

If you would like to know more about the ‘Curriculum for Excellence’ please follow the link below:
http://www.ltscotland.org.uk/understandingthecurriculum/whatiscurriculumforexcellence

http://www.scotland.gov.uk/Topics/Education/Schools/welfare/ASL


children to adult services, there is a shift from health to social care provision and this can be challenging for families as services are configured differently and the expectations from children’s services may not be met in the same way in adult services.

### Activity: Key Principles of Transition

Consider the different types of models mentioned above and identify the advantages and disadvantages of each.

<table>
<thead>
<tr>
<th>Model</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dedicated follow up service</td>
<td>Simple method</td>
<td>Requires a lot of co-ordination, meetings and consultation. There may not be an equivalent adult service available (especially for very specialist areas of practice)</td>
</tr>
<tr>
<td>Seamless service</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Begins in childhood, or adolescence, and continues into adulthood, with both child and adult professionals involved)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life-long follow-up in Paediatric Services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(There is no transition to adult services)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transition Teams</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Team approach to managing the transition)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transition Co-coordinators</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Specialist worker allocated to aid the transition)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Module 2: Understanding Complexity across the Lifespan for People with Multiple Disabilities

During this exercise you may have considered the following points:

Seamless service:
- Young people benefit from experts in paediatric issues, whilst undergoing assessment in adult context.
- Shared learning between paediatric and adult professionals.
- Timeframe set by the needs of the young person

Lifelong follow-up within the paediatric service:
- Often happens by default as there may be no adult equivalent service.
- Does ensure continuity of care and may be appropriate for those with life limiting conditions.
- However it may limit the opportunity to access other services that may be able to provide support.

Transition Team
- Ensures that all young people’s needs are assessed and transitions are managed in an equitable and consistent manner.

Transition coordinators
- Used for geographical regions and more specialised care needs e.g. paediatric to adult respiratory services.

There are some aspects of transition support which are particularly specific to healthcare:
- The age at which services will no longer see children
  - Sometimes this relates to school leaving age
  - For some services it may be 16 years
  - For others it could be 18 years
- Dependent upon an equivalent adult services being available and willing to accept young people coming into adulthood
  - Some young people who have such complex needs and very rare disorders or syndromes, may find there is no equivalent adult service
  - For some services the young people may have to travel out of area
- The handover from specialist services such as Paediatric medical staff to Primary Care Services such as GPs
  - For many parents and carers of young people with complex needs and learning disabilities, often the key medical personnel may have been the Paediatrician (Hospital or Community) and as a result may have had very little contact with GP over a period of 16-19 years.
- Issues around autonomy and decision making
  - Introduction of the Adults with Incapacity Act (2000)
- The different legislative frameworks to consider between children and adult services
  - The Children (Scotland) Act (2005)
  - The Mental Health (Care and Treatment) (Scotland) Act (2003)
  - Adults with Incapacity Act (2000)
  - Vulnerable Adults (Support & Protection) Bill (2007)
**Recommended Reading & Resources:**

<table>
<thead>
<tr>
<th>Source</th>
<th>Title</th>
<th>Link</th>
</tr>
</thead>
<tbody>
<tr>
<td>Department of Health (2007)</td>
<td>A Transition Guide for all services: Key Information for professionals about the transition process for disabled young people</td>
<td>Nottingham DCSF.</td>
</tr>
</tbody>
</table>
Ethical Issues

Ethical and moral issues are ever present in our daily lives, both personal and professional. They are often inextricably linked by our values and belief systems. Beauchamp and Childress (2001) discussed the 4 principles of biomedical ethics, which are identified as:

- Respect for autonomy
- Beneficence
- Non-maleficence
- Justice

Activity: Ethical Issues in Transition

Access the following link

http://www.rcpe.ac.uk/clinical-standards/guidance/transition-medicine.php

After reading the section on ‘ethical issues in transition’ (Pages 19-23) complete the following activity.

Considering a case from your own experience, demonstrate how you have upheld these principles in practice for an individual who has complex needs and learning disabilities:

- Respect for autonomy
- Beneficence
- Non-maleficence
- Justice

Adults with Complex Needs

Activity: Ethical Issues in Transition

Brian is a 53 year old man with Down syndrome he currently lives in supported accommodation and works part time in his local supermarket. He is overweight, diabetic and has poor eyesight. Recently he has become occasionally incontinent of urine and a little forgetful.
To help with this activity you may find it useful to access the recommended reading and resources below.

Identify the main health risks that Brian may be prone to and how these risks could be managed identifying the assessments and treatments and evaluations required.

Consider also how multiple health risks impact on each other giving examples.

Chose one health risk and identify your knowledge gaps and through further research/reading demonstrate your knowledge acquisition by making recommendations of how to manage this condition (you may produce a care plan, care pathway, protocol or assessment document to demonstrate this)

**Recommended Reading & Resources:**

- Recommended Reading and Resources
  - Downs syndrome education online
    - [http://www.down-syndrome.org/information/development/overview/?page=2](http://www.down-syndrome.org/information/development/overview/?page=2)

- Downs syndrome medical interests group
  - [http://www.dsmig.org.uk/](http://www.dsmig.org.uk/)

- Meeting the health needs of people with learning disabilities

- Social care institute for excellence

- EDSA
  - [http://www.edsa.eu/files/essentials/edsa_essentials_2_healthcare](http://www.edsa.eu/files/essentials/edsa_essentials_2_healthcare)

**Intimate Care and Invasive Procedures**

**Intimate Care**

Individuals with complex needs and high care requirements will often require a range of therapeutic interventions and invasive procedures to maintain function, good health and safety. Intimate care is defined as all care tasks associated with bodily functions, body products and personal hygiene which demand direct or indirect contact with, or exposure of intimate body parts (although other body parts may also be classified as intimate in some cultures).
Module 2: Understanding Complexity across the Lifespan for People with Multiple Disabilities

Some examples include:

- Dressing and undressing (underwear)
- Helping someone use the toilet
- Changing continence pads
- Providing catheter/stoma care
- Bathing/Showering
- Washing intimate parts of body
- Changing sanitary towels or tampons
- Inserting suppositories
- Giving enemas
- Inserting and monitoring pessaries
- Applying/renewing dressings to intimate parts of the body

Activity: Policy and Guidance

Promoting Dignity: Policy and procedural guidance on the use of Chaperones during intimate examination and care of Patients (NHS Lothian, 2011) is an example of guidance in this area.

– Does your service or area have a policy or guidance on intimate care – Access this if you can.

Activity: Intimate Care

What legal safeguards exist to protect people with complex needs particularly around the issues of consent and treatment?

Read the following reflective account from a male 1st year student nurse and discuss how you would deal with the concerns of the student and make recommendations. You may wish to refer to local and national guidelines regarding invasive and intimate care.

“During my first day on placement I was asked to take part in the intimate care of a young female resident who has a profound learning disability, no speech and is dependent on staff for all her care needs. This came as a shock to me as this was the first time I had met the client and found the situation very uncomfortable. I was unaware of any policy, procedure or consent that may or may have not been given for me to take part in the procedure. The client was the same age as me and this made me think that if the client had the ability to say no to my involvement in intimate care would they. This situation was proving morally problematic for me and I needed to raise the issue with my mentor.”

You may have mentioned
Staff need to take account of the views of individuals for example

- The person (where possible)
- The nearest relative and the primary carer (where reasonable and practicable)
- A welfare attorney of guardian (where reasonable and practicable)
- Any other person appearing to have an interest in the welfare of the person such as an advocate or friend

How do you ensure a culture that values the privacy and dignity for all people who are cared for in your organisation? What are the barriers that may exist to prevent this from happening?
Any individuals dependent on others for care are vulnerable. Factors, which may increase this vulnerability may include:

- Reduced control over their lives or decisions due to their disability or lack of understanding
- Lack of sex education which can lead to difficulty in children recognising abusive behaviour
- Reduced communication skills to let someone know they are not happy
- Multiple carers due to hospital admissions or respite/residential care
- Differences in appearance or behaviour may be attributed to a person’s disability/age and not to the possibility that something may be wrong
- Discrimination against children and adult with disabilities in society
- Individuals whose first language is not English
- Individuals suffering from a mental illness including people with dementia

How do we reconcile the pressure of a busy care environment with the wishes of individuals? Where is the time/space in your work environment to consider these issues?

How do we offer the option of a chaperone with regards to the organisation and capacity in the workforce?

Invasive Procedures
Below is a list of the most commonly considered invasive procedures that people with complex needs may require (PAMIS, 2010).

- Nasogastric tube
- Gastrostomy
- Jejunostomy
- Tracheal suctioning
- Tracheal tube replacement
- Postural drainage
- Nebuliser
- Oxygen
- Short-term intermittent ventilation
- Long-term intermittent ventilation
- Manual bowel evacuation
- Enema
- Suppositories
- Colostomy/ileostomy care
- Urethral catheters
- Supra–pubic catheter
- Pessaries
- Injections
- Applying skin creams
- Oral/Nasal suctioning

Activity: Invasive Procedures

Access the PAMIS website at: [http://www.pamis.org.uk/_page.php?id=20](http://www.pamis.org.uk/_page.php?id=20) and read their page on invasive procedures – particularly the project report summary which included recommendations and evidence of good practice.

Identify an invasive procedure from your practice, research best practice for the procedure and state your training needs in light of your research.

Return to the PAMIS report and consider the barriers to providing invasive procedures (Particularly paying attention to the conclusions).
Module 2: Understanding Complexity across the Lifespan for People with Multiple Disabilities

Identify an example from your practice that reflects similar barriers that may prevent the procedures from being carried out.

Reflect on how these barriers impact on the quality of care/life for the individuals involved in receiving that care.

Briefly describe your own feelings and attitudes towards providing intimate/invasive care.

Recommended Reading & Resources:

Access this link to find out more about the roles and responsibilities of carers in regards to intimate care
http://books.google.co.uk/books?id=QlxF6qSyPF8C&pg=PA81&dq=learning+disabilities,invasive+procedures&hl=en&ei=qldjTdroLs_z4gbl2ZnUCQ&sa=X&oi=book_result&ct=result&resnum=2&ved=0CEUQ6AEwAQ#v=onepage&q=learning%20disabilities%2Cinvasive%20procedures&f=false

Access this link to read section 5: medical treatment, care and research of The Adults with Incapacity Scotland Act

Access this link to see an example of a policy from NHS Tayside
http://www.nhstayside.scot.nhs.uk/about_nhstayside/commitees/08_iaq/29092009/item7.7app1.pdf

Older People with a Learning Disability and Complex Needs

People with learning disabilities and complex needs are now frequently living into old age due to advances in medical treatment and an increasing knowledge base to support caring for these people.
<table>
<thead>
<tr>
<th><strong>Activity: Older People</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify some common conditions that may develop due to the aging process?</td>
</tr>
</tbody>
</table>

| | Describe the knowledge and skills you require to ensure that the conditions of aging are identified and addressed in your practice? |
| | |

| | What screening processes are available to the general population to identify common conditions? |
| | |

| | In your experience do your clients have equitable access to these services? |
| | |

---

**Recommended Reading & Resources:**

- [http://www.nhs.uk/Search/Pages/Results.aspx?___JSSniffer=true&q=the+aging+process](http://www.nhs.uk/Search/Pages/Results.aspx?___JSSniffer=true&q=the+aging+process)

---

So was it when my life began;  
So is it now I am a man;  
So be it when I shall grow old. . . .  
The Child is father of the Man  
(Wordsworth, 1807 in Blythe 2010)
In 2009, the Royal College of Psychiatrists produced a report ‘Links not boundaries: service transitions for people growing older with enduring or relapsing mental illness’. This report makes recommendations which are aimed at improving the care of older people who face the possibility of moving between general services, to that of psychiatry services for older people. The following categories highlight the areas where suggested improvements could be made:

1. Development and use of transition protocols
2. Assessments
3. A smooth process of transition
4. Care planning
5. Monitoring of the individual’s health
6. Commissioning of services

Palliative & End of Life Care

Palliative care is the term used to describe the care that is given when cure is not possible. Palliative care is a proactive approach involving a multi-professional team. As well as controlling pain and other distressing symptoms, it applies a holistic approach to meeting the physical, practical, functional, social, emotional and spiritual needs of patients and carers facing progressive illness and bereavement.

End-of-life care is defined as care that:

‘helps all those with advanced progressive, incurable illness to live as well as possible until they die. It enables supportive and end-of-life care needs of both individuals and families to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support’ (National Council for Palliative Care (2006), cited in: DH, 2008: 47).

Since 1998 the National Network for the Palliative Care of People with a Learning Disability (NNPCPLD) has recorded a number of cases where people with a learning disability have not received adequate end-of-life care. Reasons for such difficulties in access include informed consent issues; communication challenges; the interpretation of behaviour and how to raise sensitive issues with the people around the person with the life limiting condition.

Activity: Older Age

Read the report from:

Discuss why age alone should not be the indicator for automatic transition to older people’s services, especially for people who have learning disabilities

The report also recommends special attention be given to the social and spiritual needs of older people - discuss why this could be very important to the individual

Discuss ways on how to involve older people in making decisions about their treatment and why this is considered important
Activity: End of Life Care

Please read the two documents below.
- Living and Dying Well: A national action plan for palliative and end of life care in Scotland  
  http://www.scotland.gov.uk/Publications/2008/10/01091608/11
- Better care every step of the way: Report on the quality of palliative and end of life care in care homes for adults and older people  
  http://www.scswis.com

Explore with your staff team / colleagues what they have in place to meet residents' palliative and end of life care needs. If your area does not have a pathway, then visit the following website and locate the integrated care pathway for palliative care and discuss how this particular pathway would work in practice in your own area.  
www.act.org.uk

Please give an example of how your team plan to meet the palliative and end of life needs of your clients/service users/families.

Activity: DNA CPR

In May 2010, a national DNA CPR (Do Not Attempt Cardiopulmonary Resuscitation) Policy was introduced for Adults. Discuss below the implications of this policy for people who have profound learning disabilities and complex needs.

Recommended Reading & Resources:

Living and Dying Well: A national action plan for palliative and end of life care in Scotland  
www.act.org.uk
www.chas.org.uk

Do Not Attempt Cardiopulmonary Resuscitation - Integrated Adult Policy  
www.palliativecarescotland.org.uk
Most people do not associate palliative and end of life care with children and young people. There are approximately 23,500 children and young people in the UK who have been diagnosed with health conditions for which there is no reasonable hope of cure. (ACT) ACT is a UK organisation which offers support to children who are considered to have palliative care needs, and their families. They not only consider the physical health of the child, but also their social, emotional and spiritual elements and place great emphasis on the quality of life for the child or young person.

Activity: DNA CPR (children under 16 yrs of age)

In December 2010, a national DNA CPR (Do Not Attempt Cardiopulmonary Resuscitation) Policy was introduced for children under 16yrs of age (see link below). Discuss below the implications of this policy in relation to young people under the age of 16 years who have profound learning disabilities and complex needs:

Recommendation Reading & Resources:

http://transitionstopalliativecare.co.uk/index.php?page=publications

www.act.org.uk

<table>
<thead>
<tr>
<th>Activity: DNA CPR (children under 16 yrs of age)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reflect on your learning within this module. Identify 5 key areas where your knowledge has developed and then write one objective for each that outlines how you can implement in practice some of the ideas you have learned about to develop either yourself or your service to provide good care and support. Discuss this with your supervisor, mentor or manager.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Key Learning – I have learned about</th>
<th>To develop this area in my practice I will</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
</tr>
</tbody>
</table>
Module 2: Understanding Complexity across the Lifespan for People with Multiple Disabilities

Key Learning – I have learned about

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>4.</td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
</tr>
</tbody>
</table>

To develop this area in my practice I will

References


Department of Health (2006) *Transition: Getting it right for young people. Improving the transition of young people with long term conditions from children’s to adult health services* DH Publications London


Kubler Ross, E. Fisher, J (no date). The Transition Cycle. Available at: http://www.ontrackresources.co.uk/model_transition.html


RCPE (2008) Think Transition: *Developing the essential link between paediatric and adult care* RCPE Edinburgh


Scottish Executive (2002) Interchange 78: *Transition in the lives of Children and Young people: Resilience Factors*
Scottish Education Department Edinburgh


Module 3: Managing Physical Health and Wellbeing
Module 3: Managing Physical Health and Wellbeing

Introduction

Module 3 addresses the physical and wider health needs of people with a learning disability and complex needs. This module will explore a number of concepts related to health and well-being. To illustrate and explore the issues in contemporary practice you will be introduced to Gareth, a young man with profound and multiple learning disabilities and Mark a man with moderate learning disability and epilepsy. Many of the learning activities within this module will focus on Gareth and Mark. Issues such as health inequalities, access to health, health improvement and promotion will be considered along with capacity, consent, care management, pain assessment, positioning and epilepsy care.

On completion of this module you should be able to:

• Demonstrate an understanding of the increased and different health needs experienced by people with complex needs and critically reflect on health promotion for people with complex needs
• Explore the key issues around capacity, consent and confidentiality with regards to people with profound learning and multiple disabilities in relation to health needs
• Critically evaluate the concepts that drive the care management process including service design, interagency/inter professional working, care coordination and user/carer involvement
• Demonstrate an understanding of a range of health needs experienced by people with a learning disability and complex needs
• Reflect on health inequalities for people with learning disabilities and explore strategies to minimise these.

Activity: Identifying Existing Knowledge, Skills & Areas for Development

Spend a few minutes identifying your existing knowledge, skills and areas for development in relation to supporting people with a learning disability and complex needs manage their physical health and well-being – make some notes below:

Existing Knowledge:

Existing Skills:

Areas for Development:
Health Needs, Health Improvement and Promotion

The World Health Organisation defines health as:

“Good health is a state of complete physical, social and mental well-being, and not merely the absence of disease or infirmity”


This definition has received criticism for being too idealistic as few people would consider themselves in a “complete” state of well-being (Ewles and Simnett, 2003).

Activity: Concepts of Health

Is complete health possible for anyone? What does complete health mean for a person with a learning disability and complex needs? Spend a few moment reflecting on this question and note down your thoughts.

If as a society we are aiming for complete health then people with learning disabilities could be viewed less positively, this definition could be viewed as having implications in terms of society’s attitudes towards people with a learning disability (and the complexity and multi layered health needs that some people experience could be seen as even further from society’s aims).

However the WHO definition does recognise that health should be viewed in a wider context than simply physical health. Dubos (1979) elaborates further and suggests that

“Health relates to the ability of individuals to function in a way which is acceptable both to them and the groups to which they belong”

Wolf-Lewis and Kuhn-Timby (1993) suggest that health includes physical, emotional, social and spiritual health and is what the individual regards health to be. These definitions recognise the need for individual empowerment and the right to make choices and fit with the concepts of person centred approaches to care.

We have already seen in Module 1 how the demography of the population of people with learning disabilities is changing and that the number of people with learning disabilities is increasing. This includes an increase in the proportion of children and older people with learning disabilities, and an increase in the number of people with more severe learning disabilities. People with learning disabilities have a higher prevalence of health needs and a particularly high level of unmet health needs compared to their peers in all age groups. The pattern and types of health need experienced by people with learning disabilities differs from that of the general population, as do the main causes of death. This has important public
health implications, and implications when developing the most appropriate community and service responses (NHS Health Scotland, 2004).

Recommended Reading & Resources:


Higher Levels of Health Need

Activity: Health Inequalities

Take a moment and note down the health needs that you know people with a learning disability are more likely to experience.

Why do you think people with learning disabilities have higher levels and different health needs from the general population?

What do you think the impact of these high health needs are?

People with a learning disability have higher levels of health needs in a number of areas including:

- Increased rates of particular cancers (e.g. people with learning disabilities are three times more likely to develop gastrointestinal cancer, people with Down’s Syndrome are particularly at risk of leukaemia)
- Coronary heart disease is a leading cause of death (14-20%). Approximately 50% of people with Down’s Syndrome have congenital heart defects
- Respiratory disease is the leading cause of death in people with learning disabilities
• The prevalence of mental health conditions and challenging behaviour are significantly higher in the learning disability population e.g. Three times greater prevalence rates for schizophrenia
• Dementia prevalence rates are higher in the learning disability population particularly in people with Down’s Syndrome (with age of onset being 30 to 40 years old)
• Prevalence rates in the following areas of health indicate that people with learning disabilities are more likely to have health concerns in regards to the following - mobility, epilepsy, sensory impairment, physical impairment, oral health, dysphagia, diabetes, constipation, osteoporosis, endocrine, accidents/injuries/falls
• Gastro-oesophageal reflux disease (GORD) is more prevalent (approximately 50% of people with learning disabilities in a Dutch institution were diagnosed with gastro-oesophageal reflux disease and there is concern that it is under diagnosed compared to the general population (Emerson and Baines, 2010). GORD has been identified as a significant contributor to sleep problems, behavioural problems, anaemia and as a risk factor in oesophageal cancer

Some of the reasons why people with a learning disability experience increased health needs include:
• Many of the causes of learning disabilities have associated health needs e.g. Tuberous Sclerosis and Epilepsy, Down Syndrome and Dementia, Prader-Willi Syndrome and affective psychosis, Congenital Rubella and sensory impairments, peri-natal trauma and impaired mobility
• Due to multiple health needs, adults with learning disabilities are more likely to be prescribed multiple drug treatments. This can adversely affect health, due to side-effects, and interaction of medications
• People with a learning disability are less likely to exercise and eat healthily than the general public
• People with a learning disability do not always have the knowledge or understanding to make healthy choices, and are reliant on others for support - the attitudes of paid carers are therefore vital and these will depend on their own background, training, motivation, and understanding
• People with learning disabilities living alone or with minimal care may not have adequate support to help them make positive choices about their health
• Ineffective and inaccessible provision of appropriate health information

Increased health needs in people with a learning disability can lead to:
• A shorter life expectancy than that of the general population.
• Poorer quality of life
• Increased risk of exclusion
• Conditions being undetected and therefore untreated

Activity: Improving Health Outcomes

Why is it important that we have this information and how can we use it to improve the health outcome for people with learning disabilities?
You may have mentioned that detailed information about health need supports service planning, delivery and allocation of resources. This is particularly important where there are inequalities in health. One example of this is how the recognition of the prevalence of breast and lung cancer within the general population has led to increased resources spent on research, treatment and health promotion in this area. Whilst no one would suggest this is not positive, people with a learning disability are less likely to experience the same high levels of these conditions and are more likely to experience gastrointestinal cancer. There are significantly less resources focusing on gastrointestinal cancer in terms of awareness and health promotion campaigns. This inequality in health patterns leads to potential inequality in having health needs appropriately met.

**Activity: Health Inequalities**

**Access and Read**


**Promoting Healthy Lifestyles**

**Activity: Healthy Lifestyles**

Think of how the choices that you make can contribute to your physical, social or mental health. List three positive and three negative choices that you make and identify how it impacts on your health, e.g. Drinking above the recommended limits may contribute negatively to your mental health or playing tennis in your local club may contribute positively to your social health and well being?

Choose someone you know with profound and multiple learning disability and consider the choices that are made either by the individual or for the individual in relation to their health. Compare these answers with your own and reflect on any differences that may arise.
You may have noticed that when we consider health we often focus more on physical health than social, emotional or mental health. It is important that we equally consider the person’s social, emotional and mental health needs. Mental health and well-being will be explored in more detail in Module 5: Mental Health and Well Being. Health promotion is the process of enabling people to increase control over and to improve, their health. It moves beyond a focus on individual behaviour towards a wide range of social and environmental interventions (WHO, 2011)

Activity: Health Promotion

Reflect on your role – what can you do to promote health for the people you support?

You may have mentioned that having a good knowledge around health could help you support others to make positive choices. You could make opportunities for activities that promote good health. You could act as a role model. You could ensure you have an understanding of the range of local services available that could help people you support access relevant health promotion activities.

Recommended Reading & Resources:

If you would like to find out more about health promotion materials that have been adapted to be accessible to people with a learning disability you can access:

http://www.fairadvice.org.uk/fmindex.htm
http://www.healthcarepromotions.co.uk/site/health-promotion-links/weblinks/108-learning-disabilities

If you want to find out more about health and health inequalities you can visit:
http://www.who.int/topics/health_promotion/en/

What is health promotion?

NHS Evidence - Learning Disability

BILD

Mencap

Promoting good health and well-being is everybody’s business not just the domain of health professionals. Carers and family members providing support on a daily basis are in the position of having most influence and ability to maximise opportunities and positive choices to be made around health.
Case Study: Gareth - Background

Gareth is a 40 year old man with a profound learning disability. Gareth has a friendly, sociable and cheery disposition. He has cerebral palsy, epilepsy and significant physical health problems. These include severe arthritis in his legs and arms, osteoporosis, frequent dental problems and poor dietary intake. His vision is deteriorating and he is prone to chest infections.

Gareth is preparing to move to a voluntary sector residence with three other adults with learning disabilities. Mum has been finding it increasingly difficult to care for Gareth at home due to the cumulative complexity of his health needs and her work commitments. However Mum and Gareth’s younger brother Tom (aged 30) plan to visit regularly and are both loving and supportive. Gareth attends a social work day service where he receives 1:1 support from his keyworker. Gareth’s social activities are predominantly confined to the day centre. He has a hydrotherapy session once a week; he likes listening to his music and is involved in the creative arts group. He previously was a member of his local bowling club but with his impending move there is concern that he may not be able to continue to attend.

Recommended Reading & Resources:

You can find out more about Cerebral palsy at:
Scope

Arthritis and osteoarthritis at:
http://www.arthritiscare.org.uk/AboutArthritis/Conditions/Osteoarthritis

Sensory impairment at:
http://clacksweb.org.uk/social/sensorycentre

Dental health at:
http://www.bsdh.org.uk/guidelines.html

Chest infections at:
http://www.nhs.uk/conditions/chest-infections-adult/Pages/introduction.aspx
Capacity, Consent and Confidentiality

For any adult in Scotland over the age of 16 it is presumed that they can give consent to treatment (Scottish Executive, 2000). In Gareth’s case his care provider is now his welfare guardian. However in line with a number of contemporary legislative and policy frameworks the Adults with Incapacity (Scotland) Act 2000 (Scottish Executive, 2000) state that all relevant carers, family, and friends should be involved in the decision making process. The National Patient Safety Agency (2004) identified that people with learning disabilities are more at risk of care needs not being met and specifically expressed their concern that the legal and practical processes are not fully adhered to. In particular they highlighted a concern that consent is often ‘attained’ not from the individual but from carers.

Activity: Consent

Gareth has been living in his new accommodation for one week and his brother has expressed concerns that his care needs are not being met. You have been asked to convene a case conference and Gareth’s mum has stated that she would like to bring along her male friend to the meeting. However Gareth’s brother Tom feels that mum’s friend has no entitlement to be at the meeting and that this is a breach of Gareth’s confidentiality. You have met with both Gareth’s mum and brother but both refuse to compromise.

Answer the following questions – you may want to explore the web sites in the recommended reading and resources box below. Spend about 45 minutes on this activity.

How could Gareth be involved in giving consent as to who attends the case conference?

What responsibility does the new care provider have over matters of consent?

Is there an alternative solution that you could suggest to resolve this situation?
You may have mentioned that although Gareth has a welfare guardian he may still have capacity to make certain decisions. His ability could be explored and assisted with support from a speech and language therapist, psychologist or psychiatrist or by the support of people who know him well.

If Gareth cannot give consent the care provider should be consulted as the welfare guardian on who should attend the meeting.

Another solution could be the involvement of an independent advocate who could provide support to mum and is bound by the rules applying to confidentiality.

Activity: Confidentiality & Capacity

If you are not sure in regards to any issues of confidentiality or capacity who could you seek advice from?

There will be specialists within each profession who have increased knowledge and experience in addressing issues of confidentiality and capacity e.g. Mental Health Officers, Hospital Liaison Nurses and Psychiatrists. NHS and Local Authority legal departments can either give advice or signpost to specialist legal services and/or you could seek advice from advocacy services in your area.

Recommended Reading & Resources:

Follow the web link below to the Scottish Independent Advocacy Alliance to find an advocate in your area.
http://www.siaa.org.uk/index.php?option=com_sobi2&sobi2Task=search&Itemid=57&sobi2Search=search...&search=Search&searchphrase=any&field_nhs_area=field_nhs_area_opt_13&field_type_of_advocacy=all&field_client_group=all
Case Study Update

Tom expressed his concerns at the case conference – he feels that no-one is interacting with Gareth, that every time he came to visit, Gareth was lying on a beanbag. He stated that “the staff seem nice enough but always seem to be agency or temporary staff.” Another concern was that his brothers modified diet was not as smooth as when he lived at home. On one occasion when being fed by an agency worker Tom noted that Gareth was coughing and spluttering a lot during the meal and becoming distressed.

A referral has been made to the community learning disability team for a health needs assessment. A screening visit has been scheduled in two weeks’ time and following the initial screening, allocation to relevant professionals within the team may vary from six weeks to three months.

What would you identify as the priorities in regards to Gareth’s health needs?

Depending on your role in your organisation (nurse, support worker, care manager) what activities would be within your remit to help address the priorities you identified?

<table>
<thead>
<tr>
<th>Discipline</th>
<th>How you would access them</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Learning Disability Nurse</td>
<td>Refer direct or through GP</td>
<td>Health Assessment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Gareth provides an example of someone with a learning disability and complex needs. He has everyday health needs such as his dental care and diet as well as specialist health needs including cerebral palsy, epilepsy, arthritis, chest infections and sensory impairment. He has multiple health needs. It is important that everyone involved in supporting Gareth, whether they are health or social care professionals, has good levels of knowledge and understanding of the health needs that Gareth experiences to ensure that appropriate care is given.

We would suggest the priorities for care for Gareth are:
- Positioning - Unsupported may lead to breathing difficulties, chest infections, scoliosis, contractures, increased pain and discomfort.
- Diet – The wrong consistency of food may lead to possible choking, aspiration and malnutrition
- New/Agency staff - Unfamiliar with guidelines, no established relationship/trust with Gareth - Need for staff education, care planning, and consistency of approach.
- Meeting Gareth’s social and emotional needs.
- Meeting Gareth’s family and carers’ social and emotional needs

We would suggest the other professionals that would have a role in Gareth’s care would be
- GP
- District/practice nurse
- Care Manager
- Support worker
- Physiotherapist
- Speech and language therapist
- Dietician
- Advocacy services

If you have missed any of these roles in the above activity you should go back and consider how you would access this service and what their role would be.

A community learning disability nurse could provide a range of input to help meet Gareth’s complex health needs.

The role of the learning disability has been described by the RCN, (2011) as:
- Undertaking comprehensive assessments of health and social care needs
- Developing and implementing plans and programmes of care
- Working in collaboration with other professionals and disciplines to meet health needs and coordinate care
- Providing nursing care and interventions to maintain and improve health and promote wellbeing
- Enabling equality of access and outcomes within health and social care services
- Providing advice, education and support to people with learning disabilities and their carers throughout their care journeys and providing education and support to promote healthy lifestyles and choices
- Providing education and development opportunities for other practitioners on the needs of people with learning disabilities
- Acting to safeguard and protect the rights of people with learning disabilities when they are vulnerable and in need of additional support learning
In relation to Gareth and his health and well-being, the role of a community learning disability nurse could include:

- Developing plans and programmes of care and implementing plans and programmes of care
- Working in collaboration with other professionals and disciplines to meet health needs and coordinate care
- Providing nursing care and interventions to maintain and improve health and promote wellbeing
- Providing advice, education and support to people with learning disabilities and their carers throughout their care journeys

Whatever your professional background it is important to recognise your limitations (NMC, 2008) and be fully aware of the expertise that specialists within the team provide. You also need to be clear where there is role overlap that each individual professional is aware of their specific responsibilities. Failing to achieve this may lead to discrimination, health and wider health care needs not being met and this can sometime lead to tragic outcomes for people with learning disabilities (Mencap, 2008). The consistent factor in many fatal accident enquiries is a lack of effective communication among all professionals. The role of co-ordination and leadership is often cited in professional literature and applied to an array of professionals roles as is the term “safeguarding the clients’ interests” (Faugier, 2004; Scottish Government, 2006), despite this, tragedies continue to occur (NPSA, 2007).

Key Knowledge and Skills
Gareth has been in his new home for 12 weeks. He has been prescribed antibiotics for a chest infection to good effect. He has had input from physiotherapy who have put in place positioning guidelines and had his chair adjusted. Gareth is now active on the community learning disability nurses caseload.

You are the individual professional/support worker who Gareth’s family will invariably contact first. You have received a phone call from Gareth’s mum who has expressed concern that Gareth seems to have lost weight and is in pain. When asked to specify why she feels this way she replied “I’m his mother, I can just tell”. Mum begins to cry and hangs up.

Recommended Reading & Resources:


National Patient Safety Agency lead and contribute to improved, safe patient care by informing, supporting and influencing organisations and people working in the health sector – find out more about NPSA at: http://www.npsa.nhs.uk/

You can read ‘Death by Indifference’ a report outlining the experiences of families and people with learning disabilities who failed to have their health needs adequately met by accessing: http://www.mencap.org.uk/document.asp?id=284
(Although we concentrate on pain and nutrition in this module feel free to identify other conditions that may fit with your learning needs).

**Activity: Assessment of Pain**

How do you assess Gareth’s possible pain?

You may have mentioned:
- Are there any previous descriptions/assessments of Gareth’s pain? Compare with direct observations
- Do records indicate if there has been any notable changes in Gareth’s behaviour, diet, sleep pattern, interactions
- Ascertain if Gareth has any current prescriptions for pain management - If yes, ascertain if prescribed medication is currently effectively managing Gareth’s pain.
- Identify who you contact for advice and support

**Recommended Reading & Resources:**

DISDAT (2008) is a pain assessment tool for people with a learning disability. You can access an article on this at: [http://prc.coh.org/PainNOA/Dis%20DAT_D.pdf](http://prc.coh.org/PainNOA/Dis%20DAT_D.pdf)


Good communication is a key skill in understanding Gareth’s needs and supporting Gareth to live a full and healthy life – module 4 will explore in depth good communication. We also draw on our communication skills in working in partnership with family carers and other professionals.

**Activity: Pain Assessment Carer Information**

You have arranged to interview mum as part of your pain and/or nutritional status assessment. Read the above articles looking at the DISDAT and the MUST and consider the questions that you hope to elicit answers to. What factors do you need to take into consideration prior to the interview?

You may have mentioned that Mum is emotionally distressed and that you would consider what counselling skills you may have to incorporate in your interview technique.
### Activity: Interview Skills

Ask a colleague if you can interview them and attempt to assess one of their clients' needs (ensure confidentiality). Record the interview and if preferred transcribe it. Assess your interview skills and consider the following questions.

You may want to have a look at the website below which gives some information about asking questions [http://www.handsonscotland.co.uk/topics/techniques/counselling.htm#asking_the_right_questions_when_counselling_children_and_young_people](http://www.handsonscotland.co.uk/topics/techniques/counselling.htm#asking_the_right_questions_when_counselling_children_and_young_people)

<table>
<thead>
<tr>
<th>Question</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did I ask open questions?</td>
<td></td>
</tr>
<tr>
<td>Did I ask closed questions?</td>
<td></td>
</tr>
<tr>
<td>Did I demonstrate empathy?</td>
<td></td>
</tr>
<tr>
<td>Did I demonstrate active listening skills?</td>
<td></td>
</tr>
<tr>
<td>Did I clarify any areas of confusion?</td>
<td></td>
</tr>
<tr>
<td>Did I paraphrase?</td>
<td></td>
</tr>
</tbody>
</table>
Accessing Health Care

The Same as You (Scottish Executive, 2000) states that people with learning disabilities want and should use the same services as anyone else within society. They further state that specialist services should be available for people with learning disabilities when required but that these specialist services should add to the existing services not replace them. As we have read above research has highlighted that people with learning disabilities have greater and different health needs than the general population and people with learning disabilities continue to have significant problems in having their health needs met. Research has further indicated that barriers exist for people with learning disabilities in accessing health care and as a result health care needs not being met.

Barriers to Addressing Health Care Needs

Gareth has now been assessed by his GP and he has identified serious health complications. The expectation is that Gareth will have to be immediately admitted to hospital. Surgical intervention is necessary and it is likely that Gareth will remain in hospital for a minimum of two weeks.

Activity: Accessing Health Care

It is evident that there have been significant changes in Gareth’s behaviour and having had a brief telephone discussion with Gareth’s brother supports, your direct observations, the evaluation of the notes and discussion with colleagues which clearly suggest that Gareth is in pain. Gareth has been receiving regular paracetamol but it is apparently having little effect. You have discussed calling the GP but your line manager has said that they have received a complaint from the GP practice for excessively and unnecessarily calling the GP. This particularly relates to the practice’s belief that the use of emergency appointments are being exploited to fit in with the organisations staffing resources. Your line manager has suggested that you make a regular appointment rather than an emergency appointment. Unfortunately the earliest appointment is in five days.

Reflect on your previous experience and consider a situation where you found yourself in a conflict of interests, and/or been over ruled when you believed that this was not in the individuals best interests. Consider what you could have done and formulate an action plan.

Identify the key principles from your action plan and apply them to the case scenario above list what you could do to ensure Gareth’s health is appropriately assessed.

Activity: Accessing Health Care

1. Identify your care pathways/information packs/care plans that would provide the appropriate information for the health professional receiving the person in your care when admitted to hospital
On admission you are being interviewed by a nurse or doctor. You have given them the information pack but it remains unopened. In response to the questions you are being asked you emphasise two key points. You emphasise that Gareth should not be laid on his back and that Gareth may appear to be refusing his medication as he will wave his arms and vocalise loud grunting noises. In regards to the latter you suggest, that taking your time, standing in front of Gareth and singing (usually a Beatles song) will ensure compliance. Your suggestion is met with a wry smile. A few minutes later Gareth is taken out of his chair and laid on his back in his hospital bed. The admitting health professional does not convey the information you gave. When you try to protest the individual abruptly dismisses you and leaves the room.

2. You recognise that you need support to communicate Gareth’s needs effectively and ensure that his care needs are met. Identify what processes you can pursue and who can support you in the process.

You may have mentioned:

- That knowledge, communication skills, person centred values and confidence would be important in this situation.
- How effectively and consistent the care is delivered throughout Gareth’s stay in hospital will influence the processes and the people and professionals that you may seek support from.
- In the initial stages you could speak to the people immediately senior to the admission team and inform your line manager of your concerns and document your concerns.
- You could ascertain if a liaison nurse is assigned to the hospital who will coordinate and facilitate Gareth’s assessed needs prior to admission through to discharge (see web link below).
- Consult with members of the learning disability team to inform care plan
- Should you have concerns that are not be acted upon then the following have to be considered: complaint procedures, inform patient safety officer or organisation or social work team in regards to supporting and protecting adults legislation

Recommended Reading & Resources:


Liaison Nurse Service

Learning disability services in south east Scotland available at:
http://www.cfr.ac.uk/reports/LDbriefing.pdf

National Patient safety Agency http://www.npsa.nhs.uk/

Adult Support and Protection Act (Scotland) 2007 http://www.scotland.gov.uk/Topics/Health/care/adult-care-and-support

Advocacy
http://www.bild.org.uk/04advocacy_about.htm
Activity: Barriers to Meeting Health Needs

Below is listed a comprehensive list of barriers to unmet health needs. Throughout Gareth’s case study how many of these barriers did Gareth, Gareth’s family and Gareth’s carers have overcome to ensure his health needs were met.

<table>
<thead>
<tr>
<th>Potential Barrier</th>
<th>Relevant to Gareth</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with learning disabilities may have limited or no verbal communication. It is therefore difficult for them to communicate pain, distress or symptoms. This can lead to delayed intervention and further complications</td>
<td>Refer direct or through GP</td>
</tr>
<tr>
<td>Health needs are overlooked by paid carers and professional and are wrongly attributed to the person’s learning disability or associated condition (diagnostic overshadowing) e.g. Person with learning disabilities and cerebral palsy whose increasing falls is attributed to his limited mobility rather than a potential visual or auditory impairment</td>
<td></td>
</tr>
<tr>
<td>Inconsistency of care workers and movement of care workers can lead to ineffective communication and no clear line of accountability. The person with learning disabilities has inconsistent assessment of their health needs and inconsistency in implementing care plans</td>
<td></td>
</tr>
<tr>
<td>General practice is designed to provide a reactive general medical service, with proactive action only for specific, nationally agreed target areas e.g. recalling women in the prescribed age categories for cervical screening</td>
<td></td>
</tr>
<tr>
<td>Individuals are considered responsible for their own health; if reassured by a GP at a first appointment about a particular symptom, carers/people with learning disabilities are less likely to arrange a further consultation if the symptom persists or becomes more severe</td>
<td></td>
</tr>
<tr>
<td>GP appointment times are often too short and additional preparation that may be required is not given due consideration</td>
<td></td>
</tr>
<tr>
<td>Follow up appointments are not given as a proactive strategy. Therefore the potential barriers that may have been experienced in initially accessing the GP may have to be overcome again or may even be more insurmountable</td>
<td></td>
</tr>
<tr>
<td>Potential Barrier</td>
<td>Relevant to Gareth</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>--------------------</td>
</tr>
<tr>
<td>Government policy states that people with learning disabilities should access mainstream services however primary care systems do not replicate the paediatric service in meeting the secondary care needs of adults with learning disabilities. Therefore adults with learning disabilities are disproportionately dependent on specialist services e.g. Community learning disability teams where immediate access to care is not always available and some learning disability professionals do not have up to date skills on general health</td>
<td></td>
</tr>
<tr>
<td>Misconstrued perceptions of normalisation and social role valorisation have led to people with learning disabilities health needs being over-looked. One example of this is when a person with learning disabilities refuse or appear reluctant to take essential medication (e.g. anti convulsant and anti psychotic medication). It has been reported that carers have accepted at face value that this is the individual’s choice and no attempt was made to assess the reason for non-compliance (e.g. side effects, dosage to high or too low). No effort has been made to explain the consequences of refusing medication and no support given to comply</td>
<td></td>
</tr>
<tr>
<td>Institutional discrimination against people with learning disabilities has been reported to exist throughout the NHS. One tragic impact of institutional discrimination is when a decision is made to not treat the person with complex needs due to the doctors perception of the individual’s quality of life and it is either supported or accepted by other health professionals that have led to tragic consequences Mencap, (2004)</td>
<td></td>
</tr>
<tr>
<td>Often it is just that no thought is given to the particular needs of people with a learning disabilities, The top priorities for the general population e.g. the impact of smoking and deprivation on health, differ from the top priorities for adults with learning disabilities who have greater inequalities. A further implication of this is that it is more difficult to access and act on relevant health information for the individual with a learning disability.</td>
<td></td>
</tr>
<tr>
<td>The health needs that are most commonly experienced differ from the most common health needs in the general population. A different hierarchy of differential diagnosis is needed to that used with the general population. In effect a more focussed health assessment is needed.</td>
<td></td>
</tr>
</tbody>
</table>
### Activity: Meeting Health Needs

Reflect on your own experiences – have you experienced any barriers to having your health needs met?

<table>
<thead>
<tr>
<th>Reflection</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

What barriers have you encountered in meeting the health and wider health needs of the people you support?

<table>
<thead>
<tr>
<th>Reflection</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

What could you do to minimise these barriers in the future?

<table>
<thead>
<tr>
<th>Action Plan</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

“It is important to remember that discrimination that is unintentional is still against the law (Mencap, 2007 p5).

#### Recommended Reading & Resources:

- [http://www.scotland.gov.uk/Publications/2006/05/16081604/14](http://www.scotland.gov.uk/Publications/2006/05/16081604/14)

**Advocacy**

- [http://www.bild.org.uk/04advocacy_about.htm](http://www.bild.org.uk/04advocacy_about.htm)

### Physiotherapy and Physical Management

In general terms, good health is the freedom from unpleasant symptoms or sensations, the degree of well-being of a person. In physiotherapy terms, we are concerned with good physical health which maximises the functional mobility and independence of an individual and prevention of secondary conditions.
### Activity: Health

How is ill health reflected in an individual and would you expect this to differ if the person has complex needs?

Why is it important to maximise function?

Good health has a direct bearing on Quality of Life. Physiotherapists working in learning disabilities aim to improve or maintain a good quality of life, despite the neurological condition of the client and the physical changes associated with this.

### Activity: Quality of Life

What are the issues for someone with a poor quality of life?

This is carried out by a Physical Management Programme. It is important to recognise that treatment cannot be seen as a short session once or twice each week. The central nervous system is responsive to what is happening all the time and not just during short intensive stimulation. If deformities and difficulties are counteracted during treatment sessions they should not be accentuated by abnormal positioning at other times during the day and night.

### Activity: Problems with Positioning

Describe what you would think of as abnormal positioning

Can you think of any problems/issues that 24 hour positioning may cause and to who? How could you counteract these problems?

A good Physical Management Programme consists of:
- Individual assessment and a client centred, needs led approach
- “Hands On” treatment or exercise as required including passive movements
- Hydrotherapy
- Positioning and use of positioning equipment
- Adapted or specialised seating for indoors and outdoors
- Mobility and provision of mobility aids as required
- Orthotic provision as necessary
- Onward referral to Consultants or other specialist units such as Orthopaedics, Spasticity Clinics,
Baclofen clinics, Epilepsy clinics etc.

- On-going training and education of clients, carers, family, provided staff, students, colleges

Individuals may use some or all of these options, depending on their individual needs.

Activity: Activities and Positioning

Consider a person you know who has limited mobility or function. Formulate an hour by hour diary of a day in the life of this person, giving their activities and the position they are in when carrying out these activities.

Deformity and loss of function are preventable if a good physical management programme is assessed, implemented and carried out consistently.

What is Positioning?

Positioning is the use of specialist equipment to achieve a correct position for the client. It is worked over a 24 hour period, in all settings and should promote maximum function and independence where possible.

Activity: Activities and Positioning

Who do you think carries out these positioning programmes?

What kind of function can be maximised and used for a client being positioned?

Why Do We Need To Position?

- There are numerous reasons why positioning is important, with the main ones being as follows:
  - Comfort of the individual
  - Prevention of deformity by stretching muscles and joints
  - Strengthens bones and maintains good joint alignment
  - Helps and improves function of kidneys, bladder and bowels
  - Provides a base from which functional movement can occur
  - Gives individuals a different view and perspective on surroundings and environment
Activity: Positioning Programme

Applying the knowledge you have now gained, and using the person you used earlier, plan and document an ideal 24 hour multi-disciplinary physical management programme for them, with activities. Based on the evidence above, explain for each activity why it is necessary and predict what you hope to achieve by the position or activity.

In real life situations, there are reasons why this 24 hour positioning programme is not always accurately carried out, or is modified or changed. List at least 3 reasons why this may be the case.

Use a problem solving approach to identify any ways in which these problems could be resolved or improved?

Module 3: Managing Physical Health and Wellbeing

- Relieves pressure on susceptible body parts, preventing deterioration in skin condition and development of pressure sores.
- Improves spatial and body awareness
- Helps improve physical skills and level of independence, such as head control and balance

Activity: Activities and Positioning

Reflecting on the daily diary of a person you know that you wrote earlier, critically evaluate the diary to verify which of these reasons for positioning are important to that particular individual?

What Happens If We Do Not Use A Physical Management Programme?

Again there are many possibilities and scenarios but the main issues are:
- Increased joint contractures, limb and spinal deformities
- Increased risk of osteoporosis, ultimately leading to fractures and joint dislocations
- Urinary and bowel systems function less well, leading to an increased risk of infections and constipation
- Increased risk of skin breakdown and pressure areas
- Loss of opportunities for stimulation and interaction

Physical management programmes, although set by the physiotherapist may be carried out by physiotherapists, but also by nursing staff, support workers, allied health professional staff, carers and families. For these to work all must work together, as part of a team. All must see the bigger picture, involve others and communicate well with others to achieve the best outcome for the person.

It is not the intention of physiotherapists to “medicalise” people with a learning disability. The aim is to maximise physical potential and facilitate function so that disabilities do not become handicaps and individuals can live as full a life as possible, regardless of the level of ability.
Module 3: Managing Physical Health and Wellbeing

Recommended Reading & Resources:


Care and Support of People with Learning Disabilities and Epilepsy

Epilepsy is common in people with a learning disability with approximately 1 in 5 having epilepsy (Kerr 2002). The risk is higher the more severe the learning disability (Bernal 2003). People with a learning disability are more likely to have difficult to control epilepsy and multiple seizure types. Conditions associated with epilepsy include Retts syndrome, Fragile X syndrome, Tuberous sclerosis, Sturge Weber syndrome, Angelman syndrome and Aicardi syndrome (Epilepsy Action 2010).

People with epilepsy have an increased mortality rate 2-3 times higher than the normal population (Hanna et al 2002). Up to a third of these deaths are directly or indirectly related to epilepsy (Neligan and Bell 2009).

It is important that people with epilepsy are correctly diagnosed and have access to specialist services and support to manage their epilepsy. Epilepsy affects many aspects of a person’s life and we will explore some of the issues for people with a learning disability who have epilepsy in this unit.

Activity: Prevalence of Epilepsy in People with a Learning Disability

In the space provided below consider the following: How many of the people your support or work with have epilepsy?

Does this compare to the statistics about epilepsy?

Before continuing with this unit test your knowledge of epilepsy by completing the quiz below

1. Epilepsy is:
   a. A mental health problem
   b. A tendency to recurrent seizures
   c. A loss of consciousness

2. A tonic clonic seizure is:
   a. A generalised seizure
   b. A partial seizure
   c. Unclassified

3. To make a diagnosis of epilepsy the doctor most importantly requires:
   a. MRI scan
   b. EEG
   c. Accurate eye witness account
4. If a person has a seizure your first priority is to:
   a. Ensure safety
   b. Open airway
   c. Put in recovery position
   d. Restrain movements

Answers
1. B
2. A
3. C
4. A

For further information about epilepsy you can link to Clinical Knowledge summaries. Available from: http://www.cks.nhs.uk/patient_information_leaflet/epilepsy

Now consider a client you look after and make some notes. You will be asked to return to this later.

1. What type of seizures do they have?

2. What first aid management is required if they have a seizure?

3. Do they require emergency medication?

4. How does the epilepsy impact on their lifestyle?
5. How do they feel about their epilepsy?

The diagnosis and management of epilepsy can be difficult in the general population. In people with a learning disability this can be more challenging due to:

- the number of different causes of epilepsy,
- multiple seizures types – often people with a learning disability and epilepsy have more than one type of seizure
- stereotyped behaviours – this can be seen particularly in people with autism which makes it difficult to distinguish between seizures and behaviours
- communication difficulties- many people with learning disabilities have some cognitive and or communication problems. Epilepsy is more likely in people with moderate and severe learning disabilities.

(Kerr 2009).

People with a learning disability should have access to the same range of services and treatment options as the general population.

Activity: Case Study

Let us now consider a case study to explore some of the issues for a person with a learning disability and epilepsy.

Mark is a 20 year old who has a moderate learning disability and epilepsy. He has difficulties communicating. He has complex partial seizures several times a week. During the seizure he will stare, smack his lips and then posture his limbs rock back and forward. This lasts about 2 minutes. He is then confused for a few minutes afterwards. He also has atonic seizures where he will fall to the ground. He quickly recovers from these but often injures himself so wears a helmet to protect his head.

Mark lives with his parents. He has a carer who comes 3 times a week.

Mark attends the local epilepsy clinic and has recently changed his medication. There has been an increase in Marks seizures since this change. He doesn’t like taking his medication and tends to spit it out.

His parents were very protective of Mark and had reluctantly agreed to carer involvement. They were becoming reluctant to allow Mark to out with the carer. Mark enjoyed going out and did a range of activities including going swimming once a week.

Activity: SIGN Guidelines

Can you note down the reasons you think Mark’s seizures may have increased?

The recent change in medication would be the first thing which may be a factor in the change in seizure frequency. There is some indication that Mark may not be taking his medication which could cause the seizures to increase. It can be difficult for someone with communication problems to be able to tell us if they have side effects. Common side effects with medication can be drowsiness, double vision, nausea, unsteadiness and mood/behaviour changes.

It is also important in people with epilepsy to ensure they do not have dysphagia (difficulty swallowing) as this could be a reason Mark has difficulty taking tablets. Other triggers include lack of sleep, intercurrent illness e.g. urinary tract infection, chest infection, stress, boredom, photosensitivity (only affects 5% of people with epilepsy), alcohol and drugs. Of these changes in sleep pattern and boredom may be a factor if Mark is not as active as he usually is.

Activity: Observation and Recording

We need to consider the importance of observing, monitoring and documenting seizures. Take down some notes.

How could you monitor Marks seizures?

What information would be important to record?

Why do you think it is important to record seizures?

Recommended Reading & Resources:

Further information can be obtained from NICE guideline page 32 and 33 available on link below http://www.nice.org.uk/nicemedia/live/10954/29532/29532.pdf
A description of the seizure including what occurs before, during and after is important to establish if it is an epileptic seizure and the seizure type. This is important to establish an accurate diagnosis, ensure correct medication prescribed and monitor effect of any changes in medication.

Documenting the time and situation allows for patterns to be identified and potential triggers for the seizures identified.

Recommended Reading & Resources:

Further information can be found in NHS Clinical knowledge Summaries; scenario on suspected epilepsy and managing a seizure. You can access these using link below; http://www.cks.nhs.uk/epilepsy.

Epilepsy Action also have good information about this which can be accessed on their website in the section on learning disabilities and epilepsy. This can be accessed using the link below. http://www.epilepsy.org.uk/info/learning-disabilities

Mark doesn’t get any warning so the seizure can occur anywhere and at any time. He is at risk of injury and does wear a helmet because of this. This will affect him both in the home and outdoors. Parents understandably worry about the risk of injury and there is a tendency to be very protective. This can limit the person with epilepsy’s choices and lifestyle. The obvious concern in Marks case may be swimming.

Activity: Risk

Due to the increase in seizure frequency Marks parents are reluctant to allow him to go out with the carer.

Note down what you think Marks parents concerned are?

How may having frequent seizures affect Mark?
Module 3 : Managing Physical Health and Wellbeing

Activity: Safety and Risk

Now read the following information on safety and risk from Epilepsy Action on link below:

http://www.epilepsy.org.uk/info/safety

Now you have read this information would you consider it safe to allow Mark to go swimming?

All health and social care workers have a duty of care to their clients so a risk assessment must be made. It is important to get the balance between risk taking and overprotection. Often people with epilepsy can be prevented from undertaking activities because of the perceived risk. With regards to swimming he may require to be constantly supervised and have someone with him. The lifeguard at the swimming pool can be informed. If there are times of the day his seizures are more likely to occur these should be avoided. An individual risk assessment must be made.

It is important that people with learning disabilities are involved in their epilepsy management and have access to the same services and resources as the rest of the population. This includes access to specialist epilepsy clinics for people with learning disabilities, professionals and voluntary organisations. People with learning disability and epilepsy, and their families/ carers should be supported to promote and maintain their choices and capabilities.

Recommended Reading & Resources:

If you are interested in finding out more about epilepsy and learning disability

Hanson, C. (2008) Improving outcomes: Overcoming the challenges of epilepsy in people with learning disabilities. Journal of Neuroscience Nursing. 4,10 pp 471- 480


Epilepsy Action
http://www.epilepsy.org.uk/info/safety
Reflect on your learning within this module. Identify 5 key areas where your knowledge has developed and then write one objective for each that outlines how you can implement in practice some of the ideas you have learned about to develop either yourself or your service to provide good care and support. Discuss this with your supervisor, mentor or manager.

### Activity: Paper to Practice

<table>
<thead>
<tr>
<th>Key Learning – I have learned about</th>
<th>To develop this area in my practice I will</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
</tr>
</tbody>
</table>
References


Module 4: Complexity in Care and Communication
Introduction

This module will provide an overview of the communication needs of people with profound and multiple learning disability (PMLD). You will consider the particular barriers to effective communication that this group of people often experience and explore the range of techniques and tools available to support them in engaging in meaningful interactions. The activities and reading within this module should take you about six hours to complete.

On completion of this module you should be able to:

- Demonstrate an understanding of the different and highly individual ways in which people with profound and multiple learning disabilities (PMLD) may communicate and how you can reflect this in the kind of support that they receive across a variety of care settings.
- Critically reflect on your own practices and how to develop these in order to enable people with PMLD to experience positive social interaction and to maximise their communicative potential.
- Demonstrate an understanding of how the communication skills of someone with PMLD may lead to them being socially disadvantaged and deprived of opportunities to communicate preferences and choices and evidence that you can apply that knowledge to remove barriers and enable service users to be active participants in their care and support.

Activity: Identifying Existing Knowledge, Skills and Areas for Development

Spend a few minutes identifying your existing knowledge, skills and areas for development in relation to supporting people with learning disabilities and complex needs manage their mental health and well-being – make some notes below

Existing Knowledge:

Existing Skills:

Areas for Development:
Prevalence and Definitions

The Same as You (Scottish Executive, 2000) states that at least 50% of people with a learning disability have significant communication difficulties, with up to 80% having some communication difficulties. In addition, the Royal College of Speech and Language Therapists (2003) estimates that about 80% of those with severe learning disabilities do not acquire effective speech. People with PMLD are amongst those people with a learning disability most likely to have some form of communication difficulty. A recent report by the Department of Health in England (Emerson, 2009) indicates that there will be an average annual percent increase of 1.8% over the years 2009-2026. Whilst there are demographic differences in the Scottish population, it would seem reasonable to suggest that there will also be an increase in the number of people with PMLD in Scotland. In Module 1, you were given the following definition of what constitutes a profound and multiple learning disability (PMLD):

“A profound intellectual disability, which means 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” (Mansell, 2010, p3).

Communication

You will now have the opportunity to consider in more detail the complex process of communication. Communication can be defined as a two-way process in which messages and information are sent and received. Sometimes communication is represented in the form of a chain, where each link in the chain represents an element that needs to be successfully completed in order for the information to pass accurately from one communication partner to another.

Activity: The Impact of PMLD on Communication

Using the above definition and applying any additional knowledge that you have about this client group, what can you infer about the impact of PMLD on someone’s communication skills?
The communication chain demonstrates the number of processes involved in a simple exchange of information. All of them require the speaker and receiver to have a “shared code” - a language that they are both able to “speak” and understand. In addition, a number of other factors are required in order for a communication exchange to be considered successful. These include the desire and opportunity to communicate, as well as the exchange being pleasurable for both parties.

Activity: The Impact of PMLD on Communication

Predict which links in the communication chain may breakdown when one of the communication partners is a person with PMLD. Provide a rationale for each of your answers:

- Difficulties receiving the message due to visual, hearing or attention difficulties
- Difficulties understanding or interpreting the message that they are being given because of their cognitive impairment
- Difficulties working out which information they wish to send, for example because they find it difficult to correctly interpret their body’s needs such as hunger/thirst
- Difficulties expressing that information perhaps due to a lack of speech and/or a lack of other means of getting their message across
- Difficulties engaging in opportunities to communicate because they appear to choose to engage in repetitive self-stimulating behaviours rather than being sociable.

All of the above are possible areas of breakdown when communicating with someone with PMLD, but they are also based on a value judgement of the skills of only one of the communication partners – the person with PMLD. When examining communication breakdown, it is important that you examine the relationship between the breakdown and both of the communication partners’ skills, not just the skills of the person who society might perceive to have the “problem”.

You might have made reference to the person with PMLD having:

- Difficulties receiving the message due to visual, hearing or attention difficulties
- Difficulties understanding or interpreting the message that they are being given because of their cognitive impairment
- Difficulties working out which information they wish to send, for example because they find it difficult to correctly interpret their body’s needs such as hunger/thirst
- Difficulties expressing that information perhaps due to a lack of speech and/or a lack of other means of getting their message across
- Difficulties engaging in opportunities to communicate because they appear to choose to engage in repetitive self-stimulating behaviours rather than being sociable.
Activity: Key Principles of Transition

Take each of the accounts of communication breakdown identified above and modify it to take into account the role of the non-impaired communication partner:

<table>
<thead>
<tr>
<th>Original Statement</th>
<th>Modified Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty receiving the message due to visual, hearing or attention difficulties</td>
<td>Difficulty receiving the message because the sender has not taken into account visual or hearing difficulties or ensured that the environment is suitable to the person’s sensory/attention needs</td>
</tr>
<tr>
<td>Difficulty understanding or interpreting the message that they are being given because of their cognitive impairment</td>
<td></td>
</tr>
<tr>
<td>Difficulty working out which information they wish to send, for example because they find it difficult to correctly interpret their body’s needs such as hunger/thirst</td>
<td></td>
</tr>
<tr>
<td>Difficulty expressing that information perhaps due to a lack of speech and/or a lack of other means of getting their message across</td>
<td></td>
</tr>
<tr>
<td>Difficulty engaging in opportunities to communicate because they appear to choose to engage in repetitive self-stimulating behaviours rather than being sociable</td>
<td></td>
</tr>
</tbody>
</table>
You will now have identified that although every link in the chain is open to breakdown, many of them can be remediated if the communication partner facilitates the communication process effectively. Although communication is a two-way process, responsibility is not equally shared in this situation, the communication partner must carry the greater responsibility if communication is to be effective.

A Good Life?

Refer back to the first module of this course and consider the factors that Johnson, Walmsley and Wolfe (2010) describe as constituting a good life. These were similarly described by O’Brien and are known as the five accomplishments (Brown and Benson, 1992). They are:

**Community Presence:** The right to take part in community life and to live and spend leisure time with other members of the community.

**Relationships:** The right to experience valued relationships with non-disabled people.

**Choice:** The right to make choices, both large and small, in one’s life.

**Competence:** The right to learn new skills and participate in meaningful activities with whatever assistance is required.

**Respect:** The right to be valued and not treated as a second-class citizen.

In order for people with PMLD to be facilitated to effectively achieve these things, it is crucial that they are given the opportunity wherever possible to communicate their views and preferences. This module will enable you to critically reflect on the communication skills that people with PMLD have and on the skills required to enhance and support them. For communication to be effective for someone with PMLD everyone in their environment needs to engage in the same effective communicative behaviours. Whilst this module is primarily directed at you developing your own learning, throughout it you should also constantly evaluate not only how you might apply the things you have learnt, but also how you can support other staff to understand and implement them too.

**Communication skills**

Often when we think of two-way communication we immediately think of spoken and written words. By our earlier definition, people with PMLD cannot generally use these routes effectively. However there are many other ways that humans communicate. So far, you have considered the communication difficulties that people with PMLD may experience, now you will be asked to demonstrate an understanding of the communication skills that they may exhibit.

<table>
<thead>
<tr>
<th>Activity: Human Communication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observe two people having an informal conversation. Draw up a list of all the attributes of communication that they use in addition to actual spoken words:</td>
</tr>
</tbody>
</table>
Paralinguistic (non-verbal) cues such as intonation, tone of voice, gesture, facial expression and body language, eye contact or eye pointing, touch
Vocalisations such as shrieks of excitement, or groans of despair
Additional resources such as pictures or written words that they make reference to during the conversation.

All of these attributes are important aspects of communication, so whilst people with PMLD may not have access to (much) speech, they may be able to use many of the other attributes described above. As you continue with this module, it is important to reflect again that each person will be individual in their communication skills and styles and that any care plans that you formulate for an individual should reflect this uniqueness.

**The Development of Communication**

Throughout this module, you will have the opportunity to consider communication from a developmental perspective. In this section, you will be asked to interpret information and demonstrate an understanding of two key stages of communication development.

**Activity: Identifying Pre-intentional versus Intentional Communication**

Consider the following list of statements:

- The behaviour does not have a communicative function for the person
- The person understands that their behaviour gains responses from others and that different behaviours elicit different responses
- The person is not attempting to elicit a response from others.
- The person vocalises when activities start or when something is taken away but does not appear to direct them at anyone.
- The person is sending a planned message in order to gain a response from others
- The behaviour has a communicative function for the person
- The person’s behaviour sends messages to others, but these messages are unintentional
- The person realises that vocalising, reaching, gestures etc has an effect on others.
- The person responds to physical discomfort by wriggling or becoming agitated, they are observed doing this even when they are not aware that someone else is present
Now, divide the statements into two groups of opposing statements in accordance with the example below:

<table>
<thead>
<tr>
<th>The behaviour does not have a communicative function for the person</th>
<th>The behaviour has a communicative function for the person</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Statements 3, 4, 7, 9 describe someone who is at a pre-intentional stage of communication, statements 2, 5, 8 relate to intentional communicators.

**Activity: Definitions**

From the information that you gained from the previous activity, draw up a definition of pre-intentional and intentional communication.

Pre-intentional communication is a normal, very early stage of communication development. It is a pre-cursor to the development of intentional communication. At birth, babies are termed unintentional or pre-intentional communicators. They cry when they are hungry or wet, but initially they do this without expecting or aiming to elicit a response from anyone, they are simply expressing what their body tells them they are feeling. At this stage, it is the adult carers who assign meaning to the baby’s cries; identifying the problem, for example “oh, you must be hungry” and providing the solution and reassurance “there, that’s better” when the baby is replete and has stopped crying. During this period, the adult carer is solely responsible for interpreting the baby’s vocalisations and responses. However, the baby is learning that when they make a noise, someone responds and so they begin to learn that they can get someone to respond to them by making a noise. At this point, the baby is demonstrating early signs of intentional communication, this usually happens consistently at around the six month stage of development.

It is important at this point to be aware that you should not think we are comparing an adult with PMLD to a baby. Rather, we are looking at what we know of the developmental process to help us to understand how best to support the adult with whom we are working at the stage of development that they have successfully reached.

Many people with PMLD remain at a pre-intentional stage of communication and it would be easy to assume that if someone is a pre-intentional communicator that they do not have anything to “say” and are not able to express their views about their everyday experiences. The following section will enable you to evaluate whether this is true.

**Activity: How do Pre-intentional Communicators Share Information?**

Consider a service user with whom you work who you judge, based on the definition above, is at a pre-intentional level of communication. If you can, try and answer the following questions about the person:

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is their favourite food?</td>
<td></td>
</tr>
<tr>
<td>What is their favourite drink?</td>
<td></td>
</tr>
<tr>
<td>Which music/singer do they prefer?</td>
<td></td>
</tr>
<tr>
<td>What are their preferred activities? E.g. hand massage, singing, having a bath</td>
<td></td>
</tr>
<tr>
<td>Which food do they dislike?</td>
<td></td>
</tr>
</tbody>
</table>
If you know the person well, you will probably have been able to answer at least some of these questions with confidence, but in order for this information to be valid and helpful to the person and to others who support them you must be able to verify it and provide evidence to support your conclusions.

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
<th>Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Which drinks do they dislike?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Which types of music are they not keen on?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What are their least preferred activities?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Activity: Providing Evidence

Complete the table again and this time in the third column you should enter the evidence that you have to support your claims. What is it that the person does that enables you to be sure of your responses? You will need to observe the person closely in order to do collect this evidence and you may wish to refer back to the activity looking at non-verbal communication to help support your answer. Be as detailed as you can, for example you should not write “facial expression” as evidence, instead you should write “his lip curled slightly and he made a grimacing face”. Note down even the smallest reactions so that you can see if they form a pattern of responses.

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
<th>Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is their favourite food?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What is their favourite drink?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Which music/singer do they prefer?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What are their preferred activities? E.g. hand massage, singing, having a bath</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Which food do they dislike?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Which drinks do they dislike?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Which types of music are they not keen on?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What are their least preferred activities?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The more detailed the information that you are able to produce about the person and their responses to certain items or experiences, the more meaningful and reliable your information is likely to be. You should compare your responses to those of your colleagues and consider any differences in your conclusions. Identifying the way in which someone consistently reacts when they like or dislike an experience can help you to identify the person’s feelings about a wide range of activities and experiences.

Activity: Evaluating the Approach

What difficulties might occur in using this approach to interpret someone’s likes and dislikes?

You may have considered that:
• Some of the responses that you have captured may reflect what the person feels at a given time, just because they did not appear to like orange juice today does not necessarily mean that they do not like it or never want to be offered it again. This may be one reason why you and a colleague recorded different responses and it is why it is extremely important that you collect as much detail as possible about what you observe. It is also important to remember that, as you document information and formulate a communication care plan, be careful that you are not limiting the person’s opportunities for experiences on the basis of a brief assessment.
• The person’s health may have affected their response on a particular day, for example they may have been post-ictal (after a seizure) when you assessed them and their sense of taste or general responsiveness may have been affected by this.

• There might be occasions on which a caregiver has projected their own likes/dislikes onto the person, for example a personal dislike of orange juice may have resulted in you making a negative face when offering it to the service user and this may have been reflected in their response.
• Or you may simply have been expecting to see a certain response and therefore that is what you observed, this is called confirmation bias.

Therefore, you can see that critical self-reflection is required when carrying out this type of approach. The above exercise was based on the assessment approaches found in the Pre-verbal Communication Schedule (Kiernan and Reid, 1987) and the Affective Communication Assessment (1998).

Recommended Reading & Resources:

If you are interested in reading more about this approach to assessment:


http://drmarkbarber.co.uk/ACAOWNERSMANUAL.pdf

Intensive Interaction

Intensive Interaction is a means of communicating with people who seem to be “difficult to reach”. This apparent difficulty may be because they are at a very early stage of communication development or because they appear
“locked in” to a variety of self-stimulating behaviours that seem to cause them to withdraw from regular social interactions. Reflect again on the modified value judgements that you proposed earlier in this module and relate them to this context. Consider that it may be lack of opportunities to experience social interaction in a way that is meaningful to the person that has failed to engage them in social communication or has resulted in them disengaging from human interaction and hooking into their own repertoire of behaviours rather than a fault on the part of the person themself.

The principles of intensive interaction are based on observations of normal social communication development between a parent and a child. As well as providing much needed social communication opportunities, intensive interaction also offers the opportunity for the person with PMLD to experience and develop their understanding of and non-verbal communication skills like eye contact and turn-taking in a naturalistic environment.

The approach works by carefully observing the person’s regular behaviours and then linking in with these by responding to them and joining in with them. This is a shared approach to communication which is led by the behaviours and responses of the person themself rather than by trying to impose new behaviours upon them.

This is an experiential approach to working with communication and it is difficult to describe in a way that makes it easy to put into practice. To help you to understand the approach, you may wish to watch the video of Ricky www.teachers.tv/videos/reaching-ricky. Although he is a child and is more mobile than many adults with PMLD are likely to be, the principles of the technique remain the same.

Activity: Intensive Interaction

Select a service user with whom you work for whom an intensive interaction session might be appropriate. Ask a colleague to observe you engage in the session. Critically evaluate your own performance and the success of the session for the service user. Ask your colleague if they noticed other aspects of the person’s behaviour that you could have picked up on and compare their observations of the session with your own.

Recommended Reading & Resources:

If you are interested in reading more about this approach to communication:


www.intensiveinteraction.co.uk/uploads/attachment/70/intensive-interaction-the-published-researchsummaries

www.phoebecaldwell.co.uk/work.html
Intentional Communication

As intentional skills develop, so we also see the development of symbolic understanding. Look at the list below:

- A coloured photograph of a cup
- The written word “cup”
- A miniature cup
- A line drawing of a cup
- A coloured symbol of a cup
- A black and white symbol of a cup
- A black and white photograph of a cup
- A real cup

Compare your list to the following, which is now in hierarchical order with the most concrete element at the top:

- A real cup
- A miniature cup
- A coloured photograph of a cup
- A black and white photograph of a cup
- A coloured symbol of a cup
- A black and white symbol of a cup
- A line drawing of a cup
- The written word “cup”

Did you have any differences? You may have considered that black and white items would be easier to understand than coloured ones or that line drawings would have been easier than symbols? In fact, it is the representations that look most like the real object that are easiest to understand, so coloured pictures are therefore generally easier than black and white ones. Using this particular hierarchy of development can help us to identify which tools will be useful in augmenting or enhancing communication for someone with PMLD. It is however once again important that you recall that people are individuals and that whilst this hierarchy of development is true for most people, some people because of, for example, visual difficulties may find some items easier to understand.

You can see that the real object and miniature objects are the easiest information for people to understand. Utilising these can be an effective way to support someone’s understanding of what is going to happen next in their day. Used in this way, these items are referred to as Object Signifiers or Objects of Reference. An Object of Reference can be defined as an object that comes to represent a specific activity or event, for
example a sponge may become an object of reference for bath-time.

In order for an object of reference to be effective, it must be used consistently and be given to the person prior to the activity on each occasion that the activity is going to happen. Objects of reference should be developed for those activities that happen frequently as the person will only be able to make associations between the object and the activity if they have many opportunities to do so. The objects chosen need to be meaningful and relevant to the person for whom they are selected.

You need to look at an individual’s preferences and experiences when considering which objects to choose, for example there is no value in selecting a maraca to represent a music group if the person regularly plays the tambourine as part of the actual activity. The activities that are being represented also need to be motivating for the person, so that the person considers the system to be of value.

For many people, real objects or miniature objects are the most effective signifiers because they are the most concrete, but sometimes this is not the case. Sometimes it is not practical to use either a real or miniature object for example for activities such as trampolining. In these cases, something less concrete can be established as an object of reference as long as it is used consistently.

Each signifier should be clearly labelled so that everyone refers to it in the same way. For example a swimming costume may be an object of reference for going swimming. However, without clear directions different members of staff may refer to the activity as going for a swim, going to the pool, going to the baths, going to waterworld. Using a key word that always represents the activity will help to maintain consistency for the service user.

An object of reference can enable the person to obtain information from several senses such as touch, vision and sound. For people with PMLD who may have sensory impairments, visual information may not be helpful so they rely instead on tactile signifiers in which case completely abstract items may be used just as effectively as long as they are used consistently.

Used in everyday situations objects of reference can give the person consistent and meaningful information about what will be happening in their day. This can give the person a sense of security, may reduce challenging behaviour and over time may enable the person to make meaningful choices about day to day activities, for example by actively selecting a signifier from a choice of two to indicate the activity that they would like to carry out.

Activity: Identifying Effective Object Signifiers

Watch the video of Samantha [www.youtube.com/watch?v=oyTFeM_r9xs](http://www.youtube.com/watch?v=oyTFeM_r9xs).

Discuss any object signifiers that you observe and evaluate their effectiveness:
You may have noticed a bottle hanging on the door of the massage room. This was intended to be an objective signifier. If you did not observe it the first time, watch the video again and evaluate the effectiveness of this signifier.

You may have critically reflected that although present, this signifier was not particularly effective for Samantha.

You may have identified the following reasons:
• Samantha was not aware of its presence as she is visually impaired
• Samantha was not supported to explore it prior to entering the room
• Samantha was not supported to experience the bottles of massage oil in the room to help her make the connection between the signifier and the activity
• Signifiers were not used routinely as part of Samantha’s day so she may have been unfamiliar with the purpose of them.

In fact, the signifier in this film may not have been intended for Samantha’s use, but it is a useful illustration of some of the issues that need to be considered when introducing object signifiers.

Activity: Formulating a Care Plan for the use of Object Signifiers

This is a detailed piece of work and will take you at least an hour to complete. When you have completed it, you should discuss it with your supervisor or present it to your study group. This piece of work makes reference to Samantha but if you would prefer to you can develop it for someone with whom you are actually working.

First make a list of the everyday activities in which you saw Samantha taking part. Now identify a possible list of objects of reference, one for each activity. Provide a clear rationale for why you have chosen them.

Develop a set of instructions to support other staff to implement them effectively. Illustrate that you have considered the difficulties that might arise by them being implemented by a large staff group, possibly over a range of environments (home, day service, respite). You may find it helpful to refer to the link below.

Finally, discuss how you will evaluate their effectiveness

Recommended Reading & Resources:

You should ensure that you have considered the following:

- Key activities such as travelling to and from home and day centre
- Objects of reference that meet the person’s sensory needs – e.g. tactile for someone who is visually impaired, not relying on sound for someone who is hearing impaired. The signifiers will need to be sufficiently different from each other that the person can identify the difference between signifiers.
- They will need to be easily portable and available to the person in all their environments.
- Your instructions should include a description of how to present them to the person, e.g. place them in their left hand.
- Difficulties may also occur if staff do not understand your rationale for introducing them or do not understand the need to use them consistently.
- Other difficulties may occur if too many are introduced at once and the service user becomes confused.
- Simple difficulties such as items getting lost may also occur so you may have considered having duplicate sets available.

Communicating Health Needs

How can you link what you have learnt about the communication skills of someone with PMLD with supporting their physical, emotional and mental well-being? Reflect again on the list of non-verbal communication skills that you listed at the beginning of this module and on the assessments that you have learnt about. Based on these, would you consider that there is information that someone with PMLD can give us about their health and wellbeing? If you wish to use the evidence that you have gathered from observing the person’s behaviours to support a better understanding of their health needs, you must be able to verify your claims by providing supporting evidence. One tool that can enable you do to this is the DisDAT (Regnard, 2003). It is designed to capture the different ways in which somebody presents when they are feeling content and when they are feeling distressed. Subtle changes in a person’s presentation can alert caregivers to the often silent signs of distress, this tool provides a way of objectively recording this information.

Activity: Using the DisDAT tool

Click on this link www.disdat.co.uk and complete a DisDAT chart for one service user whom you support. DisDAT is designed to capture the views of all the key people in the person’s life, in order that a consensus can be reached as to what each behaviour signifies. Therefore you will need to complete this exercise with other members of your team and remember to include family carers, friends and other key people in the discussion. Agree a final version for the service user with whom you are working. Critically reflect on your

Recommended Reading & Resources:

If you are interested in reading more about this approach to communication:

own skills at drawing together the information and helping others to negotiate and agree on the final completed form.

Summary and Conclusion

Throughout this module you have had the opportunity to consider some of the many means that someone with PMLD may use to communicate, you have also considered some of the reasons that they may choose to communicate. Less overtly, you may have considered some of the opportunities that people with PMLD are, or should, be offered. The model of communication by Money and Thurman (1994) below summarises the importance of all three of these areas – means, reasons and opportunities – being present in order for successful communication to take place.

Recommended Reading & Resources:

- [www.communicationpassports.org.uk/Home](http://www.communicationpassports.org.uk/Home)

If you are interested in reading more widely around the subjects covered in this module:

- Communication and people with the most complex needs: What works and why this is essential [http://www.mencap.org.uk/document.asp?id=20568](http://www.mencap.org.uk/document.asp?id=20568)
- [http://www.pmldnetwork.org](http://www.pmldnetwork.org)

---

**Means** (How we communicate)
- speech and writing
- non-verbal
- signs
- symbols
- gestures
- body language
- facial expression
- pointing
- objects and pictures
- behaviour

**Reasons** (Why we communicate)
- attention
- greetings
- wants / needs
- request information
- give information
- ask questions
- protest / deny
- feelings
- choices
- preferences
- Paralinguistic
  - volume
  - intonation
  - rate
  - tone
  - fluency

**Opportunities** (Where, when and with whom we communicate)
- partner
- time and place
- shared language
- shared communication system
- shared interests
Reflect on your learning within this module. Identify 5 key areas where your knowledge has developed and then write one objective for each that outlines how you can implement in practice some of the ideas you have learned about to develop either yourself or your service to provide good care and support. Discuss this with your supervisor, mentor or manager.

<table>
<thead>
<tr>
<th>Key Learning – I have learned about</th>
<th>To develop this area in my practice I will</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
</tr>
</tbody>
</table>
References


Introduction

Module 5 explores supporting people with a learning disability and mental health needs. Mental health wellbeing is important to everyone, as we have seen in earlier modules it is important that people with a learning disability and complex needs have equal access to health care services and this is the same when we consider mental health. Good access to health care services for people with learning disabilities often depends on good knowledge and understanding of the issues by staff providing support.

This module will explore a number of concepts related to mental health and wellbeing. To illustrate and explore the issues you will be introduced to Mohammad and Pauline who have learning disabilities and mental health needs. A number of the learning activities will consider the issues from the perspective of Mohammad and/or Pauline and their families or carers. Concepts such as mental wellbeing, the complexities in assessment, legislation, support and treatment and issues with accessing interventions will be explored.

On completion of this module you should be able to:

- Explore your understanding of the range of mental health needs people with learning disabilities may experience, including how patterns of mental health may differ in a person with a learning disability and consider the impact of this on their care
- Explore assessment of mental health problems, which can be utilised for people with learning disabilities and mental health needs and the role of client, carer and professionals within the assessment

Activity: Identifying Existing Knowledge, Skills and Areas for Development

Spend a few minutes identifying your existing knowledge, skills and areas for development in relation to supporting people with learning disabilities and complex needs manage their mental health and well-being – make some notes below

Existing Knowledge:

Existing Skills:
Areas for Development:

Mental Wellbeing refers to life satisfaction, having purpose, sense of belonging and positive relationships

Activity: Definitions

Consider all the different terms used when referring to Mental Health and note down as many as you can think of below:

Why do you think there are so many different terms that can be used interchangeably?

What do you think is important in terms of the language we use?

What do we mean by Mental Health?

Definitions of mental health are complex and dependent upon individual life experiences and life context. They are influenced by a wide range of aspects including our gender, race, religious beliefs, social class, experience of family life, and beliefs. According to NHS Health Scotland (2011) there is a growing recognition that addressing and supporting mental wellbeing can have significant benefits in terms of an approach to mental health.

In contemporary practice, mental health can be considered to consist of two dimensions mental health problems which include mental illness and mental health which includes purpose and satisfaction in life. For the purpose of clarity and in line with the guidance from NHS Health Scotland (2011) within this module we shall use the terms:

**Mental Health** as an umbrella term to refer to both mental health problems and mental wellbeing.

**Mental Health Problems** when referring to symptoms that meet the criteria for clinical problems – for example depression, anxiety, schizophrenia.
Policy Drivers

There are a number of policy drivers that influence services and support mental health. In this section we will briefly explore some of the key drivers and provide further recommended resources and reading for those who would like to find out more.

‘The Same as You’ (Scottish Executive, 2000) has formed the basis for strategic planning around services for people with a learning disability and although currently being reviewed, at this point in time remains the main Scottish Government policy driver for health and social care services.

The Same as You (Scottish Executive, 2000 p.99) clearly states that:

‘Local psychiatric services and learning disability services should focus on maintaining positive mental health and providing appropriate assessment and treatment by closely working with social work and primary care colleagues.’

and

‘Health boards should make sure that there are appropriate arrangements for people with learning disabilities who have mental health problems going into hospital. In setting up services, health boards should consider the need to have staff trained in learning disabilities and staff trained in mental health’ (Scottish Executive 2000, p100)

You can see from these statements that the importance of positive mental health is not a new message, nor is the recognition of the benefits of collaborative inter agency working or the need for appropriate assessment and treatment. Later in this module we will consider

Recommended Reading & Resources:

You can find out more about terminology and definitions by accessing:
NHS Health Scotland’s paper entitled ‘Mental health improvement terminology and working understandings’ available at:

http://www.mentalhealth.org.uk/help-information/mental-health-a-z/R/recovery/

If you are interested in finding out more about models of mental health you can access

You can access Towards a Mentally Flourishing Scotland at:
Mohammad and his experiences of the services and support he has received and you will be asked to think about how policy impacts on practice.

In addition to ‘The Same as You’ there are a number of policy drivers for mental health services that also have relevance for people with learning disabilities. These include:

- Rights, Relationships and Recovery – the report of the national review of mental health nursing in Scotland
- Delivering for Mental Health
- Towards a Mentally Flourishing Scotland
- Scotland’s Dementia Strategy

A review of mental health nursing in Scotland was carried out in 2006 resulting in Rights, Relationships and Recovery – the Report of the National Review of Mental Health Nursing in Scotland (Scottish Executive, 2006). This policy outlines the development of mental health nursing in Scotland and highlights the importance of:

- a rights-based approach to practice
- developing positive relationships as the starting point for all interventions with service users, carers and families in mental health nursing practice
- recovery as the underpinning principle of therapeutic interventions
(Scottish Executive 2006)

Activity: Definitions

Access and read the summary of Rights, Relationships and Recovery at: http://www.scotland.gov.uk/publications/2006/04/18164814/0

Consider the key messages and identify which of these are relevant for people with learning disabilities.

We would suggest that most of these are easily relevant and by merely changing the term ‘mental health nursing’ to ‘support workers’ or ‘learning disability nurses’ you can see how applicable these key messages are to your service. In particular the key messages below are clearly relevant to people with learning disabilities and the services that support them.

- Mental health nursing is focused on caring about people, about spending time with people, and on developing and maintaining helpful relationships with service users and their families and carers.
- We need to continue to develop rights-based and person-focused mental health care by promoting values and principles-based practice in mental health nursing.
- The recovery approach should be adopted as the model for mental health nursing care and intervention, particularly in supporting people with long-standing mental health problems.
- We need models of practice that are centred on relationships between mental health nurses and people, maximise nurses’ contact time
with service users, families and carers, and promote rights and recovery-based working

- Mental health nurses will continue to have a key role in contributing to supporting people with long-term and complex mental health problems and need to adopt strengths-based approaches to working with people towards recovery.
- Mental health services and mental health nursing must make the support of older people with mental health problems a priority. We need to make sure mental health nurses are prepared and developed to deliver this.
- The role of mental health nursing in providing early intervention to people at risk of developing mental health problems needs to be developed and enhanced.
- Mental health nurses must continue to develop their roles in health improvement, health promotion and tackling inequalities.
- People who use mental health services want more access to ‘talking therapies’ such as psychosocial interventions and psychological therapies, but demand outweighs supply. We need to increase opportunities for mental health nurses to be developed to deliver these therapies
- We need to develop the role of health care support workers in mental health, matching the roles and skills of heath and care workers to people’s needs.

‘Delivering for Mental Health’ (Scottish Government, 2006) sets out the targets and commitments for the development of mental health services in Scotland and this includes the HEAT targets for Health Boards. HEAT targets are Government objectives to be achieved by Health Board areas over a set period. One of the current heat target commitments states that there will be an increase in the availability of evidence-based psychological therapies for all age groups in a range of settings and through a range of providers. This includes people with learning disabilities and we will come back to this later on in module when we consider some of the psychological therapies that people with learning disabilities may find helpful.

‘Towards a Mentally Flourishing Scotland’ (Scottish Government, 2006) focuses on mental health improvement, promoting mental health wellbeing and improving the quality of life of people experiencing mental health problems. This document lays out 22 commitments to meet six strategic priorities, which are:

- Mentally healthy infants, children and young people
- Mentally healthy later life
- Mentally healthy communities
- Mentally healthy employment and working life
- Reducing the prevalence of suicide, self-harm and common mental health problems
- Improving the quality of life of those experiencing mental health problems and mental illness
Activity: Towards a Mentally Flourishing Scotland

Follow the link below to access ‘Towards a Mentally Flourishing Scotland’ read through this document and as you do take a note of the 22 commitments in the left hand column below. Then consider which of these could be relevant to your service/role and tick the box on the right if they are/could be relevant to your service/role.

<table>
<thead>
<tr>
<th>Commitment</th>
<th>Could this be relevant to your service/role</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Now choose one of the above that you think could be relevant to your service/role and expand a little bit on how this could be relevant and support you in your role or your service in meeting the needs of people with learning disabilities. Discuss this with your service manager and consider how you could progress service development in this area.
Scotland’s Dementia Strategy (Scottish Government, 2010) lays out eight specific actions to support improvements in the care and treatment of people with dementia, focusing particularly on improving the support given in the wake of a dementia diagnosis and improving hospital care. It also commits the Scottish Government to continuing its support for dementia research. The strategy has led to NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) developing a framework that outlines the knowledge, skills and behaviours needed by specific groups of staff across all sectors who work directly or indirectly with people with dementia. We will return to the Dementia Strategy when we consider Pauline later in this module.

**Recommended Reading & Resources:**

You can access The Same as You at: [http://www.scotland.gov.uk/ldsr/docs/tsay-00.asp](http://www.scotland.gov.uk/ldsr/docs/tsay-00.asp)


Find out more about Delivering for Mental Health (Scottish Government, 2006) and the HEAT targets at: [http://www.scotland.gov.uk/Topics/Health/health/mental-health/servicespolicy/DFMH/antidepressantprescribing](http://www.scotland.gov.uk/Topics/Health/health/mental-health/servicespolicy/DFMH/antidepressantprescribing)


Follow the link to and explore NHS Education for Scotland web pages outlining their work in mental health:

Activity: Risk and Protective Factors

Use the web link below to go to NHS Health Scotland’s web pages on Mental health Improvement


Read this page which includes information about the risk and protective factors determining mental health wellbeing. Reflect on a person with a learning disability that you know and consider how likely are they to experience the risk factors and the protective factors identified by NHS Health Scotland. Complete the table below.

Put a ✔️ beside each of the risk factors that you think apply to the person you are thinking about and put a ✗ next to each of the protective factors that you think do not apply to the person you are thinking about.

<table>
<thead>
<tr>
<th>Risk Factors</th>
<th>✔️</th>
<th>Protective Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Isolation and alienation</td>
<td>✔️</td>
<td>Empowerment</td>
</tr>
<tr>
<td>Lack of education, housing, transport, recreational facilities</td>
<td></td>
<td>Positive interpersonal interactions</td>
</tr>
<tr>
<td>Neighbourhood disorganisation, violence and crime</td>
<td></td>
<td>Social support and attachment to community networks</td>
</tr>
<tr>
<td>Socio-economic disadvantage</td>
<td></td>
<td>Social responsibility and tolerance</td>
</tr>
<tr>
<td>Poverty, poor social circumstances</td>
<td></td>
<td>Access to social services and a variety of leisure activities</td>
</tr>
<tr>
<td>Work, stress, unemployment</td>
<td></td>
<td>Social participation &amp; inclusion</td>
</tr>
<tr>
<td>Poor nutrition</td>
<td></td>
<td>Economic security and access to meaningful employment</td>
</tr>
<tr>
<td>Social or cultural injustice and discrimination</td>
<td></td>
<td>Ability to cope with stress</td>
</tr>
<tr>
<td>Peer rejection</td>
<td></td>
<td>Physical activity</td>
</tr>
<tr>
<td>Violence and anti-social behaviour</td>
<td></td>
<td>Good parenting, stable supportive family environment</td>
</tr>
<tr>
<td>Parental mental illness</td>
<td></td>
<td>Feelings of security and control</td>
</tr>
</tbody>
</table>
### Risk Factors vs. Protective Factors

<table>
<thead>
<tr>
<th>Risk Factors</th>
<th>Protective Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loneliness, isolation</td>
<td>Self esteem</td>
</tr>
<tr>
<td>Parental substance misuse</td>
<td>Good physical health</td>
</tr>
<tr>
<td>Low birth weight/birth complications</td>
<td>Social skills</td>
</tr>
<tr>
<td>Bereavement</td>
<td>Positive attachment &amp; early bonding</td>
</tr>
<tr>
<td>Stressful life events</td>
<td>Pro social behaviour</td>
</tr>
<tr>
<td>Physical, emotional or sexual abuse</td>
<td></td>
</tr>
<tr>
<td>Family conflict, violence</td>
<td></td>
</tr>
<tr>
<td>Substance misuse</td>
<td></td>
</tr>
<tr>
<td>Peer rejection</td>
<td></td>
</tr>
<tr>
<td>Violence and anti-social behaviour</td>
<td></td>
</tr>
<tr>
<td>Parental mental illness</td>
<td></td>
</tr>
</tbody>
</table>

### Prevalence

People with learning disabilities can develop the full range of mental health problems. It is suggested that people with learning disabilities are at increased risk of developing a mental health problem, with figures ranging from 25-40% (Smiley et al. 2007; Smiley, 2005).

### Activity: Prevalence

People with a learning disability have a high risk of developing additional mental health problems that can go unrecognised and have a major effect on general wellbeing, personal independence and quality of life as well as impacting on family and carers.

Why do you think people with a learning disability are at high risk of developing mental health problems?
You may have mentioned:

- Some of the causes of learning disabilities have associated health needs e.g. Down syndrome and dementia, Fragile X and anxiety
- Multiple health needs can lead to multiple drug treatments and this can lead to side effects and problems with interactions
- People with learning disabilities may experience a different developmental process with slower development of self and ability to adopt effective coping mechanisms
- Emotional attachment to family or carers may be more complex
- Potential for lack of opportunities, expectations, dependency on others may lead to low feelings of worth and motivation
- May be more vulnerable to abuse or neglect or negative social experiences such as bullying
- Encountering more difficulties in everyday life with reduced resources to manage these
- May have less opportunities for employment or leisure activities and less financial resources
- May experience stigma and discrimination and this could lead to low self esteem

**Recommended Reading & Resources:**

If you want to find out more about prevalence of mental health conditions in the general population you can access:

[http://www.lho.org.uk/LHO_Topics/Health_Topics/Diseases/MentalHealthPrevalence.aspx](http://www.lho.org.uk/LHO_Topics/Health_Topics/Diseases/MentalHealthPrevalence.aspx)

and


If you want to find out more about the specific prevalence rates for people with a learning disability and mental health problems you can read Chapter 3: Nature, prevalence and manifestations of dual diagnosis in:


About learning disabilities web site at:
[http://www.aboutlearningdisabilities.co.uk/mental-health-issues.html](http://www.aboutlearningdisabilities.co.uk/mental-health-issues.html)

**Activity: Prevalence of Mental Health Problems**

Follow the link below to access an article by Elita Smiley entitled Epidemiology of Mental Health Problems in Adults with Learning Disability: an update:


Read the article and complete the multiple choice questions at the end of this article.
## Activity: Introducing Mohammad

Your service has received a referral for Mohammad. He is 19 years old he lives with his parents, sister and elderly grandmother. The family are wealthy; Dad owns a number of businesses and works long hours. The family moved to Scotland from Pakistan when Mohammad was 4 years old, as a family they keep themselves to themselves and have a fairly small social network of family and friends. Dad, Mohammad and Mohammad’s sister, speak fluent English however Mum and Grandmother only speak Urdu and broken English.

Mohammad has a mild learning disability, a hearing impairment and cerebral palsy. When he is tired his speech can be difficult to understand.

The reason you have received a referral is that Mohammad attends the local college with learning support. He has been getting irritable and shouting whilst travelling on the bus and at college. Recently he pushed another student whilst waiting in the queue for lunch.

Take the following link to The Estia Centre and download the publication entitled supporting complex needs: a practical guide for support staff working with people with a learning disability who have mental health needs (save this document as we will be coming back to it)

http://www.estiacentre.org/freepub.html

Read pages 15-18 Section 2: Factors that affect mental health. Identify any points from this that could be a factor for Mohammad – make some notes opposite.

## Case Study: Working with Diversity

At your second visit to the family home Mohammad’s mother and sister Aisha are present; Mohammad has indicated that he is happy for them to be present. The family have organised for Aisha aged 15 acts as an interpreter for Mum. Aisha reports that her Dad cannot make the meeting but generally he is very supportive of Mohammad. She states that her Dad has asked her to express his concerns that you are young and female and he believes it to be inappropriate for his son to be discussing personal matters with a young woman.

What concerns may you have in regards to the communication barrier with Mum and in particular the role that Aisha plays as the interpreter?

What could you suggest to overcome potential barriers to effective communication and the accuracy of the assessment?
In regards to Dad’s concern of a female worker and adhering to principles of culture and diversity how would you manage this situation?

You may have mentioned:

• The ability of Aisha to speak her Mum’s language is not known and therefore inaccuracies could be reported
• Aisha could be influenced by her Father’s perspective, or her own and an accurate account of Mum’s thoughts and feelings could be difficult to ascertain.
• Aisha may struggle to grasp the language and concepts of mental health further detracting from the accuracy of Mum’s account
• Aisha is 15 and perhaps consideration has to be given to her emotional vulnerability in dealing with a complex and sensitive matter
• Mohammad has the right to confidentiality and may not have given consent to his younger sister’s involvement (see module 3 for further information on Adults with Incapacity)
• You could consider a referral to an interpreter service as you need someone who precisely states what Mum says rather than ‘interprets’ so that you can make an accurate assessment (however you also recognise that this suggestion may impact on your developing relationship with the family)
• You may consider transferring the case to a colleague who can speak Urdu, if this option is available
  • You may refer to a voluntary organisation that would support the specific needs of the family (e.g. BEMIS)
    - For more information on BEMIS, or other ethnic minority services see recommended reading and resources.
  • In the first instance you would attempt to ascertain what Mohammad wanted in regards to his support
  • You may transfer the case to a male colleague
  • You may support a male colleague and have a clearly defined role negotiated with the Mohammad and the family

Recommended Reading & Resources:

BEMIS http://www.bemis.org.uk/role_of_bemis.html

Shared Care http://www.sharedcarescotland.org.uk/resources/useful-links/minority-ethnic-services.html

For further information on interpreter services and the role/remit of interpreting services see link below-


Activity: Recognising Mental Health Problems

Four weeks have passed and Mohammad is now increasingly reluctant to attend college or the voluntary organisation social club that he usually enjoys. He has been having trouble getting off to sleep and has lost his appetite. His mother has always had difficulty encouraging Mohammad to wash and bath regularly but this is becoming such a problem that he has not changed out of his night clothes the last two weekends.

His mother takes him to see his GP, who suggests that his irritable behaviour may be due to Mohammad experiencing a delayed adolescence due to his learning disability or there may be an underlying mental health issue. He has asked Mohammad and Mum if they would prefer to be referred to a specialist learning disability psychiatrist or mainstream general psychiatry.

At your next meeting Mum and Mohammad reiterate the discussions at the GP and ask for your advice on which service would be most effective.

What do you think are the advantages and disadvantages of mainstream psychiatric service for Mohammad?

You may have said:

- That using mainstream psychiatric services fits with the policy direction that people should be able to use the same services as everyone else, wherever possible (Scottish Executive, 2000). This builds inclusive services
- Someone with mild learning disabilities may find it less stigmatising to access mainstream mental health services than specialist learning disability services
- If admission is required many people with learning disability may find general adult wards in mainstream psychiatry busy, chaotic and frightening
- Someone with a mild learning disability may find it difficult to communicate with some of their peers with more significant learning disabilities in specialist learning disability services
- The experiences of people with learning disability and their families who have accessed mainstream mental health services are sometimes less than satisfactory
- People with learning disabilities may be vulnerable to abuse within mainstream psychiatric units

What do you think are the advantages and disadvantages of specialist learning disability services for Mohammad?
Staff in mainstream services may not have the training or skills to meet the needs related to a person’s learning disability.

Specialist learning disability services should bring knowledge and expertise to detect mental health problems in people with learning disabilities who may have atypical presentations and communications difficulties and be experienced in using specialist assessment tools e.g. PAS ADD.

Specialist learning disability services should bring knowledge and expertise about the treatment options; the ability to modify therapeutic interventions such as cognitive behavioural therapy, the need for careful monitoring of medication due to high levels of medication treatments and the potential for unusual responses in some people.

Staff in specialist learning disability services should bring the knowledge and expertise to ensure the need for special consideration of a range of co-existing physical conditions and health needs e.g. epilepsy.

Staff in specialist learning disability services may be at increased risk of diagnostic overshadowing – Diagnostic overshadowing is the term used to describe the phenomenon when behaviours presented by a person, which might be indicative of mental health problems, are attributed instead to the symptoms of the person’s learning disability. The diagnosis of learning disability and its problems takes priority over emotional problems. The literature suggests diagnostic overshadowing is common and people’s needs may still be overlooked because of its influence.

Using specialist services does not fit with the policy direction of inclusive services and fails to address the knowledge and skills development needs of staff in mainstream mental health services.

Activity: Mainstram and Specialist Services

Follow the link below to access Supporting Complex Needs: a practical guide for support staff working with people with a learning disability who have mental health needs and read pages 33-38 'Mainstream and Specialist Services'

http://www.estiacentre.org/freepub.html

Recommended Reading & Resources:

Clark, LL. (2007), Learning disabilities within mental health services: are we adequately preparing nurses for the future? Journal of Psychiatric and Mental Health Nursing. 14, pp: 433-437


Activity: The Assessment Process

Mohammad and his family have agreed that the community nurse can ask the psychiatrist with the team to come and speak to them.

Follow the link below to access an resource entitled ‘Practice guidelines for the assessment and diagnosis of mental health problems in adults with intellectual disability’

http://www.estiacentre.org/docs/PracticeGuidelines.pdf
Read pages 21-27. Think about your role as a support worker or nurse, how may you be involved in the assessment process and are there any points from the ‘Assessment Procedure’ section you have just read that would be important for you to consider in your role?

You may have said:

- Your role may include providing background information
- You may be providing a current picture of the person’s social situation, relationships with others
- Supporting the person to communicate be understood and understand what is happening – making good use of any communication technologies
- Observing and reporting or recording your observations as part of the assessment
- Carrying out a health assessment as part of this process
- Supporting the person to attend an assessment by one of the multi professional team

Activity: Identifying Mental Health Problems

Follow the link below to access The Royal College of Psychiatrists website where you can find reliable and readable information about mental health problems.

Identify someone you work with who has learning disabilities and a mental health problem and explore the information relating to the mental health problem this person experiences then complete the table below http://www.rcpsych.ac.uk/mentalhealthinfoforall.aspx

In the left hand column of the table on the next page note down how it feels to have the problem you are considering – what are the symptoms and signs someone will experience? Then in the right hand column note if the person you are thinking about experiences the symptom or sign and how you know or do not know this – see example

Then access and read page 23-26 of the RCN guidance document available at: http://www.estiacentre.org/docs/MHGuide.pdf this gives you information about how mental health problems can present differently in people with learning disabilities – after reading this you may wish to add more detail to your notes over the page.
<table>
<thead>
<tr>
<th>Problem: signs &amp; symptoms</th>
<th>How does the person communicate this?</th>
<th>What do you observe that suggests the person is experiencing this?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>e.g feels irritable</td>
<td>Cannot express these feelings verbally</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Increased pacing and vocalisations, furrows brow and bites hand</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
This activity aims to increase your knowledge and understanding around a range of mental health problems and you may want to repeat the activity to explore a range of problems. However the activity also helps you explore the complexity of recognising mental health problems in people with a learning disability. It is important that we are aware of that people with learning disabilities experience the full range of mental health problems and that mental health problems are more prevalent among people with learning disabilities to ensure timely identification and appropriate treatment.

Every effort should be made to support effective communication with the person to elicit assessment information, person centred approaches to assessment should be used both to fully involve the person and to gather information from family, carers, other professionals and previous records to ascertain an accurate assessment and ensure the best treatment options.

**Recommended Reading & Resources:**


Follow the link below to access an resource entitled ‘Practice guidelines for the assessment and diagnosis of mental health problems in adults with intellectual disability’

http://www.estiacentre.org/docs/PracticeGuidelines.pdf

To find out more about specific assessment tools that can be used to assess mental health problems in people with learning disabilities you can access:

Assessment of mental health in learning disability
The Pas-Add - http://www.pasadd.co.uk/


**Recommended Reading & Resources:**

If you are interested in finding out more information about mental health problems you can visit The Mental Health Foundation at:

http://www.mentalhealth.org.uk/help-information/mental-health-a-z/

If you want to find out more about how mental health problems may present differently in people with a learning disability you can access and read Raghaven, R. Patel, P (2005), *Learning Disabilities and Mental Health* Oxford: Blackwell Publishing.
Module 5: Mental Health and Wellbeing

Support and Treatment

Activity: Initial Treatment

Mohammad was assessed by the psychiatrist and prescribed Risperidone for his high level of anxiety. After gradually increasing the dosage to a therapeutic range Mohammad has responded well he is no longer anxious and managing his activities of daily living. However Mohammad has reported that since the last increase in dosage he is suffering from headaches and that is tired all the time. Mum suggests that this might be a side effect of the medication and the family have considered discontinuing the treatment.

What would you advise Mum and Mohammad?

Reflect on your role in regards to giving advice on side effects of anti-psychotic medication. Consider at what juncture you would refer to a pharmacist, GP or the psychiatrist.

Where would you find information on side effects of medication?

You may have mentioned:

- That you would strongly advise that Mohammad’s medication should not be discontinued unless it has been discussed with a Doctor. In extreme cases e.g. breathlessness, convulsions then emergency services should be contacted
- Carers, support workers and nurses have a responsibility to have an understanding of any medication that is being administered to people with learning disabilities in their care. This should include understanding what the medication should do, information regarding storage, potential interactions with other medications as well as potential side effects
- Information on medication side effects are enclosed in as a leaflet in the packaging for all medication. The BNF is a source of information on medication side effects and is extensively used by Doctors and Nurses. Many internet sites may not be reliable or may not be recently updated and best avoided.
- For information on side effects of any medication consult with your local pharmacist who will be happy to help.
Unfortunately you have received a phone call from Mum stating that Mohammad’s condition has significantly deteriorated. The only person he will eat or drink for is his Dad. He has not slept for two days and if he sees any of the females who live in the house he is verbally abusive and physically threatening. On one occasion Dad had to physically restrain him. Mohammad has currently barricaded himself in his bedroom. On further discussion it has become apparent that Mohammad has been taking his medication to his room and hiding it in the box of one of his computer games.

Mum has asked that you call round to the house as soon as possible and after hearing a disturbance in the background you are aware that Mum has had to hang up the phone.

What factors do you need to take into consideration in regards to Mum’s request?

Who should you inform of the given situation?

You may have said:

- It is important that you risk assess Mohammad’s safety, the families safety and the safety of any carers. You may further assess the situation by phone to ascertain the risk to Mohammad e.g. establish if he has threatened self-harm or to take the medication. If you feel that anyone is at imminent risk then you should contact the police.
- Take account of your lone workers policy and discuss a response with your line manager.
- The duty psychiatrist and the duty social work department should be informed and guidance taken from them.

Risk assessment is an important part of any mental health assessment. Suicide and self-harm tends to be less prevalent and less severe in people with learning disabilities but this does not mean the possibility should be disregarded.

Risk assessment and management, particularly when considering longer term risk management as opposed to a crisis situation, can sometimes lead to people with learning disabilities being denied opportunities and
life experiences that the rest of us take for granted. It is important that risk assessment and management protects people but also promotes individual rights, choice, opportunity and quality of life.

**Recommended Reading & Resources:**

Find out more about risk assessment, positive risk and empowerment at:

To find out about the Care Programme Approach in Learning Disability
http://apt.rcpsych.org/cgi/content/full/6/5/380

**Activity: Community or Hospital?**

The community psychiatric nurse your line manager and you have visited the family home. You have managed to convince Mohammad to come out from his room but he clearly is still in an agitated state. Due to Mohammad threatening other family members you have asked that they retire to the family kitchen.

The community psychiatric nurse who has been liaising with the duty psychiatrist has discussed with Mohammad how he would feel about a possible admission to the local psychiatric hospital. Mohammad appears to become less agitated and surprisingly appears somewhat relieved. The community nurse does not want to leave Mohammad and has asked you to go the kitchen and discuss this possibility with the family.

The family do not receive this news well. Gran is clearly distressed and in tears and stating that she will never see Mohammad again, she is talking in broken English and Urdu but you hear the words padded cells and electric shocks. Dad is angry and adamant that his family can look after Mohammad and states “That you have no legal right to do this” Mum is staring at you passively and you are not sure if she is angry/distressed or supports the proposition.

How do you reassure gran and give an accurate picture of what a stay in hospital would be like for Mohammad?

What is the legal status in regards to Mohammad’s admission to hospital?
Module 5: Mental Health and Wellbeing

Should Mohammad’s condition deteriorate significantly how could his legal status change?

What legal protection does Mohammad in regards to a compulsory admission to hospital and his treatment?

You may have said:

- You could reassure Gran that at this stage this is only a discussion about the possibility and suggest that the family speak to the community psychiatric nurse or psychiatrist. The family may benefit from knowing that at this point Mohammad can make the decision himself and would be free to leave hospital if he wished. You could also suggest the family could seek support from patient advocacy services, BEMIS and or the liaison nurse for psychiatric services.

- That at present Mohammad would be informal and it is up to him if he goes into hospital if he has been deemed to have capacity (see Module 3 for more information about capacity)

- If the situation deteriorates significantly the decision could be taken to admit Mohammad under the Mental Health (care and treatment) act, this would require a psychiatrist and a mental health officer to agree that this was in Mohammad’s interests.

- If Mohammad was admitted as a compulsory patient he can appeal through the courts at various stages of his admission. In regards to his treatment Mohammad could have a named person who would be consulted in regards to ongoing treatment options if he was unable to do this himself. He could make an advanced statement about his preferences for any future episodes of ill health (or he may have one already).

- The Mental Health (Care and Treatment) (Scotland) Act 2003 came into effect in 2005 and brought about major changes in mental health and learning disability care in Scotland. This along with the development of the Adults with Incapacity (Scotland) Act 2000 and, the Adult Support and Protection (Scotland) Act 2007 have introduced significant changes in the ways that adults considered to be at risk, are supported in health and social care services. These changes bring a welcome and significant emphasis on Human Rights, values and attitudes.
You may have mentioned:

- That for some people with learning disabilities who have communication difficulties and more severe learning disabilities that CBT would not be appropriate
- Approaches may have to be adapted to take account of someone’s preferred communication style
- People with learning disabilities may need support/prompts to put what they have learned into practice in given situations
- CBT therapists need to have a good understanding of the needs of someone with learning disability

Cognitive Behavioural Therapy (CBT) involves talking about how you think about yourself, the world and other people and how what you do affects your thoughts and feelings (RCP, 2005). CBT is widely accepted in general adult mental health services, Williams and Garland (2002) report that it has growing evidence as an effective intervention for depression, panic disorder, generalised anxiety disorder and obsessive compulsive disorder. CBT has evolved from traditional behaviour therapy where the main emphasis is examining the meaning of beliefs and thoughts in relation to psychological problems.

You will recall that one of the current HEAT target commitments states that there will be an increase in the availability of evidence-based psychological therapies for all age groups in a range of settings and through a range of providers. The evidence base for the effectiveness of CBT with people with learning disabilities is growing and CBT is within the Matrix a guide to delivering evidence based psychological therapies in Scotland

It is recognised that a CBT model needs to be applied differently for this group to take account of their cognitive ability and support needs (Brown and Marshall, 2006).
Introducing Pauline

Case Study: Pauline

Pauline lives in supported accommodation with 3 other ladies. She has Down Syndrome and is 33 years old. She uses some speech but can be difficult to understand, she can use some Makaton signs. Pauline attends a local day service and has always travelled independently to and from her day service. She has arthritis and receives regular pain relief for this; she is also prone to recurrent urine infections. Pauline has begun to be forgetful at times and recently got on the wrong bus and ended up several miles away from home. Her GP has suggested that she may be experiencing the early stages of dementia. You are the support worker on the sleep over shift, returning from a week’s holiday you notice a significant deterioration in Pauline, she is agitated and restless and does not appear to know where she is.

What would you do in this situation?

You are concerned that the deterioration is so rapid and you make an urgent appointment with the GP. The GP suggests that it is unlikely that the rapid deterioration is due to dementia. She considers the options that:
- Pauline could have a urine infection that is causing her to become restless and agitated
- There could be other physical problems that are contributing to Pauline’s confusions and agitation.

Activity: Complexity in Assessment

The GP carries out a thorough assessment with Pauline and diagnoses delirium. Use this link to return to The Royal College of Psychiatrists and find out more about delirium and how you would support Pauline with this condition?

http://www.rcpsych.ac.uk/mentalhealthinfo/problems/physicalillness/delirium.aspx

Recommended Reading & Resources:

Access a paper by Taylor, Lindsay and Willner on CBT for people with learning disabilities, emerging evidence, cognitive ability and IQ effect at:


Read

You may have said that it is important use appropriate communications skills to reassure Pauline and reorientate her to her environment. Ensure all Pauline’s activities of daily living are met and monitor her condition.

Case Study Update

Pauline’s delirium has resulted from a combination of her pain killers for her arthritis and a urinary tract infection. It is thought that delirium could be underestimated in people with learning disabilities. Following successful treatment and management of Pauline’s delirium.

Pauline now has a diagnosis of dementia. At the staff meeting a colleague raise concerns that Pauline’s dementia is progressing and suggests that there are 3 other people in this house and how are we going to support Pauline. One of your senior colleagues whose values and attitudes you have already questioned says ‘she needs to move, we need to find her another residence, we cannot cope with her getting any worse, we do not have the resources’.

Activity: Skills and Knowledge

Scotland’s dementia strategy identifies a number of key messages including the need for a knowledge and skills framework for dementia to improve staff skills and knowledge in both health and social care services. This framework is currently being developed by NES and SSSC

What skills and knowledge would you require to support Pauline?

Access and read the draft framework at: http://www.nes.scot.nhs.uk/initiatives/mental-health/consultations

Now consider and note down how you as an individual and your service could support Pauline in keeping with the knowledge and skills framework for the stage of her dementia journey that she is at.

<table>
<thead>
<tr>
<th>How could you effectively support Pauline?</th>
<th>Show your service could effectively support Pauline</th>
</tr>
</thead>
</table>
Activity: Learning Disability and Dementia

Access the page on facts about dementia: learning disabilities and dementia from the Alzheimer’s Society [http://www.alzheimers.org.uk/Facts_about_dementia/Risk_factors/info_learningdisabilities](http://www.alzheimers.org.uk/Facts_about_dementia/Risk_factors/info_learningdisabilities) and answer the following questions.

Is there any evidence that dementia has a different effect on people with learning disabilities?

What percentage of people with Down’s syndrome have dementia in the following age ranges – 30-39 years, 40-49 years, 50-59 years, 60-69 years?

Why might dementia in learning disabilities be missed in the early stages?

How much higher is the prevalence of dementia in people with other forms of learning disability (apart from Down’s syndrome) than in the general population?

Activity: Supporting Pauline

Having looked at the draft framework think back to the staff meeting. How would you best respond to staff concerns around supporting Pauline and ensure Pauline’s best interests are met?
Module 5: Mental Health and Wellbeing

You may have said:

- That the policies clearly state that at the stage of Pauline’s dementia journey (keeping well, prevention and finding out its dementia) it is important we actively support Pauline to feel empowered and exercise rights and choices. Therefore the focus should be on finding out Pauline’s wishes are in terms of advanced planning
- You could state that it is clearly part of our job if Pauline wants to stay here that we support her
- You also need to carry out a risk assessment and identify how Pauline can make choices about positive risk taking safely.
- Look at the knowledge and information needs of family and the caring team and provide relevant training and education
- Continue to maximise social inclusion and routines for Pauline

You may have mentioned that:

- You could discuss with Pauline and make a number of referrals including to the community learning disability team, social work team and advocacy services
- You may also wish to find out about and access information from a range of support groups and services that exist locally and nationally for people with dementia

Activity: Care Pathways

Find out if your area has a Dementia Care Pathway – access and read, consider in light of what you have read in Scotland’s Dementia Strategy – How might a dementia care pathway support Pauline or someone you know with a learning disability and dementia?

Activity: Skills and Knowledge

What support services could you access that may help Pauline and the staff team to monitor, support and provide appropriate health and social care support?

Recommended Reading & Resources:

You can access the Royal College of Psychiatrists guidance on dementia and people with learning disability at: http://www.rcpsych.ac.uk/files/pdfversion/cr155.pdf

Visit the Down Syndrome Association http://www.dsscotland.org.uk/families/growingolder/dementia

Promoting Positive Mental Health

How could you promote positive mental health and wellbeing for Pauline?

Now reflect on your role – how do you promote positive mental health within your service or with the people you work with?

You may have mentioned:

- Your role involves developing a relationship that enables the person to develop ways of making sense of the experiences in their life
- Supporting the person to access opportunities for meaningful activity including education, work and social opportunities that promote wellbeing and positive mental health
- Increasing opportunities for social inclusion
- Supporting and maintaining family connections and relationships with meaningful others and promoting opportunities to develop relationships
- Promoting and supporting people to meet their spiritual needs
- That you have a role to play in administering medication and monitoring for both wanted and unwanted effects of medication
- Supporting the person to develop effective coping skills such as relaxation techniques
Social Interventions

Social factors such as intimacy and social integration are important to wellbeing. People with learning disabilities may spend a large amount of time with limited levels of activity, which can lead to boredom, challenging behaviour and depression (Hardy et al. 2005).

Activity: Skills and Knowledge

Can you think of any social interventions that you could have a role in supporting?

- Meaningful activity – supporting people to access employment or day services which promote inclusion and integration, or supporting activity within the local community that promotes wellbeing such as swimming or voluntary work
- Environment – supporting people to have choice over where and who they live with, an environment that is predictable and stable, responsibilities within the home, reasonable expectations from others, accepted by others, non-judgemental attitudes
- Person centred approaches to care – consulting people about their treatment and enabling people to have control over their lives

Children with Learning Disability and Mental Wellbeing

Similarly to adults with learning disabilities children and adolescents with learning disabilities are at greater risk of developing mental health or behavioral problems than their non-disabled peers (Emerson and Hatton, 2007). It is suggested that children with a learning disability may be 6 times more likely to have a mental health problem than children without learning disability when we include autistic spectrum disorder and attention deficit hyperactivity disorder (Emerson and Hatton, 2007).

The increased risk is partly due to the same risks as any child including family characteristics, poverty, deprivation, family composition, punitive management strategies, negative life events and psychological distress of carers. In addition children with learning disabilities may also have conditions which increase the risk of mental health e.g autism, less competent communication and coping
skills and increased physical health problems.

It is also recognised that these children are less likely to access appropriate mental health services and even when they do they are less likely to have their needs appropriately recognized and met (Burnard and Turk, 2009). Only 49% of children and adolescence mental health services (CAMHS) were reported to be accessible to children and young people with learning disabilities in 2005 (CAMHS mapping, 2005).

**Recommended Reading & Resources:**

http://www.rcpsych.ac.uk/files/pdfversion/CR163.pdf

You will find additional information on ADHD, learning Disability and CAMH’s and Autism in the early years at the following links

www.sign.ac.uk/guideline

www.chimat.org.uk (Psychological wellbeing, mental health and learning disability)

www.autism.org.uk
Activity: Paper to Practice

Reflect on your learning within this module. Identify 5 key areas where your knowledge has developed and then write one objective for each that outlines how you can implement in practice some of the ideas you have learned about to develop either yourself or your service to provide good care and support. Discuss this with your supervisor, mentor or manager.

<table>
<thead>
<tr>
<th>Key Learning - I have Learned About</th>
<th>To develop this in my area of practice I will</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
</tr>
</tbody>
</table>
References


Module 6: Managing and Understanding Complicated Behaviours
Introduction

In this module we will start to develop an understanding of why people behave in the way that they do. You will be encouraged to view behaviour as the end point of a learning process. While the behaviour itself may be deemed as challenging the learning that underpins it is in itself an indication of ability to acquire new skills. If behaviours that challenge can be acquired then they can be forgotten too. We will begin to examine how behaviours are gained and lost and how staff can influence these processes.

On completion of this module you should be able to:

• Demonstrate understanding of how people learn and the factors that affect learning
• Critically reflect on what is meant by the term ‘challenging behaviour’
• Reflect on your role in supporting people with challenging behaviour and the important role staff play in influencing behaviour and promoting quality of life for people with a learning disability
• Illustrate understanding of functional assessment and positive behaviour support

Activity: Identifying Existing Knowledge, Skills and Areas for Development

Spend a few minutes identifying your existing knowledge, skills and areas for development in relation to supporting people with learning disabilities and complex needs manage their mental health and well-being – make some notes below

Existing Knowledge:

Existing Skills:

Areas for Development:
Understanding Behaviours: What is behaviour?

For the purposes of this module we will operate a behavioural model of skills development. This is not to suggest that people with learning disability should be reduced to being viewed merely as operators of behaviours; clearly they are much more than that. Rather it is suggested that a behavioural approach to the care of a person who displays challenging behaviour is aided by the appropriate use of a behavioural perspective.

Key Features

Within that perspective it is assumed that behaviours are:
- observable
- learned
- neutral
- functional

Activity: A Behavioural Perspective

Do you agree with these assumptions? Give reasons for your response.

What benefit to caring for individuals with a learning disability and complex care needs do these principles bring to your understanding of behaviour?

If we assume these principles are valid then the tasks of understanding and responding to challenging behaviours can be simplified for staff. In questioning the validity of these assumptions we must fully examine the implications behind them for services that care for individuals with complex needs.

Behaviour is Observable

Actions that are capable of being observed are capable of being described and quantified. If we can describe actions then we can consistently attend to them. If we cannot see them it is difficult to agree precisely what happened. While there is an obvious link between behaviours, thoughts and emotions it is only the behavioural actions that we can objectively examine. For example we can see the behaviours that we agree constitute laughing or crying, but there might be quantifiable differences in the behaviours that we observe from person to person. We don’t all laugh or cry...
in exactly the same way? What is more difficult to agree on is the definition of someone showing grief or being happy. In some circumstances a happy person can show the actions we associate with crying or we can see a sad person laugh.

If we can agree on restricting our descriptions to observable actions we can more readily reach agreement on the nature of the behaviour and more easily begin to quantify the frequency of that behaviour.

**Behaviour is Learned**

Most of the behaviours that we display are actually a serious of complex actions that we acquire over a period of time. We refine and improve our repertoire until sometimes they become almost automatic. Think of the last time you played a sport or drove a car or made a meal. Compare that time to your first attempt at the same task. There will be a significant difference in the degree of difficulty you experienced and the skill level of the outcomes of the behaviours. The main point to be made here is that we can all learn new skills, no one was born ready to drive a car, or cook a meal or score a goal, what will vary will be rate at which we learn different skilled behaviours but as you will see later in the module there are factors that we can manipulate to improve the chances of successful learning.

Just as behaviours can be learned so too can they be forgotten. You may well have in the past been able to speak a foreign language or have attained a level of proficiency in playing a musical instrument but if you do not practice that skill your proficiency levels will fall, so it is with all learned behaviours.

**Behaviour is Neutral**

In itself the acquisition of a skill and the demonstration of a new behaviour is evidence only of successful learning. How that behaviour is received depends upon the social circumstances in which it is exhibited. The behaviour itself is neither good nor bad but how people respond to it endows it with social value, it is seen to be good or bad and characterises the operator of the behaviour as showing acceptable or unacceptable levels of decorum and respectability. For example punching someone would not be considered appropriate if it occurred in a political debate or the local library but if the person was engaged in a prize fight being staged under the rules of boxing the same behaviour (punching) would be considered as more appropriate.

**Behaviour is Functional**

All behaviour has meaning or function and does not occur in isolation. Think back to the last time you were a learner in a classroom setting. What caused you to behave in the way you did? There are certain “teacher pleasing behaviours” that you can make a choice to exhibit. Students can act in a manner that suggests they are thoughtful students; you can be silent when the teacher talks, take copious notes, request to participate in the lesson by raising your hand, nod in agreement, and rub your chin as deep in thought. You can also decide to show behaviours that suggest you have disengaged from the teacher, talking to our near neighbour, texting on your phone, sleeping on the desktop or even leaving the room.

If you recognise any of these behaviours then we might also associate with the intentions behind them.
Making a choice to demonstrate behaviour is based upon a perception of what is to be gained or lost from the audience who view the behaviour. In that sense the choice of what behaviour to use may be useful (or functional) to the student in the previous example. It would not be too fanciful to suggest that behaviour is caused and if you accept that position then there are likely to be a number of underlying causes of behaviour.

**A Behavioural Approach to Learning**

If we can accept the legitimacy of the key features on which behaviour can be determined then we are part way towards developing an approach to working with people who have a learning disability and complex care needs that may offer opportunities for not only seeing lower levels of behaviours that present challenges but might also help increase the amount of appropriate behaviours they display.

That approach will rely heavily on knowledge of behavioural theories. Behaviour theory draws from an evidenced base that is informed by both operant and classical conditioning theory. Operance in particular suggests that behaviours that are reinforced following their presentation are, given the same circumstances, more likely to be repeated. This is how behaviours are strengthened. Conversely behaviours that do not receive reinforcement will become be less likely to be repeated and will over time become extinct. If behaviours are rewarded in any way they may be maintained. Behaviour is seen as being maintained by the consequences for the individual. As a result it is seen as functional for the person with a learning disability i.e. it serves a purpose. The consequences may be external to the individual, for example, to gain staff attention or internal, for example, self-stimulation to relieve feelings of boredom. Behavioural models emphasise that other people’s responses can increase, maintain or reduce the challenging behaviour.

For staff then the lesson is simple we can either attend to behaviour in a way that strengthens, weakens or is neutral to it. We can help the person with learning disability learn new behaviours or choose not to demonstrate old behaviours.

**Activity: Teaching Skills**

Imagine you are to teach a new skill to a person with learning disability. Analyse and document the separate observable behaviours that constitute that skill and suggest how you might strengthen that skilled behaviour.
Reinforcement and Learning

You are now beginning to understand the link between behaviour and reinforcement that behaviourism assumes to exist. While classical conditioning theory assumes that the link made between reinforcement and the target behaviour occurs before the target behaviour; operant conditioning explains that it is the consequences of the behaviour that strengthens the association between behaviour and reward. In both theoretical frameworks removal of the reinforcement weakens the behaviour.

To concentrate more fully on consequential learning for a time; if you accept that all behaviour can be affected by its consequences, there is a number of discrete ways in which those consequences can influence the behaviour. In most literature four consequence classes are described (See Figure 1). The two main ways we can encourage behaviour is by adding consequences that strengthen the likelihood of the preceding behaviour occurring again, and we can add two classes of consequences that weaken that likelihood.

Imagine you are at a party. It is a busy social setting people are laughing and smiling. A man tells a joke and the people around him begin to laugh. The behaviour of the man, in telling a joke, had added to the environment. The group of people have responded by adding a positive, desired or pleasurable consequence to that joke telling behaviour. If this encourages the man to tell more jokes we would class the laughter as a positive reinforcer (Box A in Figure 1). In this example the behaviour has been strengthened.

Later in the evening the man tells the same joke in different company. This time there is no laughter and a woman slaps him in the face. Again in this situation something is added to the behaviour. If this slap has the effect of reducing the man’s telling of jokes then this slap has been an example of punishment – aversive (Box B in Figure 1). The joke telling behaviour has been weakened.

As the evening wears on the people are enjoying each other’s company smiling and talking, the conversation while noisy is not too loud. Suddenly a man spills his drink and swears loudly. The group around him fall silent, no one smiles and no one laughs. The smiling and laughing behaviour has been taken away from the environment as a consequence of the man’s swearing. If the removal of laughter and smiling reduces the incidence of swearing from the man in the future then his swearing behaviour has been punished (Box C in Figure 1). The swearing behaviour has been weakened.

When the opportunity to gain positive consequence is taken away for a time and then reintroduced to the environment this is called time out from positive reinforcement. When this opportunity is taken away and never returned then this type of consequence is called response cost.

Away from the party a man is watching television on a Saturday afternoon. His wife comes in to the room and complains about the state of the garden. The man listens for a few minutes; switches the programme off and goes outside to prune the rose bushes. If the man has escaped something unpleasant (his wife’s complaints about the garden) then he has removed an aversive consequence to his behaviour of watching TV. His avoidance behaviour (rose pruning) has been strengthened while his wife’s behaviour has also been strengthened (Box A in Figure 1). The next day the man is reading the Sunday papers in the kitchen when his
wife enters the room. He immediately jumps up and goes out to the garden to cut the lawn. The man is displaying avoidance behaviours as his gardening actions prevent the recurrence of an unpleasant event. Both Escape and Avoidance are examples of negative reinforcement (Box D in Figure 1).

**Figure 1 – The Four Consequence Classes**

<table>
<thead>
<tr>
<th>Added</th>
<th>Taken Away</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive Consequence</td>
<td>Avidive Consequence</td>
</tr>
<tr>
<td>A</td>
<td>B</td>
</tr>
<tr>
<td>Positive Reinforcement</td>
<td>Punishment 1 (Aversion)</td>
</tr>
<tr>
<td>C</td>
<td>D</td>
</tr>
<tr>
<td>Punishment 2 (Time out &amp; Response Cost)</td>
<td>Negative Reinforcement (Escape &amp; Avoidance)</td>
</tr>
</tbody>
</table>

**Recommended Reading & Resources:**

The website About.com.psychology gives a fuller description of operant and classical conditioning @ [http://psychology.about.com/od/behavioralpsychology/f/behaviorism.htm](http://psychology.about.com/od/behavioralpsychology/f/behaviorism.htm)

**Factors that Influence Learning**

**Activity: Influencing Behaviour**

Imagine you are to teach a new skill to a person with learning disability. What factors might influence the rate at which they develop the skill?

Please read the section entitled “Factors Influencing Behaviour” and review your response to this question.
To strengthen behaviour an appropriate reinforcement mechanism (or reward) must be found. That is it must be rewarding to the person whose behaviour we are trying to change.

Reinforcers may be primary (unconditioned) or secondary (conditioned). Primary reinforcers are natural and often physiological, food, drink, warmth and human contact, etc. Secondary reinforcers are learned, money, certificates of education or a new car are all worthless until we have learned to appreciate them. They acquire reinforcer power through association with established reinforcers. The mother's smiles and baby talk are paired with food and warmth. Consequently, the mother’s verbal and non-verbal behaviour becomes a secondary reinforcer. When these are paired with other ‘neutral’ events like toys, possessions etc., these also may become secondary reinforcers.

In essence this theory seems very simple and straightforward, but there are factors that influence learning in real life.

**Consistency**

For reinforcement to be most effective, and so that the person who displays the targeted behaviour is in no doubt as to what is being reinforced, we must always reward exactly the same behaviour. This means that there has to be explicit instruction in writing to all members of the staff team as to what constitutes successful exhibition of the behaviour. Very often programmes fail because the goal or target behaviour has not been well enough defined.

**Contingency**

For a particular reward to be most effective, it should be presented only in conjunction with seeing the targeted desired behaviour and not given in other situations. The person with learning disability and complex care needs can then more quickly make the association and the connection that “I am being rewarded for this behaviour specifically”. The desire to gain the function that we are attaching to the behaviour will be linked by the person to reproducing those actions that define the behaviour. The more clearly this connection is made the quicker the targeted behaviour will increase in frequency.

**Immediacy**

As a general rule, reward reinforces behaviour which immediately precedes it. Obviously, where an individual is more sophisticated intellectually he/she can respond to delay reward, but this too has its limits. Can you think of such a scenario in your everyday life when you are willing to delay a reward? How long would you be willing to delay?

**Value**

For a reward to be effective, it must be of sufficient value to the subject to elicit the behaviour. Again it is the subject’s perception of value, and not yours, which is crucial here. (This would explain the durability of some so called attention-seeking behaviours that persist in environments where stimulation is widely available) It is also important to note that even when a consequence is deemed to be a valuable reward today, it may not always be so. People can become satiated with a particular reward to the point where being given it would prevent a behaviour being displayed (a” Not that again” response). From being a potent reward a reinforcement class may actually weaken the prospect of some behaviours being exhibited over time.
Schedules of Reinforcement

The pattern of delivery of-reward in relation to the occurrence of the behaviour will affect the rate of acquisition, and subsequent sustainment of the behaviour. The most effective means of instituting and increasing the frequency at which behaviour can be observed is to reward on a fixed ratio, usually beginning with a ratio of 1:1, i.e. one reward for each successful example of the target behaviour that is seen, then gradually reducing the frequency of reward to another (longer) ratio of reward to successful trials. However, extinction (suppression) will occur more quickly when reward is withdrawn.

A variable ratio of reinforcement (or random reward pattern) is much less effective in instituting and increasing the frequency at which we might expect to see the target behaviour displayed. It takes much longer to increase the total number of successful trials as the association between reward and the target behaviour is more difficult to establish, but so does extinction take longer to take place. If one thinks these schedules through, then it is logical to understand the effects on rates of observable behaviours.

When learning new behaviour (skills) people are generally reinforced on a fixed ratio of reinforcement initially and this changes to a variable ratio when the skill becomes embedded in the persons' behavioural repertoire (think of toilet training for example). Changes to ratios of reinforcement must be carefully reviewed to keep motivation to display the new skill or behaviour while allowing the opportunity for reward to be applied.

Activity: A Different Perspective

Janet Carr gives an alternative explanation of learning @

http://www.intellectualdisability.info/mental-health/behaviour-management/?searchterm=skills teaching

Read the section on Positive Reinforcement and Extinction.

Does this enhance your knowledge of how people learn? Note down the points that you are clearer on and remember that you need to explain them to your colleagues if consistency of approach is to be guaranteed

Refine your skills teaching plan again now in the light of this new knowledge
In this part of the module you have reviewed the assumptions that underpin behavioural learning and considered the application of these concepts to working with people with a learning disability who have complex needs. You will have a robust and useful skills teaching plan that shows knowledge and understanding of how people with learning disability and complex care needs learn. Further information and sources used in this unit can be found in the reading list.

**Recommended Reading & Resources:**

UK health and learning disability network hosted by The Foundation for People with a Learning Disability (FPLD) is an open network with a focus on health and adults with a learning disability. To join log on to:

http://www.ldhealthnetwork.org.uk/forms/healthjoin or
http://www.learningdisabilities.org.uk/ldhn


Remington B & Evans J (1988) ‘Basic learning processes in people with profound mental handicaps: review and relevance’ Mental Handicap Research, 1,(1), 4-23

**How do Behaviours challenge?**

Having examined what counts as behaviour you can now look at considering what constitutes challenging behaviour. In constructing a framework to describe challenging behaviour you must consider the people involved in creating the social environment in which the behaviour exists. In this section you will explore a model for categorising the challenge associated with the behaviour and begin to think of the behaviour as it relates to the function it brings to the individual. You can then contextualise that function to the person’s adaptive skills repertoire. You will consider the important question who does the behaviour challenge?

The phrase “challenging behaviour” has become part of the everyday language in the field of learning disability care but what is understood by the term challenging behaviour?
Module 6: Managing and Understanding Complicated Behaviours

Activity: What is Challenging Behaviour?

Take a moment and think of situations when you experienced challenging behaviour. You may have been subjected to it, you may have displayed it or watched as someone else displayed behaviours that presented a challenge, but how would you describe it?

What it is that makes it challenging?

Definitions

“We have decided to adopt the term challenging behaviour rather than problem behaviour or severe problem behaviour since it emphasises that such behaviours represent challenges to services rather than problems which individuals with learning difficulties in some way carry round with them and was an attempt to place the emphasis on the service to meet the needs of the client, rather than suggesting that the difficulty was intrinsic to the person with a learning disability” (Blunden & Allen 1987).

Activity: Defining Challenging Behaviour?

How different are these to your definition?

What were the main differences and why?

“Behaviour can be described as challenging when it is of such intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion.” (Royal College of Psychiatrists 2007).
Did you focus on the behaviours you recalled, or the person who displayed the behaviours?

Definitions that suggest that the challenging behaviour is intrinsic to the person with learning disability and complex care needs run the risk of labelling that person. Within this definition the impact of learning and the person's living environment is largely ignored. The person exhibits bad behaviour because they are a bad person. Neither is this approach useful nor accurate. Using value laden words to describe the behaviour of people with learning disability can emphasise their “differentness” when the intention is the opposite. When working with people who have a learning disability and complex care needs there can be an unwitting tendency to view all their behaviour, including their emotional life, through the labels of disability and challenge. When taken to its logical conclusion the lives of the people you care for can be overly professionalised.

Whereas you might be angry people who have a learning disability and complex care needs demonstrating the same observable behaviours may be viewed as verbally abusive, when you might be upset they are described as emotionally disturbed. Similarly while you may enjoy going for a swim, people who challenge are prescribed access to hydro therapy, while you listen to your old record collection a person who has a learning disability and complex care needs may engage in music therapy or reminiscence therapy.

Members of staff write reports about the people they support and these powerful documents impact on the future of people who have a learning disability and complex care needs by emphasising differentness when we may actually be looking to determine normality. It is normal to attach meaning to behaviour, displaying behaviours for consequent reinforcement is a natural state. What may be unusual are the associations that are made between the behaviour and function by the person with learning disability.

Very often the person who displays durable challenges over a prolonged period of time is viewed as “having a problem”. As you earlier the acquisition of new behaviours occurs as a result of a successful learning period. To the person who has learned to display behaviours that challenge, the behaviour is logical and beneficial to them. It adds something to their life. Too often we try to change the behaviour without understanding the motivation behind it.

Challenging behaviour is a long standing descriptor that has been used widely and has been endowed with a myriad of social values. The term seems to have originated in the USA where it had been introduced in order to transfer the demands for change from the individual with severe behaviour problems to the organisation around them. In this context then it can be said to have been socially created and constructed and is a product of an interaction between the individual and their environment. Assessment of the challenge must therefore address the person, the environment and the interaction between the two parties. The challenge is for carers, services and professionals to find more effective ways of understanding the origins and meaning of a person’s behaviour and to find creative ways of responding to this challenge in order that the behaviour ceased to fulfil the same function and would therefore diminish.
Defining challenging behaviour should be approached from a person-centred context and agreement reached on the decoding of the observable behaviour and the nature of the challenge it presents. Communication between professionals, carers and service users, and the sharing of information is an essential component if a true understanding of the behaviours and its functions is to be attained.

Who does the behaviour challenge?

Challenging behaviour is not a diagnosis in the same way that Down's syndrome or a fractured femur are. It is a label and one that should be cautiously applied. Carers tend to use the phrase challenging behaviour when behaviour that is unacceptable to the social environment is observed. Our personal definition of unacceptability is idiosyncratic and subject to change over time, place and circumstance.

Some of the areas for dispute may be explained by differences in:

- Who you are – your age, culture, racial and ethnic identity, personal experiences and expectations of the nature of your job
- Your professional standpoint – care philosophy, beliefs about the purpose of your role in the service
- The nature of the behaviour – what was observable and who was involved, the environment in which it was displayed
- Your relationship with the people involved in the behaviour – diagnoses and past history with the person who challenges, their health status and personal characteristics
- Your explanation of the function of the behaviour
- Your emotional state – may be influenced by our explanations for the behaviour and estimations of attribution of responsibility or blame.

Dependent upon the mix of the variables that are considered when viewing any behaviour it can be concluded that the behaviour is more likely to be seen as challenging if a recipient of the challenge is identifiable. The behaviour might pose a challenge to services (e.g. by damaging property), staff or other people (e.g. by presenting a risk of injury to them) or to the person themselves (e.g. by placing them in jeopardy of eviction from their home or causing them to be unable to integrate fully in to the social setting).

The impact of challenging behaviour can be significant on people who have a learning disability and complex care needs resulting in an increased exposure to (often physical) abuse, injury to self or others, inappropriate interventions (such as seclusion, drug treatments or...
even physical or mechanical restraint) or in severe circumstances exclusion from the place they think of as home.

The label “challenging behaviour” can often be misused and used to refer to behaviour that is possibly awkward or defiant in nature. Staff members are still likely to see challenging behaviour in terms of a particular behavioural problem. It has been argued that the term ‘challenging behaviour’ is so inclusive that it is very difficult to identify the prevalence of distinct groupings; because of these problems with definition there may be a need to replace the term challenging behaviour to aid clarity, operational definition and empirical study (Gates, 1996).

Other problems staff struggle with in defining challenging behaviour include interpreting the range of different social rules that exist in different parts of society. What constitutes appropriate behaviour in a particular setting and how this can vary between settings, the ability of a setting to manage any disruption caused by a person’s behaviour and the ability of the person to give a plausible account for their behaviour is variable in the extreme. A commonly expressed understanding of the social context in which behaviours (and those that challenge) occur can help decide if the behaviour is appropriate or warrants further action.

Where individuals are cared for in environments that do not respond well to their needs, challenging behaviours are likely not only to develop but to be solidified in the person’s behavioural repertoire. These behaviours can become strongly resistant to change as the person thinks they have been placed on a variable ratio of reinforcement and/or the function that the behaviour attracts is very potent to them.

In order to support this group of people a strong set of ethical standards and values is required. The use of person-centred values in providing care is common in learning disability services and the principles espoused in person centred practices may help protect the human needs of the client group. Further more individualised care with a strong values base can lead to decreases in the severity and incidence of behaviours they display.

### Causes of Challenging Behaviour

#### Activity: Causes of Challenging Behaviour

Think of the service in which you work. What do you think causes challenging behaviour?

Some of the issues you might have considered will include an understanding that the causes of challenging behaviour are as complex as defining the term and is often an amalgamation of several of the following factors: behavioural, cognitive, biological, environmental and psychological. You will have considered behavioural characteristics, aetiologies, quantifiable frequencies or severities in making the case for challenge to be attached to behaviour.

What you may have overlooked and is worth reminding
you of is your effect on the people you care for.

Staff Behaviour
If carers are to work usefully with people who demonstrate challenging behaviour they must consider their own attitudes and behaviours. Some attitudes may be counterproductive.

Authoritarian attitudes
An authoritarian person will try to dominate relationships and attempt to gain control. Sometimes this domination will be quite subtle in presentation. Making rules for others or getting them to ask for permission before they do something would be examples of an authoritarian approach to a care relationship.

Over – Protective Attitudes
A person who is over protective may be very caring towards others but their expectations of, and for, the other person may be very low and that may lead to an under stimulating environment in the care setting. An over protective person may be reluctant to take risks or, have a tendency to keep things very stable without changing their approach to challenging actions.

Cold or Distant
This type of person might hide behind a professional façade. They need very little interaction with the people they support and deal well with systems and resources. Other people are consulted only where the carer values their position.

Inconsistent
This type of attitude leads to unpredictable response and it is difficult to estimate consistency in the approach and actions to be taken in delivering care. This leads to inconsistency in the care setting. In turn this operates a variable ratio of reinforcement for people who have a learning disability and complex care needs. What is an acceptable behaviour one day may be treated as challenging the next.

All of these behaviours are counterproductive in caring for people who have a learning disability and challenging behaviour complex care needs.

Attitudes and staff behaviour that are more productive in this environment are:

- A willingness to see challenges as logical and functional for that person who has a learning disability and complex care need to display.
- A belief that change is always possible.
- A desire to promote growth and enhance quality of life for the person who has a learning disability and complex care needs.
- A willingness to treat the person fairly, even when they react to you unfairly.
- Working in partnership towards interdependence rather than towards compliance
- A belief in the value of team work in trying to find and implement solutions.

Rating Challenging Behaviour

Emerson et al, (1988) defined ‘severe challenging behaviour’ as:
‘Severely challenging behaviour is behaviour of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities.’
Challenging behaviour being a description of an interaction in a certain place at a certain time has three quantifiable components, intensity, frequency and duration. Intensity descriptors can be used to signify the impact of the behaviours on all parties exposed to it. Frequency data when collated will identify how often the behaviour occurs and duration relates to not only how long each episode of the behaviour lasts but can be used to communicate how durable (or resistant to change) the behaviour actually is. More meaning can be attached to the data collected if the challenging behaviour is described on two criteria rather than one.

**High Frequency, High Intensity Behaviours.** These are behaviours that happen often and always are problematic (they provoke challenge in the environment when displayed).

**Low Frequency, High Intensity Behaviours.** These behaviours occur only occasionally but always create challenge when displayed.

**High Frequency, Low Intensity Behaviours.** Behaviours which occur more or less continuously but which are not regarded as a major challenge by staff are included in this category. These behaviours may interfere with or exclude people from learning or relationship opportunities.

**Low Frequency, Low Intensity Behaviours.** These behaviours happen only on occasion and have little impact on the environment.

Building on this earlier work Emerson et al. (2001) carried out a total population survey of people with a learning disability and challenging behaviour and produced this refined classification system.

<table>
<thead>
<tr>
<th>Less demanding challenging behaviour</th>
<th>More demanding challenging behaviour</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behaviour constitutes a serious management problem or would do were it not for specific controlling measures undertaken in the person’s current setting</td>
<td>Behaviour meets at least one of the four criteria:</td>
</tr>
<tr>
<td>• Occurs at least once a day</td>
<td>• Usually prevents person from taking part in programmes or activities appropriate to their level of ability</td>
</tr>
<tr>
<td>• Usually requires the physical intervention by one or more members of staff</td>
<td>• Usually led to a major injury i.e. requiring hospital treatment to person or others</td>
</tr>
</tbody>
</table>

This section has considered the definition of challenging behaviour. You have thought about how your attitudes and values and the environments in which people that have a learning disability and complex care needs live. To be considered challenging there must be a person, or people, challenged by the display of behaviour and you have examined frameworks that allow that challenge to be quantified.
**Recommended Reading & Resources:**

UK Continuing Care network is a network aimed at practitioners working in continuing care and learning disabilities. Membership is free to join log on to [www.jan-net.co.uk](http://www.jan-net.co.uk)

The Challenging Behaviour Foundation website is useful for all carers involved in caring for people who challenge services and can be located @ [http://www.thecbf.org.uk/](http://www.thecbf.org.uk/)

Blunden R & Allen D (1987); Facing the Challenge: An Ordinary Life for People with Learning Difficulties and Challenging Behaviour, Kings Fund


**Understanding Challenging Behaviours**

In order to support people with challenging behaviour in an effective and defensible way, it is crucial to be able to understand the nature of that challenge, and the purpose or function which the behaviour serves for the individual. You will have already reflected upon your own behaviour, and the factors which contribute to determining that behaviour. Reflect now on the individual(s) whom you support, and consider their situation, environment and the factors which might govern their behaviour, challenging or otherwise.

**Definitions**

The term Functional Assessment refers to a process of identification of the variables which may precipitate and maintain behaviour, i.e. its function. Additionally, this process attempts to determine the degree of motivation and intent behind the behaviour. Functional Analysis refers to a more 'scientific' and controlled use of the variables thought to be maintaining behaviour, in order to determine its function and purpose with greater certainty. In that purpose, Functional Analysis is a part of Functional Assessment, and both processes have their origins in the field of Applied Behaviour Analysis. In the last two decades or so, the focus of Functional
Assessment has widened to consider a greater 'systems' rather than individual contribution to challenging behaviour; considering biological, physiological, personal, interpersonal, social and environmental factors which may precipitate, cause and maintain such behaviour.

Activity: Identify possible causes of challenging behaviour

In the space provided below write down one or two possible causes of challenging behaviour under each 'category'

Biological (organic/genetic factors e.g specific syndromes, or pain/discomfort)

Interpersonal

Social

Environmental

Personal

Functional assessment also considers the communicative purpose of challenging behaviour, and the importance of understanding the cause and function of behaviour for individuals with communication difficulties. Someone with communication difficulties may, for example, behave in a way described as 'challenging' when experiencing physiological discomfort. This may
be interpreted wrongly as serving another function, for example, to gain attention, leading to responses which are insufficiently sensitive to the cause of the behaviour and outcomes which may be more distressing for the individual and others. Responses to an individual’s behaviour may also be influenced by carers' personal beliefs, values and attitudes and it is crucial to consider and reflect on these when responding to challenging behaviour. Consideration also that behaviour can serve a number of different functions, at different times and in different situations, reinforces the requirement for a thorough and effective process of Functional assessment.

### Functional Assessment – Key Elements

By carrying out a Functional Assessment, we are trying to learn more about people before interfering with their lives. There are essentially three main elements to functional assessment – indirect assessment – direct assessment and functional analysis. However, before conducting a functional assessment, it is crucial to have a clear definition of the behaviour we are attempting to address. We hear often the terms ‘aggressive behaviour’ or ‘destructive behaviour’ but what exactly do these descriptors tell us about the individual’s behaviour? How easy would it be to assess behaviour based on these descriptors? Remember that a concise definition must be understood clearly by all in order that it is recorded and/ or assessed accurately and effectively.

### Activity: Behavioural ‘terms’

In the space provided below write down one or two definitions of challenging behaviour under each ‘category’

- **‘Aggressive Behaviour’**
- **‘Destructive Behaviour’**
- **‘Anti-social Behaviour’**
- **‘Self harm’**
How did you manage with that activity? You may have definitions such as;

‘Throws objects around the room’ for ‘Destructive behaviour’ or ‘makes contact with furnishings using his head’ for ‘Self-harm’. The important factor is that the behavioural definition is as clear and concise as possible and is agreed as an operational definition with those who are in contact with, and support the individual concerned.

Indirect Assessment

This component includes interviews with the individual themselves and/or people who are familiar with the individual and their challenging behaviour. These may be structured, semi-structured or more ‘informal’. Indirect assessment also includes a review of records and recordings relating to the individual and their behaviour, and the use of behavioural checklists and questionnaires. Given the aims of intervention being to improve quality of life and enduring positive outcomes for the individual and others, some quality of life measures may be useful in determining the key areas of an individual’s life which can be focussed upon as part of a responsive behavioural plan. Functional assessment methods are increasingly and justifiably reflecting the requirement for robust ‘ecological’ analysis to determine the impact of environment, routine, activities, individual choice and opportunities for self-determination within settings on the behaviour of the individual(s) living therein. Additionally, particularly where more than one individual is within the same environment, there is a need to assess those ‘interpersonal’ compatibilities or incompatibilities impacting on the behaviour of those individuals and that of others, including care support staff.

Activity: Indirect Assessment

Write below some of the things you would like to find out about an individual and their behaviour through Indirect assessment methods

I would like to know more about

On reading the prescribed literature relating to indirect assessment methods, you will be able to reflect upon and evaluate which elements of this component of Functional Assessment are best geared to provide you with the information you noted that you need to know as entered above!

Direct Assessment

This component of Functional Assessment is concerned with the observation of the individual in order to determine the circumstances and context of the behaviour when it happens. Typically, direct assessment attempts to identify what happens immediately before behaviour takes place, how it presents, how it is responded to, and what the immediate outcomes are. Additionally, direct assessment methods address the ‘dimensions’ of behaviour in terms of its frequency (how...
often), duration (how long), latency (the time between the ‘trigger(s) for behaviour and its actual occurrence, and intensity (how severe). A very effective and well used method of recording directly observed behaviours is to use an ‘ABC’ form or chart. This method of recording details;

**A = ANTECEDENTS** - Where was the person before the behaviour happened? Who was he/she with? What was he/she doing? What was he/she thinking/feeling? (N.B. Not a directly observed outcome – would have to be reported by the individual)

**B = BEHAVIOUR** - What exactly did the individual do? What was observed?

**C = CONSEQUENCE** - What were the observed outcomes of the behaviour? How did the individual and others react? How did the person think or feel following the behaviour (again not a directly observed outcome – would have to be reported by the individual)

---

**Activity: ABC Recordings**

Design you own ABC recording form and then compare with those in the literature provided?

How well did your version turn out in terms of capturing the information you wish to know?

What are the benefits of using ABC records?

What are the limitations of the use of ABC records?

Assessment using ABC records enables some consideration of the locational, situational, social and environmental antecedents and consequences of behaviour. These can potentially produce a wealth of information if used and completed timeously and comprehensively. Additionally, these recording formats are typically easy to complete and relatively compact. Limitations include the need to complete retrospectively, and the recording of largely ‘immediate’ (proximal) antecedents and consequences where more temporally or physically ‘distant’ (distal) factors may be of more relevance to the onset or maintenance of behaviour. Another form of recording behaviour based on direct observation is that of a ‘scatter plot’ assessment. This format is used to record occurrence (and by default non-occurrence) of challenging behaviour across time and date which is ‘mapped’ to reveal behavioural patterns or trends. Other forms of Direct Assessment include Frequency, Duration and Latency recording, Interval recording and Time sampling of behaviour.

The use of direct observation in Functional assessment should be governed by ethical, procedural and cost/benefit analysis, considering principles of consent, least restrictiveness, time limited factors, and agreed protocols.

**Functional Analysis**

Information obtained via Indirect and Direct Assessment methods assists greatly in determining hypotheses regarding the causal and maintaining factors of challenging behaviour. Functional analysis is a more systematic ‘control’ of the variables identified as being relevant to the occurrence of challenging behaviour in an attempt to demonstrate the exact functional relationship
between mainly social and environmental factors/events and an individual's behaviour.

**Other Assessment Factors**

Although arguably not explicit components of Functional Assessment, the following aspects of assessment are just as crucial to the development of a well-designed, defensible and responsive behavioural support plan.

**Activity: Assessments**

Consider what other areas of assessment may be relevant towards the development of a responsive behavioural support plan?

**Motivational Assessment**

The assessment of motivation in behavioural support planning is vital to its success. Behaviour is not only caused by motivational factors, but also inhibited by motivational factors, and it is crucial to attempt to assess these elements with a view to enhancing and utilising individual motivation to produce personally and socially significant outcomes and improved quality of life for individuals with behaviour which challenges.

**Activity: Motivation**

Consider factors which motivate you to engage in behaviours viewed as positive and/or productive and write the most important motivators below.

Consider factors which motivate you to resist engaging in behaviours viewed as negative and/or not productive and write the most important motivators below.

An important consideration in Functional Assessment is to consider whether a behavioural challenge happens through motivational or skills factors. For example, we may assume (always dangerous) that a behaviour takes place because an individual chooses not to perform an activity or task of daily living, due to a lack of motivation when in fact the person actually lacks the confidence and/or skills and/or supports to perform that activity/task. In this instance a skills issue should be addressed initially. If
in doubt establish or re-establish the skill in the individual until assured that they can carry this out effectively, or ensure that the pre-requisite conditions and supports are provided to facilitate performance of that skill. It is important to identify both within-person (intrinsic) and out-with-person (extrinsic) motivators to inform effective and defensible behavioural support plans.

‘Systems’ Assessment

Another important aspect of Functional assessment is to consider the values, skills sets, resources and wider systems issues crucial to the effective implementation of the behavioural support plan. A systems assessment will consider the care staff values, skills, training and development, and resource availability required to robustly inform, maintain and continuously evaluate positive behavioural support plans.

Risk Assessment

The rationale and foundation of behavioural support plans should be reflective of the intended outcomes of support in terms of prospective risk, costs and benefits to the individual and others. Informed individual and multi-agency involvement in this assessment process will assist greatly in the determination of behavioural support plans which are both sensitive and responsive to the needs of individual and others.

Additionally, positive and defensible risk assessment is not merely about the more controversial issues of restrictiveness, such as locked doors or physical interventions. There are often more subtle, but no less important, restrictions which we may impose on the individuals we support, which are ‘legitimised’ in the name of risk management. For risk assessment and risk management to be truly positive and enabling, there is a need to consider the ‘duality’ of risk, in that, what is done to manage risk needs to consider not only the risk of harm to the individual and others, but the risk to their personal development, choice and individual responsibility. Herbert Lovett (1985) described the ‘dignity of risk’, within the context of individuals’ rights to responsibility and to supportive / enabling approaches to risk management.

Increasing opportunities and experiences for people may not be done without some level of risk, but the consequences of not doing so also present risks to the developmental well-being and rights to responsibility of those same individuals.

Positive and defensible risk assessment and risk management, therefore, requires considering all aspects of risk to the individual and others.

Recommended Reading & Resources:

Module 6: Managing and Understanding Complicated Behaviours

Activity: Rules and Routines

Reflect on your own service and your own responses to the person(s) you support, in terms of the 'rules' and routines of support provided. Write down some rules/routines which you consider to possibly be;

A – RESTRICTIVE to the rights of responsibility and development of those persons.

B – ENABLING to the rights of responsibility and development of those persons.

From Functional Assessment to Behavioural Support

Functional assessment methods are fundamentally crucial to the formulation of responsive and defensible behavioural support plans. Functional assessment is not however a discrete event, but a continuous process, to be used as an ongoing informant of support plans evaluation and review. Consideration of information obtained through Functional assessment therefore, should be used continuously to develop an individual’s behavioural support plan and ensure that this is both incorporated into, and is consistent with their ‘wider’ person centred plan.

As you progress with this module you will read about both proactive and reactive behavioural support plans which may be developed in light of a comprehensive process of Functional assessment to minimise the distress and negative impact of challenging behaviour, predominantly through the vehicle of Positive Behavioural Supports.

Recommended Reading & Resources:


You have now considered Functional Assessment and its origins in Applied Behaviour Analysis. In this section you will read about and reflect upon approaches to behavioural support based on the outcomes of Functional Assessment. Additionally, the focus will be on the use of Positive Behavioural Support as a vehicle for responding to challenging behaviour and bringing about desired behavioural change.

**Definition**

The origins of Positive Behavioural Support lie also in the field of Applied Behaviour Analysis, and typically this approach involves the use of both proactive, (before behaviour) and reactive, (after behaviour) strategies to address challenging behaviour. Proactive strategies are geared around the ‘compatibility’ of an individual with their environment and service responses and aim to reduce the likelihood of the occurrence of...
challenging behaviour. Reactive strategies address the management of the behaviour when it does occur, and the minimising of negative outcomes for the individual and others as a result of the behaviour. Both proactive and reactive strategies have a goal to improve quality of life through the development of functional skills and self-determination of the individual.

There are a number of key ‘ingredients’ of Positive Behavioural Support, some of which are:

- It is based on the principles and values of the use of behavioural supports to improve quality of life, increase community participation, presence, individual choice and self-determination
- It considers a systems approach to behavioural supports, and the requirement for long term, continuous review and evaluation of response sensitivity and effectiveness
- It uses a multi-element model of behavioural support
- It focuses on the building of skills to replace challenging behaviours
- It is based on an understanding of function of behaviour, and the personal, interactional, environmental and social factors relevant to that behaviour

**Proactive Strategies for Behavioural Support**

Broadly speaking proactive strategies look at the ‘fit’ between the individual and the services and support they receive.

- Are services and supports consistent with the needs and wants of the individual?
- Is the environment designed to realise the best service and support outcomes for the individual?

- Is there a ‘mis-match’ between the person’s needs, characteristics and ambitions and the environment, support and opportunities being provided for them?

**Activity: Compatible Elements**

Identify ‘compatible’ elements of an individual’s service / supports

Reflect on someone you know or care for who displays behaviour which challenges. Identify elements of their service or supports which are tailored to their individual needs and wishes and ‘match’ their characteristics and aspirations.

Repeat the above exercise, identifying elements of an individual’s service / supports which you consider do not ‘match’ or are ‘compatible’ with, their needs and wishes.
Proactive strategies in Positive Behavioural Supports include a number of intervention approaches, hence the term ‘multi-element’. The proactive approach considers all relevant aspects of an individual’s life and is most effectively put together in light of Functional assessment outcomes and the considerations of the individual and other key sources, such as parents, carers and professionals with input to the individual’s support plan. The key proactive strategies include;

**Environmental / Ecological Change**

This approach typically involves the adjustment of conditions known to increase the likelihood of challenging behaviour taking place, such as noise levels, adequate personal space, or using different or particular styles of interaction. Increasing predictability of routines, access to more individually managed activities, increased personal choices, support to make informed choices, support to use new skills or coping skills and support to communicate are other examples of ecologically based proactive strategies.

**Positive Programming**

Positive programming approaches are geared to help the individual to cope better with their stressors and situation, whether these are environmentally related or otherwise. This approach uses the teaching of, and support for the use of, new skills and competencies, some of which may be used to develop ways of having needs met without the need to engage in challenging behaviour(s). There are four main types of approach to positive programming, and these may be used both individually and in any combination;

1. The development of general skills focuses on exactly that, with teaching and support for the individual to develop their skills repertoire.
2. The development of functionally equivalent skills involves the teaching of and support for the use of skills which serve the same function as the challenging behaviour, and cannot be performed at the same time as the challenging behaviour; such as speaking normally to ask input from carers or others rather than shouting loudly to attract their attention.
3. The development of functionally related skills involves the ‘substitution’ of behaviours related to, but not equivalent to, the challenging behaviour in terms of its function / purpose. For example, an individual who engages in repetitive nail biting to keep nails short, may be taught how to manicure their nails and present them in a cosmetic condition which the individual then finds motivating.
4. The fourth element of positive programming involves the teaching of, and support for the use of tolerance or coping skills when faced with disappointment, or the ending to a motivating activity. For example, feeling more positive about a not being able to
participate in activities due to adverse weather conditions or when it’s time to switch off the TV set and retire for the evening. ‘I can do that again tomorrow’ or ‘I can do something else I enjoy indoors’ These approaches may also involve the use of relaxation techniques, positive imagery, distraction and other methods to inhibit arousal and produce a state of behavioural wellbeing.

Activity: Positive Programming

Think of someone you know or support who has behaviour which challenges services. Write down below an element of positive programming which you could use to support that individual to develop a general, functionally equivalent, functionally related or coping skill.

Positive programming approaches complement ecological approaches in that whilst the latter may minimise the incidence of challenging behaviours, the former addresses the ‘real world’ realisation that the setting events for these behaviours may still present, therefore developing skills may produce more durable behavioural change and empower the individual to self-manage, or have the required support to cope with, and get through, these difficulties.

Focused Support

Making the desired ecological / environmental changes and teaching / supporting the development of skills may take a significant amount of time to deliver. Focused strategies may help provide behavioural supports which may produce more immediate reduction in behavioural challenges, where these are considered so intense and/or present a danger or risk to the individual and/or others. For example there may be a decision made to use techniques known as reinforcement strategies to promote and maintain periods of non-performance of challenging behaviour.

Differential reinforcement approaches may be used to reduce or eliminate challenging behaviour through the deliberate strengthening of other, alternative or incompatible – but more socially appropriate behaviours.

Additionally, focused support strategies may include antecedent and stimulus (‘trigger’ or ‘setting event’) ‘manipulations’ and/or certain instructional strategies. The following two elements are not explicit components of Positive Behavioural Supports.

Psychological Interventions / Self Management Approaches

Over the past couple of decades, in keeping with the principles and values of greater informed choice, self-regulation and self-determination, the use of behavioural supports and approaches involving the self-monitoring and self-management of behaviour has increased. The use of behavioural self management is typically supported by psychological input and involves the combination of both behavioural and cognitive (thoughts and feelings) approaches such as self recording, problem solving and self evaluation. Although these approaches require a certain amount of cognitive ability to use to effect, they have been usefully applied by the support of visual or symbolic aids, to facilitate comprehension, behavioural change and review.
Medication
The use of medication as part of an overall behavioural support plan has been well documented, although not always without a controversy. When used appropriately, medication has its part to play in responding to behavioural challenges, particularly where biological, physiological and/or mental health issues have been identified as contributory towards these challenges. There are a number of documents outlining the prerequisites for the use of medication in the management of behavioural challenges to which the reader is referred. Some key principles include:

- The requirement for a comprehensive assessment of the cause of the individual’s challenging behaviour
- The requirement for the physiological, mental health and full medical assessment of the individual
- The evidence base for use, including full risk assessment and response to treatment
- User involvement, consent issues and the use of Mental Health Act / Adults with Incapacity Act legislative governance

Recommended Reading & Resources:
Follow links below to relevant legislation regarding individual choice, capacity, consent and rights. These links include ‘easy read’ and summary versions.


http://www.scotland.gov.uk/Publications/2008/03/25120154/0

This section has considered the more proactive elements of behavioural supports – ecological change – positive programming and focused supports. These elements are geared to both complement each other, and the wider person centred planning process, and to support desired behavioural change and improved quality of life over the longer term. You will now read about reactive strategies and their purpose to manage behavioural challenges when these happen, or appear to be about to happen.

Reactive Strategies for Behavioural Support

A reactive behavioural support plan details what should be done, and exactly how a challenging behaviour should be reacted to and managed, when it happens or is about to happen. The aim and focus of any reactive approach should be to describe what to do as early as any ‘warning’ signs of oncoming challenging behaviour present themselves. Early intervention in this context is about the speed and extent to which challenging behaviour can be prevented, minimised and managed to reduce the risks to the individual and others. When used with the proactive strategies described earlier in this unit, therefore, reactive strategies will help complement those behavioural supports in their aim to produce longer term change, by providing assurance about effectively defusing and managing the immediate situation as it
Module 6: Managing and Understanding Complicated Behaviours

presents itself. When individuals exhibit behaviour which challenges services, there are often early warning signs which may have gone largely undetected. These are sometimes referred to as ‘behavioural response chains’ where for example an incident of aggression may be preceded by stages of arousal such as;

Flushed appearance – red face – LEADING TO – loud voice tone - LEADING TO – rapid speech - LEADING TO – pacing around the room / area - LEADING TO – pushing others - LEADING TO – punching others!

Factors predictive of the onset of challenging behaviour(s) may not always be observed in the individual, but may be observed in the environment, when it becomes too noisy or warm, or in interactional / interpersonal social contact, when someone is physically too close to the individual or is speaking to them in a manner which is known to onset challenges. The functional assessment will hopefully produce, through antecedent identification and analysis, the early behavioural response or environmental/social response cues which impact on behaviours which challenge services.

Distraction and/or prompting to engage in preferred activities for the individual, might also be useful in ‘de-escalating’ and defusing a potential challenge by intervening as early in the ‘response chain’ as possible. If an individual is self managing their challenging behaviour, support by giving reminders and cues as to how they best de-arouse and become more relaxed may be indicated. Similarly, as in the examples earlier, identified environmental cues may be removed or reduced and interpersonal / interactional contact re-established in a manner which is sensitive and suitable to the support needs of the individual.

Activity: Cues

Think of someone you know or support who has behaviour which challenges services. Write down below any potential individual, environmental and/or interpersonal warning ‘signs’ that may indicate the onset of challenging behaviour.

Activity: Responses

Reflect upon the previous activity and write below how any warning signs that you identified might be managed given the reactive strategies and approaches described thus far in this Unit.

In some cases and in some situations and contexts it may not be possible to react or intervene early enough to prevent behavioural challenges. In these situations, and very much as a last resort, the individual may require physical support or management to prevent harm to themselves and/or others and minimise risk. Such approaches will require to be individually designed, be informed by the relevant statutory and legal frameworks and be consistent with the principles of good practice outlined and detailed in contemporary literature.

Systems, Process and Outcomes

In 2004, Bambara et al described Positive Behavioural Support as being:
‘...characterised by educational, proactive and respectful interventions that involve teaching alternative skills to problem behaviours and changing problematic environments’

By any standards this is a huge, but realistic, ambition. However positive behavioural supports and other behavioural support plans will only produce the most effective outcomes if they are;

- Implemented fully, faithfully and consistently
- Implemented by individuals who have the skills and knowledge required to both implement and evaluate these plans
- Supported by wider ‘systems’ supports, such as ‘fit for purpose’ environments, responsive resources and continuous service review processes

Positive behavioural supports require collaborative team processes such as effective communication systems, awareness of team strengths and areas of need, shared values and principles, team problem solving and consistency of approach. Additionally, systems-level factors such as organisational culture and support, management and resource issues, and staff recruitment, development, investment and retention are crucial to the consistent and effective application of positive behavioural supports. These factors are sometimes referred to as ‘mediators’.

Activity: Mediators

Reflect on your own working situation, environment, culture and organisation. Write down below what systems, processes and outcomes you consider to be currently in place which would complement the implementation of behavioural support plans

Reflect on your own working situation, environment, culture and organisation. Write down below what systems, processes and outcomes you consider would have to be addressed in order to complement the implementation of behavioural support plans
Any behavioural support plans should be socially and ethically acceptable, and aim to produce outcomes which are both therapeutic and improving of the quality of life of the individual and others. Interventions are referred to as 'socially valid' when they are designed to address a socially significant challenge, have clearly stated outcomes and evidence of their effectiveness in producing socially significant change(s) and are implemented within the principles of least restrictiveness, that is, using as little intervention required to produce the best possible outcomes. Increasingly, behavioural supports are being monitored, reviewed and evaluated from both quantitative (reduction in challenging behaviours) and qualitative (improvement in quality of life and personal well-being) perspectives.

The purpose of behavioural supports should clearly state the intended outcomes of intervention in terms of any perceived risks and benefits to both the individual and others. Intervention should take account of, and be responsive to, the rights, freedom of choice, and informed choice of the individual. Identification of risk factors is crucial, in order to avoid taking unacceptable risks and also to make defensible evaluations of risk which are informed by risk reduction and risk management strategies as part of the overall individual support plan.

Positive Behavioural Support uses a Periodic Service Review (PSR) to ‘govern’ the implementation of behavioural support plans. This process assists in the continuous monitoring and periodic evaluation of the implementation of support plans, staff skills and responsibilities, and the ‘systems’ supervision, mentoring, management and supports required to maintain behavioural change and quality of life improvement.

In this context the PSR governs the systems, processes and outcomes required to effectively and productively provide sensitive and responsive behavioural support.

In Module 6 you have read and completed activities about understanding and responding to challenging behaviour. The development of improved service responses to individuals with complex support needs, including behaviours which challenge services, will continue to be informed by, and develop a greater sensitivity through evidence-based practice, ongoing research activity, and the production of contemporary good practice and service guidelines.

Recommended Reading & Resources:

You can find out more about Positive Behaviour Support by accessing

Positives Behaviour Support: person focused training at:
Activity: Paper to Practice

Reflect on your learning within this module. Identify 5 key areas where your knowledge has developed and then write one objective for each that outlines how you can implement in practice some of the ideas you have learned about to develop either yourself or your service to provide good care and support. Discuss this with your supervisor, mentor or manager.

<table>
<thead>
<tr>
<th>Key Learning - I have learned about</th>
<th>To develop this in my area of practice I will</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
</tr>
</tbody>
</table>
Module 6: Managing and Understanding Complicated Behaviours

**Recommended Reading & Resources:**


**Medication**


**Physical Intervention**


PSR

La Vigna GW, and WILLIS TJ (1996) ; ‘Behavioural technology in support of values’ Positive Practices 1 (4) p 1-16
